Preface

Patient-Centered E-Health (PCEH) encompasses a foundational set of perspectives and approaches toward using the Internet to deliver healthcare services to patients and their caregivers (for brevity, “patients” is used hereafter to indicate both groups). Thus, PCEH is not a type of information technology (IT), but instead represents a new way of thinking about how to apply IT for the betterment of patients. This preface describes the trends that motivate development of a PCEH discipline, and the attributes that are essential for PCEH initiatives to succeed.

Trends That Drive Patient-Centered E-Health

Motivation for PCEH derives from three transformative trends that cross healthcare industries and society at large. The first trend accompanies the ongoing diversification of e-health (i.e., “health services and information delivered or enhanced through the Internet” (Eysenbach, 2001)). E-health has grown to encompass purely clinical applications, such as physicians consulting on a diagnosis (Wiecha & Pollard, 2004), patient records (Anderson, 2007), emergency health communication applications (Fruhling & De Vreede, 2006; Rizo, Lupea, Baybourdy, Anderson, Clossen, & Jadad, 2005), online procurement and claims management (Deluca & Enmark, 2000), disease-focused applications such as diabetes self-management support (McKay, Glasgow, Feil, Boles, & Barrera, 2002), electronic prescription refills and appointment scheduling (Wilson & Lankton, 2004), applications to support online communication between patients and physicians (Wilson, 2003), and commercial applications such as WebMD (Itagaki, Berlin, & Schatz, 2002). As e-health applications diversify into increasingly unrelated areas, this limits potential for the work of researchers or practitioners in one branch to be helpful to those in other branches. Developing a specialization toward e-health that is used by patient represents a natural response to the increasing diversification within the e-health universe (Wilson, 2008).

The second trend motivating PCEH results from the diffusion of Web applications into the business and personal activities of most adults in developed nations. As more of the population becomes familiar with the Web and relies upon the Web for services—such as information searches, banking, and shopping—consumer demand increases for Web access to other services. Although healthcare has lagged banking and other industries in providing online access to customers, demand is building among patients for such health services as online appointment scheduling, billing and payment services, and online health communication with physicians and clinical staff (Homan, 2000; Taylor & Leitman, 2002). The demand for online health services is complicated further by entrainment of Web users to expect interfaces that are easy to use and understand (Lankton & Wilson, 2007; Zeithaml, Parasuraman, & Malhotra, 2002). These factors imply that it is essential to build high-quality, user-centered applications in order for patients to accept and use e-health that is directed toward them.

The third trend motivating PCEH is an emerging consensus that IT can and should be used more effectively to improve healthcare. Much of this new interest in health IT was sparked by two Institute of Medicine reports recommending improvements in health IT as a remedy to preventable medical errors
and other healthcare quality problems (IOM, 1999, 2001). Other studies show that health IT can reduce or contain healthcare costs (Devaraj & Kohli, 2000; PricewaterhouseCoopers, 2007). To date, new government pronouncements and programs have been developed toward improving health IT infrastructures (HHS, 2004), and investment in health IT has increased substantially (Carpenter, 2005). Although much of this attention centers on development of a standardized electronic medical record (EMR) and other IT improvements to organizational infrastructure, the importance of e-health is also becoming recognized. As Microsoft Corporation Chairman Bill Gates (2007, pp. A17) writes in a Wall Street Journal opinion titled “Healthcare Needs an Internet Revolution”:

What we need is to place people at the very center of the health-care system and put them in control of all their health information. Developing the solutions to make this possible is an important priority for Microsoft. We envision a comprehensive, Internet-based system that enables health-care providers to automatically deliver personal health data to each patient in a form they can understand and use.

Individuals also understand the importance of e-health, and over half say their choice of physicians is influenced by quality of e-health services (Taylor & Leitman, 2002). Development of effective e-health for use by patients is buoyed by the emerging consensus that increased use of health IT is key to improving quality, increasing efficiency, and managing costs in healthcare.

PCEH can accommodate these trends by meeting objectives of (1) instantiating a specialized discipline around which research and practice can coalesce to address issues that are specific to e-health that is used primarily by patients and (2) promoting development of high-quality e-health applications that are desirable to patient-users and responsive to quality, efficiency, and cost objectives. To accomplish these objectives, three attributes are essential: PCEH must be patient-focused, patient-active, and patient-empowered (see Figure 1).

