Technology-Enabled Transformations in U.S. Health Care: Early Findings on Personal Health Records and Individual Use

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Abstract

Information intensive industries, such as health care, rely extensively on the ability to store, process, analyze, and use data. Although other information intensive industries have adopted information technology aggressively and reaped the benefits that result from usage, the health care industry has been notoriously slow to implement information systems, with some researchers suggesting that health care is 10-15 years behind other industries. Recognizing the critical importance of decision quality in the health care sector, together with the need to improve the speed and efficiency of operations, many have called for the transformation of the health care industry through widespread adoption and usage of information technology (IT). In this chapter, we define and discuss health information technology (HIT) and the extensive opportunities for IS research in this field. In particular, we direct our attention to the electronic personal health record (PHR) and investigate the justification for adoption of a class of software that we label a discretionary application. Finally, we report findings from an empirical investigation of PHR usage and show that specific demographic and health conditions drive value for PHRs and ultimately usage intentions.

Keywords: Health Information Technology, Personal Health Records, Electronic Health Records, Electronic Medical Records, HIT, PHR, EHR, EMR, eHealth

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Introduction

> *"Implementing a computerized record system in an urban or suburban hospital could save 60,000 lives, prevent 500,000 serious medication errors, and save $9.7 billion each year," (Leapfrog, 2004).*

> *"Existing technology can transform health care...if all Americans' electronic health records were connected in secure computer networks…providers would have complete records for their patients, so they would no longer have to re-order tests," (Gingrich & Kennedy, 2004).*

The transformational power of information technology in altering the nature of competition in an industry and creating value for both firms and consumers has long been acknowledged in diverse industry sectors such as airlines, financial services, and retailing (Copeland & McKenney, 1988; Lucas, 1999). A common characteristic among industries that have experienced such transformations is that they are *information intensive* – i.e., a significant proportion of their value-creation activities occurs through the storage, processing, and analysis of data. The transformation has typically been attributed to specific software applications – e.g., the Sabre System in the airline industry and Merrill Lynch's Cash Management System in the brokerage industry, that provide the trigger for far-reaching changes. In this chapter we explore an emergent IT application – the electronic personal health record (PHR) that arguably, offers the same potential for revolutionary, discontinuous change in the health care sector. In very general terms, an electronic PHR is a software program that an individual uses to manage his or her health information. It can be either a web-based, ASP (application service provider) model, or a stand-alone PC-based platform. Later in this chapter we provide a more elaborate, descriptive explanation of PHRs.

Health care accounts for nearly 15% of GDP in most industrialized nations (*National Health Care Expenditures: Historical Overview*, 2004). It also represents a sector with significant consequential outcomes – the quality of care delivered often spells the difference between life and death. Thus, it is not surprising that considerable emphasis is being placed by governments, policy makers, and other stakeholders in this sector in trying to better understand how the delivery of care can be improved. Human capital in the form of knowledge and skills is doubtless a critical input factor for the quality of health care; however, to the extent that health care is an information intensive, knowledge-based activity that requires high reliability in operations, another important input is technology that can aid in the "movement" of critical information.

Software innovations such as the electronic PHR are an inevitable outcome of developments in information technology and, as experience with over 50 years of IT innovation illustrates, we expect such developments to occur with some regularity. Yet as research in the adoption, diffusion, and utilization of innovations suggests, the rate at which such innovations are "absorbed" by the intended users is considerably slower. Individual users are socialized with IT both in the workplace through business information processing applications that are required on the job, as well as in their personal spheres through applications they may use at home. Indeed, home use information technologies are proliferating both in terms of the range and variety of applications and in revenue opportunities, as some have estimated consumer software to be a $2 billion market (Bear, 2000). Generally, the demarcation between these two classes of systems is fairly straightforward in that the former (workplace applications) is typically mandated while the latter (home use applications) is volitional. The electronic PHR is somewhat unique in that although the ultimate users of this technology are individual home users, there are systemic, sector-wide implications of its adoption for the cost and quality of health care. Some would argue that most PC- or web-based software applications that are used at home fall into this category. We, however, believe that electronic PHRs differ from other home-use examples because use of software by individuals for managing health care can actually drive *organizational* adoption of electronic medical record systems among hospitals and other health care institutions. In essence, we are describing a 'trickle-up' phenomenon. The more traditional, "trickle-down" approach to diffusing the technology is not entirely feasible because the ultimate success of the technology depends on the individual user.

The human issues surrounding electronic PHRs are numerous. First, the IT captures and stores highly personal, sensitive medical information, thereby introducing increased personal vulnerability to privacy and security violations. Second, to the extent that treatment and diagnosis decisions are based on the data captured in the PHR, data quality is of paramount importance. Finally, applications such as the PHR are particularly challenging since they require users to expend significant effort on data entry. To the degree that anticipated benefits to the health care sector through such applications are predicated on individual use of these systems, questions such as what are individuals' attitudes towards electronic PHRs, and what will motivate them to accept and use them, are important to address.

In this chapter we introduce the emerging technology of the personal health record and situate it within the broader context of technology-led transformations in the health care sector. We identify the roadblocks and obstacles that the technology is likely to face, and illuminate aspects of the adoption and use of this technology by individuals through empirical data. Particularly, we highlight the types of value the technology generates for users and its relationship with intended technology use in the future. Because our data were gathered at an early stage of the diffusion curve for this new technology, the findings are likely to be useful for policy makers and others concerned with successfully diffusing electronic PHRs more widely.

We also feel it is necessary to elaborate upon the terminology used here. The term 'health information technology' or HIT, is widely used in the medical informatics field and in government publications. In other disciplines and most practitioner literature, the more general term, 'eHealth' is typically used. While often used interchangeably, the terms are not synonymous. There are no standard or universally accepted definitions for either term, but the following capture their essence:

> *eHealth* – the use of emerging technologies, especially the Internet, to improve or enable health and healthcare (*eHealth Institute*, 2004)
>
> *HIT* – information technology [used] to improve the quality, efficiency, and safety of health care (*Office of the NCHIT*, 2004).

While very similar, the primary difference as we interpret the definitions, and as we use them in this chapter, is that HIT refers directly to the technology artifacts and eHealth describes the use of technology in the health care field. It could be argued that eHealth is the use and application of HIT. Since we are primarily focused on technology artifacts in this chapter, we will almost exclusively use the term HIT.

Health Information Technology

> *"In spite of more than 30 years of exploratory work and millions of dollars in research and implementation of computer systems in health care provider*

institutions, patient records today are still predominantly paper records,"
(Dick, Steen, & Detmer, 1997).

