A Study of Low-Income Health Care Consumers:
Motivations for Using Electronic Personal Health Record Systems

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A dissertation
submitted in partial fulfillment of the
requirements for the degree of

Doctor of Philosophy

University of Washington

2011

Program Authorized to Offer Degree:
Medical Education and Biomedical Informatics

University of Washington
Graduate School

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Abstract

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Health care consumers have different motivations and needs for managing their detailed medical history as well as health information to support their healthcare-related decisions. Electronic Personal Health Record systems are a form of tool that helps health care consumers collect, manage and use their health information. Despite the fact that many types of PHR systems have become available to various groups of consumers, the motivations to utilize PHRs and the barriers to widespread adoption have proven difficult to measure. In this research, I explore and define the factors that motivate individuals' decisions on whether to adopt a PHR system.

I chose a grounded-theory-based qualitative methodology to identify and explore these factors in a setting where a PHR had been available for one and a half to three years to a group of low-income individuals. Demographics of this group included elderly and

disabled individuals, many of whom had multiple co-morbidities that result in complex health information management needs.

The end results of this work are two frameworks created from the health care consumer or patient-driven perspective. (1) The Personal Interest and Involvement in Managing Health Information Framework (PIIMHIF) can be used to categorize potential adopters to help create personas and tailored approaches to designing and implementing PHR systems. This framework describes three types of potential PHR adopters by their willingness to manage their health information or use a PHR. (2) The Health Information Management Motivational Factors Framework (HIMMFF) is a comprehensive framework of issues that contribute to PHR adoption. Factors that motivate or discourage adoption as described by both PHR users and non-users are grouped into seven categories. These frameworks can be used by the PHR and health information management research community to better understand and further study PHR adoption.

This work contributes an approach to understanding patient information management needs from the patient-driven perspective. Furthermore, it advances our understanding of how information systems impact health information management in underserved populations.

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Glossary

HEALTH CARE CONSUMER - any actual or potential recipient of health care or actual of potential user of health information.

HEALTH INFORMATION (HI) – information about own personal health or about health and health care in general.

HEALTH INFORMATION MANAGEMENT (HIM) – refers to the work a patient, their aid or a caretaker does to collect, organize and use an individual's own health information to combat illness, stay healthy and navigate the health care system.

PERSONAL HEALTH INFORMATION (PHI) – information about own personal health, usually referring to an individual accessing or working with their own health information.

PERSONAL HEALTH RECORD (PHR) – a collection of health-related information that is documented and maintained by the individual it pertains to, the information in the record and access to this information is fully controlled by the individual.

Acknowledgements

I want to express sincere gratitude for the support of my family, friends and peers. I also want to thank my committee chairs Michael Eisenberg and Wanda Pratt and committee members Nicholas Anderson, Donna Berry and Brenda Zierler at the University of Washington for aiding me through the process of completing my dissertation. Finally, I want to thank the study participants who generously gave their time and energy to provide the data without which this research would not have been possible.

Chapter 1: Introduction to Personal Health Records and Personal Health Information Management

1.0 Introduction

Health care consumers are individuals who interact with the medical system, receive health care services, seek out health related information, or collect and manage their own personal health information (PHI). In the developed world, most individuals become health care consumers at some point during their lives. As health care consumers, they often need to know their detailed medical history and additional health-related information to make health care-related decisions with their health care provider (Dwivedi, Bali, & Naguib, 2007; Endsley et al., 2006; Kim & Johnson, 2002).

Because most health care consumers see multiple providers as part of their regular care, change networks of providers, jobs and insurance companies or move from one geographic area to another, different pieces of their PHI often remain where they were collected and become distributed and unavailable (Bali & Dwivedi, 2007; Beisecker, 1993). As a result, health care consumers have a need to keep track of and learn to understand their PHI to become a central point of reference between their past and current health care providers, specialists and alternative care providers to receive quality care (Kaplan et al. 2001).

As central actors in their care, health care consumers need to have access to and control over their PHI to ensure that necessary information is available in the process of care. In addition, many individuals such as those with multiple co-morbidities, rare, chronic or complex diseases may benefit greatly from managing additional types of health information, such as keeping a health diary, or tracking daily blood sugar and pressure readings, types of information which may not be stored in traditional medical records (Ralston et al., 2004; Pratt et al., 2006).

An additional motivator for helping health care consumers manage their health information and take a more active role in their health care is reducing the overall costs of health care. Two Institute of Medicine reports, "To Err is Human: Building a Safer Health Care System" and "Preventing Medication Errors" showed us that the rising costs of health care and number of medical mistakes in the US are astonishing (IOM, 1999; IOM, 2006). If individuals are more aware of the care they receive and can provide accurate health information to their provider, this information can be used to prevent medical mistakes and reduce unnecessary or repetitive care (Tang et al., 2006). Furthermore, more and more individuals are developing complex health situations, such as chronic diseases and multiple co-morbidities. The US spends more then any other country on health care, specifically because of the increasing numbers of these complex health care issues (Truffer et al. 2010).

It is possible for personal health records (PHRs) to become a potential solution that will help patients better understand their health information and help prevent unnecessary care and medical mistakes which increase the cost of health care for everyone. Having access to personal health information may help improve individual health, population level health and decrease health care spending. It may also help reduce morbidity and mortality from preventable disease and help save health care dollars (Tang et al., 2006; "Manage your", 2011).

Individuals who use PHRs to track and understand their health information become more aware of their health conditions and health choices (Tang et al., 2006). PHRs contain additional information on which providers can base more informed diagnoses and treatment decisions for individual patients. PHRs can enable different ways to have an individual's complete medical information available on hand in case of an emergency. By helping to design better personal health records and encouraging individuals to use them, we can help prevent disease and complications of disease, help consumers better manage their health care conditions and therefore improve health and reduce health care costs for everyone.

1.1 Motivation

Keeping a personal health record is an idea that has been around for many years. The first electronic PHRs appeared in the 1970s and paper PHRs have been around even longer (Dragstedt, 1956; "Computerisation of Personal", 1978; Kim, Jung, & Bates, 2011). In the 1960s and 70s the idea failed to catch on. However since then the life style and health situation of the average American has changed drastically. Most people in the US no longer have one family doctor who knows them individually and takes care of all their health care needs, people seldom have one job or work for the same company throughout their life and health insurance and health care providers can change even when a health care consumers' job stays the same. Because for most health care consumers information is no longer aggregated in one place by their health care provider, it is now crucial for the consumers themselves to keep their lifelong health information aggregated in one place where they can have access to it no matter how their life or their health situation changes.

Personal health records (PHRs) are a potentially useful and beneficial solution to address the problem of helping individuals cope with distributed health information in the current health care system. Electronic PHRs can help health care consumers aggregate, organize, manage and control access to their personal health information (PHI) (Markle, 2004; Tang et al., 2006; Pratt et al., 2006; Archer et al., 2011).

In the 1990's PHRs reappeared again and then again failed to catch on. However, many PHR products stayed on the market and at the very beginning of the new millennium the idea reappeared again and has become a hot topic. The idea of PHRs for everyone strengthened due to being connected to the movement toward electronic medical records and strong financial and conceptual support from both the European and the US government (Markle, 2004; Thompson & Brailer, 2004; Lansky, Kanaan & Lemieux, 2005; California HealthCare Foundation, 2010; HHS, 2010; "Smart Personal Health," 2011). It has been shown repeatedly in the US, Europe and other developed countries that health information technology can help save lives and reduce health care costs and electronic medical records, electronic health records and personal health records are all part of this movement (Gartner, 2009; HHS, 2011).

It is a promising trend that most research articles about PHRs have been published in the new millennium and many new government level PHR initiatives are announcing goals to reach by 2015 and 2020 (Kim et al., 2011; HHS, 2011). It is clear that personal health records keep reappearing as an important tool because the need for something that helps consumers get a handle on their health care information exists and it is now stronger then ever. However, neither the research community nor entrepreneurs have been able to offer a product that consumers are willing to adopt.

Many types of PHR applications are currently available. They vary from health portals that allow users to access their HI stored in a clinical data system to full personal health records which are controlled by the individual. PHR systems also include tools that help consumers find, record, and better manage and understand their PHI (Markle, 2004; Mandl et al., 2007; Vincent et al., 2008; Jones et al., 2010; Archer et al., 2011). With complete health information and tools in a PHR system, health care consumers can learn more about their health, better understand their health situation, and stay in control of their health conditions and treatments.

More and more health information management systems are becoming available and consumers are adopting them slowly. In 2006, there were at least 24 PHR systems that were not tethered to a specific care organization in which consumers could enter and control any health information (Cronin, 2006) and in 2010 91 functional and available PHRs were identified by Jones et al. In a 2008 survey by the Markle foundation, 2.7% of adults in the US reported having an electronic PHR, and according to the most recent 2010 survey by the California HealthCare Foundation 7% of adults use a PHR, this growing trend in adoption is promising (Markle, 2008; California HealthCare Foundation, 2010).

In the 2008 Markle Foundation survey 46.5% (106 million Americans) indicated that they would be interested in using a PHR. And in the 2010 CHF survey 40% of those not using a PHR said they would be interested in using one (California HealthCare

Foundation, 2010). These statistics show a large gap between perceived usefulness of PHRs and their actual adoption. According to newer studies, this gap is slowly getting smaller as adoption rates increase, however what contributes to it shrinking is largely unknown and not has not been studied in depth.

Finding out what factors influence adoption is one of the first steps to bridging the existing gap between the number of consumers who recognize the potential value and usefulness of PHR systems and health information management and the number of consumers actually using health information management systems such as PHRs. This study is the first step to filling this gap, it explores reasons for adoption or lack of adoption of a PHR system by identifying factors that may facilitate or deter its adoption from the consumer point of view. Knowing what motivates health care consumers to use or not use a personal health information management system, such as a PHR, can enable development of more successful and useful systems and specific features and capabilities of these systems. Knowing what motivates consumers is also crucial for developing effective educational materials and for informing PHR design and development.

1.2 Research Aims

The aim of this study was to produce knowledge about PHRs and PHR adoption from the health care consumer perspective. The resulting frameworks can be used to inform the design and implementation of PHR systems, other personal health information management (PHIM) systems and consumer health technologies that will be accepted and used by health care consumers. A framework of factors that motivate health care consumers to use personal health information management systems has been developed which represents the health care consumer point of view on PHR usage and adoption. Through interviews and observation work with consumers who used a PHR and those who did not, this study identified and defined factors that influence the consumer adoption decision to use a personal health record (PHR) system to manage their PHI.

1.3 Research Approach

The investigator studied a health care consumer sample to which a PHR has been available for one and a half to three years and developed a framework of factors that motivate consumers to use or not use a personal health record system. The setting where the study was conducted is a low-income housing authority. This particular setting was chosen because a PHR had been available to the individuals who lived there for a prolonged period of time and they had had time to make the adoption decision. This group of consumers made particularly interesting study subjects because many of them are disabled or elderly and have complex health information management needs.

Individuals were interviewed who had signed up and used the PHR and individuals who had chosen not to use it. Qualitative interviews and participant observations were selected as the most appropriate methods to obtain information about how and why these health care consumers use the record or why they are not using it.

The study employs grounded theory as an approach to generate a framework of adoption grounded in data that is a representation of the consumer view of PHR adoption. The framework emerged through an analysis of textual data provided by study participants and validated through further consumer interviews and interviews with health care professionals who helped individuals in the population to use the record. Results and findings in the final stages of research were constantly compared to PHR research literature views of adoption and general technology adoption literature.

1.4 Research Questions

This dissertation work had three aims. The first aim was to identify factors that motivate or discourage consumers to adopt and use a PHR and build a framework of these factors. The second aim was validation of this framework through further interviews with consumers and health care professionals who were involved in the PHR implementation at the research site and comparison to existing PHR research literature and technology adoption literature. The third aim was to develop recommendations to increase adoption of PHRs by health care consumers.

AIM 1:

Identify motivation factors that contribute to the use of a PHR by a consumer population and build a preliminary framework of motivational factors.

(1) Why do consumers choose to use or not use a PHR system?

(2) What factors affect how consumers use and how often they access a PHR system?

AIM 2:

Validate and refine the framework developed in AIM 1 in the context of other stakeholder views, PHR and technology adoption literature.

(1) How do factors discussed by health care provider representatives clarify, contribute to, or expand the framework developed in Aim 1?

(2) How do factors identified in AIM 1 and 2 compare to motivation factors discussed in existing PHR research literature and adoption of technology research literature?

AIM 3:

Based on the developed framework define recommendations for future directions of PHR research and development, and to encourage PHR adoption and use by consumers.

(1) What worthy future research directions can be identified in the resulting framework?

(2) What recommendations can be made to encourage PHR adoption?

1.5 Dissertation Overview

The full dissertation is presented here in 8 chapters:

Chapter 1. Introduction to Personal Health Records and Personal Health Information Management

Chapter 1 provides an overview of the scope of the study, the rationale for pursuing this research and the approach that were chosen to study the research question.

Chapter 2. Background and Significance of Personal Health Records and Their Use

This chapter introduces the idea of personal health records and discusses PHR research literature and adoption of technology literature. Existing research indicates that PHRs are a potentially valuable tool that has come against a barrier in adoption. Health care consumers are interested in PHRs and health information management but they fail to adopt technology that helps them manage and understand their health information. This research study aims to learn why this gap between perceived usefulness of PHRs by consumers and actual adoption exists.

Chapter 3. Theory and Methods Involved in the Study

This chapter describes theory and methods used to conduct this research and the actual steps taken to carry out the study. The setting where the study was conducted, the PHR system used and participant recruitment are described. In conclusion, demographics and characteristics of participants are presented.

Chapter 4. Results: Health Information Management Motivation Factors Framework

Chapter 4 describes two thematic sets that emerged from the study data. They are the Levels of Personal Interest and Involvement in Managing Health Information and the Health Information Management Motivation Factor Framework. Each participant's placement on the developed interest in PHRs and HIM scale is described.

Chapter 5. Validation of the Consumer Motivation Factors Framework

This chapter describes the results of validating the framework that emerged out of the data with additional consumer interviews and interviews with health care professionals who helped participants use the system.

Chapter 6. Thematic Synthesis and Results

Chapter 6 highlights surprising, interesting and important findings that emerged from the field study. It discusses factors that were important to the study population or not mentioned by them at all and what this means for adoption and further development of personal health records. It delves into the intents and emotions of participants in each level of interest category.

Chapter 7. Review of Models for Assessing PHRs

This chapter reviews two models that can be used for assessing the adoption of technology as they can be applied to PHR adoption. The Diffusion of Innovations Theory and the Technology Acceptance Model are discussed and their relevance to the PHR adoption process is analyzed.

Chapter 8. Contributions, Limitations, Future Work and Conclusions

The concluding chapter describes the contributions of the study including the Health Information Management Motivational Factors Framework, as well as limitations of the study and future work.

1.6 Summary

Personal heath records are a tool that can help health care consumers manage their health information, receive appropriate health care and services and take better care of their health. Many potential uses of PHRs are described in the literature and studies of health care consumers show that they are interested PHRs. However, only a small percentage of individuals actually start using a PHR when it is offered to them. In this study, the investigator explores this problem by studying a setting where a PHR had been available to a group of individuals for a prolonged period of time and a relatively high adoption rate was achieved. An opportunity existed to study why individuals had chosen to adopt a PHR system or chosen not to adopt it and to identify factors that encourage or hinder adoption of PHRs. This study identifies the factors that individuals consider when deciding to adopt a PHR system and is the first step to understanding how to bridge the gap between perceived usefulness of PHRs by consumers and actual adoption.

This research study was based on concepts from grounded theory. It employed qualitative research methods to gather data from real consumers who had had a PHR available to them and to build a framework that represents their view on adoption of personal health records. This framework of motivational factors was allowed to fully emerge from of the data. The results of this research work are a categorization of the levels of interest in PHRs and personal health information management and a framework of factors that contribute to the motivation of consumers to use or not use a PHR. The results indicate important directions for future PHR work and ways to encourage adoption of PHRs and other consumer health systems, which can become important and valuable tools for health care consumers.

Chapter 2. Background and Significance of Personal Health Records and Their Use

2.0 Introduction

Health care consumers are becoming more aware of the importance of knowing their health information and are expected to take an active role and be able to make informed decisions in the process of receiving medical care (Woolf et al., 2005). With the increasing prevalence of chronic diseases such as diabetes and lifelong diseases such as congestive heart failure or cancer, many health care consumers have to manage their health conditions daily, outside of the doctor's office (Bodenheimer, Wagner, & Grumback, 2002). To more effectively manage their health conditions, keep track of necessary health information and also to make more informed decisions outside the doctors office, health care consumers need to have access to their historical medical information as well as ways to track symptoms, medical readings and their questions, thoughts and comments about their health and medical care (Kaplan & Brennan, 2001; Civan et al., 2006). Although many consumers agree in the potential utility of such activities, a relatively small proportion actually use existing technology offered to support those activities (Denton, 2001; Markle, 2006; Markle, 2008; California HealthCare Foundation, 2010). Additionally, very little research has explored the reasons underlying this apparent gap (Mandl et al., 2007; Halamka, Mandl, & Tang, 2008; Weizman, Kaci, & Mandl, 2009; Jones et al., 2010) or evaluating the effectiveness of PHR applications (Archer et al., 2011).

2.1 The Patient's Changing Role in the Modern Health Care System

The interaction and relationships between health care providers and health care consumers are changing from paternalistic activity-passivity and guidance-cooperation relationships to more consumer-centered, collaborative relationships of mutual participation. In the paternalistic model of the past, consumers passively accepted what their health care provider told them (Szasz & Hollender, 1956), while in the consumer-centered model both the consumer and provider together make health care decisions (Laine & Davidoff, 1996; Krupat et al., 2000). In part, this model is becoming more prevalent as chronic disease becomes more widespread and health care consumers must partner with their health care providers to help make appropriate treatment decisions as well as carry out the treatment programs at home (Kuhn et al., 2006). The internet has also contributed to this change by making more health information available to health care consumers to enable them to take a more active role in their health care (Brennan & Saffran, 2003; Pratt et al., 2006).

Patient empowerment and patient activation are the two terms commonly used to describe involving health care consumers in their own care through education and information empowerment (Roter, Stashefsky-Margalit, & Rudd, 2001). Research indicates that health care consumers who are better informed about and better understand their care can choose more optimal treatments in collaboration with their clinical providers, are more determined to adhere to treatment regiments and are more content with the quality of care they receive (Butow et al., 2004; Tang & Newcomb, 1998). Research has identified many positive aspects of health care consumers being more informed about their care, such as increased ability of consumers to make medical decisions that reflect the reality of their lifestyle and of physicians to consider both their own and the patient's values and experiences in care decisions (Quill & Brody, 1996; Tang & Newcomb, 1998; Samoocha et al., 2011).

2.2 Personal Information Management and Personal Health Records

In the current health care system, and especially in the care of chronic disease, health care consumers want to be more informed about their care and need and want to have information available to them to make decisions (Civan, et al. 2006; Kaplan & Brennan, 2001; Quill & Brody, 1996; Moloney & Paul, 1991). Personal health records (PHRs) are one possible approach to help consumers collect, understand and use their health information (Markle, 2004; Tang et al., 2006; Markle, 2008; California HealthCare Foundation, 2011).

2.2.1 Patient Access to Medical Records

Allowing patients access to their medical records in clinical information systems is the most studied aspect of PHR use. One of the earliest patient-portal projects that studied giving patients access to their medical information through a web-based tool was the PCASSO project at the University of California (Baker & Masys, 1999; Masys et al., 2002). Patients favorably rated the usability and functionality of the system after using the system for 12 months (Masys et al., 2002). The Geisinger Health System portal in Pennsylvania included functionality that allowed patients to view portions of their medical record and communicate with provider electronically. Users were generally satisfied with the system and felt their information was complete, accurate and understandable (Hassol et al., 2004). In another PHR implementation, patients reported 92% satisfaction with a patient portal into an EMR system implemented by the Palo Alto Medical Foundation (Tang & Lansky, 2005). A patient owned electronic health record in Germany reported positive effects on patient empowerment of a patient-owned electronic health record (Ertmer & Uckert, 2005).

The largest integrated delivery health care system in the US is the Veterans Health Administration (VHA). In 2003 the VHA implemented a patient portal into their electronic medical record. The My HealtheVet web site enables patients to view their health information, make appointments, communicate with health care providers and enroll in clinical trials along with other functionalities (Kupersmith, Francis, & Kerr, 2007; Chumbler, Haggstrom, & Saleem, 2010).

Group Health Cooperative launched their patient web-site, MyGroupHealth in 2000 (MyGroupHealth, 2011). System adoption was studied from September 2002 to 2005 and showed 25% adoption by Group Health members receiving care in network and 94% of patients being satisfied with the MyGroupHealth system overall (Ralston et al., 2007). From June 2005 to December 2007 a 3-group randomized control trial of 778 hypertension patients using MyGroupHealth was conducted. There was a non-significant increase of patients with controlled blood pressure in the group receiving home blood pressure monitoring and web training. A significant increase in patients with controlled blood pressure was achieved in the group that also received web-based consultations with a pharmacist (Green et al., 2008). In 2009, another randomized controlled trial of the MyGroupHealth PHR was published, this time studying diabetes type 2 patients (Ralston, et al., 2009). Patients receiving web-based care management for diabetes type 2 from August 2002 to May 2004 had a significant decrease in GHb levels compared with patients receiving usual care.

A small randomized control study of 107 congestive heart failure patients compared usual care to web-based system that allowed electronic access to medical information, an educational guide and electronic communication between the patients and providers (Ross et al., 2004). After 12 months, patients in the intervention group had significantly higher general adherence then patients in the control group and were more satisfied with patient-provider communication.

A study of 3,979 patients conducted from 2005 to 2007 looked at the effectiveness of delivering health maintenance reminders through a patient portal type system (Wright et al, 2011). Patients in the intervention arm that received reminders through the patient-portal were significantly more likely to receive mammography and influenza vaccinations then patients in the active control arm that just had access to the portal without the reminders. A recent study of sensitive health maintenance reminders, such as HIV screening reminders showed that patients would prefer to receive such reminders through a PHR rather then by e-mail or through their doctor (McInnes et al, 2011). Patients saw little difference between HIV screening reminders versus reminders for cholesterol and diabetes screening; however they felt they would not want sensitive reminders to come to their e-mail inbox.

Many consumers want to know more about their health and make an effort to learn about their health. When consumers are given access to their medical records many choose to familiarize themselves with the information in their records and make an effort to understand that information. When accessing their medical records, many consumers think that knowing the information is useful in their relationship with their own doctor and enables better communication between the patient and the provider (Ward & Innes, 2003; Ralston et al., 2007). Consumers may also become more aware of the kind of information their doctor values and looks for and make more efficient use of their time with their doctor by tracking and providing that information (Civan et al., 2006).

2.2.2 Personal Health Records

The first step to consumers interacting with medical information through personal health records is making their existing information available to them electronically. Furthermore, it is important that consumers not only have access to their medical information but that they have full control of the information in their PHR (Civan et al., 2006; Markle, RWJ, & AHRQ, 2005; Ball & Gold, 2006). Studies have also shown that consumers want the ability to delegate access to all or part of the information in health record to their health care providers, family members or friends, or carry an electronic or digital copy of their record with them in case of an emergency (Civan et al., 2006; Markle, RWJ, & AHRQ, 2005).

A 2004 Markle Foundation National Health Policy Forum brief describes a PHR as a "tool to help patients take a more active role in their care" (Markle, 2004). The Healthcare Information Management Systems Society (HIMSS) defines a PHR as:

> “An electronic Personal Health Record (“ePHR”) is a universally accessible, layperson comprehensible, lifelong tool for managing relevant health information, promoting health maintenance and assisting with chronic disease management via an interactive, common data set of electronic health information and e-health tools. The ePHR is owned, managed, and shared by the individual or his or her legal proxy(s) and must be secure to protect the privacy and confidentiality of the health information it contains. It is not a legal record unless so defined and is subject to various legal limitations.” (HIMSS, 2011)

AHIMA defines a PHR as a typically electronic and universally available, lifelong resource of health information needed by individuals to make health care decisions. They also say that individuals themselves own and manage the information in the PHR, which comes from health care providers and the individual (AHIMA, 2011). That means that the individual uses a PHR to aggregate their own PHI in one place where it can be accessible from anywhere and they have their complete medical history and additional health information available in one place when they need it.

Giving patients access to their own medical record is only the first step in empowering them to take charge of their health. A PHR can be a tool that provides consumers with functionality to use that information to improve their health. In addition to giving consumers a view into their medical record, PHRs can help consumers generate and track their own personal health information. They can provide functionality consumers value, such as tools to gather daily health questions and health information, such as their notes, views and comments about any of their medical information in one place (Civan et al., 2006; Sun, 2001). Additional specialized tools like health diaries, semi-structured health journals and self-help tools can be incorporated into PHR systems (Tang et al., 2006).

Major PHR actors such as Microsoft HealthVault, WebMD, Indivo and others enable sharing of data and usage of multiple tools that help to manage health (Microsoft HealthVault, 2011; WebMD PHR, 2011; Indivo TM, 2011). Consumers can decide which information is important to gather with the help of their medical care provider and suggestions from the personal health record. PHR systems with extended functionality may help consumers better understand their own health as well as provide a window for providers about consumers' health between rare medical visits.

Although entering information into their own health record can help consumers become more aware of their health information and help them better understand it, some studies indicate that health care consumers may be more willing to adopt PHR systems if some of the information is imported from other existing sources, such as insurance information or their existing medical records (Kahn, Aulakh, & Bosworth 2009). There are a number of privacy and data exchange issued associated with this problem. A data exchange format called the Continuity of Care Record (CCR) exists for transferring information between clinical information systems, clinical information systems and PHRs and between PHRs (ASTM, 2007). The CCR standard can be used to transfer information between PHRs or to bring electronic information from multiple sources into a single PHR (Tang & Lansky, 2009). The investigator has been involved in successful pilot studies of data exchange between PHRs and EMR using the CCR standard as part of the Health Information Management System Society Interoperability Showcase (Stolyar, 2005; Stolyar 2006).

In 2006, there were more then 30 PHRs available with patient-centered functionality, where consumers could enter and manage their PHI, not just look into their medical record (Cronin, 2006). In 2010, 91 different commercial PHR systems including such major players as Google Health, Microsoft HealthVault and WebMD that offer extensive features (Jones, 2010). Different PHR systems allow patients to keep different types of information and allow different levels of control over that information. However, clinical effects of these types of functionalities have not been studied.

Initially there were multiple viewpoints in research and industry on the level of control consumers should have to edit or share parts of or their whole PHR record (Markle, 2003; Ball, 2006), however more and more it is becoming accepted that patients can and should have full control over their health information and their PHR. A recent analysis of literature shows the titles and subjects of PHR related publications moving toward being more patient-centered and patient-controlled in recent years (Kim, 2011).

2.2.3 Government Directions for PHRs

Interoperability between health care systems, including personal health record systems, has been recognized by the American government as a clear and important goal to facilitate both efficiency and quality care (HHS, 2007). In 2004, President Bush established the Office of the National Coordinator for Health Information Technology and launched an initiative to make electronic health records available to most Americans within the next 10 years (Bush, 2004). The Office of the National Coordinator for Health Information Technology was charged with developing strategies and initiatives to advance health information technology, including facilitating interoperability.

In 2006, Markle Foundation, the Robert Wood Johnson Foundation (RWJF), and the Agency for Healthcare Research and Quality (AHRQ) held the first national conference focusing on the needs of health care consumers. Results of a national survey showed 72% of Americans favoring the establishment of a nationwide electronic information exchange that would allow health information to be shared with authorized individuals over the internet (Markle, RWJ, & AHRQ, 2005). Also 7 consumer principles were developed by the Personal Health Technology Council, a group of 44 leading consumer and privacy advocates, medical professionals, informatics experts, payers, technologists, federal policymakers, bio-ethicists, and researchers and presented at the conference. These are features that are necessary to make PHRs fully functional and useful for health care consumers and patients:

1. Individuals should be able to access their health and medical data conveniently and affordably.
2. Individuals should be able to authorize when and with whom their health data are shared. Individuals should be able to refuse to make their health data available for sharing by opting out of nationwide information exchange.
3. Individuals should be able to designate someone else, such as a loved one, to have access to and exercise control over how their records are shared.
4. Individuals should receive easily understood information about all the ways that their health data may be used or shared.
5. Individuals should be able to review which entities have had access to their personal health data.
6. Electronic health data exchanges must protect the integrity, security, privacy, and confidentiality of an individual's information.
7. Independent bodies, accountable to the public, should oversee local and nationwide electronic health data exchanges. No single stakeholder group

> should dominate these oversight bodies, and consumer representatives selected by their peers should participate as full voting members (Markle, RWJ, & AHRQ, 2005).

In March of 2007, Representatives Kennedy and Reichert introduced a new version of the Personalized Health Information Act, which calls for incentives to promote use of secure, transportable and consumer-controlled personal health records and patient communication services for Americans. They called for government to get involved in making health information more available to Americans through PHRs, to improve health condition of all Americans by making care more accurate and less costly (Reichert, 2007).

In 2009 President Obama and Congress approved the Health Information Technology for Economic and Clinical Health Act (HITECH) which defined the goal of the initiative not simply as adoption alone but to achieve "meaningful use" of EHRs — that is, their use by providers to achieve significant improvements in care (Redhead, 2009). As a result of this initiative in January of 2010, the Centers for Medicare and Medicaid Services (CMS) and the Department of Health and Human Services (DHHS) published proposed meaningful use requirements and in July DHHS released a final regulation for the first 2 years (2011 and 2012) of this multiyear incentive program (Blumenthal, 2010).

2.2.4 Adoption of Personal Health Records

Adoption of PHRs has been slow although adoption rates have been increasing steadily over the last ten years. Three major nationwide, institution-neutral (not bound to any organization) and un-tethered (not bound to an EMR system) PHRs came onto the market in 2007 and 2008. These three products were the Google Health PHR, the WebMD PHR and the Microsoft HealthVault PHR. In 2011, three years after the release of their PHR Google announced that they are discontinuing their PHR product because it has not been adopted as widely as they had hoped (Goldberg, 2011). A brief history of PHR adoption is provided below.

In 2005, a majority of survey respondents said they would use a private secure personal health record account to check for mistakes in their medical records (69%), check and refill prescriptions (68%), get medical results over the Internet (58%) and communicate by e-mail with their doctors (57%) (Markle, RWJ, & AHRQ, 2005). Many of these functionalities have been made available through patient portals, yet only 10% to 25% of eligible consumers use such portals (Ralston & Carrell, 2006; Weingart et al., 2006; Baldwin, 2007). In 2001 in a research project, which measured PHR adoption, 5% of the 1000 study subjects used a PHR after 10 month, even though 11% of the study subjects (83% of 136 survey respondents) felt that consumers should keep PHRs (Denton, 2001). In a 2004 Harris Interactive Survey 13% of respondents said they used some type of electronic PHR, 41% reported keeping their health information in some other way, and 84% of those who did not thought it was a good idea to keep something like a PHR (Tailor, 2004).

Recent studies from Markle and the California HealthCare Foundation show increasing adoption rates. In a 2008 Markle survey 2.7% percent of respondents said they use an electronic PHR and in a 2010 California HealthCare Foundation survey 7% of respondents reported using a PHR. Interestingly, both studies show similar interest rates in using PHRs, Markle showing that 46.5% of Americans are interested in using a PHR and the CHF survey showing that 40% of those not using a PHR would be interested in using one (Markle, 2008; California HealthCare Foundation, 2010). A significant gap exists between the number of consumers who think PHRs are useful and a good idea and the number of consumers that actually choose to use them. Many potential reasons may exist to explain this gap and the research study conducted and the resulting framework are part of an important first step toward finding an answer.

A study of 100 health care consumers with access to their medical record revealed that many needed help understanding the contents of their health record (Pyper et al., 2004). In order to see the value of a system that helps manage their health information consumers need to feel comfortable with the information itself or know that a PHR will help them become more proficient. Consumers' lack of understanding of how PHRs will help them take better care of their health and PHR systems' lack of functionality that consumers are looking for are some of the many possible reasons for slow PHR adoption (Tang et al., 2006).

According to certain research studies, some of the types of information patients may want to work with that are not included in most personal health records may include (Tang et al. 2006):

- Symptom Tracking and Question Tracking
- Appointment and Health Needs Tracking
- Health Diary and Daily Health Notes
- Self-collected Health Readings
- Experiences of others with similar disease or condition
- Disease Specific Health Information Management Modules

Other studies with health care consumers support that these are the types of health information that consumers want to be able to manage (Civan et al., 2006; Moen & Brennan 2005).

PHR systems often lack functionality that consumers are looking for, for example:

- Helping consumers integrate medical information with their personal health data
- Enabling consumers to keep any information they find valuable such as experiential information of others from support groups
- Managing references to resources consumers use in the process of receiving or managing their care, such as support numbers or references
- Managing resources that help consumers understand their health information, such as health dictionaries or disease information
- Managing bills, statements and other financial medical information
- Sharing their record with other's and delegating access to parts of their health records (Tang et al., 2006)

It is possible that consumers do not understand how PHRs can help them take better care of their health because PHRs often lack the tools to do so. In addition to managing historical medical information, a valuable and perhaps more important part of a personal health record system can be functionality to manage types of health information that are not found in an institutional medical record. This information can include symptoms that consumers experience between visits, questions they may want to ask during a future appointment, treatment adherence and treatment reaction information, notes about visits, records of communication with their provider, and self-collected health data (Civan et al., 2006; Moen & Brennan 2005). Functionality involving this type of day to day health information may lead to consumers using PHR more often and make PHRs more useful to consumers and health care providers (Civan et al., 2006).

Even products from such large actors such as Microsoft and Google are not particularly easy to use and because of this may not appeal to consumers (Peters, Green, & Schumacher, 2009). Although these two applications as well as others such as the WebMD PHR have gotten good reviews in the press Google announced this year that they are closing down Google Health due to low adoption rates. Industry specialists such as Kenneth Mandle and Isaac Kohane have commented that there are multiple reasons for why Google was not able to reach their targeted adoption rates. Both experts said that distributed health information and lack of information flow between actors in the health care system as well as information flow to patients is to blame (Goldberg, 2011; Talbot, 2011). In addition to it being difficult for patients to get access to their health information, Mandl notes that expecting the users to enter this health information by hand is a prohibitively large amount of work. Google is using the CCR standard released in 2007 to allow users to transfer their data to Google health or to download or print their data in other ways (Google, 2011; ASTM, 2007).

2.3 Research Community Views on PHR Adoption

Personal health record applications like most technological products are created and distributed by individuals who are for the most part very technologically savvy, have high health literacy, and are not representative of average consumers. Even the biggest, most oriented to the general consumer and widely available PHRs from Microsoft and Google have been shown to not be fully user centered (Peters, Green, & Schumacher, 2009). It is important for PHR applications to be based on identified user needs and PHR researchers and developers need to ensure that PHR products are based on what consumers need and value. Lack of understanding of user work flow and work needs may result in systems that do not meet user needs and can be possible reasons for poor adoption. It is important to look at how PHRs are viewed by the research community to see how adoption can be influenced through changing research and development efforts.

2.3.1 Markle Foundation: The Personal Health Working Group Final Report

From November 2002 through May 2003, a working group of health information experts and consumer advocates met to examine the potential benefits of PHRs, consumer perception of PHRs, and issues to be addressed as PHR technologies become more widely available. Their final report defines a PHR, as an "Internet-based set of tools that allows people to access and coordinate their lifelong health information and make appropriate parts of it available to those who need it. PHRs offer an integrated and comprehensive view of health information, including information people generate themselves such as symptoms and medication use, information from doctors such as diagnoses and test results, and information from their pharmacies and insurance companies" (Markle, 2003).

The report defines six critical attributes of the personal health record (PHR):

1. Each person controls his or her own PHR. Individuals decide which parts of their PHR can be accessed, by whom and for how long.
2. PHRs contain information from one's entire lifetime and all health care providers.
3. PHRs are accessible from any place at any time.
4. PHRs are private and secure.

5. PHRs are transparent. Individuals can see who entered each piece of data, where it was transferred from and who has viewed it.
6. PHRs permit easy exchange of information with other health information systems and health professionals.

The Personal Health Working Group Final Report also defines a minimum data set for a PHR, lists risks and concerns associated with PHRs, and makes recommendations for making PHRs more acceptable to consumers (Markle, 2003).

Consequently the Markle Foundation published a number of reports on PHRs and their promotion efforts of PHRs continue. In 2004, the Markle foundation published a report describing the importance of electronic information sharing between doctors and patients, which is an important function in PHRs (Markle, 2004). In 2005, in collaboration with the Robert Wood Johnson Foundation and the Agency for Healthcare Research and Quality they published the results of a survey that showed that 72% Americans favor the creation of a nationwide electronic information exchange that would allow patients to share information with others privately and securely via the internet (Markle, RWJ, & AHRQ, 2005).

In a 2008 survey the Markle foundation reported that 2.7% of surveyed Americans used an electronic PHR (Markle, 2008). Of these individuals 46% felt it was very valuable to them, 36% felt it was somewhat valuable and 18% felt it was not valuable. It is unclear from the report why only 2.7% of respondents use a PHR if 46.5% are interested in using one. As a major organizational actor in the PHR arena, the Markle Foundation's involvement and interest as well as their views on PHRs and their adoption are important and their continual involvement in PHR research and promotion are encouraging.

2.3.2 MyPHR.com: AMIA and AHIMA on PHRs

In July of 2006, the American Health Information Management Association (AHIMA) and the American Medical Informatics Association (AMIA) released a position statement advocating the use of personal health records to empower individuals to manage their health care. They defined a PHR as "a tool for collecting, tracking and sharing important, up-to-date information about an individual's health or the health of someone in their care" (AMIA/AHIMA, 2006). The brief defines seven basic principles of that PHR applications must follow to empower individuals to manage their health care:

1. Every person is ultimately responsible for making decisions about his or her health.
2. Every person should have access to his or her complete health information. Ideally, it should be consolidated in a comprehensive record.
3. Information in the PHR should be understandable to the individual.
4. Information in the PHR should be accurate, reliable, and complete.
5. Every person should have control over how their PHR information is used and shared.
6. The operator of a PHR must be accountable to the individual for unauthorized use or disclosure of personal health information.
7. A PHR may be separate from and does not normally replace the legal medical record of any provider.

The brief also describes 16 categories of information a PHR should contain, such as opinions of specialists, test results, people to contact in case of emergency and 13 other categories. The position statement indicates what these two leading informatics associations consider to be important functionality and features of a Personal Health Record, and as organizational leaders in the research community, their position needs to be carefully considered. They also point consumers to www.myPHR.com for further consumer-centered information on creating and managing a PHR (AMIA/AHIMA, 2006).

2.4 General Adoption of Technology Models

General adoption of technology models may be able to provide some insight into why personal health records have not been more readily adopted by consumers. There are two well known bodies of work related to adoption of technology, Rogers' 1985 Diffusion of Innovation theory, which is sometimes also referred to as the Adoption of

Innovation theory (Rogers, 2003) and the Technology Acceptance Model (TAM) (Davis, 1989).

2.4.1 Rogers' Diffusion of Innovation Theory

The Diffusion of Innovations concept is based on diffusion theory, which describes the typical spread of innovations within a social system (Rogers, 2003). The theory describes factors and conditions that need to be present in order for an innovation to reach the tipping point of adoption, the point at which a technology becomes common enough to start spreading exponentially in a population.

One of the aspects of the diffusion of innovations theory focuses on the five types of adapters, 1) innovators, 2) early adopters, 3) early majority, 4) late majority and 5) laggards and how to make technologies more appealing to innovators and early adopters to help them catch on. It also states that spread of the innovation hinges on whether or not opinion leaders vouch for the innovation. These adopter types are defined below in Table 2.4.1.1.

Although the decision to adopt a technology is affected heavily by the adoption decisions of others in a social system, Rogers also described the decision process an individual goes through when considering whether to adopt or not adopt a technology. Each member of a social system faces their own innovation-decision that follows a 5-step process (Rogers, 2003):

1. **Knowledge** – person becomes aware of an innovation and has some idea of how it functions,
2. **Persuasion** – person forms a favorable or unfavorable attitude toward the innovation,
3. **Decision** – person engages in activities that lead to a choice to adopt or reject the innovation,
4. **Implementation** – person puts an innovation into use,
5. **Confirmation** – person evaluates the results of an innovation-decision already made.

Each of the five stages of the decision making process as defined by Rogers in the Diffusion of Innovations theory is described below in Table 2.4.1.2.

1 Table 2.4.1.1 Rogers' Five Adopter Categories

Adopter category	**Definition**
Innovators	Innovators are the first individuals to adopt an innovation. Innovators are willing to take risks, youngest in age, have the highest social class, have great financial lucidity, very social and have closest contact to scientific sources and interaction with other innovators. Risk tolerance has them adopting technologies which may ultimately fail. Financial resources help absorb these failures.
Early Adopters	This is the second fastest category of individuals who adopt an innovation. These individuals have the highest degree of opinion leadership among the other adopter categories. Early adopters are typically younger in age, have a higher social status, have more financial lucidity, advanced education, and are more socially forward than late adopters. More discrete in adoption choices than innovators. Realize judicious choice of adoption will help them maintain central communication position.
Early Majority	Individuals in this category adopt an innovation after a varying degree of time. This time of adoption is significantly longer than the innovators and early adopters. Early Majority tend to be slower in the adoption process, have above average social status, contact with early adopters, and seldom hold positions of opinion leadership in a system.
Late Majority	Individuals in this category will adopt an innovation after the average member of the society. These individuals approach an innovation with a high degree of skepticism and after the majority of society has adopted the innovation. Late Majority are typically skeptical about an innovation, have below average social status, very little financial lucidity, in contact with others in late majority and early majority, very little opinion leadership.
Laggards	Individuals in this category are the last to adopt an innovation. Unlike some of the previous categories, individuals in this category show little to no opinion leadership. These individuals typically have an aversion to change-agents and tend to be advanced in age. Laggards typically tend to be focused on "traditions", likely to have lowest social status, lowest financial fluidity, be oldest of all other adopters, in contact with only family and close friends, very little to no opinion leadership.

2 Table 2.4.1.2 Rogers' Five Stages in the Adoption Process

Stage	Definition
Knowledge	In this stage the individual is first exposed to an innovation but lacks information about the innovation. During this stage of the process the individual has not been inspired to find more information about the innovation.
Persuasion	In this stage the individual is interested in the innovation and actively seeks information/detail about the innovation.
Decision	In this stage the individual takes the concept of the innovation and weighs the advantages/disadvantages of using the innovation and decides whether to adopt or reject the innovation. Due to the individualistic nature of this stage Rogers notes that it is the most difficult stage to acquire empirical evidence.
Implementation	In this stage the individual employs the innovation to a varying degree depending on the situation. During this stage the individual determines the usefulness of the innovation and may search for further information about it.
Confirmation	Although the name of this stage may be misleading, in this stage the individual finalizes his/her decision to continue using the innovation and may use the innovation to its fullest potential.

3 Table 2.4.1.3 Rogers' Five Attributes of Innovations

Factor	Definition
Relative Advantage	How improved an innovation is over the previous generation.
Compatibility	The level of compatibility that an innovation has to be assimilated into an individual's life.
Complexity or Simplicity	If the innovation is too difficult to use an individual will be unlikely to adopt it.
Trialability	How easily an innovation may be experimented with as it is being adopted. If a user has a hard time using and trying an innovation this individual will be less likely to adopt it.
Observability	The extent that an innovation is visible to others. An innovation that is more visible will drive communication among the individual's peers and personal networks and will in turn create more positive or negative reactions.

Rogers also defines five attributes that are intrinsic to innovations. These are attributes of information systems that contribute to adoption and they are defined in Table 2.4.1.3 (Rogers, 2003).

In 2002, the California HealthCare Foundation released a report describing the ten critical dynamics from the Diffusion of Innovations theory that govern how new technologies are adopted in health care (Cain & Mittman, 2002). The report calls for using the Diffusion of Innovations Theory to change the pace of adoption of IT in health care. Other researchers call for use of the Diffusion of Innovations theory in health care (Fitzgerald et al., 2002; Berwick, 2003), but few studies have been published actually applying these concepts to health information technologies including PHRs.

2.4.2 The Technology Acceptance Model (TAM)

The technology acceptance model focuses on two major aspects of adoption from the point of view of the individual adopting the technology, perceived ease of use and perceived usefulness (Davis, 1989). Davis defines perceived ease of use (PEU) as "the degree to which a person believes that using a particular system would be free of effort," and perceived usefulness (PU) as "the degree to which a person believes that using a particular system would enhance his or her job performance." Six items used to evaluate each factor are described in Table 2.4.2. Some studies indicate that there maybe a causal relationship between perceived ease of use and perceived usefulness and that usefulness may be more strongly linked to use then ease of use (Spil, 2006).

The TAM model was later extended into the TAM2 model, which accounts for human and social change process variables, the subjective norm (Venkatesh & Davis, 2000; Legris, Ingraham, & Collerette, 2003). Venkatesh then used eight prominent technology adoption models to design the Unified Theory of Acceptance and Use of Technology (UTAUT) theory and instrument to assess both original TAM variables and social norm variables (Legris et al., 2003).

4 Table 2.4.2 The Scale of Items Used to Evaluate PEU and PU for TAM

Ease of Use (PEU)	Usefulness (PU)
1. Easy to learn	1. Work more quickly
2. Controllable	2. Job performance
3. Clear and understandable	3. Increased productivity
4. Flexible	4. Effectiveness
5. Easy to become skillful	5. Make job easier
6. Easy to use	6. Useful

The Technology Acceptance Model has been used in health care to evaluate the adoption of health information technology by both patients and by providers. In 2004, three models, including TAM and TAM2 were used to evaluate acceptance of an e-health product that provided access to informational health content, e-mail communication with their provider and online prescription ordering (Wilson & Lankton). The study showed that all models did reasonably well in predicting acceptance. In a study by Holden and Karsh 16 data sets were analyzed in over 20 studies of clinicians using health IT for patient care (2010). The study concludes that TAM is able to predict use and acceptance of health IT, but that the theory requires further study and modifications. This and other studies call to adopt TAM specifically to health care contexts.

2.5 Summary

In the current health care system where patients have to take more and more responsibility for managing their care, information management tools may be needed to help patients manage their health information. An additional need for PHRs and health information management arises because of the high prevalence of chronic disease in the US population and the increasing number of patients with multiple co-morbidities. These types of conditions require that the patient manage health information at home to manage their condition and these patients have complex management needs. Personal health records are tools that can help patients collect, manage and use this information and lead to improved care.

Personal health records have been actively studied and discussed in the literatures since the beginning of the millennium, the government and the media have publicized PHRs as a useful tool for consumers, but research has mostly focused on defining not evaluating PHRs. Many potential uses and benefits of PHRs have been discussed in the literature. Patients are generally satisfied with PHRs and patient-portal products and improvements in patient-provider communication and even in clinical scores have been achieved though PHR use. Despite the fact that studies have shown that PHRs have some benefits to consumers and surveys show that many consumers are interested in adopting PHRs, actual adoption rates have stayed very low and the reasons for this are unknown. This research aims to address these gaps by exploring reasons why individuals choose to adopt or choose not to adopt PHRs, what factors motivate consumers to use PHR systems and what factors discourage them. In addition, this research will explore whether we can build on existing technology adoption literature to study PHR adoption.

Chapter 3. Theory and Methods Involved in the Study

3.0 Introduction

This study was conducted in a setting where a PHR had been available for some time to a group of low income, elderly and disabled users. The time the record had been available was sufficient that the individuals in the population had had time to sign up and use the PHR if they had wanted to do so. The main goal of the study was to explore what motivates individuals to adopt and use the PHR from their own perspective. The study design was informed by grounded theory (Strauss & Corbin, 2005). Data was collected through open-ended guided interviews and data analysis was based on grounded theory concepts, where the resulting models emerged completely out of the data and were not based on any existing framework, theory or the researcher's preconceived notions.

In this chapter, approval to conduct research with human subjects and methods and theories used in the study are described in Sections 3.1 and 3.2. Section 3.3 follows with a description of the E-Medicine PHR system and the setting where the system was implemented and this study was conducted. Data analysis is described in Section 3.4 and establishment of trustworthiness in Section 3.5. The chapter concludes with a description and demographics of participants in Section 3.6.

3.1 Human Subjects

Approval to conduct research with human subjects was received from the University of Washington Human Subject Division on September 21, 2007 (application number #07-7564-E/C 01). All recruitment materials, study instruments and study procedures were reviewed and approved.

3.2 Study Design

The study design was guided by grounded theory (Strauss & Corbin, 2005). The research findings were fully grounded in data. The data came completely from the participants and the setting, no attempt was made to involve preexisting frameworks and theories to inform either the data collection or data analysis. The interview guides were semi-structured in that they focused on the participants' knowledge of personal health records, health information management and how they used the tool or managed their health information in other ways. Participants were prompted to explain in as much detail as possible their understanding of personal health records, their use and adoption.

Qualitative data collection methods were chosen because they enable the researcher to gain an in-depth understanding of individuals, groups and settings. Data analysis was a continuous, iterative process that started during data collection. Future data collection was based on the results of the in-progress analysis and both the intermediate and final results emerged fully out of the data, as opposed to being based on pre-existing expectations of the researcher or existing theories.

Data were collected in two housing authority residences between October and December of 2007. Housing authority residents, and nursing students and a social worker who helped the residents use the PHR were interviewed. As an additional validation and triangulation measure selected residents were interviewed for a second time using a "think aloud" type technique (Nielsen, 1994). All interviews were audio recorded and transcribed and notes were taken during interviews.

3.2.1 Participant Recruitment

A stratified purposive sample of residents, both users and non-users of the E-Medicine system was taken (Patton, 2002). An attempt was made to recruit as many system users as possible and a similar number of non-users. In addition, users who had used the system only once were recruited to ensure that people who might have used the system once and had no plans to use it again were represented.

Participants were recruited with the help of housing authority staff through flyers distributed to all EHA residents and posted in the two residences where E-Medicine was deployed. A letter introducing the researcher to the residents was sent out and a short news announcement about the research being conducted was included in the monthly newsletter. The interviewer also attended two resident meeting to introduce herself to the residents, so that they would be more comfortable contacting her. Flyers were placed in elevators, on the announcement boards on each floor, in the computer rooms and in the administrative offices that residents visit. Previous E-Medicine PHR activities and research studies were advertised through flyers in these locations and most users had been recruited through these flyers. Flyers instructed residents to contact the researcher by phone or e-mail to participate in the study. After the first round of interviews flyers were also placed in the mailboxes of all residents. The flyer used is included in Appendix J.

Participants read the consent form and were given the opportunity to ask questions before the start of the interview. The consent form for participation in the research is included in Appendix K. At the end of the interview, participants were given a $5 grocery store gift card as a thank you gift for their time and participation in the study.

During the interview residents were asked if they could be contacted for a second interview and 6 residents that agreed and were available were chosen to be interviewed for the second time.

Health care professionals were recruited orally or by e-mail using the script provided in Appendix L. The consent form for health care professionals is included in Appendix M.

3.2.2 Resident Interviews

Interviews were conducted with 32 residents of two housing authority buildings where the PHR had been implemented. Residents who had never used the PHR, residents who had used the PHR only once and those who had used it more then once were recruited. The 32 interviews ranged in lengths from 11 minutes to 1 hour and 7 minutes in length. Most interviews were 20 to 45 minutes in length. Interviews were audio recorded.

Interview questions centered on what participants know and think about personal health records, how they manage their health information and the E-Medicine record in particular. Various questions were asked about how they use the E-Medicine record, why they decided to sign up, what they see as the most important or valuable parts of the system, and whether there was anything they would like to change. Participants who did not use the system were asked to talk about whether and how they manage their health information. They were also asked whether they had heard of personal health records, to describe what they are and what they think about them. The researcher used the interview guide to prompt the interviewees. The interview introduction and demographic information collection form are included in Appendix A and the interview guide in Appendix B. A sample interview is provided in Appendix E.

Questions were asked in a general open-ended way that encouraged the participants to talk about issues that were important to them. Questions guided the participants to talk in depth about their health information management strategy and the role of the E-Medicine PHR system in their health information management activities. If the resident had not used the PHR system they were prompted to discuss the reasons for choosing not to sign up, their health information management strategy and willingness to use an electronic PHR system or to manage their health information at all. Statements were then analyzed and clustered in a way that made the most sense. Iterative analysis of earlier interviews was used to guide participants in subsequent interviews.

Interview questions were pre-tested with a colleague who is an expert in consumer health informatics. Additionally, this colleague participated in an initial analysis of the first set of interviews to identify areas where more probing was appropriate or necessary and helped develop additional interview prompts and questions.

3.2.3 Second Time Resident Interviews and Observations

An additional guided interview was conducted with 6 residents who had participated in the first round of interviews and agreed to be contacted for a future interview. If during the course of the first interview the researcher felt that it would be valuable to interview this person a second time, she would ask the participant if it was ok to contact them again at a later time for a second interview. Participants who appeared to be able to provide additional information that informed the research questions were selected to participate in a second interview. Some participants did not fully open up until the very end of the first interview or had interesting thoughts and ideas that could be explored further, those participants and those who seemed like they would be able to provide more information if they had their record to refer to were selected. A total of six residents were available and able to be interviewed for a second time. These sessions were also audio recorded and lasted from 13 to 53 minutes.

This second time interview was a combination interview and observation session. Instead of the interviewer leading in the interview, the participants were asked to lead, to tell the researcher what they were doing and why and what they think about the record and different parts of the record as they did this. There was an interview script, that the researcher used to ask questions when it was appropriate to do so in the conversation they were having with the participant. The interview question guide for the repeated interviews is included in Appendix C and a sample repeated interview in Appendix F.

As participants looked through the screenshots or clicked through the record, they were asked to talk about why they were changing or updating certain information, how often they update their record, how they decide when it is time to update their information, who the information is for and how they use it. Participants were also asked to talk about the type of information they store on each page of E-Medicine, whether there is any additional information they would like to see stored in E-Medicine or features that they would like E-Medicine to have or if there is anything about it they do not like, and they would like to see changed.

3.2.4 Health Care Professional Interviews

Two nursing students and a social worker who were closely involved with the PHR implementation and helped residents sign up for and use the E-Medicine PHR were interviewed. These interviews were used as a validation and triangulation tool to obtain information about PHR adoption by residents from a health care professional's point of view. The interviews were audio recorded and were 32, 49 and 52 minutes in length.

Only one social worker was interviewed because the social worker from the second building had recently changed jobs and moved out of state and could not be reached for an interview. The social worker who replaced her was not yet familiar with the PHR system and how the residents use it.

The health care professionals were asked to think about what they have heard from the residents and what they have observed about PHR use by the residents. They were asked to discuss why some residents chose to use the system and some do not. They were also asked to recall if residents had talked about their reasons for signing up or alternatively for not signing up to use the record. They were also asked to talk about whether a different type of population would have different needs and how they felt the needs of the residents might be different from other populations.

The health care professional interview guide is included in Appendix D, and excerpts from a nursing student interview and a social worker interview are included in Appendixes G and H, respectively.

3.3 System and Setting Description

The E-Medicine PHR system is a web-based personal health record[1] with basic functionality that allows users to store and organize their longitudinal health information. The E-Medicine system was designed at the University of Washington by a team of clinicians and informed by informal help from health care consumers. In 2004 the E-Medicine system was deployed to low-income, mostly elderly and disabled residents of a Seattle metropolitan area housing authority (further referred to as "the housing authority") as part of a larger study by the University of Washington Bioengineering Department.

This site was chosen for this study because it was an opportunity to study a setting where a PHR had been available and actively advertised to a group of potential users for a prolonged period of time and a significant number of residents had chosen to use it. It is also a particularly interesting setting because of the demographics of the residents; all

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[1] The E-Medicine system is also known as Personal Health Information Management System (PHIMS) from earlier research projects and sometimes this name is used in earlier publications (Lober et al., 2006; Kim et al., 2007, Kim et al., 2009).

households were low-income and many residents were elderly and disabled and had multiple co-morbidities. PHR use in this demographic group is particularly interesting to study because they are not often studied, and it has been indicated in some research that they are less likely to use a PHR even though they may need it and benefit from it more then any other demographic group (Lafky & Horan, 2005; Markle, 2008).

Section 3.3.1 will describe the setting where the system was implemented. Section 3.3.2 describes the E-Medicine PHR system itself. The details of the system implementation at these two residences will be described in Section 3.3.3.