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**Figure 1. Essential attributes of patient-centered e-health**
Patient-Focused E-Health

A patient focus refers to the condition where attention of e-health designers and administrators is primarily directed toward the patient-users. It may surprise readers, but much of the e-health that has been created to date for patients to use is not patient-focused. The first e-health applications were developed by commercial interests while healthcare organizations initially observed “from the sidelines,” due to concerns over risk, liability, and start-up expense (Lazarus, 2001, pp. 33). The e-health applications produced by these early consumer-focused initiatives specialized in providing encyclopedic health content and promoting health products and services. Because healthcare providers are not involved, e-health designed with a pure consumer focus cannot deliver the personalized features and interactions with their own providers that patients desire (Homan, 2000; Taylor & Leitman, 2002).

As healthcare organizations began to offer e-health to patients, this created the opportunity to develop personalized, interactive services connecting patients to their own physicians, clinics, and records. Yet this opportunity has been obstructed in many cases by an excessive focus on organizational objectives. Despite lagging other industries in information technology (IT) investment, healthcare has grown to support a substantial IT industry, which for most of its existence has been oriented almost exclusively on developing clinical and transactional systems for use within the healthcare organization. Health IT designers have focused narrowly on organizational goals and, where user interactions are considered, it is the clinicians, technicians, and office staff who are targeted for study (Jamar, Mattison, Orland, Giatt, Karat, & Coble, 1998). Where e-health is developed within an organization-focused initiative, design decisions tend to be based upon organizational goals and assumptions that e-health developers and administrators make regarding patients and their e-health needs (Wilson, 2008). Although this approach may be practical in traditional healthcare settings, such as in-hospital procedures, it is not effective where system use is voluntary. Patients typically have alternatives to using an e-health service, and they will reject e-health that does not meet their actual needs—even if the designers’ intentions were entirely directed toward the good of the patient (Payton & Brennan, 1999).

E-business application designers have come to understand that it is essential to create a high-quality “user experience” in order to build and retain Web traffic (Becker & Mottay, 2001; Molla & Licker, 2001) and avoid rejection by intended users. This can be accomplished only by focusing on users (Alpert, Karat, Darat, Brodie, & Vergo, 2003). E-health designers serve a population of patients who are increasingly dependent upon and proficient in using Web applications, and these patients expect their experience with e-health to be as satisfying as with other Web applications. Instead of treating patients as objects to be manipulated through e-health—such as consumers of pharmaceuticals, or receivers of medical instructions—it is necessary for designers of patient-focused e-health to understand and act upon patients’ needs, preferences, and perspectives.

Healthcare is a profession of compassion and concern, yet the culture of healthcare is based to a large extent on a paternalistic model of physician-patient relationships (Emanuel & Emanuel, 1992) in which physicians control virtually all aspects of their interaction with patients (Eysenbach & Jadad, 2001). It is important that researchers and practitioners confront this situation explicitly in developing patient-focused e-health so as to avoid reprising the paradox Warren Winkelman (2004, pp. 1) describes in his review of a study assessing a patient-accessible electronic patient record system:

[The system] shares a common identity paradox with these other systems in that it portends to be patient-centered while employing physician-centered design and evaluation frameworks. It is therefore not surprising that, in their study, patient access has little measurable impact on patient-specific health outcomes.
In order to create patient-focused e-health, patients must be seen as the overriding reason for designing e-health services, the principle source of design requirements, and the key evaluators of e-health success. This is not to say that commercial and organization goals cannot be considered in design of patient-focused e-health, just that these considerations must be secondary.

**Patient–Active E–Health**

Patient-active means that patients are given meaningful abilities to provide information as well as consume it, a perspective that has numerous implications for potential uses of e-health and the types of services that e-health should offer. A number of patient-active e-health services are becoming common, including electronic prescription refills, online appointment scheduling, and e-mail-style communication that patients can initiate (Lazarus, 2001). However, support for patient activity can be nuanced, and in some cases, achieving highly patient-active e-health will require reconceptualization of healthcare processes and information flows.

Consider the example of the personal health record (PHR). The PHR is a comprehensive personal health information repository that is controlled by the patient and potentially covers the patient’s entire lifespan (LaFky, Tulu, & Horan, 2006). E-health that offers a PHR with these characteristics provides a certain level of patient activity, in that patients are primarily responsible for making entries and maintaining these records. But there is a problem—although PHR software is offered by a number of vendors, including freely accessible versions, hardly anyone uses it (Taylor, 2004). A number of reasons have been offered for this situation, ranging from poor usability, to privacy issues and lack of health content integration (Wilson, 2006), yet numerous other software applications have overcome similar handicaps, especially where these are perceived by users as providing meaningful capabilities (Lee, Kozar, & Larsen, 2003). The PHR is typically conceptualized as being distinct from the legal medical records that institutions are required to maintain (AHIMA, 2005). In practice, this distinction has been implemented by creating a wall between the patient’s PHR and the healthcare provider’s EMR, which effectively obstructs much of the value that patients could gain from maintaining a PHR. The patient cannot enter any information into the EMR, and typically cannot incorporate information from the EMR into the PHR. This situation constrains the PHR to simply storing and organizing information that is provided by the patient, a process which requires substantial effort to achieve limited benefits. To build a PHR that is highly patient-active, linkage should be provided to the EMR as well as other data sources to which the patient has legitimate interests, including patient records held by employers, insurers, and governmental agencies.

