# Design Guidelines for an Integrated PHR System: An Approach for UI Designers to Break Down Individual-Level Barriers to PHR Adoption

by

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#### Abstract

The objective of this study is to analyze personal health records (PHR) and how they should be implemented from a primary user's point of view. The significance of the quality of healthcare information has been recognized in the health care field. How will health information reach people, including patients, health care providers, employers, and etc? How can information flow seamlessly among systems in a secure environment? In the case of individuals, how can one access, manage and share his/her health information with authorized health providers? To answer those questions, PHR plays a crucial role here. User interface design is essential for improving the usability of interactive systems like PHRs. Creating design guidelines and principles for PHR systems is an emerging need due to the reality that in the current health care environment, multiple vendor systems coexist and each of them has unique styles and design constructs. Therefore, the UI responsibilities in the process of PHR system design must be recognized by UI designers who work in the related fields. In this study, two PHR applications are examined; rules will be applied to a PHR system design prototype to demonstrate how constructing and integrating of intuitive graphic design is carried out, and how to make PHRs more user-friendly by incorporating users' daily activities into personal health decision making and medical care.

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### List of Abbreviations

AMC Academic Medical Centers

CDO Care Delivery Organization

CMS Centers for Medicare and Medicaid Services

COTS Commercial-off-the-Shelf

CPOE Computerized Physician Order Entry

CPR Computer-based Patient Record

EHR Electronic Health Records

EMR Electronic Medical Records

HCI Human Computer Interaction

HIMSS Health Information and Management Systems Society

HIT Health Information Technology

iPHR Integrated Personal Health Records

IT Information Technology

NIH National Institutes of Health

PHR Personal Health Records

ROI Return of Investment

### Glossary

<u>EHR</u>: The Electronic Health Records (EHR) is a longitudinal electronic record of patient health information generated by one or more encounters in any care delivery setting.

<u>EMR</u>: The Electronic Medical Records (EMR) is an application environment whose content can only be used by health care practitioners within a care delivery organization (CDO); it is owned by the CDO; and it is not interactive although it might allow patient access to some information through a portal.

<u>PHR</u>: A Personal Health Records system is an electronic application through which individuals can access, manage and share their health information, and that of others for whom they are authorized, in a private, secure, and confidential environment (Tang, 2006).

<u>Paper-based PHR</u>: In paper-based PHRs, personal health information is recorded and stored in paper format. It usually include clinical notes accumulated from various care providers, laboratory reports and health histories are often compiled by health care consumers in envelopes, loose-leaf binders or even shoe boxes.

Electronic PHR: In electronic PHRs, personal health records are stored and organized in various electronic formats. Basic electronic personal health records are initiated and maintained by individuals, often to help them manage a chronic illness; they can include lifelong personal health information and can be used with or without the participation of health care providers. By media technologies, it can be further categorized into two groups, Device-based PHR/ Software-based PHR and Internet-based PHR/ Web-based PHR. By the dependency of electronic PHRs to

EHRs, it can be categorized into Free-standing PHR/ Independent PHR/ Stand-alone PHR and EHR-PHR.

<u>Device-based PHR/Software-based PHR</u>: In software-based PHRs, personal health records are usually stored in devices such as USB, smart card, CD. Therefore, they are also called device-based PHRs.

<u>Internet-based PHR/ Web-based PHR</u>: in web-based personal health records systems, users can access, view and manage their personal health records through Web sites or an application that is accessed over a network such as the internet or an intranet. It can be categorized into two types, independent PHR/ stand-alone PHR and EHR-PHR/integrated PHR.

<u>Free-standing PHR/ Independent PHR/ Stand-alone PHR:</u> This PHR model is often Personal-computer-based and requires manual data entry to populate and update the record. The most common ones are either paper-based, personal-computer-based, or enabled by an Internet application.

<u>EHR-PHR</u>: This PHR model is based on the dependency of PHR to EHR(s), so it can be further categorized into Institution-specific, web-based PHR/ Tethered PHR and Integrated/ Interconnected/ Networked web-based PHR.

Institution-specific, web-based PHR/ Tethered PHR: This PHR model is a limited form of the integrated model that connects with a single provider-based EHR system or other institutional database, offering patients access to parts of their electronic health records via web portals.

Integrated PHR/ Interconnected PHR/ Networked web-based PHR (iPHR): These PHRs can be populated with patient information from a variety of sources, including EHRs, insurance claims, pharmacy data, and home diagnostics and can provide consumers as well as providers with a more complete view of relevant health information.

### 1. Introduction

#### 1.1 Problem Statement

How to construct documentation plans and build highly efficient communication systems in health fields have been long discussed issues (Rice & katz, 2001; Krizack, 1994) in the United States of America. Health information technology (HIT) is "the application of information processing involving both computer hardware and software that deals with the storage, retrieval, sharing, and use of health care information, data, and knowledge for communication and decision making" (Brailer & Thompson, 2004).

HIT includes, according to a study about the adoption of technology in the United States (Furukawa, 2008), electronic medical records (EMR), clinical decision support (CDS), computerized physician order entry (CPOE), bar-coding at medication dispensing (BarD), robot for medication dispensing (ROBOT), and automated dispensing machines (ADM), electronic medication administration records (EMAR) and bar-coding at medication administration (BarA).

There have been reports about the positive impact of HIT in Europe and America. These publications have reported that the increasing use of IT can significantly decrease the occurrence and severity of medication errors in the intensive care unit (ICU) (Claus & Colpaert, 2006); can help caregivers reduce medical errors and enhance patient safety (Chaiken & Meadows, 2002); can facilitate communication between doctors and patients and among medical team members; can advance biomedical research capabilities; can reduce expenses (Hoffman & Podgurski, 2008); and can have a positive impact on medical records staff by providing the opportunity to keep pace with changes available to them (Dill & Marzan, 2001). In addition, an examination of information technology and

its perceived quality issues in single system hospitals in the United States, "the significance of quality of information in increasing the quality of healthcare and decreasing the cost of healthcare was determined" (Byrd, 2009). In conclusion, HIT is important to address the nation's healthcare challenges.

### 1.2 Need for Study

The Obama administration has set a goal of computerizing all of America's medical records within five years (2011) as a means of improving efficiency, quality, and safety and ultimately money saving. The economic recovery package recently signed into law by President Obama will provide bonus payments of \$44,000 to \$64,000 to physicians who adopt and effectively use Electronic Health Record (EHR) systems from 2011 through 2015, and it is likely that penalties will then be introduced for physicians who do not adopt the technology.

While EHR systems are attracting significant attention, they raise questions as well. How will health information reach people, including patients, health care providers, employers, and so forth? How can information flow seamlessly among systems in a secure environment? Especially for individuals, how can one access, manage and share his/her health information with authorized health providers? To answer those questions, PHR plays a crucial role here. There are different opinions regarding how PHR systems should be implemented. The concept of integrating web-based PHRs with institutional EHRs is becoming the trend (Lee & Tang, 2009).

### 1.2.1 *The Importance of EHRs*

With time, it has become clear that the task of implementing EHRs presents multiple challenges, including rapidly rising costs, a high number of avoidable medical errors, and productivity losses due to inefficiencies and waste. A series of reports from Institute of Medicine (IOM) identified a crisis of system failure and called for information technology to transform healthcare. While EHR is hardly the sole answer to these challenges, it can help deliver better quality healthcare for each dollar spent. The EHR can also improve public health capabilities by enabling anonymous information to be shared for disease management and research purposes. An EHR can help reduce the gap from science to service by improving collaboration and communication between the research setting and real-world clinical practice (McKesson Corp., 2005).

# 1.2.2 What is an Integrated PHR (iPHR)

In today's parlance, a PHR typically refer to a computer-based record – either a free-standing/ independent/stand-alone product which are accessible on the Internet or on a USB drive, or one that is integrated with the provider's electronic health record (EHR). While the uptake of free-standing/ independent/ stand-alone PHRs has been slow, a growing number of patients actively user integrated PHRs (Detmer, 2008).

Integrated PHRs are essentially portals into the EHRs of patients' health care providers. They are populated with patient information from a variety of sources, including EHRs, insurance claims, pharmacy data, and home diagnostics and can provide consumers as well as providers with a more complete view of relevant health information.

Notably, the advantages of PHRs for providers depend on the PHR being integrated with the provider's EHR. Many of the putative financial benefits of PHRs only occur when PHRs are tightly integrated with EHRs, so that seed funding of PHRs in practices that operate an EHR might advance PHR adoption to the "tipping point."

PHRs must link to information from multiple EHRs across networks. One potential key for moving ahead with EHR adoption in the United States is for the Centers for Medicare and Medicaid services (CMS) to provide incentives for EHR use; if this occurs, it will be possible to subsequently link PHRs to EHRs to obtain the benefits previously described.

A Robert Wood Johnson Foundation (RWJF) Project Health Design (PHD) Fact Sheet capsulizes the evolution from PHRs to PHRSs:

"Next generation PHRs should pair personal health information with powerful technology tools that interpret people's health data and provide tailored feedback to support their daily health decisions. PHD envisions the PHRs of tomorrow to be part of a broader personal health record system that supports people's different levels of ability to care for themselves, health literacy, familial supports, technological fluency and other factors....The next generation of PHRs lies in their capacity to be coupled with alerts, reminders and other decision-support tools that help people take action to improve their health or manage their conditions."

The relationship between PHRs and EHRs as seen by both patients and clinicians today is shown in Figure 1-1: PHRs should include a subset of patients' medical data subtracted from EHRs, as well as their self-entered information. While the vision for the

future PHRs is shown in Figure 1-2: tomorrow the PHR is becoming a much broader concept than an EHR as more and more self-management and daily observation data is added.

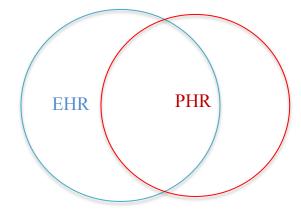


Figure 1-1: PHR Today

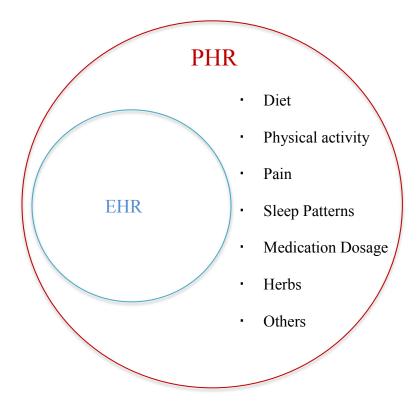


Figure 1-2: Envisioning PHR

## 1.2.3 The Importance of PHRs

Personal health record systems are more than just static repositories for patient data; they combine data, knowledge, and software tools, which help patients to become active participants in their own care. When PHRs are integrated with EHR systems, they provide greater benefits than would stand-alone systems for consumers (Tang and Ash, 2006). Figure 1-1 provides a summary of the benefits of PHRs.

Internet-based personal health records have the potential to profoundly influence the delivery of health care in the 21st Century, by changing the loci and ownership of the record from one that is distributed among the various health care providers a patient has seen in his lifetime, to one with a single source that is accessible from anywhere in the world and under the shared ownership and control of the patient and his or her provider(s) (Sitting, 2002).

While iPHRs are the trend of all PHR types, they improve the quality, completeness, depth, and accessibility of health information provided by patients; enable facile communication between patients and providers; provide access to health knowledge for patients; ensure portability of medical records and other personal health information; and incorporate auto-population of content; promote active, ongoing patient collaboration in care delivery and decision making.

KEY POTENTIAL BENEFITS OF PHRS AND PHR SYSTEMS						
ROLES BENEFITS						
Consumers,	□ Support wellness activities					
Patients and their Caregivers	□ Improve understanding of health issues					
	□ Increase sense of control over health					
	□ Increase control over access to personal health information					
	☐ Support timely, appropriate preventive services					
	Support healthcare decisions and responsibility for care					
	Strengthen communication with providers					
	□ Verify accuracy of information in provider records					
	□ Support home monitoring for chronic diseases					
	Support understanding and appropriate use of medications					
	Support continuity of care across time and providers					
	Manage insurance benefits and claims     Avail during to the state.					
	Avoid duplicate tests					
	Reduce adverse drug interactions and allergic reactions					
	Reduce hassle through online appointment scheduling and prescription refills Increase access to providers via e-visits					
Healthcare Providers	☐ Improve access to data from other providers and the patients themselves					
	☐ Increase knowledge of potential drug interactions and allergies					
	Avoid duplicate tests					
	□ Improve medication compliance					
	Provide information to patients for both healthcare and patient services purposes					
	Provide patients with convenient access to specific information or services					
	(e.g., lab results, Rx refills, e-visits)					
	□ Improve documentation of communication with patients					
Payers	☐ Improve customer service (transactions and information)					
	□ Promote portability of patient information across plan					
	□ Support wellness and preventive care					
	☐ Provide information and education to beneficiaries					
Employers	□ Support wellness and preventive care					
	□ Provide convenient service					
	☐ Improve workforce productivity					
	□ Promote empowered healthcare consumers					
	☐ Use aggregate data to manage employee health					
Societal/Population	□ Strengthen health promotion and disease prevention					
Health Benefits	☐ Improve the health of populations					
	<ul> <li>Expand health education opportunities</li> </ul>					

Figure 1-3: Key Potential Benefits of PHRs and PHR Systems (HHS, 2006)

# 1.3 Literature Review

# 1.3.1 Electronic Health Records (EHR)

According to an American Health Information Management Association (AHIMA) report, a medical record, health record or medical chart is defined as "the legal business

record generated at or for a healthcare organization. This record would be released upon request."

The idea of EHR was created to substantially improve the quality of medical care by making all relevant information available to each practitioner. An EHR is a generic term for all electronic patient care system (Waegemann, 2003). This report uses the Health Information Management System Society's (HIMSS) definition of EHR that reads:

"The Electronic Health Record (EHR) is a longitudinal electronic record of patient health information generated by one or more encounters in any care delivery setting. Included in this information are patient demographics, progress notes, problems, medications, viral signs, past medical history, immunizations, laboratory data, and radiology reports. The EHR automates and streamlines the clinician's workflow. The EHR has the ability to generate a complete record of a clinical patient encounter, as well as supporting other care-related activities directly or indirectly via interface- including evidence-based decision support, quality management, and outcomes reporting."

### 1.3.2 EMR vs. EHR vs. CPR

The electronic medical record (EMR) and the electronic health record (EHR) have been confused in the market, but the differentiation between the two has been clearly defined by HIMSS. EMR is an application environment whose content can only be used by health care practitioners within a care delivery organization (CDO); it is owned by the CDO; and it is not interactive although it might allow patient access to some information

through a portal. On the other hand, an EHR is a subset of each CDO's EMR. It is owned by a patient or stakeholder; and it provides interactive patient access as well as the ability for the patient to append information. Moreover, the EHR environment relies on functional EMRs that allow CDOs to exchange data/information with other CDOs or stakeholders within the community, regionally, or nationally (Garet & Davis, 2006).

EHRs are known by various terms. The computer-based patient record (CPR) is one of the visions of EHR. The CPR is a life time patient record that includes all information from all specialties and requires full interoperability (potentially internationally). However, this is unlikely to be achieved in the foreseeable future (Waegemann, 2003).

The relationship of PHR and EHR has been discussed in "What is an Integrated PHR (iPHR)." To better explain the relations among all three concepts PHR, EMR and EHR, as illustrated in Figure 1-4, there often is significant overlap in the content and functionalities of these records and record systems. There are equally significant differences in purpose and ownership to consider as decisions are made about the National Health Information Infrastructure (NHII) strategy (Stead, 2005).

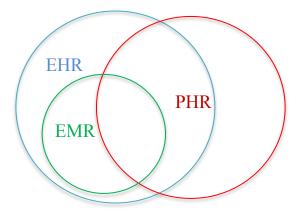


Figure 1-4: Inter-relations among PHR, EMR and EHR today

### 1.3.3 Key Components of EHRs

A report by the National Institutes of Health (NIH), focuses on commercial-off-the shelf (COTS) EHRs that may be appropriate for academic medical centers (AMC). COTS are believed to be a more attractive and cost-effective solution than other options, but some AMCs continue to believe that custom-built EHRs are a better fit than COTS EHRs.

Most commercial EHRs are designed to combine data from large ancillary services, such as pharmacies, laboratories, and radiology, with various clinical care components.

The number of integrated components and features involved in any given AMC is dependent upon the data structures and systems implemented by the technical teams.

The key components of commercial EHRs are administrative system components, laboratory components, radiology components, pharmacy system components, computerized physician order entry (CPOE) and clinical documentation.

### 1.3.4 The Challenges of EHR System Implementation

With an ever-increasing level of computerization, the adoption of EHR has been "enthusiastically promoted" by federal government and health care advocates (Hoffman & Podgurski, 2008). However, in 2008, the results of a survey conducted among all acute care general medical and surgical member hospitals showed that "less than 2% of acute care hospitals have a comprehensive electronic-records system" (Jha & DesRoches, 2009). The fact that the levels of EHR adoption in U.S. hospitals are very low have been noticed and discussed in several scholarly and practitioner articles.

The complexity of EHR systems generates many unanticipated and undesired

consequences of software and hardware failures, financial concerns and adverse patient outcomes (Hoffman & Podgurski, 2008; Harrison & Koppel, 2007).

The risks generated by these complex software systems are sufficiently serious that they demand regulatory over sight. The number one issue is that in some instances, EHR systems may generate errors rather than prevent them, especially during in the adoption process. Many of the errors could significantly harm patients. Some of the errors may cause physicians to absorb financial losses. Secondly, privacy and security concerns have been brought up by both patients and analysts. Thirdly, the introduction of EHR systems into medical practice can involve significant costs and difficulties. Transitioning to an EHR system can also place significant administrative burdens upon health care providers. Last but not least, use of EHR systems may raise important tort litigation questions (Hoffman & Podgurski, 2008).

In one of his articles, C. Peter Waegemann, the CEO of the Medical Records
Institutes of Newton, Mass., generalizes four reasons that so few EHRs are in use: lack of
a framework; lack of motivation; lack of direct benefits for practitioners; confusion about
the concept. He also claimed that three issues, information sharing within an enterprise,
taking advantage of benefits derived from components of EHRs, and patient safety, will
be the driving force of implementation of enterprise-based EMR systems by the majority
of providers (Waegemann, 2003).

To further understand "lack of a framework", a report by HIMSS has the explanation. It reads:

"EHRs use both technical and clinical standards. EHR vendors have been implementing some standards, but have had a great deal of variation in their

implementation methods, which results in systems that cannot interoperate."

In addition, because EHRs are often confused with other terms, such as EMR and CPR, the key benefit of EHRs has also been mistaken as that they require computer entry, but the real key fact is that they streamline processes.

Financial issues, to a high degree, account for the low level of implementation of EHRs. Based on research on current return on investment (ROI) for EHRs in small- to medium-sized physician offices, it usually takes over a year to see a positive number of ROI which highly depends on the level of implementation of EHRs. "The general findings are that ROI can be maximized if common barriers and benefits are addressed at implementation onset (See Figure 2, CMS, 2005)."

EHR ROI Per Physician Per Year over a 5-year Implementation Period

ROI	Year 1	Year 2	Year 3	Year 4	Year 5
Average	-\$21,700	\$21,200	\$14,600	\$47,200	\$47,200
Minimum	-\$11,900	\$8,000	\$4,700	\$20,100	\$20,100
Maximum	-\$26,600	\$41,300	\$31,400	\$85,100	\$85,100

5-Year EHR ROI Per Physician based on range of EHR Features Implemented

Feature	Light EHR	Medium EHR	Full EHR
Online Patient Charts	<b>V</b>	√	√
Electronic Prescribing		<b>√</b>	<b>√</b>
Laboratory Ordering			<b>V</b>
Radiology Ordering			<b>V</b>
Electronic Charge Capturing			<b>V</b>
Average ROI	-\$18,200*	\$44,600*	\$86,400*

<sup>\*</sup>Assumes a 5% discount rate

Figure 1-5: EHR ROI Chart (CMS, 2005)

### 1.3.5 The Role of User Interface Design in EHR Systems

User interface design is a central issue for the usability of a software product. Well-designed graphical user interfaces (GUIs) for business systems can greatly increase user productivity (Galitz, 2002).

EHRs are clinical support tools with the potential to reduce strains on clinician memory and cognition while improving efficiency in workflow and effectiveness in care quality and coordination. The safe, efficient, effective, patient-centered, equitable, and timely delivery of health care services requires tools that organize and display information which places patient data in context, synthesizes that information with available medical evidence, and supports the clinician's decision making process (Armijo, 2009). In order to accomplish these goals, the GUI must be carefully considered.