The State of the Problem

Notwithstanding the focus of the above quotation on electronic health records, a similar observation can be made for the use of information technology in the health care industry in general. Disturbingly, although the quotation dates back over seven years, the situation today is not very different. According to the most recent data from the Department of Health and Human Services, only 13 percent of the nation's hospitals and 14-28 percent of physicians' offices used electronic medical records in 2002 (Thompson, HHS Report, 2004) and as recently as 2001, only 6% of prescriptions were written electronically (Chin, 2002b; Papshev & Peterson, 2001). Critics of health information technology may challenge that medicine has been practiced for centuries without the use of IT, so why is the 21st century any different than earlier centuries? The answer is simple: today *multiple actors* have to manage the accumulated knowledge from centuries prior. The emphasis on "multiple" is key, as it is important to recognize that it is not just doctors and medical staff who have knowledge (as was typically the case in the past), but increasingly, the patients themselves are conducting searches on their own and providing their health care providers with the most up-to-date treatments and technologies. A recent study showed that about 20% of adults in the U.S. use the Internet to access health information (Baker, Wagner, Singer, & Bundorf, 2003), while another study reported that 70% of health information seekers use the information retrieved on the web to make health care decisions (Brodie, Flournoy, & Altman, 2000). This amounts to millions of people seeking health information and providing knowledge to their health care providers. It is, therefore, not unreasonable to unequivocally state that HIT is becoming mandatory for managing, retrieving, and storing medical knowledge in a useful manner.

In addition to progressive involvement by patients, health information technology has become increasingly important because Americans' lifestyles have changed so dramatically in recent decades and the health care system itself has gone through major policy transformations. For example, Kim and Johnson (2002), observe that the increased mobility of people and the provider-specific requirements of managed care insurance have forced people to seek care from several different providers, resulting in a highly-decentralized information source for individual health information. This decentralization of data and current inability of sources to communicate with each other has resulted in catastrophic quality of care consequences. The Institute of Medicine, in a 1999 report, reported that between 44,000 and 98,000 Americans die in hospitals each year as a result of medical errors (Kohn, Corrigan, & Donaldson, 1999). Other studies have shown that between 28-56% of adverse drug events are preventable by using various forms of HIT (Bates et al., 1998; Bates et al., 1997; Classen, Pestotnik, Evans, Lloyd, & Burke, 1997). One form of HIT that is slowly gaining acceptance and is viewed as offering significant benefits is the enterprise-wide, electronic medical record (EMR), sometimes known as an electronic health record (EHR). While many doctors and health systems have embraced this technology, which gives practitioners access to patients' medical records, medication information, and other medical knowledge from any computer connected to the system, others have been slow to adopt or downright resistant. Some feel that use of EMRs takes time away from direct interaction with patients and negatively affects the doctor-patient relationship. In addition, many health systems have allowed patients to access portions of the EMR through portals or direct downloads to storage devices, creating in essence, a personal health record with only their health information contained in it. Of course this too has created uncertainty amongst some practitioners with opinions ranging from highly positive, e.g. "The most profound influence of EMRs may lie in their ability to encourage patients' involvement in their own care (Tsai & Starren, 2001)," to highly negative, e.g. "Patients will be confused or misled by their record…[they] may object to information contained in it…[they will] quiz their caregivers incessantly about the meaning of test results and reports [contained in it]," (Cimino, Patel, & Kushniruk, 2002).

Another solution that is gaining momentum is for patients themselves to collect and manage their health information in an electronic personal health record. Software is currently available which can provide this application service. Some of these packages provide links to health system EMRs, while others are stand-alone applications that reside only on the patient's personal computer. This technology is the focus of this chapter and is discussed in great depth in the following sections.

Medical Informatics and Proposed Classification of Health Information Technology (HIT)

We begin by providing a brief introduction to medical informatics and reflect on the opportunities for information systems research in this domain. IS research, specifically in the health care field, is not without precedence (see Devaraj & Kohli, 2003; K. K. Kim & Michelman, 1990; Raghupathi, 2002). Although the health care setting is not typical of a traditional firm, there are numerous similarities between health care information systems and business information systems. For example, issues related to integration, implementation, interoperability, and adoption of systems are congruent in business firms or hospitals. As pointed out by Hersh (2002), the delivery of health care is an information-based science. As such, information scientists in the medical field have created their own discipline, known as *medical informatics*, that is specifically focused on using IT in a health care setting. The development of this field was due in part to the exponential improvements in computer technology in recent years, the glaring inadequacies of paper-based information, and the growing awareness that the knowledge was becoming unmanageable through traditional means.

While several definitions for medical informatics exist, a commonly shared characterization is that the medical informatics field is concerned with the management and use of information in health and biomedicine and the core theories, concepts, and techniques used in the application of information (Hersh, 2002). Others have expanded the medical informatics field to include the application of information in the problem-solving and decision-making process conducted by medical practitioners (Greenes & Shortliffe, 1990). Health care informaticians note that the medical informatics field is closely related to modern information systems research, specifically in the areas of computing and communication systems (Greenes & Shortliffe, 1990). For these reasons, it is apparent that IS scholars should be conducting research in this area and raising awareness amongst students that the health care field is a burgeoning market for IS graduates.

Given the bewildering range of IT applications in health care, it is important to structure and organize the systems used so that research opportunities and gaps can be identified. Figure 1 shows a taxonomy of the systems used in the delivery of health care. This diagram describes two distinct technology categories: administrative and clinical. From these two primary branches, several department- and job-specific information systems emerge. For example, on the left side of the diagram, one will see administrative information systems such as imaging systems that are used by the administrative staff for operational-level functions, such as retrieving an insurance ‘Explanation of Benefits’ form. On the right side of the diagram are clinical information systems that are typically populated by technicians, such as an X-Ray technician, but accessed by several interested actors including various clinicians. Some systems, such as the electronic medical record, span both the clinical and administrative branches. Clinicians use medical records for reviewing patient history and other details and the administrative systems are often directly linked to certain portions of the patient record that provide the permanent record for the patient.

Although other classifications exist, none that we are aware of are as comprehensive as the taxonomy proposed here. For instance, Degoulet and Fieschi (1997) classified key areas of medical informatics but they did not explicitly identify the systems present in a typical health care setting. Others have attempted to classify the type of information that HIT yields. For example, Hersh (2002) identified two types of information used in clinical informatics: 1) patient-specific, in which information is generated by and used in the care of patients in the clinical setting, and 2) knowledge-based information which comprises the scientific basis for health care. While our focus in this study is specifically on electronic medical records that span the administrative and clinical types, research into the other information systems is also warranted and lacking. An electronic personal health record, as described in the next section, incorporates both patient-specific and knowledge-based information in that it provides a synopsis of patient information to the practitioner while enabling knowledge-based discovery through links to clinical health information. Our study focuses on this artifact as but one of many systems present in a typical HIT environment.