The ultimate goal of patient-active e-health is to provide services that allow patients to initiate and conduct all actions that they desire to perform. This will require e-health designers to develop effective strategies for removing barriers to information exchange in an environment which is both policy-driven and highly regulated. While the challenge is difficult, similar user-activity barriers have been overcome in numerous online activities, including personal finance and investment, commercial sales and auctions, and social networking.

**Patient–Empowered E–Health**

Patient empowerment is achieved through providing powerful e-health tools that allow patients to control far-ranging aspects of their healthcare. Increasingly, patients expect to be empowered in their own healthcare decisions (IOM, 2001), and the expectation of personal control is especially strong for e-health applications (LaFky et al., 2006; Markle Foundation, 2004).
In the context of e-health, it should be recognized that empowerment has more than one dimension. First, patient empowerment implies that patients must have meaningful control of e-health services. However, this requires designers to overcome two important obstacles. As discussed previously, the paternalistic culture and attitudes which are common in healthcare can conflict with the very principle of patient control. Attitudinal biases against patient empowerment can take many forms, and these frequently are couched in concerns for the patient’s well-being (Ross, Todd, Moore, Beaty, Wittevrongel, & Lin, 2005). Tension between paternalism and empowerment is a recurring phenomenon in healthcare (Yeo, 1993), but it is important to recognize that e-health per se does not create new conflicts. Patients principally expect e-health to support activities which they already can control—for example, by making a personal visit to their health clinic. Designers should be ready to argue for extending existing forms of patient empowerment into the e-health domain wherever this can be done.

Security and financial issues can also block patient empowerment, and these may be difficult to overcome (Wilson, 2008). Healthcare organizations have the legal responsibility to maintain security and privacy of patient and provider data, and providing patient access can increase exposure to security breaches. In addition, interconnecting e-health application to internal systems can increase development expenses, especially where the internal systems have limited interoperability. Because e-health holds the promise of increasing patient services and containing costs, designers should press for long-term commitment toward interconnecting e-health with other organizational IT, even if pragmatic constraints prevail in the short term.

A further aspect of patient empowerment is ensuring that e-health provides a high level of usability. In particular, patients must be able to understand and communicate effectively within the e-health environment. From the patient’s perspective, e-health is an extension of the healthcare providers’ other services, thus it is reasonable for patients to expect e-health to be generally understandable, and for the provider to offer better explanations if the need becomes apparent. In patient-empowered e-health, it is not acceptable for designers to insist that patients’ health literacy must increase before they can use e-health services, as is suggested by Norman and Skinner (2006). Patients’ need for healthcare services is not dependent upon their literacy level, and requiring patients to be highly literate in order to use e-health is no more defensible than requiring literacy in order to schedule medical examinations or other healthcare services (Wilson, 2008). The examples of online banking and financial services demonstrate that people who are only marginally literate can successfully interact with Web applications when they are provided with an effective interface. Usability of e-health applications can be increased by applying user-centered design (UCD) principles and related methods (Nielsen, 1993; Preece, Rogers, & Sharp, 2002). These methods have greatly improved usability of Web applications in general (Becker & Mottay, 2001) and in the healthcare contexts where they have been applied (Johnson, Johnson, & Zhang, 2005).

Patient-empowered e-health is not a call to give patients controversial new forms of control or to require patients to change how they interact with healthcare providers. Instead, the key objective is to bring as many aspects of patients’ existing empowerment online as possible.

How PCEH Contributes to Research and Practice

This book introduces PCEH as a conceptual framework, but it must be recognized that study and development of e-health centered around patient needs is not new. Around the world, researchers and practitioners are engaged in creating e-health applications that intermingle patient focus, patient activity, and patient empowerment, the essential attributes of PCEH. Furthermore, this development is being undertaken across multiple fields—prominently including medical services, user-centered design (UCD), computer science, information systems (IS), and consumer health informatics. Advances are occurring,
but they mostly arise within “development islands” which are isolated by geography and training. Recognition of PCEH as conceptually distinct from other forms of e-health is an important first step in bringing these islands together and increasing information exchange and mutual understanding. However, it is becoming clear that PCEH has important disciplinary characteristics, viewpoints, and methods beyond its conceptual impact which can be important to improving the productivity of research and design. Thus, the further purposes of this book are to organize and integrate PCEH activities that are occurring spontaneously, promoting research and development as a PCEH discipline forms and evolves.