Several articles have discussed the importance of UI design in EHR systems. How time consuming and problematic an EHR system is depends largely upon its user interface design (Hoffman & Podgurski, 2008). How well an EHR serves its functions in a complex care environment is the direct result of an interface that is designed to collect, organize, and display patient information in a manner that is meaningful to clinicians at the point of care, consistent, and aligned with cognitive workflows. Given the reality that multiple vendor systems, each having unique styles and design constructs, coexist in the current health care environment, creating standard design elements and principles for EHR interfaces is an emerging need (Armijo, 2009).

### 1.3.6 Definition of Personal Health Records (PHR)

Former president Bush and Secretary Leavitt have put forward a vision that, in the Secretary's words, "would create a personal health record that patients, doctors, and other health care providers could securely access through the Internet no matter where a patient is seeking medical care( HHS press, 2005)." In most scholarly articles, PHRs are

described as "an electronic application through which individuals can access, manage and share their health information, and that of others for whom they are authorized, in a private, secure, and confidential environment (Tang, 2006)."

Currently, PHRs and their associated health management tools are heterogeneous and evolving. There is no uniform definition of "personal health record" in industry or government (HHS, 2006). However, the Markle Foundation's Connecting for Health collaborative, a public-private endeavor working toward an interoperable health information infrastructures define PHR as follows:

"The Personal Health Record (PHR) is 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. Individuals access their PHRs via the internet, using state-of-the-art security and privacy controls, at any time and from any location. Family members, doctors or school nurses can see portions of a PHR when necessary and emergency room staff can retrieve vital information from it in a crisis. People can use their PHR as a communications hub: to send email to doctors, transfer information to specialists, receive test results and access online self-help tools. PHR connects each of us to the incredible potential of modern health care and gives us control over our own information."

### 1.3.7 Benefits of PHRs

PHRs have a number of benefits for both consumers and clinicians. For the first group, one of the most important PHR benefits is greater patient access to a wide array of credible health information, data, and knowledge. A critical benefit of PHRs is that they provide an ongoing connection between patient and physician, which changes encounters from episodic to continuous, thus substantially shortening the necessary time to address problems that may arise. Access to more data helps them make better decisions. One way to accomplish this is that patients entering data into their health records can elect to submit the data to their clinicians' EHRs.

### 1.3.8 Barriers to PHR Adoption

As might be expected, there are a number of obstacles to overcome for widescale PHR adoption, including technical issues, environmental barriers, legal concerns, and individual-level barriers. First, technical issues include difficulties with data exchange, authentication of information, and summarization tools. The second barrier, environmental, results from the fact that currently health information on each patient resides in multiple locations. Thus, integrated PHRs must reach across organizational boundaries to interface with multiple EHR systems. A related and equally problematic barrier is that EHRs must not only exist in individual offices and hospitals, but must also be able to communicate with various PHRs. Economic and market forces are obstacles to PHR (and EHR) adoption. Another sensitive issue is that of legal concerns.

While consumers appropriately desire protection of their private health information, aggressive protection measures might hamper PHR access by patients and clinicians and

impede optimal care. Finally, individual-level barriers impede adoption of PHRs. At the level of the individual, healthcare consumers must understand and accept their roles and responsibilities related to their own healthcare. However, consumer-related interfaces, technology, and access issues specific to PHRs are not yet well-understood. Also, the workflow models for both providers and patients are poorly understood. An understanding is necessary of how the PHR can fit into the existing flow of day-to-day activities for both providers and patients. Part of this process includes providers and patients developing different mindsets and levels of trust of each other.

Behavioral change is difficult. In the case of PHR adoption, change management issues involve providers, consumers, and regulators. In each case, there must first be a motivation to change.

*Understanding and Breaking Down the Barriers to PHR Adoption* 

The two main mechanisms for breaking down the barriers to PHR adoption are education and research. Behavioral research can identify optimal educational strategies. Provider sites that currently offer integrated PHRs offer a good starting point to determine which individuals tend to use the PHR, how frequently, and for what purposes, as well as impacts on healthcare and workflows.

As for privacy issue in PHR adoption, basic principles for uses and disclosures of health information have already been defined by HIPAA as follows("Health Information Privacy," 2012): A major purpose of the Privacy Rule is to define and limit the circumstances in which an individual's protected heath information may be used or disclosed by covered entities. A covered entity may not use or disclose protected health information, except either: (1) as the Privacy Rule permits or requires; or (2) as the

individual who is the subject of the information (or the individual's personal representative) authorizes in writing. These principles can be used in guiding transferring health information between individuals, health providers and the third party in legitimate procedures.

### 1.4 Objectives of Study

The primary objectives of the current study are as follows:

- To research the correlations between information technology, patients and hospitals.
- To examine the environment and work flow of personal health management systems.
- Analyze and evaluate existing personal health management systems.
- Identify main components and primary users of personal health records.
- Conduct user research to learn more about user needs and the correlation between design and user experiences.
- Develop new findings and rules for graphic design accordingly for mobile and web-based systems.
- From a primary user's point of view, determine guidelines of how to design an interactive system for hospitals to improve patient safety and hospital quality.
- Present a user interface design to demonstrate the guidelines.

### 1.5 Assumptions

This study utilizes a number of assumptions, described below:

- Since the medical institutions, health insurance system and health-related education in the United Sates cannot represent all such institutions in the world, the research results and theories used in this report cannot be completely applicable in other countries and areas.
- There should be some universal principles and guidelines that are applicable to all medical care places.
- The prototype only demonstrates how the guidelines could be applied to a personal health record design process.
- If any of the time, location or environment in the considerations are changed, the principles and guidelines should be adjusted according to the situation.
- This study is conducted to explore how to visually and logistically design a better experience for PHR users, so legal and financial issues will be discussed but not addressed in the prototype.

## 1.6 Scope and Limits

This study was conducted based on the following scope and limits:

- The focus was to gain more knowledge from the consumer/primary user's perspective, and to guide designers to design a more user-friendly self-health-management system.
- The approach used in this study was to examine different types of PHRs through extensive research and user surveys, and to gather information on various aspects of PHR systems.
- In terms of the geographical scope, this study was conducted in the Unites States

of America. The studied products and participants were chosen in the United States of America

• Due to time limitations, the research of developing a user behavior and thinking mode on how to incorporate user's daily activities into personal health decision making and medical care was not in-depth.

### 1.7 Procedures and Methods

The objective of this study is to analyze PHRs and how they should be implemented from a primary user's point of view. PHR is a multi-disciplinary subject so the study will be conducted in many areas.

To achieve the goals of this study, the following procedures were used:

- Identify and evaluate the trend in PHR systems through existing research and governmental support in terms of policies and funds.
- Learn about different types of PHR tools and systems.
- Research the main components in human-computer interaction.
  - PHR is a type of human-computer interaction. It is important to fully understand the foundations of such systems.
- Research the main components in PHR systems.
  - Identify primary users and PHR tools.
- Analyze existing PHR systems.
  - Examine the interaction media, product technology, functions, features, benefits, problems and existing solutions.
- Conduct primary user research on PHR tools.

- Research online reviews of a health care application for mobile devices.
- Conduct a user survey using questionnaire with a group of health management website users.
- Categorize feedback using standards from previous analysis of existing PHR systems.
- Develop principles and guidelines for an integrated PHR system.
  - New findings and rules for graphic design will be developed accordingly for mobile and web-based systems.
  - Introduce the sequence of use in PHR systems.
  - Design for better PHR experiences.
- Guidelines application and evaluation.
  - An example project will be developed following the guidelines.
  - The project will be evaluated based on the guidelines.
  - A pilot test will be conducted to quickly assess the effectiveness of the guidelines application.

### 2. Human Computer Interaction in Medical Care

#### 2.1 Human-Computer Interaction in General

Human-Computer Interaction (HCI) is the study and the practice of usability of computers. It is about understanding and creating software and other technology that people will want to use, and will find effective when used. (Carroll, 2002). HCI draws on many disciplines and must be accepted as a central system in computer science and systems design. HCI involves the design, implementation and evaluation of interactive systems in the context of the user's task and work (Dix, 2004). HCI is the subfield of Computer Science that studies how people interact with and through computational technologies (Ackerman, 2008). Four largely independent threads of technical development from the 1960s and 1970s provided the foundation that allowed this interdisciplinary program to grow rapidly in 1980s. The four threads were prototyping and iterative development; software technology and human factors; new user interface software; model, theories and frameworks (Carroll, 2002). This chapter examines what HCI's roots are, and studies various approaches to the design of HCI.

#### 2.1.1 Foundations

#### 2.1.1.1 The Human User

When discussing human-computer interaction, this does not necessarily envisage a single user with a desktop computer. A user may mean an individual user, a group of users working together, or a sequence of users in an organization, each dealing with some part of the task or process. The user is whoever is trying to get the job done using the technology available (Norman, 2008). Individuals differ in their capabilities and that

affects the HCI (Ackerman, 2008).

A study conducted by Uruchurtu, Rist and MacKinnon evaluated the extent to which interface affect and familiarity influence learning performance under different interface conditions (cited in Bryan-Kinns, 2006). The results suggest that interface style does has an impact on learners' interface affect which seems to be mediated by perceiving turn, interface affect have an impact on the learning performance. The results also indicate that certain features of the interface design and ultimately the adaptive behavior of a learning system can be matched to the user's individual differences in order to promote positive interface affect and more effective learning.

### 2.1.1.2 The Computer

For HCI to advance a better understanding is needed of the emerging dynamic of interaction in which the focus task is no longer confined to the desktop but reached into a complex networked world of information and computer-mediated interactions (Carroll, 2002). Uses of HCI can be found in three common fields: business applications, home applications, and mobile users. In the rest of the research, all three fields will be discussed over how to develop PHRs.

## 2.1.1.3 Paradigms

The primary objective of an interactive system is to allow the user to achieve particular goals in some application domain, that is, the interactive system must be usable (Dix, 2004). Theories on how to develop an interactive system to ensure its usability, and how the usability can be demonstrated or measure, have long been discussed.

In the Dix's (2004) book *Human Computer Interaction* twelve different paradigms were discussed in order to serve as a history of interactive system development. The paradigms are as follows.

- 1) Time sharing
- 2) Video display units
- 3) Programming toolkits
- 4) Personal computing
- 5) Window systems and the WIMP (windows, icons, menus, pointer) interface
  - 6) The metaphor
  - 7) Direct manipulation
  - 8) Language versus action
  - 9) Hypertext
  - 10) Multi-modality
  - 11) Computer-supported cooperative work
  - 12) The world wide web

In contrast, an article by Harrison (2006), argued that there are three paradigms of HCI (Harrison, 2006): Human-Factors, Classical Cognitivism/ Information Processing Based paradigm, and Phenomenologically-Situated paradigm. All three drive design in different ways. Identifying the three allows a clearer valuation of work. The three paradigms are described in Figure 2-1 below.

	Paradigm 1: Human Factors	Paradigm 2: Classical Cognitivism/ Information Processing	Paradigm 3: Phenomenologically Situated	
Metaphor of in- teraction	Interaction as man-machine coupling	Interaction as information communication	Interaction as phenomenologically situated	
Central goal for interaction	Optimizing fit between man and machine	Optimizing accuracy and efficiency of information transfer	Support for situated action in the world	
Typical ques- tions of interest	How can we fix specific problems that arise in interaction?	What mismatches come up in communication between computers and people? How can we accurately model what people do? How can we improve the efficiency of computer use?	What existing situated activities in the world should we support? How do users appropriate technologies, and how can we support those appropriations? How can we support interaction without constraining it too strongly by what a computer can do or understand? What are the politics and values at the site of interaction, and how can we support those in design?	

Figure 2-1: Paradigms Compared (Harrison, 2006)

In another discussion, Rode and Brumby (2009) explained two paradigms of interaction design, interaction design and experience design. Each of which reflects a different orientation to problem solving and learning. These two approaches align themselves with engineering design and creative design respectively.

In another way to analyze HCI, Beaudouin-Lafon (2004) stated that there are three primary interaction paradigms: computer-as-tool, computer-as-partner, and computer-as-medium. In this article, it was believed that ultimately, all three paradigms must be integrated into a single vision.

In final analysis, the interaction between humans and computers can be enhanced through numerous ways. However, the fundamental tension within HCI is not of design theory, methods, nor cultures of evaluation but is instead an issue of how to frame interaction. After all, as designers, we are designing interaction, not interfaces.

### 2.2 Human-Computer Interaction in PHR Systems

### 2.2.1 The Primary Users

Although social interactions between patients and staff members are obviously important from the perspective of patient satisfaction (Frampton, 2003), based on the nature of PHRs, the patients or people whoever seek medical care are primary users of PHRs, not medical workers such as physicians, nurses and technician.

A national survey among representative sample of 1849 adults on consumers and health information technology documents that there are positive effects from using health IT (Figure 2-2), in particular PHRs, despite currently low usage. It also explores consumers' frustrations with the management of their health care and their attitudes toward health IT more generally. The survey highlights are listed as follows (Undem, 2009-2010).

- About 7 percent of those surveyed say they have used a PHR more than double the proportion identified two years earlier in separate research (Figure 2-2 and 2-3).
- Users are most likely to have a PHR supplied by their health insurer, followed by their doctor/ health care provider (Figure 2-4).
- Half or more of users indicate that the ability to look at test results, renew their prescriptions online, or email their providers is somewhat or very useful. Making sure their information is correct ranks highest in terms of usefulness (Figure 2-5).
- Although higher-income individuals are the most likely to have used a PHR, lower-income adults, those with chronic conditions, and those without a college degree are more likely to experience positive effects of having their information accessible online (Figure 2-10)

- Two-thirds of the public remain concerned about the privacy and security of their health information, but the majority of those who are using a PHR are not very worried about the privacy of the information contained in their PHR (Figure 2-7, 2-8 and 2-9)
- Most PHR users and non-users say privacy concerns should not stop learning how health IT can improve health care.
- More than half of adults are interested in using online applications to track health-related factors, and almost half are interested in medical devices that can be connected to the Internet. Of those who do not have a PHR, 40 percent express interest in using one (Figure 2-11).
- Having trust in the organization that provides the PHR is a top factor in signing up for one. More than half of non-users say they would or might sign up if their doctor expressed confidence in the safety of information in a PHR (Figure 2-9).

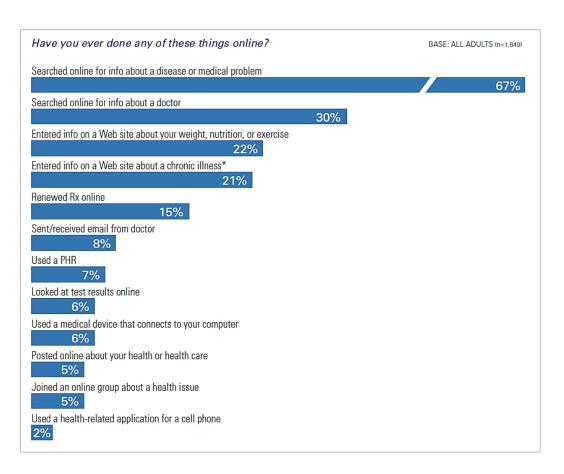


Figure 2-2: Overview of Consumers' Use of Health IT. Note: \* Among those with chronic illness.

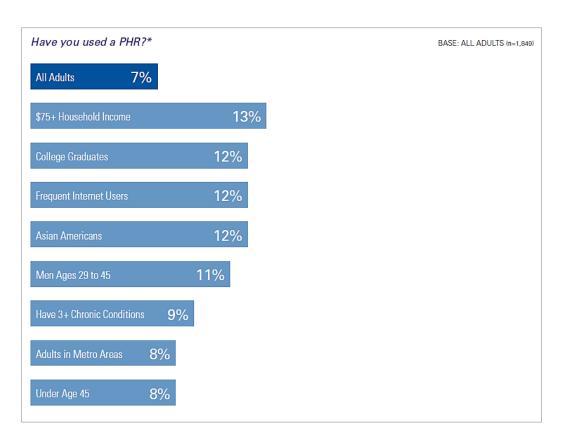


Figure 2-3: Use of PHRs, by demographic groups (Undem, 2010).

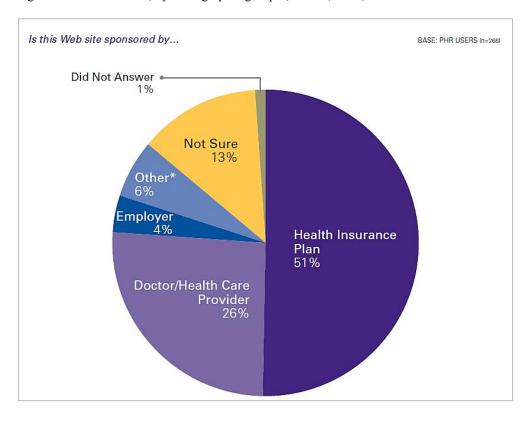


Figure 2-4: Sources of PHRs. Note: Percentages don't add to 100 percent due to rounding. Other

includes online sources such as WebMD and ihearthrecord.org.

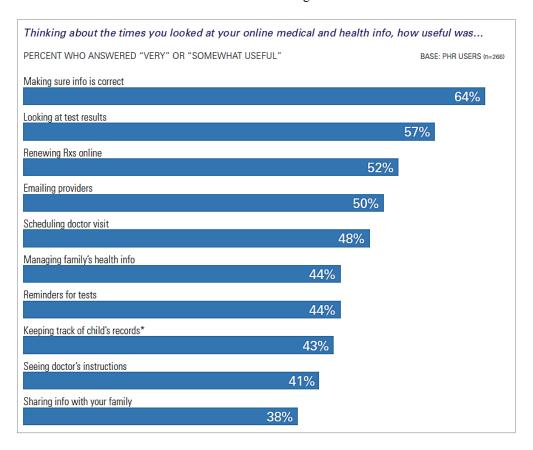


Figure 2-5: What is Useful about a PHR?

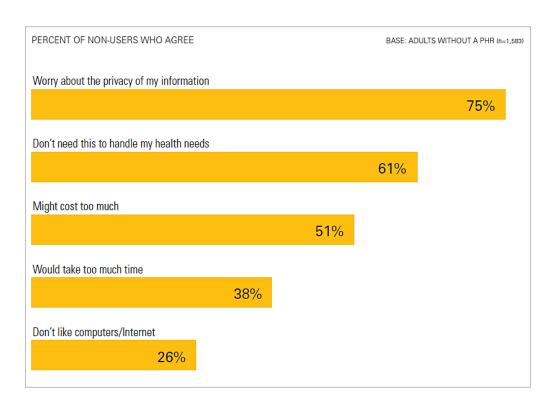


Figure 2-6: Potential Barriers to Using a PHR

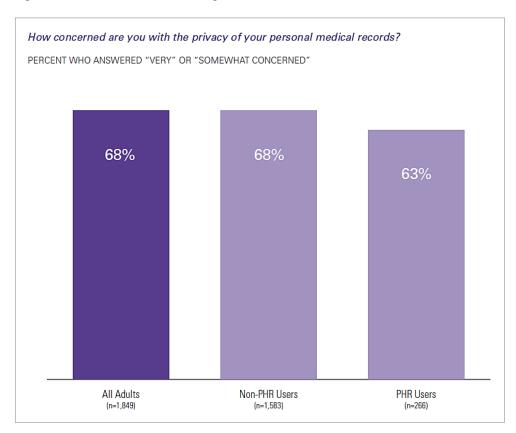


Figure 2-7: Attitudes About Privacy of Medical Records

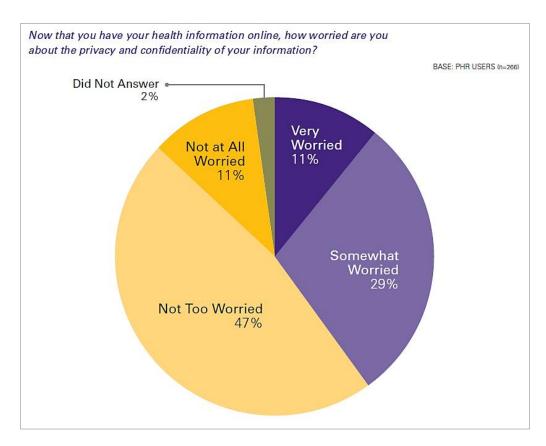


Figure 2-8: PHR Users' Attitudes about Privacy of Information in Their PHR

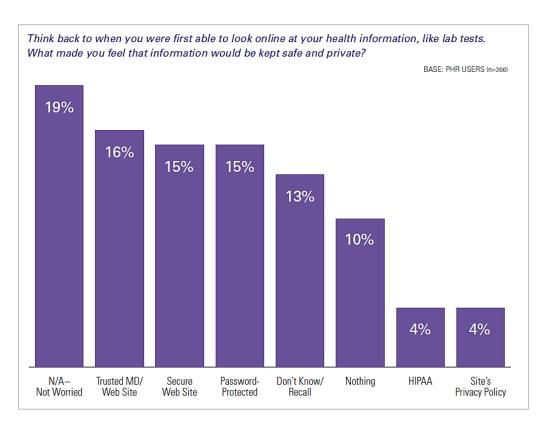


Figure 2-9: What reassures PHR Users About Privacy Concerns?