<< INSERT FIGURE 1 NEAR HERE >>

Electronic Personal Health Record (PHR)

Description of the Technology

A patient's medical record is a record used by health care professionals while providing patient care – it is sometimes known as a chart or patient-chart. It is typically used as a means of reviewing patient data and documenting observations. With an electronic medical record, some or all of the data contained in a typical paper-based record would be available in a computerized, electronic form. This type of record is maintained by the provider (doctor, hospital, clinic, etc.) but in some institutions, patients can also add information through a secure Internet portal.

Health care providers across the country are adopting this new class of information system, the electronic medical record (EMR), albeit at a very slow pace. While adoption statistics of EMRs in the U.S. vary (Cain & Mittman, 2002; Goldsmith, Blumenthal, & Rishel, 2003; Von Knoop, Lovich, Silverstein, & Tutty, 2003) – with some estimates as low as 13% and some as high as 30% – the one reality is that the U.S. if far behind such European counterparts as the United Kingdom with a 58% adoption rate and Sweden with almost 90% adoption (Chin, 2002a). Today, adoption of EMRs in the U.S. is just beginning to creep up the steep portion of the S-shaped diffusion of technology curve (Rogers, 1983). Some of the reasons underlying the sluggish acceptance rates for EMRs are the lack of one standardized clinical terminology (more accurately, the multitude of various classifications, nomenclatures, dictionary codes and standards (Orthner, 1997, p. xi), which essentially results in an unstandardized approach), concerns about data privacy, confidentiality, and security, physician data entry challenges, and the difficulty associated with the integration of record systems with other information resources in the health care setting (Shortliffe, 1999).

On the other hand, the potential advantages of capturing patient information in an electronic record are numerous. First, because of the need to apply guidelines accurately and consistently, complete and up-to-date patient information, such as that stored in the electronic record, is essential (Elson & Connelly, 1995; Elson, Faughnan, & Connelly, 1997). Second, having information easily accessible reduces the cognitive burden on the care provider (e.g., doctor), thereby facilitating higher quality in decisions (Benbasat & Nault, 1989). Finally, the cognitive resources released as a result of not having to search for information can be devoted to better information interpretation (Elson & Connelly, 1997).

For this study, we are particularly focused on the intent to use electronic *personal* health records, which suffer from some of the same barriers, and reap some of the same benefits as EMRs. A Personal Health Record (PHR) is slightly different from a doctor's EMR. A PHR is a document containing health information that is stored and maintained by the patient and typically includes features such as self-tracking and monitoring of health information and self-entry of information related to diagnoses, medications, laboratory tests, and immunizations (see Figure 2a & 2b, Table 1). It usually has the ability to receive and store information from a doctor's electronic medical record or other electronic data source. Some PHRs include features that notify the user of drug-to-drug interactions and dosage warnings.

<< INSERT FIGURE 2a and 2b NEAR HERE >>

<< INSERT TABLE 1 NEAR HERE >>

As a means of further clarifying the concept of a PHR, it may be helpful to draw a connection between a PHR and a personal financial management software package such as Quicken®**.** With Quicken, an individual can track her finances by monitoring personal checks, logging ATM transactions, and tracking deposits, to name but a few features. Then, at the end of the month, the individual can compare the previous-month's transactions with those on file at the defined bank. This process could be labeled as dissociative, since both 'systems' operate in isolation. On the other hand, Quicken offers a feature that allows the user to continue to maintain her private banking information on her personal computer, but also gives the option of downloading data directly from the participating bank as a means of reconciling the account.

A PHR is similar in this respect. A user can maintain all health information on her personal computer, entering data from doctor visits as they occur and tracking medications and dosages. In this case, two separate databases (in actuality, several databases are maintained, as it is very common for people to see multiple health providers and it is typical that each maintains its own isolated medical database record) are managed independently. There is, however, technology available such that a user/patient can have a direct link through the Internet or a portable device such as a USB-flash drive to participating providers' electronic health record systems. In most cases, information is only made available for download to the patient's personal record, but in some systems, such as one run by Brigham and Women's Hospital in Boston, MA, patients are also given the ability to upload notes and data into their permanent medical record, schedule appointments, and email doctors, to name a few features.

Discretionary Application Software

Application software is defined as a program that performs useful functions in the processing or manipulation of data. This type of software is written for a specific application to perform functions by end users. There are different types of application software such as database managers, word processors, spreadsheets, and other programs that enable the useful manipulation of data (Laudon & Laudon, 2004). The use of application software in a business setting is normally considered to be mandatory. In addition, the choice of application software is not often left to the users; it is typically dictated by corporate directive. On the other hand, software that is used primarily outside of a work context is most often volitional. Such is the case with PHRs. We take this one step further and identify and classify PHR software as a discretionary application (Grudin & Palen, 1995). In our operationalization, we define a discretionary application as, 1) Software that is typically used outside of a work context with no agency issues associated with its use, and 2) Software for which usage is associated with increased cognitive load and volitional work.

Elaborating on the first point, there are no compensatory rewards associated with usage of discretionary applications. In a work setting, software usage is typically rewarded by management in the form of a salary and job security. If employees choose not to use software, strict punishments such as discipline, demotion, or severance can result. We know from prior work that software use at home is unique to use in an office setting (Venkatesh & Brown, 2001), so the first part of the definition should not be too surprising. The second part of the definition may not seem initially as intuitive. An example here may provide the best explanatory power. Approximately 40% of the U.S. population keeps track of their personal or family medical history and only 13% track their medical information using a computer program ("Harris Interactive: Two in Five Adults," 2004). However, there is a growing group of special-interest users who choose to use a program such as a PHR even though it generates work beyond that which is necessary. So why would anyone choose to use a discretionary application that can actually be burdensome? The answer is that the application fulfills some real or perceived need, which is likely to differ between individual users of the technology. Some may choose to use the application because it provides structure and organization, others because it is fun for them, and still others because it provides features not readily available through substitutes, e.g. electronically searching versus physically searching through filing cabinets of paper. Potential examples of other types of discretionary applications are ‘living-will’ software, ‘resume-making’ software, ‘home and landscape architecture’ software, and ‘family-tree’ software.