3.3.1 Setting Description

The research setting is a housing facility for low income, disabled and elderly residents where a personal health record (PHR) system called E-Medicine has been deployed and available to the residents of two housing authority apartment buildings. These two housing authority residences serve approximately 500 households. At any given time, approximately 330 individuals and families live in the two residences. Most residents had household incomes below 100% of the federal poverty line, although the eligibility for residency is income below 250%. The majority of residents were elderly (age 65 or over) and had a high prevalence of multiple chronic illnesses.

E-Medicine was deployed at the first building which served approximately 180 residents in December of 2004. More then two years later in May of 2006 it was deployed at the second building which serves around 150 residents. Socioeconomic status and age distribution of the residents in the second location were similar to those in the first apartment building, except that about 30% (45/150) of residents in the second building were immigrants whose primary language was Russian.

At the start of data collection for this study, the record had been available for almost three years to the residents of one housing authority building and almost a year and a half at a second building. As of August 2007, there were a total of 70 accounts in the system, but only 44 users were still living in the two buildings (Lober et al., 2006).

The average age of residents who used the E-Medicine system was 63 years and 71% were female (Herbaugh, 2009).

During the time the PHR was offered, two graduate nursing students visited the complex once a week (mostly Thursdays from 10:00 a.m. to 2:00 p.m.) to help the residents create and manage (enter, update, delete or print) their record. One housing staff member (social worker) occasionally helped the residents as well. For Russian-speaking residents, a translator service was also made available. Informational sessions were conducted regularly to introduce the E-Medicine system to the residents and demonstrate how to use it.

In 2004, approximately 80% (145/180) of residents at the first building where the PHR was deployed did not have Internet access (Lober et al., 2006). Consequently, a computer room equipped with 6 PCs with a broadband Internet connection and a printer was set up for the residents. When the deployment was expanded to the second building in 2006, the second location already had a computer room with 4 Internet-linked PCs and 2 printers.

Multiple research studies have been conducted to evaluate both the deployment of the E-Medicine PHR system and how residents use the system (Lober et al., 2006; Kim et al., 2007). The Lober 2006 study evaluated barriers to use of the E-Medicine personal health record and included complete survey data on 38 residents of the 57 who had used E-Medicine up to that time. Most residents (78%) reported needing assistance to update their E-Medicine records. Self-reported barriers to use of the PHR included, computer literacy (63%), computer anxiety (58%), cognitive impairments (34%), health literacy (29%) and physical impairments (26%) (Lober et al., 2006). In 2009, a survey was administered to 14 users who had taken their record with them to their health care provider and showed that users felt this was a positive experience that made the appointment smoother and more productive (Herbaugh). A 2010 survey of 10 users showed that users felt the PHR helped them manage their chronic conditions (Shinstrom). Both studies report that residents felt that using the record made it easier for them to communicate with their health care providers (Herbaugh, 2009; Shinstrom, 2010).

3.3.2 E-Medicine Personal Health Record System

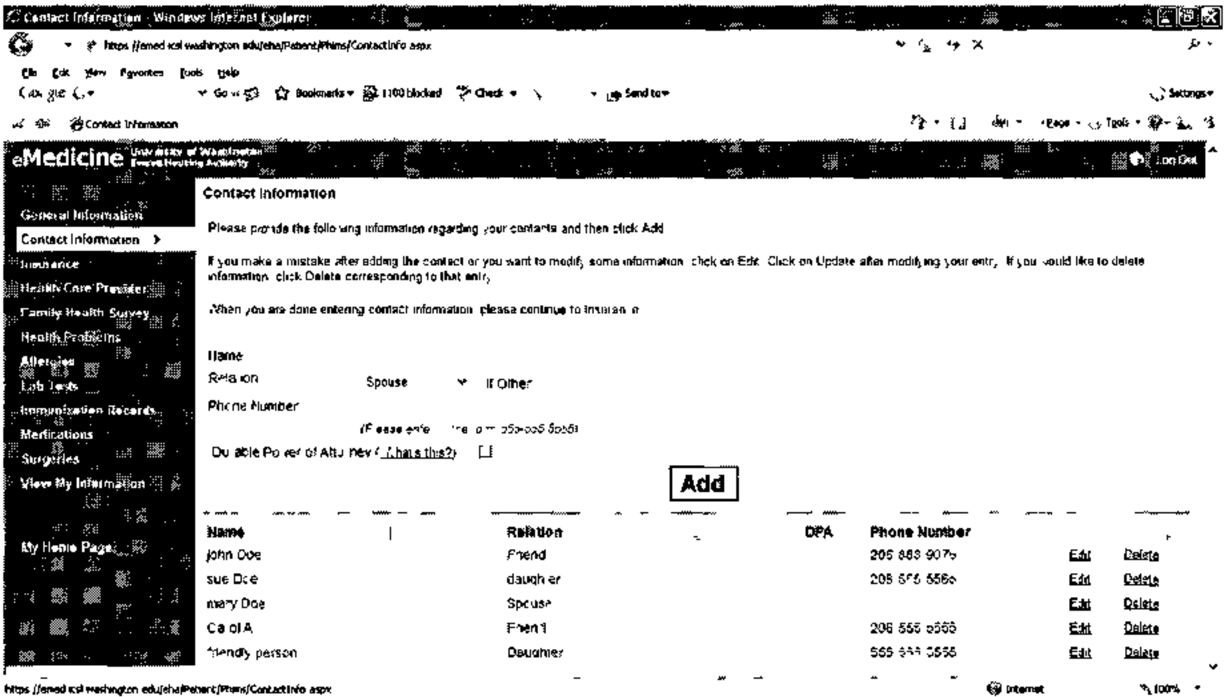
E-Medicine is a PHR system that is institution-neutral (not bound to any organization) and un-tethered (not bound to an EMR system). It is an individually-controlled, web-based repository of personal health information. It allows users to enter, update or delete structured information in 11 different categories. These categories are the general types of information any health care consumer might manage and most PHRs have similar sections for managing health information (Tang et al., 2006; Li, 2011).

1. General Information
2. Contacts
3. Insurance
4. Care Provider Information
5. Family Health Survey
6. Health Problems
7. Allergies
8. Lab Tests
9. Immunization Records
10. Medications
11. Surgeries

Each health information category has multiple information elements. For example, under medications a user can record dosage, effectiveness, prescribing doctor's name, and reasons for taking and stopping each medication. Many categories have free-text boxes where any additional information a user wants to record can be entered. A user can enter questions, notes or topics they wish to discuss with their providers in special text boxes.

In a 2007 article, Kim presented usage of the E-Medicine PHR from the system perspective by looking at access patterns for the E-Medicine application. The authors report that the 46 users who had used the record between December 2004 and May 2006 had populated at least 7 of the 11 health information categories. Medications and health problems were the two most frequently updated categories of health information, and lab tests and immunizations were least frequently updated (Kim et al., 2007). The E-Medicine system generates a printable summary page that lists all the information a user has entered into the system. It does not include functionality to share the record with health care providers or others electronically.

Screenshots of the system are presented below and in Appendix I.



Contact Information

Please provide the following information regarding your contacts and then click Add

If you make a mistake after adding the contact or you want to modify some information, click on Edit. Click on Update after modifying your entry. If you would like to delete information, click Delete corresponding to that entry.

When you are done entering contact information, please continue to Insurance.

Name

Relation Spouse If Other

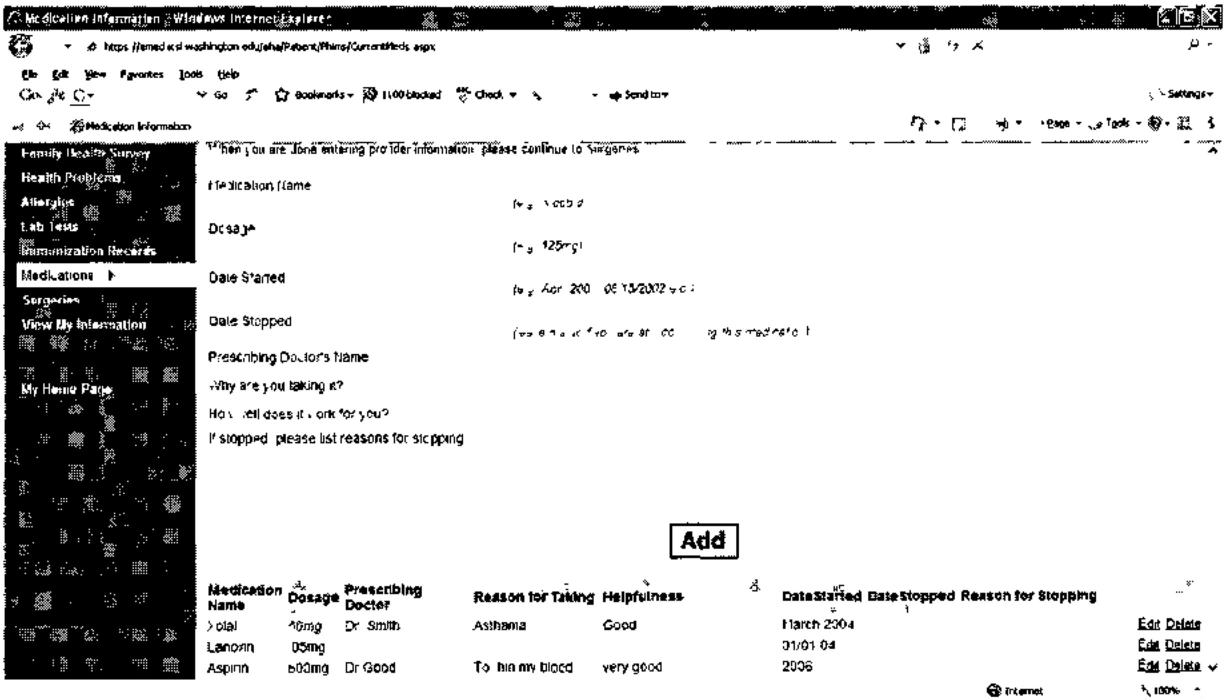
Phone Number

Durable Power of Attorney? (What's this?) ☐

Name	Relation	DPA	Phone Number		
John Doe	Friend		206 883 9075	Edit	Delete
sue Doe	daughter		206 575 5560	Edit	Delete
mary Doe	Spouse			Edit	Delete
Carol A	Friend		206 555 5555	Edit	Delete
friendly person	Daughter		555 555 5555	Edit	Delete

https://emed.icsl.washington.edu/eha/Patient/Phins/ContactInfo.aspx

1 Figure 3.1 Screenshot of the "Contact Information" page with sample data



https://emed.icsl.washington.edu/eha/Patient/Phins/CurrentMeds.aspx

When you are done entering provider information, please continue to Surgeries.

Medication Name

Dosage

(e.g. 125mg)

Date Started

Date Stopped

Prescribing Doctor's Name

Why are you taking it?

How well does it work for you?

If stopped, please list reasons for stopping

Medication Name	Dosage	Prescribing Doctor	Reason for Taking	Helpfulness	DateStarted	DateStopped	Reason for Stopping	
Xolair	40mg	Dr. Smith	Asthama	Good	March 2004			Edit Delete
Lanoxin	05mg				01/01 04			Edit Delete
Aspirin	600mg	Dr Good	To thin my blood	very good	2006			Edit Delete

2 Figure 3.2 Screenshot of the "Medication" page with sample data

The E-Medicine PHR system is a simple and all-encompassing system that for the purposes of this research was viewed as a model system that allows users to manage basic information included in any PHR system. Interviews were guided in such a way that participants were encouraged to talk about their HIM strategies both related to the system and outside of it. Those participants who had never used E-Medicine were encouraged to talk about their management strategy and after looking at screenshots of the E-Medicine PHR talk about whether they would want to and feel they could manage using the system.

Because the E-Medicine system was available and actively advertised to all residents, they had been able to find out about this particular, PHR and think about PHRs and HIM in general and to come to some conclusions about health information management and PHR use. This was the information that the study focused on and was discussed during the interview. The residents could draw on their personal adoption decision and their observations of other residents to answer questions about factors that contribute to the willingness or not willingness to use a PHR system or manage health information.

3.3.3 E-Medicine Implementation at the Housing Authority

As of October 2007, when data collection for this study was started approximately 44 residents had active accounts in the E-Medicine system. There were a total of 70 accounts in the system (Kim et al., 2009). Informational sessions about E-Medicine to which all residents were invited were held regularly at both buildings. Flyers were regularly placed around both authority buildings with a brief description of the system both to advertise the informational sessions and to inform residents when the nursing students were available to help residents sign up and use the record.

When a resident came for the first time to an arranged meeting with a nursing student, the nursing student set up an account for them in the E-Medicine system. Then the student would help them enter health information. Some residents chose to use the system on their own after the initial meeting and some made appointments with the nursing students every time they needed to update their record.

In one building, nursing students used the record with the residents in the computer laboratory. During these sessions the laboratory was closed to other residents. For participants who did not want to use the laboratory, social workers allowed the nursing students and residents to use their office upon request. In the second location a computer was placed in a separate room especially for E-Medicine use.

Most of the time, nursing students visited the buildings twice a week. Also the social workers at both buildings talked to the residents about the record and encouraged them to use it. One of the social workers was particularly good at promoting the system, he had also helped residents use their record when nursing students were not available.

Residents were given a card with the system URL, their log in and password to carry in their wallet for their own use and to be found in case of emergency. They were also given printouts of the filled out record at the end of every session with the nursing students.

3.4 Analysis

At the basic level, data analysis was conducted using grounded theory (Strauss & Corbin, 2005). Grounded theory helps create an evolving hypothesis through systematic coding of data even as data is collected. Field notes were taken during the interviews and observation sessions. Interviews were transcribed by the investigator and all identifiers were removed from the data.

The researcher made no attempt to identify themes of interest prior to data collection and analysis or to base the data collection or analysis on an existing framework or theory, all themes were allowed to emerge out of the data and are grounded in the data.

Initial codes identified were topics repeatedly mentioned by more then one participant. At first transcribed interviews were read and initial results were discussed with a colleague who is an expert in consumer health informatics and additional questions or areas to pay additional attention to during interviews were identified.

Quotations ranged in length from part of a line to 5 or 6 paragraphs in length where a participant was discussing a larger idea. One quotation could be coded with multiple codes if multiple subjects were touched. Within the longer quotations, smaller quotations could be coded with different codes.

The researcher continued to do interviews while she was receiving additional information pertinent to the research question and was able to find more individuals who were willing to participate in interviews. Although it was difficult to determine whether saturation was reached because the topic of the research is of a wide and overview like nature, interviews were stopped when the topics discussed by interviewees started to repeat, no new topics were emerging and the emerging results were formed enough to use them for validation.

Further analysis was done using the Atlas.ti software (Atlas.ti, 2011), version 6.2.26 and followed the common steps for qualitative research guided by grounded theory described by Strauss and Corbin (2005). In step 1, data was collected and transcribed. In step 2, "open coding" more then 257 distinct codes were generated that were tied to almost a thousand quotations. In subsequent steps "axial coding" and "selective coding" codes were sorted, added, combined and deleted to form the subsequent theory and model. After this 191 codes were left. Eventually codes that were not related to the emergent thematic sets were removed and 118 unique codes and 822 quotations were left in the data.

3.5 Trustworthiness

Establishing trustworthiness enables a qualitative study to establish methodological soundness. Truth value of the data is established through credibility, applicability of the research findings to other similar populations and settings through transferability, consistency through dependability and neutrality or objectivity of the study through conformability (Lincoln & Guba, 1985).

3.5.1 Credibility

There are five common activities that increase the credibility of findings: (a) prolonged engagement, (b) persistent observation, (c) triangulation, (d) member checking and (e) peer debriefing. Data were gathered through prolonged engagement in the field and the interviewer engaged in rigorous note taking. Data was collected over a period of about 3 months during which even individuals who were at first reluctant about approaching the researcher had the opportunity to engage in the study. I was able to learn the culture, fears and expectations of the residents and over this time all relevant findings and atypical findings were identified.

Triangulation was achieved by interviewing residents who never used the record, those who had used it once and those who had used it more then once. Triangulation was also achieved by obtaining information from multiple types of sources. Interview data was supported with additional observation data and also with interview data from health care providers who were familiar with the system design, implementation and use by residents and who were involved in helping residents use the system.

As part of member checking, emerging results were repeatedly reported back to the participants during the following interviews. Some participants even asked about what other participants had said about the PHR and managing health information.

Peer debriefing was also iteratively done by presenting emerging results to colleagues in the field of biomedical and health informatics.

3.5.2 Transferability

To ensure transferability research methods, research subjects and the research setting where the study was conducted are described in detail. Thick description of the research methods and theories ensures that research findings of this work can be compared to other research.

3.5.3 Dependability

Dependability is about ensuring that a qualitative study is consistent and reliable. It ensures that if a study would be replicated with similar participants in a similar context it would be able to give repeatable findings. Intercoder reliability was done to ensure that if another researcher had access to similar data they would come to similar conclusions about the research results.

One and a half percent (1.5%) of all codes were selected using a random number generator. There were 1015 quotation in the data at the time intercoder reliability was conducted. Quotations ranged in length from part of a line to multiple paragraphs. A random number generator on the random.org site was used to select 15 quotations (15 random numbers from 1 to 1015 were generated).

Three coders who were somewhat familiar with the content and purpose of the study were asked to code each quote or part of a quote as they saw appropriate using the three Levels of Interest (Interested in Management, Minimally Interested in Management and Not Interested in Management) and using the seven factor groups (Information Access, System and Technical, Information Management, Medical System, Personal Health and Life Situation, Social and Privacy and Security).

Agreement was counted when at least one of the codes for each quotation matched between the reliability coder and the researcher. For Rater 1, 8 out of 15 coded quotations agreed with the researcher's coding, for Rater 2, 10 out of 15 quotations agreed, and for Rater 3, 10 out of 15 quotations agreed (had at least one code in common).

3.5.4 Confirmability

Confirmability ensures the objectivity of the study. To ensure confirmability scrupulous notes were kept that can be used to track activities and methodological decisions made during the study.

3.6 Participant Characteristics

Of the 32 residents interviewed, 19 had used the system at least once and 13 had never used the system. In the following chapter participants are often described as "potential users" because the E-Medicine personal health record was made available to all housing authority residents and some had chosen to sign up and use it and some had not, but all residents were "potential users" of the PHR.

5 Table 3.7.1 Demographics of the Recruited Sample of 32 Participants[2]

1. Ethnicity
   White Caucasian: 27 (84%)
   American Indian: 1 (3%)
   African American: 1 (3%)
   Other: 2 (6%)
   No answer: 1 (3%)

2. Gender
   7 (22%): male
   25 (78%): female

3. Participants' age and gender distribution

Age	Male	Female	Total
19-25	0	1	1 (3%)
26-64	4	14	18 (56%)
65-84	3	8	11 (34%)
84+	0	2	2 (6%)

4. Participants' perception of their own personal health
   12 (38%): very good or excellent
   19 (59%): good or fair
   1 (3%): poor

5. Participants' self-assessment of their involvement in HIM
   28 (88%): I manage all my health information
   4 (12%): I manage most of my health information by myself
   0 (0%): Someone else mostly manages my health information

6. Residence type
   All informants lived independently in separate apartments.
   All informants except one lived alone.

7. Sufficient income
   Yes: 20 (62%) participants
   No: 12 (38%) participants

Participant demographics are reported in Table 3.7.1, the structure of which was borrowed from a study by Moen and Brennan (2005). Most study participants were

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[2] Demographic questions and structure for this table were based on those used by Moen and Brennan, Health@Home: The Work of Health Information Management in the Household (HIMH): Implications for Consumer Health Informatics (CHI) Innovations.

female (25 participants, 78%) and 7 participants (22%) were male. Almost all participants (90%) were between the ages of 24 and 84, 56% were aged between 26 and 64 and 34% were 65 to 84 years of age. Most participants (82%) were white Caucasian.

All of the 32 study participants were from low-income households as this was a requirement for residence in the housing authority housing. However, 62% of participants reported having a sufficient income to meet their needs, and 38% reported that their income was not sufficient. Although most participants managed multiple chronic diseases, 38% considered their own health to be excellent or very good, 59% considered it to be good or fair and only 3% considered it to be poor. A majority of participants (88%) reported managing all health information on their own and 12% managed with some help from others. None reported that someone else managed their HI for them.

In Table 3.7.2, participants are described by gender and the number of times the E-Medicine record was utilized. Of the 32 interviewees, 13 (40%) had never used the record, 6 (19%) had used it once and 13 (40%) had used it more then once. Of the 57 total users at the housing authority a total of 16 users were recruited for the study (28%).

6 Table 3.7.2 E-Medicine Use Among 32 Study Participants

Number of times used	Male	Female	Total
Never	3	10	13 (40%)
Once	3	3	6 (19%)
Two or more times	1	12	13 (40%)

Participants were sampled to make sure that some had not used the record, some had used it only once and some had used it more then once. Most participants were female as is the case in most research about managing health information (Moen & Brennan, 2005). Because this research was conducted in a low-income housing residence all participants were low income, most were elderly and some were disabled.

3.7 Summary

This study used a grounded theory approach to study a low-income, elderly and disabled population and their use of a personal health record. This is a group of potential PHR users which has not been studied in-depth, although some research indicates that PHRs may be particularly useful for them because of their complex HIM needs (Lafky & Horan, 2008). Data were gathered using qualitative methods and analyzed using a grounded theory approach of iterative coding, reflection and analysis. A stratified purposive sample of 32 residents was obtained of which 13 (40%) had not used the personal health record and 19 (60%) had used the PHR at least once. In the following three chapters the results of the study are presented.

The E-Medicine personal health record application was viewed in this research study as a model health information management system that was made available to a group of potential users that were available to be sampled and studied. Interview questions were asked in such a way that participants were encouraged to talk about health information management (HIM) in general and not only about the use of the particular system. In fact a number of participants described their HIM strategies as related to the use of a different PHR, a self devised management scheme or other HIM strategies. As a result, study results are discussed as being related to health information management in general and not the particular PHR system that was used as a model in the study.

Chapter 4. Results: Health Information Management Motivational Factors Framework

4.0 Introduction

Two major thematic sets that emerged from the data will be described in this chapter: **Thematic Set 1 - Personal Interest and Involvement in Managing Health Information** describes the types of potential PHR users or the levels of personal interest and involvement expressed by the study participants; **Thematic Set 2 - The Health Information Motivational Factors Framework** outlines and describes the factors that motivate potential users to use a PHR or discourage use and adoption.

This chapter is divided into two major sections each describing one of the theme sets. Section 4.1 describes each of the three levels of personal interest and involvement in the Personal Interest and Involvement in Managing Health Information theme set. Section 4.2 describes each of factors in the Health Information Management Motivational Factors Framework.

The Health Information Motivational Factors Framework includes seven groups of factors that increase or decrease personal interest and involvement in PHR use and health information management (HIM). Each group of motivation factors except Privacy and Security is divided into facilitators and barriers.

In the Health Information Management Motivational Factors Framework, facilitators are sub-factors that contribute to a higher level of interest and involvement and barriers are sub-factors that contribute to a lower level. A facilitator can be a system feature, a benefit provided by the system or something in an individual's life that encourages or enables them to use the system. A barrier is something about the system, an individual's perception of it or a factor in their life that distracts them from HIM or using the PHR or makes it more difficult for them to use it.

To help the reader follow this long chapter, the sections are outlined here.

Section 4.1.4 describes the relationship between participants' level of interest and involvement in HIM management as described in the previous three subsections and their actual use of the PHR.

4.1 Levels of Personal Interest and Involvement in Managing Health Information

4.1.1 Individuals Interested in Management
4.1.2 Individuals Minimally Interested in Management
4.1.3 Individuals Not Interested in Management
4.1.4 Interest Level and System Use

Each motivational factor section, except Privacy and Security has two subsections: facilitators and barriers.

4.2 Health Information Management Motivational Factors Framework

4.2.1 Information Access
4.2.2 System and Technical
4.2.3 Information Management
4.2.4 Medical System (Establishment)
4.2.5 Personal Health and Life Situation
4.2.6 Social Factors
4.2.7 Privacy and Security

A diagram that outlines each of the three interest levels is included in the beginning of Section 4.1 and a diagram that outlines the seven motivational factor groups is included in the beginning of Section 4.2. A similar diagram is included before each facilitators and barriers section to remind the reader about which factor is being described in the context of other factors.

4.1 Levels of Personal Interest and Involvement in Managing Health Information

A large subset of codes that emerged from the interviews reflected participants' perceptions of the idea of personal health records (PHRs) and the participants' general openness to using such a system. These levels of interest in health information management formed the first thematic set. Statements made by participants reflected a general level of interest, awareness and willingness of a particular group of respondents or potential PHR users[3] to be involved in health information management (HIM) tasks such as documenting, reviewing or using their health information (HI).

All quotations that were part of this theme set are related to the participants' willingness to store, manage and use their HI. The investigator coded all statements about using any PHR system or using in particular the E-Medicine PHR system as part of this theme set. Detailed descriptions of how a participant manages their data or of their involvement in management were coded as implying interest in management. Actual quotations are included in Sections 4.1.1, 4.1.2 and 4.1.3 below for each level of interest.

Three code groups that emerged from the data and are outlined in Figure 4.1 are: 1). Quotations that expressed interest in and a general willingness to manage information and use a PHR system and explicit requests to want to use the system; 2). Quotations related to wanting limited interaction with health information, personal health information management and the health care system in general, and a wanting to reduce the amount of time and energy spent thinking about and dealing with such issues; and 3). Quotations that explicitly expressed not wanting to manage information or have any interaction with such information at all. These respectively describe users that are:

(4.1.1) Interested in Management (Managers or Potential Managers)

(4.1.2) Minimally Interested in Management (Minimal Managers)

(4.1.3) Not Interested in Management (Not Managers).

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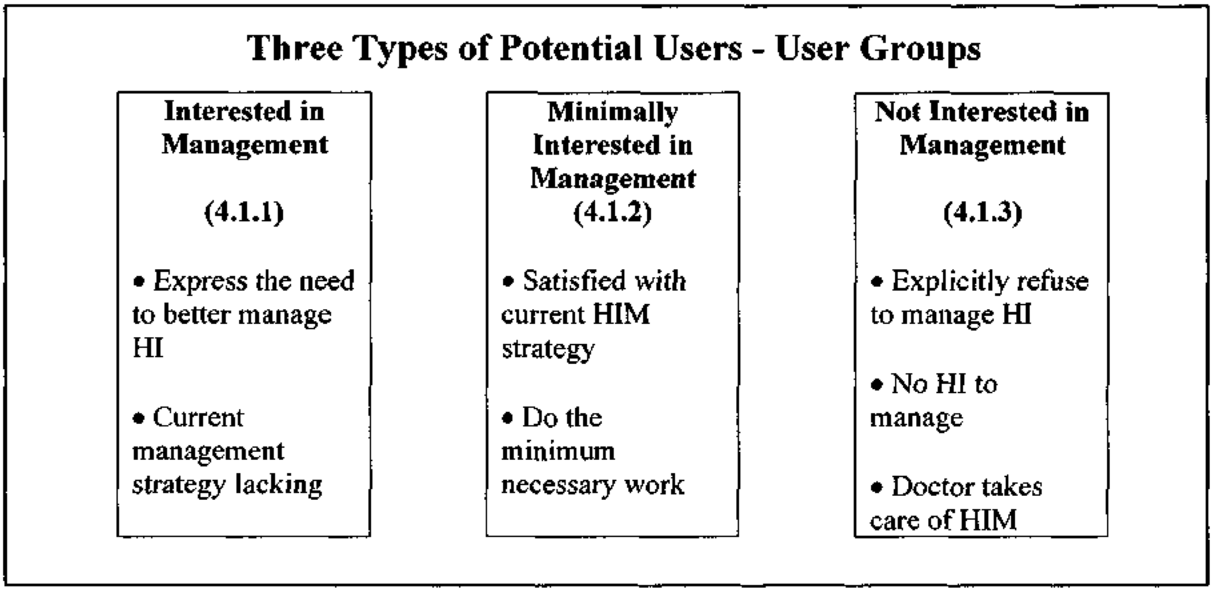
[3] Study participants are described as potential PHR users because some are non-users, but all housing authority residents had the record available to them and had an opportunity to participate.



Three Types of Potential Users - User Groups

Interested in Management (4.1.1)	Minimally Interested in Management (4.1.2)	Not Interested in Management (4.1.3)
• Express the need to better manage HI	• Satisfied with current HIM strategy	• Explicitly refuse to manage HI
• Current management strategy lacking	• Do the minimum necessary work	• No HI to manage
		• Doctor takes care of HIM

3 Figure 4.1 Types of Potential Users

Because interview questions were asked in a general way about health information management tasks and strategies and qualitative data can be viewed in general as statements that people expressed about themselves, the surrounding world as they see it and the way it is related to them, these themes can be thought of as three self-organized categories of potential users. Grouping potential users in this way helps to understand and characterize the types of potential users that someone who is researching, developing, implementing or offering a PHR or an HIM product to a population may deal with.

This section (Section 4.1) describes these three types of potential users with composite statements that reflect mindset and opinions expressed by multiple participants and example quotations[4] about their management strategies that place them in the following categories. The following section (Section 4.2) - Health Information Management Motivational Factors describes the individual factors that contribute to use or non-use of the system and health information management in general.

In Table 4.1 composite statements that generalize the types of views expressed by participants in each user group show that potential users who are interested in

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[4] NOTE: In this document italics are used to represent direct quotations from participants.

management show a general interest in health information management (HIM) and a general willingness to manage their HI. Individuals minimally interested in management tend to want minimal interaction with HIM and want to minimize time and energy spent dealing with health issues. Potential users who are not interested in management openly say that they do not want to manage their HI or do any kind of HIM.

7 Table 4.1 Composite Views Expressed by Three Types of Potential PHR Users[5].

(4.1.1) Interested in Management (Managers)	**(4.1.2) Minimally Interested in Management (Minimal Managers)**	**(4.1.3) Not Interested in Management (Not Managers)**
Realizes the need to track information (e.g., I need something like a PHR)	Wants to keep the HI management to a minimum, to keep it simple (e.g., I do what the doctor tells me, I eat well and take my medicine, don't feel I need to manage too much)	Sees no need to manage (e.g., I just do what I need, I don't see why I need this)
Mentions that the record is important to them, or that it is useful to help then do what they need to do	Was initially interested in the system, used it once or twice, but hasn't thought about the PHR and its capabilities or forgot about the system all together, might be interested, but doesn't have a strong need to manage	Explicitly says that has no interest in using the record naming various reasons or refusing to name reasons
Says that managing health information is second nature, or a usual thing for them	Says that they do not get a lot of new information, and therefore doesn't know why they would need the PHR	Satisfied with current management strategy (e.g., I already do everything that the PHR offers, I don't

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[5] The statements in this table are a composite drawn from statements made by multiple participants. This is done to help the reader understand the general opinions and mindsets of the participants. Because the statements were spread out over a general discussion of PHR management there are no short quotes to characterize each opinion. Although the statements are aggregated they remain true to the intent of the participants and reflect the essence of what the participants were saying.

	(e.g., I don't go to the doctor often)	need it or it doesn't meet my needs)
Strives to manage better	Mostly just files PHI away or throws it away	Doesn't want changes in life
Feels that the PHR is an alternative to the current management strategy	Doesn't want to worry too much about health and health information	Doesn't want to think about health and managing HI
Realizes the need to improve management and discusses bad record keeping in the past (e.g. I have looked for a HIM strategy in the past, kept HI records or kept simpler records, I have tried other PHR systems)	Feels that managing health information would make them worried about their health, increase stress level (e.g., Doing too much would make me worry about my health)	Feels that it is not necessary to manage health information because everything is under control (e.g., I'm in good health, I don't need to manage my health information)
Manages information on paper (e.g. I file away papers I get about my health and write down or track certain HI)	Wonders if doctors can input information for them, doesn't want to enter the information by hand or from memory	Wants to leave keeping health records for the doctors (e.g., Doctors need to do things like this, not patients)
Has considered or is considering changing to electronic HIM	Interested in own health information, but not necessarily management	Feels that the doctor has all information necessary and there is no reason to do anything else
Might use a PHR without help, wants to use more often or more regularly	Might consider managing information if some additional help provided or additional motivator emerges	Feels that the doctor manages for them (e.g., I have one doc, he knows everything, so I don't need to manage)

Each of these three potential user groups is discussed in detail below. Individuals interested in management are described in Section 4.1.1, the minimally interested in management group in Section 4.1.2 and the not interested in management group in Section 4.1.3.

4.1.1 Individuals Interested in Management

Individuals at the Interested in Management level are individuals who want to or are open to the idea of managing their health information. This means that during the interview they discussed how they organize and manage their health information, expressed wanting to start organizing their HI, expressed the need to improve the way they manage their HI or to manage in a different way or discussed how their current management strategy is lacking and that they would like to change or improve it.

There were 74 quotations that fit within this category. Statements or quotations that relate to individuals being interested in management were expressed by 17 of the 32 participants[6]. Of these 17 participants 8 were non-users of the system, 3 were one-time users and 6 were many-time users.

User Groups (1st Thematic Set) – Interested in Management

Interested in Management (4.1.1)	**Minimally Interested in Management (4.1.2)**	**Not Interested in Management (4.1.3)**
• Express the need to better manage HI • Current management strategy lacking	• Satisfied with current HIM strategy • Do the minimum necessary work	• Explicitly refuse to manage HI • No HI to manage • Doctor takes care of HIM

4 Figure 4.1.1 Individuals Interested in Management

The types of quotes that fit within this category are those expressing the need to better manage health information, discussing poor information management strategies in

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[6] While these numbers are reported to give the reader a general feeling of the data, please keep in mind that quotations can 3-4 paragraphs and longer, can be a part of a paragraph or can be as short as one part of a single line. In addition, one paragraph can be coded with multiple codes and each of these codes is counted in Atlas.ti as a single quotation. For example, a paragraph coded with "Interested in Management" and "Minimally Interested in Management" will be counted once in each coding family.

the past or how the current management strategies are lacking. Individuals interested in management often describe their management strategies in a lot of detail independent of whether they use a PHR system or manage their HI in some other way.

Some participants openly discussed wanting or needing a system that would help them store and organize health information or to find a better way to keep, organize and access their health information. They discuss reasons why they are looking for a health information management strategy or personal health record-like application. The participant below expressed some interest in using the PHR if help was available to start using it.

> *I need something like that [E-Medicine summary sheet], if I was going to do it. It would be fun if I had the chance, but, you'd have to have a computer and someone here to help me through it*[7]*. P04*[8]

Many participants realized that their current management strategy is lacking or that they are experiencing problems managing their health information and that is why they need to start managing or manage their HI better. Common problems related to managing HI were not finding HI when it was needed, loosing information that was written down or forgetting to write something important down and then not having access to the information when it was needed.

> *I think that I need to care a little bit more, as far as, as, um, keeping things together and getting information together somewhere. P05*

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[7] All italicized text in this manuscript are direct participant quotes.

[8] P04 is a participant number, a participant number is included after each quote. Participants are coded with P01 through P32, nursing students will be coded as NS1 and NS2 and the social worker with SW.

> *To do a job in one paper, one, one bundle.... But it hasn't been the whole answer because I, and neither is this nor... [laughs] ... Because I've just got a lot to keep track of.... And change. P28*

Two activities that often lead to a realization of a need for a better HIM strategy or a personal health record were medication management and providing background health information about oneself at the clinician's office or to emergency personnel (filling out intake forms).

> *I had thought for years, Jeez, I wished I had something that would keep all this together and then when I go to a new [doctor], all I have to do is hand them [the printout of the E-Medicine summary sheet]. P07*

> *And I mean, it's dangerous the way I do pills, so I need to, I need to change, as far as my medicine is concerned, so, yeah, um, keeping records is very very important, it's just that sometimes you have to, somebody has to remind you of certain things, else you wouldn't know, and had we not did this right here, I wouldn't have thought of it. But it's a good idea. P05*

Many participants noted that they had thought about HIM strategies in the past. One participant, P16, discussed that they had known from an early age that tracking their lifelong health information was a useful thing to do.

> *The other thing, was just like I said, ever since I was a young person, I knew I should be keeping track, but I didn't you know. Because, for whatever reason, I didn't. So, um, I guess basically that's why I originally signed up [started to use the E-Medicine PHR]. P16*

A number of participants described realizing the need after dealing with a particular health problem or having a particular encounter with the health system, and some after their information accumulated and the amount of information became too big for them to manage on paper and by memory.

> *And that was part of what I was doing, was keeping track of this. When did I last have an antibiotic, what was it for, that kind of thing. And I pretty much remember all that stuff, but it's still, I'm in looking at 20, 30 years worth of medical stuff, you know, it's nice, when did that happen? [laughs] That kind of thing. So it's a good idea to keep track of that and I do... P20*

4.1.2 Individuals Minimally Interested in Management

Most individuals who are minimally interested in management indicated that they are satisfied with their current management strategy and do not wish to do more then they already do. But individuals minimally interested in management are somewhat interested in managing their HI and they are overall interested in taking care of their health and improving or maintaining their HIM strategy.

User Groups (1^{st} Thematic Set) – Minimally Interested in Management

Interested in Management (4.1.1)	**Minimally Interested in Management (4.1.2)**	**Not Interested in Management (4.1.3)**
• Express the need to better manage HI	• Satisfied with current HIM strategy	• Explicitly refuse to manage HI
• Current management strategy lacking	• Do the minimum necessary work	• No HI to manage
		• Doctor takes care of HIM

5 Figure 4.1.2 Individuals Minimally Interested in Management

There are 37 quotations that expressed minimal management sentiments and discussed why minimal managers are interested in health information and might consider managing HI or keeping a PHR. Minimal management quotations were expressed by 13 participants of whom 7 were non-users, 3 were one-time users, and 3 were many-times users.

Minimal managers do the minimum necessary work and are satisfied with their current management strategy. Their view of health information management can be condensed into the following three perspectives:

1. Minimal mangers feel that they don't need to do more to manage.
2. They are busy with other aspects of their life more then with HIM.
3. They don't want to worry about their health or make themselves worry.

These perspectives are closely related to the second thematic set, Health Information Management Motivation Factors that contribute to use and although they are used here to describe the minimal managers as a group of potential PHR users, the individual factors will be described in detail in Section 4.2.

Individuals who do not need or want to do more to manage

Many minimal managers say that they do not need to do more to manage their health information because they have one doctor and he takes care of everything or they just file all medical paperwork away and don't feel like they need or want to do anything more.

There are three general types of statements that minimal managers make when asked about their HIM strategy.

1. I just do what I need or I do what my doctor tells me to do and I don't need to do anything else.
2. My doctor takes care of everything so I don't have to do anything else.
3. I just file this medical stuff away and don't do anything else with it.

The first type of potential user **just does what the doctor tells them to do**, such as taking their medications or tracking their diet and does not feel like they need to do more. These are usually individuals who have a stable health situation and have been managing the same health problems for some time, they have them under control and do not feel like they need to change or improve their health information management strategy. Below are brief descriptions of management strategies of such individuals.

> *I call my doctor and I talk to his nurse, you know, with different things, and then I have my checkups from him. ... he tells me what to do. ... But outside of that, no, I don't have any written information from him. But he just tells me what to do and I do it. P23*

> [Interviewer: "How did you keep track of things before you did the e-medicine?][9] *Um, just a list of all the meds and what they were for... And what doctors were giving them to me. P28*

The second type of minimal management individuals **feel that their doctor has all their health information and they do not need to do any additional management**. These individuals say that their doctor takes care of everything and that they can get their health information from their doctor if they need it, so they don't feel the need to do anything else. These are often individuals who have been seeing the same doctor or have been in the same health care system for a long time, such as people who have been receiving care from the Veteran's Administration or are members of Group Health. The following quotes demonstrate that these individuals in the minimal management group feel that their health professional takes care of managing health information for them. Participant 15 is the most representative of what most participants said.

> *My doctor does most of the managing of my health information. Because I see*

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[9] Text by the interviewer is in square brackets and quotations.

> *him, probably every other month and he does the blood tests and all the screening and stuff, and we talk about things that are going on. But as far as my medications and stuff, I manage all those, I take those myself at home, so... P15*

> *Because I've seen [this particular doctor] for the last 20 years, so he knows everything you know... P12*

> *Well, they are just talking about putting it on the computers, up, all your medicines and everything, to, um a your doctor... No, I don't need that cause I've got it... GroupHealth... All my records from the time I went there in 1971. P22*

The third type of minimal manager **just files away the medical papers** they get from their doctor and rarely use them for anything. Some of these minimal managers even throw away all the papers, because they feel they can never find them anyway and when they need health information they call their doctor or just wait until the next time they see the doctor. The following quotations express that these individuals often don't see the point of keeping and managing HI or they just keep the HI in one place with no intention to use it or understanding for what they might need it.

> *Uh, yeah, I'll have to keep the papers and hope that they are clear... Yeah, I'll have to sort through those. But, the thing, I guess my thing was I am waiting to go to my doctor, and, and see you know, um, get everything set up through her, is what I thought I am supposed to do... P05*

> *Not recently, not, not where I live. It's hard to get organized here. Cause I don't have everything, so I just file it away... blood values, and I file away what my doctor writes me, little notes, this test is turn out good or bad or whatever. P04*

> *[A helper] just keeps track of [the medical papers], that's all [he doesn't manage for me]. Because I take them down to her. ... Well, she told me to bring them down once a month, so that she can put them in her computer... P19*

Individuals whose lives do not revolve around HI and its management

An idea commonly expressed by certain participants about their HIM strategy is that their lives are busy and do not revolve around HI and its management. Being busy with non-health related aspects of their lives is a reason for wanting to minimize HIM activities and for wanting to keep HIM as simple as possible. Individuals who are minimally interested in management also forget about managing information or give up management of HI for some time because they are busy with other aspects of their lives. The experience of Participant 30 is representative of this situation, - when his health improved and he became busy with going to college and other activities he stopped managing his health information and using the E-Medicine PHR system.

> *...because I have been better lately and everything, I have a tendency to kind of forget those things and get caught up in things like my work and I was going to school for a couple of years there, and, it's easy and all that for me to kind of, put that on the back burner and forget about it because I got so caught up in everything else I was doing. P30*

Individuals minimally interested in management discussed forgetting that they had a PHR record and not remembering to update it. Minimal managers, like Participant 17, whose quote is presented below, are busy with things other then HI management and do not consider managing health information to be their most important priority, so they forget about it and give their attention to other things. Alternatively, individuals like P03, might not sign up for the record at the time it is offered because they are busy with other aspects of their lives.

> *No, [I haven't used it more] because I haven't needed anything to update. ... Although, I think I might. I have to look at the page again and remember what some of the questions are on it. P17*

> [Interviewer: "The reason you didn't sign up in the past was because you didn't know that it would be useful?"] *I didn't think about it. P03*

For some minimal managers forgetting to manage information is related to a worsening of their health situation to the point where they cannot manage their health information anymore or with helpers taking over their health information management. For example, Participant 19 stopped managing their HI and using the E-Medicine record after signing up because of a worsening of his health situation and lack of help from his friends and relatives.

> *I had a cousin that took care of me quite a while back, but then she died. And now that I cannot do the things that I used to do... that's what I'm saying, if I did have any family it would be a different story, but right now I don't have anybody, my mother died, my stepdad died, my real dad died, and my cousin she died and that makes it worse for me because I don't have anybody to help me to do things for myself anymore, so I have to do my own thing, I have to watch out for things and I have to do myself. P19*

Although these participants' lives do revolve around their health and health problems, they do not necessarily revolve around HI management. Some of these individuals have achieved a stabilization of their health situation and want to focus on other aspects of their lives. Others have found ways to avoid HI management, such as relying on helpers or their doctor and doing the minimum possible themselves.

Individuals who don't want to worry too much about their HI

Another common sentiment of individuals who are minimally interested in management is about not wanting to worry about their health and HIM because they don't want to make themselves worry and that thinking too much about their health and health information management would make them more worried about their health. Participants 22 and 27 talked in depth about how worrying about their health information would make them feel worse and participant 32 implied that their mother was ill because she worried about everything including her and her children's health and HIM.

> *So, you know, you just keep track of it and take the meds and don't worry about it. If I worried about it, my goodness me. Nah, nah, nah, nah, can't do that. ... God knows it wouldn't be good for the blood pressure. P27*

> *I can look up every bit of it. So I mean, I don't, what for? To remind me that something isn't working right, nuh-huh, that's dumb. Really dumb-dumb, cause then you worry, and we've got people right here, worry, worry, worry, because they were told there was something wrong. I am not that type of person. P22*

> *Well, I really don't care what it's for. I mean seriously, as long as I am in good health and I feel good, I am not going to worry about my health. P22*

> *I think it helps [having the PHR]. I just don't think about it a lot. ... Everything is in the pile... my mother was ... nagging, and nagging, and nagging about that for years! And then she died! What do you think really caused her disease?... The need to nag! P32*

Individuals minimally interested in management want to do as little work as possible. They don't want to worry too much about their health information, but at the same time they are generally interested in their health information. They realize that there are some situations where they might need their health information and they might not have it available with their current minimal management strategy and they might be willing to do some minimal work to manage their health information, although not as much as individuals who are strongly interested in management. Although they discuss the barriers to HIM and generally try to do as little management as possible they usually: 1). Are generally interested in their health information; 2). Realize that there are some situations where they might need to know their HI; and 3). Might be willing to manage their health information.

1. Are generally interested in their health information.

> *I don't know. I can't remember, that, but he said though that it would keep everything on there. That I could have to take to my doctor if he wanted to check me out for what I had in the past, you know. P18*

2. Realize there are some situations where they might need this information.

> *Well, they basically had explained to us what it would do. And that was why I decided to do it, because I wanted to have something to keep track of all this. So I didn't have to keep writing it over and over and thinking what was what, you know. I never thought of trying to manage it myself at home because I didn't have the concept in my head of how to do it, like they do. P07*

> *See, I don't think I have been able to get back into it, when I started, cause I wanted to do updates and keep that kind of stuff too. When I was 12 years old, I met a Polish woman who was in her 50's, and she had... her medical history, every shot she ever had, every medicine she'd ever had, and I'm thinking that would be so great! But you know what? I never did it. P16*

3. Might be willing to do something to manage their health information.

> *Because I've been doing it, so long, it's, it's second nature. Um, my kids are the same way, they do it, because I started them doing it, all when they were little. You know, just went to the doctor, DPT shots, you know that type of thing. Um, that it's, it's just something I do, I don't even, I don't consciously do it... It's just, if I am given a new med, when I get home, that's it, I sit down, I write it down, I cross off if I have to, and that's it. It's done, it's over with and I don't have to mess with it, unless I do it again. P27*

4.1.3 Individuals Not Interested in Management

Individuals not interested in management explicitly talked about not wanting to manage health information or avoiding health information management altogether. They discussed either having no need to manage HI because they have a handle on their HI management or not having enough information to manage either because they are healthy enough or because their doctor manages their health information for them.

User Groups (1st Thematic Set) – Not Interested in Management

Interested in Management (4.1.1)	**Minimally Interested in Management (4.1.2)**	**Not Interested in Management (4.1.3)**
• Express the need to better manage HI	• Satisfied with current HIM strategy	• Explicitly refuse to manage HI
• Current management strategy lacking	• Do the minimum necessary work	• No HI to manage
		• Doctor takes care of HIM

6 Figure 4.1.3 Individuals Not Interested in Management

There are a total of 112 quotations expressing sentiments that are indicative of not being interested in health information management. These statements were made by 18 of the 32 participants. Of these 18 participants 10 were non-users, 4 were one-time users and 4 were many-times users of the E-Medicine PHR system.

Some participants very explicitly from the very beginning of the interview talked about not needing a system to manage their health information or that the PHR system offered did not meet their needs. Participant 2 is representative of such individuals. Other participants, like Participant 8, said that they did not want to manage their information at all, saying that this was either unnecessary for them or that they did not want to be bothered with it.

> *Ok, I go to the doctor, I get my prescriptions and I get them filled and I bring them home. And I am not going to just go into something else at this late date, so I think I am kind of fine the way I am. P02*

> *I make appointments for doctors and stuff, and that's about it... Well, if I need some pills. I mean, if I need ... pills I can just call them up and they can patch them to the pharmacy... If I need a physical, I'll make one. P06*

> *It just, it just doesn't interest me. My doctor knows everything that he needs to know about me, I know everything I need to know about me, my son knows everything that HE needs to know about me, he's my beneficiary on everything, he's... no, I don't think I would need it. P08*

Some participants had a very specific HIM problem that they felt they needed help solving and they thought of the PHR system in terms of this problem. One participant felt that communication between doctors was a problem in their management because they saw many doctors and they often needed to exchange information, the participant viewed the E-Medicine system in terms of this problem and if the system did not address these problems that they needed help with they felt that it didn't address their needs or in the words of Participant 9, "*it wouldn't help me*".

Some participants would ask the interviewer about specific problems they needed help solving. They asked about the system helping them prevent problems with medication allergies or cross-interactions, sometimes forgetting to take medicines, taking too much or taking the wrong ones. They made the decision to use or not use the system based on the presence or absence of one perceived need and feature or features that address it.

> *So I don't think that the E-Medicine would improve [my doctors'] communication. That's my sense, is that it wouldn't help me. P09*

Another reason quoted by participants for not wanting to use a personal health management system is that they do not have information that needs to be managed. They discussed either being in good health and not needing to manage anything or having a routine of health activities so well worked out that they don't need to manage any additional information in writing or electronically. Participants 21 and 22 are particularly representative examples of such individuals.

> *I've had very little problems ... So I can forget about it. Now, I am going to live for a while. P21*

> *Well, I really don't care what it's for. I mean seriously, as long as I am in good health and I feel good, I am not going to worry about my health. P22*

> *I had a doctor and I still have him and that's it. ... I haven't had lab tests done in years, and I don't know. I am very good health. P03*

Some participants discussed being happy with the way they manage their health information or with the fact that they don't manage it and said that they do not want to change anything. These statements are closely related to the statements about being satisfied with a current management strategy but also with an additional strong tendency to reject changes or improvements to their strategy. These statements are also related to not wanting to worry about health information but are strongly negative about HIM. These people like Participants 2 and 22 don't want to change anything and they don't want to hear about or think about doing anything with their health information.

> *Because that's the way that I choose to live my life, is to keep things. I am not going to say that they are all in order in that box, but that's where they go. So I know where they are. P02*

> *Well, when I really get ill, that would be the time to worry. ... If I was in the hospital, I couldn't move or do anything ... P22*

> *I just don't think about it a lot. ... Everything is in the pile... P32*

A number of participants used a similar reason for not wanting to manage as that discussed by minimal managers – my doctor manages information so I don't need to do anything. Quotes from Participants 6, 8, 21 and 32 below are representative of people who rely on their doctor instead of managing any health information themselves.

> *It just, it just doesn't interest me. My doctors knows everything that he needs to know about me, I know everything I need to know about me... P08*

> *Well, um, I know the doctors keep it there and I just go to the doctor, and they pull up the files for me. P06*

> *But I have no reason to keep those records, because they got them, and so far they haven't got it set up where we as a patient can get into them. But they eventually, they will, they said. P21*

> *I'd leave it up to the people. I mean, I'm sorry if it sounds stupid. ... I go to my doctors to be monitored every three months, and I go, um, I have a primary care physician... P32*

A number of participants made statements that fit well both well both within the non-management and minimal management groups, which may indicate that they are on the edge between not wanting to manage and doing some management.

Of the 32 participants, 14 made statements that fit both the minimal management and non-management categories of these 8 were non-users, 4 were one-time users, and 2 were many-times users. There were five participants that made statements only in the minimal management group, but not in the non-management group and two participants who made statements in the non-management group but not in the minimal user group.

4.1.4 Interest Level and System Use

Based on a combination of the number of quotations in each interest level and the total word count for these quotations the investigator mapped each participant into a general interest level in the Personal Interest and Involvement in Managing Health Information framework. Table 4.1.4.1 shows the number of times each participant used the PHR and their general level of interest as indicated by how many statements from each interest level they made during their interviews.

Table 4.1.4.1 shows side by side data concerning the level of interest in managing health information for each participant and the number of times they used the E-Medicine PHR system. Participants are sorted by the interest level and then by participant number. For each participant the number of statements they made in each level of interest is shown as well as the total word count for these quotations. In between, the level of interest for that participant is shown. The investigator determined the level of interest by the number and length of quotation in each interest category for that participant and verified it by their statements in the interview regarding management. Listed in the next to last column is the number of times each participant used the E-Medicine PHR record.

The table shows that statements of 11 of 32 participants (34%) indicated that they were mostly interested in managing their health information. Another six participants (19%) were interested to minimally interested in managing their health information. Of the 13 participants who had never used E-Medicine 10 (77%) positively characterize PHR systems and managing health information. Two participants use a different personal health record system (Group Health, Health-e-Vet) and cite that as a reason for not using E-Medicine and two use elaborate self-devised systems. Eight participants say that they just file away the medical paperwork that they get and one participant did not discuss a management strategy at all.

Only five of the participants who had never used E-Medicine brought up privacy and security concerns. Of the participants concerned about privacy three were strongly concerned and for two the concerns were minimal and were outweighed by benefits of using a PHR. Other participants who had not used a PHR did not mention privacy during the course of the interview even when asked if there was anything that would make them reluctant to use the record.

Tables 4.1.4.2 and 4.2.4.3 present a comparison of the interest level of participants to the number of times participants used the E-Medicine PHR record. Table 4.1.4.2 presents participants in three groups: 1). Participants who used the record twice or more; 2). Participants who used the record once; and 3). Participants who had never used the record. Table 4.1.4.3 combines all participants who used the record into one group. The table shows that a subset of participants who were interested in health information management had not used the PHR system (a few of these individuals indicated during the interview that they would like to sign up to use the system). It also shows that most participants are interested to minimally interested in using the PHR.

8 Table 4.1.4.1 Number of Times Used and Interest Level Compared by Participant

	Quotation Count				*Word Count*				
	Int.	*Min.*	*Not*	**Interest Level**	*Int.*	*Min.*	*Not*	**Use/Don't Use**	Notes
P01	*9*	*2*	*0*	**Interested**	*926*	*153*	*0*	**Used (2)**	
P04	*9*	*4*	*0*	**Interested**	*708*	*221*	*0*	**Not**	
P07	*3*	*0*	*0*	**Interested**	*277*	*0*	*0*	**Used (12)**	
P09	*2*	*0*	*1*	**Interested**	*232*	*0*	*20*	**Not**	
P13	*0*	*0*	*0*	**Interested**	*0*	*0*	*0*	**Used (4)**	
P14	*0*	*0*	*0*	**Interested**	*0*	*0*	*0*	**Used (6-7)**	
P16	*9*	*2*	*0*	**Interested**	*1407*	*162*	*0*	**Used (2)**	
P20	*7*	*1*	*7*	**Interested**	*2494*	*231*	*943*	**Not**	[10]
P26	*2*	*0*	*0*	**Interested**	*125*	*0*	*0*	**Used (3-4)**	
P28	*3*	*9*	*0*	**Interested**	*510*	*1458*	*0*	**Used (4-5)**	[11]
P31	*0*	*0*	*0*	**Interested**	*0*	*0*	*0*	**Used (3)**	
P05	*6*	*8*	*0*	**Int-Min**	*721*	*1017*	*0*	**Not**	
P11	*6*	*3*	*9*	**Int-Min**	*458*	*283*	*854*	**Not**	
P24	*2*	*2*	*0*	**Int-Min**	*113*	*385*	*0*	**Used (2)**	
P25	*4*	*2*	*0*	**Int-Min**	*309*	*133*	*0*	**Not**	
P27	*7*	*7*	*4*	**Int-Min**	*1149*	*896*	*629*	**Used (1)**	
P29	*0*	*2*	*0*	**Int-Min**	*0*	*345*	*0*	**Used (1)**	[12]
P10	*1*	*3*	*1*	**Minimally**	*93*	*260*	*83*	**Used (1)**	
P15	*0*	*2*	*1*	**Minimally**	*0*	*140*	*59*	**Used (2)**	
P17	*0*	*2*	*0*	**Minimally**	*0*	*85*	*0*	**Used (1)**	
P18	*0*	*5*	*1*	**Minimally**	*0*	*910*	*66*	**Used (2)**	
P19	*0*	*7*	*3*	**Minimally**	*0*	*907*	*333*	**Used (1)**	[13]
P30	*1*	*6*	*2*	**Minimally**	*72*	*993*	*389*	**Used (1)**	[14]
P03	*0*	*7*	*4*	**Min-Non**	*0*	*406*	*281*	**Not**	[15]
P06	*0*	*5*	*5*	**Min-Non**	*0*	*306*	*390*	**Not**	
P22	*2*	*7*	*14*	**Min-Non**	*101*	*529*	*1143*	**Not**	[16]
P23	*0*	*11*	*10*	**Min-Non**	*0*	*964*	*703*	**Not**	
P32	*0*	*8*	*6*	**Min-Non**	*0*	*795*	*572*	**Used (2)**	[17]
P02	*0*	*5*	*17*	**Not Interested**	*0*	*440*	*1474*	**Not**	
P08	*0*	*0*	*5*	**Not Interested**	*0*	*0*	*425*	**Not**	
P12	*0*	*2*	*6*	**Not Interested**	*0*	*196*	*498*	**Used (1)**	
P21	*3*	*0*	*12*	**Not Interested**	*353*	*0*	*1703*	**Not**	[18]

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[10] All *not interested* quotations are about being satisfied with the current management strategy and the system not meeting her needs, but she is strongly interested in managing HI in general.