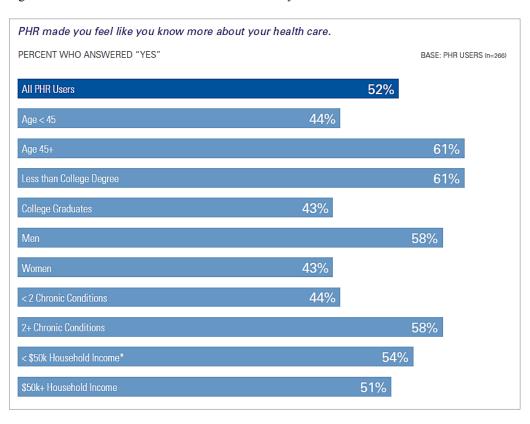


Figure 2-10: Users' Knowledge about Their Health Care as a Result of PHR, by Demographic

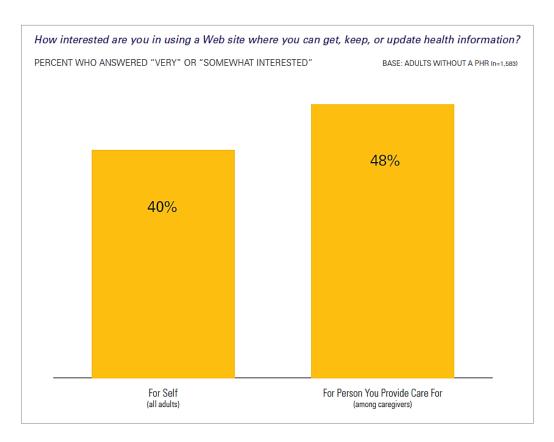


Figure 2-11: Non-Users' Interest in Using a PHR

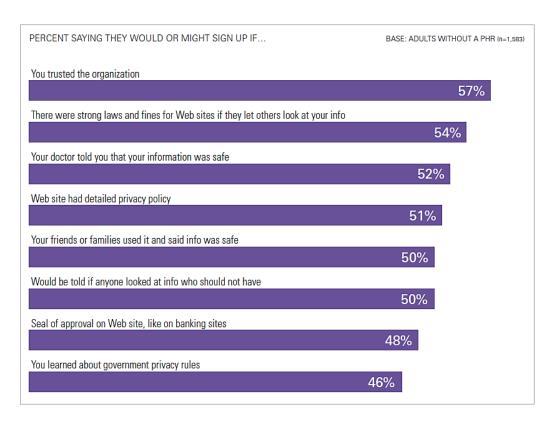


Figure 2-12: Factors that Would Encourage Signing Up for a PHR

Since people with chronic diseases have a higher chance using PHRs, it's important to know the characteristics of this group of people. The patient is the person who seeks professional help. Almost every person becomes a patient at some time. Understanding the patient's predicament helps design a system that responds more respectfully (Purtilo, 2002). Most challenges facing patients are related to the altered role of chronically sick persons in society and to the physical and mental changes a patient experiences in the transition of everyday routine. Common themes among chronically ill patients include maintaining wellness, reckoning with change, loss of former self-image, and special challenges of inpatients.

The necessity for spending time confined in a health care facility may significantly disrupt an individual's personal life, as well as the lives of family, occupational

associates, and friends. Whatever the individual's personal responsibilities, he or she is likely to be affected both socially and economically. In addition to the disruption, a person is often aware that entering the hospital signals that he or she is not winning the battle of coping with an illness. This psychological defeat can be as deleterious to her or his welfare as the physical manifestations of the illness itself.

With the rapid development of technologies and the growing usage of health applications on various devices, PHRs provide various ways of communication between health care providers and patients with diseases, or people with diseases, or people who simply need medical information.

#### 2.2.2 Existing PHR Systems

Many healthcare information technology vendors and healthcare providers already have the tools available to offer PHRs to their customers and patients. Based on existing PHR specific literature, this section will focus on the fundamentals of PHRs: the background, paradigms, models, functionality, and benefits.

### 2.2.2.1 PHR Background

PHRs are consumer-centric tools that can strengthen consumers' ability to actively manage their own health and health care. Although the capabilities of PHRs vary significantly in the current marketplace, they typically include provisions to capture information about an individual's diagnoses, medications, allergies, lab test results, immunization records, and other personal health information. Many PHRs also provide communication tools to assist patients in connecting with various health care

professionals, such as requesting an appointment and requesting prescriptions.

The concept of a PHR is not new. Individuals and families have used personal health records for decades because they needed one place to store and access their complete medical history. Those paper-based documents including clinical notes accumulated from various care providers, laboratory reports and health histories are often compiled by health care consumers in envelopes, loose-leaf binders or even shoe boxes.

With the emerging of computer technology, basic electronic personal health records emerged as people began collecting personal health information and entering it into computer-based, word processing templates or spreadsheet application. These records are initiated and maintained by individuals, often to help them manage a chronic illness; they can include lifelong personal health information and can be used with or without the participation of health care providers.

To generalize, there are two basic formats of PHRs: paper-based PHRs and electronic PHRs. Paper-based PHRs are the first, the most common and widely used PHRs (Jones & Shipman, 2010). In paper-based PHRs, personal health information is recorded and stored in paper format. Paper-based PHRs may be difficult to locate, update and share with others. They are also subject to loss and damage, such as a natural disaster. Paper-based PHRs can be printed from electronic PHRs.

The most basic form of electronic PHRs would be a health history created in a word processing program. It can be copied, printed and shared with anyone with a compatible word processor. One commonly seen example is the USB-based PHRs. Each is designed to be attached to a keychain or lanyard and carried with a patient. It has the capabilities of storing a variety of health information, and each offers password security

and encryption. One example is the 911 Medical ID, which is an USB electronic data card developed and manufactured by MEMI Tech LLC, a company based in Louisville, Kentucky (911medicalid, 2012).



Figure 2-13: 911 Easy to Use Solution

In today's parlance, a PHR typically refer to a computer-based record – either a free-standing/ independent/stand-alone product which are accessible on the Internet or on a USB drive, or one that is integrated with the provider's electronic health record (EHR). While the uptake of free-standing/ independent/ stand-alone PHRs has been slow, a growing number of patients actively user integrated PHRs (Detmer, 2008).

#### 2.2.2.2 PHR Models and Paradigms

Today, there is a spectrum of dominant PHR models (Sprague, 2006). Some PHRs are available for anyone who wishes to use them, while others required enrollment in a particular health plan and/or under a particular employer or with a particular provider (Jones & Shipman, 2010). Figure 2-14 shows that there are three main categories for PHRs: Individually maintained, "tethered" to a health plan or employer, and

comprehensive. As a result, three primary PHRs models are identified as well: free-standing/ independent/stand-alone PHRs, institution-specific, web-based PHRs/ tethered PHRs, and integrated/ interconnected/ networked web-based PHRs.

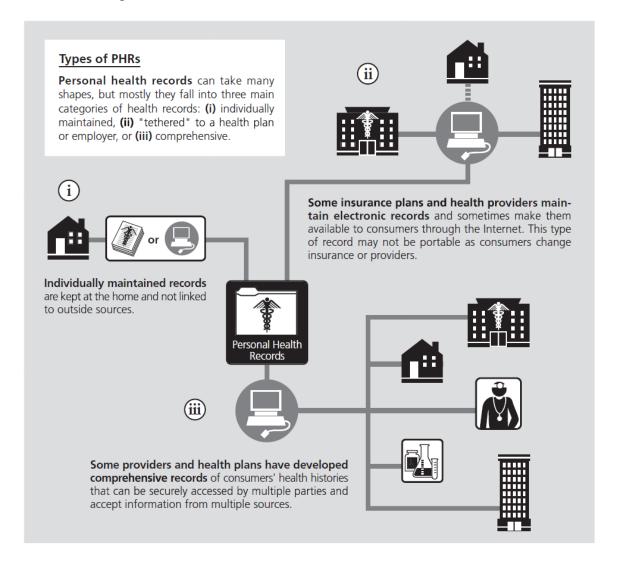


Figure 2-14: Types of PHRs

Free-standing/ independent/stand-alone PHRs are often personal computer-based and require manual data entry to populate and update the record. The most common free standing PHRs are either paper-based, personal computer-based, or enabled by an Internet application. Key limiting factors of using a free-standing PHR are that manual

data entry is typically required to populate and update the record and practitioners may question the accuracy and completeness of self-entered information. For example, My Family Health Portrait (see Figure 2-15) is a web-based PHR that uses an Internet browser on a user's personal computer. It claims that a user can access it on the web and fill out forms easily, then it will generate assemble the information and generate a family tree. As an internet-based tool, it helps health care providers provide better care for the users. In addition, like paper-based records, non-web-based PHRs such as a USB-based PHR, are vulnerable to destruction, theft, and loss

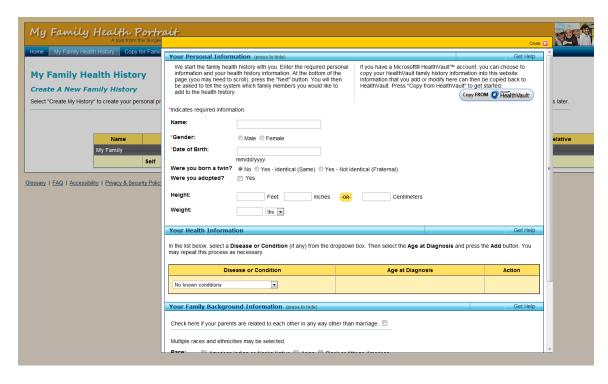


Figure 2-15: My Family Health Portrait

Institution-specific, web-based PHRs/ tethered PHRs are a limited form of the integrated model that connect with a single provider-based HER system or other institutional database, offering patients access to parts of their electronic health records via web portals. For example, AG Family Medicine (see Figure 2-16) is a medical care

facility based in Suwanee, GA. It provides patients a web portal where patients can login to see their records. These PHRs are a patient-facing extension of the clinician-controlled HER, accessed via the internet. Patient data are under the physical control of the health care provider; however, in some systems, consumers can add to or annotate portions of the records.



Figure 2-16: AG Family Medicine

Integrated/ interconnected/ networked web-based PHRs (iPHRs) can be populated with patient information from a variety of sources, including EHRs, insurance claims, pharmacy data, and home diagnostics and can provide consumers as well as providers with a more complete view of relevant health information. The consumer is an important contributor to the integrated PHR content and is typically allowed to enter information

into selected areas of the record. Integrated PHRs provide access for consumers to provider-based records; may eliminate duplication, and improve quality; enhance efficiency and convenience with online transaction tools; and promote a more comprehensive view of health status and health care activity. Some iPHRs are offered in connection with services related to a specific health condition or disease and feature patient data integrated with personalized health advice and guidance. For example, ePHR (see Figure 2-17) is a PHR website which enables consumers to proactively ensure that their health providers have the latest information to guide them in their decision making. It provides the consumer with an intuitive web-based application to create, view, store and share healthcare information about themselves or on behalf of those they look after; to communicate with their care providers; and to access needed health-related information relating to their specific conditions through the power of the internet; and to simply perform mundane tasks, like re-filling a prescription for themselves or one of their dependents.

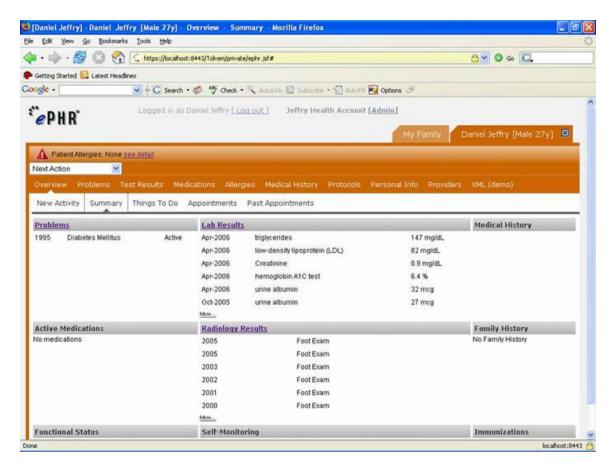


Figure 2-17: ePHR User Interface

Like many other types of HIT, a PHR consists of three primary components: data, infrastructure, and applications. For example, data includes healthcare claims information, laboratory and imaging results, medication history, and lists of patients' medical problems. Infrastructure is the computing platform(s) which exchange and process healthcare data. Lastly, applications include data exchange and transactional capabilities such as appointment scheduling and medication renewals; analytical capabilities such as patient decision support; and content delivery capabilities such as patient=oriented care guidelines or disease education materials. All three components are critical for effective health information systems and interoperability between health

information systems. The PHR functions exist in the PHR infrastructure and applications and process data used in the PHR

One paradigm (Kaelber, 2008) for a PHR is to envision a PHR system as a hub and spoke model, with a patient-controlled PHR at the center connected to different stakeholders who exchange data and interact with patients (see Figure 2-18). In this paradigm, the PHR becomes more valuable when the hub is bigger with more and thicker spokes.

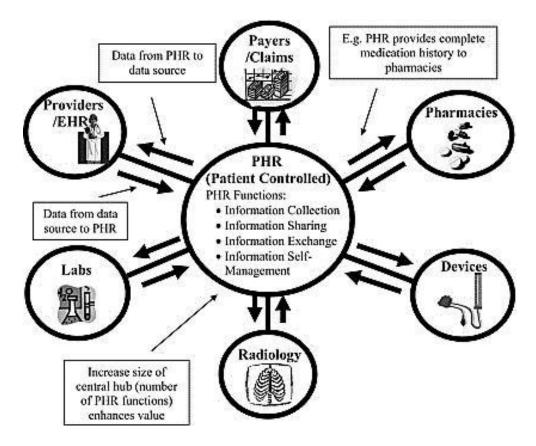


Figure 2-18: Idealized hub and spoke concept of a PHR system

This PHR paradigm can be adapted to other PHR models. For example, tethered PHRs might be considered in the hub and spoke model with just one thick spoke. An independent PHR could be envisioned as a hub without any spokes. A claims-based PHR

could have more data than an independent PHR, but would be unlikely to have as much as a provider-tethered PHR. The relative advantages and disadvantages of different types of PHRs and how a complete hub and spoke PHR system would be developed vary depending on how specific patients receive care and have not been rigorously evaluated from a research perspective (Kaelber, 2008)

Moreover, as with other types of HIT, interoperability is an essential component in PHR architecture. Interoperability refers to the ability of systems to interact with one another and exchange data according to a prescribed method in order to achieve predictable results (Detmer, 2008). If, like discussed in "need for study", PHRs are to be viewed as central data repositories of a patient's data, then interoperability, both in terms of importing information into a PHR and exporting information from a PHR is critical.

#### 2.2.2.3 PHR Functions & Features

PHRs can be kept in many forms, and the content will differ from patient to patient. However, there are some key pieces of information that should be included in every PHR (AHIMA, 2012):

- Personal identification, including name, birth date, and Social Security number
- People to contact in case of emergency
- Names, addresses, and phone numbers of physician, dentist, and other specialists
- Health insurance information
- Living wills and advance directives
- Organ donor authorization
- A list and dates of significant illnesses and surgeries

- Current medications and dosages
- Immunizations and their dates
- Allergies
- Important events, dates, and hereditary conditions in family history
- A recent physical examination
- Opinions of specialists
- Important tests results
- Eye and dental records
- Correspondence with providers
- Permission forms for release of information, operations, and other medical procedures
- Any other miscellaneous information about patient health such as exercise regimen, herbal medications, and any counseling

While most PHR products have some common elements, their features can vary (Pagliari, 2007), including some of the following.

- Access to provider's electronic clinical record (summary or detailed)—e.g. history, drugs, test results
- Personal health organizer or diary—e.g. clinics, doctors, tests, dates, non-prescribed treatments,
  - scanned documents
- Self-management support—e.g. care plans, graphing of symptoms, passive biofeedback, tailored
  - instructive or motivational feedback, decision aids, or reminders

- Secure patient-provider communication for booking appointments, reordering prescriptions, or seeking
  - advice (e.g. patient-doctor email)
  - Links to static or interactive information about illness, treatments, or self-care
  - Links to sources of support—e.g. patient organizations or virtual peer networks
- Capture of symptom or health behavior data—by self-report or objective monitoring through electronic
  - devices (fixed or portable)

### 2.2.2.4 PHR Benefits

There are a number of benefits to consumers who use PHRs. One of the most important is greater access to credible health information, data, and knowledge, which patients can use to improve their health and manage diseases. For those patients with chronic illness, a PHR will allow better tracking of their diseases in conjunction with their providers, thus promoting earlier interventions when encountering a deviation or problem. The improved communication of a PHR will allow patients and caregivers to more easily ask questions, set up appointments, requests prescription refills and referrals, and report problems. These systems also allow caregivers, such as family members, to provide better care for patients. Finally, because patients value ready access to test results and improved communication with physicians, PHRs are valuable in that they promote communication between patients and their healthcare providers (Groen, 2008).

Other potential benefits of PHRs include several facets of patient empowerment,

such as enhanced responsibility for health maintenance and self-care, better compliance with treatment plans, increased participation in decision making, greater health knowledge, health gains, quality of care, and a reduced burden of care. In terms of quality of care, PHRs allow improved relationships, communication, and trust with healthcare professionals, more flexible access to services, increased patient safety, reduced provider liability, and tracking of hidden patient behaviors and medicine use. The burden of care is reduced for both patients and healthcare providers due to fewer unnecessary visits and reduced waiting times, lower costs due to better health and reduced use of services, and reduced provider liability through increased safety and health self-management (Pagliari, 2007).

## 2.2.3 Problem Identification

#### 2.2.3.1 Consumer Confidence and Trust

Although results from recent surveys suggest that Americans are increasingly interested in the use of electronic health records to help improve their health care experiences and reduce costs, perceived public concerns about security and confidentiality are still a major barrier to the electronic exchange of personal health information.

A 2005 survey found that consumers rank the following issues as the absolute top priorities regarding the attributes of a health information exchange network (Markle Foundation ,2005).

• The identity of anyone using the system would be carefully confirmed to prevent any unauthorized access or any cases of mistaken identity.

- Individuals would be able to review who has had access to their personal health information.
- Only with an individual's permission could medical information be shared through a network.
- Employers and insurance companies would not have access to secure health information exchange networks.

## 2.2.3.2 Lack of technical Standards for Interoperability

As discussed in "PHR Models and Paradigms", interoperability poses significant challenges and research opportunities, including assessment of the limitations of specific standards and data reliability. Several standards c=necessary for integrated PHRs are described below (Detmer, 2008).

- Data interchange standards. The codification of data, the structure and format of messages, and the health care vocabularies that promote comparable and consistent information.
- Common data set/minimum data set. A core data set to ensure that a minimum amount of data is available to consumers and providers for self-care and clinical encounters, such as patient and provider identification, insurance information, allergies, medications, and diagnoses. A default set of fields will likewise have implications for PHR developers, EHR developers, and custodians of professionally-sourced health data, such as health plans, pharmacy benefits managers, and retail pharmacies (Markle Foundation, 2004).
  - Consumer terminologies. Use plain language for consumers.

- Identification processes. Positive patient identification processes and systems to facilitate networking of patient information, to avoid breaches of confidentiality, and to avoid preventable medical errors (Lee, 2005; Gray, 2006; Bittle, 2007; McDonald, 2006).
- Security standards. Administrative procedures, physical safeguards, technical data security services and technical security mechanisms.
- Data integrity processes. Security mechanisms to ensure that data has not been altered or corrupted, either accidentally or intentionally in an unauthorized manner.
- Privacy standards. Outlining of specific rights for individuals and obligations for organizations holding PHR data regarding protected health information (Markle foundation, 2004). This may include developing privacy options for those individuals whose concerns for privacy are of less importance to them than their interest in sharing their person-specific health information for medical research or other socially beneficial uses.