Empirical Studies of Electronic Health Records

There are very few studies that have focused directly on PHRs, and even fewer that examine the impact PHRs have on health outcomes, compliance, or convenience. A few recent studies have investigated the perceived value that people receive from PHRs (Angst, 2004), the receptiveness of patients to accessing a doctor’s electronic health record (Masys, Baker, Butros, & Cowles, 2002), and the usability of a patient-interface with an EMR (ibid.). The common findings from these studies are that respondents rated usability and functionality quite favorably while commenting that having records available to them electronically was very valuable.

Some recent non-empirical studies of electronic record use by patients have speculated that access will contribute to avoiding double or unnecessary tests, providing better comparison with existing data from earlier examinations, reducing the number of ineffective treatments, increasing patient’s compliance with clinical care processes, reducing length of stay within hospitals, and providing a lifelong health record across institutional boundaries (Ueckert, Goerz, Ataian, Tessmann, & Prokosch, 2003).

Currently, two on-going projects are investigating patient usage of electronic medical record systems. Tsai and Starren (2001) briefly discuss two patient involvement projects: PATCIS (Patient Clinical Information System), which provides patients with the ability to view lab results and text reports via a web interface and enter such data as vital signs (Cimino, 2000) and IDEATel (Information for Diabetes Education and Telemedicine), a 4-year, $28 million randomized-clinical trial enabling diabetes patients to connect to their providers (*IDEATel*, 2004). Finally, Kim and Johnson (2002), provide a useful review of the state-of-the-art of PHRs in their article which highlights the functionality of several PHRs currently on the market.

The apparent lack of empirical studies of PHRs is in no way reflective of the interest level in using PHRs by patients. In a May 2001 survey, Fowles and colleagues (2004) conducted a study which randomly sampled 4,500 adults who had a recent clinic visit asking them if they had any interest in reading their medical records. Of the 81% who responded to the survey, 36% were very interested in reading their medical record. The primary reasons for their interest were, being very concerned about errors in care, lacking trust in physician, seeing what their physician said about them, increasing their involvement in their health care, and understanding their condition better.

In contrast to PHR studies, several studies have investigated EMR adoption and use. Safran (2001) claims that electronic records have already made a direct impact on the practice of medicine and he offers as evidence, studies that show marked improvements in quality of care and medication errors (Safran et al., 1995), reductions in physician and nurse time (Safran, Sands, & Rind, 1999), and improvements in practical experience and training for new physicians and medical students (Patel, Cytryn, Shortliffe, & Safran, 2000).

Barriers to Adoption and Use of PHRs

In previous sections we identified key barriers to adoption of EMRs in a clinical setting. While some of these issues are unique to the EMR, others cross over into the PHR spectrum as well. For example, privacy concerns are a major challenge to widespread adoption. Data accuracy and integrity also greatly impact diffusion. Are the challenges to diffusion unique in this setting relative to other industries in which technology is used? We believe the answer to this question is both yes and no. We are still confronted with people's reluctance to use any system which is not easy to use or useful to them (Davis, 1989), but acceptance is also confounded by high levels of uncertainty about information security and privacy and the relative importance of the information contained in a health record – after all, the ramifications of using erroneous information can result in adverse health outcomes or even death.

Privacy Concerns

Due in large part to forward-looking policy-makers, individuals should feel some degree of relief regarding the security and privacy of their personal health information. HIPAA, the Health Insurance Portability and Accountability Act, is the first federal law that addresses health privacy in a comprehensive way. It requires all 'covered entities' – health care providers, plans, and clearinghouses – to protect individually identifiable health information. Personal Health Information (PHI), includes any information that relates to the physical or mental health of the individual, the provision of health care or payments for health care, and that information which can be used to identify an individual (Swartz, 2003). HIPAA gives patients more control over their health information and gives them certain rights to privacy and confidentiality. In addition, it establishes appropriate safeguards that health care providers and others must implement to protect the privacy of patients' health information, and most importantly, it holds violators accountable by imposing civil and criminal penalties with fines up to $250,000 and prison terms up to 10 years in length, (HIPAA Privacy Implementation Guide, 2002). One of the primary goals of HIPAA is to simply improve quality of care in the U.S. by restoring trust in the health care system (HIPAA Privacy Essentials, 2002).

Data Accuracy and Reliability

A second significant barrier to diffusion of PHRs is the quality of the information that is contained in the program. The fact that PHRs are maintained by the patients themselves – even though the information is often input or downloaded from providers – raises the question of the accuracy and reliability of the information contained within them. Of course these issues are not unique to health care systems. They can, however, lead to more catastrophic results than incorrectly recording a number in a financial spreadsheet. There have been no studies of which we are aware that investigate the accuracy or reliability of information in a PHR. There has been extensive work investigating this phenomenon as it relates to paper records and EMRs (Aronsky & Haug, 2000; Brennan & Stead, 2000; Elson & Connelly, 1997; Logan, Gorman, & Middleton, 2001; Stausberg, Koch, Ingenerf, & Betzler, 2003; Stein, Nadkarni, Erdos, & Miller, 2000). In a study conducted by Hogan and Wagner (1997), the accuracy of data in a computerized patient record is assessed using: *Correctness* – proportion of recorded observations in the system that are correct, and *Completeness* – proportion of observations that are actually recorded in the system. These authors propose methodological guidelines for studying accuracy after reviewing 235 papers discussing data accuracy (of which they found only 20 relevant articles). A common theme underlying research in this area is that computerized health records should be better than paper-based because of validity checks and usage of standards. Many researchers agree that computerized systems can be an efficient way of reducing errors of omissions and improving adherence (Overhage, Tierney, Zhou, & McDonald, 1997). However, it should be acknowledged here that regardless of the accuracy and reliability of the information in a medical record – whether paper or electronic – the condition of the patient can only be approximated through a patient record. The only true indicator of the condition of the patient is the actual state of the patient (Hogan & Wagner, 1997).

In summary, although electronic PHRs offer patients greater control over the storage, management, and dissemination of their personal medical information, they are not without challenges. In the next section, we investigate the phenomenon of usage of this discretionary software application and explore the antecedents of its use related to PHR adoption. We embarked on this study because we anticipate a rapidly growing user-base for this technology as government agencies and health systems begin to push for increased adherence. President Bush, in his Health Information Technology Plan, has created a strategy to ensure that most Americans have electronic health records within the next 10 years (Bush, 2004) and others in top federal government positions have given bi-partisan support to this directive (Gingrich & Kennedy, 2004). Thus, it is important to understand the characteristics and concerns of potential users at an early stage of the diffusion cycle, so that appropriate implementation strategies can be crafted.