[11] Min. management quotations are all "interested in own health information".

[12] Min. management quotations are all "interested in own health information".

[13] Does not have enough help form family to be able to use the system.

[14] Used the system a long time ago and then became busy and forgot about it.

[15] Wants to try the PHR after talking to a resident who uses it.

[16] Reflects positively on managing and using a PHR record.

[17] Can't find time to meet with the nurses to update the record.

[18] Uses the VA system to access health information and does not wish to do more.

9 Table 4.1.4.2 Comparison of Participants' Interest Level in HIM to Number of Times Participants Used the PHR System

	Interested	*Int. to Min. Interested*	**Minimally Interested**	*Min. to Not Interested*	**Not Interested**	**Total**
Used 2+ times	**8**	*1*	**2**	*1*	**0**	**12**
Used 1 time	**0**	*2*	**4**	*0*	**1**	**7**
Not Used	**3**	*3*	**0**	*4*	**3**	**13**
Total	**11**	*6*	**6**	*5*	**4**	**32**
%	**34%**	*19%*	**19%**	*16%*	**12%**	
%	**53%**		**35%**		**12%**	**100%**

10 Table 4.1.4.3 Comparison of Interest Level in HIM of Participants Who Used the PHR System and Did Not Use the PHR System

	Interested	*Int. to Min. Interested*	**Minimally Interested**	*Min. to Not Interested*	**Not Interested**	**Total**
Used	**8**	*3*	**6**	*1*	**1**	**19**
Not Used	**3**	*3*	**0**	*4*	**3**	**13**
Total	**11**	*6*	**6**	*5*	**4**	
%	**34%**	*19%*	**19%**	*16%*	**12%**	
%	**53%**		**35%**		**12%**	**100%**

Of the 17 participants (53%) who were either mostly interested or interested to minimally interested in managing their health information six (32%) had not used the system. Only one person of 19 who had used the system indicated that they were mostly not interested in using the system. And one more was minimally interested to not-interested. The other 17 participants of the 19 who had used the system at least once were interested or minimally interested in managing their health information and therefore open to using some sort of personal health information management system.

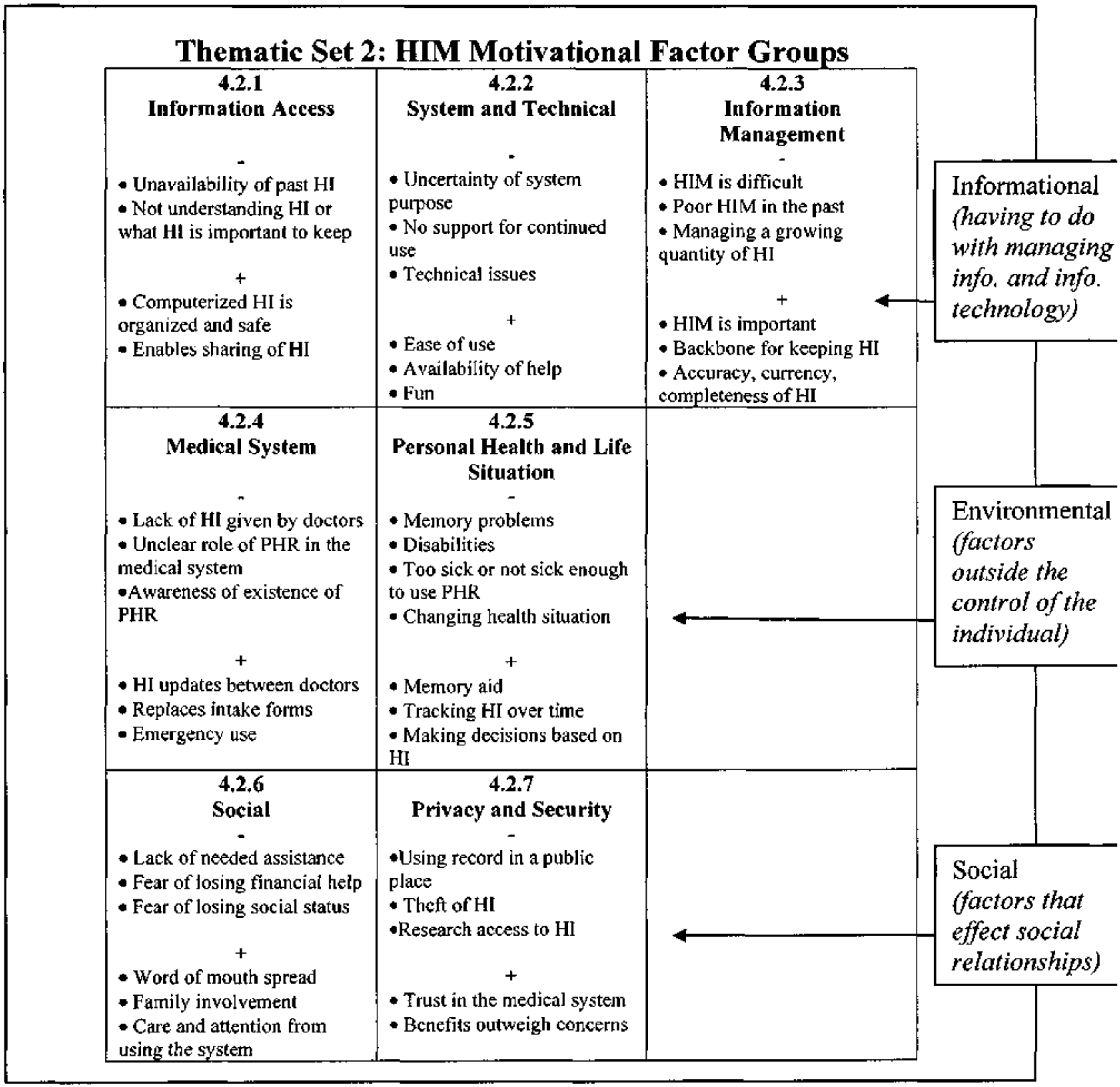
There were six participants who were interested or minimally interested in managing HI who had never used the E-Medicine PHR record (P04, P09, P20, P05, P11, P25). Two of them had expressed during the interview that they wanted to meet with the nurses to sign up to use the E-Medicine system and the remaining four used a different paper based of electronic system to manage their HI. One participant was strongly concerned about privacy and data use for research purposes. However, it is possible that if someone had addressed her questions she would feel positively about using the system.

Although the question was not asked directly, no participants said or indicated during the interviews that they would be totally unwilling to use the PHR system offered. Of the participants only four indicated that they are unwilling to manage their HI, and five that they are minimally interested to mostly unwilling to manage their HI even with the help of the nurses.

4.2 Health Information Management Motivational Factors Framework

A major aim of this study was to find out and systematically describe what motivates health care consumers to start using a personal health record (PHR). Participants' statements about their perceptions of PHRs, how they use the PHR offered or why they do not use it were analyzed and seven groups of factors that motivate or deter from using the PHR were identified in the interviews. These seven groups of factors contribute to the willingness of an individual to use or adopt a personal health record and will be discussed in the remaining part of this chapter. This second thematic set which includes seven groups of factors emerged from the data and were not formed or determined a-priori by the investigator. Figure 4.2 is the main schematic of the seven groups of factors that emerged from the data. A similar diagram is included in the beginning of each factor description to help the reader orient themselves.

Although in the context of this study participants may have been discussing the E-Medicine system because it was the system available to them, not a single participant said that this particular system is unique and that they would want to use only this system or alternatively they'd never use this particular system but would be willing to use another. It was clear that participants were talking about managing health information in general and this system was a tool that most found to be useful. Because participants were asked questions generally about their health information management their answers do not relate only to the particular system used but to HIM in general and can be extended to any PHR or HIM system.



Thematic Set 2: HIM Motivational Factor Groups

4.2.1 **Information Access**	4.2.2 **System and Technical**	4.2.3 **Information Management**
- • Unavailability of past HI • Not understanding HI or what HI is important to keep + • Computerized HI is organized and safe • Enables sharing of HI	- • Uncertainty of system purpose • No support for continued use • Technical issues + • Ease of use • Availability of help • Fun	- • HIM is difficult • Poor HIM in the past • Managing a growing quantity of HI + • HIM is important • Backbone for keeping HI • Accuracy, currency, completeness of HI
4.2.4 **Medical System** - • Lack of HI given by doctors • Unclear role of PHR in the medical system •Awareness of existence of PHR + • HI updates between doctors • Replaces intake forms • Emergency use	4.2.5 **Personal Health and Life Situation** - • Memory problems • Disabilities • Too sick or not sick enough to use PHR • Changing health situation + • Memory aid • Tracking HI over time • Making decisions based on HI	
4.2.6 **Social** - • Lack of needed assistance • Fear of losing financial help • Fear of losing social status + • Word of mouth spread • Family involvement • Care and attention from using the system	4.2.7 **Privacy and Security** - •Using record in a public place • Theft of HI •Research access to HI + • Trust in the medical system • Benefits outweigh concerns	

Informational *(having to do with managing info. and info. technology)*

Environmental *(factors outside the control of the individual)*

Social *(factors that effect social relationships)*

7 Figure 4.2 Health Information Management Motivational Factors

These are the factors that individuals consider and think about when thinking about the PHR and health information management, when deciding whether to try using a PHR and whether to use a PHR for the second time. Both factors that are intrinsic to the system and factors in their outside environment play into their decision. Brief descriptions of the seven factor groups that emerged from the data are described in Table 4.2.

11 Table 4.2 Descriptions of the Seven Motivational Factors

Section	**Motivational Factor**	**Description**
4.2.1	Information Access	Related to access to health information including access to historical HI, receiving new HI in a way that can be entered into a record and also factors related to access to HI in the record and giving access to others.
4.2.2	System and Technical	Having to do with a particular PHR system and its implementation in a particular setting.
4.2.3	Information Management (Process)	Related to the information management processes of collecting, entering, adding, organizing and understanding HI.
4.2.4	Medical System (Establishment)	Related to the medical system, individual's interaction with the system and care providers and the place for management of HI within this system.
4.2.5	Personal Health and Life Situation	Related to the health situation such as disabilities, being healthy enough to physically use the system and using information management to improve health.
4.2.6	Social	Social factors having to do with support from others, issues with the living situation and people surrounding the health care consumer.
4.2.7	Privacy and Security	Privacy and security perceptions and how they influence the willingness to use a PHR system.

Each of the seven factor groups, except for Privacy and Security is broken down into facilitators and barriers. Facilitators are factors that positively influence individuals toward adoption of personal health records or in other words help encourage users to start and continue using a PHR. Facilitators are the reasons why an individual starts and continues to use the system, they answer the question of why individuals adopt and use PHR systems. Barriers are factors that deter participants from using the system. Within each factor group first barriers and then facilitators are described supported by participant's statements.

4.2.1 Information Access

To better manage personal health information (PHI) and use this information to make decisions regarding health care and lifestyle choices a person must have access to this information. Many people keep PHI in memory (Civan, 2006) and retrieving it when it is needed can be problematic. Many people have lost their records or have no way of getting access to their past medical records.

The first motivational factor, Information Access, is highlighted in Figure 4.1.2 with a blue background and will be discussed in this section.

HIM Motivational Factors (Thematic Set 2) – Information Access

4.2.1 **Information Access** **Barriers** • Unavailability of past HI • Not understanding HI or what HI is important to keep **Facilitators** • Computerized HI is organized and safe • Enables sharing of HI	**4.2.2** **System and Technical** ***	**4.2.3** **Information Management** ***
4.2.4 **Medical System** ***	**4.2.5** **Personal Health and Life Situation** ***	
4.26 **Social** ***	**4.2.7** **Privacy and Security** ***	

8 Figure 4.2.1 Information Access HIM Motivational Factor

4.2.1.1 Barriers

Two sub-factors were discussed by participants as major information access barriers: 1). Not having access to past health information that can be aggregated in one place and managed by the individual and 2). Individuals feeling that they do not understand their health information and do not know what needs to be kept, how to organize it and manage it.

4.2.1
Information Access

Barriers
- Unavailability of past HI
- Not understanding HI or what is important to keep

Facilitators
- Computerized HI is organized and safe
- Enables sharing of HI

9 Figure 4.2.1.1 Information Access Barriers

4.2.1.1.1 Unavailability of past information

A major information access barrier to using PHR systems is lack of access or unavailability of historical health information. Common reasons for not having access to information were: 1) Lost medical records; 2). Not knowing where to request medical records because the participants had moved or the practice had closed or moved; and 3). Not having records from childhood, keeping information in memory only and at the moment having forgotten some of it or all of it.

These quotes show that participants have lost their records or do not have access to them in order to get information they need to manage.

> *I came here from Minnesota, so they um, they gave me some um, medical records to bring with me, and that was back when I first came... I have no idea where those are. P05*

> [Interviewer: "Under what circumstances would you decide to use a personal health record system?"] *If I had access to all my medical records, a lot of it is in my storage, so I don't have a lot here, so it all be a lot from memory. P04*

> *Well, sometimes I've thought that, but, then I think back, and I think, as far back as that is, those doctors, well I know the doctor I had for many years, he's gone, now he's past away and I'm sure that the records are gone. So, there wouldn't be any way I could go and get anything like that. But, with this kind of a program you could, I mean, you could keep that. P07*

Unavailability of health information was a factor often discussed even by participants who manage their HI. Participants implied that health record should have accurate and complete information and were not comfortable entering information that was incomplete or the accuracy of which they were not sure about.

A common strategy for getting started with the record was to bring all available health documents to the meeting with the nursing student to have them enter these records into the PHR or to dictate all known health information from memory. Housing authority residents who did not have access their past medical history or were aware that they didn't know a large chunk of their history may have chosen not to use the record or put off signing up to a later date because they were embarrassed or felt it was not valuable to record a partial history. The following statements are examples of participants being concerned with lack of access to their past health information.

> *I have some boxes at my son's house and some at my daughters, and I thought someday I would just go through them, and organize them, put them all together. P25*

> *So, to get a complete record would be very difficult. To get a current record to where I am and have been very recently would be quite easy. P09*

Many statements were related to forgetting health information and using that as a reason for not keeping a record. Participants also described problems encountered because their HI was not available and techniques for dealing with this lack of access to HI. For example, Participant 9 discussed leaving a piece of paper out in the apartment and writing down on it any HI they happen to remember during the day as a tactic to restoring their lost health information sheet where their health information summary was kept.

> *I had a list of all the things that are wrong with me as far as depression, anxiety... physical things that are wrong with me... So I had a list like that, and then I don't know what happened to it. So I started to make out a new list today and I'll just leave it out until I feel like I've gotten all the stuff on it again. P09*

Participant 16 described a technique she called the timeline to help recall and write down forgotten information. This technique is a way to recreate an approximate chronological history by noting large events or health events in one's life and then try to remember and write down when other health events happen relative to those large events.

> *A timeline is, here is your birth, your first, second, third, fourth... you know, sixteenth, 65, birthdays right. The important things that have happened to you during that time are on that timeline. Like when my first baby was born, my second baby was born... But, I do have that, and the reason I did the timeline, was because I wanted to list my surgeries in here as to what years and stuff. And by*

> *remembering between, cause now like when my son was born in 65, I ended up in the hospital shortly after he was born and, um, for gallbladder, had my gallbladder and appendix removed. And at the same time I was seeing another doctor, who... found that I had tuberculosis. And... so I ended up at [some] sanitarium, um, and that was in that year too, in 65. So... that was why I put the timeline together, so that's about the only thing that I would have. P16*

Potential PHR users may not understand that even a partial history or a history kept from the current time on is valuable to keep and better then not having a history at all. Users should be informed that they can start by entering just the information they know or have access to and then fill in the rest of the information, clarify or correct information as they find it or remember it.

4.2.1.1.2 Not understanding HI or what information is important to keep

Another major information access barrier is being able to understand own health information enough to try to track it and organize it. Participants, who managed their HI using the E-Medicine PHR or in other ways, easily talked about their health information management and were relatively confident about knowing enough about their health. However some participants expressed that they did not understand what information needs to be entered or can be entered into the PHR or knew so little about their health information that they did not even consider tracking it in any way. The following statements demonstrate that these participants didn't understand their health information enough to be able to manage it meaningfully.

> *And the young lady ... she was one of the computer wizards. ... I just asked her some questions and she put it on the computer, and that was it. P19*

> *I know, all I know, is what I take is my medicine, it's all I need to know. P12*

> *And, um, I don't know what I'd put on there. I just don't have much that I could put on there. That I don't know already in my head. P21*

There were participants who explicitly said that they were confused about their information. Other participants said that they do not have the information that needs to be entered into the record, for example they don't know about medications that they are taking and their health conditions. Many cited reasons, such as being too sick to keep track of them, their doctor not giving them enough information or in general just not being interested in understanding more. The following statement was made by a participant whose medications change very often because of what Medicaid covers that this person is not able to keep track of what medications they are taking.

> *I used to be able to keep track of it real good, but now I don't, I just let them do it. And because the labels are not on an individual bottle and I don't set them up the same way, I am lost. And then Medicaid will change, every month, they'll change on the meds that they'll accept and they'll have to, give you a different brand or something, that's cheaper. And it's a different color, or a different shape. P28*

The statements below demonstrate that participants who did not understand their health information may have been reluctant to sign up for the record and try to use it.

> *... you could just go in there and I don't know, bring your health information, or, I figured you had bring something, you know. ... And, um, because what would you bring? I don't know. And um, the nurses would enter in your information or something. P09*

> *Is they don't have any idea of what they really want to get out of it. So they're putting all this in, but, no, aw, that's cute, another piece of paper. P20*

Explaining to potential users that the information they keep in their PHR is both for them, for emergency situations and for their physician may help them realize that even tracking information for their own purposes is useful and may be beneficial in case of emergency or a first step to further health information management.

4.2.1.2 Facilitators

There were two information access sub-factors that participants cited as positively effecting their decision to use a PHR: 1). Keeping HI on the computer helps them keep this information organized, safe and always available when it is needed and 2). Keeping information computerized enables easily sharing it with others, such as printing copies for family members and providing information in emergency situations.

4.2.1
Information Access

Barriers

- Unavailability of past HI
- Not understanding HI or what HI is important to keep

Facilitators

- Computerized HI is organized and safe
- Enables sharing of HI

10 Figure 4.2.1.2 Information Access Facilitators

4.2.1.2.1 Computerized information is organized and safe

Many participants said they use the PHR because it keeps their information computerized, keeps it all in one place and in such a way that it can be retrieved when necessary. The following quotes illustrate that participants valued that the information cannot be lost as easily as paper information and if they misplace their paper copies they can always print out a copy of the information in the PHR. In addition, they value the electronic PHR as a backup of their health information that can be retrieved at any time.

> *Because I couldn't find anything, you know, all of the information was a real hassle for me, cause I'm one who is not, I can't find things once I bring them home, let's put it that way. And I have a personal file, I have a filing cabinet, but if I don't put it in there as soon as I get it, who knows what happens to it. So if it's on a computer thing, it's going to be there, as long as I don't lose the disk. And the older you get the more you forget, the more you think, well I'll put this here, so I'll know right where it's at, but the date comes that you were supposed to get it for your information, you can't find it. P24*

> *Because you're information is right there, all you have to do is just punch it in, but you know it'll come up, that way you're not guessing, you know. It's, it's a sure way to know, to know that the information, other then that you could, um, have different information that's not correct each time, you know, if you ask. P05*

Participants who used the record and even those who did not saw that having health information computerized is a major benefit and has many positive aspects. These aspects included having all health information kept together in one place where it can be accessed and retrieved at any time. It is also a backup of their paper records and allows easy access to historical health data when necessary.

4.2.1.2.2 Sharing information with others

Many participants thought of the E-Medicine PHR system as a tool that helped them share health information with others. There were three different sharing situations discussed: (1) Sharing information with doctors or emergency personnel in order to have access to information in case of an emergency (especially if the patient is unconscious, cannot talk or cannot remember their information) or in other situations when HI is needed for providing medical care; (2) Providing information to family members to ensure that they are informed of the participant's health situation and are able to provide the participant's health information when it is necessary for provision of medical care; and (3) The participant him or herself having the information available for sharing when they cannon remember or do not know HI and need it for their own self-management or to provide to caregivers. These quotations demonstrate that participants consider sharing information with family and having information available to provide to health care providers to be useful functionalities of the PHR.

> *Well put it in the records, and then update my family on it. So, they would do it, get in on their computers and get all the information they needed, if they didn't have one printed in my apartment. P03*

> *Because if I were ill and I ended up in the hospital, [health care providers] could check if it's on the computer, they could check, rather then asking me questions, and I can't talk very well, and it's right there in front of them. P10*

Participants expressed different levels of comfort with sharing their information with others. Some participants wanted to carry a card with their PHR log-in and password in their wallet or purse so that if paramedics or doctors searched their belongings in an emergency they would find the card and have full access to their HI. Other participants carried their children's or another emergency contact's information, so that this person could provide medics with HI in an emergency. Others carried on their person or had in their apartment copies of HI for themselves only. Interestingly, some individuals that carried information for themselves or had it somewhere in the apartment were in fact hiding it from others. They hoped that if paramedics needed their HI they would look for it hard enough to find it, but that other people would not be able to have access to it.

Many participants who use the record, when asked if there was anything about it they wanted to change or additional functionality they wanted it to have, mentioned that they wanted to be able to give electronic access to other. Some even specifically mentioned creating separate log in and password for their family members or doctor so that they could access their record when needed. The following two quotes are participants' requests to be able to give electronic access to others.

> *I would appreciate it if each person could come up with some kind of password or code so that your doctor can, um, gain access to the records any time they need to, as well as hospital staff, in case on an emergency. P17*

> *If I coded in a number, it could be attached into this program, so that if someone, a doctor, needed some information off of here, that all he'd have to do is type in this, this thing and that would access the information, only the information off of that sheet, to whatever he needed or she needed, or whatever. P24*

Participants view sharing of information with others as a major function of PHR systems even though they may share their information differently based on their needs and their privacy preferences.

4.2.2 System and Technical

The second group of factors that encourages or discourages adoption and use of a PHR system are factors related to the system itself and its implementation. Additionally, this includes factors such as availability of help and technical support.

The design and functionality of the E-Medicine PHR system were simple, and in general many participants mentioned that they liked the system and were satisfied with the functionality. No one said that they didn't like or didn't use the system because it poorly designed or implemented and many participants suggested or requested additional functionality.

HIM Motivational Factors (Thematic Set 2) – System and Technical

4.2.1 **Information Access** ***	**4.2.2** **System and Technical** **Barriers** • Uncertainty of system purpose • No support for continued use • Technical issues **Facilitators** • Ease of use • Availability of help • Fun	**4.2.3** **Information Management** ***
4.2.4 **Medical System** ***	**4.2.5** **Personal Health and Life Situation** ***	
4.26 **Social** ***	**4.2.7** **Privacy and Security** ***	

11 Figure 4.2.2 System and Technical HIM Motivational Factor

4.2.2.1 Barriers

4.2.2 **System and Technical** **Barriers** • Uncertainty of system purpose • No support for continued use • Technical issues **Facilitators** • Ease of use • Availability of help • Fun

12 Figure 4.2.2.1 System and Technical Barriers

Barriers to personal health record use discussed by participants included not knowing what the PHR system is for and how to use it, not having enough support or knowledge to use the system on their own when help was not available and encountering technical issues that made it difficult to access or use the system.

4.2.2.1.1 Misunderstanding or uncertainty of system purpose

A number of participants discussed being unsure or of no understanding the purpose of the system, their personal role in using the system, how the system works, for whom the information is stored and how and by whom it will be used. These participants hadn't had a chance to ask questions about the system or were not able to understand the information they received. The following quotes demonstrate that some participants were not certain about what would be done with their information and about the purpose and benefits of the offered PHR system.

> *I think it was supposed to be just to kind of keep a general record that they could, um, show other people like yourself, about my progress and stuff like that. Other then that, I wasn't told a lot about it, so I never really got around to using it. P30*

> *...it would be a benefit but I don't know what it would do, until probably I died. P03*

> *I just don't understand the system... How am I supposed to use it, other then taking it down to my doctor and asking him how he's going to use it... I don't know. P32*

Even some individuals who were using the system said that they were not certain about its purpose. They were generally aware of one or two major benefits or uses of the system and that was enough to convince them to try the system or even use it more then once. Perhaps if they better understood the system they could have used it more effectively and for a wider variety of purposes. In the following quotes, Participant 27 talks about not having enough information to understand the purpose of the system and Participant 20 about his perception of other people who don't understand what they want to get out of the PHR and even when they use it they perceive it as just another piece of paper and because of this perceived lack of usefulness they choose not to use the PHR.

> *I really wasn't told anything, other then whatever information is put in there, if a doctor needs it, um, he can go in and get it. Basically, and that's all I know about it. P27*

> *You see, I think that's the real problem... is they don't have any idea of what they really want to get out of it. So they're putting all this [information] in, but, no, aw, that's cute, another piece of paper. P20*

The following quote shows that some participants can be overwhelmed with information. Even the simplest PHR system can appear complex to the lay user, especially at first. More training, multiple chances to receive information and different ways of receiving information about the system, its purpose and functionality may be needed to make sure that all potential users who want to find out about the system have a chance to do so.

> *I got such a big description about what everything was supposed to be about in the first place, that I just wasn't sure of what the full extent of what it was supposed to be about. P30*

When an individual does not understand the system, they are likely not going to want to use it or start using it. And individuals who are ill or elderly may have particular trouble understanding the purpose of a PHR despite a variety of attempts to inform them about the system and what it can be used for. Attempts should be made to inform users in different ways that can include informational sessions, printed information and availability of one on one contact with both system designers and also contact with individuals within their setting that they trust and that have information and can answer questions or help them use the system.

4.2.2.1.2 Uncertainty of system capabilities or functionality

Despite multiple sessions and opportunities to find out more about the system during the time that the E-Medicine PHR was available in the housing authority buildings, many users and non-users were not aware of the capabilities or functionality of the PHR. These quotes illustrate uncertainty about how the system works, what it really for and what they as users could do with it.

> *I don't know, I really don't know. Um, would the doctor keep it? Is it in the computer, or...? P10*

> *You know, that somehow these records were ... going to improve communication between the doctors. If they were in the same system... P09*

> *And I was curious to what it was, but I knew it was computer, that I was just computers... I was curious about what it included. But what, it's made up of. Just medical charting? P04*

Some participants mentioned functionality that was already included in the system as something that they needed or would like to see in the system. Or they did not know or think about certain uses of the system that were available to them. This applies even to such simple functionality as printing out a copy and keeping it on their person or in their apartment for emergency purposes as discussed by Participant 14.

> *No, I don't, but I probably should [have a copy] for emergencies. I never gave that a thought. P14*

Another common problem was that some participants automatically assumed that the system would not meet their needs or have useful functionality as expressed in the following two quotes.

> *Not much [the system can do for me] cause there's not much wrong. Except the, like I say, the prostate cancer, and that's not bothering me. I was dizzy, I was, told I have it five years ago, so... and I don't seem to have any problems. P21*

> *Well I can see, like I say, how the program can be helpful for certain people, um, it probably doesn't go as far as I even go. In synthesizing personal information, so, for somebody like me who's got to keep track of this stuff. Your system, it probably wouldn't give me what I wanted to, in any way. Because it wouldn't be as detailed as I need it. P20*

Possibly if these participants tried using the system they would realize that it is not as difficult to use as they imagined, that it has useful functionality that they were not aware of and that it can be useful in certain situations, such as emergency situations.

4.2.2.1.3 Lack of a strategy for continued use

There were a number of residents who had met with the nurses once to enter information into the PHR and then either could not set up another meeting or did not try to meet with the nurses again. Not knowing how to use the system on your own is discussed by Participant 10 below, if more guidance was given or if this person understood that they could meet with the nurses any time they could have been a more active user of the system.

> *There's something that they told me, that if I wanted to see what I had put down that I could contact on the computer, but I don't know where that was, so... P10*

Some participants, like Participants 9 and 24, whose quotes are provided below, talked about not knowing how to use the system or needing help multiple times to learn how to use it or to be comfortable enough to use it on their own.

> *So, without someone there to guide me, even though I might have gone through it a thousand times before, I still need that person here, to help me get in. P24*

> *...the nurses would enter in your information or something and then, and then I didn't know, you know, I figured it was like their computer, so then how was I going to manage that information? P09*

Potential users may need to be given some information about when they need to update their information and what new information warrants an update. They may also need to discuss with support staff how they can update the record, either with a helper or on their own. Extensive efforts need to be made to inform potential users when helpers are available and where and when computers are available. Many users also need hands on experience with the record and help transitioning to independent-use.

4.2.2.1.4 Technical issues and support

Technical difficulties are a barrier to using any system and a PHR system is no exception. Any system experiences technical problems and needs technical support to answer users' questions and help them resolve problems they encounter. Although technical and support problems are specific to a particular system, it's design and implementation, some categories of technical and support issues are described to help identify places where interventions can be implemented and support can be targeted.

When a system is targeted at elderly, disabled, not technologically savvy, severely ill or chronically ill individuals who may have to deal with a lot of information and may not be able to focus their full attention on learning and exploring the system, additional measures must be taken to introduce the system to the users, show them how to use it and provide them with support. Even though such precautions were taken during implementation of E-Medicine system users still discussed a variety of problems they encountered. Described briefly here are the general technical and support issues mentioned by the E-Medicine users.

No access or lack of awareness of access to computers

Although in both buildings there were computer rooms available, and also offices of the staff were made available upon request to use in private to enter health information, some users still expressed that they were not aware of having access to computers. One participant did not know that there was a computer room in their building; another was concerned about spending too much time using a computer in staff member offices.

> *I just don't understand, if you don't have a computer, you can't do it.*
> [Interviewer: "Ok, ok. So you actually have a computer room here in the building."]
> *I don't know.*
> [Interviewer: "Ok, you don't know about that?"]
> *Nuh-huh [negative]. P04*

> *I figured it was like their [nursing students'] computer, so then how was I going to manage that information? Because they are not going to leave their computer here, you know. P09*

Some participants were concerned about using a computer in a public place or public computer room and wanted to have their own computer to make sure their information stayed secure and private and to not have to worry about time limitations or be bounded by computer room hours. Quotes below illustrate their concerns about using public computers or computers in a public place.

> *I'd sort of want to have my own computer. So that I could play with it and diddle with it, you know? ...So, you know, so I could fix and change it, I'd rather have my own computer to do it. P04*

> *I don't want to use that computer room. P32*

> *...they don't know how to clean off anything. I mean, anybody can go, I can go into one of those computers and find out who did what, when, where and why. And if I can do it! So, plus people are looking over your shoulders. P27*

Some participants were also not aware of the resources available to them, perhaps because the recruitment material said to come meet with the nursing students and they would help you do everything, so some participants who did not have a computer assumed that they would not be able to do it.

Additional help needed

Many participants expressed that they needed help using the system and the computer. And many participants described the help that they received from the nursing students, social workers and program support, these experiences are described to outline the kind of assistance this kind of population may need. The quotes below show that some participants were willing to use the system if someone else entered the information for them, some were willing to use it themselves if a helper was nearby to oversee what they were doing, and some expressed wanting someone next to them for the first few times and then perhaps being comfortable enough to use it on their own.

> *If I was to go in, you know, let's say, all of this stuff is already in there... if I was to go in to change something or something like that for at least the first two, three times, I'd want somebody with me who knew what they were doing. P27*

> *Actually when [the social worker] was here he was the one that got me going on it and he helped me learn how to do it and everything, if I needed help I'd call him. Most generally it was to help with my computer, though. P07*

> *I couldn't even get it turned on, let alone anything else. So, without someone there to guide me, even though I might have gone through it a thousand times before, I still need that person here, to help me get in. P24*

Many participants expressed a need for general support, someone to show them how to use the system or help them if there were problems. They wanted to know that there is someone nearby the help them if they have questions or have a problem. Participant 32 below says that help was needed to use the system at least some of the time, and Participant 4 says they would require help to use the system.

> *Oh, I was inputting the information while the nurse, she would ask questions, or she'd help out, some of the time. P32*

> *I need something like that, if I was going to do it. It would be fun if I had the chance, but, you'd have to have a computer and someone here to help me through it. P04*

Having a medical professional that could help users input information and also helped them understand and sort out some of their health information was also helpful. Residents were comfortable working with health information in front of the helper and with this person having access to this information directly or indirectly.

Fear of using computers or the system

Many participants expressed reluctance to use the computer of the E-Medicine system because they wouldn't know what to do or because they didn't know how to use a computer. In general this can be characterized as a fear of trying something new or perhaps a fear of doing something wrong or breaking the system that will be discussed lower. The quotes below show that many participants were not comfortable using computers and updating information on their own.

> *I am not, I am not real good at the computer, it's been several years since I've used one, if, as far as logging all of my... my medical and everything, I'd be afraid to kind of do it. P04*

> *If I had to update it by myself, and stuff? ... I'd be lost. [laughing] ... I don't know the computer. ... I don't use the computer. P01*

> *I don't know. It's kind of difficult.*
> [Interviewer: "It looks difficult?"]
> *Yeah, I need help and stuff. P06*

Some participants like those who are quoted below, were generally not sure of how to use the system or how to organize or work with their health information.

> *I don't know how I would organize it though. I am not real good at that any more. I haven't been in school for 10 years. [laughs] ... P13*

> *I really wasn't told anything, other then whatever information is put in there, if a doctor needs it, um, he can go in and get it. Basically, and that's all I know about it. P27*

Some participants have very concrete fears of using the system, perhaps associated with previous experiences of using a computer. A major fear associated with the computer is breaking the computer and a major fear associated with the record itself is a fear of accidentally deleting all or some of the information. The following statements are examples of computer related fears that the participants expressed.

> *I have a fear of computers that I haven't completely resolved. ... I just had to force myself to sit down and, you know, e-mails I could do that, handle that ok, but I was afraid I'd push the wrong buttons and blow the computer up. A lot of people are like that. P25*

> *I wouldn't touch it, believe me, I, nuh-huh, no. I would not touch it, cause I, with my luck, I delete everything, [laughs], not good. P27*

Another major computer fear is associated with privacy and security of computer records and is discussed in depths in Section 4.2.7, Privacy and Security.

Remembering to use the system and access information

Participants discussed needing reminders to use the system and to remind them to review information in the system in order to decide whether it needs to be updated. Participants discussed needing specific types of reminders that were based on the information stored in the PHR, such as reminders to take medications, reminders to refill prescriptions and appointment reminders. Participant 24 discussed needing reminders to take and refill his medications.

> *Well, the only other thing that I need, would be like, bells and whistles to go off to remind me to take my meds in the morning, um, and to remind me, when to order*

> *my [prescriptions] and when to fill my meds, so that I don't come down to the last day and say, oh dear, I am out of this. P24*

Participants also discussed needing reminders to access their record. Reminding users to review their information before an appointment as part of an appointment reminder and a reminder to review and update information after the appointment could increase how often the record is used. Participants quoted below discussed using the advertising materials as reminders to use the system.

> *When I see the sign up sheet, and I know that something's changed, then I know immediately that's when I got to make an appointment to go see them, so that I get this changed. P24*

> *...if I don't see something coming across once in a while that reminds me of something then I'll forget all together. Not purposefully necessarily, it's just because I haven't been reminded of it for some reason of another. P30*

Another major issue discussed by the participants is trouble remembering log in and password information.

> *Kept changing my password and couldn't get in, couldn't get in... I imaging some of it my own fault, being I didn't have it written down or whatever, you know that kind of thing. P16*

> *...as long as I have someone sitting next to me, instructing me again on how to get on the computer, what to do, how to bring the thing, I can never remember, my, draw up number, your identifying thing that you have to have in order to raise your computer thing... Your ID number, I guess is what it is... I can never*

remember that. I can't remember, um, what I use as the secret word, or whatever that they say, um, I have to have... P24

I would like it if you can tell what my password is, cause I don't remember. P17

Provisions should be made in the system design and implementation for multiple types of reminders. Potential reminders to keep in mind are: reminders to review information in the system, to update the information after doctor's visits, reminders about doctor's visits and medications based on the information stored in the system and also ways to recover log in and password information that would be easy and convenient for elderly, disabled or ill users.

4.2.2.2 Facilitators

System and technical facilitators to PHR use include perceptions of the system as being easy to use and as being fun to use, which can be enabled by advertising and education to create the perception and system design to reinforce these perceptions once the system is used. The third factor, having help readily available is especially important for elderly and not computer literate populations.

4.2.2
System and Technical

Barriers

- Uncertainty of system purpose
- No support for continued use
- Technical issues

Facilitators

- Ease of use
- Availability of help
- Fun

13 Figure 4.2.2.2 System and Technical Facilitators

4.2.2.2.1 Ease of use

A personal health record for elderly, disabled, low-income users should be very easy to use and understand. Although people who are chronically ill or just have a lot of information to manage also might prefer a simpler record that takes less time to understand. Participants were shown a screenshot of the system and most said that the record looked like it was easy to use and they would be able to figure out how to use it. Participants who used the record also expressed that it was easy to use. Some of their quotes are provided below.

> *Well, I thought it would be fairly user friendly because, it said you didn't have to have any computer knowledge, which of course I do, quite a bit. And it said the nurses could do it all for you, that that wasn't a problem. So I figured that it was pretty easy to use. And that you know, you could just go in there and I don't know, bring your health information, or, I figured you had bring something, you know. I didn't know what. And, cause I don't think it said on the flyer, or maybe it did and I have forgotten. P09*

> *Well, like the information, the format is easy to follow, if you've ever used the computer. If you read directions [laughs]. P14*

> *It's easy once you get in there. ... After I finally got the right web site, it just goes right to it, and I just click on update and find my name and there we go, we're off and running. Yeah, it's easy, real easy. P15*

> *I really though it was going to be more... technical, I think. ... I thought there would be more... you know, where like here, please remember to check, you know, and gender and that, you know, you have little boxes that you fill out and you have the drop down arrows and things, it's so simple. Is, you know, I thought it was going to be more complicated, I really did. P16*

4.2.2.2.2 Availability of Help

Availability of help with both system use and regarding health information was deemed important by users. When they had problems or if they did not know how to start using the record, the users had someone they could turn to for advice or support. The quotes below illustrate some reasons why participants felt they could not use the record on their own or wanted help using the record.

> *I can never get into the silly thing by myself and even with the nurses help I can't get into it sometimes. P16*

> *HAVE YOU EVER USED THE E-MEDICINE SYSTEM ON YOUR OWN? No. ... I've always had someone else help me. ... Because I can't remember how to get on. P24*

> *So we did part of it in Judy's office and that was like, oh god, at least two hours. And then the rest of it, she said I was supposed to go in and do it. I am going, I am not going to do that, I'd go in and I am going... heaven only knows what I'd do. P27*

> *Oh, I was inputting the information while the nurse, she would ask questions, or she'd help out, some of the time. P32*

4.2.2.2.3 Fun

Some participants chose to use the PHR system because to them it sounded interesting and just in general seemed to be a good idea. A number of participants expressed that the system sounded cool when they heard about it and that is why they wanted to try using it. Many system users, like those quoted below, expressed positive thoughts about the record and said it was fun, cool or interesting.

You know, that would be fun for me to do, I just never did it, never thought about it. Cause I kept files on everything. P04

It sounded cool ... I found some of the process aggravating. ... But for the most part, I found it pretty cool. P17

Well, I guess they asked me. You know? So I did it, you know? Thought it a good idea... P12

4.2.3 Information Management

HIM Motivational Factors (Thematic Set 2) – Information Management

4.2.1 **Information Access** ***	**4.2.2** **System and Technical** ***	**4.2.3** **Information Management** **Barriers** • HIM is difficult • Poor HIM in the past • Managing a growing quantity of HI **Facilitators** • HIM is important • Backbone for HI • Accuracy, currency, completeness of HI
4.2.4 **Medical System** ***	**4.2.5** **Personal Health and Life Situation** ***	
4.26 **Social** ***	**4.2.7** **Privacy and Security** ***	

14 Figure 4.2.3 Information Management HIM Motivational Factor

Information Management factors are those related to the processes involved in managing health information. These processes include collecting health information and finding where to get accurate historical or recent health information, entering information into the record and understanding it enough to know what to enter into the record, and organizing, understanding and using HI to make health related decisions.

4.2.3.1 Barriers

Information management barriers discussed by participants included health information management being a difficult process for a number of reasons, such as not having access to all necessary health information or not being able to understand it, or the process of entering or organizing information being difficult. Participants also discussed that a major barrier to managing health information now is that they did not manage it in the past and now do not understand or remember what happened to them in the past and do not have access to past information. Another barrier, especially for a population with many health issues is the difficulty of collecting, understanding and using a large amount of information that accumulates over time.

4.2.3
Information Management

Barriers

- HIM is difficult
- Poor HIM in the past
- Managing a growing quantity of HI

Facilitators

- HIM is important
- Backbone for HI
- Accuracy, currency, completeness of HI

15 Figure 4.2.3.1 Information Management Barriers

4.2.3.1.1 Management of Health Information is Difficult

Management of health information (HI) can be difficult. There is a lot of information to keep and often it is difficult to understand for lay people. Many participants described in detail their health information, their health problems and the kind of information they need to keep in order to characterize how difficult management is or would be for them. Participant 5 below is an example of a person who has so much going on in their life and health situation that they are unable to get the information into an organized and usable shape. This person talked about wanting to manage their information but just repeated over and over all the things that were wrong with them.

> *I do have the other kidney, so, they just take care of that one and um, I have Hepatitis C and um, cirrhosis of the liver, so, I don't know. I, I am going to have to get to a point where I care a little bit because now I have to take care of myself health wise, and I think I am going to be the one, see my son did it all before. Um, but I've been in the hospital and nursing home since June 3rd and this is my first time out, so, and before that I was in a group home and before that a nursing home, before that a group home, and so I didn't really have to care about myself, as far as that went. Um, I had a wound, an open wound on my body, and that's what everybody was concerned about that, as far as infection and all that. P05*

When asked about managing information using a PHR system, on paper or in another way, participants expressed views that suggested that they perceived the process as difficult or time consuming and that they would like to find ways to make it easier. Participant 9 say that getting their information into the record would take a while and might be difficult for people who do are not computer users. Participant 7 jokes about way to make collecting and managing information easier.

> *I think it would be, it would take a while. But it would be, it would be easy to do. But then, I am very computer literate, so, for me it wouldn't be a problem. P09*

> *Yeah, do it all itself for me. [laughing] That would be nice. Touch a button to my finger and it would just do it [laughing]. P07*

Others, like Participant 9 below, say that they either have too much information to manage, which makes it difficult for them, or that entering information is too much work and they don't want to do it.

> *No. Too much work. [laughs] I am getting awful lazy. P09*

4.2.3.1.2 Poor Management of Health Information in the Past

Using poor management practices in the past leads to a situation where people do not understand their health information because they were not tracking it in the past and when it is needed they do not have access to past health information because they were not storing it. The quotes below illustrate that consumers have difficulty getting access to past health information because this information is lost or destroyed.

> *Um, the last 5 years, yes. But before that my records are pretty fair. ... I just didn't believe at the time that it was important. ... I didn't see the importance of it, but now I know that it is important. P25*

> *In the cupboard, um, well, I keep just the medicine one in the cupboard. No, because I write them on a piece of paper and my doctor keeps them. ... I have them all over the house. [laughs] ... Um, I have, and luckily I have found it, because I kind of keep them in the same filing cabinet thing, but yeah. P01*

Many participants expressed that they do not know what information is important to manage. Like Participant 19 below, they do not get information from their doctor and they do not seem to know what information they would want to have from their doctor.

> *I get once in a while, maybe a piece of paper from them, but it has to, but it states, you know, if he gives me a paper, if, like the hospital my bill. That was in the year 2006 in August, that came from the Providence hospital. I had the doctor's name, but I don't even know what I did with the paper now. I know it's in my drawer someplace, but I got to hunt for it. P19*

Many participants relied on their memory in the past to keep track of health information and some continue to rely on it now. Many participants mentioned that they forget information or that forgetting their information has led to problems, but most participants still continue to use this strategy because it is the easiest.

> *Yeah, because see, I went, if I went into the hospital, um, it's been probably about three years ago now, and they did all kinds of tests on me and I couldn't tell you what they were, which I am going to have to go to the hospital and ask them for the records of what was taken. Um, but I know I had at least one CAT scan, if not two. And I know I had a spinal tap... P16*

> *I've learned so much about me, it's in here. And I do have it all here* [pointing to their head, meaning in their head or in memory]. *And I, I don't know, I just, this is the only thing I have that's written down, where it is. P10*

> *I have like a, date planner, well, it's a calendar. You know, little small pocket calendar that I write my appointments down in. So I rely on that and my memory to remind myself ... I do well with taking my meds, so that's the main thing I have to really make myself remember. P09*

When asked what problems they would anticipate encountering if they tried to enter their health information in the PHR in addition to worrying about entering so much information participants mentioned trouble remembering information.

> *No. Well, except for remembering things from the past. That would be the problem. P09*

These past practices have led to a situation where information is on separate pieces of paper, stored in different places and in memory and getting it together and organizing it is a difficult task.

4.2.3.1.3 Management of Growing Information

A constant task of updating information, deciding which information is useful and which is not and how to archive it or mark it as inactive is difficult. A constant task participants have to do is making sure that their records have the most useful and most current information instead of all information which becomes useless and overbearing. These quotes show that managing a long history of health information is perceived to be difficult by participants, even in the E-Medicine PHR users had to make the decision on which information they should keep for historical purposes and which to delete to keep their record less cluttered.

> *Well, that would be ok, but .. I don't know, you get this old you have such history.. you know.. it's kind of hard in a way. P04*

> *I don't, you know, and lab tests. [laughs]. I mean, they want every time I've had lab work, or MRIs or CT scans or selective injections or head, head thingy-me-diggies and EEGs and... EKGs. My god, you're supposed to be able to keep it all separate, nuh-huh. P27*

> *And your doctors, you know, now I do, I have um, I don't delete them, what I do is keep them in there so I know who I've seen in the past. You know, and what the diagnosis was and then medications that they've... prescribed for me and everything. And it helps to know all of this. This stuff, you know, as I go along each year, it seems like there's more I press on that. P07*

Many participants discussed making mistakes in their management strategy such as not tracking or throwing away their old lab tests, readings or records and then realizing that they might need that older data. A few individuals, like Participant 21 discussed realizing later that they might need information they deleted or did not keep.

> *Yeah, just the dates and the times and what it's for. And then I erase them. I should not do that, I have just figured out, here the other day, I should not erase them, I should let them stay for that month, because, [.........] or a year back. Because right now, I don't remember what the last time I had a, a, a hormone shot for my, I am taking hormone therapy for the cancer, and the Zolodex I am taking, that I get every three months, and I've forgotten when it was. I am sure they know down there, but you know... P21*

> *I've been on and off lots of medication. Have not kept very good track of them. You know, you know, when they take me off something, I just go, that's the end of that one, throw it away, you know, go on to the next one with a little bit of hope. And so, I don't even remember all the medications I've been on, let alone the order, or when it was, or you know, I've been hospitalized, you know. P09*

Other participants didn't realize the value of keeping older information and discussed deleting information or just not knowing what to do with the old information. They discussed wanting to clean their record.

> *I check weekly for blood pressure, and then the blood glucose testing ... I would like to keep track of that. You know, and say after 6 months, then start a fresh, or something you know. Cause after a while, it's going to be... quite a long... But you can purge old stuff you know, old stuff like that you know, and just take out maybe the highest and then lowest on such an such a date and then go on from there. P16*

> *Lab test, I don't know... I don't know why they'd want a record of those, um, I mean, mine would go on for ever and a day. Um, I don't understand that. Allergies, of course yes. Lab tests I don't understand. P27*

Some participants perceived their record as a picture of their current health situation and not a historical record. They do not know or realize that their historical information can be useful and that it can be stored and displayed in such a way that it will not obstruct retrieval of the newest information but could be available when necessary.

4.2.3.2 Facilitators

There were three groups of information management sub-factors that positively spoke for PHR use. The first is that participants many times reflected that health information management (HIM) is important. The second is that the PHR forms a backbone for their HI that helps them track and organize information. With the help of the PHR they know that information to track and learn more about their health information from having it stored in a structured way. The third is that accuracy, completeness and currency of HI are important and the PHR helps individuals track and have access to more accurate, current and complete HI. These three sub-factors are broken down further in this section.

4.2.3
Information Management

Barriers

- HIM is difficult
- Poor HIM in the past
- Managing a growing quantity of HI

Facilitators

- HIM is important
- Backbone for HI
- Accuracy, currency, completeness of HI

16 Figure 4.2.3.2 Information Management Facilitators

4.2.3.2.1 Management of Health Information is Important

Some participants talked about the importance of knowing their health information at any point, such as most current or past medications, immunizations or doctor visits. The quotes below show that participants perceive the health information they are tracking to be important and that it is important to have it organized well for optimal use.

> *Cause that's what I deal with mostly now. Is medications and doctor visits, and like I said, um, um, why I am going to the doctor, what I got out of going to the doctor, and, stuff like that. Medications are important when you get my age, so you'd want to update them cause they change all mine around. P04*

> *But all the meds are in there, and that's what's important. The doctors names, contact information, like for emergencies, that's important. P32*

Some participants discussed realizing that managing their information is important over time as information aggregated or was lost or after some event in their life when they needed their health information and it was not available. Participant 5 discussed realizing that they need to track their health information better after accidentally taking wrong medications which led to a hospitalization.

> *...it's dangerous the way I do pills, so I need to, I need to change, as far as my medicine is concerned, so, yeah, um, keeping records is very very important, it's just that sometimes you have to, somebody has to remind you of certain things, else you wouldn't know, and had we not did this right here, I wouldn't have thought of it. But it's a good idea. Should I have been doing it? P05*

> *Yeah, and moving, things have gotten, I have some boxes at my son's house and some at my daughters, and I thought someday I would just go through them, and organize them, put them all together. ... Because it's important I think. P25*

Many participants discussed the importance of tracking their health information or the importance of knowing information in particular health information categories.

4.2.3.2.2 PHRs are an Information Backbone That Make Management Easier

Tracking and organizing health information in an electronic system is easier then doing it in other ways. The information is not just a pile of papers that needs to be searched to find useful information, it helps the user know what information is important and needs to be entered in the computer when they receive it and then it is stored in an organized fashion an can be retrieved when needed. Quotes below illustrate participants talking about using the PHR to organize their health information.

> *Well, I think it's all computerized, your records are on the computer. And I think that's a great idea. ... It's easy to manage and control. P25*

> *Just having a more organized way of doing things. And in my past I've moved around a lot! ... And so, being able to have access to my information to give to the new doctors that live in that area was always important... And sometimes that information gets lost, I know it did in my past and everything, and certain things would be overlooked because they didn't get all the information that should have been there for them in the first place. Um, so when they talked about organizing things, so it's easier to use and everything. That fit into my thinking concerning all that in the past. And I think that's probably why I got interested in that. P30*

> *It's so much easier to keep records on the computer then it is to keep them in a file someplace, you know. ... The other thing, was just like I said, ever since I was a young person, I knew I should be keeping track, but I didn't you know. P16*

PHR systems help track and organize information in such a way that makes it more understandable to the user and at the same time familiarizes the user with the information. It helps them take the next step to processing and using this information for decision making. Participants expressed that they would not have known how to track the information before they used the system, but they realized how useful it is after they started using it.

> *And if you have it, the record, on the computer, you can keep it covered, keep it updated and so forth, it's a way to know what's going on with your health. P05*

> *And that was why I decided to do it, because I wanted to have something to keep track of all this. So I didn't have to keep writing it over and over and thinking what was what, you know. I never thought of trying to manage it myself at home because I didn't have the concept in my head of how to do it, like they do. P07*

A PHR also provides a back bone for health information. The structure of information within the system provides some guidance on what information is important to track and fill out. Participants realize that having the PHR helps them learn about what information is important. The quotes below illustrate this idea.

> *Let's see, just, general information, contacts, insurance, health care provider, family health survey, health problems, yeah... asking a question like, how you manage the problems, under health problems, that's good. Makes, forces the person to think. P32*

> *Well, yeah I do. What, what I know, and what I have records of, I'd have to get all of those organized and um, start typing. [laughing] ... Yeah, I don't know how I would organize it though. I am not real good at that any more. P04*

> *And most of this stuff can be done with a pencil and a piece of paper, and it doesn't need a fancy program. But there are people who really need to be guided along through a program to help them figure out. P20*

4.2.3.2.3 Accuracy, Completeness and Currency or Health Information

Using a PHR encourages accuracy and completeness of the information stored in the record. Keeping information in a PHR system encourages users to have the newest and most accurate information recorded and can also encourage them to keep and to know more complete information about their health. Participants quoted below talk about how the PHR helps them keep the most accurate, complete and current PHI.

> *To know where I'm at, keeping an accurate information about what's going on with me, where I'm at, what medicines I am on. P25*

> *I think it's complete as far as I am concerned. It's, um, yeah. Yeah, this, this, I think is a really major function to it for me, and, and, and these allergies cause I can never remember when you go to the doctors office, what are you allergic to, you usually leave something out, you know. P26*

> *It'd keep me up to date. Um, I'll be more aware of what's going on health wise... Um, I'd be more apt to give the information out to physicians that's asking for health information, my background or anything of that sort. They might be trying to treat something and they need some background on, of the health issues that you have. P05*

Participant 9, quoted below discusses the importance of having the most current and complete information and keeping up the record on a regular basis instead of frantically trying to recall information when it is needed.

> *I could update it as some point before my next appointment, and, because that would be an easy thing to do. And if you let it slide, then it's going to become a burden. And that would be bad, because then it gets all behind and it isn't any use to anyone. P09*

Using a PHR can encourage users to find older information and fill in gaps in their record and in their knowledge of their own health and medical history. Users try to enter all the information they know so that they have access to it all in one place. When the information is stored in one place they can easily give it to providers and emergency personnel when it is needed, they don't need to search for it, worry about it being inaccurate or incomplete or giving health care providers piles of paper where the concrete information needed cannot be found easily

> *Well, I've been trying to remember my surgeries and stuff like that, so when I remember them, I write that down. I have what I call a timeline... P16*

> *I can't think of anything, as long as the information is kept up... Yeah, alright, I gave them all that, they asked me all those questions, and I gave all the answers... That I knew of. So everything is pretty much updated, still that way, except for this part. P29*

Individuals realize the importance of having all information, past information and even future information about their health and that it can be important in a situation where decisions need to be made about their health care.

> *I know I have a surgery coming up here in the future, probably within the next two or three months, it would be nice to have that on there, so that I could give that information to whoever needs it. P15*

> *Because you're information is right there, all you have to do is just punch it in, but you know it'll come up, that way you're not guessing, you know. It's a sure way to know, to know that the information, other then that you could, um, have different information that's not correct each time, you know, if you ask. P05*

4.2.4 Medical System (Establishment)

Another group of factors that participants discussed were factors related to the medical system as the establishment where they receive care. Participants discussed the aspects of the medical care system that make it more difficult for them to access and manage their health information. Participants also discussed opportunities within the medical care system where having the information in their record enables them to more easily use the health care system or receive better care. Major benefits of the PHR included using it to help fill out intake forms and emergency use of the PHR.

HIM Motivational Factors (Thematic Set 2) – Medical System

4.2.1 **Information Access** ***	**4.2.2** **System and Technical** ***	**4.2.3** **Information Management** ***
4.2.4 **Medical System** **Barriers** • Lack of HI given by doctors • Unclear role of PHR in the medical system •Awareness of existence of PHR **Facilitators** • HI updates between doctors • Replaces intake forms • Emergency use	**4.2.5** **Personal Health and Life Situation** ***	
4.26 **Social** ***	**4.2.7** **Privacy and Security** ***	

17 Figure 4.2.4 Medical System HIM Motivational Factor

4.2.4.1 Barriers

There are three types of barriers that emerged in the medical system factor group. First is individuals feeling that they do not get enough information from their doctor or that they do not receive any information they can take home with them to review. They discuss not remembering information given orally by the provider in enough detail to enter in to the record. Another barrier to PHR use is that patients do not understand the role of the PHR in the medical system, they are not sure about how to tell their doctor that they are using a PHR or when to present it to the medical staff. They can be unsure or afraid of how the medical staff will react to the PHR. The third barrier is a concern about how in an emergency the treating emergency personnel or medical personnel in a hospital or emergency room would know that they have a PHR that could be used to make more informed treatment decisions. These will be discussed in more detail in this section.