#### 2.2.3.3 Uncertain Market Demand

Like other forms of electronic health records, integrated PHRs offer both significant potential benefits for users and a high degree of risk for potential investors. The uncertain market demand lies in following factors (Detmer, 2008).

Absence of information about whether there is adequate value for each stakeholder.

- Concerns about who should pay and how much they should pay.
- Concerns about strong incentives for some stakeholders to develop proprietary systems with limited functionalities.
  - Concerns about the need for a critical mass of data sources and level of

integration.

• Absence of information on how workforce and work processes will change.

#### 2.2.4 Solutions

In order to overcome existing and potential barriers to wider usage of PHRs, a number of solutions will need to be developed and implementing, in a combination of existing and potential solutions. Not all solutions will be viable or useful, but in determining which solutions will be most beneficial, certain ideas should guide that search.

#### 2.2.4.1 Research Support

Broad areas for research and evaluation for PHR systems are identified as following: consumer, health services, and technical research and the development of metrics to assess the implementation and impact of PHR systems on multiple dimensions of health and health care (HHS, 2006).

Consumer research should identify who is adopting PHR systems; how individuals use the systems; barriers to adoption and successful user; and access, pricing and usability issues, among other things. Identification of these factors can inform decisions about the functions and drivers for PHR systems adoption.

Health services research should address issues related to PHR systems' impact on workflow, particularly its effects on efficiency and utilization. Some areas for further research with respect to patient management include whether and how PHR systems change the way individuals relate to healthcare providers and the healthcare systems; whether PHR systems lead to better self-management of chronic conditions; whether

PHR systems improve the availability of clinically relevant information before, during and after encounters; and whether PHR systems contribute to modifying unhealthy lifestyle behaviors such as smoking, lack of exercise, and poor diet.

Technical research would examine methods to optimize the interface between PHR and HER systems; the optimization of standards for interoperability; approaches to authentication, identification, and role-based permissions; and the ability to execute data-source annotation.

## 2.2.4.2 Meeting User Needs

This study is trying to address the issue of how to implement PHR systems from a primary user's point of view. Therefore, further development should be guided by user/ patient-oriented research targeted to evaluate the performance and usability of PHR systems.

In addition, because many personal health care tools are available on mobile devices, these applications should be examined to see how they collect and integrate observations of daily living into personal health decision making and medical care. Through the study of these applications, user motivation can be explored to guide designing better PHR products that will match users' needs and preferences.

## 3. Primary User Research on PHR Tools

## 3.1 Selection of Participants

# 3.1.1 Nike + GPS anonymous reviewers

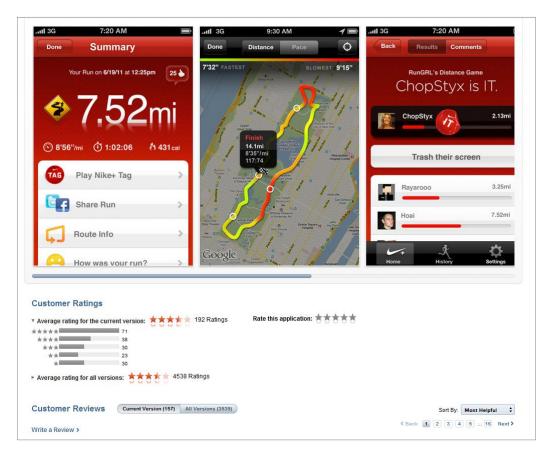


Figure 3-1: Customer Ratings for Nike + GPS

Mobile phones have truly become an essential part of American's lives: more than 90% Americans use mobile phones. An info-graphic report done by Wilson Electronics illustrates that there were 0.87 cellphones per person in the US in 2010 (Indvik, 2010), given the trend, it is likely that there are more now in 2012.

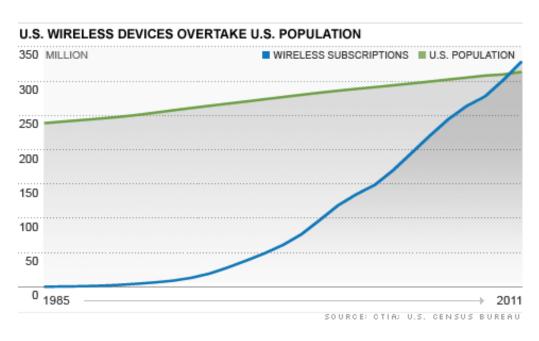
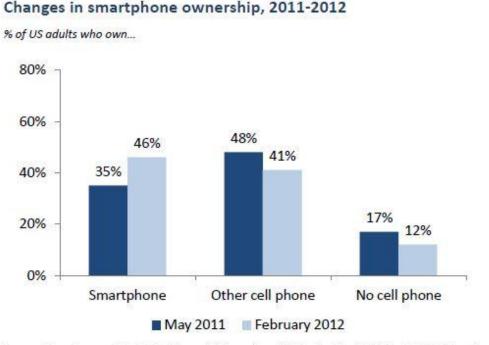


Figure 3-2: U.S. Wireless Devices Overtake U.S. Population (CNN MoneyTech, 2011)

The chart above shows that the number of wireless devices in the United States now outnumbers the people living here. The growing popularity of smartphones and tablets like the iPad means that many Americans may have two or more devices with a wireless plan (Goldman, 2011). Among these wireless plan subscriptions, the majority of users are smartphone users. A study has found that smartphone users now outnumber basic phone users, and every major demographic group shows a considerable jump in smartphone growth from the year before (Murphy, 2012).



Source: Pew Research Center's Internet & American Life Project April 26-May 22, 2011 and January 20-February 19, 2012 tracking surveys. For 2011 data, n=2,277 adults ages 18 and older, including 755 interviews conducted on respondent's cell phone. For 2012 data, n=2,253 adults and survey includes 901 cell phone interviews. Both 2011 and 2012 data include Spanish-language interviews.

Figure 3-3: Changes in Smartphone Ownership, 2011-2012

The chart above shows that 46% of American adults now own a smartphone of some kind, up from 35% in May 2011 (Smith, 2012).

Mobile applications will eventually be as important for companies as web pages today (Jahns, 2010. S, 2012). With its mobile devices and iOS, Apple has captured the majority share of the smartphone application market (Figure 3-4).

2010 Rank	Store	2009 Revenue	2009 Share	2010 Revenue	2010 Share	Year-Over-Year Growth
1	Apple App Store	\$769	92.8%	\$1,782	82.7%	131.9%
2	BlackBerry App World	\$36	4.3%	\$165	7.7%	360.3%
3	Noka Ovi Store	\$13	1.5%	\$105	4.9%	719.4%
4	Google Android Market	\$11	1.3%	\$102	4.7%	861.5%
	Total	\$828	100.0%	\$2,155	100.0%	160.2%

Figure 3-4: Global Mobile Application Store Ranking in 2010 and 2009 (Ranking by Revenue in Millions of U.S.Dollars). Source: HIS Screen Digest February 2011.

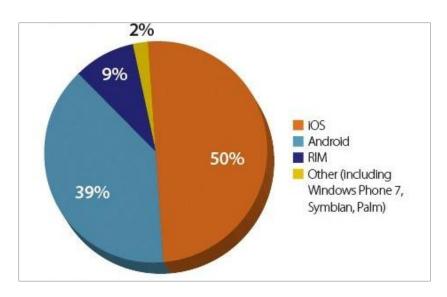


Figure 3-5: Application Platform Mix, Ranked by Revenue. Source: Milennial Media, 4/11

The market for mobile health services delivered via smart phone applications is growing rapidly. Mobile and tablets will continue to play an increasingly important role in the marketplace (Oracle, 2011). Figure 3-6 and figure 3-7 below show mobile health applications revenue sources that include app download, marketing, transaction, service and devices sales (Research2Guidance, 2012).

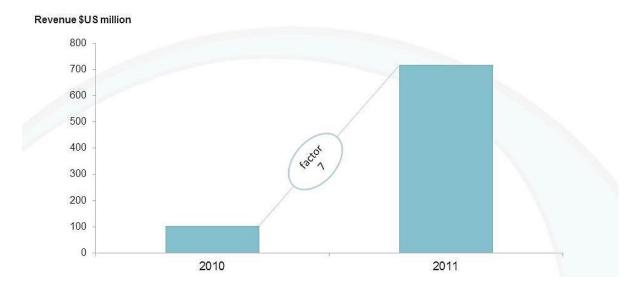


Figure 3-6: Global Smartphone mHealth App Market 2011 (Research2Guidance, 2012)

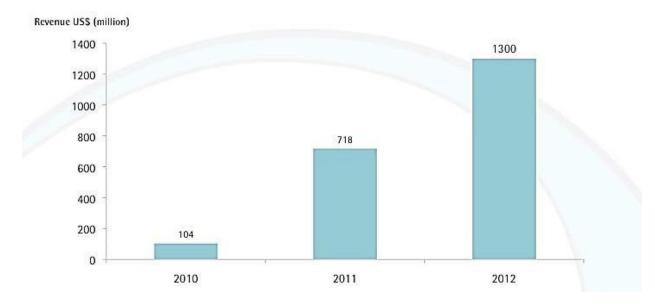


Figure 3-7: Global Revenue for Mobile Healthcare Applications in 2012 (Research2Guidance, 2012)

Given the increase of both smartphone users and health related application, it is important to learn the needs and activities of mobile health application users.

Theoretically, the potential market for mobile health applications is enormous given the overall worldwide healthcare market size of US\$ 6 trillion (WHO estimate) and the potential use cases and benefits for mobile patient healthcare support (Jahns, 2012).

Smartphone users and frequent internet users are among the most interested in online health applications (Undem, 2009-2010. Figure 3-8). Studies have found that 42% of iPhone users track their paces while working out, 75% consumers share progress with their friends, 74% consumers believe that technology has a positive impact on their health and 72% said it increases their motivation (Murphy, 2012).

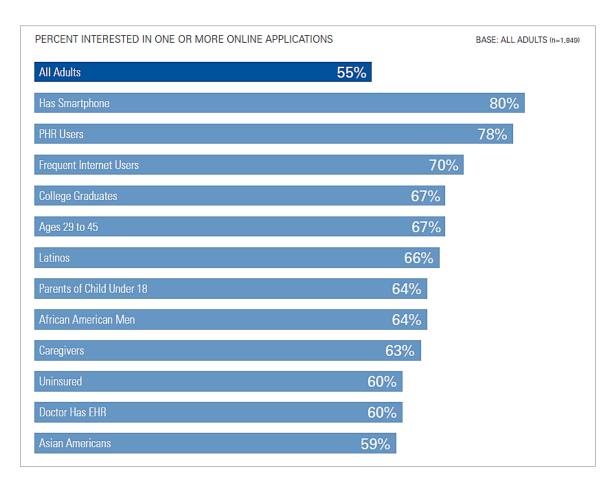


Figure 3-8: Interest in Health Applications, by Demographic Group

To conclude, designing a better user experience for PHRs will most likely require a mobile application for PHRs and the understanding of what mobile users need from this application. Nike + GPS is a popular workout applications that Apple provides exclusively to make available care for consumer wellness. Nike+ (also called Nike Plus) is a brand for Nike's running devices and services. It provides a rather complete system including Nike+ website, Nike+GPS app, Nike + gears such as FuelBand, SportWatch (Nike Plus home, 2012).

Due to the exclusiveness of Nike +GPS to iPhone and iPod Touch, to get to know its users, it is necessary to know the demographics of iPhone and iPod Touch users. A study at demographics of iPhone and iPod Touch users (AdMob, 2009) revealed that

74% iPhone users are older than the age twenty-five, 78% iPhone users and 66% iPod Touch users have an annual house income of \$25,000 or more, more than 70% of users are male, and 50% use mobile web more than they read newspapers or magazines.

The background, the market and the user demographics for Nike+GPS have been briefly explained. Nike+GPS will be analyzed more in details as a PHR tool.

## 3.1.2 MyActiveHealth Users

MyActiveHealth is a web-based personal health management system. Customers can register on the website using the information provided by their health plan or company.



Figure 3-9: MyActiveHealth Account Login

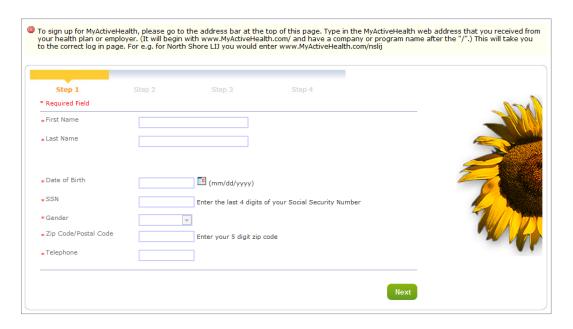


Figure 3-10: MyActiveHealth Sign-up

A national survey among representative sample of 1849 adults on consumers and health information technology documents that (see in "The Primary Users", Chapter 2):

About 7 percent of those surveyed say they have used a PHR — more than double the proportion identified two years earlier in separate research. Users are most likely to have a PHR supplied by their health insurer, followed by their doctor/ health care provider. Half or more of users indicate that the ability to look at test results, renew their prescriptions online, or email their providers is somewhat or very useful. Making sure their information is correct ranks highest in terms of usefulness. The majority of those who are using a PHR are not very worried about the privacy of the information contained in their PHR.

### 3.2 Selection of PHR Tools

From studying the reviews and feedback from actual users, we were expecting to

learn how both mobile users and web users interact with personal health management applications on different platforms. Based on popularity and availability, two products representing two types of PHRs were chosen: Nike+GPS and MyActiveHealth.

To develop a mobile application, it is important to understand the mobile landscape and the characteristics of the users of a particular platform or mobile device. Nike+ GPS is an auto-monitored exercise application for iPhone and iPod users. It requires iOS 4.0 or later (Figure 3-11). The description of Nike + GPS is as follows.



Figure 3-11: Nike+GPS on iTunes

It maps user's runs, tracks the progress and Provides the motivation user needs to go even further. It plays mid-run cheers every time a user's friends like or comment on the run status or outruns them in a game of Nike+ Tag. With this app in hand, a user can track every indoor and outdoor workout easily, without a sensor. A user can also record the pace, distance and run route using the iPhone's GPS and accelerometer technology to see the progress over time and push him or herself to go even further.

For the functions and features that Nike + GPS has, it is a perfect study object as a mobile health management application. Given the fact that mobile applications are very popular, people who are already iPhone/iPod users will easily have access to it, and the motivating factors are already built in.

MyActiveHealth is a typical insurance-based PHR website that is provided by insurance company. It was chosen primarily because it was the most complete PHR design accessible for the author.



Figure 3-12: MyActiveHealth Logo

MyActiveHealth is developed by ActiveHealth Management ("about ActiveHealth management", 2012). In 1998 a cardiologist named Dr. Lonny Reisman took a hard look at the health care system he was working in every day. He recognized that there had to be a better way. The system had too many gaps in communication. There were too many places where it just didn't deliver the right care at the right time. Dr. Reisman envisioned a revolutionary system that would close the gaps in communication and care. So he started a company to deliver his vision. Today that company, ActiveHealth Management,

serves nearly 18 million people nationwide. Headquartered in New York

City, ActiveHealth has expanded to offer a complete integrated system of services that includes coaching for people with chronic health conditions, services that help doctors and patients make smarter health care decisions, and personal health records.

## 3.3 Selection of Methods

With the development of social media, online review websites have become providers of rich information about product properties. These reviews are not only useful to customers, but also serve as product performance indicators to stake holders and designers. However, it can be challenging and time consuming to work with such a large volume of information available in an attempt to identify particular patterns and trends. For example, there were a total of 3702 reviews for all versions of Nike+GPS on iTunes (iTunes is a media computer player computer program that was introduced by Apple Inc) by the date of March 1, 2012. Due to the limited time available for this study, the reviews used were for version 3.3.1 which had ninety-two reviews by the date of March 1, 2012 (See Figure 3-13).

For the purpose of this study all ninety-two reviews for Nike+GPS were collected and saved in a Microsoft Word document. The file contained all standard data fields that appear on iTunes: review title, reviewer's nickname, version, date, description, and whether or not other customers found it helpful. Next, all reviews were divided into two categories based on the customer's indicated intention to like or dislike Nike+GPS.

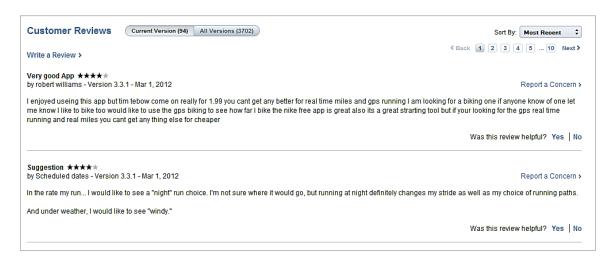


Figure 3-13: Customer Reviews on Nike+GPS Homepage on iTunes on March 1, 2012

In this study qualitative techniques were used to assess how MyActiveHealth users interact with their medical records. Questionnaires were used to collect feedback. Condensation and categorization strategies for inductive research were used to analyze the frequency of use for primary users, the primary interaction media, the level of easiness to use, the satisfaction to primary users, and what primary users expect from using a PHR website.

## 3.4 The Process of User Survey

From existing user reviews on "Nike+GPS", user needs and expectations were generalized from a mobile user's point of view. Word categorization was used to identify happy and unhappy customers, positive and negative feedback.

For the MyActiveHealth PHR, user surveys (see Appendix 1) were conducted through questionnaires (see Appendix 2) given to ten employees at a company required to use MyActiveHealth. Once the questionnaires were returned, the responses were categorized and generalized using standards of previous analysis of existing PHR

systems.

#### 3.5 Analysis

The first analysis applied to compiled reviews for Nike+GPS is word categorization. The main purpose of this type of analysis is to compare and contrast the main topics in the reviews of happy and unhappy customers. The top most frequently used word categories in positive reviews were: "love," "great," "best," "recommend/recommendation," "motivated/motivational" and "worth". The top words discussed in negative reviews were ""frustrated/frustration," "GPS," "calibration," "battery," "accuracy," and "tag".

It is logical for application reviews of all kinds to contain words referring to the application itself and its functions and features. However, differences in the happy-and-unhappy category are quickly apparent. Happy customers refer to intangible, emotional components (e.g. "A lot of fun to use," "more social," "motivated"), while unhappy customers discuss the tangible, functionality aspects of the application operations (e.g. "GPS," "battery"). Granted, a high-tech-based application like Nike+GPS relies heavily on all the technological aspects mentioned above. Regardless, it should be kept in mind that, in most cases, people who are willing to spend money and time on products, who want to enhance the quality of their lives by engaging newly-designed products in their daily activities, are people who actually care about and pay attention to how well the product is designed and operates. Also, the results showed that the financial category was more dominant in negative reviews. This category included such words as "I want my money back". This suggests that unhappy customers are more concerned about financial

issues (such as the price they paid for their perceived poor experience) than are happy customers (indicating that guests will be less concerned with price if they were satisfied). Results are shown in figure 3-14, 3-15, 3-16 and 3-17 below.

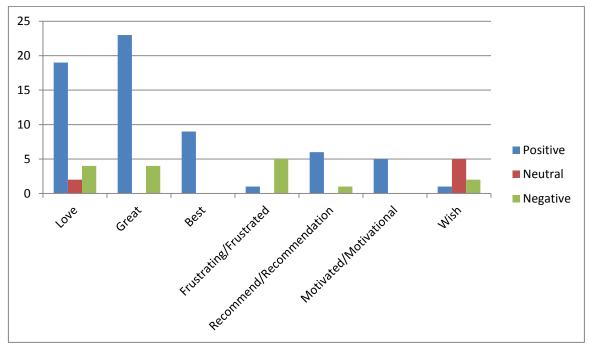


Figure 3-14: Emotion Category for Nike + GPS Version 3.3.1 Reviews

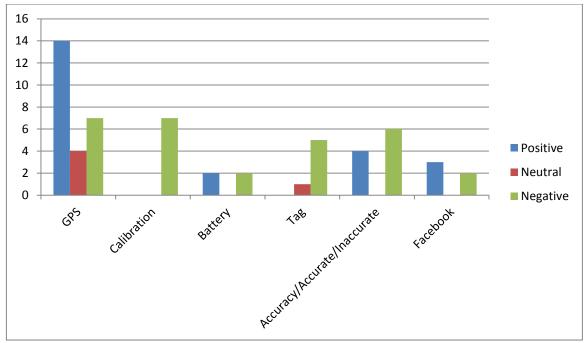


Figure 3-15: Functionality Category for Nike + GPS Version 3.3.1 Reviews

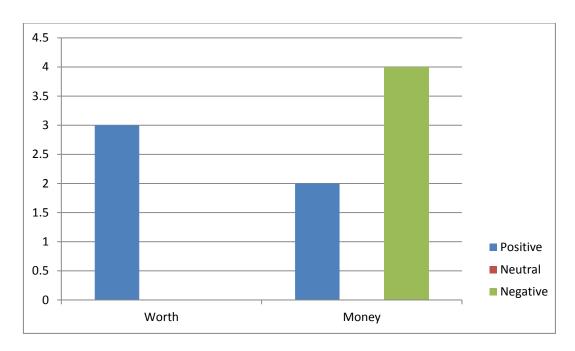


Figure 3-16: Financial Category for Nike + GPS Version 3.3.1 Reviews

The total number of Reviews was ninety-two, but two of them were posted twice.