**Organization of the Book**

The book is organized within two sections: Foundations and Applications. Nine chapters in the Foundations section address central topics of philosophy, structure, and research methodologies underlying PCEH. A brief description of each Foundations chapter follows:

Chapter I explores the role e-health plays in the broader context of patient-centered care. The authors conduct a historic review of the development of health IT and the patient-centered care movement. They then present a conceptual framework of the considerations and requirements that are essential for PCEH to bridge these two disparate fields.

Chapter II identifies techniques of user-centered design (UCD) that are particularly appropriate to PCEH. The authors describe the techniques and administration procedures in an understandable manner and in sufficient detail to be used as a guide by practitioners and researchers who do not have previous experience with UCD.

Chapter III presents a foundational discussion of the psychological issues inherent in applying computer-mediated communication (CMC) to the context of e-health. The authors’ contention that certain aspects of CMC may actually benefit patient health motivates an important discussion of future research directions in PCEH.

Chapter IV introduces the personal health record (PHR) as a central component of PCEH. This chapter reviews historical development of the PHR, including objectives of governmental and regulatory agencies and challenges to success.

Chapter V explores the role of PCEH in the under-researched context of disabled workers. The author argues that health IT can profoundly change the application and maintenance processes for disabled workers to receive benefits, concluding with a set of recommendations for automating these processes.

Chapter VI confronts the issue of PCEH as a marketing venue. The authors present a clear and well-balanced overview of the marketing methods that are most applicable to PCEH. Their approach promotes the constructive benefits of marketing that is well targeted and sensitive to patients’ interests.

Chapter VII introduces a privacy management framework for PCEH. In grounding this framework, the author rigorously reviews privacy and privacy management literatures, and explicitly addresses the diverse interests involved in patients’ use of e-health services.

Chapter VIII addresses the issue of trust as a means of overcoming patients’ concerns regarding privacy and confidentiality in PCEH. The authors review the trust literature and identify how trust relates to e-health developed by medical content aggregators, health-based online communities, and patient-physician portals.

Chapter IX comprehensively discusses ways to involve patients and the general public in e-health research. The authors propose key principles to guide researchers in designing and conducting e-health studies, and then describe how they used these principles to gain public involvement in an Internet-based intervention to aid diabetes self-management.
A further seven chapters present research findings from actual applications of PCEH. A brief description of each Applications chapter follows:

Chapter X presents a case study in which interaction design and usability evaluation methods were applied to improve the user interface of a personal health record (PHR). The authors applied the think-aloud technique for observing PHR users through two design iterations, finding that significant improvements could be made from a relatively small number of observations.

Chapter XI uses focus group research methods to explore patients’ perceptions of empowerment and need for quality and cost information when choosing healthcare providers. The authors’ study suggests that a previously-proposed theoretical compatibility model can have utility in predicting patients’ healthcare decisions.

Chapter XII describes results of a survey conducted among rural Nebraska residents, which asked their perceptions regarding access to e-health. Special attention in this study is directed toward identifying key dimensions of rural residents’ perceptions about e-health from a qualitative analysis of their open-ended responses.

Chapter XIII uses interview methods to study effects of an e-health application to aid self-management of chronic respiratory conditions. Qualitative analysis of interview data identified important ramifications regarding evidence-based medicine, the doctor-patient relationship, and the role of e-health in improving collaboration and communication with patients.

Chapter XIV investigates asthmatics’ reasons for not adopting e-health for asthma self-management. The authors interviewed four asthmatic individuals to identify why a well-funded e-health application had failed to gain acceptance, finding that the designer’s image of asthmatics as primarily striving to be symptom-free was incompatible with interviewees’ actual objectives.

Chapter XV studies hospital e-health Web sites in a design based upon an extended version of the technology acceptance model (TAM). From interviews with 30 study participants, they find usefulness, ease of use, trust, privacy, and personalization are important elements in deciding whether to use hospital e-health.

Chapter XVI develops and tests a new rational-objective (R-O) model of e-health use that accounts for effects of facilitating conditions as well as patients’ behavioral intentions. Results from a longitudinal survey design show that predictions of actual use were improved by more than 300% by considering effects of facilitating conditions.

REFERENCES

AHIMA. (2005). The role of the personal health record in the HER. *Journal of AHIMA, 76*(7), 64A-D.