4.2.4
Medical System

Barriers

- Lack of HI given by doctors
- Unclear role of PHR in the medical system
- Awareness of existence of PHR

Facilitators

- HI updates between doctors
- Replaces intake forms
- Emergency use

18 Figure 4.2.4.1 Medical System Barriers

4.2.4.1.1 Receiving Information from Doctors and Communication Issues

Many participants expressed frustration about their interactions with the medical system that are related to receiving and managing their health information. One major issue that participants described are short doctor visits and insufficient time for the doctor to adequately review information, discuss health issues with the patient and discuss what to do further with the information resulting from the visit. This is also related to participants feeling that their doctor is not interested in their health information and not willing to spend time to get familiarized with it. The statements below show how the PHR was used to deal with the issues listed above.

> *With a GP now days, when you go in to see you GP, you have to tell them the problem ahead of time, you get your five minutes, and they don't want to talk about anything else but that. So, you better have your ducks in a row, but only*

> *about that. If you have something that affects it, you can throw it in. But ... you better have an idea of what's going on. P20*

> *That is [the PHR] for the patient's benefit and the doctor's benefit, takes less time at the doctor's, not that they ever read stuff, so, don't kid yourself, they are still not reading it. P20*

> *Well, this information that you give to the doctors and they help... prevents them asking the same thing every time you go and visit. P14*

The second issue is having new doctors all the time and communicating past information to new doctors. Many participants received care at a local community clinic where every time they went in for a visit they saw a different doctor. This adds the complexity of having to relay past information every time an individual goes in for a visit. Every time, the individual has to spend their time to recall past health information and to fill out an intake form and spend some of their visit time to relay this information to their doctor and answer questions related to history and past information. Basically they have to familiarize the doctor with their health history every time. The statements below illustrate how the PHR helps consumers improve communication during visits.

> *Sometimes when I go to a new doctor, they want to know if I've been on, if I've taken any new medicines lately and sometimes I know and sometimes I don't. P25*

> *Well, it just eliminates all of that... um, I went to the dentist, just before I got involved with this, and, and I only went to have my partials fixed and they wanted to know all of my health records. ... Now, I would hand it to them, and let them do whatever they wanted to do with it. So that's, that was the, same thing as going to the chiropractor when I was sick recently, it's the energy doctor, not a, not a bone, you know. P26*

> *Being able to have access to my information to give to the new doctors that live in that area was always important, because they don't know where to start unless they get that information and sometimes that information gets lost, I know it did in my past and everything, and certain things would be overlooked because they didn't get all the information that should have been there for them in the first place. P30*

The following statement show that participants feel they do not receive sufficient information from the doctor or their doctor doesn't give them information in a form they understand or could do something with it.

> *No, the doctor doesn't give me any... medical papers on it. He has it in his office. Just my meds, are there, that I don't have it in the... well, I've got three sheets that tells what medicines I'm on and that's it. P03*

> *He don't give much information, he just tells me you know. P12*

> *No. I got, if the do a prescription, well, I can't say that either. Maybe I did get something. Cause ... usually they give you, um, I can't even say that they give you something that they've done, cause I don't remember that. ... You know, ... if you're in emergency and they are doing all these test, I am sure they are keeping track of what they are doing. ... You know, but I don't think they let you know what they've done. I don't remember ever seeing anything like that. P16*

Some participants expressed that even when they get paperwork from their doctor, they don't know what to do with it or do not have much use for it.

> *Oh, my transplant nephrologist, he gives me, I always ask for a, like, when I do, every time I stay in, I have to go to the blood lab, it's every three months now. It used to be every month, now it's every 3. And I get a printout of the blood work, ok... I have those. But they don't stick around long. ... Eventually they end up in the [trash]... P32*

A PHR helps alleviate these issues by helping to have at hand information needed to give to a new doctor or information to answer own or doctor's questions by addressing the barriers of memory problems and strain or stress of having to remember this information when it is necessary. However it is still difficult for patients to receive and process source information about their health. They don't have sufficient time one on one with their doctor to ask questions and really understand their information, and often they don't receive any written information about their health or their visit that they can review or research later or even input into their records. This creates the problem of incomplete or misunderstood information and patients not taking as active role in their health as they possible could have with more complete information.

4.2.4.1.2 Unclear Role of PHRs in the Medical System

Some participants were not aware of how the record could be useful as part of their medical care. These individuals that do not understand how managing information can help with their health care or to take care of themselves better and also don't realize how it can help them during visits with their doctor or in their interactions with the medical system will probably be unmotivated to use the record. The following quotes illustrate that participants are unsure about how the PHR can be useful in their interactions with the medical system.

> *So I don't know where I stand with, hopefully it would help the doctor in case something happened to me.... Or my family. Mainly my family, it would help my family a lot. P03*

> *Um, I just know it's available for the doctors to get online and see your updates and what you've put in and go over it and share it with new doctors that you're going to. P01*

> *...my doctor in Virginia Mason has got the computer right in the examining room and he pulls it up right there. But I am not sure about [my primary care provider] if he looks at it at a later time or before I, if he knows I have the appointment, if he looks at it before I have the appointment or whatever. So, I couldn't tell you how he does it... P15*

Some users were also not sure how to present their PHR information to a doctor. Some individuals feel that they don't really know what information their doctor needs and so they cannot know what information in the record will be useful to them. Some participants like Participant 20 feel that their doctor is not going to care and others, like Participant 32 do not understand what the doctor can do with their record.

> *Yeah, for me. Because that's who it's for really, it's for me. Cause like I say, the doctors really don't read it, and unless I bring it to somebody's attention, realize that there's a problem here, which, I am not a doctor so I can't actually know where there is a problem. P20*

> *Well, I know it's supposed to be used in the case of, like a tsunami... and things like that. I don't know how to use it for my doctor, to be honest. It might have been explained to me, but I really, I never really remembered to ask them, or if I, I don't remember what they said, or something like that. That happens a lot. P32*

> *How am I supposed to use it, other then taking it down to my doctor and asking him how he's going to use it... I don't know. P32*

The most common use of the PHR in the medical system was for individuals to have a copy with them during visits or emergencies as a memory aid to help fill out intake forms and help them answer questions about their health or to speak for them in an emergency if they were not able to speak for themselves. Most residents were not aware of any uses of the PHR other then having a copy of it in their emergency packet in their apartment for the EMTs or on their person in case something happened to them when they were out of the house. Emergency use and filling out intake forms are two of the Medical System benefits discussed in the next section.

The following barrier further illustrates another way in which participants are not sure how the record can be used within the medical system. Some participants brought up the issue of how medical personnel would know that an individual keeps a PHR in an emergency when they need information.

4.2.4.1.3 Awareness of the Existence of the PHR

Some participants brought up the issue of how a doctor would know that an unconscious patient has a PHR with their health information. Since one of the major uses of PHR that was advertised was for emergency purposes, it was significant that patients realized the problem and didn't know how a doctor will know that they have a PHR if they are unconscious and cannot provide this information.

> *If mother, if mother forgets everything, which is not gonna happen, but you know, if you're unconscious or something, somebody got to know, particularly if you're not in your own home town. ... Cause that's when it's a problem usually. P27*

> *I could do that, or that they could, you know, just... Log into the program and bring up what they needed, but that would have to be given by my permission, but it would be accessible for people to do that in emergencies. P24*

This problem is not as sharp when a person has an emergency within their apartment where people nearby know them, friends or family can be contacted or an emergency information sheet can be found, but it becomes a question when an emergency situation happens outside their home or while traveling further and people may not know where or how to look for their PHR. Participant 27 discusses the issue of how emergency personnel in another state would know that she has a PHR with her health information.

> *I don't even know how they'd know anyway, but I mean if I was say in Seattle in a car accident, um, if I am not awake to tell them that it's there, I doubt they'd look. Seattle might, but Southern California I very much doubt would. P27*

Other participants also discussed not knowing how a doctor would know that an unconscious patient has a PHR and where to look for it or how to access the record. Some participants like those quoted below suggested potential solutions for this problem.

> *As I mentioned before, I would appreciate it if each person could come up with some kind of password or code so that your doctor can, um, gain access to the records any time they need to, as well as hospital staff, in case on an emergency. Because, usually if it's an emergency you're not going to be awake to tell them. P17*

> *In case if something goes wrong and I can't talk or something, or somehow they can, if I don't know, if I can't remember, I can give them the code word, if I can remember that, and they can look it up on the computer. ... And find out what information they can get out of it. P29*

One idea suggested by a participant is the card with access information in their wallet. However standard ways need to be developed for health practitioners to know whether a person they are caring for has a PHR and where to look for it.

> *So, it's, and I keep an emergency thing in my wallet. Contact in case of emergency. So, and penicillin, it's in my wallet as well, I used to wear a bracelet, but I don't have one no more. Said I was allergic to penicillin, but I don't have one anymore. P29*

> *... if in an emergency, if I'm not able to speak for myself, that I have a card in there. They can search my personal belongings, and they'll find that card with the, what the, what all the computer information they need, like password and things like that, they can look it up. P32*

If or when there will exist a centralized way to find information about patients, then the problem will come down to identifying the individual. But for now having a bracelet with information or a card in the wallet, although not the most secure way of keeping this information, but one that partially ensures that if the doctors are searching for information about the patient they may find it.

4.2.4.2 Facilitators

There are three medical system facilitators that support or reinforce PHR use. One is that the PHR can be used to help the patient keep multiple physicians that they see informed of the changes to their care or health situation. The second is that the PHR can help replace intake forms or help the patient remember information that needs to be filled out on an intake form. And the third is the record being found and used in emergency situations to make better treatment decisions. These are discussed further in this section.

4.2.4
Medical System

Barriers
- Lack of HI given by doctors
- Unclear role of PHR in the medical system
- Awareness of existence of PHR

Facilitators
- HI updates between doctors
- Replaces intake forms
- Emergency use

19 Figure 4.2.4.2 Medical System Facilitators

4.2.4.2.1 Information Updates between Doctors

Participants describe the record as being a good way to update their doctor on what other doctors have done between their last and current visit and other updates to their health information. The following quotes illustrate the record being used to help the doctors know what health changes have happened between visits.

> *Um, to better help my doctor know what's going on. Um, in case, cause I have like so many different doctors, that I take a copy to each doctor and they know what the other doctors are doing and keeping a better record. P01*

> *Uh-huh, they usually take a copy of the whole thing. The whole things is in there, and then, if I, if I go back in to my regular doctor, and I am having issues here, they just copy the one page, the you know, that. P26*

> *And that way, if you have a good general practitioner that person can organize all that and say ok, these are what your problems are currently, or were in the past, so what is your problem today and how it relates to that. That way they can come*

> *to a concise, hopefully, and good diagnosis of what's happening with you right now. Does that make sense? P20*

Many participants saw the record as a way to help their doctor and felt that they kept it for their doctor. Participants, like those quoted below, felt that having this more complete and accurate information available would help their doctor.

> *Yes, I decided to sign up for it, because I saw it as a venue that would benefit doctors more. P29*

> *Well, I have been told that when they filled out the form with my medicine stuff, that I could take it to my doctor and if he had any ... If he doesn't know what to do, he can look at what they put on the paper and, and check everything. So I really don't know other then that. P10*

Many participants discussed that their doctor likes the record. For the patient the record reduces the stress of having to recall information and worrying about its accuracy and completeness and for the doctor it helps to have complete and accurate information available to review in a useful form. These statements are examples of positive feedback received by the participant from their provider about using the PHR.

> *Well, this information that you give to the doctors and they help, prevents them asking the same thing every time you go and visit... Yeah, and I've been praised for bringing it in, cause it helps them too. P14*

> *That I could take it to a new doctor and they could exactly see what is going on, what medications I am on, the dosages, um, that's the main part. See you know, what you know, other doctors I see, I don't have to go over everything with them,*

> *they can just look at that and... I just changed to a new family practice and she really liked it, so, yeah. P01*

Participants who see multiple doctors and update their record enable their providers to see right away what other doctors have done since the last time they saw this patient. This is especially useful when a patient sees multiple specialists or ends us receiving care in an emergency room, being hospitalized or prescribed new medications between visits. Having an accurate summary of health events, current medications and other health information is helpful for the doctor to have complete information about the patient's state of health and changes to that state.

4.2.4.2.2 PHR Information Replacing or Supplementing Intake Forms

Many participants described their frustrations about filling out intake forms at the doctor's office. Many participants described having to fill out these types of forms very often as they see more then one doctor regularly and they have to see new doctors all the time because doctors in the public clinic they use change very often. A second issue is that many participants were elderly or had memory problems and it was difficult and stressful for them to recall all surgeries or medications or to remember detailed information, such as medication dosages or dates or immunization dates to put on the intake form. Having a PHR summary sheet helped them have this information at hand.

Patients using a PHR can update the record regularly or any time their information changes and use it to aid recall of information about their past health care encounters. They can either provide the PHR summary sheet instead of an intake form or copy over the historical information from the sheet onto the doctor's intake form. These uses of the PHR as discussed by the participants are provided below.

> *If I have a new doctor to go to, just hand it to him and say, I'm not filling out all your damn paperwork. Here is my history, right. I can fill out my name, address and phone number I have no problem with that. But to sit there and do all those*

> *questions, of all the paperwork, I am just not going to do that anymore. And that's one of the reasons I signed up, was because, uh, because there's times where I had five doctors at one time. You know, and trying to remember all that stuff it's just, ugh, ridiculous. P16*

> *See like if you go, as you go to um, a different doctor, a lot of doctors would like to know your complete medical background... It's a lot of times that um, um, even some surgery that has to be done, they need a lot of your medical history, your medical background, some medical records on what's been going on with you, and this would be easier, because you could just print it out, yeah, that way you're not sitting there fumbling with what you think you need to say. P05*

> *Because it was getting harder to you know, you go to new doctors, I've had so many new doctors lately that, it's hard to remember all that stuff and you know. I had thought for years, Jeez, I wished I had something that would keep all this together and then when I go to a new one, all I have to do is hand them that. Lot of them still prefer that you do their own forms, but I've had some, that had said, hey, you don't even need to do our own forms, this is sufficient. And so, that is a help right there. P07*

Many participants described how stressful or frustrating it can be to fill out intake forms, because there is a lot of detailed information they have to remember and recall. Participants discussed filling out intake forms often and often in stressful situations which are not conducive to concentrating and recalling information. The quotes below illustrate that participants consider it helpful to have a PHR at hand in these situations.

> *That I could take it to a new doctor and they could exactly see what is going on, what medications I am on, the dosages, um, that's the main part. See you know, what you know, other doctors I see, I don't have to go over everything with them,*

> *they can just look at that and... I just changed to a new family practice and she really liked it, so, yeah. P01*

> *Well, this information that you give to the doctors and they help, prevents them asking the same thing every time you go and visit. P14*

> *Now, I would hand it to them, and let them do whatever they wanted to do with it. ... I hate any kind of forms! P26*

Some participants, like Participant 15 quoted below, said that their doctor found the information in their PHR to be useful and used it to help structure the health encounter and to reduce the number of questions he had to direct to the patient.

> *It's just easy, it's just easier for him rather then sitting and asking a bunch of questions, he's got it right there in front of him, and he can... you know he will ask questions about the information that he sees on there, just to double check and see if anything's changed. ... I haven't talked to [my primary care provider] about it, so I don't know what his response is to it. All I know is I took everything in, I signed up, I got all the papers, I took them in, I said here, this needs to go in my file, or on the computer, or however he wants to do it. So, we haven't really discussed how he does it. But [DR at Virginia Mason] likes it a lot. P15*

Having the information stored in a PHR and having this information available when it is needed reduces strain and stress of remembering or not being able to remember necessary health information. It also enables the individual and the physician to have more complete and accurate information than what an individual would be able to recall from memory. This benefit was often discussed by participants, who appreciated having the information in the PHR to help them prevent these stressful situations.

4.2.4.2.3 Emergency Use of PHRs

Emergency use of the PHR was advertised at the housing authority as a major benefit of the E-Medicine PHR system. Many participants described carrying a paper printout of their PHR on their person or having one in the emergency pocket in their apartment. Participants described the record as useful both in an emergency situation where the patient is unconscious and cannot provide information and also as an aid when an individual might need to recall HI in a stressful emergency situation. It is easy to forget something important in such a situation or not be able to recall details. Emergency uses of the PHR as discussed by the participants are provided below.

> *Because, usually if it's an emergency you're not going to be awake to tell them. Ok, yes, I'm allergic to this, I'm allergic to that, my family's had this, my family's had that. I need to, I'd prefer if medical providers could have access to it whenever they needed it. P17*

> *...in an emergency, if I'm not able to speak for myself, that I have a card in there. They can search my personal belongings, and they'll find that card with the, what the, what all the computer information they need P32*

> *...living alone I put it in my cupboard. I have a copy in my cupboard, in case of an emergency, they can come in and get all the information right there in my cupboard. ... For the paramedics or anybody. P01*

> *I have one that's in my cupboard, we have to have an emergency sheet, I keep my E-Med deal in there. So that [emergency personnel] can just take a look at it. I've had it taken to the hospital, when I come to the hospital and they appreciate it. P07*

The PHR could also be used to facilitate communication between providers in an emergency situation. In the quotes below participants discussed that the PHR provide vital allergy and current medication information when the individual is unconscious or can not remember it. Additionally, the record has easy accessible information for people that need to be contacted in case something happens to the individual keeping the record.

> *I keep my contact numbers, um, my, my allergies, and things that would be needed immediately should something, should I be um, carried out of there on a stretcher and not able to talk, all the information that they would need would be there on the slip, and um, that could possibly save my life, you know, if I am allergic to something, then they can't give me that. P24*

> *Well, if something happened to me, then they could check it all out. I mean, my children, and the medics if they had to come here, or something like then. P18*

It can be even more stressful to recall health information in an emergency than doing it in a doctor's office when filling out intake forms. Additionally, the accuracy of information can prove to be critically important when treating a patient in an emergency. Participants reported that having the record reduces the strain and stress of having to remember and provide accurate information about their health in emergency situations.

> *...it took at, a, a weight off, off, because I hate trying to remember when this happened and that happened, alright, so I carry it all the time in my purse in case, um, and, and, I, something should happen, and somebody needed the information. P26*

> *...it keeps your records, you don't have to look for them, you go to a new doctor you don't have to worry about well did I remember this, did I remember that, did I tell them everything, you hand them that and they can just look through it. P01*

4.2.5 Personal Health and Life Situation

A person's decision to use or not use a PHR may be based on their current personal health or life situation. Health factors are those such as physical and visual disabilities that can make it harder or impossible to use a computer. And other factors, such as memory problems or having too much or too little health information to manage. Life situation factors are those related to not having support, a changing health situation that makes it harder to understand and manage HI.

HIM Motivational Factors (Thematic Set 2)
Personal Health and Life Situation

4.2.1 **Information Access** ***	**4.2.2** **System and Technical** ***	**4.2.3** **Information Management** ***
4.2.4 **Medical System** ***	**4.2.5** **Personal Health and Life Situation** **Barriers** • Memory problems • Disabilities • Too sick or not sick enough to use PHR • Changing health situation **Facilitators** • Memory aid • Tracking HI over time • Making decisions based on HI	
4.26 **Social** ***	**4.2.7** **Privacy and Security** ***	

20 Figure 4.2.5 Personal Health and Life Situation HIM Motivational Factors

4.2.5.1 Barriers

Life and health situation factors that may be barriers to using a personal health record include disabilities that can make it harder for an individual to use the system and memory problems that can create difficulties in recalling and managing HI. An individual's perception of being not sick enough or too sick to use such a system or get involved in HI management can negatively impact PHR use or adoption. And the third factor is a changing health situation which may make it difficult for a person to know what information is important to keep in a PHR and also to find time to use a PHR or manage HI. These factors are described in detail below.

4.2.5
Personal Health and Life Situation

Barriers
- Memory problems
- Disabilities
- Too sick or not sick enough to use PHR
- Changing health situation

Facilitators
- Memory aid
- Tracking HI over time
- Making decisions based on HI

21 Figure 4.2.5.1 Personal Health and Life Situation Barriers

4.2.5.1.1 Memory Problems

Memory problems were often discussed by participants when asked about using a PHR or managing HI. Participants discussed four types of issues associated with memory.

1). Some participants said that their memory is simply "not good". It is not possible to remember everything, which is why it may be necessary to provide help to

PHR users to collect, recall or request historical health information. The quotes below illustrate what PHR users say about their memory and how the PHR helps them.

> *I have, excuse me, a lot of trouble remembering things some times. You know, I'll be saying some and then I'll say, what in the world was I going to say? P02*

> *I'd find it kind of difficult without having all the information I have with me. ... Cause, my memory is not the greatest. P04*

> *Yeah, cause my mind goes-a-blank. I can't think and [the PHR] helps me. P13*

> *Yeah, this, this, I think is a really major function to it for me, and, and, and these allergies cause I can never remember when you go to the doctors office, what are you allergic to, you usually leave something out, you know. P26*

2). Some participants discussed that their memory has declined with age. This is particularly a problem with older individuals who may have age related memory loss.

> *My memory is just not as good as it used to be. P01*

> *Because those are things that would, for me, would be good. Um, because you know when you get to be my age, or sometimes, older, younger, whatever, sometimes you are asking a question and your memory doesn't play, doesn't come in contact with the, that you've had surgery. Well, I think I had surgery but I don't know when. P10*

> *Yeah, because my memory gets worse every day, it's like, it just goes, [whistles], and the most frustrating thing is that I, I'm trying to say something and I know what I want to say but the words will not come to my head. P24*

> *That doesn't mean that somewhere down the line I am not going to, you know, get up every morning and take my seven pills, but I don't know what the heck ... I'm taking them for. You know, and I am not going to say, that's not going to happen and that terrifies me, and I think it does any older person. P27*

3). Some participants discussed physical disabilities or problems related to memory loss. These kinds of conditions also make it more difficult for people to use a personal health record.

> *And it is a strain on your mind when you're sitting there and you're trying to think, oh my gosh, what date was that or, you know, you tend to forget when you get my age. And two, I've been in a couple of car wrecks and that hasn't helped my memory any, so. P07*

> *Well, when I see new doctors they want to know, you know, some personal information about medications, what medications I am on or have been on and if I've had any, any problems, you know. Cause I think I can remember but sometimes I don't, especially since the stroke. P25*

> *I have a terrible memory. And it's been one of my problems for a long time because of my epilepsy and over the years that's taken a toll, you know, because of the seizures and stuff, um, on my being able to remember things. P30*

4). Some participants said that they have so much HI and other information to manage they can't remember all of it. Quotations demonstrating issues related to having too much information to remember and manage are provided below.

> *Because of my memory. Because it was getting harder to you know, you go to new doctors, I've had so many new doctors lately that, it's hard to remember all that stuff and you know. P07*

> *"Some of [my prescriptions] change and ... when I did it myself [organized the pills], I had them in an order where I take, take these were for depression and this for IBS and this was, did this and this would do this, and whatever, all the way down in some order. So that, I didn't get new ones thrown at me without knowing which place they went right off the bat. ... And half my prescriptions don't say what they are for. Although I know it's the same bunch of stuff, and if they happen to put the sticker on the back though, this is instead of this - I know what it is for a month, but when they take the sticker out, then I don't know anything. ... Cause my memory is real crappy, excuse my French. P28*

Memory problems are a barrier to using the system and managing health information, but also a reason to use the system. These quotations show that some participants realized that once they had their information in a PHR it would serve them as a memory aid and help them have information at hand when it is needed.

> *No. I mean, yes, and no. They asked me something, it takes me a while to remember it all, [laughs]. Cause a lot, a lot happens, you know I can't remember every detail. That was the reason why I wanted it on, on the computer, so they can look it up. P29*

> *It's kept me from having to strain myself trying to remember you know. And it is a strain on your mind when you're sitting there and you're trying to think, oh my gosh, what date was that or, you know, you tend to forget when you get my age. And two, I've been in a couple of car wrecks and that hasn't helped my memory*

> *any, so. You know, it's hard. I thought I gotta do something with this and when they brought this in, I thought, All right! Finally! P07*

Memory problems can be an especially difficult issue for older adults. However, remembering information that is needed in emergency and other situations is difficult for everyone, especially if an individual has a complex medical history. Using a PHR as a memory aid is a corresponding facilitator discussed in Section 4.2.5.2.1 below.

4.2.5.1.2 Disabilities

Some participants described various disabilities as a barrier to using the system. In addition to physical impairments and illnesses that lead to memory problems and were described above, visual and physical impairments can also make it hard for individuals to use the system and were brought up by participants.

> *So I can see where it would be beneficial, um, for some people. But I do fine on my own, and, like I say, I can't really type anymore. I have what they have Reynard's. ...it is incredibly painful. But it's also, look at my hands right now. ... Well, they are incredibly red, they are swollen, look at the difference in the colors. ... And then I have arthritis on top of that. ... And so, so, my hands are curved of course from the arthritis. P20*

Many participants mentioned bad eyesight and problems with vision both as a general barrier to using a computer and as something to consider in record design and printout formatting.

> *I always, I had some eye problem, but being I got older now, my eyes are, I can't see small print without glasses. P29*

> *And I yet I need an eyes in bed, I can't see in the dark. Even with the lights on, I still can't see. ... I, everything looks kind of star shaped in my eyes, and if I am setting here just using this eye, the plant and everything over there looks blurry to me. ... I had [glasses] a long time ago. I've gotten a pair last year, but someone here stole them. I've had a bit of a run of bad luck. P17*

> *So, my first thought, the first thing that strikes me I have to say that this type is way to small, way to small for many users, including myself without my reading glasses. I can read it but it's a strain. P09*

As part of this PHR implementation individuals with these types of disabilities were still able to use the record because they received help from the nursing students and social worker. The health care professionals helped residents enter information. They could also help read from the screen and increase font size on the screen and the printout for those who had difficulties seeing and they could explain information and help participants recall pertinent health information.

4.2.5.1.3 Too Sick or Not Sick Enough to Use the System

Some participants discussed that they do not use the record because they feel that they do not need to be involved with their health information, basically saying that the record is for sick people, not for them. These participants said that they don't need to remember a lot of health information or they do not need to keep track of their health information to manage their health conditions. Some said that a sick person would use the record more often and refer to it more often than they would.

> *I don't have much to put down. Because I only take four, um four medications, and one's for example, and they are easy to remember ... I just keep it in my head. And, um, I don't even use the VA's, Health-e-Vet, except to order, reorder my pills. P21*

> *And these people in this building, you know, they really need help, and any help they can get is great. And, I'm a special case anyway because of my transplant, I might as well, I may be in good shape anyway, but I might as well do it. P32*

Some participants expressed that they either have so much information that they cannot manage it or they are too sick to manage. This can be both a reason to want to use the record and a factor that actually stops participants from using it. Participants below discuss that having a lot of information may be confusing. A potential user may not know what to start entering into their record, they may not understand how to get their information into a manageable form and they may feel overwhelmed and not able to manage their health information.

> *...it hasn't been the whole answer because I, and neither is this nor... Because I've just got a lot to keep track of. P28*

> *No. I mean, yes, and no. They asked me something, it takes me a while to remember it all, [laughs]. Cause a lot, a lot happens, you know I can't remember every detail. That was the reason why I wanted it on the computer, so they can look it up. And once I get another copy of it, I'm going to put it on the wall. P29*

One participant discussed that they do not see the point of managing their health information because there is nothing they can do about their health situation. This can particularly be a point of view for terminally ill individuals, although these were not necessarily represented in this study.

> *See, um, I have um, two terminal illnesses [chronic illnesses] that I can't do anything about. And so, for me, personally, I am not all that interested in anything*

> *else that has to do with my health, because I'm at a point where I am saying what's the use. P05*

In fact this participant was talking about chronic problems that were under control but could not be cured completely, kidney problems and cirrhosis of the liver. But this point of view that there is no point in managing because their disease cannot be cured is somewhat similar to the participants who said that they just do what needs to be done to control their illnesses and do not want to do anything else – there is no point.

4.2.5.1.4 Changing Health Situation

Some individuals discussed that their current health situation is not conducive to starting to use a PHR. Individuals may feel overwhelmed with information or be distracted with other aspects of their life and health related events, in such a way that they cannot deal with managing or organizing their HI at the moment.

There are participants who perhaps do not have a handle on their health information at the moment when a personal health record is offered to them. It is also possible that at that moment they may not understand or not know how to manage their current and past health information.

> *Not recently, not, not where I live. It's hard to get organized here. Cause I don't have everything, so I just file it away. P04*

The following participant when talking about what to keep in a PHR says that their medical history is a mess. They do not have a good enough handle on the information to process it and be able to put it into a record of some sort.

> *Well, I could put my medical history which has been a mess. P28*

These participants think that they would not be able to find or recall information about their past history, and so they feel that they can only put current information in the record and not historical information. Some people based on this information decide that it's not valuable to use a PHR system if the only information in it is the unchecked information from memory.

Some individuals stop tracking information because their health improves and so they become busy with other aspects of their lives. Other aspects of their lives become more important and take more time and they stop or forget about tracking their HI. This aspect of HIM was discussed in detail by Participant 30, who is quoted below.

> *I, um, because I have been better lately and everything, I have a tendency to kind of forget those things and get caught up in things like my work and I was going to school for a couple of years there, and, it's easy and all that for me to kind of, put that on the back burner and forget about it because I got so caught up in everything else I was doing. P30*
>
> *Right, and then that, the information, um, I think I don't really get a lot of paperwork concerning that anymore, you know. I, because of my last surgery and everything, a lot of my stuff has been, um, taken care of to a pretty good degree. P30*

Sometimes individuals stop tracking health information because they feel they no longer have a need to manage it. Some reasons provided by participants are quoted below and include not tracking because they've gotten older, they don't go to the doctor a lot, or their life has slowed down and they no longer feel the need to manage their HI.

> *Um, well, it's getting harder as I get older, because I don't go to the doctor a whole lot. Um, as much as I did in my 40-ies and stuff. P04*

> *No, I wasn't interested in it at that time... I had a doctor and I still have him and that's it. P03*

There are participants who say that they do not use the record because there are so many things going on in their life at the moment. This is related to information overload. Something has changed lately and the person is visiting the doctor a lot, has a lot of new information and information that often changes and needs to be frequently updated.

These individuals might have just changed doctors or are in the process of choosing a new doctor or they have been recently diagnosed with a new condition that involves a lot of information management, such as diabetes. An individual may feel that their information is too unstable to be entered into the record or be so overwhelmed with dealing with new issues and information that they do not have time to enter information or don't know where to start and what to enter (they don't have a grasp on their health information and don't know what to enter into the PHR).

> *I think, I had a lot of things going on at least in the last 8 years, so... but they were small, surgeries were small. P29*

There is an opposite side to the statement that something has changed a person's health situation lately. For some people, when they suddenly end up with lots of health information that needs to be tracked and they realize that this is an important and useful thing to do. Some people realize at some point in their lives that information needs to be tracked and track it from then on.

> *Um, I am experiencing mini-strokes and I've fallen quite a bit, and I've had to use my lifeline...*
>
> [Interviewer: "Do you feel like you have pretty good records of, you know, your past and current health?"]

> *Um, the last 5 years, yes. But before that my records are pretty fair. ... I just didn't believe at the time that it was important. ... I didn't see the importance of it, but now I know that it is important. P25*

4.2.5.2 Facilitators

There are three facilitators that encourage use of a PHR to aid in the personal health situation and life situation. One is that the PHR can be used as a memory aid to both help manage health issues, be aware of health issues and care that has been received and is planned. The PHR also helps track health information over time and having this information makes certain life situations easier to manage. Having the PHI from a personal health record also makes making decisions about health easier.

4.2.5
Personal Health and Life Situation

Barriers
- Memory problems
- Disabilities
- Too sick or not sick enough to use PHR
- Changing health situation

Facilitators
- Memory aid
- Tracking HI over time
- Making decisions using HI

6 Figure 4.2.5.2 Personal Health and Life Situation Facilitators

4.2.5.2.1 Memory Aid

Participants described the personal health record as being a memory aid for them. For them it provides not only a snapshot of current health information, but also a place to review the most relevant and past health information.

> *I could remember to take my pills every day. And remember what the dosages are. Which I do pretty good at that ... well, I do have some limitation as to things that I can do, I can't remember my surgeries ... Because I've had so many that I forget when they were and you know dates and that kind of stuff. I could call that, I can call that, just things like that I think. Um, and, anything that would happen in the future would be a good, would be a good thing to have on there too. Like I know I have a surgery coming up here in the future, probably within the next two or three months, it would be nice to have that on there, so that I could give that information to whoever needs it... I think having a personal health record for me would just a good way for me to remember things. P15*

Many individuals discussed the major benefit of the record is the ability to look up information when it is needed and to take a printout of the record to the doctor to provide accurate information. Because many participants described how stressful it is for them to recall this information and that they are worried about it being accurate, keeping their record updated and using it to provide accurate health information was a major benefit.

> *... it took at, a, a weight off, off, because I hate trying to remember when this happened and that happened, alright, so I carry it all the time in my purse in case, um, and, and, I, something should happen, and somebody needed the information. P26*

> *It's, it's a sure way to know, to know that the information, other than that you could, um, have different information that's not correct each time, you know, if you ask. Yeah, and with me, with my memory, that would be a good thing. Since, I am very forgetful. P05*

Having this information available when it is needed instead of having to recall it from memory and worry about whether it is complete and accurate makes it easier to deal with health related life situations.

4.2.5.2.2 Tracking Health Information over Time

Participants felt that tracking health information over time using a PHR helped make their life easier. Participants 4 and 5 talked about using the PHR to monitor the kind of health information they need to be aware of on a daily basis. Participants in this study expressed the needs to manage information about medications, health problem progress or regress, lab results and appointments.

> *Yeah, um, aw, just to follow your health, it's important, that way you can follow what progress you made and what is different with your new meds and stuff like that. P04*

> *Um, monitor my progress or regress. [laughs] You know, monitor whether I'm doing good, as far as my medical condition, um, usually review it and see what would come next or what has to be done about certain things if something comes up, and it's a medical problem, I can always go to the record. And most of the time what it is, is you have to call a certain doctor for certain things, so, it depends of what medical problem there is, you know, to go to that doctor. In my case, a lot of times, I go to my um, I go to my primary doctor and I tell her what's going on and what my need is and um, I need a referral to go to so and so doctor, you know. P05*

Many participants, like Participant 7 realize that having all health information in one place is valuable because you never know what information will be needed at some point in your life. This participant also talks about accumulating information that surfaces over the years, such as accruing information about family history of disease.

> *You know, so. That's a good plus. And your doctors, you know, now I do, I have um, I don't delete them, what I do is keep them in there so I know who I've seen in the past. You know, and what the diagnosis was and then medications that they've....prescribed for me and everything. And it helps to know all of this. This stuff, you know, as I go along each year, it seems like there's more I press on that. [family history check boxes]. P07*

Some participants talked about functionality that was not included in the E-Medicine PHR that was available to them. Some participants talked about charting information on paper to understand what is going on with their health and they described this functionality as something they would want in a PHR.

> *You might be able to make charts and graphs. You might be able to track something like your weight over time. Um, which would encourage you if you were losing weight. If you had diabetes you could track your blood sugar, you know, you know over time. P09*

Because the E-Medicine PHR did not have the functionality to visualize or compare information, some advanced users said that they can do more complex management on paper that is available in the PHR. Less advanced users were happy to be able to compare the lab results that they entered into the PHR in chronological order. This suggests that different user types may have different needs and suggest the needs for different modules and different levels of complexity for different users.

4.2.5.2.3 Making Health Care Decisions Based on the Information Managed

Participants discussed that making health decisions based on PHR data is an important use of the information stored in the PHR. Having accurate and complete information in the PHR enables the patient and their doctor to review this information when it's needed and make more informed health care decisions. Participants 20 and 27 discussed making health care decisions based on the information in the PHR.

> *Well, basically it's a conglomerate of what all of your doctors are saying about your situation and your condition. And that way, if you have a good general practitioner that person can organize all that and say ok, these are what your problems are currently, or were in the past, so what is your problem today and how it relates to that. That way they can come to a concise, hopefully, and good diagnosis of what's happening with you right now. P20*

> *If I've had, if I'm having a problem, then I will check back to see when I had the last problem, if I can't remember, you know, I'll check back, and go, ok, well it wasn't last month, you know, this isn't, not something that's just picking up in frequencies. P27*

Participant 20 discusses reviewing basic health data to better understand her health situation. The PHR allows individual to make knowledge about themselves from their health data. Having all information in one place and having access to historical health information helps to generate new knowledge about an individual's health situation or better understand changes in their health status.

> *Well, you can keep track of what's going on with you physically and down the year. And say, ok, not only have you had this and gotten over it, and you should have antibodies built up against this, this, and this, but also you can keep track of your allergies. Cause allergies change over the years. You can also keep track of any injuries down the road, and that way you can say, ok, I've sprained my ankle 16 times, why? What is going on that you've sprained it 16 times? And or if you keep having the same symptoms, then you can not only track the number of times*

> *per year you have these symptoms, ok, why does this continue to happen, to these, this particular person. P20*

The quote below from Participant 32 shows that users realize that even the process of using the record, putting the information in one place in a structured way forces a person to think and helps them see things they might otherwise had not noticed.

> *Let's see, just, general information, contacts, insurance, health care provider, family health survey, health problems, yeah... asking a question like, how you manage the problems, under health problems, that's good. Makes, forces the person to think. P32*

Collecting and reviewing health information in the PHR to make better health care related decisions and having this information for their provider when it's needed are valuable uses of the PHR discussed by the participants. However individuals have different information needs and want to work with their HI in different capacities.

4.2.6 Social Factors

Social factors that motivate individuals to use the PHR have to do with receiving or not receiving support from others, living situation issues, and various issues having to do with the people surrounding the PHR user. Barriers to PHR use that are of a social nature include lack of assistance and people feeling unsupported by those around them, fear of losing social status and fear of loosing financial support. Although it was anticipated that people would be worried about losing their housing if it was discovered that they could not take care of themselves, this fear was not discussed by participants in the study. Facilitators to PHR use included learning about the PHR or hearing about it from the individual's social network, receiving help from family to use the PHR and receiving positive feedback about the PHR information being available to family. Some participants discussed that using the PHR made them feel like someone cares about them.

HIM Motivational Factors (Thematic Set 2) – Social

4.2.1 **Information Access** ***	**4.2.2** **System and Technical** ***	**4.2.3** **Information Management** ***
4.2.4 **Medical System** ***	**4.2.5** **Personal Health and Life Situation** ***	
4.26 **Social** **Barriers** • Lack of needed assistance • Fear of losing financial help • Fear of losing social status **Facilitators** • Word of mouth spread • Family involvement • Care and attention From using the system	**4.2.7** **Privacy and Security** ***	

23 Figure 4.2.6 Social HIM Motivational Factors

4.2.6.1 Barriers

Social barriers to PHR use discussed by participants include not having necessary assistance from family and friends to be able to use the record, fear of loosing financial help as a result of using the record, and fear of loosing social status if information in their PHR is lost, stolen or accidentally discovered by others. One participant talked about filling out the record and hiding the paper copy in her apartment so that no one could accidentally find it. This fear of losing social status was discussed more than once in relation to mental health information.

4.2.6
Social

Barriers

- Lack of needed assistance
- Fear of losing financial help
- Fear of losing social status

Facilitators

- Word of mouth spread
- Family involvement
- Care and attention from using the system

24 Figure 4.2.6.1 Social Barriers

4.2.6.1.1 Needing Additional Help in Life to be able to Manage HI

Some participants discussed needing more help in their everyday lives to be able to manage HI. Some individuals felt that they had too many things going on in their lives, they were overwhelmed with their life issues they did not want to even try managing their health information.

Participant 20 discussed this issue in detail. During his interview he repeatedly talked about not having anyone to help him instead of talking about the personal health record. What he was trying to say is that he had used the record once, but because there is no one helping him now, he is so overwhelmed that he is not able to continue to use it. He feels that he is unable to manage his health information because he needs more help in his life from family and others.

> *...if I did have all of my family, they would help me out. But, right now, you know, I am on my own and I, you know, thank god I got the payee that helps me out. And besides that, everything is going ok, just you know, just perfect. And I take care of myself, I don't rush around insane, I don't go out the door insane, I don't forget*

> *this, I don't forget that, cause I say, nuh-huh. I want to walk slowly, I want to take my time. P20*

Other participants also discussed that a lack of help and social support make it less likely that they would use a PHR, perhaps because there is no one to help them use it when and if they need help. Participant 28 who used the record, discussed that a friend from a support group that helped them use the PHR. Using the PHR with the help of a friend or family member may be a factor that facilitates use.

> *I am not computer literate at all, and, it's not just anybody who I'd trust to do it. My family, but they don't have time, and, this gal from the fibro group, she's pretty much adopted me. P28*

Because of a small number of study participants the full scope of social issues could not be identified. However the issues brought up by participants suggest that a lack of confidence in their life situation and not having anyone to help makes it less likely for individuals to want to use the PHR.

4.2.6.1.2 Fear of Losing Financial Help

Another barrier for using a PHR is a fear of suffering financially if someone finds out about your health information. Again because of a small number of participants, all potential fears and circumstances could not be identified. One issue is s that were brought up by participants had to do with not receiving a job or being insured because of your past health history or family health history and the other, but two issues were uncovered.

> *Cause they've already started using stuff like, it's only a matter of time before they'll look back in your genetic record and say, oh your mother and your sister had breast cancer, you might get breast cancer, so we're not going to hire you. ...*

> *And, you know, or you're going to have to pay higher insurance rates. Or we're not going to insure you at all. P20*

Only individuals who can live independently can live in the housing authority residences where the study was conducted. Although no one talked directly about worried of being dislocated is someone found out that they cannot manage their health situation, one participant discussed being worried about loosing his financial support or perhaps receiving some additional financial support as a result of using the record.

> *Well, I just want to know if it would effect my other, like medical coupons and stuff? P06*

Most individuals understand that the personal health record carries no more danger than talking to your neighbor about your last trip to the hospital. However some individuals may worry about financial circumstances of their health information being accidentally uncovered or stolen and misused.

4.2.6.1.3 Fear of Losing Social Status

Some participant discussed their fear of losing social status if certain information in their record was allowed to become public. Participant 15 discussed the trade off of having sensitive information stored in their record so that it could be used by their doctor or in case of emergency to treat them, versus the danger of someone finding out this information accidentally or on purpose.

> *Well, I have some real sensitive information, that I don't know whether I should add it in there or not, but probably should. ... My doctor is aware of it, cause I told him when I got out of detox. You know, I made an appointment. But I haven't put it on there, because I'm not sure how many people can see this information ... And so I haven't, it's a pretty sensitive issue, you know. So, um, that's the only*

> *thing that I haven't put in there, yeah. Cause, is there anybody that can see, I mean, can anybody get into this. P15*

Mental health issues were also mentioned by a few participants as issues that were sensitive. Participant 24, quoted below is representative of participants who were worried about putting mental health information in their PHR because someone might accidentally find out about it.

> *... the only thing that I would not particularly want out would be my mental health records, because there is hospital things there. And the way the world is, when you speak of mental health, because I got depression, people say, oh man, she's nuts. You know, and there's a lot of people out there with depression, it doesn't make them nuts. ... But the way that people look at things, oh mental health, she's been in a mental hospital, oh no. You know, she's got to be insane... P24*

Most people realized that information in their PHR is protected and used the PHR accordingly. However, some individuals, like Participant 24 balanced their worries about recording sensitive information in a PHR with the benefits of having full health information available when it's needed. Participant 24 even talked about hiding their PHR print out in their apartment, so that curious visitors or others may not accidentally or on purpose read this information.

4.2.6.2 Facilitators

Social facilitators of PHR use were word of mouth spread and face to face advertising between fellow residents, family involvement in PHI management, such as family members helping the resident use the PHR and having the information in the PHR available for family. In addition, some residents reported that having the record available made them feel like someone cared about them. It is unclear how much this is related to the individual help from the nursing students being available.

4.2.6
Social

Barriers

- Lack of needed assistance
- Fear of losing financial help
- Fear of losing social status

Facilitators

- Word of mouth spread
- Family involvement
- Care and attention from using the system

7 Figure 4.2.6.2 Social Facilitators

4.2.6.2.1 Receiving Recommendations to Use from a Trusted Other

A major facilitator of PHR use discussed by participants is advertising by fellow residents or word of mouth adverting. Participants discussed hearing about how other residents uses the PHR and its benefits and decided that they want to try using the record as well, such as participants 3 and 18 below. Others, like participant 13 discussed that the social worker asked them about using the record, explained what it is about repeatedly and reassured them that it was safe and useful and would in no way impact their position in the housing authority as a reason why they finally decided to try using the PHR.

> *I was trying to figure out if I should I shouldn't, then I keep on hearing people in the background, so I went down to Jon and talked to him. Then he signed me up... P13*
>
> [Interviewer: "So the reason you didn't sign up in the past was because you didn't know that it would be useful?"]

> *I didn't think about it. ... I am very stubborn. But today, [anonymized, resident] brought some things up that sounded interesting. And I would like to put it down on record for me. P03*

> *I know [a friend] said that she is on it. And so I thought, oh well, I'll take it in... P18*

Some participants talked about making the recommendation to use to others. Participants 1 and 7 were particularly representative of the type of person who advertises to others.

> *I say, I've been doing it for quite a while and I've never had a problem. I say, they give you secret number and the only problem is, is finding the secret number. P01*

> *That it keeps your records, you don't have to look for them, you go to a new doctor you don't have to worry about well did I remember this, did I remember that, did I tell them everything, you hand them that and they can just look through it. I mean, this doctor that I just went to, really, really liked it. P01*

> *I've enjoyed it, I mean it's helped me a lot. Really has. I swear by it, I keep telling everybody get on this, you need to get on it. [laughing] P07*

Word of mouth advertising, hearing about the record repeatedly and receiving a recommendation to use from a trusted other were often discussed by participants as reasons why they decided to use a PHR. Additionally, these personal communications were an opportunity to find out about the system and to ask questions and receive answers about the PHR in a stress-free informal surrounding. The PHR had been available for a prolonged period of time and residents had the opportunity to repeatedly hear about it from project staff, building staff and other residents which encouraged them to try it.

4.2.6.2.2 Being Able to Communicate Health Information to Family Members

Two aspects of family involvement were discussed as social facilitators for PHR use. One was the PHR use of providing information to family and the other was family helping with managing information or even with inputting information into the record. The following quotes demonstrate that participants used the record to be able to provide their family member with health information they may need to know.

> *Well I'd make copies and give them to my sister so that they would know what's going on. P13*

> *Yeah, yeah, your family could keep it, so if they needed it they could go back in, you know. That's what I am going to do, my daughter's going to have access to this if she needs it. I think she already does have access to it. So, if she needs it she can get into it, stuff to let anybody know, what she needs to let them know. P07*

> *Well put it in the records, and then update my family on it. So, they would do it, get in on their computers and get all the information they needed. If they didn't have one printed in my apartment. P03*

Most participants used the record on their own, with the nursing student or the social worker, but some residents used it with the help of family members, like participant 26. This quote was about technical difficulties the resident had, but it was direct proof that a family member was asked to update information rather than the resident doing it by herself.

> *Well I expected it to be able to get into it and make adjustments and make, update, and correct it. And, and I can't, that's the frustrating part about it.*
> [Interviewer: "Have you gotten into it in the past?"]

> *Uh-huh.*
>
> [Interviewer: "By yourself?"]
>
> *Well, my son does, does that part of the computer stuff, so. ... I just ask him to update it, and he couldn't get in. P26*

Involvement of family members may be one of the reasons why some participants choose to use a PHR.

4.2.6.2.3 Receiving Additional Personal Care and Attention

Another social facilitator of PHR use is receiving care and attention as part of using the system. The source of attention can be other residents who want to know more about the system, a care provider who encourages the individual to keep using the PHR or even the attention received from the PHR support personnel. Both participants 10 and 32 appreciated that someone cared enough to come and help residents improve their health.

> *Yeah. Well, first of all, I like the way they come out here to where we live, and they say that we could do this and that and they tell us why, it's nice that they come here, rather than we have to get it on the bus and go down to where they are. That, I like that. P10*

> *Because they are here, they take the time and trouble to care about us. They are coming down all the way from the University of Washington, which I think is really awesome. And these people in this building, you know, they really need help, and any help they can get is great. And, I'm a special case anyway because of my transplant, I might as well, I may be in good shape anyway, but I might as well do it. P32*

Because of a small number of participants in the study, not all social aspects of PHR use were likely mentioned.

4.2.7 Privacy and Security

Privacy and security factors do not break up into benefits and barriers like other factors. Instead this section is divided into statement indicating concerns about privacy and security and quotes that talk about residents not being concerned about privacy and security. Participants were not asked about privacy and security concerns directly, but among other topics were asked to talk about whether there is anything in the PHR that concerns them or makes them not want to use the system. Some residents used this as an opportunity to discuss privacy and security concerns. Other residents talked about privacy and security issues without being prompted. Being ensured of the security of the system and privacy or personal data can encourage individuals to use a PHR, and privacy and security concerns can be a barrier to use.

HIM Motivational Factors (Thematic Set 2) – Privacy and Security

4.2.1 **Information Access** ***	**4.2.2** **System and Technical** ***	**4.2.3** **Information Management** ***
4.2.4 **Medical System** ***	**4.2.5** **Personal Health and Life Situation** ***	
4.2.6 **Social** ***	**4.2.7** **Privacy and Security** **Concerned** •Using record in a public place • Theft of HI •Research access to HI **Not concerned** • Trust in the medical system • Benefits outweigh concerns	

26 Figure 4.2.7 Privacy and Security HIM Motivational Factors

Privacy and security can be a sub-factor in any of the other factors, most clearly a sub-factor of the System and Technical Factors, Medical System Factors or Social Factors. It is clearly related to all three – a person can be concerned about privacy and security because they are concerned about privacy and security of computers and computer system, about privacy of medical information related to knowledge of theft or distribution of health information in the medical system or generally concerned about someone wanting to harm them, or feeling unsupported socially and generally distrustful of others. It can also be related to all the other factors, Information Access, Information Management and Health and Situational Factors.

Privacy and security can be considered a 2nd Level Factor that can be related to any of the other factors. This is because privacy and security concerns may stem from aspects of any of the other factors as described in Table 4.2.7.1 below.

12 Table 4.2.7.1 Relationships between Privacy and Security and Other Motivational Factors

1st Level Factors	2nd Level Factor	May be related to:
Information Access	Privacy and Security	Access to information by unwanted persons, accidental or intentional.
System and Technical		Breaking into the system, theft or sales of personal health information.
Information Management		Entering too much information or wrong information that can be stolen or misused.
Medical System		Past experiences or knowledge of medical information being stolen.
Personal Health and Life Situation		Experienced information theft in the past or concerns about the privacy of a certain subset of sensitive information.
Social		General fear or distrust in computers or the medical system (establishment). A feeling or not being supporter, that anyone can cause harm.

There were a total of 55 general quotations related to privacy and security. Eight participants did not bring up privacy during the interview. Of the participants who did not mention privacy, 4 used E-Medicine at least once and 4 were non-users. Those participants that did mention privacy and security mentioned it from 1 to 8 times during the interview.

Of the 55 quotations by 26 participants that did mention privacy in their interview, 26 were expressing concerns about privacy, 28 were quotations not expressing concern.

13 Table 4.2.7.2 Quotations Expressing Concern or Lack of Concern about Privacy and Security

Concerned	Not concerned
I worry about computers because they've got all these viruses now, and everyone can... play with it and get information from somebody else they're not really, that they are not supposed to get. That's... one thing I don't like about computers. P29	*And how would it be kept secure? That was a thought I had. And maybe I would have a password, you know, but then they would know the password, but they are a health care provider, so that's ok, you know, because they would keep it confidential. P09*
All your information put into a computer and whoever wants it can get it... [that's] a bad thing... I don't trust computers that far. P27	*I personally have never had a computer blow up or be virused. So, I think that they are well, if they are well kept, well used, that's great. P16*
I am not computer literate at all, and, it's not just anybody who I'd trust to do it. P28	*I like that it's confidential, there is no way that anyone can get into it. P07*
I don't want my health things plastered all over the city. P02	*I've been doing it for quite a while and I've never had a problem. P01*
When you start tracking it in databases and things like that, I just, sooner or later it's going to be out there for sale. P20	*Well, reluctance is on the computer's part, and the people who misuse it, rather than in the system itself... I know it's a secure site. P31*
I don't like people keeping track of human genetics... it's only a matter of time before	*...if it's used for a good reason, I don't see a problem with it myself... I just can't*

they'll look back in your genetic record and say, oh your mother and your sister had breast cancer, you might get breast cancer, so we're not going to hire you. P20	*imagine in my head, why somebody wants, well, maybe if I was some well known persons, maybe that I had a ton of money. P30*
...fear of people getting a hold of my medical history. P01	*If they want to have my information and know all about me, it's not going to do them any good. P22*
...you have to be careful because [personal health records] are thrown in dumpsters ... They are not taken care of properly. P08	*Well, I was worried about it at first, but there's nothing to worry about anymore. Cause the people has got to know, if you can't talk to them, cause they'll have it right here. P13*
...the only thing I don't care about, is if somebody else can get on there and find out about me. P01	*I have some real sensitive information ... I don't know whether I should add it or not, but probably should. P15*
I would just be afraid someone else would get a hold of it ...but I don't have anything to hide really. P04	*...information getting out on the internet? ...that wouldn't be a big deal to me these days. P30*
I really don't want my information to get in the wrong hands, you know. But they explained to us, how it worked and everything, and then there was like a wall there, a deal where other people couldn't get through to it. And they pretty much assured me, so, it made me feel better. P07	*...something concerning me medically I am not sure how that would interest somebody else, other than someone in your field or, who would actually has a medical reason to enter some of that information. ... What are they going to do with that? P30*
Well, um, it's, they tell me it's as safe as they comes, and the way they do it off the computer, I sometimes wonder why people get into things now days. But, I don't want it all over the country, so I just, I really hesitated for a long time. P28	*I'm an open book, I don't know, I don't care who knows about the different things about it. P18*
I'd originally said, I won't do it on the computers downstairs. They don't know how to clean off anything. I mean, anybody can go into one of those computers and find out who did what, when, where and	*I don't think [I am concerned]. But, well, I wouldn't want anybody looking what I have on there. P10*

why. So, plus people are looking over your shoulders, no, nuh-huh! P27	
I don't put a lot of faith in computers... every time you turn on the news somebody's stolen somebody's records... gotten into somebody's computer system... P28	*So we just leave everything under control, people who love computers in charge or everything and don't give it any thought. P32*

Many participants who did not express concern about the system said positive things about security and privacy.

> *I like that it's confidential, there is no way anyone can get into it. P07*
>
> *I've been doing it for quite a while and I've never had a problem. P01*
>
> *I'd originally said, I won't do it on the computers downstairs. They don't know how to clean off anything. I mean, anybody can go into one of those computers and find out who did what, when, where and why. So, plus people are looking over your shoulders, no, nuh-huh! P27*

Participants who expressed concern but still used the record or considered using the record expressed one of two main reasons for this decision: (1) that it was a medical system and that medical personnel were inputting the data (trust in the medical system and medical personnel) and (2) that the benefits outweighed the concerns.

Trust in the Medical System

Participants felt their data would be kept secure and private because the E-Medicine system was a medical system and information would be stored and kept with all safety and security precautions being taken as well as in any hospital medical system. Project staff had explained to the residents that project servers were in a university's medical center secure server room, and the data was encrypted, and access logged in the same way as for all clinical data in the hospital. Many participants that expressed concern but still used the system mentioned that they felt this system was as secure as the medical information system in my hospital or that they had concerns, but through discussions with the nurses they had alleviated their concerns. They felt comfortable that the system was a medical system and entrusting medical professional (nursing students, social worker) to help them use it and to input their personal data under their supervision.

> *I know that this stuff's down at the clinic, the Everett Clinic where I go, and I know that they do that on the computer. In fact, they do it, they have them, ah, the modems right in the offices, in every little examining room now, and that's fine. You know, they are doing it, they are taking care of it. P27*

Some participants also said they were not concerned because there is no reason for people to steal medical data. They either felt that their medical data would not be valuable to thieves, or didn't think there was any way that it could be misused against them or that they didn't care who knew their medical data.