Ninety of them were actually counted in while calculated in the following chart (see Figure 3-17).

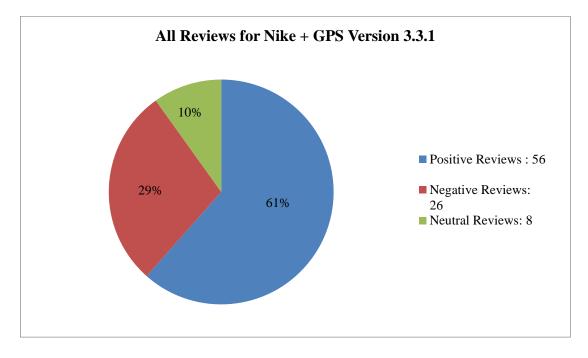


Figure 3-17: All Reviews for Nike + GPS Version 3.3.1

The measure of each reviewer's attitude was established by comparing the positive and negative parts in each review. Positive reviews must contain such words as "great," "best," "love," or "recommend," or other description that was equally seen as positive emotions or comments. Positive reviews might contain some suggestions or negative words, but in general, the positive part outweighs the negative. In contrast, negative reviews were lower than three stars as rated in the original post. They normally contain words with negative connotations such as "frustrating," "horrible," "terrible," or "money." Neutral reviews might contain words such as "wish" to express an equal amount of positive and negative feelings.

The survey of MyActiveHealth users resulted in three major findings. Firstly, most respondents did not incorporate MyActiveHealth into their health care routines due to lack of motivation. In this respect the finding is similar to previous demographics information reporting that people tend to "forget" to use it. The second major finding was that 50% of respondents expressed concerns about security and privacy issues. Furthermore, 40% of respondents indicated a negative attitude regarding a third party, other than patient and doctor, having access to the information. Last but not least, the information provided in MyActiveHealth is very general and limited, and also is difficult to manage. There were complaints regarding how poor the operation is, such as adding beneficiary information.

All respondents only had used MyActiveHealth on Windows PC. Regarding purpose, 60% indicated that they only used or will use MyActiveHealth for specific reasons. Regarding length of use, 10% only had used it for less than a week, while 50% had been using it over 3 months. All users that used the application over a year, 30% of

respondents only used it occasionally. Of the remaining users, 10% said they only used it once or twice per year, while the other 20% said they would try to use it as little as possible.

For the measure of "Learning Curve for MyActiveHealth", a smaller number is considered to be better in website performance. When the average rating was calculated, the order of the numbers for this measure was switched from what the Likert scale typically uses. On a scale of 1 to 5, "2" was calculated as "4" to represent a higher rating, "3" remained the same, and "5" was "1" as the lowest rating. According to the results, the discoverability of information isn't necessarily associated with the learning curve. Results are shown in figure 3-18.

Questionnaire	Layout	Value	Functionality	Discoverability	Learning	Average
				of Information	Curve	Rating
1	3	3	3	3	3	3
2	4	3	4	4	2	3.3
3	3	2	3	3	4	3.1
4	3	3	3	3	4	3.2
5	4	3	3	2	4	3.2
6	1	1	1	1	1	1
7	5	5	4	4	2	4
8	2	1	1	2	5	2.2
9	2	1	2	2	4	2.2
10	3	2	3	3	3	2.8
Average	3	2.4	2.7	2.7	3.2	2.8

Figure 3-18: MyActiveHealth Ratings Distribution from chosen questionnaires

### 3.6 Conclusion

In this chapter, a mobile health application and a PHR website were studied to learn the user needs and identify problems. Although Nike+GPS is not typically a PHR application, like a PHR, it is both a user-centered, and personal information management design. Therefore, studying the functions and features of Nike+GPS can lend a hand in understanding a PHR system. By looking at Nike+GPS users experiences, it is learned that what might be beneficial for the user experience to include in a PHR system. Theme analysis revealed that for MyActiveHealth users privacy is the biggest concern, there is a lack of motivation to use, and excessive information is hard to manage. Users were concerned about how best to transition information management between personal devices to medical care providers.

In general, the development of technologies may facilitate products performance, but human beings are never that easy to please. Motivating users is a complex job. It requires designers to have a solid understanding of what users really need in a system, and then design to fulfill their needs. First, they need to specify features and functions a PHR system should provide. In the next step, they need to take a closer look at issues involved with those requirements, and try to solve these. All the effort and time needs to go in the right direction in supporting motivation of users and a good user experience.

Now that the issues with PHR systems in both mobile application and website have been identified, the proper sequence of use in PHR systems should be demonstrated from the primary user's perspective, developing design principles and guidelines while designing interaction for PHR systems. Finally, a PHR system prototype will be designed to demonstrate the principles and guidelines.

## 4. Design Criteria for an Integrated PHR System

Provider group and health plan organizations emphasizing PHR adoption highlight the value of using the PHR focusing on consumer-to-PHR and PHR-to-consumer interactions as levers to improve health and reduce costs (Kahn, 2011). Before discussing any design criteria, the following common types of PHR interactions should be considered as each of them will affect the choices of adoption of PHRs. The first, consumer-to-PHRs connections, enable users to update their record with new information from connections such as a home monitoring device. The second, PHRs-to-consumer interactions, should include ways of sending automated notices for upcoming events from the system to the users. The third type of connections, consumer-to-consumer, promote online social networks such as emails and health forums. Finally, PHR-to-PHR connections allow transfer of information between PHRs, promoting usability by gathering and grouping user activities and experiences (see Figure 4-1).

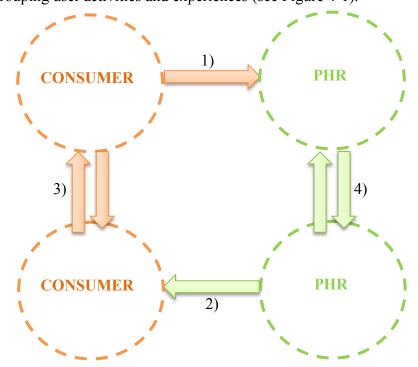


Figure 4-1: 4 Types of PHR Interactions

Provider group and health plan organizations emphasizing PHR adoption highlight the value of using the PHR focusing on consumer-to-PHR and PHR-to-consumer interactions as levers to improve health and reduce costs (Kahn, 2011).

## 4.1 Sequence of Use

After considering the types of connections, the sequence of use for primary users should be planned. Based on previous research, the ideal sequence is as follows.

Authorization to the PHR system should be granted based on certain common demographics, and users should have a common method of accessing the systems. In the United States, users should be authorized to register simply by being a resident of the United States, and a government-issued identification number, such as a social security number, will be used to activate the account. As shown in Figure 4-1 below, once registered, the user will have access to view and manage all his or her personal information, health records, and the PHR provider's information via a web-based portal or mobile application.

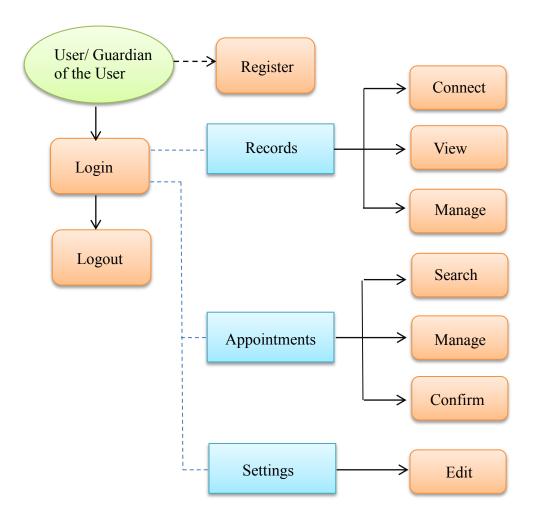


Figure 4-2: The Sequence of Use in PHRs from Primary User's Perspective

## 4.2 Designing for Better PHR Experiences

As discussed in the previous chapter, three key issues inhibit the use of PHRs: privacy concerns, lack of motivation, and operational difficulty. Designing for maximum usability should be the goal, in order to improve user experience and solve problems in PHR development and adoption. Design criteria in the form of principles and guidelines provide direction for design, in both general and concrete terms. In this study, design criteria are outlined in order to enhance the interactive properties of the PHR system.

## 4.2.1 Design Principles

Among the first principles to consider are those that support usability. These principles should motivate visitors and users to actually use the PHR. A designer can begin by asking questions from the user's perspective, including questions such as how one can enjoy the task, what can be done to make the task fun for users, and what can be done to make the task the best part of a user's day. The questions will lead the designer in motivating users.

When considering the questions from an aesthetics perspective, designers need to make the PHR look friendly by using graphics of friendliness. From a marketing perspective, the designer should list all the values of using a PHR, and the consequences of not using one. Customers are more likely to take action because of the raised awareness of needs and perceived consequences (Thompson, 2012).

When determining what values to list, the designer should take into account a number of sociological factors, especially the motivators of family, independence, order, status, and tranquility (Reiss, 2002). Concerning family, the PHR should send the message that the PHR takes care of both the user and his or her family. In addition, the PHR should allow independence, or control over the user's information. The website should show visitors how the information will be exchanged or shared between the system and all users, as well as how all users access and manage data, thereby giving a sense of control over the dissemination of personal information. Order is also important. The system should clearly show users the organization that supports the system and related websites, such as user forums, review sites, and introductory pages from the sponsor. In addition, because status is important to users, the PHR website or mobile app

should deliver a message that the user's health is important to the PHR, and his or her health will be taken care of on a personal level by a network of professionals and features provided by the PHR.

Furthermore, the PHR should emphasize privacy and security features to allow for tranquility, closely related to independence in this schema. Building trust for the system is one way to motivate users. Developing a high level of perceived value and credibility lies in site content and aesthetics factors. One small but very important item to include is legal copy on the website or application. Its inclusion will aid in promoting reliability, so designers needs to keep this part discoverable, accessible, and readable. In addition, confidence in services being provided will give users and visitors a positive impression. For example, Apple uses words such as "amazing," "beautiful," "magical," and "unbelievable." The choice of verbiage reflects the company's confidence that has led to a successful marketing campaign. Currently, icons play a major role in web design. Visually appealing icons are more often used because websites with elegant icons attract more customers (Anum, 2012; Friedman, 2008). High quality of icons gains more user trust for the PHR system.

One aspect of websites and applications that many users like is the availability of forums or review sites, where verified users and practitioners can give and share valuable feedback. The PHR system should provide a platform that allows this. Another important consideration is timeliness of information. Outdated information will detract from the perception of the PHR as an efficient system.

Navigation and data entry are two central characteristics of both the website and application that should be easy to use; certain web design principles should be applied.

First of all, the site should be kept simple so that novice users can gain understanding of how to use a PHR initially and then attain a maximum level of performance. In other words, the learnability of the PHR system is of utmost importance. For example, providing a few simple categories and most recent news on the homepage will keep users interested and educated without being overwhelmed. Also, design elements should be kept consistent. Certain aesthetics guidelines should be applied to every single item designed for the PHR system. A designer should consider how to integrate the disparate elements to look like parts of a cohesive whole. Definitions should be clear, as well. To maintain clarity, it is crucial for the designer to decide which features to provide in the ideation stage. Throughout development, definition statements allow the designer to decide if potential features and behaviors make sense

Finally, comprehensive footer site navigation is vital. The main function of the footer is to complete the layout, while navigation is one of the most important elements in web design. Because PHRs are very complex systems that include a large amount of information, a PHR website needs to provide users a simple and user-friendly way to locate information. Therefore, site mapping, contact details, and brief site and site owner information need to be placed in the footer. Footers are often forgotten or ignored, so providing comprehensive footer site navigation will impress visitors (Friedman, 2008; Lennartz, 2008).

## 4.2.2 Design Guidelines for some Concrete Issues

In addition to the type of connection and usability principles already considered, some concrete issues need to be addressed during development. A set of guidelines are

developed accordingly in regard to visual purpose, operational purpose and navigational purpose as follows.

- Visual Guidelines:
  - Branding
  - Security Assurance
  - Format
  - Inform Interactive Elements
- Operation Guidelines:
  - Instructional Aids
  - Identification Process
  - Terminologies
  - Options
  - Modularity
  - Mobile Application
- Navigation guidelines:
  - Consistent Navigation Controls
  - Content Types

## 4.2.2.1 Branding

The display of a PHR website or application should emphasize the brand identity and core principles of the organization or company.

The origins of branding were reflected in the American Marketing Association

(AMA) 1960 definition of the brand, which focused on tangible brand attributes as points

of differentiation: "A name, term, sign, symbol or design, or a combination of them intended to identify the goods and services of one seller or group of sellers and to differentiate them from those of other sellers." A good branding will deliver the message clearly, confirm the credibility, connect targeted prospects emotionally and motivate the consumer. For example, components containing introduction information, core principles and team/contacts information should be placed at the most accessible place on a PHR site. All information should be generalized and displayed in a simple manner. Therefore, visitors get a good impression and are motivated because the general information users typically look for in a new site is already there, they do not have to look for it.

## 4.2.2.2 Consistent Navigation Controls

The use of navigation should remain consistent throughout the site unless there are areas requiring custom control unique to a specific function.

Because users need to quickly recognize the navigation tools of the display, the use of control should remain consistent. For example, a PHR site should keep a set of navigation elements in the same place throughout the site, using consistent wording and appearance so as not to confuse or disorient the user.

#### 4.2.2.3 Instructional Aids

The PHR site and application should include instructional aids such as text, illustrations or videos, to define the services provided and explain the process if applicable.

Since health information is a sensitive subject and a PHR system can be very

complex, visitors might be overly concerned about any unexpected consequences from activities within the PHR system. Instructional aids are helpful for users, especially for new visitors. It encourages non-users to register by emphasizing the value of using PHRs and assures users by convincing them with high quality services. Many successful websites have instructional videos for each of their products or services to show customers or users new features and sequences of use. Similarly, in traditional industrial design, pictures of user figures are often illustrated to demonstrate intended use of the produce in the intended environment. For example, by providing a combination of text and graphs that illustrates what the registration process is, visitors can get a preview of what is going to happen if they decide to register. With newly gained knowledge and trust, it is more likely for them to create an account.

## 4.2.2.4 Security Assurance

An integrated PHR system should assure users of the privacy and security of the system by providing educational description and illustrations regarding how users' identity and information will be used and protected.

Previous research shows that security and privacy are main concerns for most users. By listing and demonstrating all securing methods throughout the site, the PHR system will gain trust from the user and facilitate the adoption of the PHR system. For example, placing an illustration of how user's information is encrypted and transferred at the registration will give users a sense of security and encourage them to continue processing the registration.

### 4.2.2.5 Identification Process

An integrated PHR system should process identification information in a secure and timely manner.

Privacy and confidentiality are primary concerns for a health information exchange system. Therefore, user registration and identification must be processed in secured steps with clearly stated rules and procedures. An illustration of registration process should be provided to encourage users to register. While registering, users should be constantly informed which step they are at in the registration process. When there is confidential information required, such as a social security number, a PHR system should acquire it from the user by phone; at the same time, the PHR system needs to inform users what is happening and what will happen next.

## *4.2.2.6 Terminologies*

The PHR system should speak the users' language, with words, phrases and concepts familiar to the user, rather than official medical terms.

Following real-world conventions makes information appear in a natural and logical order. For example, on a record from a medical care provider, there are many terms and statistics that only professionals are able to understand and interpret. Since the PHR system is a user-centric system, all information and data should be organized and displayed in the manner that is easy to read and understand for primary users. Only in this way can users truly get benefits from using PHRs.

#### 4.2.2.7 Format

User information received from medical care providers must be organized and displayed in a format that is easy to view and assistive to decision making for users.

Because integrated PHR systems work as a central point of all health information for a primary user, there may be many different kinds of health information, such as appointment information, provider profile information, and recent hospital visit information. To assist users with decision making, each type of information must be accessed and viewed quickly and easily by users. For example, all the recent collected records that have not been confirmed by users should be listed in a table which shows the name of event, result/medication (if applicable), hospital/ doctor name, time, and options to view, confirm and flag.

# 4.2.2.8 Content Types

The PHR site or application should distinguish content types from general content to current page content by text, colors, contrast, or graphic cues.

By clearly distinguishing between different types of contents, a designer is able to intentionally guide the users through a pre-determined hierarchy of information. For example, the header text should be a different size or font from the body text so as to distinguish one from the other.

### 4.2.2.9 Inform Interactive Elements

When there are interactive elements, there should be changes in colors or size to highlight or indicate the interaction.

By changing the color or size of an interactive element, users are informed that the item is functional and they will gain a sense of control and orientation. For example, if the action of clicking a button "register" leads to the register page, the color of the button changes on mouse over. Also, keeping some of the content interactive and dynamic is more likely to keep users engaged and interested.

## 4.2.2.10 Options

Multiple options should be provided to users in order to achieve the maximum of functionality and flexibility.

People have their own preferences and perceive information differently. As a result, when containing long lists or large amount of information, the display of a PHR site or application should provide multiple viewing options. For example, a user is looking for a specific record. The PHR site should display a list of records by types and time of the records. The user can view the records by choosing from viewing options of "care providers," "immunizations," "medications," "illnesses and surgeries," and "allergies." The user can also view the records by choosing from "the latest to oldest" and "the oldest to latest". By providing necessary options, the content is well organized and assists users with information location.

### 4.2.2.11 Preferences

Users should have the ability to adjust their privacy preferences.

It is common for websites to provide users account settings where they are given options for part of their account information, such as choosing to show or not show their

real names or email addresses. For an integarated PHR system, both the credibility and performance are upgraded by account settings when it assists users with decision making.

## *4.2.2.12 Modularity*

An integrated PHR system should be modular so as to add more components to accommodate customers with specific needs.

People have different needs, and some people might even have chronic conditions or physical impairments that require them to pay extra attention to. For example, if a female user finds out that she is pregnant, she can add the "pregnancy" feature to her PHR profile to acquire specific control over all pregnancy-related records and hospital visits.

# 4.2.2.13 Mobile Application

Because mobile devices may serve as an entry point for customers to access their PHRs, studying the characteristics of mobile platforms accordingly before designing a mobile application is a must. Most mobile operational systems now have their own UI guidelines, so a set of requirements specification different from the one for a PHR website are required when designing a mobile application for the PHR system.

Since it's more likely for mobile devices to get lost or destroyed, mobile application should only serve as an entry point for a PHR system and contain limited functions and features when compared to the PHR website for privacy and security considerations.

Another factor that adds to the risk of mobile PHR is consumers' failure to treat their smartphones like tiny little computers. Few consumers have any form of anti-malware software on their mobile devices and have little consideration for security (McNelley,

2012). Many are willing to download applications of completely unknown provenance from application stores. Failure to consider the vulnerability of private information contained within a mobile application leaves the door open for identity theft and PHR system manipulation. However, with the increased demand and use of mobile applications, having a mobile version of an integrated PHR system is a value added to the overall user experience.

## 5. Design Guidelines Application

## 5.1 Design Process

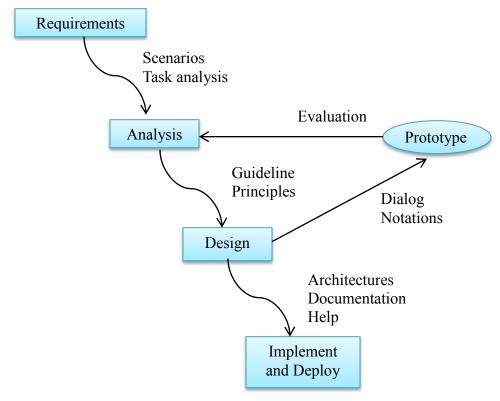


Figure 5-1: Interaction Design Process

Figure 5-1 shows the development process of interaction design. The first stage is to establish what exactly is needed, as done in chapter 3, where primary users' needs have been studies and analyzed. With the key issues explored, the hierarchies of tasks and goals will be laid out in the current chapter. User interaction interfaces will be developed accordingly in order to demonstrate the sequence of use. Then scenarios will need to be explored to further evaluate the design prototype. Finally, when the design is completed, the product must be created and deployed. In this study, only a prototype will be created to demonstrate how the design principles and guidelines are applied in PHR design. To conduct this study, the following procedures and methods were used (see figure 5-2).

