PREMIER REFERENCE SOURCE

Patient-Centered E-Health

E. Vance Wilson

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Section I
Foundations

This chapter provides a conceptual foundation by exploring the existing literature on traditional healthcare, patient-centered healthcare, and the progression of e-health in enabling the movement towards patient-centered care. This chapter also discusses enhancing the relationship between the patient and the healthcare provider through e-health. We conclude with a discussion of the future of patient-centered e-health and future research opportunities in this area.

Chapter II introduces a series of techniques and tools useful for developing patient-centered e-health. To create quality e-health, designers must attend to the needs and wants of users by engaging them in the design and testing processes. User-centered design (UCD) is a formal approach to ensuring that new products address the needs, wants, skills, and preferences of the user throughout the tool's development. UCD is a design and evaluation process which pays special attention to the intended users, what they will do with the product, where they will use it, and what features they consider essential. This chapter focuses on UCD methods and techniques, giving examples of how to use them and when.

In Chapter III we look at some fundamental aspects of communicating about ourselves and our health through technology. In particular, we examine how the social psychological theories of self-presentation and self-regulation might be applied to online health-communication. It is argued that the specific qualities of text-based communication might have unique benefits for health-communication through the interplay between the writing process and the concerns posed by health-issues. An understanding of how psychological processes are connected with online health communication is believed to be fundamental in understanding trends within self-help and user-driven health communication, and to predict possible outcomes of such behavior. Also, this knowledge might inform the design and development of patient-centered solutions for health-communication and heath-service delivery.

An increasing focus on e-health and a governmental push to improve healthcare quality while giving patients more control of their health data have combined to promote the emergence of the personal health record (PHR). The PHR addresses timeliness, patient safety, and equity, goals that the Institute of Medicine has identified as integral to improving healthcare. The PHR is vital to the National Health Information Network (NHIN) that is being developed to give all Americans access to electronic health records by 2014. This chapter looks at how PHRs address the needs, desires, and expectations of patients, explores the data quality concerns regarding patient-generated information (data capture, sharing and integration with other systems), discusses social implications of adoption, and concludes with a discussion of the evolving role that PHRs play in the growth of patient-centered e-health.

Newly disabled workers are often unemployed, uninsured, and indigent. They are in desperate need of Social Security OASDI monthly benefits, and the Medicare health insurance that follows 24 months after benefits begin. Applicants must prove that their medical conditions (excluding drug and alcohol abuse) have resulted in severe functional limitations that prevent them from any gainful employment. Delays and denials of benefits result when applicants cannot find or retrieve medical records from providers familiar with their medical history, health status, and functional limitations. The disability application workflow is complex, particularly for applicants with cognitive and mental health impairments. Health information technology (HIT) has been used to automate care delivery workflow through provider-controlled, electronic health record systems (EHRs). Disability applicants' workflow could, just as well, be automated through consumer-controlled, unbound, and intelligent personal electronic health record systems (PHRs), which are not tethered to a health plan or employer network, and which automatically exchange information updates with authorized providers' EHRs. Applicants' PHRs may later prove helpful with self-management of chronic conditions prior to Medicare coverage and with periodic reevaluations of their medical status.

In Chapter VI we review key concepts, using the marketing mix framework, to identify the needs of healthcare consumers, and the tools and services that can fulfill these needs. Unlike traditional healthcare delivery, patient-centered e-health (PCEH) involves the consumer as a partner and has a number of marketing implications. A more informed understanding of PCEH will help practitioners and researchers to formulate marketing strategies that improve healthcare outcomes and are acceptable to patients.

This chapter introduces the privacy management framework as a means of studying patient-centered e-health. The chapter raises some important issues in regards to the privacy domain of e-health and offers a privacy framework to look at the issue that addresses some of the concerns people and industries have regarding privacy. The framework does not neglect the important distinction between the different interests affected by e-health. It acknowledges the voluntary nature of the way in which individuals have surrendered control over personal information in exchange for the benefits that information technology brings. Because the applications of information technology are logically malleable, there are sufficient strategic reasons to suggest that privacy management as a concept and practice will survive, and that to ignore privacy issues might be fatal for the success of PCEH.

Patient-centered e-health (PCEH) offerings see the emergence of divergent, new third parties, through initiatives, including (a) medical content aggregation, (b) health-based online communities, and (c) patient-physician Internet-based portals. Here, the product is digital and heterogeneous for medical content aggregators; virtual and heterogeneous for online communities; and digital, context-specific, and asynchronous for patient-physician portals. With patients expressing privacy and confidentiality concerns in communicating personal health information electronically, growing numbers of PCEH initiatives give rise to many unique issues with respect to patient trust. Existing electronic commerce research focuses on trust in online vendors, potentially providing an incomplete picture with respect to patient trust in PCEH. An accurate and holistic understanding of patient trust encompasses different combinations of cognitive processes, disposition to trust, and institution-based trust, all shaping trusting beliefs in these different PCEH initiatives.