Benefits outweigh the concerns

During interviews most participants discussed the many benefits of the system. When asked about concerns many of them mentioned concerns that they are aware of, but these are things that do not stop them from using the system. Some participants explicitly mentioned that benefits outweighed their security and privacy concerns.

> *Well, I was worried about it at first, but there's nothing to worry about anymore. Cause the people has got to know, if you can't talk to them, cause they'll have it right here. P13*

Many participants discussed that they are aware that information could possibly be stolen or misused, but because they in general don't safeguard their health information, they discuss it with other people or carry copies of health records in their purse and because they don't feel there is anything about their health information that could be misused against them they could put their health information into the record.

> *I'm an open book, I don't know, I don't care who knows about the different things about it. P18*

In general it was felt that it is more important to have the information available when needed, for example in an emergency than it was to keep it hidden from everyone. Many participants said they had no concerns about the record.

> *...if it's used for a good reason. P30*

Participants were aware that it is possible for their information to be stolen or misused no matter how well it is protected and no matter how many safety precautions are taken, but they still use the record and consider it a positive technology.

Many participants had very simple conceptions of security and privacy and of what precautions could be taken to ensure security and privacy of their data. They basically trusted the health care provider they interacted with, with their data,

> *And how would it be kept secure? ... And maybe I would have a password, you know, but then they would know the password, but they are a health care provider, so that's ok, you know, because they would keep it confidential. P09*

Many users just said that they have no concerns about the system and did not elaborate.

Specific privacy and security issues that stood out were:

- Using record in a public place

- Mental health issues and tracking sensitive mental health questions in the system
- Concerns about research access
- Concerns about data being stolen
- Concerns about privacy with helpers, using the record with helpers who will keep your information confidential.

4.3 Summary

The end result of this study of PHR adoption are the two frameworks that can be used to describe and further study PHR adoption. The first framework or thematic set – Personal Interest and Involvement in Managing Health Information describes the types of potential PHR users or the levels of personal interest and involvement expressed by the participants. The second thematic set and framework – The Health Information Management Motivational Factors Framework outlines and describes the factors that motivate potential users to use a PHR or discourage them from using it. Tables 4.1 and 4.2 are the key summaries of the findings.

The main contribution of this research is the broad overview of the problem of PHR adoption provided by the Personal Interest and Involvement in Managing Health Information and the Health Information Management Motivational Factors frameworks. These frameworks can be used to understand potential PHR users and the problems they consider when choosing to adopt a PHR. In the following chapters these findings are further described, validated and discussed.

Chapter 5. Validation of the Motivational Factors Framework

5.0 Introduction

The Health Information Management Motivational Factors Framework was developed based on data from interviews with health care consumers. After interview data was collected two types of additional interviews were conducted as a validation and triangulation measure. In order to validate this framework six participants were selected for a second interview and two nursing students and a social worker who were involved in the PHR implementation were interviewed.

During the repeated interviews instead of the interviewer guiding the conversation with questions, the participants either guided the conversation while they used the record or discussed what they did the last time they used the record. The second-time interviews were analyzed in the context of the Personal Interest and Involvement in Managing Health Information and Health Information Management Motivational Factor Framework thematic sets. Topics discussed during these interviews were consistent with the thematic sets that emerged from analysis of the main interview data.

As an additional triangulation and validation measure two nurses and the social worker who had helped the residents of the housing authority use the PHR were interviewed. They were asked to discuss the findings and factors identified in the interviews. They were also asked to discuss their view of PHR adoption in the context of the E-Medicine PHR project. Their views also are consistent with the thematic sets that emerged from the data. In addition, they strongly suggested that an extensive educational and advertising campaign is needed to encourage adoption of PHRs in this particularly vulnerable population who perhaps need to manage health information more than the general population.

5.1 Repeated Interviews with Selected Participants

The second interview was a combination interview and observation session where participants were asked to tell or show how they use the system. These interviews were conducted after the main data was preliminarily analyzed to discover emerging themes. Six participants were selected to participate in these repeated interviews.

In Table 5.1, these participants are characterized by their interest level as defined in the Personal Interest and Involvement in Managing Health Information theme set and the number of times they had used the record. Four participants were interested in managing their personal health information, one was interested to minimally interested and one was minimally interested. One participant had never used the record prior to the interview, one had used it once and was using it for a second time during the interview and four participants had used it at least twice.

14 Table 5.1 Second Time Interview Participant Descriptions

Participant	Interest Level	Number of Times Used
P01	Interested	2-3 times
P07	Interested	12+ times
P09	Interested	0 times[19]
P14	Interested	7 times
P17	Minimally Interested	1 time[20]
P24	Interested to Min. Interested	2 times

Participants were asked either to show the interviewer how they use the E-Medicine PHR or use screenshots and their memory to describe the last time they updated the record. One participant had met with the nurses recently to update her information and

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[19] This participant used the record for the first time during the interview.

[20] This participant used the record for the second time during the interview.

using screenshots as a guide she described what she had done with her record and why. The other five participants chose to log into their records and either showed the researcher how they usually update it or actually used this session as a chance to enter information and update their record.

One of these participants was entering their information into the PHR record for the first time. Another participant always had the nurse enter information for her and she asked the researcher to help her update some of her information during the interview, because she was uncomfortable doing it herself. The other three logged in independently, navigated through the record and did all the changes without the researcher's help.

Participants confirmed that they use the record as a memory aid to provide information to their health care providers, to emergency personnel or to have it available for a caretaker or family member to provide in case of emergency. Another major benefit described by these participants is having information from multiple doctors integrated into one record and that record being available to each doctor to see what other health care providers have prescribed and treated. One participant discussed updating the record before she went to the doctor to make sure all information he might ask about is updated and after the visit entering new information. One participant was particularly concerned about privacy and said she would most likely hide the printout. She filled out the record because it would be of value to her to have that information all in one place when she needed it. Another participant described the record as something that keeps her on target with what she is doing and helps her know what has been done in the past and why.

Those participants who use the record with the help of the nurses might not understand as much about their health information: they feel more comfortable having the nurses decide which information needs to be entered into their record. But even these users, who probably do not reap the full benefits of the record helping them organize and manage their health information saw the value of having this information on hand. The action of deciding what new information needed to be entered into the record helps users understand their information, become more involved in their own care and take charge of their health.

5.2 Interviews with Health Care Professionals

Three health care professionals (two nursing students and one social worker) who were involved in the implementation of the record were interviewed. Two nursing students from the University of Washington came twice a week to help residents update their information. The social worker posted fliers about the project and the schedules of the nursing students, he answered questions posed to him by the residents and often explained to the residents what a PHR is and what benefit it would be to them. He was a person the residents trusted and they often approached him with questions. He was very active in the promotion of the project and in addition helped those residents who came to him sign up for the record and enter information. There had been two other social workers in the two buildings, one of whom had also very proactively advertised the record and helped residents use it but no longer worked at the housing authority at the time of the research project and was not available to be interviewed.

The social worker knew the residents well and deeply cared about their health and wellness. He felt that residents who used the system were those to whom it had been properly explained and who understood what benefits the system might provide them. In the quote below he says that those residents who want to do something about their health and understand that the PHR system will help them do it choose to use the system.

> *They want to do something about their health... they understand the concept of what it's supposed to do. SW*[21]

The social worker discussed that most residents who approached him understood that the PHR is a computer representation of the health information they've always had in some form and when using the PHR they are in charge of collecting and managing their information. He said that having the PHR gave them a clear picture of what's going on

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[21] Participant numbers SW, NS1 and NS2 are used for the social worker and two nursing students.

with all their providers and it was a tool that helped the line of communication across multiple providers.

The social worker thought that using the PHR brought up issues, such as how long a resident had been taking a particular medication or how long it's been since they've seen a particular provider or had received some care or treatment that might otherwise go unnoticed by that individual. In this quote he talks about how putting this information in the PHR, "on paper", helps them make this information more real and actionable.

> *I think when they see it on paper, it allows them to kind of, you know, do something about it. SW*

He discussed that this population has particular issues such as having many health conditions and seeing many providers in parallel, especially when you also struggle with illness and memory problems associated with ageing.

> *If you see multiple doctors it can be confusing, and if your memory isn't what it used to be and if you've been sick, all the stuff can get away, get away from you. And you have caregivers come in that take care of you and have everyone else doing stuff and you have three or four people in your life helping you do this and so they've all got a little bit of your history and you may not be aware of all of it. SW*

He thought that increased understanding of the benefits of a PHR would help increase adoption. He said that some individuals in this population need constant reminders to continue using the record, because not all of them understand why it's valuable to have this information as complete and current as possible, they see the benefits of having the record abstractly. In the quote below, she says that getting praise from their doctor about the record makes the usefulness of the record real to the individual. From the data, and his comments it appears that those individuals who had taken the record to their doctor and received praise tend to feel it is beneficial and continue using it.

> *I think it would have to be more clear as to what it would do and the benefit. But you know, if your doctor, an average person if their doctor says I want you to do it, then people will do it. If your doctor says, I think this is helpful between you and I and your relationship with your doctor, I can treat you better. Then I think people would probably [do it]. SW*

The social worker said that he saw two main reasons why residents chose to try the record and continued to use it. One is when he strongly recommended the record to a resident who he felt could use it and benefit from it. Because the residents trusted him, some of them followed his advice. Some residents, however, were excited about the idea on their own. They had heard about PHRs in the media or from other people and felt that the medical system is moving in that direction anyway and that computerized information is the way of the future.

Residents who don't fully understand the benefits of the PHR but fill out the record and keep the information can see the benefits when the record becomes useful in certain situations. Some reasons why residents said they continued to use the record were: (1) Praise received from the doctor which helps the residents see the benefit of having the PHR; (2) The record being used in an emergency situation to get necessary information; and (3) The record helping to provide accurate information to the doctor and not having to wade through piles of papers to get at it.

The nursing students also confirmed that praise from their doctor can be a strong motivator to continue to use the record. In the quote below they discuss the residents realizing that their PHR record is really useful after receiving praise from their doctor.

> *After they've done it once, they come back and say that they doctor likes it, but I don't think initially they know that... that their doctors are going to like it. But*

> *after they have taken it to their doctor, then they can see how it can benefit to both. NS1*

A number of participants also mentioned this factor in the interviews. The nurses also confirmed other themes that emerged from the main interviews and are included in the Motivational Factors Framework, such as the record being a memory aid and an organizational tool that helps manage health information and organize their care.

> *They have a place that they can look at it, instead of getting out a piece of paper and forgetting where that lab tests was at home, you know, if they had the paper to begin with, which a lot of them didn't. Now they can just go to the computer and look at it real quick, you know, not have to file through a bunch of papers and, or go back and call their doctor and find out what that was. I think they like having that information so they can look at it themselves, instead of having to go back the doctor. NS1*

The nursing student confirmed that having the professional help available is an additional benefit that was mentioned by participants.

> *I am here with them, they can ask me questions, is they are just doing it on their own, they don't really have that advantage to ask a health professional questions, other than their doctor, so they have to remember to ask those points to the doctor. And I think this is a tool that can help them remember those questions to their doctor before, by documenting something before they get to the doctor and then bringing it up to them, or a nurse there. NS1*

The nursing students were also surprised that many individuals were not scared of technologies and as mentioned by the social worker that many residents saw the benefit of the technology and that everything was moving in that direction and were willing to try it and use it.

> *They are definitely more, um, at ease with computers, um, you know they are not afraid to put it out there on the internet. And I think they just realize that, the importance of having correct information for themselves and for another provider. NS2*

The social worker and the nursing students both mentioned that in the population studied there is a subset of individuals who are not trusting, they are afraid of tracking technologies and do not use credit cards, supermarket club cards and other technologies that they feel could be used to track them. Because this population is older, some of these residents are not open to change, but others, even if initially reluctant, can be interested in the PHRs. They can ask questions and are willing to not only change their mind about the record but become active users who are also active participants in their own health care.

5.3 Summary

Secondary interviews and health care provider interviews confirmed that the themes that emerged are those they thought were important to residents. Health care professionals involved in the project felt that many of the residents would be potential users if there was more help available and increased opportunities for residents to talk about the record, its benefits and to have their questions answered.

A smaller number of residents was not open to the technology or was just in general reluctant to share any information with others. Only these participants would be completely unwilling to use a PHR and it is possible if their health or life situation changed they might change their minds. Participants and health care professionals all felt that the PHR summary sheet was a valuable addition and possible replacement for the emergency packet that residents keep in their apartments and that having this record which was much more detailed.

Chapter 6. Thematic Synthesis and Results

6.0 Introduction

In the previous two chapters, two thematic sets were presented that emerged out of interviews with 32 individuals who lived in low-income housing where a PHR system had been made available to residents and assistance offered to sign up and use the system. The investigator conducted open-ended guided interviews with individuals who had signed up and used the record and those who had not. The interviews were focused on health information management and the use of a PHR. However, participants were never asked directly why they use this PHR system or asked to state whether they were interested in using a PHR or in managing health information.

All results emerged out of the statements made by participants during interviews and were validated through additional interviews with selected participants and health care professionals who helped the residents use the PHR system. In Chapter 4, the three levels of interest in health information management and seven groups of factors that affect the adoption decision-making process were described. Each level of interest and factor group was described in detail, backed up by participants' quotations. In Chapter 5, validation of findings through additional interviews was described. In this chapter the significance of the levels of interest in personal health information management and the motivational factors for managing health information thematic sets and three important findings that stand out in the motivational factors framework are discussed.

6.1 The Emergence of Two Thematic Sets

The two thematic sets are the main contribution of this research to the field of personal health records. These frameworks provide the big picture view of the personal health record adoption problem from the point of view of the health care consumers themselves. In order to help the reader understand the data and results, how the thematic sets emerged is described here. The strength of a grounded theory based data analysis approach is in the iterative and ongoing analysis process that starts during data collection and continues until the final stages of research reporting. The research methods that were described in detail in Chapter 3 are described again here in relation to the results to help the reader see how they emerged from the data.

6.1.1 Thematic Sets

The initial step of the grounded theory analysis process is called "open coding" (Strauss & Glaser, 2005). During this step, names or "codes" are assigned to parts of the data that are related to the research question. After the initial round of open coding the data set included over 257 codes that were tied to about a thousand quotations. These codes were interesting topics identified in these quotations that were relevant to the research questions.

During subsequent analysis, initial groupings of codes emerged. They looked very similar to the final groupings, however many codes represented similar ideas and after further iterative organizing and recoding some were combined and some deleted. After this step, 191 codes related to the study questions remained. As a result of further refinement and sorting based on the categories that emerged as part of the two thematic sets – the Levels of Interest in Health Information Management and the Health Information Management Motivational Factors – 118 unique codes and 822 quotations were used in the analytic coding.

The first thematic set, the Levels of Interest in Health Information Management, is related to the interest level of individuals in PHRs and health information management (HIM). The statements made by participants related to their interest in managing health information lead to the creation of three types of potential users or three levels of interest and involvement in HIM. The three levels are described in Section 4.1 and Table 4.1 and are as follows:

1. (4.1.1) Individuals who are interested in managing their HI
2. (4.1.2) Individuals who are minimally interested in managing their HI
3. (4.1.3) Individuals who are not interested in managing their HI

These categories emerged from the codes generated from the all the interviews, which means they emerged in a generalized fashion from statements made by all participants. Later in analysis process each participant was placed somewhere on this scale based on the quantity and length of statements they made that fit within each level. Based on these quantities, it was determined that some participants consistently made statements that fit into more than one category, indicating that these participants did not belong to one of the three levels of interest, but belong between the first and second or the second and third levels. Participants' placement on the level of interest scale is described in Section 4.1.4.

The second clustering of results formed the Health Information Management Motivational Factors Framework that includes seven groups of factors that affect the decision-making process for adopting or not adopting a PHR. These factors motivate or deter individuals from using a PHR or being involved in HIM. Participants' statements describing how and why they manage their health information or why they do not manage led to these seven groupings of motivational factors (see Table 4.2):

1. (4.2.1) Information access
2. (4.2.2) System and technical
3. (4.2.3) Information management
4. (4.2.4) Medical system
5. (4.2.5) Personal health and life situation
6. (4.2.6) Social
7. (4.2.7) Privacy and security

When starting this research and collecting data the researcher made no predictions about what the factors that concern participants might be. The review of existing literature indicated that privacy and security might be a significant barrier to using a PHR and that improvement in information access and information management might be facilitators. The researcher also anticipated that medical system factors and participants' life situation factors could potentially impact individuals' ability and desire to use a PHR.

After the initial round of analysis nine categories emerged. However, after axial coding and further reorganization of codes and categories the system factors and technical factors were combined into system and technical factors and the health factors and life situation were also combined into a single factor group based on the similarity of ideas discussed in these groups. The resulting thematic set, the Health Information Management Motivational Factors Framework, came to have seven categories.

Potentially there may be an eighth category, management of financial and insurance information, but for this population who was mostly on Medicare and Medicaid this was not at all a factor that they identified. However, as indicated in other studies (Moen & Brennan, 2005; Pratt et al., 2006; Markle, 2008) for some population groups managing bills, insurance coverage and benefits can be a large health information management task.

In the motivational factors thematic set, managing bills and insurance information can be part of the information management factor group and perhaps in the personal health and life situation group, because management of financial aspects of medical care can be a significant management task and financial issues can also be part of the life situation that impacts medical care and the ability and desire to manage health information.

6.1.2 Conclusions

Two primary conclusions can be made based on the results of this research. One important conclusion is that it is possible to categorize both types of potential PHR users and the factors that help these potential users make the adoption decision. These categorizations are a starting point for assessing needs of this population, further improving PHRs and increasing PHR adoption. Even more importantly, this research is the first step to identifying transition states between interest levels and how to encourage individuals to be more interested in managing their health information.

The second important conclusion of this research is that even this disadvantaged group of consumers is largely interested in adopting PHRs. This general trend is apparent in most surveys of the general population, but more importantly this study indicates that a higher adoption rate can be achieved with the right approach. The adoption rate in this particular population is higher than the adoption rates for the general population. However, this group is far from the young and technology savvy consumers who tend to have higher technology adoption rates than other potential user groups. These individuals were not only able to make the adoption decision but also able to identify factors that increase their desire or ability to use the system and factors that deter them from using the system, make them not want to use it or feel that they cannot use it.

6.2 Five Types of Potential PHR Users

Consumers who are potential PHR user make statements about PHR use that fit into three groups – a general interest in using PHRs, minimal interest in using PHRs and managing HI and a lack of interest – these statements indicate whether they want to or are interested in managing their health information. Based on these interest levels PHR products can be tailored to better meet the needs of each type of user. More importantly for initial adoption, PHRs may need to be advertised and explained differently to different groups.

This difference in the personal interest in PHRs and health information management may be a reason why most PHRs are adopted by only a part of the target population. The results of this study indicate that PHR creators need to target three to five different groups of users and create records tailored to the needs and concerns of each group. Furthermore, this categorization is the first step to identifying transition states between groups, factors that can encourage people minimally interested in management to become more interested, or those not interested to become somewhat interested.

As discussed above, three interest levels clearly emerged out of the data and were confirmed by reviewing the statements that participants were making about their interest in the PHR and their desire to use it. The researcher was also able to place study participants into one of the categories on the levels of interest scale. There were some participants that better fit between two levels, because some of their statements indicated interest and some minimal interest, or alternatively for some participants their statements varied between indicating that they were minimally interested and not interested.

Intents and emotions (outstanding motivational factors) of people who are interested in managing their health information, those who are minimally interested and those who are not interested differ and are described below. These categories which emerged from qualitative research data are mostly descriptive and they need to be further explored in and validated through future research. These levels of interest should lead to tailored approaches to PHR design and implementation for each group of users in a way that will encourage PHR adoption by that group.

6.2.1 Intents and Emotions of Participants Who Were Not Interested in PHRs and HIM

Two of the four participants who were not interested were concerned about privacy and security and two did not express concerns. A common factor was that each of them felt that their health information was stored and accessible in one place and under their control. One participant had a helper who helped them keep all their health information at home in one place. Two participants had had the same doctor for a long period of time and felt that the doctor had all of their information and managed it for them. The fourth participant in this category received care through the Veteran's Health Administration (VHA) system and had all of their records from the past 40 years in the VHA system.

Potential users who are not interested in PHRs and HIM expressed:

- Being happy with the way they are now
- having a stable health situation and the same set of health conditions for some time, being used to managing them and knowing how to do it
- having one doctor that knows all the information or using a system like the VA Health-e-vet that has all of their health information in one place

Typical quotations from participants who were Not Interested in Management are presented in Appendix AA.

6.2.2 Intents and Emotions of Participants Who Were Minimally Interested to Not Interested in PHRs and HIM

The participants who were minimally interested to not interested in health information management had some outstanding motivational factors that are similar to the not interested group. They discussed:

- having a stable health situation for some time, being used to managing their health problems and knowing how to do it
- having one doctor that knows all the information or have access to their health information through some other system (i.e. Group Health)

However, they expressed some interest in management because they were not completely satisfied with their current management strategy. They were interested in:

- having information in their emergency packet in their home
- organizing the information they had in filing cabinets and files in their home

As opposed to participants who were not interested at all in managing their health information, these participants saw some potential benefits of HIM. However for each individual it would take probing to see what tools or functionality could be offered that would improve their management strategy. For some of these participants, if their health situation changed or their life became less busy they would be more willing to use a PHR to improve the way they manage their health information.

Typical quotations from participants who are between Not Interested and Minimally Interested in HI Management are presented in Appendix BB.

6.2.3 Intents and Emotions of Participants Who Were Minimally Interested in PHRs and HIM

The six participants who were minimally interested in health information management (HIM) had all used the PHR one or two times. It is possible that these users had enough interest in the system to try it, but were not able to figure out what benefits they could gain from using the system, were not able to find a place for it within their health care related work or did not find a way to use the record that fit within their life style and needs. Ages of participants in this group varied widely, one participant was in her 20's, one was in his 40's, one was in the mid 60's, two were in late 60's and early 70's and one was over 85 years of age. They discussed the following factors that contribute to being less interested in managing health information than they otherwise might be:

- they do not go to their doctor often and do not need to manage their health information on a regular basis
- they use the record to have the information available in an emergency or to present to their doctor
- they use it as a memory aid, because they either have a lot of past information or do not use the information often and tend to forget it
- they mention starting to use the record because the social worker suggested it to them repeatedly

These six participants used the record because it seemed interesting to them, but they did not find it to be very useful for improving their health situation. Four of them said they had tried it because the social worker had suggested it, not because they had a preexisting health management need that they needed to address. All participants in this group said that they do not go to the doctor often, implying that they do not have a lot of information to manage. One participant reported that his health has improved since he first used the record and that is why he has not used it again. Another participant said that he no longer receives help from his family and because of this he cannot use the record, implying that he is too busy taking care of other aspects of his health and life.

For these users a change in their life or health situation could result in movement up on the interest scale. These individuals tried the record and they know what it is about but they did not find a use for it in their current life and health situation.

Typical quotations from participants on the Minimally Interested level are presented in Appendix CC.

6.2.4 Intents and Emotions of Participants Who Were Minimally Interested to Interested in PHRs and HIM

Individuals who were minimally interested in HIM, reported knowing very little about PHRs and their purpose, but had used the record because it was recommended to them by others. Two of the six participants in this category also reported that they started to use the record because it was recommended by the social worker and others in the housing authority. However, individuals between the minimally interested to interested levels expressed more awareness of their needs and knowledge about PHRs. Unlike the minimal mangers these individuals were more aware of what PHRs are and why they should be used, in fact they discussed in detail functionality and usefulness of PHRs. Two of the six participants in this group who were not users expressed during the interview that they actually want to sign up to use the record, one participant used his own health information management system and because of this was not interested in the PHR offered and the other three had used the E-Medicine PHR. However, they used it in a limited way because like the others in this group they expressed:

- mostly wanting to track information for their doctors to review
- wanting to keep their information management strategy simple
- wanting to have all their information in one place and available to be accessed when necessary
- wanting information available for emergencies

Five of these six participants were between 26 and 64 years or age and one was in the 65 to 84 age category. These participants knew of the potential benefits of PHRs but, something deterred them from being fully interested in using one and they perceived and used the PHRs in a very limited way. For one participant this issue was concerns about privacy in combination with fears of doing something wrong on the computer. For the two participants who were not using the system but said they wanted to, it was not being able to find the time to sign up or be able to get in touch with the nursing students to receive help. It might be very easy to get these three to become active users with a little advising about the PHR and help learning how to use it. Even for the participant who used his own system, if someone could help him compare his system and the one offered, he would perhaps be willing to change to the PHR offered or use it as an addition to his own system.

Typical quotations from Minimally Interested to Interested participants are presented in Appendix DD.

6.2.5 Intents and Emotions of Participants Who Were Interested in PHRs and HIM

Of the eleven participants who clearly expressed being interested in managing their health information eight used the PHR system offered. Seven of them had taken their PHR to their doctor and five had been praised for bringing it. The other two participants discussed using it to help fill out intake forms, in fact both of them said they hated filling out intake forms and used the PHR to help them with this process. Three participants who were interested in management but did not use the record kept their own more detailed records, and in addition one of them was very concerned about privacy. The potential users interested in management were similar to the minimally interested group except they:

- wanted to track information for themselves and for their doctors (not only for their doctors like the Minimally Interested to Interested potential users)
- they were highly aware of their health information needs
- they were highly aware of what the PHR can do for them

What separated this group from all the other groups is that all of the participants in this group knew a lot about the E-Medicine PHR project and PHRs in general. This indicates that potential users Interested in PHRs and HIM either learned about PHRs in the process of using the system or that users that had been originally better informed about PHRs were more interested in and more likely to use the PHR. This trend indicates that in order to increase adoption all potential users need to be very well informed and need to be given the chance to have their questions about PHRs answered. Potential users who were Interested in Management were also highly aware of their HIM needs and their limitations regarding remembering and giving out HI when necessary. These potential users could easily articulate benefits and potential users of the PHR for them.

Typical quotations from the eight participants who were Interested in Management and used the E-Medicine PHR are listed in Appendix EE. Sample quotations from the three participants who were not using the system, which give insights into why they chose not to use it are presented in Appendix FF.

The Levels of Interest and Involvement in PHRs and HIM gives researcher and PHR designers a way to understand potential PHR users and how their PHR products and implementation and advertising efforts can be better tailored to increase PHR adoption. Educational and advertising campaigns can be tailored to accommodate the most sensitive issues, factors of interest to a particular group. However, access to one-on-one help and individual consultations may be necessary to identify and address the issues that are barriers to each group of individuals.

6.3 Disadvantaged Consumers Are Interested in Using PHRs

A particularly important result of this study is that despite a range of health conditions, older age and low socioeconomic status the majority of study participants were interested in health information management or assisted management. This result is surprising because the population studied was older than that included in most research studies, and in addition they were mostly women, had low computer literacy and were from low income households.

Outstanding facilitators cited by participants who used the record or were strongly interested in using the record:

- To have information available in an emergency situation.
- To have accurate medication information and allergy information.
- To have information handy to present to the physician, during appointments and filling out of intake forms.

- Being sure that information is stored in the record and is accurate. Not having to recall information or worry about not recalling properly or accurately from memory.
- Having nurses to help or to enter information into the record.

Outstanding barriers:

- Unavailability of past information, not having complete information to enter into the record
- Not understanding who the record is for. Not sure how it would help them and how it would help their doctor, or how their doctor would react to it.
- Disabilities making it hard to use the record
- Changing health condition making it difficult to find time or to get together information to start of update the record, too busy with other things.
- System does not do what I need it to do, my needs are more complex.

Because of the attrition of residents at the housing authority over the time that the record was offered it is impossible to calculate an exact percentage of residents who have used the system. At any given time, about 330 to 350 residents live in the two buildings where the record was offered. Of the 32 residents who were interviewed 19 had used the system. There had been a total of 66 registered accounts, but as of April 2010 it was known that 3 residents who had used the record had died and 6 moved from the housing facility. As a result, there were a total of 57 active accounts in the system at the time the data was collected and 46 accounts were used regularly.

However the percentage of housing authority residents who used the record is higher than the adoption rates in the general population. In the population studied, 13-16% of the residents used the record (46 or 57 users of 350 residents). In 2010, 7% of respondents in the general population said they had used a PHR of some sort and 11% in western states (California HealthCare Foundation, 2010). In addition, the adoption rate for the population in this study is much higher than the 2.7% that reported keeping electronic health records in the 2008 Markle survey, which was closer to the date of the study.

Some reasons for such high adoption rates could be the lengthy education and advertisement campaign conducted at the residences and the availability of help from social workers and nursing students who came to the buildings. Residents trusted the social workers who bought into the system and genuinely recommended it to residents who would benefit from it. Residents were able to receive answers to their questions about the system and receive help using the system in a number of ways that were convenient for them.

Only four of the 32 potential users who were interviewed were clearly not interested in using the record and managing health information. One of them used the Health-E-Vet system at the VHA and the others felt that they had their information under control, and for the most part had very little information to manage. Another five potential users who also expressed mostly being not interested in using the record (minimally interested to not interested), were somewhat open to the idea of managing health information and using a PHR and so they potentially could move up on the interest in PHRs and HIM scale.

It is surprising and very encouraging that most participants were positively inclined toward PHR use. Although many recognized that there would be technical issues and some recognized that there might be privacy and security issues, this group of individuals was still generally willing to use such a system. They saw that the benefits outweighed the risks, even though some did not fully realize the utility of such a system.

6.3.1 Financial Health Information Management Not an Important Issue for Participants

Management of financial health information, such as insurance statements and bills is part of health information management for most individuals (Moen & Brennan, 2005; Civan, 2006; Markle, 2008). One surprising finding of this study is that the question of managing financial health information was not brought up by participants.

This overwhelming management task that is brought up as being important in most health information management studies was not something this population was concerned about.

Three topics related to insurance and payments were brought up by participants. One participant discussed being unsatisfied with their insurance company as related to a number of problems she had encountered with them recently. A number of participants discussed problems with Medicare and Medicaid, mostly as related to paying for prescriptions, and changing them to generics. Two participants discussed having a "payee" – a service that managed their finances, paid their bills, including medical bills and gave them a monthly allowance and additional money they needed.

The fact that participants did not discuss this issue when talking about health information management shows that it is not an important health management task for this population. The only instances of "management of health related financial information" in the data is when participants briefly mentioned that they just file away "those papers" from Medicare and Medicaid and don't do anything else with them.

For the most part, management of financial information was not discussed by participants. This is potentially an interesting distinction for this population which may explain why more individuals in this population use a PHR. It is possible that financial information management can be viewed as an additional level of complexity to managing health information and when this level of complexity is taken away more people are able to focus on managing their health information and use PHR systems and HIM tools.

6.3.2 Privacy and Security Concerns Were Not a Significant Barrier

Another interesting and important finding of this study is that privacy and security of health records was not a definitive factor for this population in deciding whether to use a PHR. Of the nine participants that had significant privacy concerns, only four were not using the E-Medicine PHR system. Many participants discussed privacy and security but most felt that benefits of managing information outweighed the privacy and security risk. Some also discussed that they do not consider opportunities for misuse of lost of stolen health information to be as dangerous as for financial information.

It is possible that over the time the PHR had been offered the privacy and security questions residents had had been addressed. In this particular setting privacy and security concerns were addressed in two ways. One approach was the lengthy information and advertising campaign at the housing authority that specifically focused on addressing privacy and security concerns. The information sessions held and informational materials handed out during the study period specifically focused on describing the system architecture and precautions taken to protect the private health information stored in the PHR system as one of the important issues to explain to potential users. In addition, the availability of in person help and access to nursing students and social worker who where computer literate and could answer participant's questions about privacy and security could also be an additional reinforcing factor. Participant statements support the fact that residents had had the opportunity to find out about the privacy and security measures implemented in the record and to have their privacy and security questions answered.

The second factor that was discussed by a number of participants, is that participants were aware of and felt reassured by the fact that the PHR record and the information in it were physically stored on the servers along with the medical records of a national medical center and that their information in the PHR was just as protected as information in any medical information system. In addition, participants mentioned that they see more and more health information technology at the places where they receive medical care and they feel that if their health information is already digitized than having the same information in a PHR does not put them at more risk as long as the information in the PHR is as protected as the rest of their medical information.

Because of the lengthy presence of the PHR project at the building and the active informational campaign about the PHR and privacy and security residents trusted that the PHR system would keep their information safe. Participants were also not afraid to let nursing students and social workers act as helpers to enter and access their health information. Housing authority residents felt confident about their health information being stored on UW Medicine servers and being secured and backed up along with UW medical record information.

6.3.3 Assisted Management and Addressing Potential Users' Questions Are Important

Assisted management, availability of help, and having an opportunity to get answers to their questions was perhaps a deciding factor that helped individuals in this elderly and disabled population overcome their fears of computer systems and use a PHR system to manage their personal health information. The active advertisement campaign, help available to residents who wanted to use the system, numerous informational sessions explaining what the record was, how it worked and having the opportunity to ask questions and having social workers from the buildings, whom the residents trusted involved and educated about the PHR system and its benefits are all possible reasons for such a positive perception of the record and the reason for relatively high adoption rates.

The educational campaign that continued constantly while the PHR system was being offered was perhaps crucial to successfully engaging this population. This group of people who are older, do not use and may not trust computers and may have low health literacy although perhaps they are well informed about their health conditions. They trusted the medical professional (social workers and nursing students) with their health information, both to help them understand it, help them enter it into the system and for help with the system itself.

A number of residents indicated during interviews that they used the system on their own without help from the nursing students or social worker. This was also confirmed database access data from the system that showed that the system was sometimes accessed outside of business hours, at night or on the weekends when help from the social worker and nursing students was not available. However, some participants during the interviews said they were afraid to use the PHR on their own, because they were not comfortable using computers and would use it only with help. Other participants were willing to use it on their own after a number of training sessions with the nursing students, once they've had a chance to see how the record works and how to use it.

6.4 Summary

The Health Information Management Motivational Factors Framework is a much needed overview of the issues that concern potential PHR users and issues that facilitate PHR adoption. The two frameworks that emerged from this study can be used to further understand and assess needs of populations to which a PHR is offered and to tailor PHR applications and educational campaigns. Interesting findings of this research with implications for PHR systems development, training and use are:

1. Individuals can be categorized by their level of interest in PHRs, and furthermore with the right approach the majority of even such a disadvantaged population as that which was studied are interested in using PHRs and personal health information management.
2. Financial information management is not a significant barrier for this population and might be an additional reason why this population seemed more interested and involved in health information management.
3. Privacy and security was not a significant barrier for this population, despite their tendency to be less trusting than other populations.
4. The surprisingly high adoption rate and minimal concerns about privacy and security in this population could be explained by the lengthy educational and advertising campaign which helped potential users understand the benefits of the PHR system and the security precautions taken to protect their information.

The E-Medicine PHR system was offered to residents of a housing authority for a prolonged period of time and the research team and the PHR as a product were able to grain trust of both employees and residents of the housing authority. Assisted management, availability of help, and having an opportunity to get answers to their questions was perhaps a deciding factor that helped individuals in this elderly and disabled population overcome their fears of computer systems and use a PHR system to manage their personal health information.

Chapter 7. Review of Models for Assesing PHR Adoption

7.0 Introduction

The results of this work are two frameworks that characterize PHR adoption from the consumer point of view. These frameworks are an overview of the problem of PHR adoption and although further work is needed to expand and validate them, it is valuable to compare these big-picture findings to other adoption of technology literature. The Technology Acceptance Model and Diffusion of Innovations Theory are two bodies or work related to adoption of technology and innovations. These two approaches to studying adoption look at different aspects of adoption: the Diffusion of Innovations Theory focuses on the spread of an innovation within a social system or a society and the Technology Acceptance Model looks more closely at the aspects of the system itself.

Both approaches are valuable and are part of adoption and the results of this research are loosely aligned with each of these models, as they encompass both characteristics and points of view of potential adopters and aspects of the system which encourage or discourage adoption. The two thematic sets or frameworks that are the result of this study are not a perfect fit to either work, but they indicate that additional work can lead to an expansion of understanding and perhaps a link between these two bodies of work as they are related to adoption of personal health records.

7.1 Rogers' Diffusion of Innovations

As described in Section 2.4.1 Diffusion of Innovations is a theory that attempts to explain how and why new technologies spread through a culture. The theory covers numerous aspects of adoption, however, there are three aspects that are interesting to compare to the results of this research - the decision making process adopters go through when deciding whether to adopt a new technology, the types of adopters and five factors or characteristics of an innovation that influence the adoption decision.

For the purposes of the discussion below, the innovation is the PHR that was made available in the housing authority and the residents are adopters.

7.1.1 Five Stages of the Adoption Process

The five stages of the adoption process are described by Rogers as the mechanism of adoption. How these stages appeared in this PHR implementation and adoption process is described below.

> **Knowledge** – person becomes aware of an innovation and has some idea of how it functions

This research identified two ways individuals became aware of the innovation, one was through mass media or health care institutions talking about PHRs and the other was informational sessions and information available as part of the PHR implementation research work.

> **Persuasion** – person is interested in innovation and seeks out information and details about the innovation, at this stage the individual forms a favorable or unfavorable attitude toward the innovation

In this PHR implementation, this part of the decision process was supported well. There were multiple sources where a resident could find information about the PHR. In addition to informational sessions, residents could approach the nursing students and the social worker to receive additional information and answers to their questions. Residents felt that the nursing students were approachable, although some said they did not see the flyers or were not able to get in touch with the nursing students at the hours when they were available because of their personal schedule.

> **Decision** – person weighs the advantages and disadvantages of using the innovation and decides whether to adopt or reject the innovation

This stage is considered by Rogers to be very individualistic and therefore difficult to study. It is obvious that different individuals engage in the decision making process differently, some actively and some more passively and for some it takes a considerably longer period of time. There were two ways of going about this for the residents of EHA, either they liked the idea of the PHR and decided to try it, they thought it would help them get a handle on their health information, they thought it would be a valuable tool to help present information accurately, quickly and painlessly to their doctor or the social worker said it would be beneficial to them and they decided to try it.

> **Implementation** – person puts an innovation into use and determines the usefulness of the innovation

The residents implemented the record differently. Some used it online, some printed out forms, some residents kept these forms in their apartment or on their person in case of emergencies and some took these forms to their doctor to either inform the communication process and keep the doctor informed about what other doctors were doing or to help fill out historical and current information on the intake forms. The way the record was implemented corresponds to how it was evaluated in the next stage.

> **Confirmation** – person evaluates the results of an innovation-decision they made and finalizes his/her decision to continue to use the system

Residents cited three factors that helped them finalize their decision to use the PHR. One was that when they took it to their doctor, their doctor positively responded to it, and they continue to use it and bring to their appointments. Some residents eagerly discussed how much easier it was to fill out intake forms when bringing the record with them to their doctor. For others, the information was used in emergencies. Because they found these uses for the PHR, they felt it was a useful way to keep their health information in one place and keep it current and updated.

Some people filled out the record and just placed the printout somewhere in their apartment or in their purse. They never took it to their doctor and never had to use it in emergencies. Some of these residents understood that it may be useful when an emergency happens and kept using (updating) the record to keep it current, others did not see the usefulness of it and forgot about it.

Individuals who were interested in using PHRs, even those who were not using the PHR offered at the housing authority knew a lot more about PHRs, their own health information management needs and strategies and about the E-Medicine system than those who were not interested. This was confirmed by the social worker who also observed that those people who knew the most about the record, who understood it well were those interested in trying the record and they were likely to continue using it even if they did not see a direct benefit of its use. These individuals engaged in information collection during the persuasion and decision stages. Because these elderly and disabled low-income individuals may not seek out ways to change their lives and may in fact be resistant to change, it may be important to more actively bring information to their attention to ensure that they have enough information to make the adoption decision.

7.1.2 Adopter Categories

Diffusion of Innovation theory identifies five categories of adapters, (1) innovators, (2) early adopters, (3) early majority, (4) late majority and (5) laggards. It states that in order for an innovation to be adopted by a society it needs to be appealing to innovators and early adopters who then connect and communicate with other adopter categories and the information they share persuades the other adopter categories to make the adoption decision.

The Levels of Interest thematic set identified in this study is loosely aligned with the Adopter Categories described in the Diffusion of Innovations theory. The levels of interest are mapped to adopter categories in Table 7.1.2. Users who where strongly interested in management correspond to innovators and early adopters, who right away liked the idea of the PHR, sought out information about it and started to use it. Only a few of them made the decision not to adopt. They thought the PHR would be useful to other residents and they discussed the PHR and its benefits with other residents in order to persuade them to adopt.

15 Table 7.1.2 Mapping between Diffusion of Innovation Adopter Categories and the Levels of Interest in HIM and PHR Adoption

Diffusion of Innovations		Levels of Interest in PHR Adoption
Adopter category	**Definition**	**Level of Interest**
Innovators	First individuals to adopt an innovation. Take risks, youngest, highest social class, very social and interact with other innovators.	Interested
Early Adopters	Second fastest to adopt. Highest degree of opinion leadership. More socially forward than late adopters and more discrete in adoption choices than innovators.	
Early Majority	Slower in the adoption process, have above average social status, contact with early adopters, and seldom hold positions of opinion leadership in a system.	Interested to Minimally Interested Minimally Interested Minimally Interested to Not Interested
Late Majority	Adopt after the average member of the society. Approach an innovation with a high degree of skepticism and after the majority.	
Laggards	Last to adopt an innovation. Have an aversion to change and tend to be advanced in age. Focused on "traditions", likely to have lowest social status, lowest financial fluidity, be oldest of all other adopters, in contact with only family and close friends.	Not Interested

The minimally interested to interested, minimally interested, and minimally to not interested correspond to the early and late majority. Some of them discussed deciding to adopt after the social worker or another resident talked to them about the benefits and ease of use of the PHR. The residents not interested in adopting the PHR and management of health information are the laggards. In this older, poorer and not high in social status population they were not necessarily the oldest or the poorest, however they seemed to be those residents who were the least able to take care of themselves, and so they were not interested in the innovation that would help them do this.

7.1.3 Characteristics of the Innovation

Rogers defines five intrinsic characteristics of an innovation that contribute to an individual's decision to adopt or reject an innovation. Relative advantage and compatibility are positively related to the rate of adoption and are considered by Rogers to be the factors that most impact the adoption rate. Complexity is negatively related to an innovation's rate of adoption and the trialability and observability are positively related. These characteristics and their application to the E-Medicine system are described below.

Relative Advantage – how improved the innovation is over the idea it supersedes

Many participants discussed that the idea that the PHR supersedes is either the doctor's medical record, which has the disadvantages of being non-complete (only covers the information from one doctor) and not easily accessible to the individual. Or that it supersedes their own personal paper record which covered their whole lifetime and all doctors they see. But the electronic PHR has the advantages of not being lost as easily, and can be retrieved and re-print it at any point necessary and removes the stress of having to look for it when it is necessary.

Compatibility – how consistent the innovation is with the existing values, past experiences and needs of potential adopters

The innovation is compatible with the needs of potential adopters especially with the new characteristics that force the individual to take more responsibility on themselves. However for many adopters who are used to having one medical care provider and relying on them to do all of their information management this becomes incompatible with existing values and past experiences. However for those who have experienced changing health care providers, loosing health record and having to recall and provide medical information from memory the record becomes compatible with past experiences.

> **Complexity of Simplicity** – the degree to which an innovation is perceived as being difficult to understand and use

Only one participant mentioned that they thought the system would be difficult to use. Others mentioned that they were afraid of computers in general but that they thought the system would be easy to use in general especially with help of the nursing students. Those participants who used the system described it as being very simple, easy to understand and easy to use.

> **Trialability** – how easy it is to try or experiment with the innovation, if the individual has a hard time trying to use it, they are likely to not adopt

The E-Medicine system could be used on a limited basis, it was not necessary to fill out the whole record in one sitting. In fact, it appears that many people filled out what they knew from memory during the first session, and then filled out additional or more detailed information at a later time. It was also suggested by the nurses and social worker to update the medication list first to have an accurate list of medications and then to fill out the rest later. The record was also able to accept information in many different formats, so participants could try to enter the information in the way that seemed most logical to them and then change it later if they desired. For example, in the date fields they could enter an exact date, the year or even "around 1998".

> **Observability** – how visible the innovation is to others and how easy it is to observe and describe to others

The PHR was actively advertised with flyers and information sessions. In addition information sessions with detailed information about the record and its use were regularly held. Participants described talking to other residents about the record, how easy it was to use and useful and some participants talked about wanting to try to record because another resident had told them about it.

The E-Medicine system as an innovation should have a positive rate of adoption based on the perceived attributes of the innovation described above. However, according to Rogers they explain about half the variance in the actual rates of adoption. The other four variables that affect the rate of adoption are the type of innovation-decision, communication channels, nature of the social system and the extent of the change agent's promotion efforts. These variables are not described in detail as it is beyond the scope of the research to fully analyze it in terms of the Diffusion of Innovations model.

The adopter categories as described as part of the Diffusion of Innovations theory are related to the interest levels of residents in the E-Medicine system and health information management. The decision making process as described in the Diffusion of Innovations theory could be observed in the adoption process at the housing residence.

7.2 Technology Acceptance Model

The technology acceptance model focuses on two major aspects of adoption from the point of view of the individual adopting the technology, perceived ease of use and perceived usefulness. Although participants were not specifically asked to evaluate the system on these aspects, many when reflecting positively on the system described such aspects as are listed under Ease of Use, such as it being simple and easy to understand (clear and understandable and easy to learn), that it is easy to start using it and to become skillful in using the system. Also many participants described the system as Useful, talked about it helping them fill out information forms more quickly or very quickly provide information in emergency situations. Also that it reduced the stress and anxiety of having to recall information accurately sometimes in stressful situation when information is needed quickly.

Study participants felt that the E-Medicine system was clear and understandable, flexible, controllable and easy to learn and to use. No one talked about it being easy to become skillful at, perhaps because it was a simple system and those participants who mastered the system talked about needing further features to work with their health information. Participants discussed that the system made it easier to retrieve health information when it was necessary, that they could retrieve information quickly and effectively. The information was accurate and having it at hand made their job of managing their information and retrieving it when necessary easier. Many discussed that they found the system to be useful.

7.3 Summary

Both the Technology Acceptance Model and the Diffusion of Innovation Theory can be compared alongside the findings of this study. There is an opportunity to further study PHR adoption both using the idea of usefulness or benefits of using a PHR as perceived by potential users and part of a social system as postulate by Diffusion of Innovations, especially keeping in mind that this innovation is aimed at the general population.

It may be more effective to implement PHRs within certain organizations where it is easier for information about the system to spread through informal communication channels and then target and advertise it to the general population. The Technology Acceptance Model suggests that whatever PHR is targeted to a population it should be tested for its ease of use and to make sure it is useful to the population or certain groups within the population.

Chapter 8: Contributions, Limitations, Future Work and Conclusions

8.0 Introduction

In this study of elderly and disabled residents of a low-income housing community the researcher explored the reasons why people chose to manage their health information and use a personal health record (PHR). The result of the study is an encompassing overview of the problems people face when choosing to adopt a PHR: factors that aid in adoption and factors that deter adoption. This work provides an overview of the PHR adoption problem from the health care consumer point of view. The results indicate that even older, socially disadvantaged and financially poorer individuals can realize the benefits of PHRs and choose to use them.

Based on interviews with PHR users and non-users two frameworks describing adoption were developed. The Levels of Personal Interest and Involvement in Managing Health Information Framework identifies the types of potential users by their level of interest in health information management and PHRs. Considering the types of individuals for whom PHRs are developed and their level of interest in health information management can be valuable for tailoring PHR systems and determining how to advertise or present a PHR to potential users. The second framework that emerged from this work, the Health Information Management Motivational Factors Framework includes seven categories of factors that are important to health care consumers who have complex health information management needs.

8.1 Contributions

The main contribution of this study is a big-picture view of factors that impact adoption of PHRs from the point of view of health care consumers, who have a low-income and manage chronic diseases with multiple co-morbidities. The two frameworks developed as a result of this work show a broad view of the adoption problem, the factors health care consumers must face when choosing to adopt a PHR and a view of the potential adopters themselves. Identifying and describing these factors that concern consumers defines a real structure for focusing future research, identifying ways to improve PHRs and identifying problems and solutions to increase adoption of PHR implementation efforts.

8.1.1 Specific Contributions of the Developed Frameworks

The main contribution of this study is in describing PHR adoption and use from the consumer point of view. Most studies of PHR adoption and research and reports that guide PHR design are not based on consumer needs and perceptions, but on what information is needed by health care providers (Tang et al., 2006; AMIA/AHIMA, 2006; Shortliffe et al., 2011). However, to interest consumers in using PHR systems developers need to understand and meet the needs of health care consumers as the potential users. This study identifies the issues that consumers consider when adopting and using a PHR and can be used by researchers and system developers to understand what motivates individuals to use a PHR system or turns them away from using a PHR.

Table 8.1.1 is a revision of Figure 4.1 that was first presented in Chapter 4 and is recreated here. The table shows the three levels of personal interest and involvement in health information management and potential users' general perceptions of health information management. The following are some suggestions for improving PHR system design based on knowledge of the types of users the PHR must appeal to.

16 Table 8.1.1 Levels of Personal Interest and Involvement in Managing Health Information

4.1.1 Interested in Management	**4.1.2 Minimally Interested in Management**	**4.1.3 Not Interested in Management**
• Express the need to better manage HI	• Are satisfied with current HIM strategy	• Explicitly refuse to manage HI
• Current HIM strategy lacking	• Do the minimum necessary work	• No HI to manage
		• Doctor takes care of HIM

Systems designed for individuals who are interested in management can be based on the current management strategy of such individuals. Many of them keep or have kept paper or electronic health records and have a good understanding of both how they manage health information and what management tasks they need to accomplish. The ideal, most functional PHRs can be based on the needs and strategies of these consumers who are interested in management and have a better understanding of the management tasks. This design of a PHR for optimal use can then be simplified and enhanced to meet the needs of individuals who are not as interested in management.

A number of participants who were interested in management were advanced users, they said that the basic PHR offered was too simple to satisfy their needs, they needed more advanced information collection tools, visualization tools to work with their health information and reminder and note taking tools to keep track of their plans and questions. These individuals may not need as much individual help to use the record, understand their health information and get access to health information.

Individuals who are minimally interested in management may require more help to understand how using the record would enhance their current management strategy or help them improve their health. For minimally interested individuals, the approach of importing health information from other sources to minimize the amount of work the user has to do in the record would be a valuable approach. For these individuals, PHRs need to be designed to be as simple and work free as possible, and tools that can help them transition to more active management if they want to do so need to be designed. If their health situation changes and they suddenly need to work more with their health information or integrate and understand a larger amount of health information they would be happy to have some basic information already in their record to build on. Individuals who are not interested in management can be asked to review their health information for correctness and they may still be interested in using other feature of PHR systems such as communication with their doctor and appointment reminders or health maintenance reminders that they rely on their doctor to provide.

The first three factor groups of the Health Information Management Motivational Factors Framework are the information access factors, system and technical factors and information management factors. These factor groups are related directly to managing health information as well as having access to the health information and a tool or system that helps them do this task. Table 8.1.2 is an excerpt of these first three factors from Figure 4.2.

Most of the facilitators from these factor categories are inherent in the technology. Information stored in the computer system is inherently more organized and safer than information stored on paper, a PHR enables easier sharing of information because the information is all stored in one place and can be shared both electronically and through printed copies, a PHR provides a backbone that enables the user to know what information needs to be entered and managed and helps ensure the information is accurate, current and complete. The system and technical facilitators need to be incorporated into the design of the system rather than the functionality and structure, the systems should be easy to use and fun and help to use them should be provided.

17 Table 8.1.2 Informational and Technology Related Factor Groups

4.2.1 **Information Access**	**4.2.2** **System and Technical**	**4.2.3** **Information Management**
-	-	-
• Unavailability of past HI • Not understanding HI or what HI is important to keep	• Uncertainty of system purpose • No support for continued use • Technical issues	• HIM is difficult • Poor HIM in the past • Managing a growing quantity of HI
+	+	+
• Computerized III is organized and safe • Enables sharing of HI	• Ease of use • Availability of help • Fun	• HIM is important • Backbone for keeping HI • Accuracy, currency, completeness of HI

To address the barriers in the information access and information management categories, PHR systems should be designed to help people get access to their past medical history and to help them remember or recreate the history if it is not possible to access it from other sources. PHR systems should also help people understand or "make sense" of their health information. If a person has access to their medical information, but does not understand it, they effectively do not have access to the contents of it that may help them take better care of their health. Functionality could be included that either helps people understand their health information in the record or allows them to indicate which information they need help understanding so that their care provider or personnel supporting the personal health record can help them better understand their HI.

In terms of the information management factor facilitators, health information management can seem difficult for many reasons and poor management of health information in the past can be one of the reasons. PHR systems can focus on helping people aggregate information or making the initial work load for using the system lower to encourage people to try the PHR and eventually help them add more information, more complex factors and help them manage and work with information over time. System and technical barriers need to be mostly addressed by educating consumers about PHR systems and their functionalities and by minimizing technical problems which can be an especially large barrier for individuals who are not competent computer users.

18 Table 8.1.3 Factor Groups Related to the Individual's Environment

4.2.4 **Medical System**	**4.2.5** **Personal Health and Life Situation**
-	-
• Lack of HI given by doctors • Unclear role of PHR in the medical system •Awareness of existence of PHR	• Memory problems • Disabilities • Too sick or not sick enough to use PHR • Changing health situation
+	+
• HI updates between doctors • Replaces intake forms • Emergency use	• Memory aid • Tracking HI over time • Making decisions based on HI

Some of the medical system and personal health and life situation factors in Table 8.1.3, which is a part of Figure 4.2 from Chapter 4 cannot be fully addressed by system design. They are factors that are inherent in the environment of the individual and therefore a PHR system can only make dealing with these factors easier but cannot change the factors themselves. The barriers to PHR system use in these two factor groups are mostly constraints brought onto health information from the medical system and the individual's living and health situation and therefore cannot be fixed though information system design.

However, improvements to PHR system design can be made by focusing on the facilitators in these two factor groups. PHR systems should incorporate functionality that helps users keep doctors informed about what other doctors that are treating this individual have done and about the individual's own health care activities. They also need to include functionality to help the patient fill out intake forms. Even though, even such a simple solution as printing out a full copy of your health history to take with you on a medical appointment is useful, additional functionality can be designed to help individuals. Ways to make the PHR more useful in an emergency and to ensure that treating physicians are aware of a PHR being available for their patient need to be developed. Designing the system to serve as a memory aid for the consumer and a tool that helps them gather information over time can also influence the design of PHRs.

19 Table 8.1.4 Social and Privacy Factors that Depend on Relationships with Others

4.2.6 **Social**	**4.2.7** **Privacy and Security**
-	-
• Lack of needed assistance • Fear of losing financial help • Fear of losing social status	• Using record in a public place • Theft of HI • Research access to HI
+	+
• Word of mouth spread • Family involvement • Care and attention from using the system	• Trust in the medical system • Benefits outweigh concerns

Factors in the last two factor groups, the social and privacy and security factors presented in Table 8.1.4 can be more related to the mindset of the users than the design of the system. Perceptions of these factors can be changed by increased knowledge about the system and its social implications, and by ensuring users that information in the system is as protected as possible. According to this research, especially for such a disadvantaged and "wary" population, more personal contact is needed to ensure they receive information multiple times, their questions can be answered on a regular basis and they hear about the PHR from trusted individuals. These informal communication methods are especially necessary when information needs to be provided regarding privacy and security of health information. A personal health records that allow electronic sharing of information should be designed with interfaces that allow the user to specify which parts of their records are shared and show what information can be and has been accessed by others. A system design that makes sharing of information and reviewing which information has been viewed by others can increase the value of the system as a social tool and increase the sense of security of health information.

People are wary of systems provided by the government, insurance companies, and for-profit companies (Markle, 2003). The Markle report states, "People trust their doctor to host, manage, and access their PHR. People do not want their PHR maintained by their insurance company, their employer or the government, and they want to limit family members' and others' access to it without their specific permission" (2003). However, doctors are not the only entities that are not tied to the government, insurance companies and making a profit. It is possible that the E-Medicine PHR system was more trusted by the residents because it was not offered by a for-profit company and was not tethered to a medical information system but was offered by an entity tied to research and a well-known academic health care institution.

People are aware that their medical records are kept with all possible security precautions and even elderly people are aware that many health care providers keep their records electronically. Those individuals who were reasonably concerned about privacy, security and safety of the information in their record were reassured by the fact that the information in the PHR was kept on the same servers and all the same safety precautions were taken to protect it as are taken to protect the information of a large and well respected academic medical center.