In the research phase, health related products and services are identified and studied. Primary users of representative products needed to be studied as well. Main issues are introduced and analyzed. Further, design criteria, including principles and guidelines are generalized from the analysis of primary user research. Based on the design criteria, concept development starts from the requirements specification, which concentrates on a description of what the eventual system will be expected to provide. The next activities concentrate on how the system provides the services from it, which requires an architectural design. An architectural design provides a decomposition of the system description that allows for isolated development of separate components which will later be integrated. The next activity is a detailed design, which is a refinement of the architectural component description provided by the architectural design. At last, a prototype is developed and evaluated by user testing and the criteria. In the end, the conclusions are summarized, and recommendations are made.

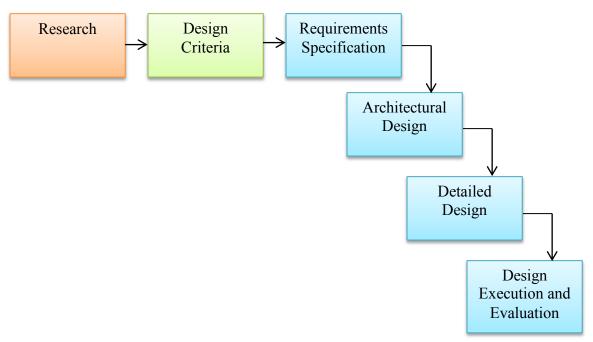


Figure 5-2: The Activities in the PHR System Design Process

## 5.2 Requirements Specification

Main Functionality: The PHR system collects, stores and organizes users' health information, including standard health records from providers, and user provided personal information. The PHR system should include a website and mobile application for primary users. Both the site and application should allow users to access, view and manage their health records and information that are direct from medical care providers and authorized by the system and the user. Users are also able to enter or upload other health related information, such as data from a home monitoring device, or a scanned copy of old medical document.

Accounts: Due to privacy and security concerns, an account can only be created on the PHR website and cannot be created on the mobile application. The mobile application can be downloaded by anyone, but cannot be used to create an account for the PHR system. Therefore, in the following design process, only the PHR website will be shown to demonstrate guidelines application and the maximum of functionality.

<u>Site Contents</u>: For non-users, the PHR system shows and educates visitors what it is, how it works, and what the features, terms and condition, and privacy policy are. For registered users, functions are provided for managing three main components: records, appointments, and system settings. To make it more user friendly, the PHR system should have public pages on popular social networks such as Facebook and LinkedIn.

### 5.3 Architectural Design

Unless computer-mediated communication systems are structured, users will be overloaded with information. But structure should be imposed by individuals and user

groups according to their needs and abilities, rather than through general website features (Hiltz and Murray, 1985). To accomplish this, an architectural design is developed for the PHR website, to describe the interdependencies between separate components and the sharing of resources that will occur between components (Figure 5-3). The decomposition of main components is also shown (Figure 5-4 and Figure 5-5).

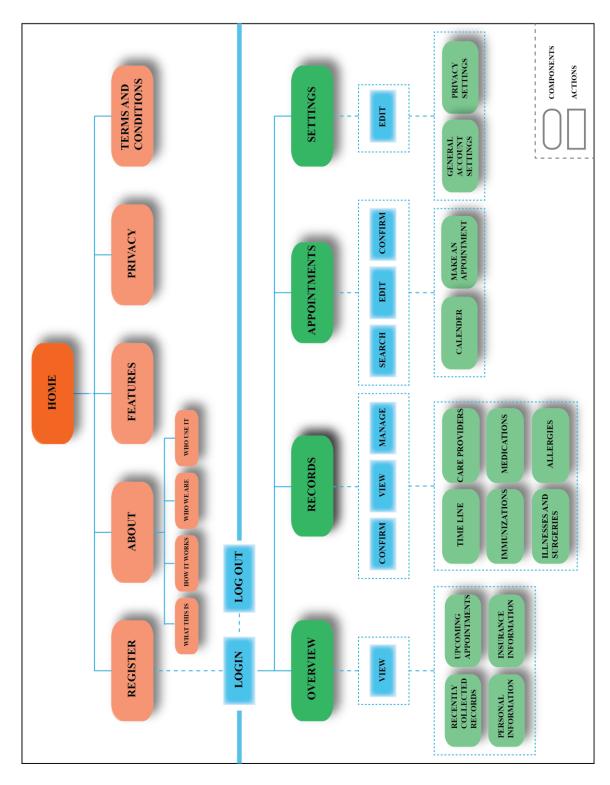


Figure 5-3: Architectural Design of the PHR website

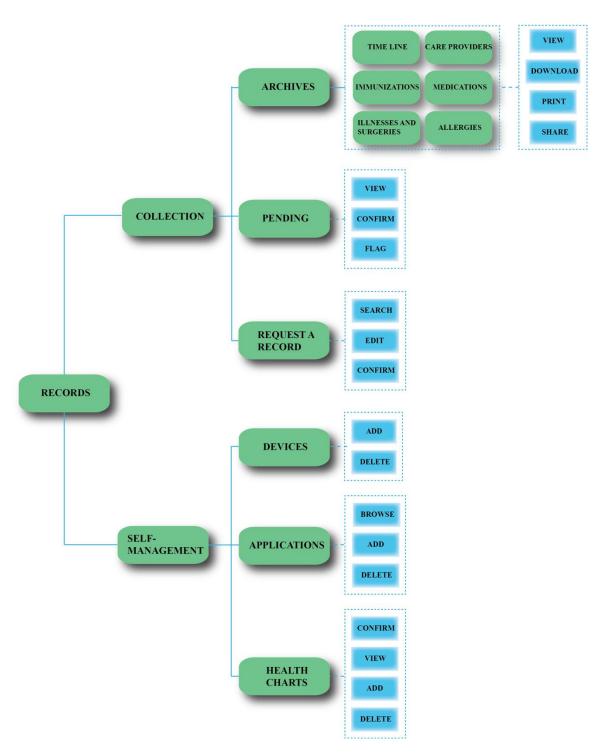


Figure 5-4: A Decomposition of Records

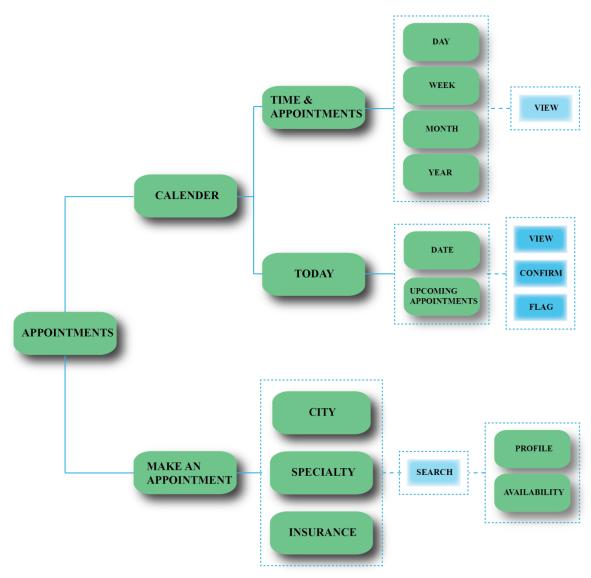


Figure 5-5: A Decomposition of Appointments

## 5.4 Detailed Design

The architectural design shows the main components and their relations. In order to provide a sufficiently detailed description of the architectural design, task decomposition and sequence for the PHR website are described as follows.

# Task 1: Determine if this Website is Legitimate/Credible (See Figure 5-6).

The user views the website promotional description and video on the homepage.

Then he or she opens and reads the "about" and "privacy" to determine who runs the system, and if the customers' privacy is protected. The user does a Google search to see if there are reviews for the website. The user then visits the website's Facebook and LinkedIn pages to see more information.

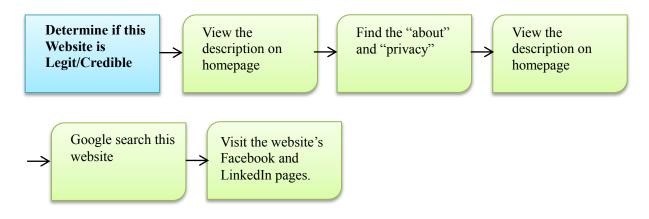


Figure 5-6: Task 1

## Task 2: New User Wants to Register (See Figure 5-7).

The user clicks "create an account" and fills out "basic information", including name, birth date, primary email and password. The user then is asked to provide a primary phone number and is given two options, "phone call," or "text message," to receive a confirmation code. When the user gets the code, he or she enters to proceed. A notification will pop to show that the system is calling the primary phone number and will need user's identification information. Then, the user provides his or her social security number and birth date on the phone. Once the phone call ends, the user is asked to enter the last four digits of his or her social security number to proceed. The user then is asked to read and sign an authorization to release healthcare information. At last, by checking all the agreements, he or she agrees to the release form and finishes the registration by clicking "complete the registration" button.

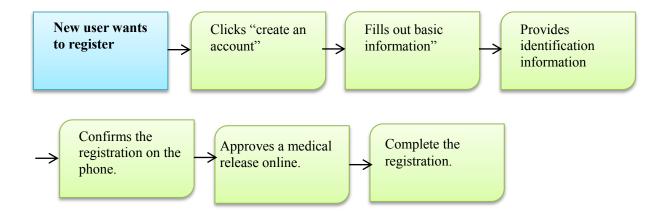


Figure 5-7: Task 2

### Task 3: User edits personal information.

At this point, the user logs into the system and goes to "personal information" under "overview". Alternatively, user clicks the name tag on the top right to go to "personal information" directly.

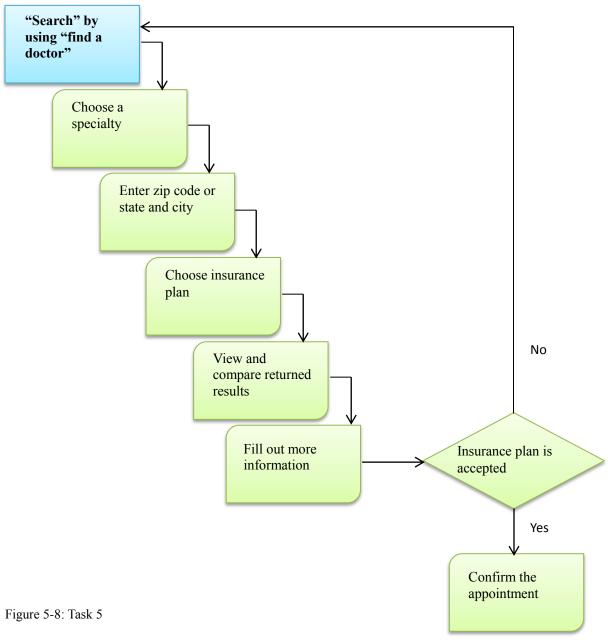
## Task 4: User wants to view specific health records.

For this task, the user logs into the system and goes to "records." He or she can view the records by "time line," "care providers," "immunizations," "medications," "illnesses and surgeries," or "allergies." For example, if the user wishes to view his or her TB record, he or she enters the keyword "TB" to find that record.

## Task 5: User wants to make an appointment (See Figure 5-8)

To make an appointment with a healthcare provider, the user logs into the system and goes to "appointments". To make an appointment with a previous doctor, the user goes to "past appointments" and selects one. To make an appointment with a new doctor, the user searches for doctors by using "find a doctor". Within this sub-screen, the user selects "specialty" and chooses one, "dermatologist" for example, and enters the desired zip code or city and state. The user looks at doctor profiles and compares available times,

dates and reviews. After selecting a provider, the user then fills out more information to book an appointment. If, for example, the user sees that the provider does not accept his or her insurance, the user returns to "search" or proceeds through the confirmation anyway by selecting "I'll choose my insurance plan later" or "I'm paying for myself." At last, the user receives a notification in his or her primary email that the appointment has been confirmed by the provider. A new appointment also shows in user's name tag on the top right in the website.



# Task 6: User wants to share specific records with a practitioner.

To do this task, the user logs into the system and goes to "records." He or she finds the records by viewing under "time line," "care providers," "immunizations," "medications," "illnesses and surgeries," or "allergies." The user can also enter a keyword to find a specific record. Then he or she opens the record by clicking the "open" button, which leads to more options including a "print" button. If desired, the user then prints the record and brings it to the practitioner.

### Task 7: User wants to add an application.

If the user wishes to customize his or her PHR, he or she may log into the system and goes to "applications" under "records." He or she then browses through all available applications. Finally, the user chooses one, downloads it and installs it. The related features and functions in user's profile on the PHR website will be activated.

# Task 8: User wants to add health information from a monitoring device.

The user logs into the system and goes to "devices" under "records." He or she browses through monitoring devices list and chooses a category that matches the device. He or she then is given instructions on the screen to upload the data from the device. Following these instructions, the user plugs the device in the computer or chooses to sync the device with the computer via wireless connection. The information is received, stored and organized by the PHR whenever the device is being used and connected to the computer.

#### 5.5 Design Execution

The PHR system should include a website and a mobile application. In order to

show maximum functions, in this study only the website was designed to demonstrate the integration and evaluation of the developed design guidelines and principles.

The user interfaces were designed in Adobe Illustrator CS5.1. To show the basic sequence of use and some functions, the animations were created in Adobe Flash CS5.5 using ActionScript 3.0. The following ActionScript 3.0 codes shows the key actions used to navigate through the website.

```
stop();
     header mc.overview btn.addEventListener(MouseEvent.CLICK, gooverview);
     function gooverview (event:MouseEvent):void{
      gotoAndStop(1);
     }
     header mc.records btn.addEventListener(MouseEvent.CLICK, gorecords);
     function gorecords (event:MouseEvent):void{
      gotoAndStop(2);
     }
     header mc.appointments btn.addEventListener(MouseEvent.CLICK,
goappointments);
     function goappointments (event:MouseEvent):void{
      gotoAndStop(3);
     }
     header mc.settings btn.addEventListener(MouseEvent.CLICK, gosettings);
     function gosettings (event:MouseEvent):void{
```

```
gotoAndStop(4);
}
```

## 5.6 Prototyping

In this example project (see Appendix 3), the PHR website is named "HealthConnects." The user interface of HealthConnects website was developed following guidelines detailed in Chapter Four.

Once in "HealthConnects," visitors can navigate through information including website introduction, features and legal statements (Figure 6-14). It takes three easy steps to sign up: creating an account, approving identification information, and approving a medical release online (Figures 6-15, 6-16, and 6-17). After signing up, user can login (Figure 6-18) and view his or her profile, which includes "overview," "records," "appointments," and "settings." (Figures 6-19, 6-20, 6-21, and 6-22) The user is then able to view and manage his or her personal information, health information, and account information.

# 5.7 Guidelines Application

HealthConnects website was developed based on the guidelines to achieve the effectiveness of the interface.

## 5.7.1 Application of Branding

"The display of a PHR website or application should emphasize the brand identity and core principles of the organization or company."

Figure 5-9 shows the homepage of HealthConnects website. The logo is placed at the very top of the page, leveraging all of the credibility and power through its recognizable design and wording. In addition, the logo is effectively displayed throughout the site for both visitors and users. The core values and principles associated with the PHR system and organization behind the logo are illustrated in tabs of "what it is," "how it works," "who we are," and "who use it," the features, and pictures implying good care. The site is perceived as professional and motivational through the consistency in its layout, navigation and aesthetics.



Figure 5-9: Application of Branding in Homepage

# 5.7.2 Application of Consistent Navigation Controls

"The use of navigation should remain consistent throughout the site unless there are areas requiring custom control unique to a specific function."

The navigation controls are consistent in each level of the site. Figure 5-19 and 5-20 show that the same set of tab controls are used to navigate categories in the user's profile. All the sub-categories under each category are displayed in the same place with same font and color. The main form of navigation throughout the site is accomplished by using tab-bars to control first and secondary levels of information. Information under each category is navigated by icons combined with text representing sub-categories or functions (see Figure 5-10 and 5-11). As a result, users can browse through main categories quickly through tab-bars, and go into the next level of information hierarchy through more detailed controls. For a complex system with a large amount of information, HealthConnects does not overwhelm users because of its intuitively organized navigation and consistent controls.



Figure 5-10: Records Tab

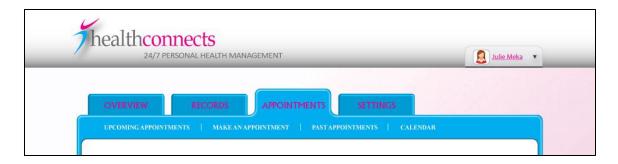


Figure 5-11: Appointments Tab

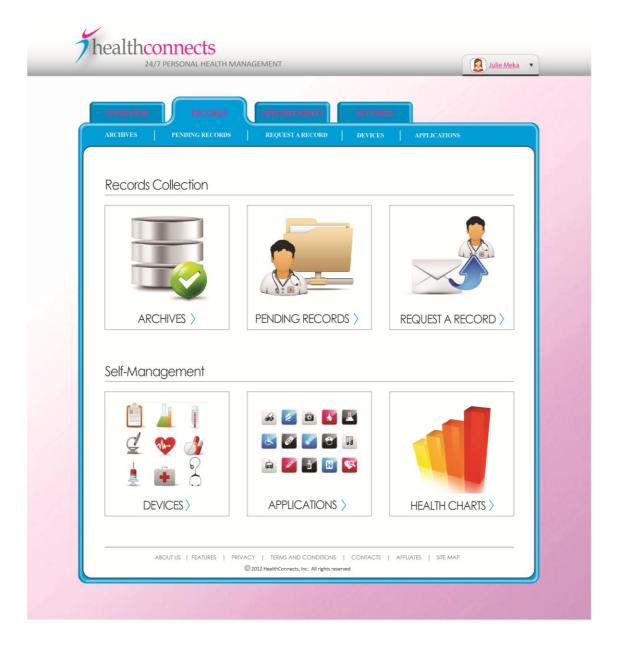


Figure 5-12: Icons Combined with Text

# 5.7.3 Application of Instructional Aids

"The PHR site and application should include instructional aids such as text, illustrations or videos, to define the services provided and explain the process if applicable."

HealthConnects website emphasizes two subjects to educate visitors with: how it works and the sign-up process. Navigation tools are used all throughout the site to encourage visitors to learn how the site works by viewing the illustration of a process or clicking on buttons to watch the promotional video (see Figure 5-13). During registration process, steps are clearly listed to show the sign-up process (see Figure 5-14). Visitors gain knowledge about the PHR system, and are given the opportunity to view what is going to be like after signing up. Visitors are motivated to create an account based on the gained experience, knowledge and trust of the site.

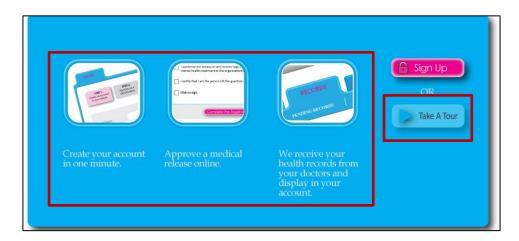


Figure 5-13: Illustration in How it Works

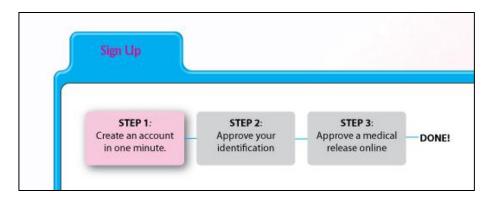


Figure 5-14: Sign up Steps

# 5.7.4 Application of Security Assurance

"A PHR system should assure users with the privacy and security of the system by providing educational description and illustrations regarding how users' identity and information will be used and protected."

As discussed in Chapter One to Chapter Four, security and privacy are main concerns for most users. HealthConnects site has security-and-privacy-related description and illustration in features, during sign-up process, and at the site footer (see Figure 5-15, 5-16 and 5-17). A "lock" icon is placed right next to "create account" and "login" to give visitors/users a visual indication of safety (see Figure 5-18). The site reflects its high quality of services and performance through these securing methods, and reassures visitors with a high level of security within the system.