Early Adopters of PHR: Who are They and What do they Value?

In order to understand the characteristics of individuals who are early adopters of PHR software, we conducted an exploratory empirical study. An additional goal of the study was to examine, in general, the drivers of usage intentions of discretionary software applications. Following from the theory of reasoned action (Ajzen & Fishbein, 1980), the conceptual model underlying the study, shown in Figure 3, suggests that individual characteristics of two varieties: demographics, and those related specifically to the individual's medical condition, predict the value cognitions individuals possess in regard to using the software. These cognitions, in turn, drive their usage intentions. Additionally, we allow for the possibility that individual characteristics exhibit direct effects on usage intentions, over and above their mediated influence via perceived value.

<< INSERT FIGURE 3 NEAR HERE >>

The demographic variables included in the study were age, education, and income. The medical condition-related variables were, the existence of a chronic health condition in the individual's circle of care, whether or not multiple medications are required for this chronic condition, and the total number of doctor visits. Our *a priori* expectation was that – as with most other software innovations – income, and education would be positively associated with perceived value (Rogers, 1995). The relationship of age to perceived value, however, is somewhat less clear. In general, empirical evidence across numerous software innovations suggests that younger people tend to view such technologies in a more positive light (Rogers, 1995.) On the other hand, to the extent that an individual's health condition tends to decline with age, the value of a PHR may become more evident with increasing age.

As in the case of age, the relationship between variables that describe the individual's health and perceived value is less straightforward – it could be that greater severity in medical condition is associated with lower perceived value because of the perception that the PHR distances the individual user from the human care-provider (e.g., a doctor). Alternatively, insofar as the PHR allows for better recording and sharing of information between patient and care provider, a positive relationship is also plausible. We tested this model using data gathered through a field study – the study context and our findings are described below.

Study Context and Sample

We mailed a survey to 813 purchasers of an electronic personal health record. These 813 users represent people that had purchased the software through the company's website, ordered it over the telephone, or through a 3rd party distributor in the 3-month period just prior to our study. There were 47 unusable or undeliverable surveys and 190 complete surveys, representing a 24.8% response rate. Descriptive statistics are shown in Tables 2 and 3. In other work (Angst, 2004), we found that individual's beliefs with regard to the value of PHRs consisted of three distinct dimensions: "structure, organization and compliance (PVa)," "relationship and connectedness with one's health care provider (PVb)," and "convenience and empowerment" (PVc; see Appendix A for scales). Individual characteristics were measured using the scales shown in Appendix A, while the behavioral intention construct was adapted from Davis (1989).

<<INSERT TABLES 2 AND 3 NEAR HERE >>

Data Analysis, Results, and Discussion

We used structural equation modeling techniques with the EQS computer program to perform all confirmatory factor and structural analyses (Bentler, 1985). The psychometric properties of the variables are acceptable and the reliability of the constructs is adequate (Cronbach Alpha, BI= .85, PVa=.93, PVb=.92, and PVc=.75). We first tested the relationship between the demographic and medical condition variables and behavioral intention (see Figure 4) and found only DEM_AGE (the age of the subject) and DEM_ED (the education level of the subject) to be significant predictors of intention to use. These results showed that younger and less educated users have greater intentions for future use. Our next step was to test a mediated model with the perceived value constructs acting as mediators. When we introduced the mediators, both age and education became non-significant and PVa and PVb emerged as significant predictors of BI, collectively explaining over 40% of the variance in usage intentions (see Figure 5).

<< INSERT FIGURES 4 AND 5 NEAR HERE>>

Our findings show that the effects of individual characteristics on usage intentions for PHR software are fully mediated by a multi-dimensional perception of value. Interestingly, the results suggest that value is perceived very differently across the demographic and medical condition variables. Education is the only variable significantly related to the desire for structure, organization, and compliance (PVa), and this relationship is negative. Thus, less educated users believe that the software will assist them in becoming more organized in managing their medical information. The presence of a chronic medical condition is associated with a perception that the PHR can yield a closer relationship and greater connectedness with health care providers (PVb), while age and income are negatively related to such value. Not surprisingly, younger individuals have a lower desire for close relationships because their health is more likely to be in good condition. High income users possibly have other mechanisms for ensuring high-quality health care (e.g., using private physicians.) Finally, the convenience and empowerment aspects of using a PHR (PVc) are negatively associated with age, and positively associated with the severity of the health condition as assessed by the need for multiple medications on a daily basis and more frequent doctor visits. Overall, the medical condition variables predict PVb and PVc, but not PVa.

We also find that convenience and empowerment (PVc) is not a significant predictor of usage intentions. This finding is somewhat surprising as an important aspect of the value proposition of a PHR is that it affords patients greater control over managing their own medical information. One potential explanation is simply that the measure for this dimension needs refinement: as opposed to the other two dimensions, convenience and empowerment does not tap into perceptions related to using the PHR. Alternatively, it could be the case that contrary to what is commonly claimed, patients do not desire such control and would rather have a trained medical professional manage their health information for them. Both explanations point to the need for further investigation.

In summary, the pattern of results reveals that individual profiles in regard to demographic and medical condition factors yield varying levels and types of value perceptions. The lack of a relationship between the medical condition variables and perceived value in the form of structure, compliance, and organization suggests that such value is likely to be salient for most users, independent of whether they have a need to manage their health proactively. As might be expected, value perceptions related to closer interaction with a health care professional and empowerment are amplified in the presence of severe medical conditions. Economically disadvantaged users that may otherwise be challenged in regard to receiving medical attention view the PHR as an important means for staying more connected with their doctors. To the degree that behavioral intentions drive actual adoption and use, overall the findings indicate that the early adopters of PHRs are likely to be individuals who are less educated, older, less wealthy, and suffering from a chronic illness.

Conclusion

Our goal in this chapter was to introduce an emerging technology – the electronic personal health record – that has transformational potential for the critical health care sector. We examined the state of IT use in health care and proposed a framework that helps organize the range of IT applications used by hospitals, physicians, and other medical professionals. We described the functionality of the PHR application, together with the issues surrounding its adoption and use. Finally, we presented empirical data demonstrating that individuals with different demographic and medical condition characteristics perceive different types of value in the PHR, and that two dimensions of such value are significant predictors of future use intentions. Our data offer some useful insights into the acceptance of this technology at a very early stage of the diffusion curve and provide a glimpse into the profiles of individuals who are likely to be among the early adopters of such technology.