Other organizations that are trusted by people can also offer PHRs. Offering PHRs to residents, employees, regular visitors, clients, students of community organizations and ensuring that help is regularly available to use the system are two potential strategies which could lead to increased adoption of PHR systems. Senior centers, hospitals, employers could offer PHRs. Schools could offer PHRs to parents and their children, colleges and universities could offer PHRs to their students. Because for many people the idea of keeping a health record for themselves is new, because it can be uncomfortable and confusing, because paper records that can be destroyed or hidden can seem to many people intuitively more secure than electronic records, we need to make the idea of personal health records more understandable and common in every day life. If people know what personal health records are, if they understand them and feel comfortable with the idea they will be more likely to adopt them.

When a potential user sees information about a PHR in a comfortable everyday environment, when they know they can turn for help to medical professionals who deal with health information every day, when they know that they ask questions and receive help, and seeing information about PHRs during everyday activities and in many places can help people bridge that gap of being afraid of using PHR records. Having an opportunity to use a PHR in a private room at a local library, or having a nurse at a local hospital help you use a PHR record, explain the system and answer your questions can be the move that finally helps spread PHR records and move us toward the attainment of the 2020 goals of EHR/PHR adoption (Leavitt, 2007).

In this study, factors that potential PHR users consider when deciding to use or continuing to use a PHR are identified and described. These factors need to be considered when developing PHR systems and making implementation decisions. When implementing a PHR the needs and capabilities of the potential users need to be assessed. Some users cannot or will not use a PHR system on their own and need personal help to use a PHR, at least initially. This study shows that an active advertisement campaign where all individuals have repeated opportunities to learn about the system can be crucial for adoption. There are some users who may never use the system on their own, but even they reap some benefits from using it with assistance.

8.1.2 Contributions to PHR Systems Development

The Levels of Personal Interest and Involvement in Managing Health Information Framework characterizes individuals by their interest level in managing their health information. This breakdown gives PHR developers and researchers a new way to tailor PHR system design and education. The emerging groups show that people are not all alike, some are into management and some are not. Other PHR research has confirmed that some groups of users have different needs, for example Lafky and Horan showed that health status may affect PHR needs (2008). This study confirms this finding and indicates that not only disabilities which were studied by Lafky and Horan affect PHR needs, but other factors as well, such as managing a chronic disease or multiple co-morbidities, receiving care from multiple providers and taking a large number of medications.

The PHR system studied was not connected to an electronic medical record and did not allow doctors to access information about consumers electronically. However, the improvement in doctor patient communication that has been cited in the literature as a benefit of systems that allow electronic access to patient information (Markle, 2003; Tang, 2006; Archer, 2011) was achieved by PHR users through printed copies of the PHR that were taken to the doctor. Despite the fact that this PHR did not include functionality for electronic sharing of data and was not interactive for the providers, the participants used paper copies of their record interactively. Participants would update their record before going to see a provider, they would print a paper copy to use with the provider and they would update their PHR after the visit. Many participants made hand written notes on the printed copy and used these notes as reminders when updating their record.

Participants discussed electronic sharing as a wanted feature, but reported that even a printed copy of the medical information that is brought to a visit is valuable to make sure the doctor is aware of all recent and historical health information, has a full view of the medical history on which to base his decisions. Some participants mentioned in the interviews that they wanted their doctor, children or caretakers to have electronic access to their PHRs. Other participants even felt comfortable enough to give trusted individuals their log in and password information so that they could access the information in their record directly. Sharing of health information is an important task patients do (Civan et al., 2006; Pratt et al., 2006; Skeels, 2010). Some studies have shows improved patient-provider communication enabled by improved sharing of information though both electronic and paper PHRs (Tobacman, 2004; Wald, 2006). This study has shown that patients use the PHR to both to understand information better themselves and as an aid to enhance communication with their provider and PHR systems need to be designed to enhance both these uses of the system.

Many of the individuals in the population studied feel they need one-on-one help at least initially to use the system. Some individuals who are not comfortable using computers or do not understand their health information need help every time they use the system, others might need help the first few times and could than use the system on their own. However, the results of this study lead the author to suggest some areas that can be improved to increase self-use of PHR systems. These three areas are better support for medication management, personal "review" of PHR information and tools for helping users recall and capture historical information.

Most participants talked about medication management as an important task they do and many had trouble understanding and entering medications into their PHR. Most participants were prescribed many medications and were not always aware of what the medications were called, what they were for, when to take them or what the dosages were. Not knowing what each medication was became especially problematic when individuals were changed to generic medications or when they were given the same medication but of a different dosage. Because the appearance and name of a generic medication is different than the brand name, people would often forget what this pill was for and what pill it was replacing, which made medication management more difficult and sometimes lead to not taking medications as prescribed.

Many participants described bringing all their medication bottles to the meeting with the nursing students and figuring out together what medications they took and which they did not, what medications were for what, when they were supposed to be taken and in what dosage. Only the users themselves know which of the medications they get from the pharmacy they take, how much of each one they are taking and whether the medication helps. There is no automated way to discover this information. In addition, this can be an opportunity to teach PHR users about their medications and develop strategies to help them take their medications properly. The problems related to medication management need to be studied in depth and tools developed to help individuals understand and manage their medications.

A second way to encourage PHR use without in-person help is to use guides and wizards to encourage the user to enter as much information as possible and then have a qualified professional review this information. A number of individuals in the study indicated that they did not use the record or did not enter some information because they did not know whether it is useful or not, and what details need to be entered. People will be more comfortable entering information if they know someone will review it and let them know if it is not complete, if they are missing information or could be doing something in a better way. Individuals should be encouraged to enter as much information as they know and then the "reviewer" can help point of what information is not necessary or what useful information is missing. However, if possible, some individuals still need to use the record for the first time and do the initial data entry with the help of a health care professional that knows the system and can show them what to do and then use the guided review approach later.

This approach could be applied to the medication problem, where users can be asked to enter everything they know about their medication, such as the name from the bottle, the dosage, if or when they take it and what it is for. The instructions should guide the user to enter as much information as possible, show where the necessary information can be found on the bottle and encourage the user to enter questions marks in the fields they do not know or do not understand. This information can be reviewed by a qualified professional, who can assess how this individual could be helped to improve their medication management. If necessary they could contact the individual or their doctor with suggestions.

Another specific suggestion to improve self-use is to build on a concept called a "timeline" to help individuals recall their historical information. A number of participants felt that they did not know enough of their health information to enter into the record and indicated that they waited to use the record until they would get this information from somewhere. Some individuals would potentially never start using the record because they would never get all their health information in a way that could just be entered into the record. It should be clearly explained to users that having any information, even if it is not complete is already useful.

Additionally, tools, such as a "timeline" should be developed to help individuals recall information to be entered into their record. The timeline is a tool that maps important events in a person's life, such as a marriage, birth of a child, a move or a historical event and then guides the individual to recall when health evens happened in relation to those "known" events. It is easier to recall that a surgery happened right after a move to a new city or that a group of health issues was diagnosed and treated before or after the birth of a child. The "timeline" allows the user to map health events in relation to key events in their life. This is the health story of the patient that they would have to provide background information to providers and also to keep the "story" evolving over time for themselves.

These suggestions and the developed frameworks could be also used to improve other consumer health technologies, such as mobile health applications. System implementations need to include some amount of personal help, and some populations may require more help than others. Some users will not use PHRs or other consumer health technologies without help, but are willing to try it if help is available and some will then switch to self use. This support should be provided at least initially to increase adoption. Another approach to increase use and adoption of consumer health technologies is to encourage individuals to enter any or all information they know and then having a volunteer or health professional check their record to provide feedback and suggest improvements. A personal approach and the opportunity to receive feedback would encourage individuals to try the application even if they were not sure about how to use it.

8.1.3 Contributions to PHR Research

The research community needs a flexible framework for studying PHR adoption and factors that contribute to adoption and deter from it. The created Health Information Management Motivational Factors Framework is such a framework, it is a big-picture flexible real structure for studying and understanding PHR adoption in a population. It however, needs to be further expanded and verified with other populations who have complex management needs. It can be applied to other user groups, such as younger users, who have can have quite different management needs and caregivers or mothers with children who have different management needs.

Many studies have defined what PHR architecture, content and features should be like (Tang et al., 2006; Vincent et al., 2008; AMIA/AHIMA, 2006) or have proven or proposed that certain benefits can be achieved with the use of PHRs (Tang et al., 2006l Ralston et al., 2009; Ross et al, 2004). However no study has looked at the whole problem of PHR use and adoption from the consumer point of view. This study contributes this piece by defining what PHR users think about and what functionalities and uses of the PHR they feel are important. Knowing what worries and attracts consumers is especially important for tailoring PHR advertising materials to focus on issues that are important to consumers, not to health care providers. Consumers may not be as interested in the fact that using a PHR can help them decrease their hemoglobin A1C levels or improve adherence to medications, however knowing that it would help them fill out intake forms and keep track of questions they want to ask their provider may appeal to them.

Some subset of people would never use the record on their own. They do not see how the record would help them; nor do they not know how to start working with or aggregating information for their record. The fact that some people would not think of signing up for a PHR just because it's a good idea and they saw advertising materials for it has not been described in the literature. However, this is an important finding and consideration if we want to increase the adoption rates of PHRs.

One of the strategies to get more people to use a PHR is having personal help available, accessible people that can assist during PHR use and answer questions. Having a personal presence makes it easier for consumers to ask about the record and ask for help once they have gotten used to the idea of a PHR. Knowing that they would receive help might help some consumers decide to use the PHR. In fact 17 of the 19 users who used the PHR were interested to minimally interested in HIM. This suggests that if more people are given the chance to try a PHR at least once, they are likely to see how it is useful and keep using it. We need to enable people to try PHRs, make PHRs available in places where people go, settings where consumers are comfortable and trustful.

In the setting studied, some people used the record with the help of the nursing students once and then used it on their own, some people said they would want to use it with the nurses a few times to feel comfortable before they used it on their own and people always met with the nurses to update their record. It appears that without personal help that is regularly available some subset of the adopter population would never use the PHR. In fact, this subset could be quite large, in previous studies of this setting it was found that 77% of user activities occurred while the assistance from nursing students and social worker was available (Kim et al., 2009). This need for support and help may also be needed for other health consumer technologies and it may also be more prevalent in an older population, a population that is less familiar with computers or a population that is less health literate.

Independent of whether they used a PHR, 88% of participants said they managed their health information mainly on their own, that they do not receive help in managing their health information. In a study by Moen and Brennan on the work of health information management in the home, 64% of respondents reported managing their information on their own and 31% reported managing most of the HI in the household (2005). Because the participants in this study mostly lived alone, the burden of health information management was fully on them and because of this they were aware of their needs related to health information management. This is supported by the study results, which show that individuals for whom the family or doctor managed health information did not feel that they wanted to or had the need to use the PHR, both because they did not know how to manage HI, and they did not understand how the system could help them. However, if they stopped receiving help from their doctor or family and were forced to manage their health information on their own, they might realize that they do need the PHR to help them.

PHR systems can enable consumers to better understand and manage their health information by providing tools that help consumers better interact with their health information and the health care system. Ultimately, this research will positively impact people's health by helping design PHR systems that will help health care consumers take better care of their health and receive better health care. The researcher hopes that this work will result in guidelines and recommendations to aid in development of more effective PHRs that are more attractive to consumers and will enable more successful adoption of such applications by consumers.

8.1.4 Applicability of Adoption Theories to PHR Research

The two frameworks that emerged as a result of this work highlight issues that are aligned with factors in both the Technology Acceptance Model and the Diffusion of Innovations theory and show that these theories can be applied to PHR adoption. As discussed in Chapter 6, study participants clearly described going through the five stages of the adoption process described by Rogers in the Diffusion of Innovations theory (2003). In addition, the five adopter categories described by Rogers and often cited in the literature correspond to the levels of interest scale. The innovators, early adopters and early majority are more like individuals who are interested in health information management and minimally interested and the late majority and laggards are closer to individuals who were minimally interested to not interested in managing their HI. The identified thematic sets can be thought of as an overview of the problem of PHR adoption and should be filled it and expanded in relation to the Diffusion of Innovations theory. Moreover, Rogers' attributes of the innovation are also applicable to the PHR system studied and PHR systems and PHR adoption in general.

Some research has suggested that it may be difficult to study the adoption of PHRs using the Technology Acceptance Model because the PHR is a novel task to all users and because there are many types of users with different needs and limitations (Lafky & Horan, 2008). For example, it is difficult to measure perceived ease of use if the users do not have a mental model of the task being done, as it is a task that was not done before by most people. However, results of this research show that many people do tasks similar to the ones done with the help of the PHR. In fact, 88% of participants managed all of their health information in their home and therefore were closely familiar with the HIM tasks. Many users were able to describe their health information management tasks in detail and even request features or describe ways to enhance their management approach. This indicates that Technology Acceptance Model can be applied to personal health record use and systems that aid in health information management.

Details of system attributes and system use are loosely aligned with both measurements in the Technology Acceptance Model and with the issues discussed by the Diffusion of Innovations theory. These similarities between the developed frameworks and existing technology adoption models support the validity of the data collected and the emerging frameworks. Studying PHR adoption and use with the help of these two bodies of work is an opportunity for future work.

8.2 Limitations

This research attempted to cover and describe the full picture of what motivates PHR adoption from the point of view of individuals who are potential PHR users. However, a single piece of work done by one researcher cannot fully explore this complex issue. The results of this work show that there are many factors that contribute to PHR adoption and use and it was not possible for one researcher to study all of them in depth in one research study.

Qualitative studies result in a large amount of data that comes from a small number of participants and allows the researcher to describe in depth the issue at hand, but not to focus on the impact of a specific issue or identify a specific reason for a particular state or situation. An inherent limitation in qualitative studies is that they are intrinsically better at studying the breadth of a question. The identified interest levels and motivational factors identify and place in context all issues that play into PHR adoption and further work is needed based on these frameworks to find the impact of each piece of the created frameworks.

A sampling limitation of this study is that individuals who chose to respond to calls to participate in this research were in some way self selected. It is possible that individuals who were not interested in information management or did not manage their information did not respond to study calls, because they were not interested in the subject. However, there were a number of participants in the study who were not interested in management and did not manage their HI and their views are also reflected in the data. This limitation is inherent in qualitative studies where individuals who can inform on the study question are chosen to participate, and this limitation was addressed by stratified sampling that included non-users. It would in fact be difficult to gain useful information about PHR use and why someone does not use such a system from someone who does not know anything about health information management and such systems.

The researcher had access only to one setting where a PHR was used. The frameworks developed are more applicable to older populations that have a large number of health problems and complex health information management needs. There are no identical settings and although the results of this study can be applied to other settings, it would be beneficial to study additional settings and additional types of users to expand and validate the frameworks and make them more generalizable. It is possible that in the population studied some issues appear to be more important than they would be for a different group of users. One example of this is the financial information management issue, which is discussed in literature (Markle, 2003) as being an important health information management task, but was not brought up as an important task by the health care consumers studied.

The results obtained in this setting do not directly extend to other settings and further work with other demographic groups is needed to make the results generalizable to other groups of users and other settings. However, the possible benefits obtained by this population from using a PHR are great. Using a PHR can help health care consumers better understand their health information, better manage their health care and have information available in case of emergencies to enable better care and reduce the possibility of medical mistakes and drug-interactions.

8.3 Future Work

There a number of directions for future work based on the results of this study. One is to further expand and elaborate the groups of factors that contribute to PHR adoption and study connections between the user groups and the factors that impact adoption and use. The developed Levels of Personal Interest and Involvement in HIM and the Health Information Management Motivational Factors Framework should be applied to other populations and other settings to validate and expand them. Another future direction is studying the frameworks in other settings in the context of the Diffusion of Innovation Theory and Technology Acceptance Model. These models might need to be adapted and undergo evolution to be useful in PHR adoption research. In addition, this framework can be applied to other consumer health applications and individual factors can be studied qualitatively to evaluate their weight in the adoption decision in different settings, for different systems and different groups of users.

Further studies of actual PHR use are needed to further elaborate on each factor category and the relationship between factors. One potential direction is to study the weight of each factor group and specific facilitators and barriers in different populations. Researchers and designers need to know what factors are more important to different user groups and which factors should be given priority over other factors in system design.

Some studies show that elderly and disabled users might be more interested in managing health information (Lafky & Horan, 2008), but that it can be difficult for some of them to use computerized information management systems such as the PHR system studied (Kim et al., 2009). The developed frameworks apply more directly to such users, but need to be verified in other populations. That financial information management was not an important task for the participants studied, as was indicated in a survey of the general population (Markle, 2008), also indicates that it is possible that different populations might have significantly different health information management needs.

An individual's intent to use, which is reflected in surveys and whether the individual actually acts on it, which is better studied by looking at actual use are often very different (Bagozzi & Warshaw, 1992). To know what people do and what functionalities need to be supported by PHRs, researchers need to study people who manage health information and be knowledgeable of the tasks they already do and how they can be improved. The technology acceptance model and the theory of reasoned action which it extends both assume that when an individual intends to do something they will be free to act without limitation (Davis, 1989). However in the real world there are many limitations (Bagozzi & Warshaw, 1992). This research indicates that there are many limitations to the intent to use a PHR and further studies are needed to study this in context of the TAM and other adoption of technology work.

There are many other populations that could greatly benefit from PHRs. New facilitators and barriers to PHR use may be discovered in other populations. Strategies need to be developed to have younger people start using the records early before they become ill and access to their health information becomes critical. When information is collected over time, the large burden of assembling life long health information at a later time is reduced and the process of collecting and reviewing HI can easily lead into full fledged use of PHR records for managing complex health information that appears later in life. Quantitative studies of PHR adoption based on framework concepts need to be conducted. The developed frameworks can also be used to inform design of other consumer health technologies and to study motivations to adopt such technologies.

8.4 Concluding Remarks

A gap exists between the number of health care consumers who believe that a PHR is useful and say that they want to use such a system and the number of people who actually use PHRs. This research project addressed this gap by studying factors that motivate individuals to adopt and use a PHR or deter them from using one. A population of low-income individuals with complex health information management needs was studied to uncover reasons why people chose to adopt PHRs. The frameworks that are the results of this study are a potential comprehensive overview of the issue on which quantitative studies of adoption can be based.

In this study, extensive interview data collected from PHR users and non-users was analyzed and a framework of factors that motivate adoption as seen by the consumers themselves emerged. The Levels of Interest in Health Information Management Framework characterizes an individual's level of personal interest and involvement in managing health information. It can be used to characterize the type of statements potential PHR adopters make and place them along a scale based on their willingness to adopt a PHR or be involved in health information management in general. This framework is a first step toward allowing researchers to categorize PHR users and create tailored products, educational materials and tailored levels of support.

The second thematic set, the Health Information Management Motivational Factors Framework, is a broad and comprehensive framework of factors that motivate individuals to use a PHR or manage their personal health information. Seven factors were identified that users are concerned about and that encourage or discourage them from using a PHR. Within each factor category, barriers and facilitators to adopting and using a PHR are described. Future studies of PHR adoption and adoption of other consumer health information technologies can be based on these factors. This framework should be generalized to other populations and weight of different factors for different user groups and populations should be determined. This will allow researchers to systematically assess PHR systems and implementation, compare the success of different PHR systems and develop improvements and new approaches to PHR design and implementation.

A number of interesting and surprising factors were identified. One is that this group of disadvantaged consumers was generally interested in using a PHR despite their low technology skills and age. Using an advertising and education campaign tailored to the audience and providing supporting mechanisms can help even such unlikely adopters chose to adopt PHRs. Another interesting finding is that these consumers were not concerned with managing financial health information, which is an important and difficult task for younger consumers who must pay for their care and manage payment and insurance information. The reduced strain from not needing to manage financial information may be an important factor that contributes to adoption rates. If the financial aspect of health care does not detract form information management, better adoption of PHRs and management could be achieved. The third interesting finding is that privacy and security concerns were not a significant barrier. There were some individuals who made the decision not to adopt because of strong privacy and security concerns, but they were few. Most individuals discussed the benefits outweighing the risks and others talked about not being concerned about others finding out about their medical information.

In addition, two general adoption of technology models were analyzed and were found to be applicable to the adoption of personal health records. Future research work studying adoption of PHRs in different populations and in different settings can draw on the Technology Adoption Model and Diffusion of Innovations theory to study the adoption of PHRs. Researchers can draw on the framework and factors identified in this research study to know what concerns need to be addressed in the design, implementation and informational materials advertising personal health records.

References

AHIMA. (2011). Personal Health Records. Retrieved from www.ahima.org/resources/phr.aspx.

AMIA/AHIMA. (2006). The Value of Personal Health Records A Joint Position Statement for Consumers of Health Care. Retrieved from library.ahima.org/xpedio/groups/public/documents/ahima/bok1_033819.hcs.

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

ASTM. (2007). Specification for the Continuity of Care Record. Retrieved from www.astm.org/Standards/E2369.htm.

Atlas.ti. (2011). Atlas-ti: The QDA Software. Retrieved from www.atlasti.com.

Bagozzi, R.P., & Warshaw, P.R. (1992). Development and test of a theory of technological learning and usage. *Human Relations 45*(7), 660–686.

Baldwin, G. (2007). Behind the Wires. *HealthLeaders Media*. Retrieved from www.healthleadersmedia.com/content/TEC-90274/Behind-the-Wires.html.

Bali, R.K., & Dwivedi, A.N. (2007). *Healthcare Knowledge Management*. New York: Springer.

Ball, M.J., & Gold, J. (2006). Banking on Health: Personal Records and Information Exchange. *Journal of Healthcare Information Management, 20*(2), 71-83.

Beisecker, A.E. (1993). Using Metaphors to Characterize Doctor--Patient Relationships: Paternalism Versus Consumerism. *Health Communication, 5*(1), 41-58.

Berwick D.M. (2003). Disseminating innovations in health care. *Journal of the American Medical Association, 289*(15), 1969-75.

Blumenthal, D., & Tavenner, M. (2010). The "Meaningful Use" Regulation for Electronic Health Records. *The New England Journal of Medicine, 363*, 3.

Bocchino, C. (2006). America's Health Insurance Plans, "Testimony on the AHIP/BCBSAHealth Insurance Plan Personal Health Record Project," before the American Health Information Community's Consumer Empowerment Subgroup. Retrieved from www.hhs.gov/healthit/ahic/materials/meeting07/cemp/testimony/2-bocchino.pdf.

Bodenheimer, T., Wagner, E.H., & Grumbach, K. (2002). Improving Primary Care for Patients With Chronic Illness. *Journal of the American Medical Association, 288*, 1775-1779.

Brennan, P., & Safran, C. (2003). Report on conference track 3: patient empowerment. *International Journal of Medical Informatics, 69*(2-3), 301-4.

Bush, G.W. (2004). Incentives for the Use of Health Information Technology and Establishing the Position of the National Health Information Technology Coordinator, Executive Order of the President of the United States.

Butow P., Devine R., Boyer M., Pendlebury S., Jackson M., Tattersall M.H. (2004). Cancer consultation preparation package: changing patients but not physicians is not enough. *Journal of Clinical Oncology, 22*(21), 4401-9.

Cain, M., & Mittman, R. (2002). Diffusion of Innovation in Health Care. California HealthCare Foundation and Institute for the Future Report. Retrieved from: www.chcf.org/~/media/MEDIA%20LIBRARY%20Files/PDF/D/PDF%20DiffusionofInnovation.pdf

California HealthCare Foundation. (2010). Consumers and Health Information Technology: A National Survey. Retrieved from www.chcf.org/publications/2010/04/ consumers-and-health-information-technology-a-national-survey.

Chumbler N.R., Haggstrom D.A., & Saleem J. (2010). Implementation of Health Information Technology in Veterans Health Administration to Support Transformational Change: Telehealth and Personal Health Records. *Medical Care, 48*(12).

Civan A., Skeels, M.M., Stolyar, A., Pratt, W. (2006). Personal Health Information Management: Consumers' Perspectives. *AMIA Annual Symposium Proceedings*, 156-160.

Computerisation of personal health records. (1978). *Health Visitor, 51*(6), 227. PMID 248054.

Cronin, C. (2006). Personal Health Records: An Overview of What is Available to the Public. AARP, Washington DC. Retrieved from assets.aarp.org/rgcenter/health/2006_11_phr.pdf.

Davis, F.D. (1989). Perceived Usefulness, Perceived Ease of Use, and User Acceptance of Information Technology. *MIS Quarterly, 13*(3), 319-340.

Denton, I.C. (2001). Will patients use electronic personal health records? Responses from a real-life experience. *Journal of Healthcare Information Management, 15*(3), 251-9.

Dragstedt, C.A. (1956). Personal health log. *Journal of the American Medical Association, 160*(15), 1320.

Dwivedi, A.N., Bali, R.K., & Naguib, R.N.G. (2007). Building new healthcare management paradigms: A case for healthcare knowledge management. In R.K. Bali and A.N. Dwivedi (Eds.), *Healthcare Knowledge Management* (pp. 3-10). New York: Springer.

Endsley, S., Kibbe, D.C., Linares, A., Colorafi, K. (2006). An introduction to personal health records. *Family Practice Management 13*(5), 57-62.

Ertmer, A., & Uckert, F. (2005). User acceptance of and satisfaction with a personal electronic health record. *Studies in Health Technology and Informatics 116*, 861-6.

Fitzgerald, L., Ferlie, E., Wood, M., Hawkins, C. (2002). Interlocking Interactions, the Diffusion of Innovations in Health Care. *Human Relations, 55*(12), 1429-49.

Gartner. (2009). eHealth for a Healthier Europe: Opportunities for a better use of healthcare resources. Retrieved from www.sweden.gov.se/content/1/c6/12/98/15/5b63bacb.pdf.

Goldberg, C. (2011) What Killed Google Health? And What Does Its Untimely Demise Mean? Retrieved from commonhealth.wbur.org/2011/07/killed-google-health.

Google Blog. (2011). An Update on Google Health and Google PowerMeter. Retrieved from googleblog.blogspot.com/2011/06/update-on-google-health-and-google.html.

Green, B.B., Cook, A.J., Ralston, J.D., Fishman, P.A., Catz, S.L., Carlson, J., Carrell, D., Tyll, L., Larson, E.B., Thompson, R.S. (2008). Effectiveness of home blood pressure monitoring, web communication, and pharmacist care on hypertension control: a randomized controlled trial. *Journal of the American Medical Association, 299*, 2857–2867.

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

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

HealthyPeople.gov. (2010). 2020 Topics & Objectives. Retrieved from www.healthypeople.gov.

Herbaugh, A.L. (2009). *Resident survey on the usefulness of a personal health record when shared during a patient-provider encounter* (Master's thesis). University of Washington, Seattle, Washington.

HHS. (2010). HHS Strategic Plan FY 2010-2015. Retrieved from aspe.hhs.gov/hhsplan.

HHS. (2004). National Health Information Infrastructure. Retrieved from aspe.hhs.gov/sp/NHII.

HIMSS. (2007). HIMSS Personal Health Records Definition and Position Statement. Retrieved from www.himss.org/content/files/PHRDefinition071707.pdf.

Holden R.J., & Karsh B-T. (2010). The Technology Acceptance Model: Its past and its future in health care. *Journal of Biomedical Informatics, 43*, 159–172.

IHE. (2007). Integrating the Healthcare Enterprise. Retrieved from www.ihe.net.

Indivo TM. (2011). About Indivo TM. The Personally Controlled Health Record and Platform for Health-Data Innovation. Retrieved from indivohealth.org.

Institute of Medicine (IOM). (1999). To Err Is Human: Building a Safer Health System. The National Academies Press. Retrieved from iom.edu/Reports/1999/To-Err-is-Human-Building-A-Safer-Health-System.aspx.

Institute of Medicine (IOM). (2006). Preventing Medication Errors. The National Academies Press. Retrieved from www.iom.edu/Reports/2006/Preventing-Medication-Errors-Quality-Chasm-Series.aspx.

Kaplan, B., Brennan, P. F., Dowling, A. F., Friedman, C. P., & Peel, V. (2001). Toward an informatics research agenda: key people and organizational issues. *Journal of the American Medical Informatics Association: JAMIA*, *8*(3), 235-41. Retrieved from www.ncbi.nlm.nih.gov/pubmed/11320068.

Kaplan, B., & Brennan, P.F. (2001). Consumer Informatics Supporting Patients as Co-Producers of Quality. *Journal of the American Medical Informatics Association: JAMIA*, *8*(4):309-16.

Kim, E-H., Stolyar, A., Lober, W.B., Herbaugh, A., Shinstrom, S.E., Zierler, B.K., Cheong, B.S., Kim, Y. (2007). Usage Patterns of a Personal Health Record by Elderly and Disabled Users. *AMIA Annual Symposium Proceedings,* 409-13. PMID: 17238394.

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

Kim J., Jung H., & Bates D.W. (2011). History and Trends of "Personal Health Record" Research in PubMed. *Healthcare Informatics Research, 17*(1), 3-17.

Kim, M.I., & Johnson, K.B. (2002). Personal Health Records: Evaluation of Functionality and Utility. *Journal of the American Medical Informatics Association: JAMIA*, *9*(2), 171-80.

Krupat, E., Rosenkranz, S.L., Yeager, C.M., Barnard, K., Putnam, S.M., Inuii, T.M. (2000). The practice orientations of physicians and patients: the effects of doctor-patient congruence on satisfaction. *Patient Education and Counseling, 39*, 49-59.

Kuhn, K.A., Wurst, S.H.R., Bott, O.J., Guise, D.A. (2006). Expanding the Scope of Health Information Systems: Challenges and Developments. *Methods of Information in Medicine, **45***(1), S43-52.

Kupersmith, J., Francis, J., Kerr, E., Krein, S., Pogach, L., Kolodner, R.M., Perlin, J.B. (2007). Advancing evidence-based care for diabetes: lessons from the Veterans Health Administration. *Health Affairs (Millwood), 26*(2), w156–w168.

Laine, C., & Davidoff, F. (1996). Patient-centered medicine: a professional evolution. *Journal of the American Medical Association, 275*, 152–56.

Lansky, D., Kanaan, S., & Lemieux, J. (2005). Identifying Appropriate Federal Roles in the Development of Electronic Personal Health Records: Results of a Key Informant Process. Retrieved from odphp.osophs.dhhs.gov/projects/PHRecords/default.htm.

Lafky D.B., & Horan, T.A. (2008). Prospective Personal Health Record Use Among Different User Groups: Results of a Multi-wave Study. *Proceedings of the 41st Annual Hawaii International Conference on System Sciences.* Retrieved from www.cgu.edu/pdffiles/KayCenter/30750233.pdf. doi: 10.1109/HICSS.2008.363.

Leavitt, M.O. (2007). Testimony before the House Ways and Means Committee, Washington, DC.

Legris, P., Ingham, J., & Collerette, P. (2003). Why Do People Use Information Technology? A Critical Review of the Technology Acceptance Model. *Information and Management 40*(3), 241-255.

Li, Y-C., Detmer, D.E., Shabbir, S-A., Nguyen, P.A., Jian, W-S., Mihalas, G.I., Shortlife, E.H., Tang, P., Haux, R., Kimura, M. (2011). A global travelers' electronic health record template standard for personal health records. *Journal of the American Medical Informatics Association: JAMIA*, (in press). Retrieved from jamia.bmj.com/content/early/2011/08/16/amiajnl-2011-000323.full.html.

Lincoln, Y.S., & Guba, E.G. (1985). *Naturalistic inquiry.* Beverly Hills, CA: Sage.

Lober, W.B., Zierler, B., Herbaugh, A., Shinstrom, S.E., Stolyar, A., Kim, EH., Kim, Y. (2006). Barriers to the use of a Personal Health Record by an Elderly Population. *AMIA Annual Symposium Proceedings,* 514-8. PMID: 17238394.

Managing Your Health Information Online. (n.d.). Retrieved from www.medicare.gov/navigation/manage-your-health/personal-health-records/personal-health-records-overview.aspx.

Mandl, K.D., Simons, W.W., Crawford, W.C., Abbett, J.M. (2007). Indivo: a personally controlled health record for health information exchange and communication. *BMC Medical Informatics and Decision Making, 7*, 25.

Masys, D., Barker, D., Butros, A., Cowles K.E. (2002). Giving Patients Access to Their Medical Records via the Internet: The PCASSO Experience. *Journal of the American Medical Informatics Association: JAMIA*, *9*(2), 181–91.

Markle Foundation. (2003). The Personal Health Working Group: Final Report. Retreived from www.providersedge.com/ehdocs/ehr_articles/The_Personal_Health_Working_Group_Final_Report.pdf.

Markle Foundation. (2004). Working Group on Policies for Electronic Information Sharing Between Doctors and Patients. Connecting Americans to Their Healthcare: Final Report. Retrieved from www.connectingforhealth.org/resources/wg_eis_final_report_0704.pdf.

Markle Foundation, Robert Wood Johnson Foundation (RWJF), & Agency for Healthcare Research and Quality (AHRQ). (2005). Americans support online personal health records; patient privacy and control over their own information are crucial to acceptance. Retrieved from www.rwjf.org/pioneer/product.jsp?id=21844.

Markle Foundation. (2008). Americans Overwhelmingly Believe Electronic Personal Health Records Could Improve Their Health. Retrieved from www.markle.org/publications/401-americans-overwhelmingly-believe-.

McInnes, D.K., Solomon, J.L., Bokhour, B.G., Asch, S.M., Ross, D., Nazi, K.M., Gifford, A.L. (2011). Use of electronic personal health record systems to encourage HIV screening: an exploratory study of patient and provider perspectives. *BMC Research Notes, 4,* 295-306.

Microsoft HealthVault. (2011). Microsoft HealthVault Personal Health Record. Retrieved from www.microsoft.com/en-us/healthvault.

Moen, A., & Brennan, P.F. (2005). Health@Home: The work of health information management in the household (HIMH): Implications for consumer health informatics innovations. *Journal of the American Medical Informatics Association: JAMIA, 12,* 648-56.

Moloney, T., & Paul, B. (1991). The consumer movement takes hold in medical care. *Health Affairs, 29,* 171-83.

MyGroupHealth. (2011). Retrieved from www.ghc.org.

Nielsen, J. (1994). Estimating the number of subjects needed for a thinking aloud test. *International Journal of Human Computer Interaction, 41,* 385–397.

Patton, M.Q. (2002). *Qualitative Research and Evaluation Methods* (3rd ed.). London: Sage.

Peters, K.A., Green, T.F., & Schumacher, R.M. (2009). Improving the User Interface and Adoption of Online Personal Health Records. *Human Factors and Ergonomics Society Annual Meeting Proceedings, 53*(11), 704-8.

Pratt, W., Unruh, K.T., Civan, A., Skeels, M.M. (2006). Personal health information management. *Communications of the ACM, 49*(1), 51-5.

Pyper, C., Amery, J., Watson, M., Crook, C. (2004). Patients' experiences when accessing their on-line electronic patient records in primary care. *British Journal of General Practice 54*, 38-43.

Quill, T.E., & Brody, H. (1996). Physician recommendations and patient autonomy: finding a balance between physician power and patient choice. *Annals of Internal Medicine 125,* 763-9.

Ralston, J.D., Carrell, D., & Moran, M. (2006). Use and satisfaction of a patient Web portal with a shared medical record between patients and providers. *AMIA Annual Symposium Proceedings, 1070.*

Ralston, J.D., Carrell, D., Reid, R., Anderson, M., Moran, M., Hereford, J. (2007). Patient web services integrated with a shared medical record: patient use and satisfaction. *Journal of the American Medical Informatics Association: JAMIA, 14*(6), 798-806.

Ralston, J.D., Hirsch, I.B., Hoath, J., Mullen, M., Cheadle, A., Goldberg, H.I. (2009). Web-based collaborative care for type 2 diabetes: a pilot randomized trial. *Diabetes Care, 32*(2), 234-9.

Ralston, J.D., Revere, D., Robins, L.S., Goldberg, H.I. (2004). Patients' experience with a diabetes support programme based on an interactive electronic medical record: qualitative study. *BMJ, 328*(7449), 1159-62. doi: 10.1136/bmj.328.7449.1159.

Redhead, C.S. (2009). The Health Information Technology for Economic and Clinical Health (HITECH) Act. Retrieved from www.policyarchive.org/handle/10207/bitstreams/19401.pdf.

Reichert, D. (2007). Reichert Introduces Personal Health Record Bill: Healthcare groups trumpet their support and Microsoft leads the implementation effort.

Rogers, E.M. (2003). *Diffusion of Innovation* (5th ed.) New York: Free Press.

Ross, S.E., Moore, L.A., Earnest, M.A., Wittevrongel, L., Lin, C.T. (2004). Providing a web-based online medical record with electronic communication capabilities to patients with congestive heart failure: randomized trial. *Journal of Medical Internet Research, 6*(2), e12.

Roter, D.A., Stashefsky-Margalit, R., & Rudd, R. (2001). Current perspectives on patient education in the US. *Patient Education and Counseling, 44*, 79–86.

Samoocha D., Snels I.A., Bruinvels D.J., Anema J.R., van der Beek A.J. (2011). Effectiveness of an Interactive Website Aimed at Empowerment of Disability Benefit Claimants: Results of a Pragmatic Randomized Controlled Trial. *Journal of Occupational Rehabilitation,* (in press).

Sands, D.Z., & Halamka, J.D. (2004). PatientSite: Patient-Centered Communication, Services, and Access to Information. In R. Nelson & M. J. Ball (Eds.), *Consumer Informatics: Applications and Strategies in Cyber Health Care* (1st ed.) New York: Springer.

Shintrom, S.E. (2010). *The use of a personal health record to support self management of chronic illness: a survey of an elderly underserved population* (Master's thesis). University of Washington, Seattle, Washington.

Smart Personal Health: New European Effort to Promote Personal Tools for Health and Wellness. (2011). Retrieved from sph.continuaalliance.org/resources.html.

Spil, T. (2006). E-Health Systems Diffusion and Use: The Innovation, the User and the Use It Model. Hershey: Idea Group Publishing.

Sprague, L. (2004). Electronic Health Records: How Close? How Far to Go? National Health Policy Forum Issue Brief, 29, 800.

Stolyar, A., Lober, W.B., Drozd, D.R., Sibley, J. (2005). Feasibility of Data Exchange with a Patient-centered Health Record. *AMIA Annual Symposium Proceedings,* 1123.

Stolyar, A., Lober, W.B., Drozd, D.R., Sibley, J. (2006). A Patient-centered Health Record in a Demonstration Regional Health Information Network. Paper presented at the annual meeting of the Ist Annual Distributed Diagnosis and Home Healthcare (D2H2) Conference, Arlington, VA.

Strauss, A., & Corbin, J. (2005). *Basics of Qualitative Research: Techniques and Procedures for Developing Grounded Theory* (2nd ed.). Thousand Oaks: Sage.

Sun, K. (2001). Development of a Model and Comparison of Personal Health Record and Related Health Sites. Retrieved from www.informatics-review.com/thoughts/ksun.html.

Szasz, T.S., & Hollender, M.H. (1956). A contribution to the philosophy of medicine; the basic models of the doctor-patient relationship. *American Medical Association Archives of Internal Medicine 97*(5), 585-92.

Tailor, H. (2004). Two in five adults keep personal or family health records and almost everybody thinks this is a good idea: Electronic health records likely to grow rapidly. *Health Care News, 4*(13).

Talbot, D. (2011). How a Broken Medical System Killed Google Health. Retrieved from www.technologyreview.com/web/37935/?a=f.

Tang, P.C., Ash, J.S., Bates, D.W., Overhage J.M., Sands, D.Z. (2006). Personal Health Records: Definitions, Benefits, and Strategies for Overcoming Barriers to Adoption. *Journal of the American Medical Informatics Association: JAMIA, 13*(2), 121-6.

Tang, P.C., & Lansky, D. (2005). The missing link: bridging the patient-provider health information gap. *Health Affairs, 24*, 290 –1295.

Tang, P.C., & Newcomb, C., (1998). Informing patients: a guide for providing patient health information. *Journal of the American Medical Informatics Association: JAMIA, 5*(6), 563-70.

Thompson, T., & Brailer, D.J. (2004). The Decade of Health Information Technology: Delivering Consumer-centric and Information-rich Health Care: Framework for Strategic Action. Retrieved from www.hhs.gov/healthit.

Tobacman, J.K., Kissinger, P., Wells, M., Prokuski, J., Hoyer, M., McPherson, P., Wheeler, J., Kron-Chalupa, J., Parsons, C., Weller, P., Zimmerman, B. (2004). Implementation of personal health records by case managers in a VAMC general medicine clinic. *Patient Education and Counseling, 54*(1), 27–33.

Tran, D.T., Zhang, S., Lober, W.B., Stolyar, A. (2005). Patient - centered Design for a Personal Health Record System. *AMIA Annual Symposium Proceedings*, 1140.

Truffer, C.J., Keenan, S., Smith, S., Cylus, J., Sisko, A., Poisal, J.A., Lizonitz J., Clemens, M.J. (2010). Health spending projections through 2019: the recession's impact continues. *Health Affairs, 29*, 522–9.

Venkatesh, V., & Davis, F.D. (2000). A Theoretical Extension of the Technology Acceptance Model: Four Longitudinal Field Studies. *Management Science, 46*(2), 186-204.

Venkatesh, V., Morris, M. G., Davis, G.B., Davis, F. D. (2003). User Acceptance of Information Technology: Toward a Unified View. *MIS Quarterly, 27*(3), 425-478.

Vincent, A., Kaelber, D.C., Pan, E., Shah, S., Johnston, D., Blackford M. (2008). A Patient-Centric Taxonomy for Personal Health Records (PHRs). *Journal of the American Medical Informatics Association: JAMIA*, 763-767.

Wald, J.S., Middleton, B., Bloom, A., Walmsley, D., Gleason, M., Nelson, E., Li, Q., Epstein, M., Volk, L., Bates, D.W. (2004). A patient-controlled journal for an electronic medical record: issues and challenges. *Studies in Health Technology and Informatics, 107*(Pt 2), 1166–70.

Wang, M., Lau, C., Matsen, F.A., Kim, Y. (2004). Personal Health Information Management System and its Application in Referral Management. *IEEE Transactions on Information Technology in Biomedicine, 8*(3), 287-97.

Ward, L., & Innes, M. (2003). Electronic medical summaries in general practice — considering the patient's contribution. *British Journal of General Practice 53*, 293-7.

WebMD PHR. (2011). WebMD Personal Health Record. Retrieved from www.webmd.com/phr.

Weingart, S.N., Rind, D.,Tofias, Z., Sands, D.Z. (2006). Who uses the patient internet portal? The PatientSite experience. *Journal of the American Medical Informatics Association: JAMIA, 13*(1), 91-5.

Weitzman, E.R., Kaci, L., & Mandl, K.D. (2009). Acceptability of a Personally Controlled Health Record in a Community-Based Setting: Implications for Policy and Design. *Journal of Medical Internet Research, 11*(2), e14. doi:10.2196/jmir.1187.

Wilson E.V., & Lankton N.K. (2004). Modeling Patients' Acceptance of Provider-delivered E-health. *Journal of the American Medical Informatics Association: JAMIA, 11*(4), 241-8.

Woolf S.H., Chan E.C., Harris R., Sheridan S.L., Braddock C.H., Kaplan R.M., Krist A., O'Connor A.M., Tunis S. (2005). Promoting informed choice: transforming health care to dispense knowledge for decision making. *Annals of Internal Medicine, 143*(4), 293-300.

Wright, A., Poon, E.G., Wald, J., Feblowitz, J., Pang, J.E., Schniper, J.L., Grant, R.W., Gandhi, T.K., Volk, L.A., Bloom, A., Williams, D.H., Gardner, K., Epstein, M., Nelson, L., Businger, A., Li, Q., Bates, D.W., Middleton, B. (2011). Randomized Controlled Trial of Health Maintenance Reminders Provided Directly to Patients Through and Electronic PHR. *Journal of General Internal Medicine,* (in press). doi: 10.1007/s11606-011-1859-6.

Yamin C.K., Emani S., Williams D.H., Lipsitz S.R., Karson A.S., Wald J.S., Bates D.W. (2011). The digital divide in adoption and use of a personal health record. *Archives of Internal Medicine, 171*(6), 568-74.

Appendix A: Resident Interview Introduction and Demographic Interview Script

Subject #: ___________

Date: ___________

Good morning (afternoon),

My name is Anna Stolyar. I am a graduate student in Biomedical and Health Informatics at the University of Washington.

I am working on a research project that explores what people think about personal health records and how they use personal health records. I will use the information to search for solutions to help people organize and manage their health information. The information you give me will be kept private. The information will not be used for any purposes other than those related to this study.

Today we will be covering three areas. The first one will gather background information. The second one will focus on what you think E-Medicine and Personal Health Records are about. And the third will ask questions about what you why you use or don't use E-Medicine, and how you use the E-Medicine system if you use it.

In order to proceed, you will need to sign a consent form stating your agreement to participate in the interview. Please review the consent form carefully and ask any questions you may have. After reviewing the form you may sign your name indicating your consent.

0.5 Have you used PHIMS, the E-Medicine system? How often?
____ Never
____ Once
____ More than once

1. Which ethnic or cultural group do you most identify with? (Interviewer will present card)
____ White
____ African American or Black
____ Latino
____ Asian

____ American Indian or Alaska Native
____ Pacific Islander
____ International (Please identify :____________)
____ Other ______________

2. Interviewee's Gender: Male Female

3. Please list the ages and respective genders of all the people currently living at home. (Interviewer will present card)

Age	Number	Gender
0-6		
7-18		
19-25		
26-64		
65-84		
85+		

4. In general, would you say your health is: (Interviewer will present card.)

___ Excellent
___ Very Good
___ Good
___ Fair
___ Poor

5. What is your view of your family's health? (Interviewer will present card.)

___ Excellent
___ Very Good
___ Good
___ Fair
___ Poor

6. In general, does your household have sufficient income to meet your needs?

___ Yes
___ No

7. How involved are you with managing the health information at home? Please check one. (Interviewer will present card.)

    ____ I manage all of the health information at home.
    ____ I manage most of the health information at home and share some of the responsibility.
    ____ I manage some of the health information at home and share most of the responsibility.

Appendix B: Resident Interview Guide

In general how would you say you health is, excellent, very good, good, fair or poor? What is your view of your family's health, excellent, very good, good, fair or poor?
Have you heard about the Personal Health Information Management Systems (PHIMS) or the E-Medicine project? Could you tell me what do you know about the E-Medicine system? Do you know what a personal health record it? Can you describe what it is?
What kinds of things do you think you can do with a PHR? What kind of functionality do you think a PHR has?
Why did you choose not to sign up to use E-Medicine?
Why did you originally sign up to use E-Medicine? What did you expect E-Medicine to be like? What did you expect you would do when you signed up for the project? Now that you've used E-Medicine, how did it meet or not meet your expectations?
How many times do you think you have used E-Medicine? How often have you updated your E-Medicine record? Why do you think you have only used E-Medicine once? Why have you used E-Medicine more than once? How do you decide when to update your E-Medicine record?
What about E-Medicine do you like? What about E-Medicine don't you like?

What about E-Medicine is particularly useful? What about E-Medicine is particularly frustrating?
Looking at the categories of information you can store in E-Medicine, which categories are particularly useful to you? Which are not very useful? Which categories do you update most often? Why?
Is there anything about the E-Medicine system you would change? Is there anything you would like the E-Medicine system to do that it does not do?
If you do not use E-Medicine, how do you keep track of your health information and medical appointments? Does anyone help you keep track of your health information? If yes, how? If you do use E-Medicine, do you keep some types of health information outside the E-Medicine system?
Is there any thing else you would like to tell me about how you use E-Medicine?

Appendix C: Resident Interview and Observation Guide for the Second (Repeated) Interview

I want to find out more about how you use E-Medicine.
Can you show me how you usually use E-Medicine? Which categories of information do you usually update? Can you show me which fields you usually fill out for each category of information (each page in E-Medicine)?
Can you remember last time you used E-Medicine? Why did you use it that time? What lead you to decide to use it? Can you show me what you did? What types of information (which fields) you updated last time you used E-Medicine?
Can you tell me more about why you did that (a particular use of E-Medicine)? Can you tell me more about which fields in E-Medicine you think are the most important?
What do you think about the information you can keep on this page in E-Medicine? What do you about the general organization of information in E-Medicine?
Participants have told me that they use E-Medicine to do "…..". Do you ever use E-Medicine to do that?
Is there anything you wish E-Medicine would do that it doesn't do? Is there anything you would fix or improve in the E-Medicine system? Is there anything you want to do that E-Medicine does not do?
Is there any thing else you would like to tell me about how you use E-Medicine?

Appendix D: Health Care Professional Interview Guide

What is your perception of why some residents choose to use or not use the E-Medicine system? What reasons have you heard from residents about why they use or do not use it?
Why do you think some residents use the system once and do not use it again? Why do you think some residents choose to use E-Medicine often or more than once?
Residents have told me that "…this…" is one reason they use/do not use E-Medicine. Have you heard this reason before? What do you think about this reason? Can you think of why residents would think "…this…" is a particularly good feature? Can you think of why residents think "…this…" is a barrier to using the system? Can you think of a way to overcome this barrier to help residents use E-Medicine?
Do you think consumers outside the Everett Housing Authority would have similar perceptions of a system like E-Medicine? Why or why not? Do you thing they would have dissimilar or similar reasons for using or not using a PHR system? Why or why not?
Is there anything else you'd like to tell me about how residents use E-Medicine? Is there anything else you'd like to tell me about why and how residents chose to use or not use the E-Medicine system?

Appendix E: Sample Resident Interview

SO THEN, YOU MAINLY SIGNED UP FOR E-MEDICINE SO THAT YOU, UM, WOULD HAVE TO REMEMBER ALL THE INFORMATION, SO YOU WOULDN'T HAVE TO RELY ON YOUR MEMORY?[22]

Yeah, because my memory gets worse every day, it's like, it just goes, [whistles], and the most frustrating thing is that I, I'm trying to say something and I know what I want to say but the words will not come to my head. And it's like very frustrating, and then I am standing there like an idiot, quiet, trying to think of what I'm saying, and everybody is like, well, spit it out, spit it out.

SO WHEN YOU SIGNED UP FOR E-MEDICINE, WHAT DID YOU EXPECT IT TO BE LIKE?

Exactly what it is.

OK. UM, SO CAN YOU JUST TELL ME A LITTLE BIT ABOUT, WHAT…

Ok, what did I expect, let's see. Well, I expected it to be something that could be put on a computer disk or something, which I don't have it on a disk, but I do have it on a, like to get it on a disk, so that I can just, update it wherever, but… Um, just, I thought it would be something that would make it easier for me to function, to communicate with others and in times of, of I say, mental flatulence, why it just goes, you know. And when it goes, it's embarrassing, so I don't have to worry about times like that. And the older you get the more forgetful you get, and, um, you know, the more you collect, because you don't remember picking this up here, and coming in the house, where'd that…, just like those silly cards. I don't know, I don't even know where I am coming from! [both giggle]. And I am a pack rat, so, [laughs]. Ok.

OK.

That's pretty much what I figured it would be.

OK. SO WAS IT, UM, WAS IT WHAT YOU EXPECTED?

Yes, very much so, I was very pleased.

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[22] In the interview transcripts participant's words are typed in sentence case and interviewer's words are typed in all capitals for ease of reading and coding.

OK, AND UM, YOU KNOW, NOW THAT YOU HAVE USED E-MEDICINE, UM, I MEAN SORT OF, DID YOU, WAS THERE ANYTHING THAT SURPRISED YOU?

I have taken computer classes when I went to college, and I still don't know diddly about a computer, because I can't remember what I learned in class. So, um, when I had, as long as I have someone sitting next to me, instructing me again on how to get on the computer, what to do, how to bring the thing, I can never remember, my, draw up number, your identifying thing that you have to have in order to raise your computer thing. Oh, I can't even think of the name of it... What...? Your ID number, I guess is what it is.

YOU USER NAME?

Yes, I can never remember that. I can't remember, um, what I use as the secret word, or whatever that they say, um, I have to have, or I did have on record in the office, until the lady quit, um, all of that information there, so that when I went in there they'd have it on a card, and say this is your information, your user information, how to get..., you can get on the computer, and it was just for my use, but it was there.

OK.

So that as..., my mind doesn't remember, it just, it's there for me step by step by step, in order to get into the computer, and I think, think that should be important for anyone who uses that, for an option for a person to have, like when they come in to the, to, um, where the computer is, to say, hey I am going to need my cheat card, let's call it that, so that I can get into this function, because right now, and then, I couldn't even enter into it.

OK.

And if, if a computer doesn't have Word on it, a word program on it, I'm just stuck. And if I am going from one computer to another, like Apple, I know nothing about Apple computers, nothing, they got new Apple computer up there, and I sat down in front of that thing, I couldn't even get it turned on, let alone anything else. So, without someone there to guide me, even though I might have gone through it a thousand times before, I still need that person here, to help me get in, and when I would go to the computer, in order to type up my book and all that kind of stuff, I had to have my cheat card there, step by step, how to do this thing. And, because I have severe learning, you know things, I don't remember what I read, and that's been a lifetime struggle, so I have to have all these little, I call them cheat cards, in order to function normally through the day, so that's, it's just little suggestions for your program, to maybe help other people in my condition, to be able to function.

UH-HUH. SO HAVE YOU EVER USED THE E-MEDICINE SYSTEM ON YOUR OWN?

No.

NO.

I've always had someone else help me.

OK, AND SO YOU'VE GONE DOWN TO SEE THE NURSING STUDENTS WHO COME?

Yes, those that, when they are there, and only when they are there.

UH-HUH.

Because I can't remember how to get on.

OK, AND SO, YOU KNOW, THE SECOND TIME THAT YOU USED E-MEDICINE, DO YOU REMEMBER WHY YOU DECIDED TO COME IN FOR THE SECOND TIME?

To, to update, to update some of the things on the file.

WAS IT BECAUSE PARTICULAR THINGS HAD CHANGED?

Yes.

OK, AND THEN WHAT DID YOU, SO I KNOW THEY USUALLY GIVE YOU A BRAND NEW PRINT OUT OF EVERYTHING WHAT YOU ARE DONE...

Well, they couldn't, they had to go to another computer, because the printer wasn't working, and we had to go around the barnway, in order to get me a print out, but generally I do get a print out.

OK.

Yeah.

SO YOU DID GET A NEW ONE?

Yeah, I did, yeah.

SO WHAT DID YOU DO WITH THAT PRINT OUT?

I stuck it on the door over my cabinet so I'd know where it is. So that I wouldn't lose it.

OK, AND IS IT STILL THERE?

It's still there.

UM, DO YOU KEEP ANYTHING ELSE THERE, IN TERMS OF HEALTH INFORMATION?

Um, I keep my contact numbers, um, my, my allergies, and things that would be needed immediately should something, should I be um, carried out of there on a stretcher and not able to talk, all the information that they would need would be there on the slip, and um, that could possibly save my life, you know, if I am allergic to something, then they can't give me that.

RIGHT, RIGHT.

And it's a help.

Appendix F: Sample Second Time Resident Interview

HAVE YOU GOTTEN A PNEUMONIA VACCINE?

Yeah, I don't remember what year I did it. Ah, it doesn't say.

NO, CAUSE YOU HAVE TO PUT THAT IN IF YOU KNOW.

It was two or three years ago, I'm not sure, but I do have it.

AND DO YOU HAVE TETANUS, HAVE YOU GOTTEN A TETANUS SHOT?

No, probably not.

ALRIGHT.

Anything else?

I DON'T KNOW, WHAT DO YOU USUALLY DO. I AM WONDERING WHAT YOU USUALLY DO?

Just what I've done.

JUST WHATEVER HAS CHANGED?

Yeah. I am seeing double.

THIS IS THE ALLERGIES.

Uh-huh, um… what is that, penicillin?

IT SAYS PCN, IS THAT PENICILLIN?

Penicillin and aspirin, those are my allergies.

OK, HOW COME THEY, YOU'RE USING ACRONYMS?

The nurse gave me those, the acronyms.

I DIDN'T KNOW THAT WAS THE ACRONYM FOR ASPIRIN, ASA.

I couldn't spell them, so they gave me those.

IS THERE ANYTHING ELSE, YOUR HEALTH PROBLEMS DON'T CHANGE VERY OFTEN?

No, just the two. Alright, is well with my eyes, well I don't think I need to put that in there.

RIGHT, RIGHT, IT'S, NOT NECESSARILY, NOT REALLY A HEALTH PROBLEM.

No. [laughs]

YOUR EYES ARE NOT A HEALTH PROBLEM.

I just can't see.

YEAH.

Now, I can sit over there and I can read that real good, it's totally clear.

AFTER YOUR SURGERY?