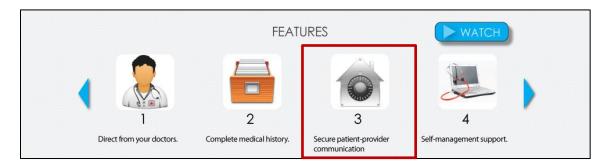


Figure 5-15: Secure patient-provider communication



Figure 5-16: Safe & Secure



Figure 5-17: Privacy in Footer



Figure 5-18: Lock Icon

# 5.7.5 Application of Identification Process

"A PHR system should process identification information in a secure and timely manner."

During registration, the user is asked to provide his or her identification information.

Figure 5-19 shows that HealthConnects site provides a clear view of necessary steps to

register, and highlights the user progress. When there is sensitive information involved, the system acquires the information by phone and generates a confirmation code for the user to proceed securely. As a result, identification information is processed in secured steps with clearly stated rules and procedures.

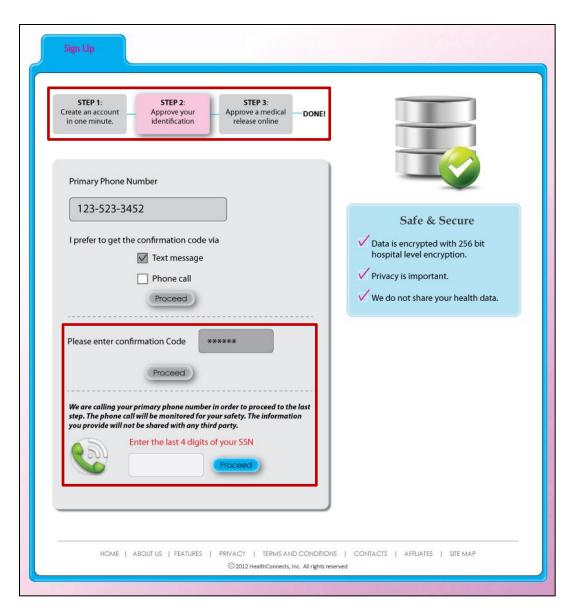


Figure 5-19: Identification Process

# 5.7.6 Application of Terminologies

"The system should speak the users' language, with words, phrases and concepts familiar to the user, rather than official medical terms."

Figure 5-20 shows that everyday language is used in HealthConnects website to facilitate the usability. For example, user information is categorized into four main subjects: "overview," "records," "appointments," and "settings." Those are all common concepts. Another example is, instead of using the word "tuberculosis", "TB" is used as it is easier to read and more familiar to users. In this way, users can quickly browse through and pick up the information they are looking for. Benefits are gained by users through the content management of HealthConnects site.



Figure 5-20: Terminologies in Archives

## 5.7.7 Application of Format

"User information received from medical care providers must be organized and displayed in a format that is easy to view and assistive to decision making for users."

HealthConnects site displays collected records in a table (see Figure 5-21) including

"the name of event," "result/medication (if applicable)" "hospital," "time," and options to "view," "confirm," and "flag." By listing only important factors in a record,

HealthConnects site assists users with decision making in a timely manner.

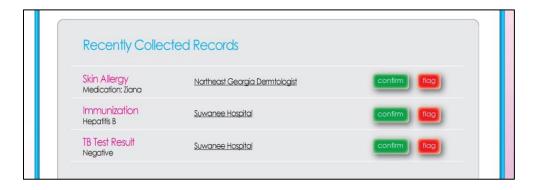


Figure 5-21: Format of Recently Collected Records

# 5.7.8 Application of Content Types

"The PHR site or application should distinguish content types from general content to current page content by text, colors, contrast, or graphic cues."

Tabs and color highlights are used all throughout HealthConnects site to inform users where they are and what they are viewing (see Figure 5-22).

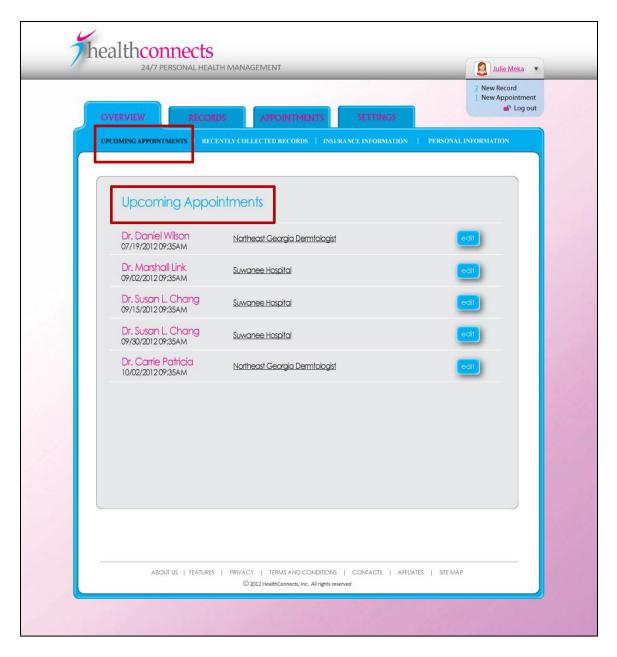


Figure 5-22: Content Types in Overview

# 5.7.9 Application of Inform Interactive Elements

"When there are interactive elements, there should be changes in colors or size to highlight or indicate the interaction."

Figure 5-23 shows in HealthConnects site, when there is an interactive element, such

as a clickable tab, the color of the text changes to indicate the interaction. The quality of navigation controls is reinforced by expectable actions and information in the site.



Figure 5-23: Highlight "Who We Are"

## 5.7.10 Application of Options

"Multiple options should be provided to users in order to achieve the maximum of functionality and flexibility."

As detailed in guideline "option", Figure 5-24 shows that users are given different options to view and locate a record. Users are also given multiple usable options when looking for a doctor (see Figure 5-25). Although a PHR system is complex with a large amount of information, the content is easily digested due to well organized display with necessary options.

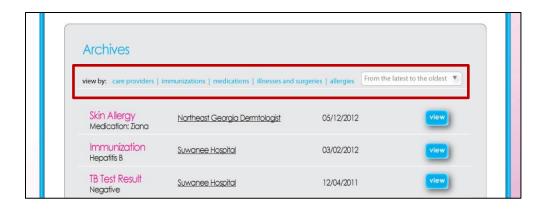


Figure 5-24: Options in Archives

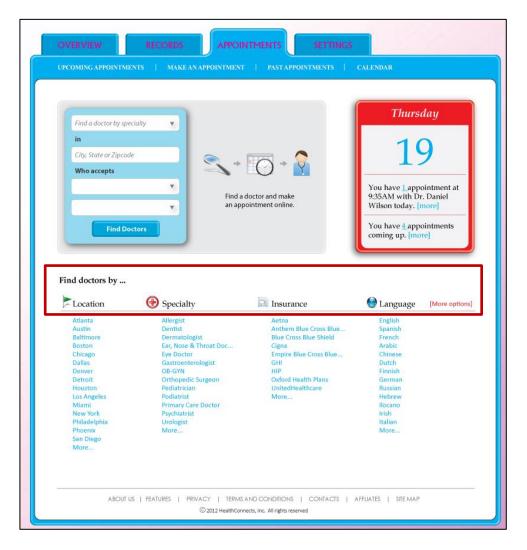


Figure 5-25: Options in Find a Doctor

# 5.7.11 Application of Preferences

"Users should have the ability to adjust their privacy preferences."

In HealthConnects site, users are given a set of options regarding operational purpose (see Figure 5-26). For example, if the user chooses to turn on "allow automatic records update from medical providers", when the user has a hospital visit, the hospital will send his or her medical records automatically through the PHR site. The user will be able to view the record under "recently collected records" and choose to "confirm" or "flag." If the user chooses to turn off this option, he or she will have to manually "request a record," which is another function provided under "records" by HealthConnects. For some users, turning off the option might be what they need because they prefer more control with their own information. For others, they might see it as a convenient way to keep having all records coming, without having to request all the records by themselves. By providing options in account and privacy settings, HealthConnects reinforces its core principles of a user-centric, integrated system to gain more credibility and achieve a higher performance.

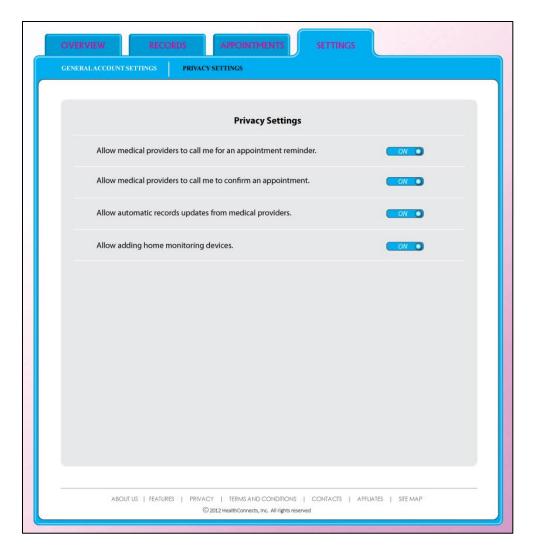


Figure 5-26: Preferences in Privacy Settings

# 5.7.12 Application of Modularity

"PHRs should be modular so as to add more components to accommodate customers with specific needs."

HealthConnects site includes "self-management" as a component that encourages and assists users adjusting the capability of the PHR system by adding their own devices or applications, and generating or uploading additional health charts (see Figure 5-27). As PHRs are developing to be a more comprehensive concept containing more than just

information from medical care providers, "self-management" is an important component for an integrated PHR system.

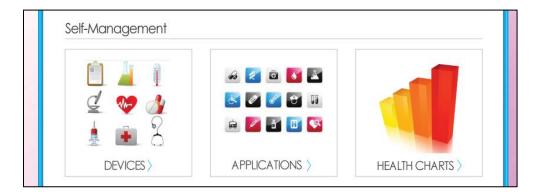


Figure 5-27: Modularity in Self-Management

# 5.7.13 Application of Mobile Application

"Because mobile devices may serve as an entry point for customers to access their PHRs, studying the characteristics of mobile platforms accordingly before designing a mobile application is a must. Most mobile operational systems now have their own UI guidelines, so a set of requirements specification different from the one for a PHR website are required when designing a mobile application for the PHR system."

The mobile application for HealthConnects was not developed in the example project. For future references, when designing a mobile application for an integrated PHR system, the research phase should include more studies on recent mobile technologies and mobile user demographics and behaviors. Comparison charts of leading mobile operation systems and mobile devices should be included in the research as well. In general, a comprehensive study of mobile industry should be conducted beforehand to provide a solid foundation for developing a good mobile application design for an integrated PHR system.

### 5.8 User Testing

A pilot test was conducted to quickly assess the effectiveness of the guidelines application. It was done with a female user who was in her late twenties. It was her first time using a personal health records website. She was asked to give her honest opinion while viewing the website, creating an account and viewing her user profile in flash format.

Her comments are generalized as follows. At the beginning, while clicking through the site as a visitor, she specifically commented on the overall attractive visual design, and the nicely-organized contents. In addition, she was able to find exactly what she was looking for in a website without getting confused or misled. She then started the sign up process. She was glad that she was not asked for a great deal of information, which might have intimidated her and other people. She liked that there were instructional pictures and process descriptions, which really helped her make decisions and proceed to the next steps. Finally, she logged in as a user. She liked the features and functions that she saw in her profile, especially the "self-management" section, which made her feel like she had more control, interaction and fun with the system.

After she was done using the website she did a brief review. She was very impressed with the overall experiences and would love to recommend it to other people. She expressed that she would not fear to go back to use it because it was so useful and easy to navigate. She commented that in addition to being very easy and accessible, the website felt very open yet secure.

#### 6. Conclusions

# 6.1 Summary of the Study

The objective of this study is to analyze PHRs and how they should be implemented from a primary user's point of view. The results of the literature review and studies of existing systems show that when designing a PHR system, it is important to take into account aesthetic factors, sociological factors and marketing factors. Design principles and guidelines were carried out to help designers to create a PHR system. A prototype was built to demonstrate the design process and the guidelines application.

Chapter One assesses what the subject of study is. It begins with a problem statement, need for the study and goes into a literature review that takes a brief look into all aspects of the subject. Furthermore, it concludes with the objectives, assumptions, scope and limits, and finally the procedures and methodology.

Chapter Two examines HCI design, which provides the structural support for the study. It also begins the preliminary research of PHRs. This is where the primary users and PHR systems were studied.

After the primary users and products were defined, Chapter Three introduced the surveys and questionnaires. Enough information has been found at this point to develop design guidelines, so Chapter Four put together design criteria for an integrated PHR system.

Next, Chapter Five takes the criteria and applies it to a fictional PHR website called "HealthConnects." This chapter shows the design process and the evaluation of the prototype as well.

# 6.2 Recommendations

This set of design principles and guidelines were geared towards designing a usercentric and integrated PHR system. They can always support guiding designers along the design process. In addition, they could be used in designing other user-centric or personal information management systems.

With the fast developing pace of mobile industry, the relationship between a PHR site and a PHR mobile application may change. Policies for health information may be improved to facilitate a better environment for the adoption of PHR systems. The principles and guidelines can always be modified when necessary.

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# Appendix 1

For Information or help contact THE OFFICE OF RES Phone: 334-844-5966 e-mail: hsubjec@auburn.edu	EARCH COMPLIANCE, 115 Ram	say Hall, Auburn University uburn.edu/research/vpr/ohs/
Revised 03.26.11 – DO NOT STAPLE, CLIP TOGETHER ONLY.	web Address: <u>http://www.d</u>	Save a Copy
1. PROPOSED START DATE of STUDY: Feb 1, 2012 -		***************************************
PROPOSED REVIEW CATEGORY (Check one): FULL BOARD  2. PROJECT TITLE: DESIGN GUIDELINES FOR AN INTEGRATED PHR  AN APPROACH FOR UI DESIGNERS TO BREAI		EXEMPT RIERS TO PHR ADOPTION
3. YUAN ZHOU INDU PRINCIPAL INVESTIGATOR TITLE	STRIAL DESIGN 334-524-4423 DEPT PHONE	YZZ0007@AUBURN.EDU AU E-MAIL
4264 CHATHAM CREST LANE, BUFORD GA 30518 MAILING ADDRESS	FAX	YUAN.ZHOU86@GMAIL.COM ALTERNATE E-MAIL
4. SOURCE OF FUNDING SUPPORT:   ✓ Not Applicableinternal	External Agency:	Pending Received
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Do you need IBC Approval for this study? ✓ No Yes - BUA #	Expiration	n date
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Figure 6-1: Research Protocol Review Form Page 1

#### 7. PROJECT ASSURANCES

PROJECT TITLE: DESIGN GUIDELINES FOR AN INTEGRATED PHR SYSTEM

--- AN APPROACH FOR UI DESIGNERS TO BREAK DOWN INDIVIDUAL-LEVEL BARRIERS TO PHR ADOPTION

#### A. PRINCIPAL INVESTIGATOR'S ASSSURANCES

- 1. I certify that all information provided in this application is complete and correct.
- I understand that, as Principal Investigator, I have ultimate responsibility for the conduct of this study, the ethical performance this project, the protection of the rights and welfare of human subjects, and strict adherence to any stipulations imposed by the Auburn
- I certify that all individuals involved with the conduct of this project are qualified to carry out their specified roles and
- responsibilities and are in compliance with Auburn University policies regarding the collection and analysis of the research data.

  I agree to comply with all Auburn policies and procedures, as well as with all applicable federal, state, and local laws regarding the protection of human subjects, including, but not limited to the following:
  - a. Conducting the project by qualified personnel according to the approved protocol
  - Implementing no changes in the approved protocol or consent form without prior approval from the Office of Human Subjects Research
  - Obtaining the legally effective informed consent from each participant or their legally responsible representative prior to their participation in this project using only the currently approved, stamped consent form
  - Promptly reporting significant adverse events and/or effects to the Office of Human Subjects Research in writing within 5 working days of the occurrence.
- If I will be unavailable to direct this research personally, I will arrange for a co-investigator to assume direct responsibility in my absence. This person has been named as co-investigator in this application, or I will advise OHSR, by letter, in advance of such arrangements.
- I agree to conduct this study only during the period approved by the Auburn University IRB.
- I will prepare and submit a renewal request and supply all supporting documents to the Office of Human Subjects Research before the approval period has expired if it is necessary to continue the research project havened the time period has expired if it is necessary to continue the research project havened the time period has expired if it is necessary to continue the research project havened the time period has expired if it is necessary to continue the research project havened the time period has expired if it is necessary to continue the research project havened the time period has expired if it is necessary to continue the research project havened the time period has expired if it is necessary to continue the research project havened the time period has expired if it is necessary to continue the research period the time period has expired if it is necessary to continue the research period the time period has expired in the period has ex

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. F	ACULTY ADVISOR/SPONSOR'S	ASSURANCES			
k e	By my signature as faculty advisor/sponsor on this research application, I certify that the student or guest investigator is knowledgeable about the regulations and policies governing research with human subjects and has sufficient training and experience to conduct this particular study in accord with the approved protocol.  I certify that the project will be performed by qualified personnel according to the approved protocol using conventional or				
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Figure 6-2: Research Protocol Review Form Page 2

#### 8. PROJECT OVERVIEW: Prepare an abstract that includes;

(400 word maximum, in language understandable to someone who is not familiar with your area of study):

- L.) A summary of relevant research findings leading to this research proposal:

  (Cite sources; include a "Reference List" as Appendix A.)
- A brief description of the methodology,
- III.) Expected and/or possible outcomes, and,
- IV.) A statement regarding the potential significance of this research project.

The objective of this study is to analyze personal health record (PHR) and how it should be implemented from a primary user's point of view. Design guidelines will be provided for user interface design in PHR systems.

In health care field, there have been many long discussed issues. Among those issues, governments, providers and practitioners have focused on how to make the best use of the computerized health information systems such as electronic health records (EHR) and personal health records (PHR). The significance of the quality of information has been recognized in health care field. Resources are invested and positive outcomes are expected (Black, 1992; Kim&Johnson, 2002; Luo, 2006; Tang&Ash, 2006; Tang&Lee, 2009).

The Obama administration has set a goal of computerizing all of America's medical records within 5 years as a means of improving efficiency, quality, and safety and ultimately saving money(ARA, 2009). The economic recovery package recently signed into law by President Obama will provide bonus payments of \$44,000 to \$64,000 to physicians who adopt and effectively use EHRs from 2011 through 2015, and it is likely that

providers will then be introduced for physicians who do not adopt the technology.

While EHR is drawing such attention, it raises questions as well. How will health information reach people, including patients, health care providers, employers, and etc? How can information flow seamlessly among systems in a secure environment? Especially for individuals, how can one access, manage and share his/her health information with authorized health providers? To answer those questions, PHR plays a crucial role here. There are different opinions regarding how PHR systems should be implemented. The concept of integrating web-based PHRs with institutional EHRs is becoming the trend(HHS, 2006).

#### METHODOLOGY

- 1.) Based on existing user reviews on the application for apple mobile devices "Nike+GPS" from iTunes, I will generalize user need and expectations from a mobile user's point of view.
- 2.) Questionnaire will be used to conduct a user survey on MyActiveHealth website(see attached questionnaire).
- The feedback will be categorized and generalized using standards from several related articles.
- 4.) New findings and rules for graphic design will be developed accordingly for mobile and web-based systems.

#### **EXPECTED OUTCOMES & SIGNIFICANCE**

User interface design is essential for improving the usability of interactive systems like PHRs. Creating standard design elements and principles for EHR and PHR systems is an emerging need due to the reality that in the current health care environment, multiple vendor systems coexist and each of them has unique styles and design constructs. Therefore, the responsibilities in the process of PHR system design must be recognized by UI designers who need to work in the related fields. In this study, guidelines will be applied to a PHR system design prototype to demonstrate how the constructing and integrating graphic design is carried out, and how to make PHRs more user-friendly by incorporating user's daily activities into personal health decision making and medical care.

#### 9. PURPOSE.

a. Clearly state all of the objectives, goals, or aims of this project.

The objective of this study is to analyze personal health record (PHR) and how it should be implemented from a primary user's point of view. Design guidelines will be provided for user interface design in PHR systems. New findings and rules for graphic design will be developed accordingly for mobile device and PC use.

b. How will the results of this project be used? (e.g., Presentation? Publication? Thesis? Dissertation?)