The motivation for this study, as articulated earlier in this chapter, is the pressing need to contain burgeoning health care costs while simultaneously ensuring that medical errors are reduced and patient safety is enhanced. Technologies such as the PHR can assist in these endeavors by both providing a repository of critical data for use by clinicians, and aiding patients in becoming more proactive in the management of their health. These technologies, however, are only the tip of the iceberg. There are a host of other areas where HIT, by virtue of its ability to increase the velocity and availability of accurate and reliable information flows, has an important role to play. Mobile technologies such as hand-held devices can aid in the distribution of medical expertise by providing clinicians with easy access to needed data on drug interactions at the point of patient care. Likewise, systems such as Computerized Prescription Order Entry (CPOE) offer the capability of reducing medication errors (Bates, 2000; Bates et al., 1998; Bates et al., 1999). The transformation of the health care sector is dependent on the ongoing and persistent diffusion of these technologies.

Much more research remains to be done. Technology artifacts such as the PHR create new vulnerabilities for users in regard to privacy and security. Indeed, most “discretionary” software applications for home use give rise to such concerns. How do such concerns inhibit the acceptance of these technologies? How may they be mitigated? These questions are worthy of investigation. The health care system has been slow to adopt information technologies that have provided considerable value to other industry sectors, both in terms of achieving operational excellence and in improving the quality and effectiveness of business processes. To the extent that such gains in the health care sector are contingent upon the willingness of individuals to adopt and use technologies such as the PHR, on going research that can aid in developing adoption strategies is critical.

Appendix 1.1

Survey Instrument

Value: Structure, Organization and Compliance (PVa)

- Using the PHR helps me to perform my health care activities (by reminding me to make and keep my appointments, etc.)
- Using the PHR helps me to stay on schedule with my health care activities (such as getting my regular checkup)
- Using the PHR helps me perform my health care activities at the appropriate times (such as refilling prescriptions)
- Using the PHR helps me remember to perform my health care activities (like testing my blood sugar)
- Using the PHR allows me to accomplish more of my health care objectives (such as losing weight)

Value: Relationship and Connectedness (PVb)

- Using the PHR improves communications between my care providers and me
- Using the PHR improves my relationship with my care providers
- Reducing the number of forms to fill-out during registration by having the information available on my PHR is valuable to me

Value: Convenience and Empowerment (PVc)

- It would be valuable to have my health information available at all times
- It would be valuable to have my complete medical record with me at all times
- It is critical to have my emergency medical information with me at all times
- It would be valuable to have all of my health care information located in one place

Behavioral Intention to Use

- I intend to use the PHR in the near term
- I believe my use of the PHR will be more extensive in the future
- I intend to use the PHR more frequently in the future

DEM_AGE

What is your age?

(1) □ <20

(2) □ 21 - 30
(3) □ 31 - 40
(4) □ 41 – 50
(5) □ 51 - 60
(6) □ 61 – 70
(7) □ 71 – 80
(8) □ 81 +

DEM_ED

Level of Education:

(1) □ Some High School
(2) □ Completed High School
(3) □ Associates Degree
(4) □ Some college
(5) □ Undergrad/Bachelor's degree
(6) □ Post-graduate study

DEM_INC

Household Income (Annual before tax):

(1) □ Less than $20,000
(2) □ $20,000 - $29,999
(3) □ $30,000 - $49,999
(4) □ $50,000 - $69,999
(5) □ $70,000 - $89,999
(6) □ $90,000 - $109,999
(7) □ $110,000 - $129,999
(8) □ $130,000 - $149,999
(9) □ $150,000 - $174,999
(10) □ $175,000 or more

DEM_ILL

Does anyone in my care have a chronic health condition?

(0) □ No
(1) □ Yes

DEM_MED

Does anyone in my care take multiple medications on a daily basis?

(0) □ No
(1) □ Yes

DEM_DOC

Estimate the total number of doctors that those under my care (including myself) would see in an average year (including dentists, family practitioners, specialists, eye doctors, OB/GYN, Psyc/Soc, etc.)

(1) □ 0
(2) □ 1 – 4
(3) □ 5 - 10
(4) □ 11 - 20
(5) □ 21 - 30
(6) □ 31 - 40
(7) □ 41 - 50
(8) □ 51 +

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<u>Figure 1. Health Information Technology (HIT) Taxonomy</u>