But this is very fuzzy, where it was the reverse before I had my surgery.

DO YOU KNOW, IS THAT SUPPOSED TO GET BETTER OVER TIME.

Yeah, I'll just get a new pair of glasses. They told me absolutely not to wear those, because one eye's normal and the other one is for nearsightedness. And that's why I was getting my headaches, that's why I went ahead and got this done.

OK, OK, THAT'S INTERESTING. UM, OK, LET ME SEE IF I CAN… UM, SO DO YOU FEEL LIKE, THAT, BASICALLY, YOU CAN KEEP ALL YOUR HEALTH INFORMATION IN THIS SYSTEM? OR DO YOU MAYBE SOMETIMES FEEL LIKE THERE IS SOMETHING YOU CAN'T DO?

If I remember how to do it, it's very good. Cause, I can't remember everything.

AND DO YOU USUALLY GO THROUGH AND SEE IF YOU CAN ADD THINGS, OR DO YOU ONLY… OR, YOU KNOW, CAUSE THIS ASKS YOU FOR A BUNCH OF INFORMATION THAT YOU USUALLY MIGHT NOT THINK OF PUTTING IN.

Yeah.

SO DO YOU TRY TO GO THROUGH AND SEE IF THERE IS ANYTHING ELSE YOU CAN PUT IN?

Oh, when I bring it up, I go there, go through it, kind of like I did today. Something goes to my eye, I go there and take care of it.

RIGHT, SO IT SOUNDS LIKE, WHEN YOU WENT IN TODAY YOU WENT STRAIGHT TO SURGERIES AND YOU UPDATED THAT, SO WOULD YOU USUALLY THEN LOG OUT OR WOULD YOU USUALLY…?

Well, I'll check, see if there is anything else that needs changing. I try to get it all done at once, then I don't have to keep going back.

OK, ALRIGHT. SO, YOU KNOW, I ASKED YOU THIS QUESTION BEFORE ACTUALLY, BUT NOW THAT YOU'RE LOOKING AT THIS. IS THERE ANYTHING ABOUT IT THAT YOU LIKE PARTICULARLY WELL, OR THAT YOU DON'T LIKE?

Well, it just keeps me [straight] on track, keeps my mind on what I am doing.

AND THEN OTHER THEN, YOU SAID YOU PRINT A COPY FOR YOUR DOCTOR AND TAKE IT IN, SOMETIMES TAKE IT IN FOR YOUR VISITS, DO YOU DO ANYTHING ELSE WITH THE INFORMATION THAT YOU HAVE IN HERE?

No, I don't feel that I need to. But in my head, to get something for some other purpose I would get that.

SO MOSTLY, YOU JUST PUT EVERYTHING IN HERE AND THEN YOU TAKE IT TO YOUR DOCTOR TO KEEP THEM UPDATED ABOUT WHAT'S GOING ON?

Uh-huh.

OK, SO, BUT DO YOU FEEL LIKE IT HELPS YOU ALSO NOW, KIND OF, WITH WHAT'S GOING ON, OR…?

Yeah, it keeps me on target with what I am doing. It keeps me, well, instead of forgetting what's been done, it keeps me reminded. I try to do it right away, after it's…, like my surgery Wednesday, I would have put it in probably Thursday if I could have seen. But since I can see enough to do it now…

OK, AND IS THAT, USUALLY, YOU UPDATE IT AFTER YOU COME BACK FROM YOUR DOCTOR, RIGHT AWAY?

I try to remember to. Within a few days, you know.

CAUSE I NOTICED… YOU HADN'T PUT IN THAT LABORATORY TEST EVEN THOUGH IT WAS DONE IN OCTOBER.

Yeah, I hadn't checked that for… Well, if I had gotten a paper copy of the test I probably would have used that to update it.

AND DO YOU USUALLY GET A PAPER COPY?

I usually have to ask for it, but I didn't this time.

OK, AND IS THAT SOMETHING YOU USUALLY REMEMBER, BUT YOU JUST DIDN'T THIS TIME?

Yeah.

YEAH, EVERY DOCTOR'S DIFFERENT; SOME WILL ALWAYS DO IT AND SOME WILL NEVER DO IT.

Yeah, when they give you about 5 minutes in the office… Well, he gives us longer then that. But, you have to have point blank questions for him, and they just go through that and they don't branch out on the other stuff.

AND DO YOU, DO YOU USUALLY GET, SO I NOTICED RIGHT NOW, YOU SAID, HE JUST SAID THAT YOUR HEMOGLOBIN VALUE WAS GOOD, BUT DOES HE USUALLY TELL YOU THE VALUE IS TOO?

Yeah, uh-huh, because we compare it with the time before.

OH, GOOD. AND DOES HE HAVE ALL THE PAST ONES TOO?

Oh, yeah, it's in my file, in my chart, they call it.

Appendix G: Excerpt from a Nursing Student Interview

OK, SO ACTUALLY MY FIRST QUESTION IS, SINCE YOU'RE BEEN INTERACTING WITH RESIDENTS AT THE HOUSING AUTHORITY, DO YOU HAVE A PERCEPTION OR FEELING FOR WHY PEOPLE CHOOSE TO USE E-MEDICINE?

I think that they are concerned about their health, um, you know a lot of them have multiple doctors and a lot of medications. And, um, I think it's just because they are concerned about their health, you know, they sometimes have a lot, they have a lot of chronic health problems, and they know it, I mean, you know…

YEAH.

So I would say the main thing is the chronic diseases.

OK, AND WHAT IS IT, I MEAN, WHAT'S SORT OF THE BENEFIT TO THE PEOPLE WHO ARE USING IT… I MEAN…

Um, they can update their medications, which is probably a really, an important thing, and that's usually what they seem to update is medications, not so much with the diagnosis because it usually, it's mainly the medications.

OK, SO YOU THINK MAYBE IT'S HELPING PEOPLE SOMEHOW EITHER KEEP TRACK OF OR UNDERSTAND THEIR MEDICATIONS BETTER?

Um…

OR ARE THEY USING THAT PHYSICAL LIST FOR SOMETHING, I MEAN WHAT'S SORT OF THE DIRECT BENEFIT?

Yeah, they take the, I think the physical list helps when they take it to the doctor, and I think that's what the doctor appreciates because after working in a doctors office, um… sometimes people get a little bit confused about their medications, you know they are not sure if they, if they are given a new medications if they are supposed to stop… and I've had lots of patients who were given a medication and didn't realize they were supposed to… or, I am sure they were instructed, stop this medication, but the message didn't get through.

UH-HUH.

I did run into one person who was not taking a medication… what was the deal? He wasn't taking it, he had been given… it was a new medication and he hadn't been taking it, and so I had to explain to him that, it was like Digoxin or something, you know really kind of… but um… so what was the original question [LAUGHS]?

SO WHAT ARE SOME REASONS THAT YOU'VE SEEN FOR WHY PEOPLE ARE CHOOSING TO USE THE E-MEDICINE AND THE PERSONAL HEALTH RECORD?

I think so that they can take it to another doctor and they can see the medication list and they can see their history, instead of… and also the demographics too, so instead of if they go to a specialist which a lot of them do, they don't have to repeat all the things over again, and I've heard that a lot.

YEAH, I HAVE TOO.

And also emergency room visits, because they get, you know, quite a few 911 calls there, and there is already in the apartment some kind of list, they put it on the inside of their kitchen cupboard. I've personally never seen it, but I think it's not very detailed, and so lots of them will put this there in case, you know, they do get called to, you know, a 911 call. Because I had one lady complain that she hadn't taken it with her to the emergency room, and you know, she said, oh they had to ask me all the same questions over again, which is true, you know?

UH-HUH, RIGHT.

Are you there?

YEAH, I AM.

Oh, ok.

I THINK MAYBE BECAUSE I'M ON SPEAKER PHONE, WHEN YOU'RE SPEAKING YOU PROBABLY CAN'T HEAR ME, IT'S A SPEAKER PHONE THING.

I want to make sure to give you time to write things down.

WELL, ACTUALLY I'M RECORDING IT SO DON'T WORRY, JUST…

Oh, ok… I'll have to be a little more logical then.

NO, THAT'S TOTALLY FINE, YOU'RE MAKING COMPLETE SENSE WHICH IS GOOD, MORE THEN I CAN SAY FOR SOME PEOPLE I'VE INTERVIEWED.

Yeah, they probably have a little dementia though.

YEAH, JUST A LITTLE BIT.

They can be difficult.

SOME HAVE BEEN VERY DIFFICULT TO SPEAK TO.

Oh, really?

OH, YEAH, JUST BECAUSE THEY ARE NOT QUITE, I MEAN A LOT OF THEM AREN'T SURE ABOUT WHY THEY ARE DOING SOMETHING OR WHY THEY ARE NOT DOING SOMETHING BECAUSE THEY HAVEN'T THOUGHT ABOUT IT…

Right, and they don't probably update it often enough, you know, cause there is… they can't do it themselves.

RIGHT, RIGHT.

So… but there are a few people who do come to get it updated when they have new medications, there are a few that do that.

YEAH, AND I'VE SPOKEN TO A FEW WHO ALSO DO IT ON THEIR OWN.

Yes.

AND YOU KNOW, ARE, AND I'VE SPOKEN TO AT LEAST A COUPLE OF PEOPLE WHO SAID, YOU KNOW AT FIRST I WENT AND SAW THE NURSES, AND THEN I KIND OF SAW WHAT IT WAS LIKE AND THEN I JUST DECIDED THAT IT WAS EASY ENOUGH TO USE ON MY OWN.

And a few of the people have done it for all the reasons that I have already said, and to give to a family member also, like a daughter or something who is their emergency contact. So I have had a few people say that.

Appendix H: Excerpt from a Social Worker Interview

OK. ALRIGHT, AND HAVE YOU HAD RESIDENTS TELL YOU WHAT SOME OF THEIR REASONS HAVE BEEN FOR DECIDING TO USE IT OR NOT USE IT?

Yeah, most of them will say, because, you know, you were talking about it. We have gone to residents and said, here's your history, this might be a benefit to you, you might look into it. They trust us, that, and tried it and liked it. Then, it could be that another resident said, my doctor thought it was good, and they went ahead and did it. Um, or they, some people have just signed up, walked in right away when we first started doing it, because it just sounded like an interesting idea to them, they could see that that might be part of the way the future is going… you hear about it in the news, and president wanted it a few years ago, talked about having personal health records for everybody, some think that Group Health is doing it, the idea is out there and I think that it just appeals to some people.

UH-HUH, OK, YEAH. UM, SO ONE OF THE REASONS PEOPLE KEEP MENTIONING FOR WHY THEY USE THE E-MEDICINE RECORD IS TO SERVE AS A MEMORY AID TO THEM. AND IT'S ACTUALLY, I THINK IT'S BOTH TO HELP THEM REMEMBER WHAT'S GOING ON WITH THEIR HEALTH AND ALSO TO FILL OUT FORMS AND GIVE INFORMATION TO THE DOCTOR.

Um, and another reason would be, sometimes they want their children to have that. And I forgot that we also have an emergency sheet in everybody's apartment, that the fire department and emergency personnel can ask, can, can access, but these are better, they have the fib sheet the personal health record sheet, it's actually better, it's got more information on it. So that is again another reason that some people are doing it. Say, somebody that's going to give me some sort of services, medical attention, this might be helpful to them.

UH-HUH. YEAH, I'VE HAD A LOT OF PEOPLE TELL ME THAT THEY, THEY MAKE A COUPLE OF PRINT OUTS AND THEY TAKE ONE TO THEIR DOCTOR, AND THEY STICK ONE IN THAT POCKET THAT YOU GUYS HAVE IN THE APARTMENT FOR THE EMERGENCY CONTACT SHEET.

Yeah, and then we encourage that, I think that's good. Any time that anybody comes in, a paramedic or a doctor, the more information the better to treat them, especially if they have a lot of different conditions. What we offer up is voluntary, that they can do, and it's got some helpful information on what they take, but it doesn't list their past histories, it doesn't say anything. And that information might be handy when somebody is found on the floor, not breathing, thrown in the ambulance. That might conceivably make a difference in their health care before they get the hospital, or even there.

UH-HUH, AND ON THE SHEET THAT YOU GUYS GIVE THEM, I THINK IT'S… I KNOW THAT PEOPLE HAVE SAID THAT MEDICATIONS ARE ON THERE, AND EMERGENCY CONTACTS…

Yeah, there's a place for medications, and emergency contacts and conditions.

YEAH, OK.

But it's, it's… compared to the fib sheet, it's like… it's a thumbnail sketch compared to something that's a lot more fleshed out, with that. So that's why, I tell people, if you want to do it, that's a benefit right there, you put it right up in your cupboard and people can have access to it. And sometimes because that has appealed to people who are not as healthy, they think somebody might really need access to their health records, and again then, you're right, there's a lot of people here like that.

YEAH, SO HAVE YOU HAD ANYBODY… THERE'S BEEN THIS IDEA THAT PEOPLE WANT… SO IF SOMEONE IS KEEPING THEIR MEDICAL HISTORY FOR THEIR DOCTOR AND IF THEY ARE KEEPING IT FOR THEMSELVES THEY ARE GOING TO DO IT DIFFERENTLY…

Well, that's probably true. I mean, this isn't the doctor's history, they already have their records, so this is a self-curated history, and so it might be prone to a different interpretation, maybe the severity of which they perceive what happened in the past is different then what actually happened. You know, it's their version of events. And yes, it could be, I haven't heard… I haven't though of them writing it for the doctor, but they could be writing it, if they thought someone else was going to read it, maybe a family member, maybe they would change it. Usually for the doctor, I don't think people… people know it needs to be as accurate as possible, if the doctor is gonna look at it… the doctor may look at it knowing that it's not written exactly for him and have to take it with a grain of salt when they look at it, but um… I don't think it's supposed to be the last word on their medical history. Someone gets out of the hospital, they come back, they have got some sort of nagging injury, they can write… they can come down, get it updated, and take it to their doctor. And that might be something that reminds them to talk about their condition, where is if you go to the doctor, you have five minutes to spill it all out, and if you forget anything, you've got to make another appointment to come back, you know… that's the way the world of medicine is here, right now, so, it's just another… It's just a tool, and I think, yeah, it could be not used in the right way.

UH-HUH. SO DO YOU THINK FOR E-MEDICINE, WHEN A RESIDENT FILLS IT OUT, DO YOU THINK MOST RESIDENTS SEE IT AS A TOOL TO HELP THEM,

OR DO YOU THINK MOST RESIDENTS SEE IT AS WAY OF GIVING INFORMATION TO THEIR DOCTOR, OR GIVING INFORMATION TO NEW DOCTORS? SO, IT'S LIKE, ARE THEY FILLING IT FOR THEMSELVES OR FOR THEIR DOCTOR?

I don't know. I mean, I think we… so, as, is always a benefit to themselves, so the doctor has a better idea of what they are doing, then that helps them out. I don't think it's ever written… it's, write down what it is that's going on with you to present to your doctor or the people that take care of you, I think that's how it's described.

So, to the best of my knowledge that is how they do it. If they think that, oh, somebody might read it that they don't want to, yeah, maybe they could change it, but they don't share that information. And, no one's ever said, I think I am gong to write it, so that when my doctor reads it, she doesn't know how bad things are. It could be, but I'm not aware of that. I think the way it's set up, it's supposed to be confidential, and you give it to the people that you want. So if someone wants it that you don't want to read it, then don't give it to them.

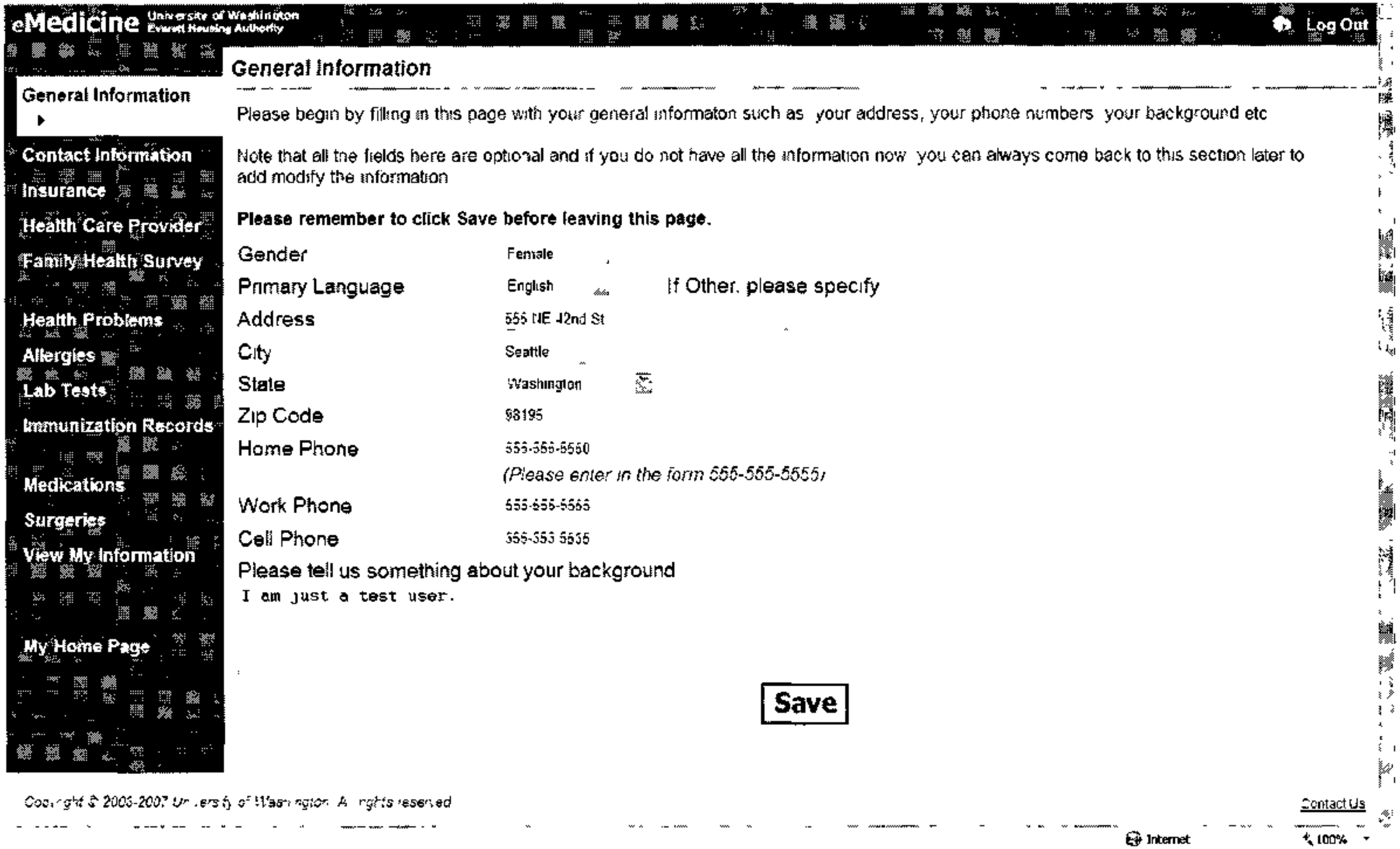
UH-HUH, YEAH, I THINK THAT SOME PEOPLE ARE EVEN WORRIED ABOUT HAVING IT IN THEIR APARTMENT AND HAVING SOMEBODY FIND IT ACCIDENTALLY.

Yeah.

AND THE AMOUNT OF INFORMATION THAT'S ON IT, YOU KNOW, IF YOU PUT EVERYTHING ON THERE, YOU KNOW THAT'S A LOT OF INFORMATION.

Yeah, that is a lot of information. But, it is locked up in their apartment, um, no body else has access to that but people in their apartment, I mean, the people [employees of the housing authority], certainly don't have access to it, they might give it to, open the apartment door, let the firemen take a look at, but they are responsible. I just don't think that somebody else would look at it. But you know, that… there is a potential risk then, if you have a piece of paper with your medical history on it, just as if you have you social security card in your apartment or any other document that's personal. Yeah. But people already have piles and piles of medical papers sitting there, and I think it helps people not wade through those slips of release forms from the hospital, if they had a condition the last month or two, but just get down and look at the nitty-gritty real quick.

Appendix I: E-Medicine Personal Health Record (PHR) System Screenshots[23]



General Information

Please begin by filling in this page with your general informaton such as your address, your phone numbers your background etc

Note that all the fields here are optional and if you do not have all the information now you can always come back to this section later to add modify the information

Please remember to click Save before leaving this page.

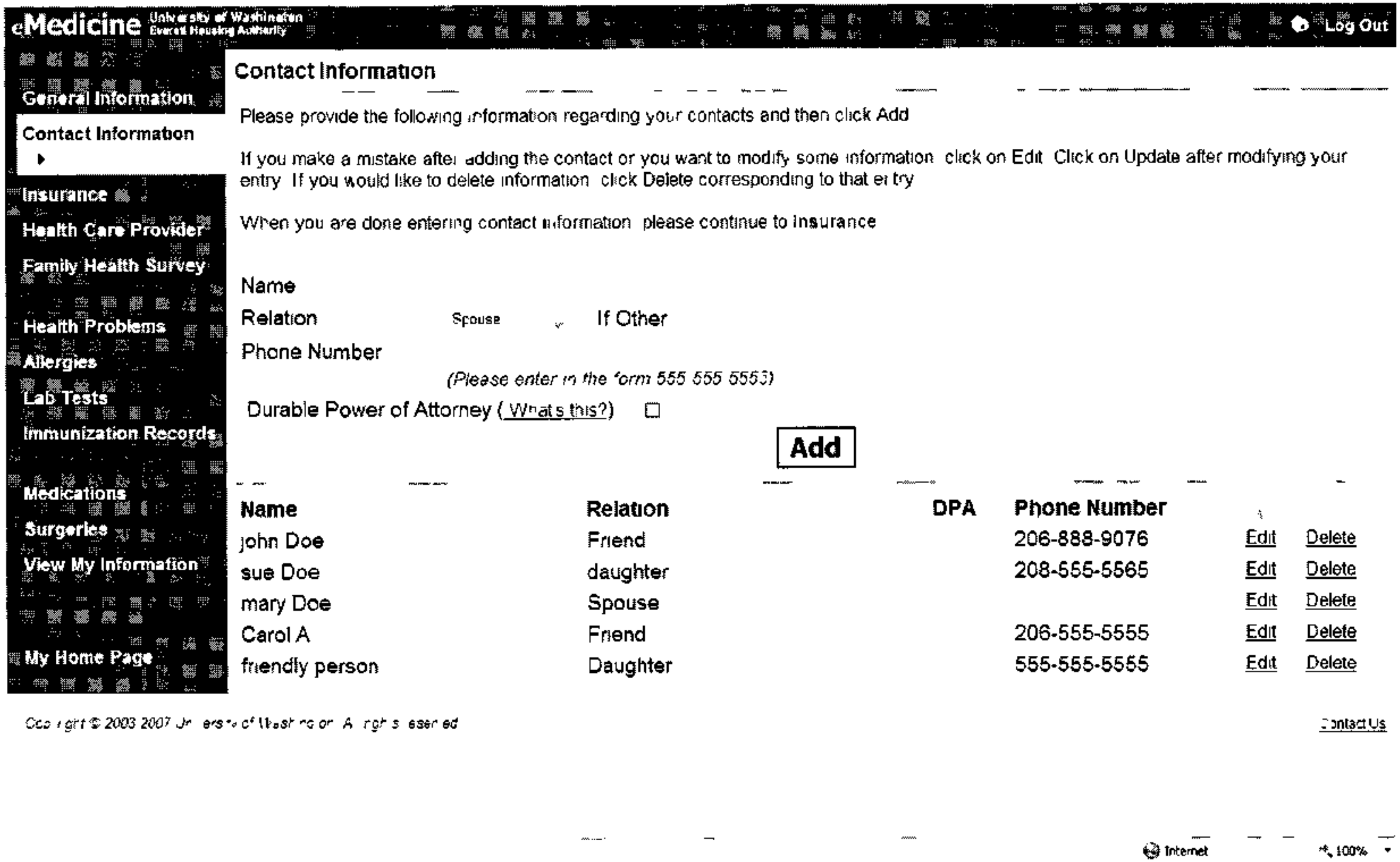
Gender	Female	
Primary Language	English	If Other, please specify
Address	555 NE 42nd St	
City	Seattle	
State	Washington	
Zip Code	98195	
Home Phone	555-555-5550 *(Please enter in the form 555-555-5555)*	
Work Phone	555-555-5555	
Cell Phone	555-553 5555	

Please tell us something about your background

I am just a test user.

---

[23] All screenshots contain sample data, not real information.



Contact Information

Please provide the following information regarding your contacts and then click Add

If you make a mistake after adding the contact or you want to modify some information click on Edit Click on Update after modifying your entry If you would like to delete information click Delete corresponding to that entry

When you are done entering contact information please continue to Insurance

Name

Relation Spouse If Other

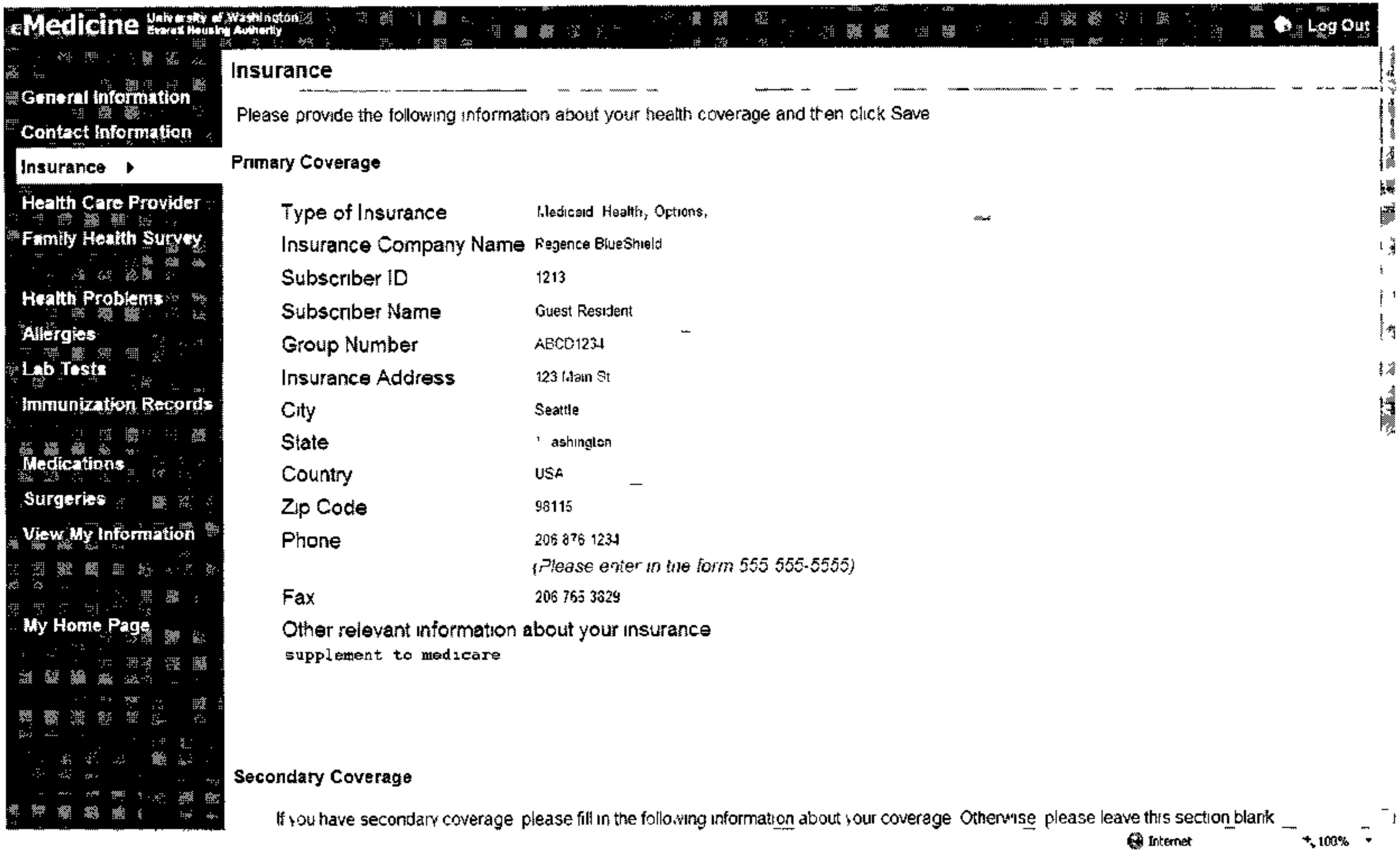
Phone Number

(Please enter in the form 555 555 5555)

Durable Power of Attorney (What's this?) ☐

Name	Relation	DPA	Phone Number		
john Doe	Friend		206-888-9076	Edit	Delete
sue Doe	daughter		208-555-5565	Edit	Delete
mary Doe	Spouse			Edit	Delete
Carol A	Friend		206-555-5555	Edit	Delete
friendly person	Daughter		555-555-5555	Edit	Delete

Contact Us



Insurance

Please provide the following information about your health coverage and then click Save

Primary Coverage

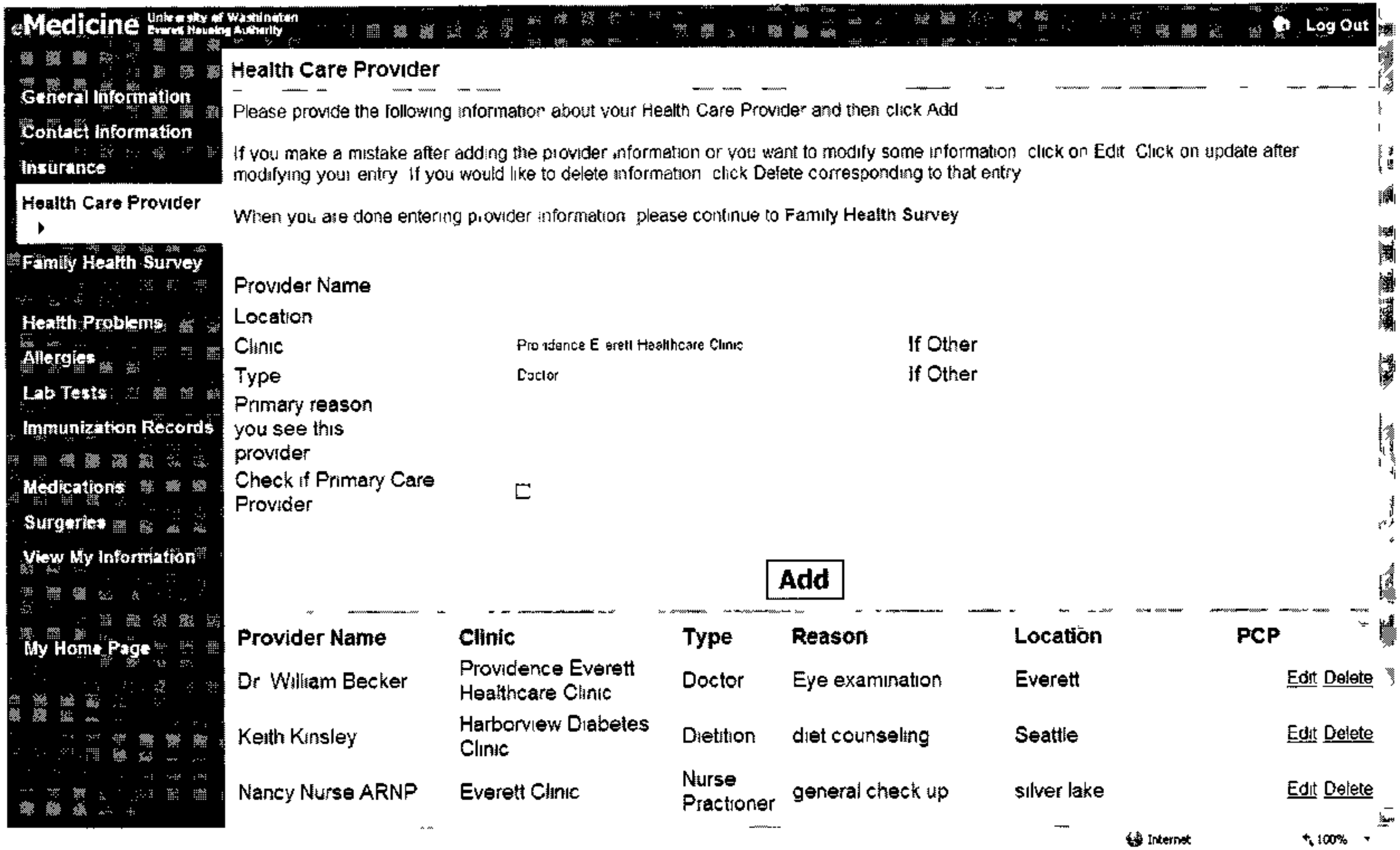
Type of Insurance	Medicaid Health, Options,
Insurance Company Name	Regence BlueShield
Subscriber ID	1213
Subscriber Name	Guest Resident
Group Number	ABCD1234
Insurance Address	123 Main St
City	Seattle
State	Washington
Country	USA
Zip Code	98115
Phone	206 876 1234 (Please enter in the form 555 555-5555)
Fax	206 765 3829

Other relevant information about your insurance

`supplement to medicare`

Secondary Coverage

If you have secondary coverage please fill in the following information about your coverage Otherwise please leave this section blank



Health Care Provider

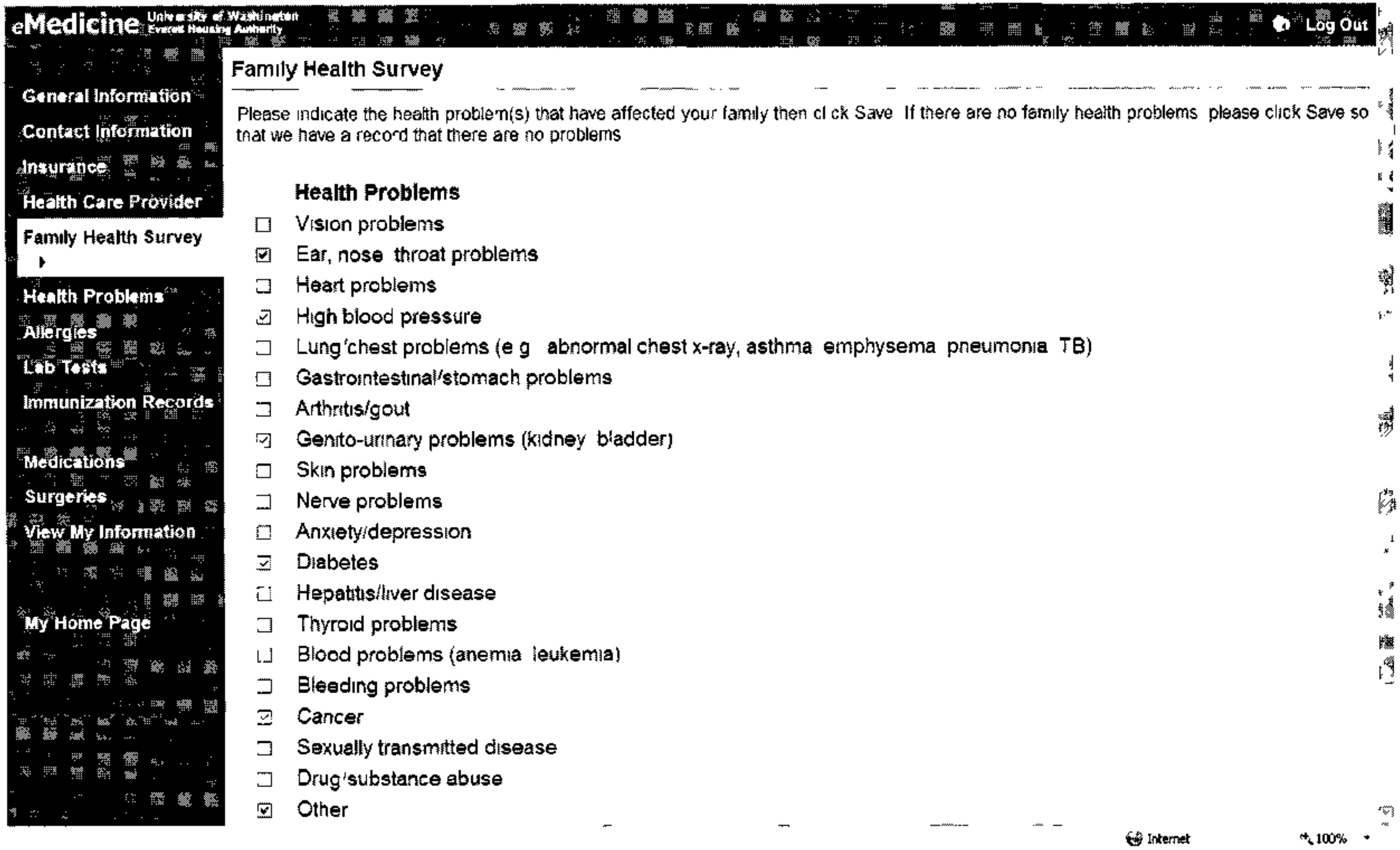
Please provide the following information about your Health Care Provider and then click Add

If you make a mistake after adding the provider information or you want to modify some information click on Edit Click on update after modifying your entry If you would like to delete information click Delete corresponding to that entry

When you are done entering provider information please continue to Family Health Survey

Provider Name		
Location		
Clinic	Providence Everett Healthcare Clinic	If Other
Type	Doctor	If Other
Primary reason you see this provider		
Check if Primary Care Provider	☐	

Provider Name	Clinic	Type	Reason	Location	PCP	
Dr William Becker	Providence Everett Healthcare Clinic	Doctor	Eye examination	Everett		Edit Delete
Keith Kinsley	Harborview Diabetes Clinic	Dietition	diet counseling	Seattle		Edit Delete
Nancy Nurse ARNP	Everett Clinic	Nurse Practioner	general check up	silver lake		Edit Delete

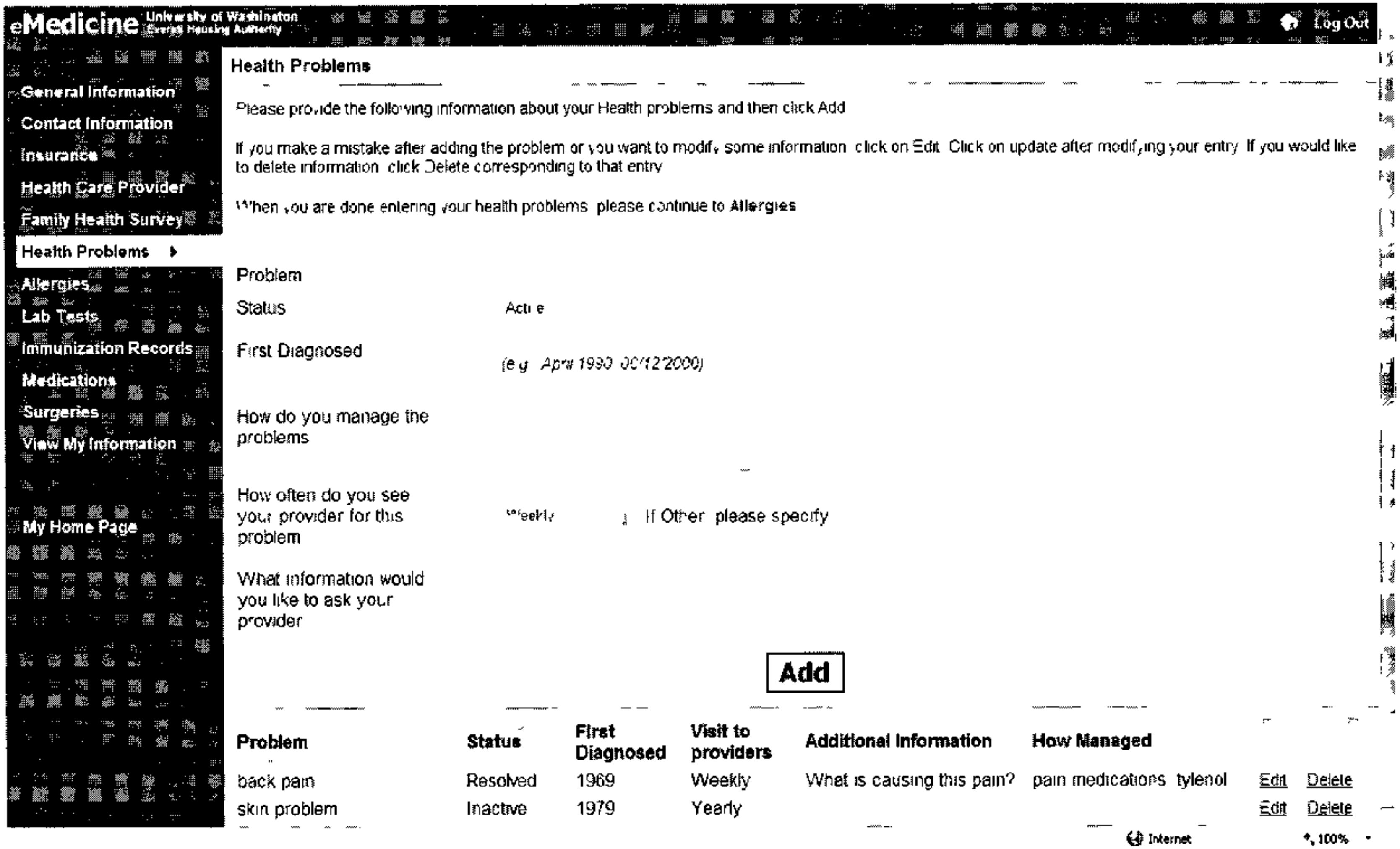


Family Health Survey

Please indicate the health problem(s) that have affected your family then click Save If there are no family health problems please click Save so that we have a record that there are no problems

Health Problems

☐ Vision problems
☑ Ear, nose throat problems
☐ Heart problems
☑ High blood pressure
☐ Lung/chest problems (e g abnormal chest x-ray, asthma emphysema pneumonia TB)
☐ Gastrointestinal/stomach problems
☐ Arthritis/gout
☑ Genito-urinary problems (kidney bladder)
☐ Skin problems
☐ Nerve problems
☐ Anxiety/depression
☑ Diabetes
☐ Hepatitis/liver disease
☐ Thyroid problems
☐ Blood problems (anemia leukemia)
☐ Bleeding problems
☑ Cancer
☐ Sexually transmitted disease
☐ Drug/substance abuse
☑ Other



Health Problems

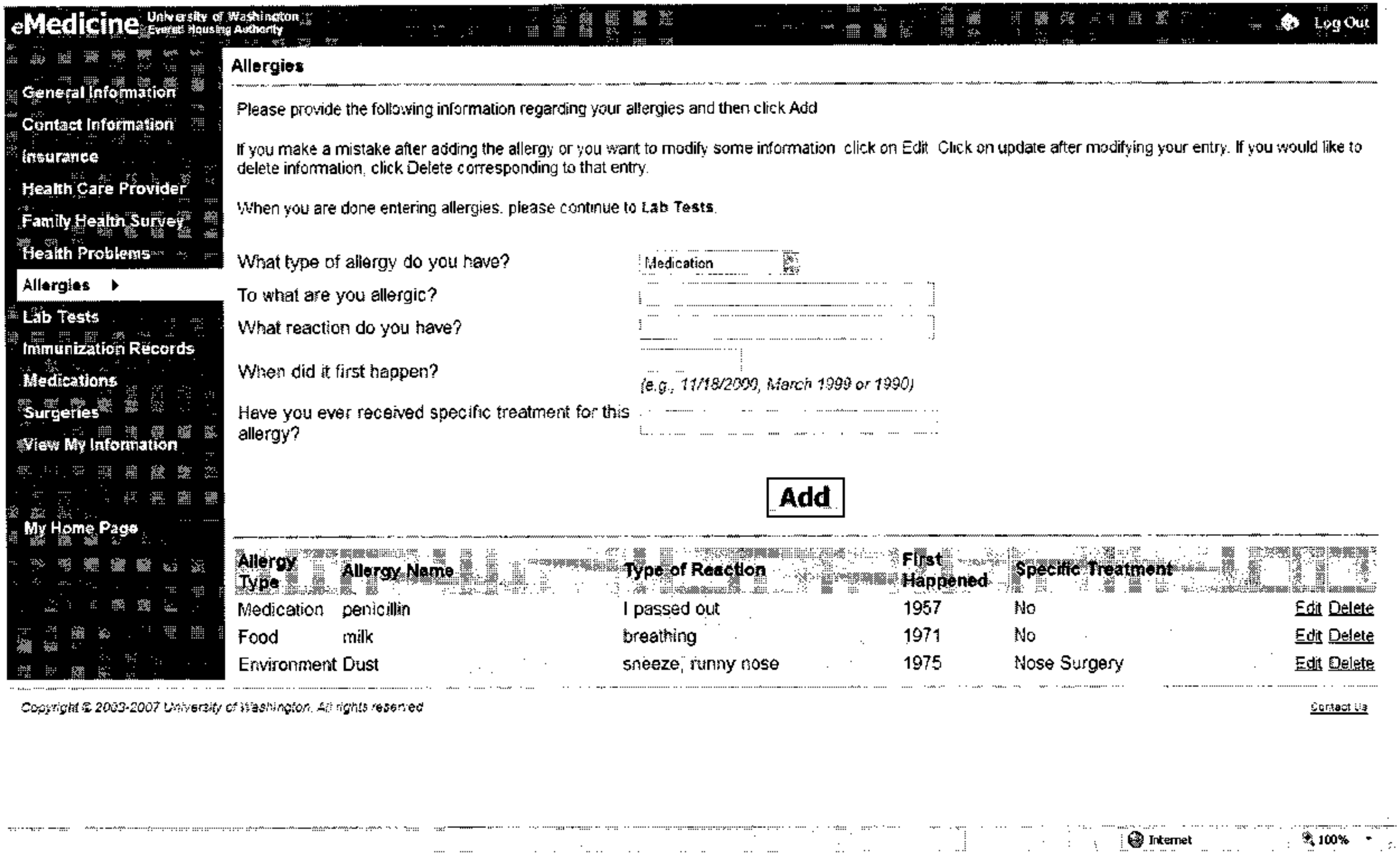
Please provide the following information about your Health problems and then click Add

If you make a mistake after adding the problem or you want to modify some information click on Edit Click on update after modifying your entry If you would like to delete information click Delete corresponding to that entry

When you are done entering your health problems please continue to **Allergies**

Problem	
Status	Active
First Diagnosed	*(e g April 1990 00/12/2000)*
How do you manage the problems	
How often do you see your provider for this problem	Weekly If Other please specify
What information would you like to ask your provider	

Problem	**Status**	**First Diagnosed**	**Visit to providers**	**Additional Information**	**How Managed**		
back pain	Resolved	1969	Weekly	What is causing this pain?	pain medications tylenol	Edit	Delete
skin problem	Inactive	1979	Yearly			Edit	Delete



Allergies

Please provide the following information regarding your allergies and then click Add

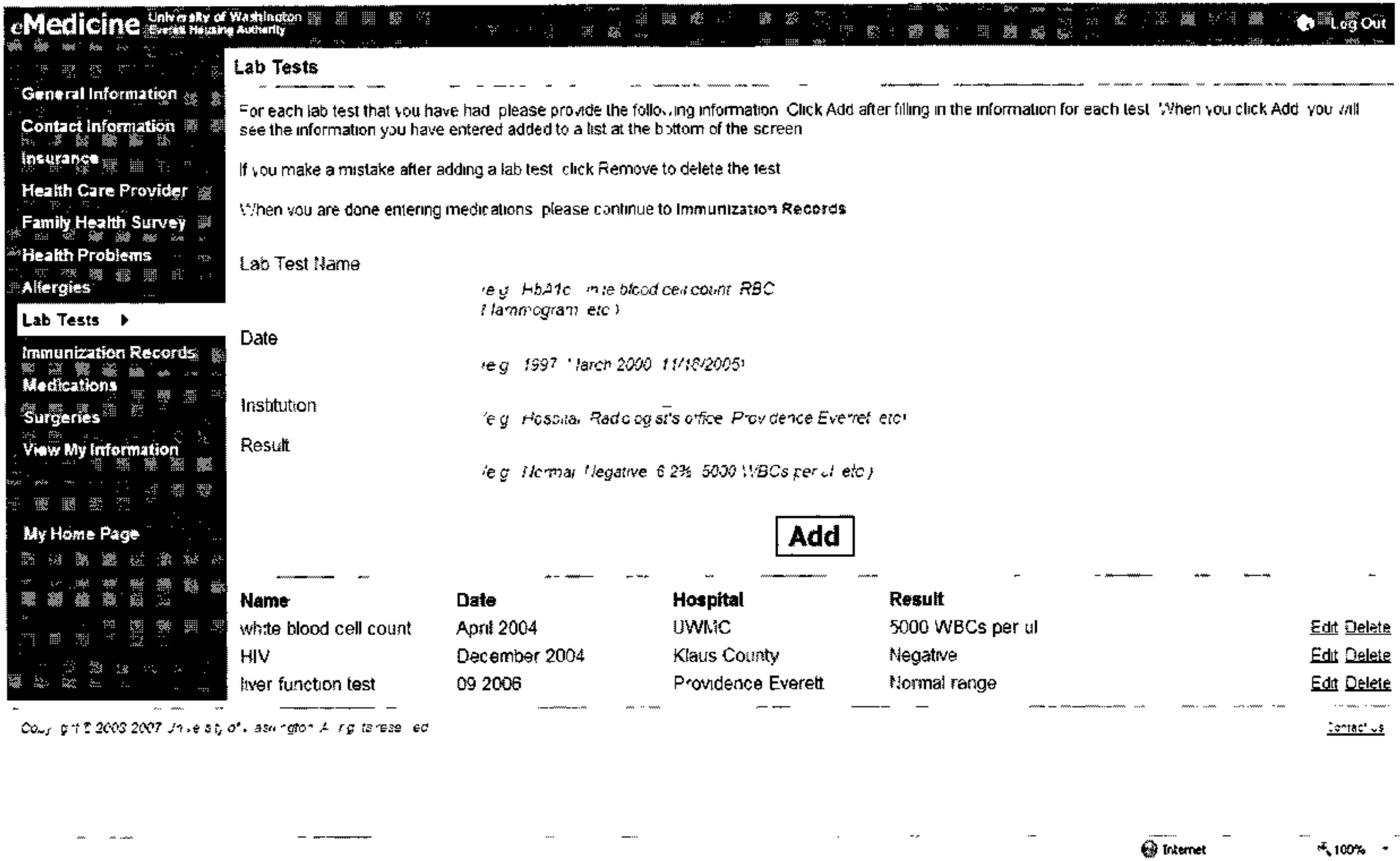
If you make a mistake after adding the allergy or you want to modify some information click on Edit Click on update after modifying your entry. If you would like to delete information, click Delete corresponding to that entry.

When you are done entering allergies, please continue to **Lab Tests**.

What type of allergy do you have?	Medication
To what are you allergic?	
What reaction do you have?	
When did it first happen?	(e.g., 11/18/2000, March 1999 or 1990)
Have you ever received specific treatment for this allergy?	

Allergy Type	Allergy Name	Type of Reaction	First Happened	Specific Treatment	
Medication	penicillin	I passed out	1957	No	Edit Delete
Food	milk	breathing	1971	No	Edit Delete
Environment	Dust	sneeze, runny nose	1975	Nose Surgery	Edit Delete

Contact Us



Lab Tests

For each lab test that you have had please provide the following information Click Add after filling in the information for each test When you click Add you will see the information you have entered added to a list at the bottom of the screen

If you make a mistake after adding a lab test click Remove to delete the test

When you are done entering medications please continue to **Immunization Records**

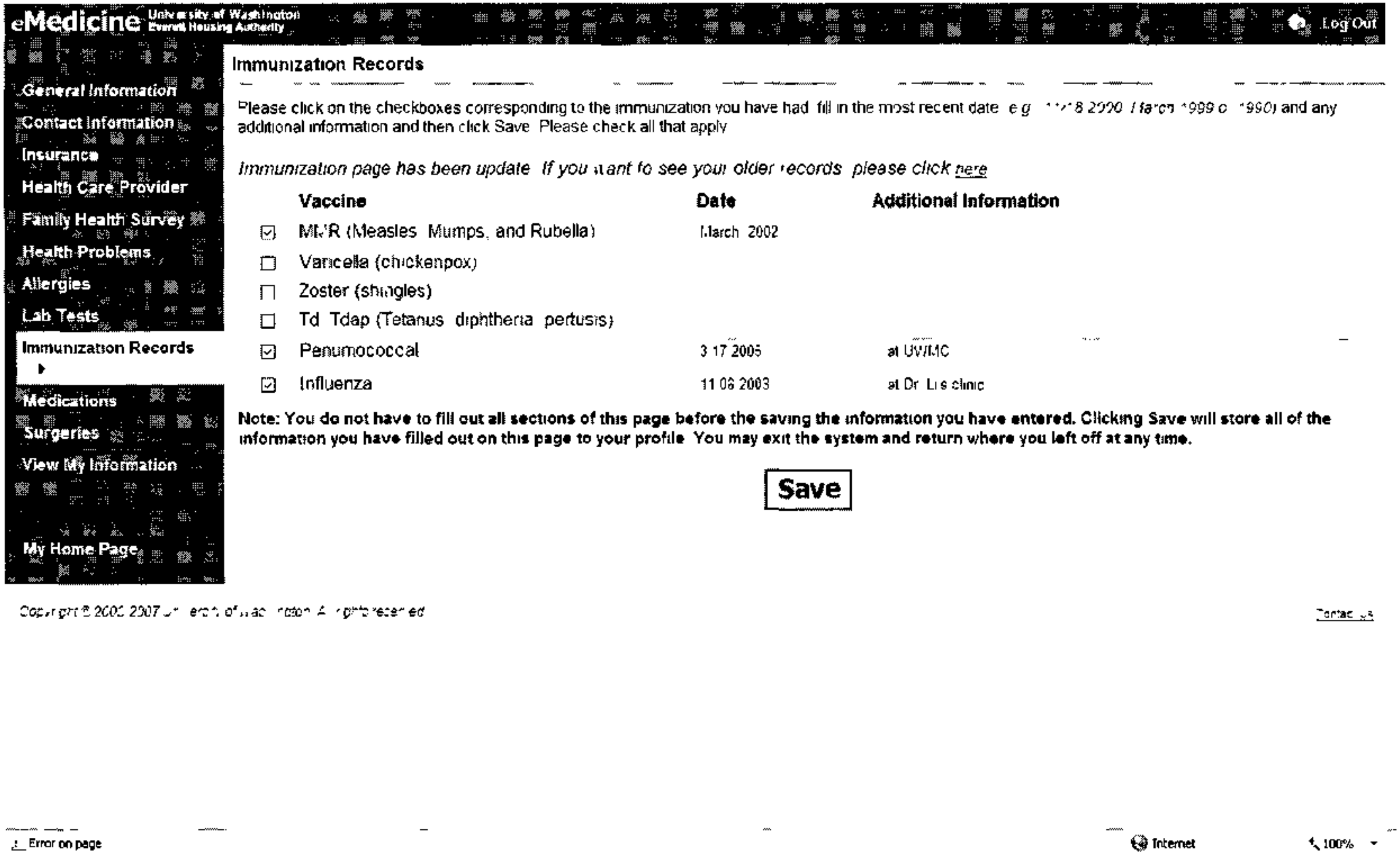
Lab Test Name (e g HbA1c white blood cell count RBC Mammogram etc)

Date (e g 1997 March 2000 11/18/2005)

Institution (e g Hospital Radiologist's office Providence Everett etc)

Result (e g Normal Negative 6 2% 5000 WBCs per ul etc)

Name	**Date**	**Hospital**	**Result**	
white blood cell count	April 2004	UWMC	5000 WBCs per ul	Edit Delete
HIV	December 2004	Klaus County	Negative	Edit Delete
liver function test	09 2006	Providence Everett	Normal range	Edit Delete



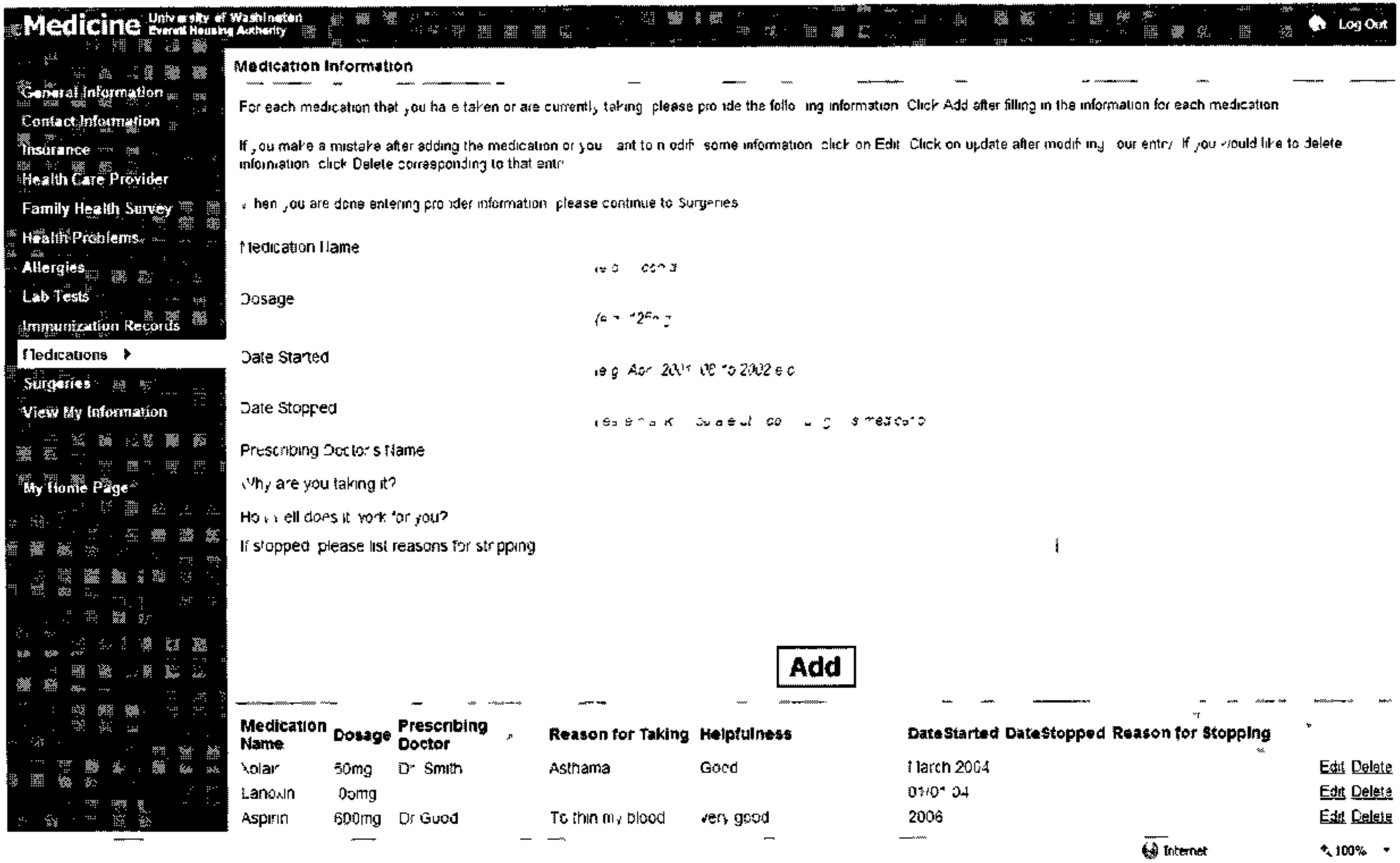
Immunization Records

Please click on the checkboxes corresponding to the immunization you have had fill in the most recent date (e.g. 11/18 2000 / March 1999 or 1990) and any additional information and then click Save Please check all that apply

Immunization page has been update If you want to see your older records please click here

	Vaccine	Date	Additional Information
☑	MMR (Measles Mumps, and Rubella)	March 2002	
☐	Varicella (chickenpox)		
☐	Zoster (shingles)		
☐	Td Tdap (Tetanus diphtheria pertusis)		
☑	Penumococcal	3 17 2005	at UWMC
☑	Influenza	11 06 2003	at Dr Li's clinic

Note: You do not have to fill out all sections of this page before the saving the information you have entered. Clicking Save will store all of the information you have filled out on this page to your profile You may exit the system and return where you left off at any time.