Thesis

3

Figure 6-3: Research Protocol Review Form Page 3

Yuan Zhou Principle Investigator	Title:	yzz0007@auburn.edu E-mail address
Dept / Affiliation: Industrial design, Auburn Univ	versity	yzz0007@auburn.edu E-mail address
Roles / Responsibilities:		
Designing and conducting the research.     Analyze the results from research.		
ndividual: Dept / Affiliation:	Title:	E-mail address
Roles / Responsibilities.		
ndividual:	Title:	E-mail address
Dept / Affiliation:		
Roles / Responsibilities:		
		×
ndividual: Dept / Affiliation:	Title:	E-mail address
Roles / Responsibilities	2	
ndividual:	Title:	E-mail address
Dept / Affiliation:		
ndividual: lept / Affiliation:	Title:	E-mail address
Roles / Responsibilities.		
OCATION OF RESEARCH   List all locations w	there data collection will	take place. (School systems, organizations, businesses, built

Figure 6-4: Research Protocol Review Form Page 4

12	DAI	RTICIPANTS.
12.		Describe the participant population you have chosen for this project.  Check here if there is existing data; describe the population from whom data was collected & include the # of data files.
		GROUP 1: Online anonymous reviewers for the mobile & web-based application Nike+GPS for Apple smart mobile devices.
		GROUP 2: MyActiveHealth users. MyActiveHealth is a web-based personal health management system.
		•
	b.	Describe why is this participant population is appropriate for inclusion in this research project. (Include criteria for selection.)
		GROUP 1: This participant group are people who have been using Nike+GPS.
		GROUP 2: This participant group are people who have been using MyActiveHealth.
		2.
	C.	Describe, step-by-step, all procedures you will use to recruit participants. Include in <u>Appendix B</u> a copy of all e-mails, flyers, advertisements, recruiting scripts, invitations, etc., that will be used to invite people to participate. (See sample documents at <a href="http://www.auburn.edu/research/vpr/ohs/sample.htm">http://www.auburn.edu/research/vpr/ohs/sample.htm</a> .)
		GROUP 1 All reviewers and their reviews for the product Nike+GPS are found on iTunes(iTunes is a media computer player computer program that was introduced by Apple Inc).
		GROUP 2 Questionnaires will be used. I will print them out on paper. Then, 1) I will give them to a friend of mine who works at a company where they are all required to use MyActiveHealth. 2) He will ask at least ten people to fill out the questionnaires. 3) He will return the collected questionnaires to me.
		What is the minimum number of participants you need to validate the study? 10
		Is there a limit on the number of participants you will recruit?
		Is there a limit on the number of participants you will include in the study? 🗹 No 🔲 Yes – the number is
	d.	Describe the type, amount and method of compensation and/or incentives for participants.  (If no compensation will be given, check here ✓.)
		Select the type of compensation: Monetary Incentives Raffle or Drawing incentive (Include the chances of winning.) Extra Credit (State the value) Other
		Description:

Figure 6-5: Research Protocol Review Form Page 5

#### 13. PROJECT DESIGN & METHODS.

- a. Describe, step-by-step, all procedures and methods that will be used to consent participants.
- ( \_\_ Check here if this is "not applicable"; you are using existing data.)

**GROUP 1: existing data** 

#### GROUP 2:

- 1.) An informed consent will be attached to the questionnaire.
- 2.) In the informed consent, they will be asked to check the box on each page to confirm that they have received the information provided and if they are willing to participate in the survey.

  3.) Neither signature nor date is required in the informed consent because it will be the only directly or indirectly identifiable information
- which might cause discomfort for people to participate.
- b. Describe the procedures you will use in order to address your purpose. Provide a <u>step-by-step description</u> of how you will carry
  out this research project. Include specific information about the participants' time and effort commitment. (NOTE: Use language that would be understandable to someone who is not familiar with your area of study. Without a complete description of all procedures, the Auburn University IRB will not be able to review this protocol. If additional space is needed for this section, save the information as a .PDF file and insert after page 6 of this form.)
- I. Research on human-computer interaction (HCI) in medical care.
  - 1.) HCI in general
  - 2.) HCl in personal health record systems: the user, the systems and the paradigms
  - 3.) Analysis of existing PHR systems
- II. User research on existing health management products based on the previous research.

  1.) From existing user reviews on the application for apple mobile devices "Nike+GPS" from iTunes, I will generalize user need and spectations from a mobile user's point of view. (See attached picture I for this application.)
  - Questionnaire will be used to conduct a user survey on MyActiveHealth website(see attached questionnaire).
     The feedback will be categorized and generalized using standards from previous analysis of existing PHR systems.

- Iii. Design guidelines will be carried out for an integrated PHR system.

  1.) New findings and rules for graphic design will be developed accordingly for mobile and web-based systems.
  - 2.) Introduction to the sequence of use in PHR systems.
- 3.) Designing for better PHR experiences.
- IV. Design guidelines application. 1.) Design development.
  - 2.) Final model.

6

Figure 6-6: Research Protocol Review Form Page 6

13c. List all data collection instruments used in this project, in the order they appear in Appendix C. (e.g., surveys and questionnaires in the format that will be presented to participants, educational tests, data collection sheets, interview questions, audio/video taping methods etc.)
Questionnaires

d. Data analysis: Explain how the data will be analyzed.

The feedback will be categorized and generalized using standards from previous analysis of existing PHR systems. Comparison charts will be developed during the analysis.

14. RISKS & DISCOMFORTS: List and describe all of the risks that participants might encounter in this research. <u>If you are using deception in this study, please justify the use of deception and be sure to attach a copy of the debriefing form you plan to use in <u>Appendix D.</u> (Examples of possible risks are in section #6D on page 1.)</u>

NONE

7

Figure 6-7: Research Protocol Review Form Page 7

	ndividuals. Provide a copy of any emergency plans/procedures and medical referral lists in Appendix D.	
	No directly or indirectly identifiable information will be collected during the research.	
H	using the Internet to collect data, what confidentiality or security precautions are in place to protect (or not collect) lentifiable data? Include protections used during both the collection and transfer of data. These are likely listed on the server's website.)	
	Public, non-identifiable information from internet will be collected so there is no precautions.	
	G.	
	*	
	ENEFITS.  List all realistic direct benefits participants can expect by participating in this specific study.  (Do not include "compensation" listed in #12d.) Check here if there are no direct benefits to participants. ✓	
	•	
	•	
	List all realistic benefits for the general population that may be generated from this study.	
	204 000 0 000 000 000 000 000 000 000 00	
	The design guidelines will benefit medical system designers especially visual designers and researchers in medical management system fie	eld.
	8	Ċ

17.	PR	OTECTION OF DATA.
	a.	Will data be collected as anonymous?
	b.	Will data be collected as confidential?
	c.	If data are collected as confidential, will the participants' data be coded or linked to identifying information?  Yes (If so, describe how linked.)  No
	d.	Justify your need to code participants' data or link the data with identifying information.
		/A
		# 5
	e.	Where will code lists be stored? (Building, room number?)
	N.	,
	f.	Will data collected as "confidential" be recorded and analyzed as "anonymous"?  (If you will maintain identifiable data, protections should have been described in #15.)
	g.	Describe how and where the data will be stored (e.g., hard copy, audio cassette, electronic data, etc.), and how the location where data is stored will be secured in your absence. For electronic data, describe security. If applicable, state specifically where any IRB-approved and participant-signed consent documents will be kept on campus for 3 years after the study ends.
	Si si	nce the only means to identify the participants are their signatures from the questionnaires, there will be no any means of signing date and gnature required. The anonymous data will be stored on printed paper in a folder that I will keep at home for as long as required.
		•
		*
1	h.	Who will have access to participants' data?  (The faculty advisor should have full access and be able to produce the data in the case of a federal or institutional audit.)
		ie principle investigator , Yuan Zhou <sup>i</sup> culty advisor, Shu-Wen Tzeng
j	•	When is the latest date that <u>confidential</u> data will be retained? (Check here if only anonymous data will be retained.   ✓)
j	N/	How will the confidential data be destroyed? (NOTE: Data recorded and analyzed as "anonymous" may be retained indefinitely.)  A

Figure 6-9: Research Protocol Review Form Page 9

## Appendix 2



## College of Architecture, Design and Construction Department of Industrial and Graphic Design

# (NOTE: DO NOT AGREE TO PARTICIPATE UNLESS IRB APPROVAL INFORMATION HAS BEEN ADDED TO THIS DOCUMENT.)

#### INFORMATION LETTER

for a Research Study entitled
"Design Guidelines for an Integrated PHR System
--- An Approach for UI Designers to Break Down Individual-Level Barriers to
PHR Adoption"

You are invited to participate in a research study to analyze personal health record (PHR) and how it should be implemented from a primary user's point of view. The study is being conducted by Yuan Zhou, graduate student under the direction of Shu-wen Tzeng, assistant professor in the Auburn University Department of industrial design. You were selected as a possible participant because you are a MyActiveHealth user and are age 19 or older.

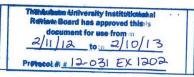
What will be involved if you participate? If you decide to participate in this research study, you will be asked to fill out the attached questionnaire. Your total time commitment will be approximately 10 to 25 minutes.

There are no known risks associated with participating in this study.

Are there any benefits to yourself or others? Although there is no direct benefit to you, we hope to learn about your experiences, needs and expectations from using MyActiveHealth.

There is no cost or compensation associated with participating in this study.

If you change your mind about participating, you can withdraw at any time during the survey by discarding this letter and survey. Your participation is completely voluntary. Your decision about whether or not to participate or to stop participating will not jeopardize your future relations with Auburn University or the Department of Industrial Design.



1/2

Figure 6-10: Questionnaire Page 1

Any data obtained in connection with this study will remain anonymous. To minimize any possible risks, we will not collect any directly or indirectly identifiable data from you. Information collected through your participation may be presented at a professional meeting, and used in my thesis.

Please do NOT provide any of your personal information, work information, medical care information or medical insurance information, including your name, age, the name of the company, your job tile, the location, etc., as they can be directly and indirectly identifiable.

If you have questions about this study, please ask them now or contact Yuan Zhou by phone 334-524-4423, or e-mail at  $\underline{\mathtt{yzz0007@auburn.edu}}$  , or Dr. Shu-wen Tzeng at szt0004@auburn.edu or 334-844-2361.

If you have questions about your rights as a research participant, you may contact the Auburn University Office of Human Subjects Research or the Institutional Review Board by phone (334)-844-5966 or e-mail at <a href="https://hsubjec@auburn.edu">hsubjec@auburn.edu</a> or IRBChair@auburn.edu.

HAVING READ THE INFORMATION PROVIDED, YOU MUST DECIDE WHETHER OR NOT YOU WISH TO PARTICIPATE IN THIS RESEARCH STUDY. IF YOU DECIDE TO PARTICIPATE, THE DATA YOU PROVIDE WILL SERVE AS YOUR AGREEMENT TO DO SO. THIS LETTER IS YOURS TO KEEP.

2/20/2012

Signed, Yuan Zhou, Investigator

The Auburn University Institutional Review Board has approved this ment for use from

2/2

Figure 6-11: Questionnaire Page 2

### QUESTIONNAIRE

Please check the number that best describes your opinion.

When you feel that you have known this product well enough and completed the questionnaire, please return it.

1. How long have you been using MyActiveHealth?  □ Less than a week □ 2 to 4 weeks □ 1 to 2 months □ 3 to 6 months □ 6 to 12 months □ More than a year
<ul> <li>2. How often do you use this website? If you haven't had your MyActiveHealth account long, how often do you intend to use it from now on?</li> <li>Never</li> <li>Occasionally</li> <li>Only for specific purposes</li> <li>Everyday</li> </ul>
3. On what platforms have you used MyActiveHealth?  ☐ Windows PC  ☐ Windows Phone/ Windows Tablet  ☐ Macintosh PC  ☐ iPhone/iTouch/iPad
For example, 1 means poor and 5 means excellent. If you think it is $OK/average$ , then circle number 3.
1. How satisfied are you with the Content?
Layout
Poor 1 2 3 4 5 Excellent
Value
Poor 1 2 3 4 5 Excellent
Functionality Poor 1 2 3 4 5 Excellent
4. How easy is it for you to use this website?
Discoverability of Information
Poor 1 2 3 4 5 Excellent
Learning Curve for MyActiveHealth
Short 1 2 3 4 5 Long

1/2

Figure 6-12: Questionnaire Page 3



## Appendix 3

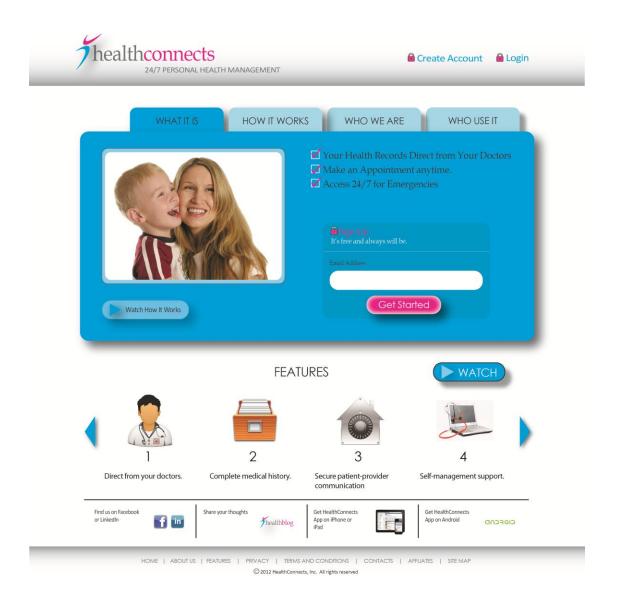


Figure 6-14: Homepage

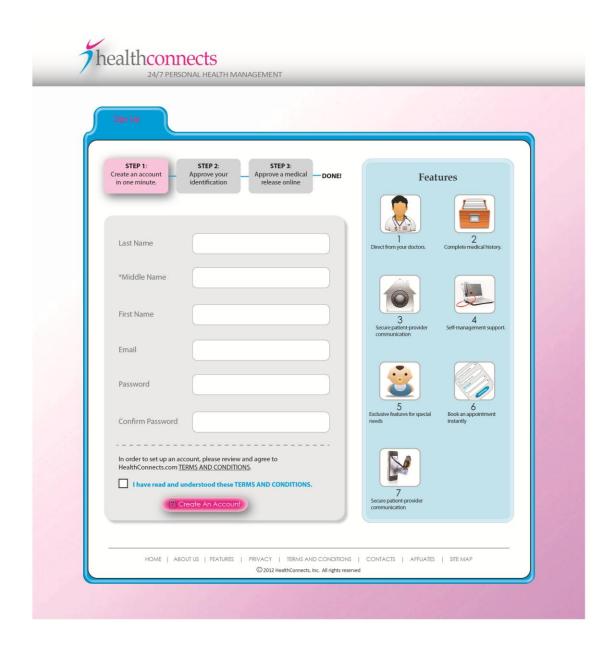


Figure 6-15: Sign-up Step 1

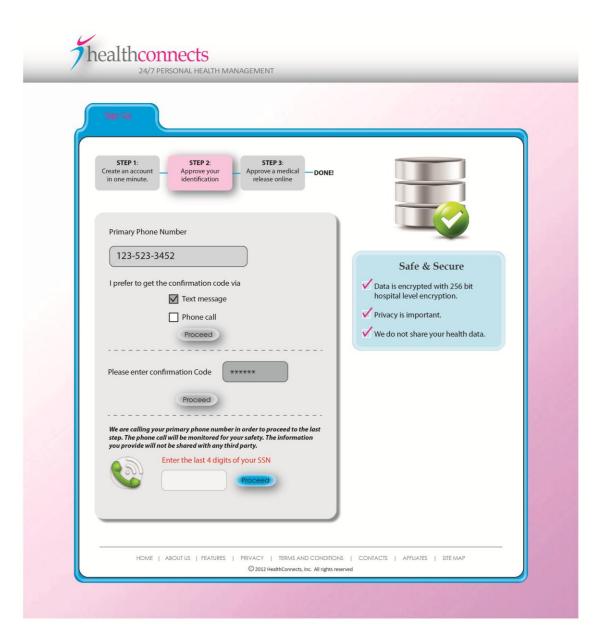


Figure 6-16: Sign-up Step 2



Figure 6-17: Sign-up Step 3



Figure 6-18: Login



Figure 6-19: User Homepage

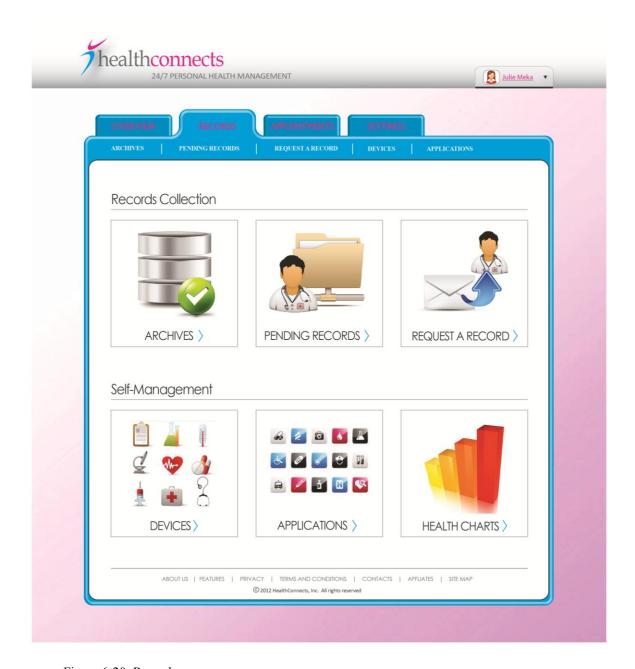


Figure 6-20: Records

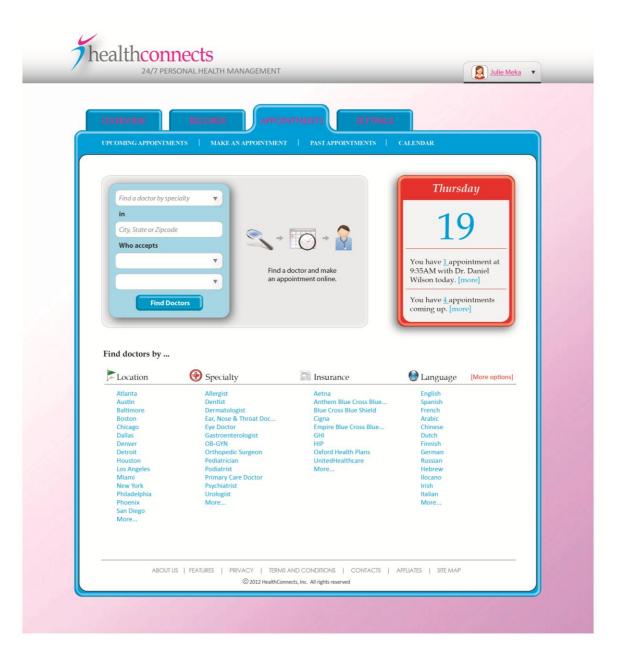


Figure 6-21: Appointments

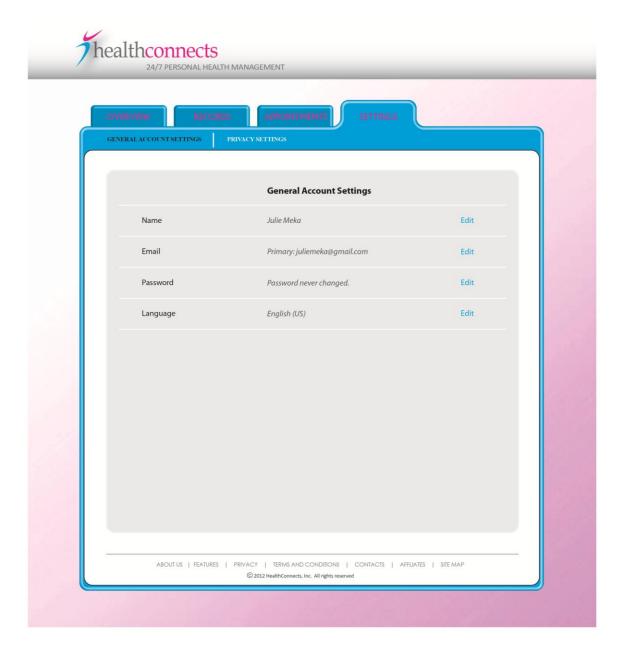


Figure 6-22: Settings