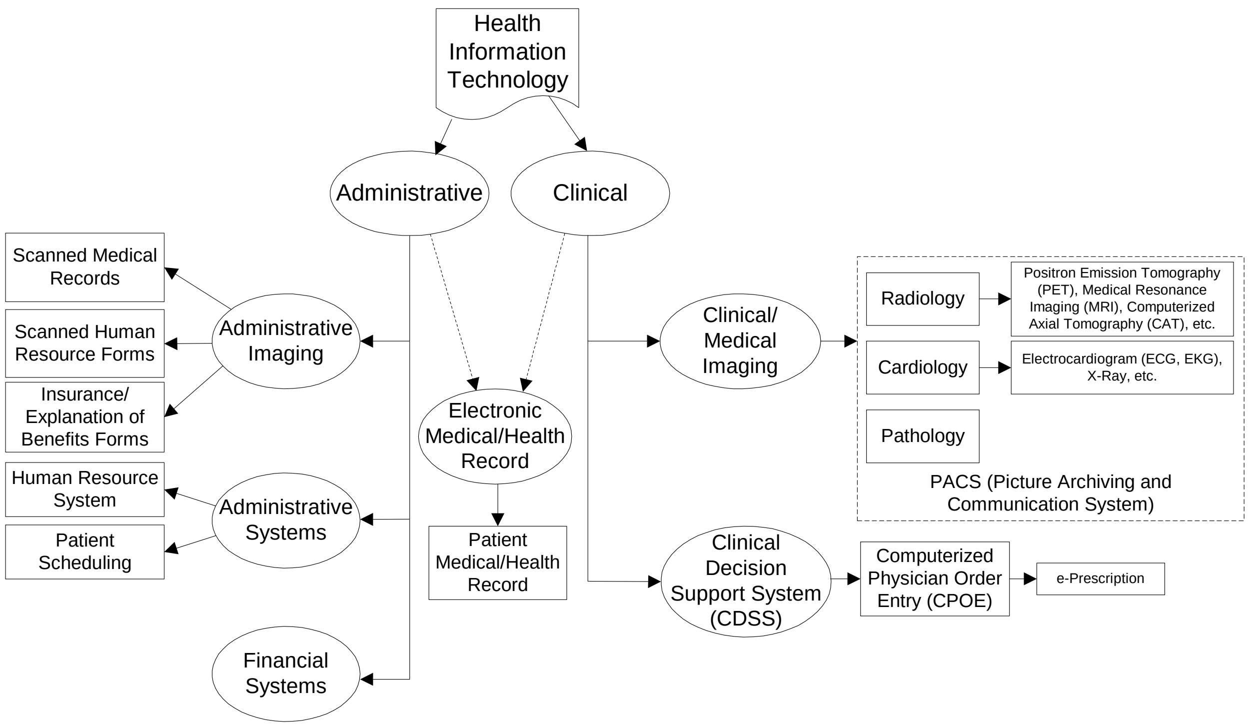

Figure 2a. Screen Shot of a Typical PHR

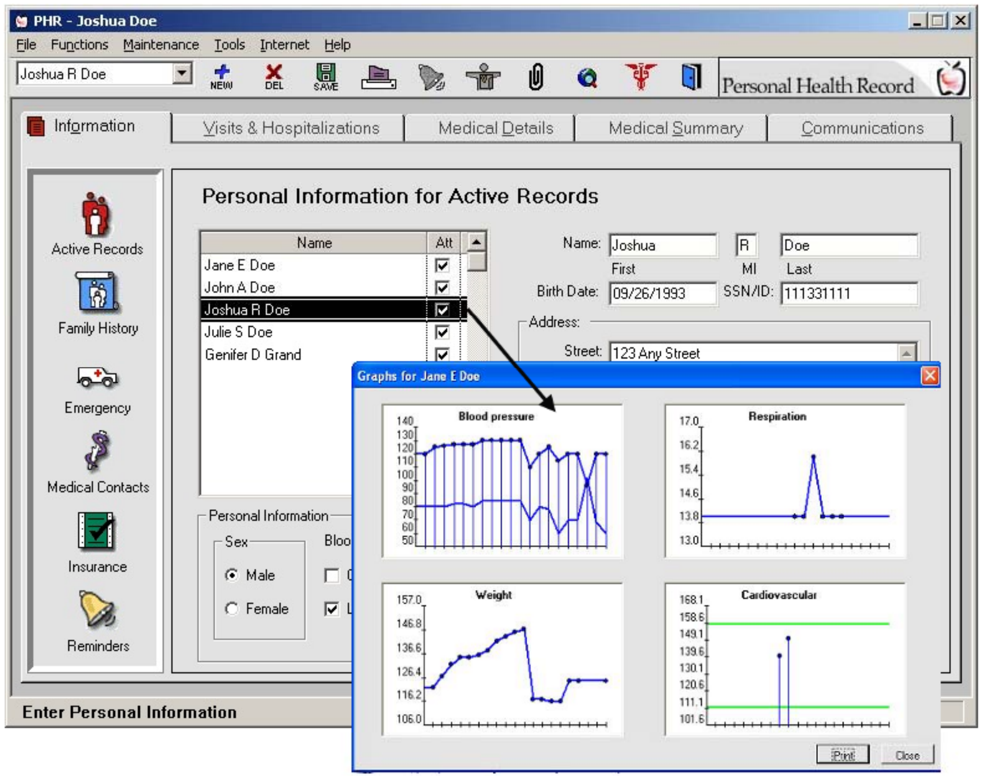

Figure 2b. Screen Shot of a Web-based PHR

Figure 3. Conceptual Model

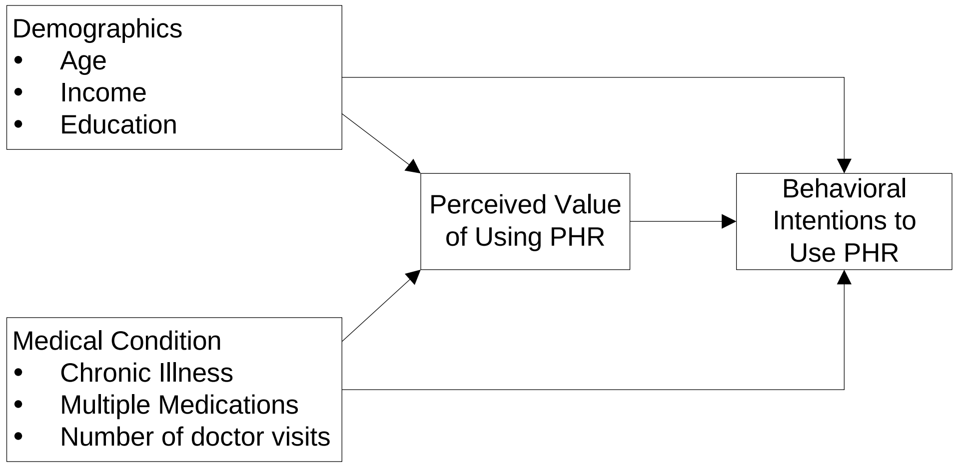

Figure 4. Direct Path Analysis

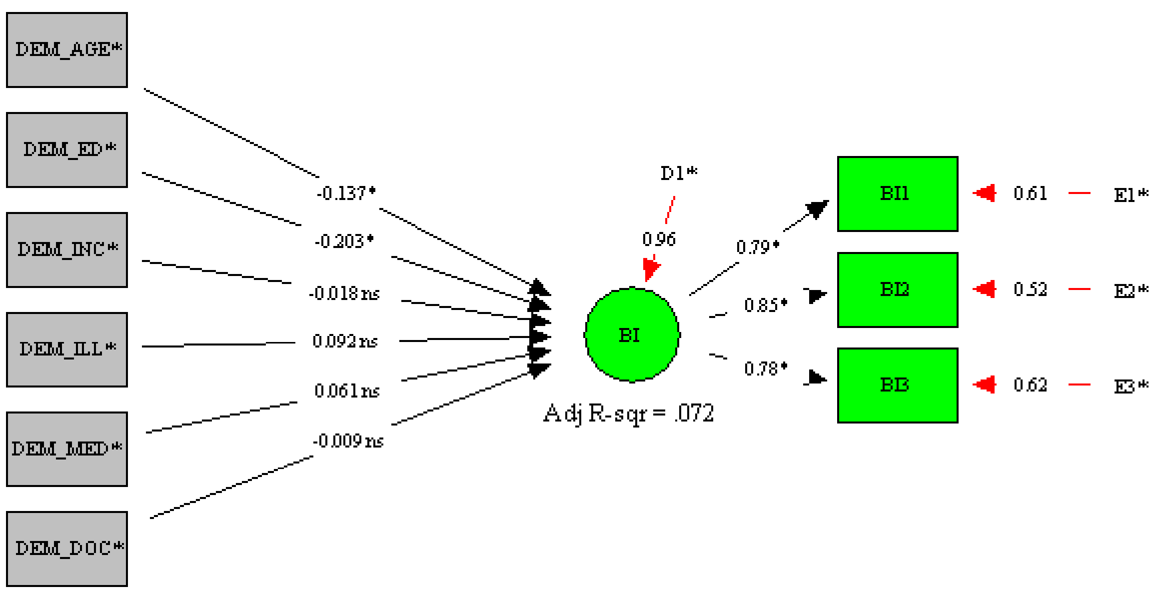

Figure 5. Direct Path Analysis

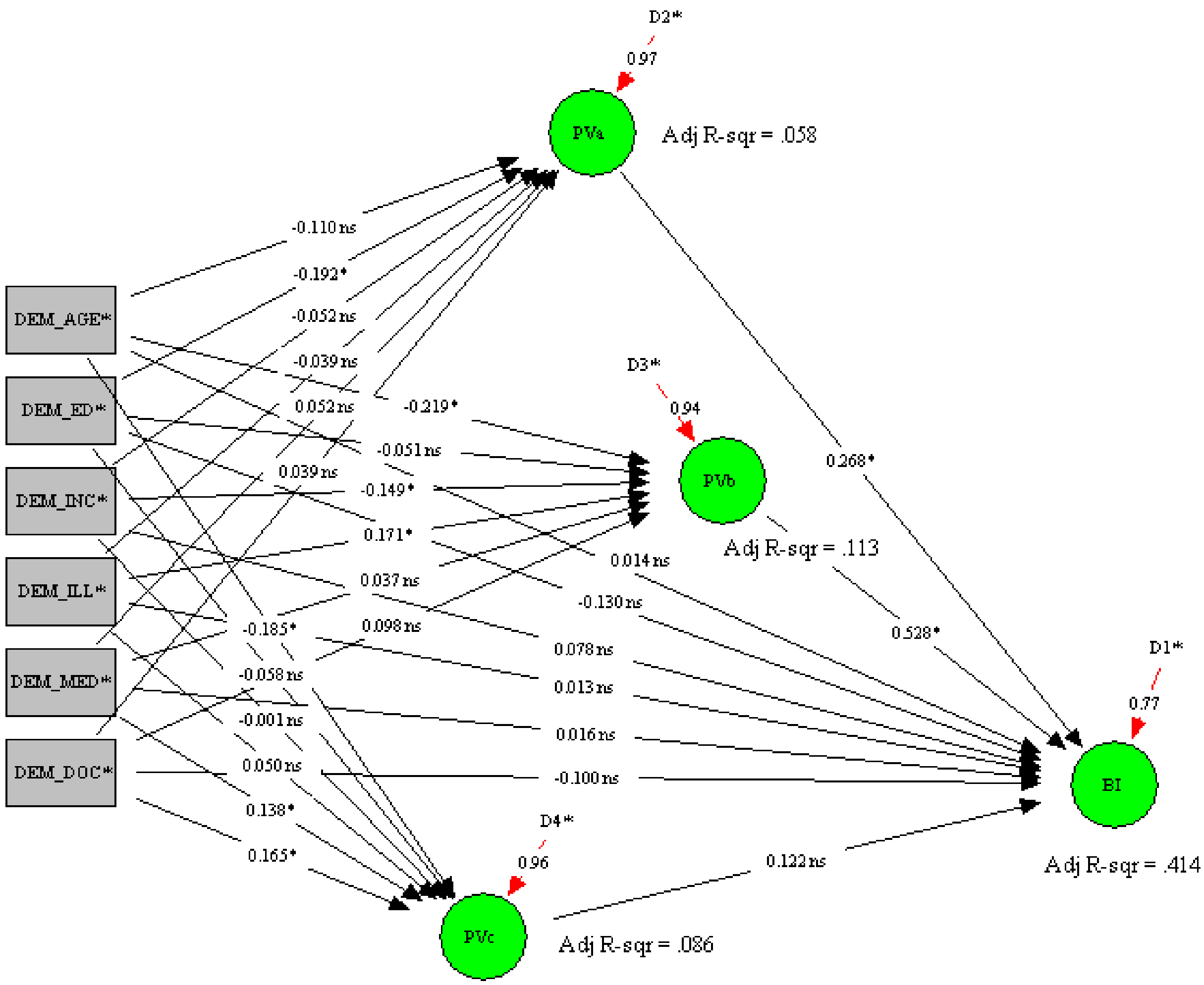

Table 1. Typical PHR Functionality

Information • General personal information • Family medical history • Emergency contacts • Personal medical contacts • Insurance coverage(s) • Reminders	**Visits and Hospitalizations** • Conditions • Tests • Treatments • Medicines • Immunizations • Miscellaneous data
Medical Details • Active conditions • Vitals and profiles (incl. graphing) • Test results • Treatments received • Drugs administered • Immunizations • Miscellaneous data	**Medical Summary** • Conditions, problems • Tests • Immunizations • Medications • Treatments and therapies • Other orders, recommendations
