

Creating Patient–Centered E–Health

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INTRODUCTION

As e-health applications have increased in number and variety, the generalized concept of e-health as “health services and information delivered or enhanced through the Internet” (Eysenbach, 2001) has lost much of its value as a mechanism for guiding development and research in this emerging field (Pagliari et al., 2005). E-health has expanded to comprise purely clinical applications (e.g., physicians consulting on a diagnosis) (Wiecha & Pollard, 2004), emergency health communication applications (e.g., for distributing information about SARS) (Rizo, Lupea, Baybourdy, Anderson, Closson & Jadad, 2005), disease-focused applications (e.g., diabetes self-management support) (McKay, Glasgow, Feil, Boles & Barrera, 2002), applications to support electronic communication between patients and physicians (Wilson, 2003), and commercial applications that have no association with a patient’s own health care provider (e.g., WebMD) (Itagaki, Berlin & Schatz, 2002). It is clear that the needs of both users and researchers vary widely across these diverse applications, and I argue that both groups would benefit from development of finer-grained approaches to thinking about e-health.

BACKGROUND

Initial e-health applications were designed from a *consumer-centered* perspective, drawing upon an e-commerce business model in which vendors expected to profit from consumers paying directly for products and services they would acquire through the e-health Web site or from advertisers paying for exposure to consumers (Wilson, 2006). Most of these commercial e-health ventures failed during the dot-com bust (Itagaki et al., 2002). However, health care provider organizations have emerged to fill the void by supplying *provider e-health* to their own patients,¹ including generalized informational content as well as appointment scheduling, prescription refilling, and online communication

with physicians and clinical staff (Lazarus, 2001; Wilson & Lankton, 2004).

Despite the goal of serving patients, most provider e-health has been developed from an *organization-centered* perspective that is based upon the provider’s needs and economic interests. Patients’ needs tend to be based on assumptions made by e-health developers and provider administration rather than being driven by patients themselves (Wilson, 2006). As a result, patients sometimes ignore e-health applications that providers assume will be the most essential to their interests. For example, Payton and Brennan (1999) describe e-health that provided Alzheimer caregivers a sophisticated, interactive, decision-support utility, e-mail communication with a nurse-moderator, an electronic bulletin board, and an online medical encyclopedia. The decision support system was considered by developers to be essential to caregivers and was substantially more expensive to deliver than other components. Yet monitoring over an 18-month period showed that decision support was used less than one-tenth as frequently as simple online communication services consisting of an electronic bulletin board and e-mail communication with a nurse-moderator.

CENTERING ON THE PATIENT

This chapter approaches e-health from a *patient-centered* perspective. Patients comprise a large and growing constituency of e-health users (Krane, 2005), and surveys indicate there is very high interest among patients in increased access to provider e-health for a variety of specific interaction needs (e.g., physician-patient communication) (Taylor & Leitman, 2002). Leaders in the medical community are coming to recognize that patients *expect* to be empowered in making health care decisions (Institute of Medicine, 2001), and that the expectation of personal control is especially strong for e-health applications (Lafky, Tulu & Horan, 2006; Markle Foundation, 2004). However, health care provider organizations have only recently

begun to provide patients with online access to health care services, and numerous obstacles are present that can block development of effective patient-centered e-health applications. These include:

1. Financial disincentives for participation by outside parties (i.e., participants in e-health other than the patient, including physicians and provider administration)
2. Reduced work quality resulting from participation by outside parties
3. Reluctance of outside parties to relinquish control to patients
4. Restrictive interpretation of privacy and security regulations
5. Discomfort of patients and other key parties with computing environments.

A complete discussion of means for overcoming such obstructions is well beyond the scope of this chapter (for such a discussion, see Tan, Cheng & Rogers, 2002). Potentially, obstructions can be overcome as has been the case for other heavily regulated, traditional industries (e.g., banking and financial services), which have successfully transitioned to the online environment.

Guiding Principles for Creating Patient-Centered E-Health

In order to meet patients' expectations, it is essential for developers to focus on several guiding principles that are distinct from alternative approaches. Specifically, these are:

1. Focus on desired interactions in which the patient is an active participant
2. Incorporate only those services that meet the expressed needs of patients or are validated against patient needs
3. Be understandable to patients
4. Provide easy access for patients to completely manage and control functionality
5. Provide ready interoperability to support interaction with outside parties (e.g., physicians and pharmacy) and with other health information systems (e.g., hospital billing)

These principles correspond to a large extent with user-centered design principles that have proved im-

portant to the success of developing Web applications across numerous contexts outside the health care domain (Lazar, 2001).

The first principle emphasizes patient *involvement*, thereby distinguishing patient-centered e-health from other applications such as telemedicine, where the patient is primarily an object of the interaction rather than an active participant. The second principle addresses patient *interest* and specifically cautions against relying on untested assumptions about patients as a basis for e-health design. By emphasizing patients' involvement and interest, the first two principles help to ensure that patients will have inherent motivation to use related e-health applications. They also guide the process of eliciting patients' interaction needs and mapping these to e-health services. The remaining principles center on accessibility and source of control.

Principle 3 proposes that e-health information and communication should be understandable to patients. Some researchers argue that it is patients' own health literacy that must increase in order for e-health to succeed (Norman & Skinner, 2006). However, this type of idealistic mindset ignores first that patients' *need* for health care services is not dependent upon their literacy level, and second, that patients can benefit greatly if e-health designers make the effort to incorporate simple explanations and illustrations where these are practical. Many individuals who are only marginally literate have proved to be highly capable of interacting with online applications (e.g., banking) when they are provided with effective technological support. Further, requiring patients to be highly literate in order to use e-health is no more defensible logically than requiring high literacy in order to schedule exams or other health care services that the provider may offer. From the patient's perspective, e-health is simply an extension of the providers' other services; thus, it is reasonable for patients to expect e-health to be generally understandable and for the provider to offer mechanisms by which better explanations can be obtained if these are needed.

Principle four presents a clear statement that ultimate control of patient-centered e-health must flow to the patient. Increasing patients' involvement in e-health has been promoted recently as part of the U.S. plan for "delivering consumer-centric and information-rich health care" (Thompson & Brailer, 2004). However, achieving patient control faces two key obstacles. First, medical institutions are only slowly moving away from

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