Chapter IX
Involving Patients and the Public in E-Health Research 115
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Chapter IX deals with the principles and practice of patient and public involvement in e-health research, and discusses some of the issues raised. In the first part of this chapter, we discuss the problems of defining an "e-health consumer," and discuss why, how and when to involve consumers in e-health research. We also set out principles to guide effective consumer involvement, and the benefits that this can bring in the e-health arena. In the second part of this chapter, we describe how consumers were successfully involved, through a variety of methods, in the development and evaluation of an Internet-based intervention to aid diabetes self-management. Patient and public involvement in research is not the same as undertaking research on patients or the public. It is about understanding, incorporating and benefiting from the relevant consumer perspective, at various levels, throughout the stages of a project.

Section II
Applications

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Using Interaction Design to Improve Usability of a PHR User Interface Based on Visual Elements.. 127
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This chapter presents a case study of using interaction design methods for exploring and testing usability and user experience of a personal health record (PHR) user interface based on visual and graphical elements. To identify problems and improve the design of PHR user interface we conducted two task-oriented usability testing based on the think-aloud technique for observing users during their interaction with a high-fidelity PHR prototype, and questionnaires and semistructured interviews for measuring user satisfaction. Our study demonstrates that a user-centered approach to interaction design involving the final users in an iterative design-evaluation process is important for exploring innovative user interfaces and for identification of problems in the early stages of the development cycle of a PHR

Chapter XI
Healthcare Quality and Cost Transparency Using Web-Based Tools 143
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This chapter explores the use of Web sites to provide patients with understandable information about the quality and price of healthcare (healthcare transparency). Our first objective is to discuss patients' perceptions of empowerment and need for quality and cost information when choosing medical providers and facilities for healthcare procedures. To meet this objective, we address issues of patient awareness of sources of healthcare quality and cost information, perceived responsibility for managing healthcare costs, and knowledge of appropriate actions to exercise choice of providers. Our second objective is to investigate the potential of Web-based tools, which provide healthcare quality and cost information, to facilitate patients' decision-making processes regarding choice of provider for healthcare services, particularly common outpatient procedures. To meet this second objective, we use insights from user-centered design procedures (e.g., focus groups and in-depth interviews) associated with the development of a healthcare transparency Web-based tool.

Chapter XII
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This chapter is drawn from a comprehensive study that examined the effect Human-computer interaction usability factors had on rural residents' perception of trust in e-health services. Written comments provided by participants were drawn upon to develop a qualitative assessment of dimensions that are important to rural residents' perceptions of e-health. Identification of these dimensions will aid e-health system designers and administrators in creating better e-health applications.

Chapter XIII
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This chapter explores how in developing patient-centred e-health systems it is possible to accommodate heterogeneous characteristics of end-users and their diverse health and care contexts. It concurs with conventional sociotechnical design paradigms that argue systems must be easy to use, fulfill a perceived need, and present a clear value proposition to ensure successful adoption and utilisation by patients. The chapter also highlights the need for awareness of a number of key challenges relating to emerging discourses on 'empowering patients' and 'e-health'. The implications of these challenges for the development of a truly patient-centred e-health approach are explored in a detailed case study. This chapter contributes to research focused on supporting patients to become genuine co-participants in their own care, health and well-being. However, it also acknowledges that part of the challenge of achieving this goal requires a focus on assisting clinicians to learn to respond to this shift in the autonomy of decision-making.

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Chapter XIV investigates asthmatics' reasons for not adopting an e-health system for asthma self-management. An understanding of these reasons is particularly relevant, because clinical evidence indicates that, if used, such systems lead to better asthma management. The investigated asthma system is, however, based on a taken-for-granted image of asthmatics as, per se, striving to be symptom-free. This image is incompatible with interviewed asthmatics' day-to-day performances of their asthma, and renders invisible (a) that their asthma performances emphasize an economy of good passages and of feeling capable, (b) that they achieve the objective of feeling capable in quite different ways, and (c) that feeling capable does not per se equal being symptom-free all the time. To attain long-term use of self-management systems and other patient-centred e-health systems, such systems must acknowledge and link into the manifold performances that comprise users' ways of living with their disease.

Chapter XV

Exploring the Technology Adoption Needs of Patients Using E-Health 201

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An extended version of the technology acceptance model (TAM) is applied to study hospital Web sites, one specific area of e-health. In a review of literature, five significant factors from TAM research are identified that are logically related to e-health sites from the user's perspective: usefulness, ease of use, trust, privacy, and personalization. All five factors emerged in the data analysis of 30 participants using a hospital Web site. We discuss the implications of this study for guiding development of effective patient-centered e-health.

Chapter XVI

Predicting Patients' Use of Provider-Delivered E-Health: The Role of Facilitating Conditions 217

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This chapter presents a new rational-objective (R-O) model of e-health use that accounts for effects of facilitating conditions as well as patients' behavioral intention. An online questionnaire measured patients' behavioral intention to use a new e-health application as well as proxy measures of facilitating conditions that assess prior use of and structural need for health services. A second questionnaire administered three months later collected patients' self-reported use of e-health during the intervening period. The new model increased predictions of patients' e-health use (measured in R^2) by more than 300% over predictions based upon behavioral intention alone, and all measured factors contributed significantly to prediction of use during the three-month assessment period.