Communications • Records of letters, calls, faxes, emails • Printable emergency card • All screens generate into reports • All reports can be printed or emailed	**Optional: Sponsor customization** • Introductory branded screens and reports • Custom pick-lists of PHR information • Dedicated web links • Dedicated field-level links (condition, medication, treatment-specific) • Customized profiles, guidelines • Custom "Community of Care" page that auto-builds to user's needs based on sponsor-selected information

Table 2. Sample Description

Description	**Value**
Surveys sent	813
Unusable or undeliverable	47
Usable surveys	190
Response Rate	24.8%
Male/Female	72/28
% of users with chronic illness	63%
Average number visits to doctor/yr	7.1
Avg years of computer experience	15.3

Table 3. Descriptive Statistics

	N	Minimum	Maximum	Mean	Std. Deviation
DEM_AGE	190	1	8	5.06	1.267
DEM_EDUC	190	1	6	5.01	1.291
DEM_INC	157	2	10	5.91	2.588
DEM_ILL	192	0	1	.59	.492
DEM_MED	186	0	1	.75	.433
DEM_DOC	190	2	8	3.02	.951
PVA_AVG	190	1	5	2.84	1.023
PVB_AVG	188	1	5	3.35	.937
PVC_AVG	193	1	5	4.22	.738
BI_AVG	190	1	5	3.96	.904
Valid N (listwise)	145				