Medication Information

For each medication that you have taken or are currently taking please provide the following information Click Add after filling in the information for each medication

If you make a mistake after adding the medication or you want to modify some information click on Edit Click on update after modifying your entry If you would like to delete information click Delete corresponding to that entry

When you are done entering provider information please continue to Surgeries

Medication Name [illegible]

Dosage (e.g. 125mg)

Date Started (e.g. Apr 2001, 06 to 2002 etc)

Date Stopped [illegible]

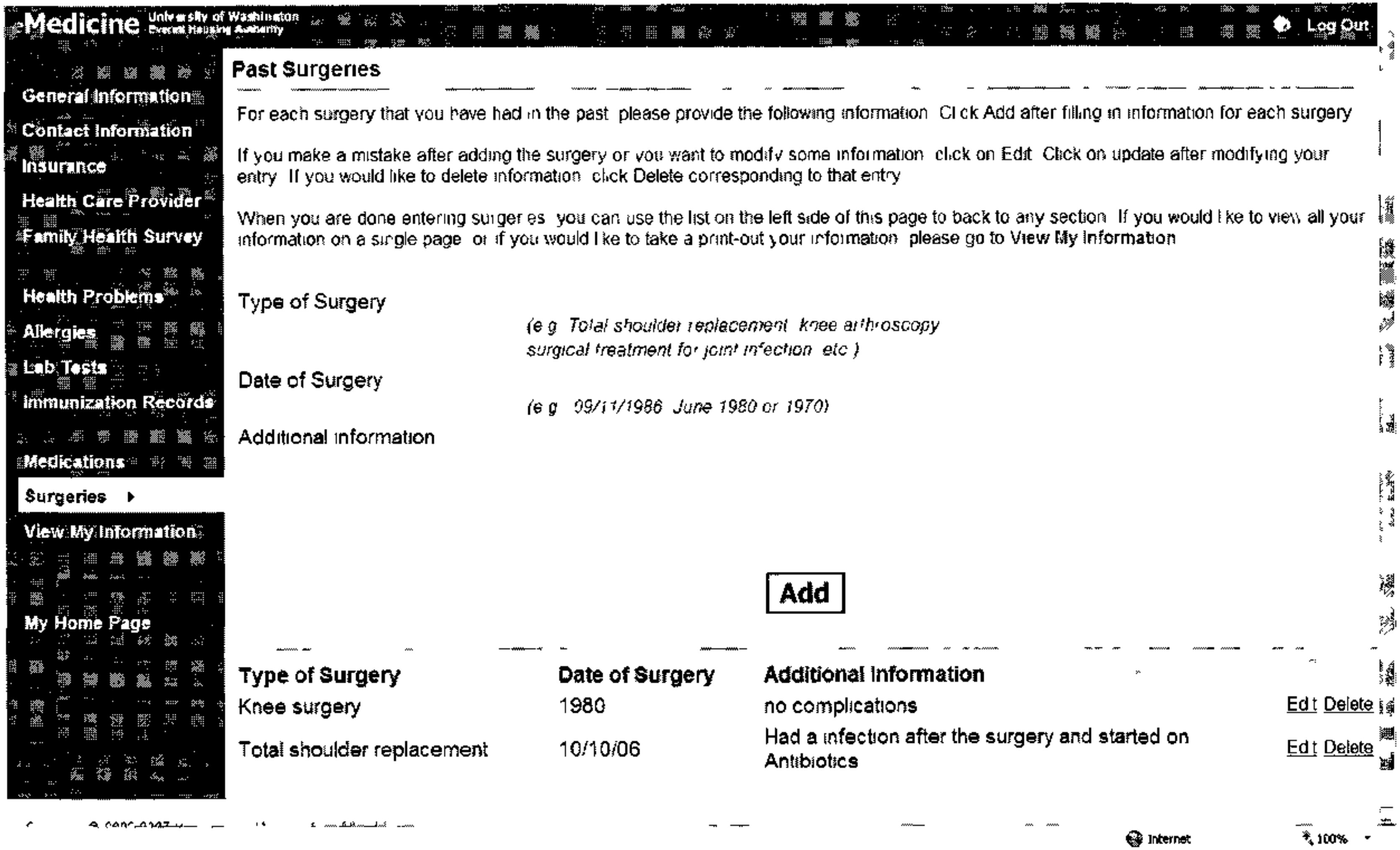
Prescribing Doctor's Name

Why are you taking it?

How well does it work for you?

If stopped please list reasons for stopping

Medication Name	Dosage	Prescribing Doctor	Reason for Taking	Helpfulness	DateStarted	DateStopped	Reason for Stopping	
Xolair	50mg	Dr Smith	Asthama	Good	March 2004			Edit Delete
Lanoxin	0omg				01/01/04			Edit Delete
Aspirin	600mg	Dr Good	To thin my blood	very good	2006			Edit Delete



Past Surgeries

For each surgery that you have had in the past please provide the following information Click Add after filling in information for each surgery

If you make a mistake after adding the surgery or you want to modify some information click on Edit Click on update after modifying your entry If you would like to delete information click Delete corresponding to that entry

When you are done entering surgeries you can use the list on the left side of this page to back to any section If you would like to view all your information on a single page or if you would like to take a print-out your information please go to View My Information

Type of Surgery

(e g Total shoulder replacement knee arthroscopy surgical treatment for joint infection etc)

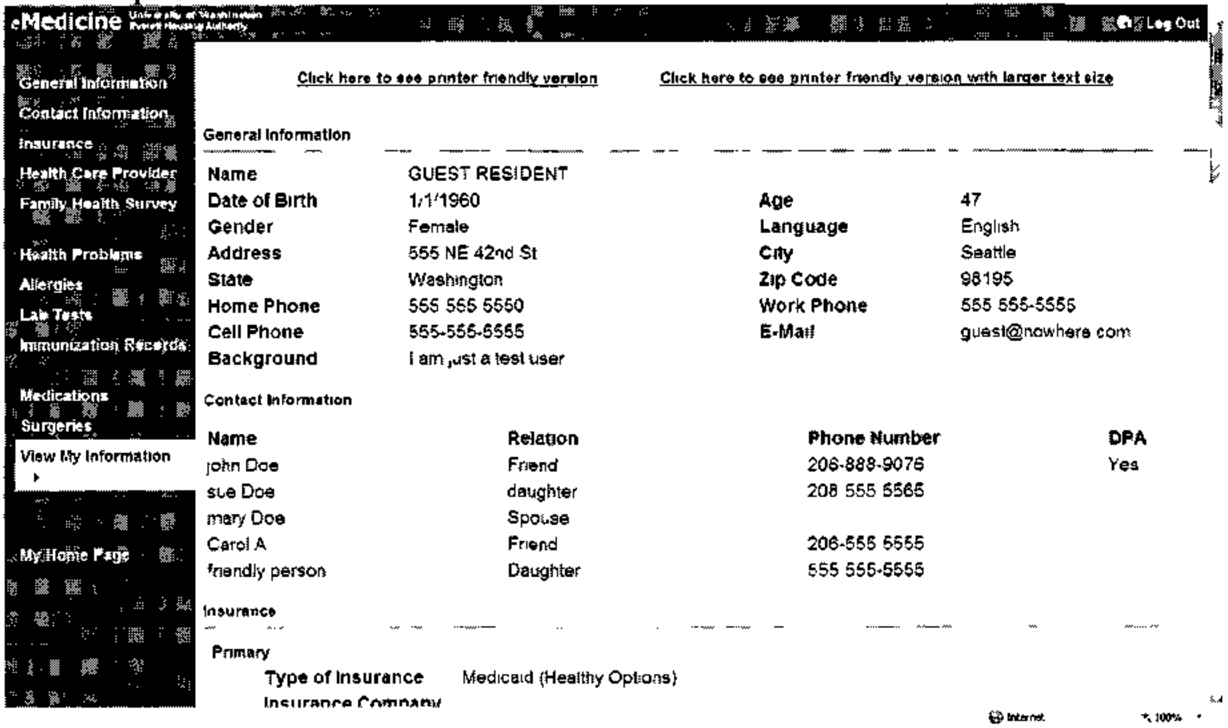
Date of Surgery

(e g 09/11/1986 June 1980 or 1970)

Additional information

Type of Surgery	**Date of Surgery**	**Additional Information**	
Knee surgery	1980	no complications	Edit Delete
Total shoulder replacement	10/10/06	Had a infection after the surgery and started on Antibiotics	Edit Delete

The E-Medicine summary sheet includes all the information that is stored in the E-Medicine personal health record.



Click here to see printer friendly version

Click here to see printer friendly version with larger text size

General Information

Name	GUEST RESIDENT		
Date of Birth	1/1/1960	**Age**	47
Gender	Female	**Language**	English
Address	555 NE 42nd St	**City**	Seattle
State	Washington	**Zip Code**	98195
Home Phone	555 555 5550	**Work Phone**	555 555-5555
Cell Phone	555-555-5555	**E-Mail**	guest@nowhere com
Background	I am just a test user		

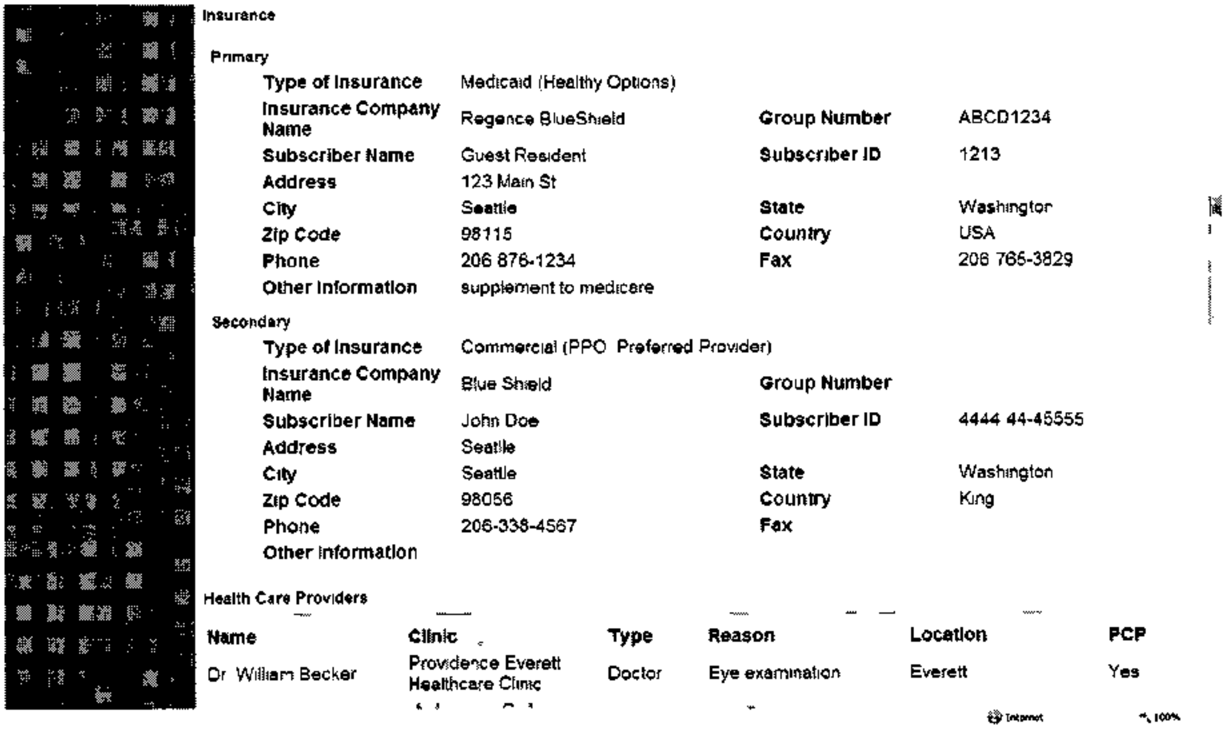
Contact Information

Name	Relation	Phone Number	DPA
john Doe	Friend	206-888-9076	Yes
sue Doe	daughter	208 555 5565	
mary Doe	Spouse		
Carol A	Friend	206-555 5555	
friendly person	Daughter	555 555-5555	

Insurance

Primary

Type of Insurance	Medicaid (Healthy Options)
Insurance Company	



Insurance

Primary

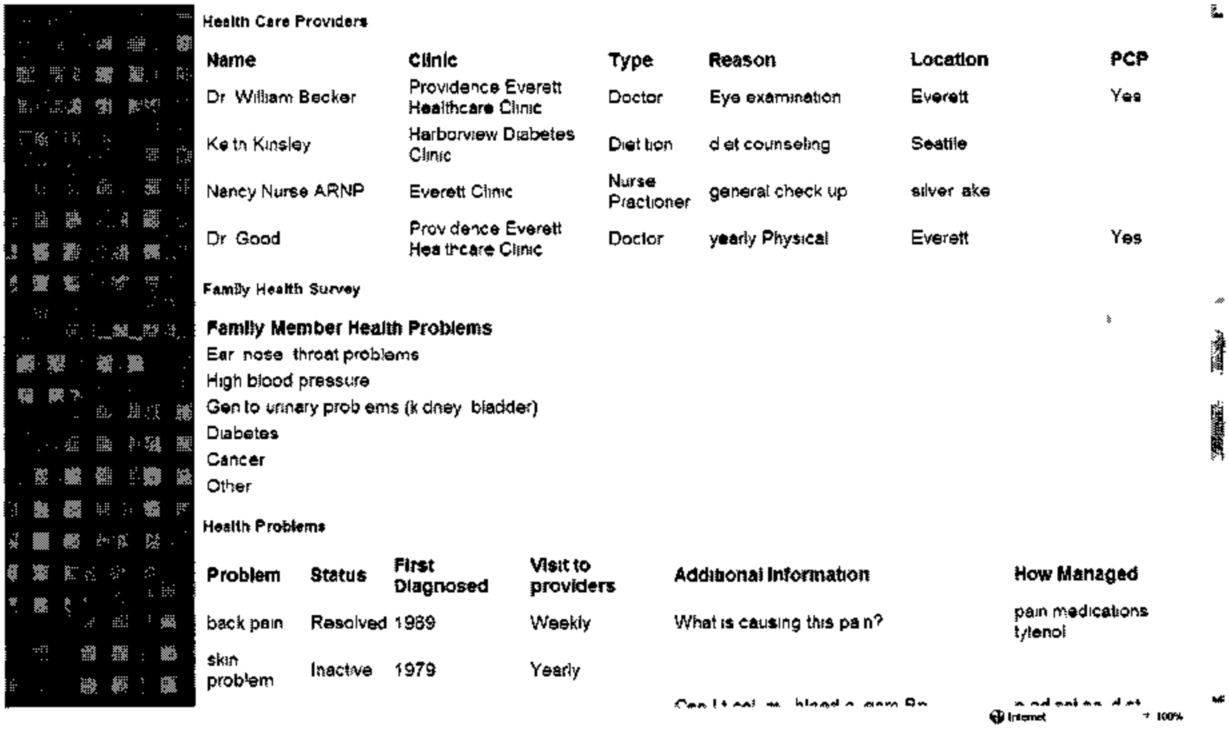
Type of Insurance	Medicaid (Healthy Options)		
Insurance Company Name	Regence BlueShield	**Group Number**	ABCD1234
Subscriber Name	Guest Resident	**Subscriber ID**	1213
Address	123 Main St		
City	Seattle	**State**	Washington
Zip Code	98115	**Country**	USA
Phone	206 876-1234	**Fax**	206 765-3829
Other Information	supplement to medicare		

Secondary

Type of Insurance	Commercial (PPO Preferred Provider)		
Insurance Company Name	Blue Shield	**Group Number**	
Subscriber Name	John Doe	**Subscriber ID**	4444 44-45555
Address	Seattle		
City	Seattle	**State**	Washington
Zip Code	98056	**Country**	King
Phone	206-338-4567	**Fax**	
Other Information			

Health Care Providers

Name	Clinic	Type	Reason	Location	PCP
Dr William Becker	Providence Everett Healthcare Clinic	Doctor	Eye examination	Everett	Yes



Health Care Providers

Name	Clinic	Type	Reason	Location	PCP
Dr William Becker	Providence Everett Healthcare Clinic	Doctor	Eye examination	Everett	Yes
Keith Kinsley	Harborview Diabetes Clinic	Dietition	diet counseling	Seattle	
Nancy Nurse ARNP	Everett Clinic	Nurse Practioner	general check up	silver lake	
Dr Good	Providence Everett Healthcare Clinic	Doctor	yearly Physical	Everett	Yes

Family Health Survey

Family Member Health Problems

Ear nose throat problems

High blood pressure

Genitourinary problems (kidney bladder)

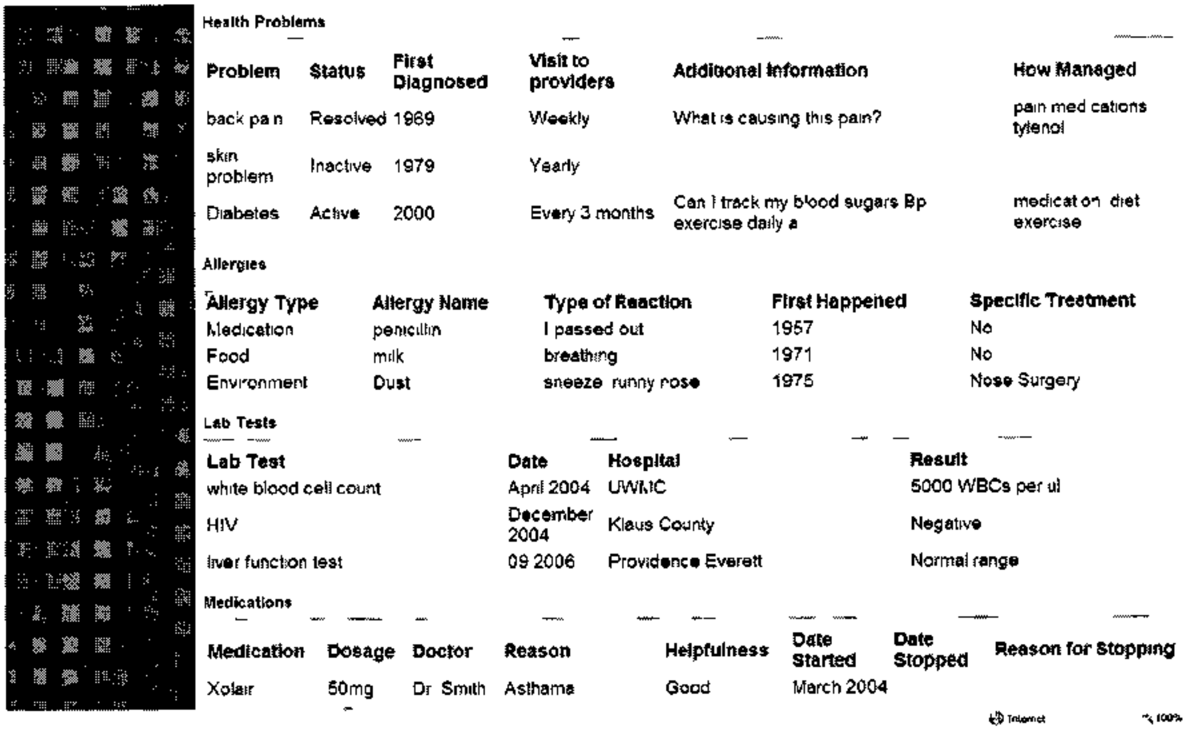
Diabetes

Cancer

Other

Health Problems

Problem	Status	First Diagnosed	Visit to providers	Additional Information	How Managed
back pain	Resolved	1989	Weekly	What is causing this pain?	pain medications tylenol
skin problem	Inactive	1979	Yearly		



Health Problems

Problem	Status	First Diagnosed	Visit to providers	Additional Information	How Managed
back pain	Resolved	1969	Weekly	What is causing this pain?	pain medications tylenol
skin problem	Inactive	1979	Yearly		
Diabetes	Active	2000	Every 3 months	Can I track my blood sugars Bp exercise daily a	medication diet exercise

Allergies

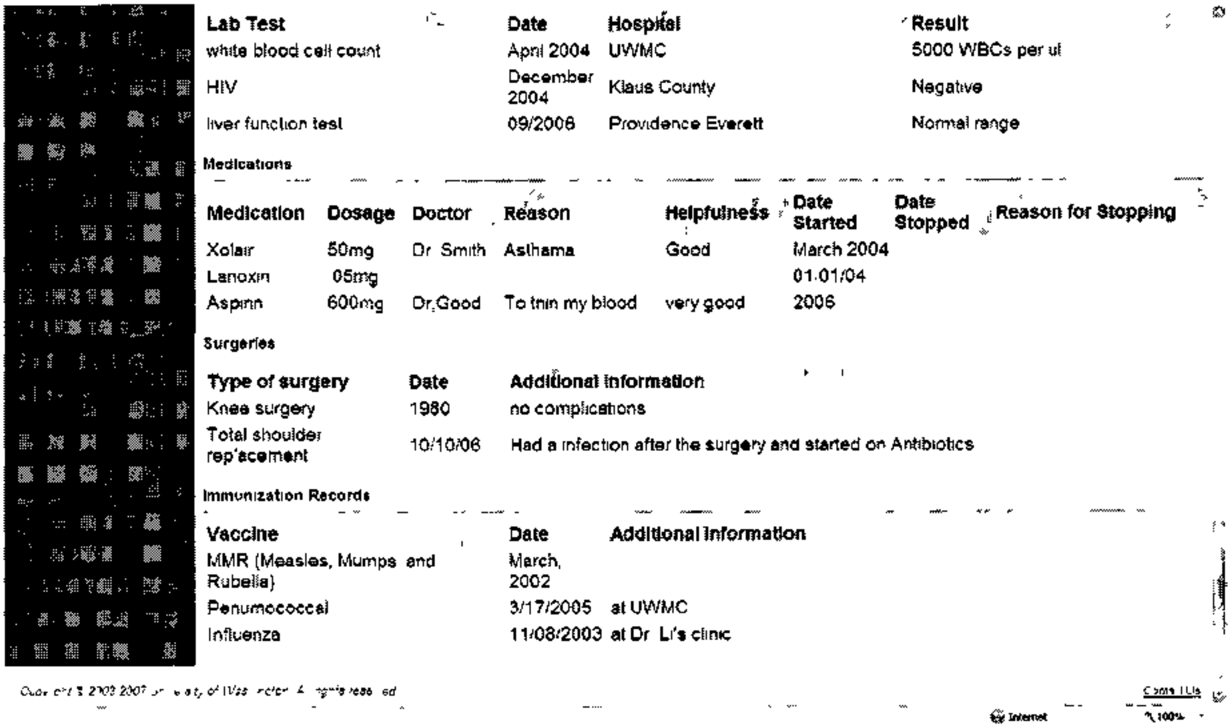
Allergy Type	Allergy Name	Type of Reaction	First Happened	Specific Treatment
Medication	penicillin	I passed out	1957	No
Food	milk	breathing	1971	No
Environment	Dust	sneeze runny nose	1975	Nose Surgery

Lab Tests

Lab Test	Date	Hospital	Result
white blood cell count	April 2004	UWMC	5000 WBCs per ul
HIV	December 2004	Klaus County	Negative
liver function test	09 2006	Providence Everett	Normal range

Medications

Medication	Dosage	Doctor	Reason	Helpfulness	Date Started	Date Stopped	Reason for Stopping
Xolair	50mg	Dr Smith	Asthama	Good	March 2004		



Lab Test	Date	Hospital	Result
white blood cell count	April 2004	UWMC	5000 WBCs per ul
HIV	December 2004	Klaus County	Negative
liver function test	09/2006	Providence Everett	Normal range

Medications

Medication	Dosage	Doctor	Reason	Helpfulness	Date Started	Date Stopped	Reason for Stopping
Xolair	50mg	Dr Smith	Asthama	Good	March 2004		
Lanoxin	05mg				01.01/04		
Aspirin	600mg	Dr.Good	To thin my blood	very good	2006		

Surgeries

Type of surgery	Date	Additional information
Knee surgery	1980	no complications
Total shoulder replacement	10/10/06	Had a infection after the surgery and started on Antibiotics

Immunization Records

Vaccine	Date	Additional information
MMR (Measles, Mumps and Rubella)	March, 2002	
Penumococcal	3/17/2005	at UWMC
Influenza	11/08/2003	at Dr Li's clinic

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Appendix J: Resident Recruitment Flyer

E-Medicine

Would you like to participate in an interview about the E-Medicine system?

RESEARCH PARTICIPANTS NEEDED!

Division of Biomedical and Health Informatics
University of Washington

Have you ever used E-Medicine? Have you thought about trying it?
I would like to talk you about what you think about the E-Medicine system and other tools that help you organize your health information! Participants will be asked to tell me about themselves and what they think about E-Medicine,
and to show me how they interact with the E-Medicine computer health record.

Participants will receive a **$5 grocery store gift certificate** for a **1 hour session.**

*****To participate you must be able to read and understand English.*****

*****The meeting will be tape recorded.*****

Please contact Anna Stolyar at (206) 931-8762
or by email **as0@u.washington.edu** if you
have questions or are interested in participating.

Appendix K: Resident Consent Form

UNIVERSITY OF WASHINGTON
CONSENT FORM
Healthcare Consumers' Perceptions of Personal Health Records

Researchers:

Anna Stolyar, Pre-Doctoral Fellow, Dept. of Med. Education & Biomedical Informatics, School of Medicine, 206-931-8762, as0@u.washington.edu.

George Demiris, PhD, Associate Professor, School or Medicine, School of Nursing, 206-221-3866, gdemiris@u.washington.edu.

Michael B. Eisenberg, PhD, Dean Emeritus and Professor, The Information School, 206-616-1152, mbe@u.washington.edu.

Please note that we cannot ensure the confidentiality of information sent via e-mail.

Researchers' statement:

We are asking you to be in a research study. The purpose of this consent form is to give you the information you will need to help you decide whether to be in the study or not. Please read the form carefully. You may ask questions about the purpose of the research, what we would ask you to do, the possible risks and benefits, your rights as a volunteer, and anything else about the research or this form that is not clear. When we have answered all your questions, you can decide if you want to be in the study or not. This process is called "informed consent."

We will give you a copy of this form for your records.

PURPOSE OF THE STUDY

The purpose of this study is to understand health care consumers' perceptions of personal health records and why consumers choose to use or not to use such records to manage their personal health information.

STUDY PROCEDURES

If you chose to participate, we would like to interview you up to two separate times. Each interview will last about an hour.

The first interview will ask you questions about yourself, such as your age, race, and your perception of your health status. We will also ask you what you think about personal health records, the E-Medicine system, and how you manage and organize your health information. The researcher will NOT ask you to tell us anything about your own health information. You do not have to answer every question.

We will ask some people to take part in a second interview. In the second interview, we will ask you to show us how you use the E-Medicine system. A blank E-Medicine record will be created for you and you will not be asked to share any of your private health information. We are interested in how you use the E-Medicine record. You do not have to answer every question.

The interviewer will take notes during each interview. We would also like to audio record each interview so that we can have an accurate record of what was said. Only the research team will have access to the recordings, which will be stored in a secure location at all times. We will transcribe the recordings and assign a study code or pseudonym to the transcript. We will destroy the recordings by December 2008. You may review and edit the recording of your interview at any point before it is destroyed by contacting one of the researchers listed at the top of this form.

RISKS, STRESS, OR DISCOMFORT

This study will involve reflecting on why you have chosen to use or not use a computer system such as a personal health record to organize your health information. You may experience minor discomfort when talking about your experience of interacting with computer technology. You can choose not to answer any question or ask to pause or stop the interview at any time if you feel fatigued.

BENEFITS OF THE STUDY

We hope the findings of this study will help develop more successful and useful medical record systems. Although we hope the findings of this study will benefit society, you may not directly benefit.

OTHER INFORMATION

Taking part in this study is voluntary. You can stop at any time. Choosing to take part in the study, to not take part in the study, or to withdraw from the study will not affect benefits to which you are otherwise entitled. For example, your choice will not affect benefits you receive from the Everett Housing Authority.

Information about you is confidential. We will code the study information. We will keep a link between your name and the study information until December 2008 and then we will destroy the link. If the findings, of this study are ever presented or published, we will not use your name.

Although we will make every effort to keep your information confidential, no system for protecting your confidentiality can be completely secure. It is possible that unauthorized persons might discover that you are in this study, or might obtain information about you. University and government offices sometimes review studies such as this one to make sure they are being done safely and legally. If a review of this study takes place, your records may be examined. The reviewers will protect your privacy. The study records will not be used to put you at legal risk or harm.

We will give you a $5 gift certificate to a grocery store of your choice for each interview that you take part in.

____

Printed name of study staff obtaining consent   Signature   Date

Subject's statement:

This study has been explained to me. I volunteer to take part in this research. I give the researchers permission to audio record my interviews as described above in the consent form. I have had a chance to ask questions. If I have questions later about the research, I can ask one of the researchers listed above. If I have questions about my rights as a research subject, I can call the Human Subjects Division at (206) 543-0098. I will receive a copy of this consent form.

Printed name of subject	Signature of subject	Date

Copies to: Researcher
Subject

Appendix L: Healthcare Professional Oral or E-mail Recruitment Text

Good morning (afternoon),

My name is Anna Stolyar. I am a graduate student in Biomedical and Health Informatics at the University of Washington.

I am working on a research project at the University of Washington that explores what people think about personal health records and how they use personal health records. I will use the information to search for solutions to help people organize and manage their health information.

Is this a good time for you to talk to me? Would you like to hear more about the study?

Since you have helped residents at EHA understand and use the E-Medicine system, I would like to interview you once for about an hour to find out about your perceptions of the E-Medicine project at the Everett Housing Authority. I will ask you questions about your perceptions of how the residents are using E-Medicine and your perceptions of the reasons why some residents chose to use E-Medicine and some do not. I would like to take notes during the interview and also to audio record the interview.

Taking part in this study is voluntary. Choosing to take part in the study, to not take part in the study, or to withdraw from the study at any point in time will not affect any benefits to which you are otherwise entitled.

If you would like to participate in the study, is there a good time for us to meet for an hour to do the interview?

Thank you for your time. If you have any questions about this research study or would like to contact me in the future, you can call me at 206-931-8762 or by e-mail, as0@u.washington.edu. Please not that I cannot ensure the confidentiality of information sent via email.

Appendix M: Healthcare Professional Consent Form

UNIVERSITY OF WASHINGTON
CONSENT FORM
Healthcare Consumers' Perceptions of Personal Health Records

Researchers: Anna Stolyar, Pre-Doctoral Fellow, Dept. of Med. Education & Biomedical Informatics, School of Medicine, 206-931-8762, as0@u.washington.edu.

George Demiris, PhD, Associate Professor, School or Medicine, School of Nursing, 206-221-3866, gdemiris@u.washington.edu.

Michael B. Eisenberg, PhD, Dean Emeritus and Professor, The Information School, 206-616-1152, mbe@u.washington.edu.

Please note that we cannot ensure the confidentiality of information sent via e-mail.

Researchers' statement:

We are asking you to be in a research study. The purpose of this consent form is to give you the information you will need to help you decide whether to be in the study or not. Please read the form carefully. You may ask questions about the purpose of the research, what we would ask you to do, the possible risks and benefits, your rights as a volunteer, and anything else about the research or this form that is not clear. When we have answered all your questions, you can decide if you want to be in the study or not. This process is called "informed consent."

We will give you a copy of this form for your records.

PURPOSE OF THE STUDY

The purpose of this study is to understand health care consumers' perceptions of personal health records and why consumers choose to use or not to use such records to manage their personal health information.

STUDY PROCEDURES

If you chose to participate, we would like to interview you once for about an hour.

The interview will ask you questions about how and why residents at EHA have chosen to use or not use the E-Medicine system. We might ask you about what reasons residents have discussed for using or not using E-Medicine, what your opinion is of why E-Medicine is or is not being used by certain residents and how you think health care consumers outside EHA might react to a system like E-Medicine. We will also ask you what you think about personal health records and the E-Medicine system. The researcher will NOT ask you to tell us anything about your own health information. You do not have to answer every question.

The researcher will take notes during the interview. We would also like to audio record each interview so that we can have an accurate record of what was said. Only the research team will have access to the recordings, which will be stored in a secure location at all times. We will transcribe the recordings and assign a study code or pseudonym to the transcript. We will destroy the recordings by December 2008. You may review and edit the recording of your interview at any point before it is destroyed by contacting one of the researchers listed at the top of this form.

RISKS, STRESS, OR DISCOMFORT

This study will involve reflecting on why some consumers have chosen to use or not use a computer system such as a personal health record to organize their health information. You may experience minor discomfort when talking about your experience of interacting with consumers and computer technology in the context of E-Medicine and personal health record systems. You can choose not to answer any question or ask to pause or stop the interview at any time if you feel fatigued.

BENEFITS OF THE STUDY

We hope the findings of this study will help develop more successful and useful medical record systems. Although we hope the findings of this study will benefit society, you may not directly benefit.

OTHER INFORMATION

Taking part in this study is voluntary. You can stop at any time. Choosing to take part in the study, to not take part in the study, or to withdraw from the study will not affect benefits to which you are otherwise entitled.

Information about you is confidential. We will code the study information. We will keep a link between your name and the study information until December 2008 and then we will destroy the link. If the findings, of this study are ever presented or published, we will not use your name.

Although we will make every effort to keep your information confidential, no system for protecting your confidentiality can be completely secure. It is possible that unauthorized persons might discover that you are in this study, or might obtain information about you. University and government offices sometimes review studies such as this one to make sure they are being done safely and legally. If a review of this study takes place, your records may be examined. The reviewers will protect your privacy. The study records will not be used to put you at legal risk or harm.

Printed name of study staff obtaining consent Signature Date

Subject's statement:

This study has been explained to me. I volunteer to take part in this research. I give the researchers permission to audio record my interviews as described above in the consent form. I have had a chance to ask questions. If I have questions later about the research, I can ask one of the researchers listed above. If I have questions about my rights as a research subject, I can call the Human Subjects Division at (206) 543-0098. I will receive a copy of this consent form.

Printed name of subject	Signature of subject	Date

Copies to: Researcher
Subject

Appendix AA: Sample Quotations of Participants Not Interested in Management

> *I go to the doctor, I get my prescriptions and I get them filled and I bring them home. And I am not going to just go into something else at this late date, so I think I am kind of fine the way I am. P02*
>
> *It just, it just doesn't interest me. My doctors knows everything that he needs to know about me, I know everything I need to know about me, my son knows everything that HE needs to know about me, he's my beneficiary on everything, he's... no, I don't think I would need it. P08*
>
> *Me use your system, no, I don't think so.*
> [Interviewer: "And can you tell me a little bit about why?"]
> *Well, I got plenty of help, you know, plenty of help. You get too much help and I get spoiled, see, so... P09*

Appendix BB: Sample Quotations of Participants Minimally Interested in Management to Not Interested in Management

> *Actually, that's one of the reasons, I don't know. About the only thing I'd say putting on there, is um, possibly maybe my prostate problem and the, what they do from time to time, you know, like I am only on the hormone therapy.*
> [Interviewer: "Right."]
> *And it seems to be working so why change it. And, um, I don't know what I'd put on there. I just don't have much that I could put on there. That I don't know already in my head, because four pills are not hard to keep up with. And I always put those in a little, so I won't mix them up, you know, I can put those in little containers for the week. P32*

> *No, I wasn't interested in it at that time.*
> [Interviewer: "Could you just tell me a little about why you felt like you didn't want to do it or you weren't interested."]
> *No, because I had a doctor and I still have him and that's it.*
> [Interviewer: "So why do you, just tell me a little more about why you think it's not going to be useful for you."]
> *Well, it will be useful to him, if he's contacted to have some information, if he doesn't have it at the office and stuff, but the lab, I haven't had lab tests done in years, and I don't know. I am very good health.*
> [Interviewer: "Good."]
> *So I don't know where I stand with, hopefully it would help the doctor in case something happened to me.... Or my family. Mainly my family, it would help my family a lot. P03*

Well, I really don't care what it's for. I mean seriously, as long as I am in good health and I feel good, I am not going to worry about my health. P22

I really don't keep track of it, because I always know what to do, you know, for myself and how to take care of myself, which I do. P23

Appendix CC: Sample Quotations of Participants Minimally Interested in Management

My doctor does most of the managing of my health information. Because I see him, probably every other month and he does the blood tests and all the screening and stuff, and we talk about things that are going on. P15

I would appreciate it if each person could come up with some kind of password or code so that your doctor can, um, gain access to the records any time they need to, as well as hospital staff, in case on an emergency. Because, usually if it's an emergency you're not going to be awake to tell them. Ok, yes, I'm allergic to this, I'm allergic to that, my family's had this, my family's had that. I need to, I'd prefer if medical providers could have access to it whenever they needed it. P17

Because of, if I were ill and I ended up in the hospital, they could check if it's on the computer, they could check, rather then asking me questions, and I can't talk very well, and it's right there in front of them. P10

Well, like I said, because [the social worker], kept coming and advertising so often, until I thought I guess I better go look into it and see what it was about. ... He said though that it would keep everything on there. That I could have to take to my doctor if he wanted to check me out for what I had in the past, you know. P18

I had a cousin that took care of me quite a while back, but then she died. And now that I cannot do the things that I used to do, which I don't, but my two cousin's daughters just don't do nothing for me at all anymore, they got their own families... But, that's what I'm saying, if I did have any family it would be a different story [I would be able to manage my health information]. P19

Because I have been better lately and everything, I have a tendency to kind of forget those things [health related things] and get caught up in things like my work and I was going to school for a couple of years there, and, it's easy and all that for me to kind of, put that on the back burner and forget about it because I got so caught up in everything else I was doing. So, when I do go [to the doctor], it's usually a very basic general type of, um, just normal um, review of what's going on, basically. Just a minor physical and make sure that everything's ok.. P30

Appendix DD: Sample Quotations of Participants Minimally Interested to Interested in Management

Because you're information is right there, all you have to do is just punch it in, but you know it'll come up, that way you're not guessing, you know. It's, it's a sure way to know, to know that the information, other then that you could, um, have different information that's not correct each time, you know, if you ask. Yeah, and with me, with my memory, that would be a good thing. Since, I am very forgetful. P05

If, you had to see the doctor continually, like I do... you probably would have to refer back to it quite often, I was, I was a, it could be from a few times each month, to a couple of times each month at least. P05

For myself, I, I don't see any real benefit [in the PHR system offered] over and above what I already do. ... My information management is based on Johnson and Johnson's Diabetes Care program. So it provides for, primary, endocrinology, other medical professionals on my health care team, and um, of course the basic demographics for the individuals and then for the, of course, the complete diabetes management notation for other, other care necessities. P11

Well the E-Medicine program is a way of tracking your records on computer. With your medicines and your doctors so that you don't have to run and bring all kinds of papers when you go to see your doctor, you have the information right in your hand, and it's, it's just a handy way of keeping track of all, of everything you do and it's just, it's just very, very helpful. P24

Well, I think it's all computerized, your records are on the computer. And I think that's a great idea. ... Well, I think it's important to keep an inventory of what's going on with me, and any new medications that have been added. P25

Sometimes when I go to a new doctor, they want to know if I've been on, if I've taken any new medicines lately and sometimes I know and sometimes I don't. [So the system would help me] know where I'm at, keeping an accurate information about what's going on with me, where I'm at, what medicines I am on. P25

If mother, if mother forgets everything, which is not gonna happen, but you know, if you're unconscious or something, somebody got to know,[has to be able to get access to your health information] particularly if you're not in your own home town. P27

[I want to just] leave [my health information] in the computer, if you can get it on the computer and just keep a copy on, on me, upstairs somewhere, filed up. P29

I'd just keep it for, in case, I don't know, in case of emergency or something, you know how ambulances or fire department want to know what about you, they ask you questions you can't answer them, then you know where the paper is, and they look at it and they just, and then they know, they pretty much all know what to do, the main thing. P29

Appendix EE: Sample Quotations of Participants Interested in Management Who Were Using the E-Medicine PHR

I would be able to keep track more of my, my own health. Um, [pause] and being living alone I put it in my cupboard. I have a copy in my cupboard, in case of an emergency, they can come in and get all the information right there in my cupboard. P01

I know that, the nurses come and they, you don't have to know anything about computers, and that they help you manage your health information so that you can share information with your doctor, over the computer. P09

Well somebody keeps on asking me this or that, my mind goes a blank. I know I have it, cause I have it [E-Medicine summary print-out] on my wall, so I go to it and find whatever I need for them. P13

Well, this information that you give to the doctors and they help, prevents them asking the same thing every time you go and visit. Yeah, and I've been praised for bringing it in, cause it helps them too. P14

[Interviewer: "And then what do you think a personal health record is?"]
Well, it's just a record of your personal health. It's just what it says. ... [It helps] keep track of your medicines that you're talking and you have information available when you go see your doctors. That's... That's what I use it for.
[Interviewer: "Ok, that sounds good. So, do you remember why you originally decided to sign up for the e-medicine?"]
Well, what I just said is, so that I have the information with me and I wouldn't have to remember it off the top of my head. P14

Well I know it keeps the history of whatever we put into it, it's keeping it as a history. Um, I like that idea because I've had surgeries and invariably I'm asked, oh you had a hysterectomy when did you have that, well, you know just off the top of your head you're not going to remember. So, but taking this into the doctor, I mean, you just hand it to them and say, psst, there it is, you know. So I have been trying to get my history, you know, memory wise, it's been a little difficult to remember just exactly what year, you know, that I had some of the stuff done. P16

I check weekly for blood pressure, and then the blood glucose testing and um, because there is some of these people here that test three, four times a day. I don't, but I do it every other day, I would like to keep track of that. You know, and say after 6 months, then start a fresh, or something you know. Cause after a while, it's going to be...
[Interviewer: "A very long list."]
Yeah, quite a long... but, if you can purge that, that's no... purge now see that's a computer thing. [laughs] But you can purge old stuff you know, old stuff like that you know, and just take out maybe the highest and then lowest on such an such a date and then go on from there. So, I would like to see that on there. Now, I don't know whether it's on there now or not, I don't know, I know it's a medical and the medicines and the, uh, people to contact. So, uh, we can go from there you know. P16

If I have a new doctor to go to, just hand it to him and say, I'm not filling out all your damn paperwork. Here is my history, right. I can fill out my name, address and phone number I have no problem with that. But to sit there and do all those questions, of all the paperwork, I am just not going to do that anymore. And that's one of the reasons I signed up, was because, uh, because there's times where I had five doctors at one time. You know, and trying to remember all that stuff it's just, ugh, ridiculous. P16

Well, I've been trying to remember my surgeries and stuff like that, so when I remember them, I write that down. I have what I call a timeline, have you ever heard of the timeline?
[Interviewer: "No."]
Timeline is, here is your birth, your first, second, third, fourth... you know, sixteenth, 65, birthdays right. The important things that have happened to you during that time are on that timeline. Like when my first baby was born, my second baby was born, blah, blah, blah, so I have a timeline. It's a very...
[Interviewer: "Detailed?"]
Messy, yeah detailed, it's detailed to the point where it's so messy you can hardly read it. But, I do have that, and the reason I did the timeline, was because I wanted to list my surgeries in here as to what years and stuff. And by remembering between, cause now like when my son was born in 65, I ended up in the hospital shortly after he was born and, um, for gallbladder, had my gallbladder and appendix removed. And at the same time I was seeing another doctor, who, which was unbeknownst to me, because he didn't tell me what was wrong. They were, they found that I had tuberculosis. And um, all they would say was that you have something on your lungs, they wouldn't... you know, and I would have never thought of tuberculosis in the world. Um, so I ended up at [some] sanitarium, um, and that was in that year to, in 65. So, I've been keeping, that was why I put the timeline together. P16

Well, I think, I think I first was introduced to it two years ago, or maybe three years ago ... and it took at, a, a weight off, off, because I hate trying to remember when this happened and that happened, alright, so I carry it all the time in my purse in case, um, and, and, I, something should happen, and somebody needed the information. You know, I went to a chiropractor recently and you just hand, *you don't have to go through that garbage when you start out, so I, it's been a real relief to me. Except when I couldn't get into it, I was really frustrated. P26*

I've always tried to keep a list of my meds. And the only problem I have now, they put them in a MedCat box for me at the pharmacist now. Cause I thought, man, I've got 25, 30 pills. ... And, I have trouble remember which ones I for which, just what time of day they are and the hole. You know? [laughs]. And um, I used to be able to keep track of it real good, but now I don't, I just let them do it. And because the labels are not on an individual bottle and I don't set them up the same way, I am lost. And then Medicaid will change, every month, they'll change on the meds that they'll accept and they'll have to, give you a different brand or something, that's cheaper. And it's a different color, or a different shape. I wish they did, like they do at the U at the pharmacy there, and had pictures of the pill. ... Lots of times I have to call the pharmacy, what's this one in here? Is this the same thing as that? Sometimes they'll put a sticker if it's a new one, but the next month they don't. P28

Well, having put it on computer and it would be in one place. You could go to your doctor or various doctors and have them just pop it up on computer, rather then go through the piles of papers. P31

Appendix FF: Sample Quotations of Participants Interested in Management Who Were Not Using the E-Medicine PHR

> *Cause that's what I deal with mostly now. Is medications and doctor visits, and like I said, um, um, why I am going to the doctor, what I got out of going to the doctor, and, stuff like that. Medications are important when you get my age, so you'd want to update them cause they change all mine around, not that long ago, in May. P04*

> *If I had my own computer, you know, I could do it myself. You know, that would be fun for me to do, I just never did it, never thought about it. Cause I kept files on everything. P04*

> *You might be able to make charts and graphs. You might be able to track something like your weight over time. Um, which would encourage you if you were losing weight. If you had diabetes you could track your blood sugar, you know, you know over time. Um, you could communicate with your doctor by e-mail, swapping information back and forth. Um, your doctors if they were in the same system, like the UW Med system, could communicate with each other. But they can do that already, if they are in the same system. ... Um, but I imagine that you can manipulate the data, you know, like with these charts and graphs that I mentioned, that would possibly provide you with new information, or at least present it in a new way that might give you new ways of looking at your health data. P09*

> *Well, basically it's a conglomerate of what all of your doctors are saying about your situation and your condition. And that way, if you have a good general practitioner that person can organize all that and say ok, these are what your*

problems are currently, or were in the past, so what is your problem today and how it relates to that. That way they can come to a concise, hopefully, and good diagnosis of what's happening with you right now. P20

Well, basically, as far as I know, you're keeping, um, people are putting their information, their pills, their problems, etc. etc. etc, doctor's names, into an, form that you designed and so they can keep track of that and of course print it out when they need to go to the doctor. That is for the patient's benefit and the doctor's benefit, takes less time at the doctor's. P20

My understanding is that you folks use that information in an aggregated form, to do whatever you do with it. Which, that was what bothered me. Cause I couldn't get a straight answer out of the people as to what you were doing with it, and on top of that the original people who came were not just like nurses or students or anything, they were actually from the genetics department and that bothered me too. Why are geneticists doing this.[24] *P20*

Well, you can keep track of what's going on with you physically and down the year. And say, ok, not only have you had this and gotten over it, and you should have antibodies built up against this, this, and this, but also you can keep track of your allergies. Cause allergies change over the years. You can also keep track of any injuries down the road, and that way you can say, ok, I've sprained my ankle 16 times, why? What is going on that you've sprained it 16 times? And or if you keep having the same symptoms, then you can not only track the number of times per year you have these symptoms, ok, why does this continue to happen, to these, this particular person. P20

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[24] The original E-Medicine research project was started by the Bioengineering department. This participant mistakenly thought it was the Genetics department. During the course of the interview, I clarified what bio-engineering was. However, the underlying issue stays the same, no one was able or willing to answer her question about the entities involved in the project and what was done with the data.

CURRICULUM VITAE

ANNA STOLYAR

EDUCATION:

2004 - 2011	Ph.D. in Biomedical and Health Informatics University of Washington, Seattle, WA Advisors: Michael Eisenberg, Ph.D. and Wanda Pratt, Ph.D.
2001 - 2004	B.S. in Informatics University of Washington, Seattle, WA Advisor: Batya Friedman, Ph.D.

PUBLICATIONS:

2009	Kim, E.H., **Stolyar, A.**, Lober, W.B., Herbaugh, A.L., Shinstrom, S.E., Zierler, B.K., Soh, C.B., Kim, Y. August 26, 2009. Challenges to Using an Electronic Personal Health Record by a Low-Income Elderly Population. *Journal for Medical Informatics Research, 11*(4), e44.
2008	Kahn, P.H., Friedman, B., Gill, B.T., Hagman, J., Severson, R.L., Freier, N.G., Feldman, E.N., Carrere, S., **Stolyar, A.** May 8, 2008. A plasma display window? – The shifting baseline problem in a technologically-mediated natural world. *Journal of Environmental Psychology, 28*(2), 192-199.
2007	Kim, E-H., **Stolyar, A.**, Lober, W.B., Herbaugh, A.L., Shinstrom, S.E., Zierler, B.K., Soh, C.B., Kim, Y. November 12, 2007. Usage Patterns of a Personal Health Record by Elderly and Disabled Users. Paper presented at the American Medical Informatics Association Annual Symposium, Chicago, IL.
2006	Civan, A., Skeels, M.M., **Stolyar, A.**, Pratt, W. November 15, 2006. Personal Health Information Management: Consumers' Perspectives. Paper presented at the American Medical Informatics Association Annual Symposium, Washington DC.
2006	Lober, W.B., Zierler, B., Herbaugh, A., Shinstrom, S.E., **Stolyar,**

	A., Kim, E-H., Kim, Y. November 14, 2006. Barriers to the use of a Personal Health Record by an Elderly Population. Paper presented at the American Medical Informatics Association Annual Symposium, Washington DC.
2006	**Stolyar, A.**, & Lober, W.B. May 16, 2006. Preliminary Observations of Diabetes Support Groups to Inform Personal Health Record Design. Poster presented at the American Medical Informatics Association Spring Congress, Personal Health Records Track, Phoenix, AZ.
2006	**Stolyar, A.**, Lober W.B., Drozd, D.R., Sibley, J. April 3, 2006. A Patient-centered Health Record in a Demonstration. Poster presented at the Transdiciplinary Conference on Distributed Diagnosis and Home Health Care (D2H2), Arlington, VA.
2005	**Stolyar, A.**, Lober, W.B., Drozd, D.R., Sibley, J. 2005. Feasibility of Data Exchange with a Patient-centered Health Record. Poster presented at the American Medical Informatics Association Symposium, Washington DC.
2005	Tran, DT., Zhang, X., **Stolyar, A.**, Lober WB. 2005. Patient-centered Design for a Personal Health Record System. Poster presented at the American Medical Informatics Association Symposium, Washington DC.
2004	**Stolyar, A.**, Johnson-Crowley, N., & Kedzierksi, M. 2004. Health Information and Addiction Recovery: An Interprofessional Community-Campus Partnership. Poster presented at the Undergraduate Research Symposium, University of Washington, Seattle, WA.
2004	Johnson-Crowley, N., **Stolyar, A.**, & Kedzierksi, M. 2004. Challenges of Meeting the Goals and Needs of an Interprofessional Community Campus Partnership. Paper presented at the All Together Better Health Symposium, University of British Columbia, Vancouver, BC.
2003	Hendrickson, A., **Stolyar, A.**, Kahn, P.H., Friedman B., Carrere, S., Hagman, J. 2003. Physiological Effects of Viewing a Plasma Display "Window". Poster presented at the Undergraduate Research Symposium, University of Washington, Seattle, WA.

2003	**Stolyar, A.**, Doan, K., & Lau, H. 2003. Online Ottoman Historical Dictionary (OHD). Poster presented at the Undergraduate Research Symposium, University of Washington, Seattle, WA.

SELECTED RESEARCH EXPERIENCE:

2007 - 2008	Intel Research, Seattle Advisor: Beverly Harrison Research Focus: Investigation of situated activities by elders in their homes, "SmartHome" applications for the elderly, use of RFID tags to track object usage.
2004 - 2007	National Library of Medicine Research Fellow Biomedical and Health Informatics, University of Washington Advisor: William Lober, M.D. Research Focus: Personal Health Record (PHR) design, implementation and evaluation, interoperability of PHRs with clinical information systems.
2002 - 2003	Information School, University of Washington P.I.: Batya Friedman, Ph.D. Research Focus: Effects of using plasma display technologies as a substitute for a natural window, impact of using a plasma display "window" on physiological and cognitive function.

HONORS/AWARDS:

2007	Healthcare Information Management Systems Society (HIMSS) Ph.D. Scholarship Recipient
2004 – 2007	National Library of Medicine (NLM) Pre-Doctoral Fellowship Recipient
2004	Excellence in Informatics Student Award, Information School, University of Washington
2004	Mary Gates Leadership Scholar, University of Washington
2003	Mary Gates Research Scholar, University of Washington