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# FOUNDATIONS OF PATIENT-CENTERED E-HEALTH

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## ABSTRACT

*E-health that is created by healthcare providers for online delivery of patient services constitutes a fast-growing Internet segment. This paper proposes that e-health developers can fulfill patients' expectations best by applying patient-centered design principles that are anchored in user-centered development practice. The paper further outlines a training approach for e-health developers that is based upon a recently-developed personal health informatics agenda.*

## KEYWORDS

Electronic Healthcare, User-Centered Design, Human-Computer Interaction, Personal Health Informatics (PHI)

## INTRODUCTION

E-health is broadly defined as “health services and information delivered or enhanced through the Internet” (Eysenbach 2001). 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 website or from advertisers paying for exposure to consumers (Wilson 2006a). Most of these commercial e-health ventures failed during the dot-com bust (Itagaki, Berlin, & Schatz 2002). However, healthcare provider organizations have emerged to fill the void by supplying provider e-health to their own patients<sup>1</sup>, including generalized informational content as well as appointment scheduling, prescription refilling, and online communication with physicians and clinical staff (Lazarus 2001; Wilson & Lankton 2004).

E-health is a fast-growing form of e-service, and it may be anticipated that e-health applications will be developed and administered in large part by Information Systems (IS) professionals. Thus, e-health is an important practical area of study for IS researchers. 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 healthcare

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<sup>1</sup> In this paper, the term “patient” is used to refer, as applicable, to the patient as well as to his or her caregivers.

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

- financial disincentives for participation by outside parties (i.e., participants in e-health other than the patient, including physicians and provider administration)
- reduced work quality resulting from participation by outside parties
- reluctance of outside parties to relinquish control to patients
- restrictive interpretation of privacy and security regulations
- 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 paper (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 (such as 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, developers should:

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 support for interaction with outside parties (e.g., physicians and pharmacy) and with other healthcare information systems (e.g., hospital billing)

These principles correspond to a large extent with user-centered development principles that are important to success of developing web applications across numerous contexts outside the healthcare domain (Lazar 2001). However, certain characteristics of the healthcare environment are unique, and require specialized attention from developers.

Principle 1 focuses on 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. Principle 2 addresses patient interest and specifically cautions against relying on untested assumptions about patients as a basis for e-health design. By emphasizing patient 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 healthcare 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, such as 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 ethically than requiring high literacy in order to schedule exams or other healthcare 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 4 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 a firmly-embedded authoritarian or "paternalistic" model of physician-patient relationships (Emanuel & Emanuel 1992) in which physicians expect to control virtually all aspects of their interaction with patients (Eysenbach & Jadad 2001). Embedded cultural practices can take significant time to change, even in the face of substantial social pressures. Therefore it is likely in foreseeable future that many physicians and other outside parties will resist allowing patients to exercise complete control over e-health or other aspects of healthcare. Second, healthcare provider organizations are reluctant to open up healthcare information systems (HIS) to access by patients. Reluctance is based on several factors, none of which are necessarily unreasonable. Providers have the responsibility to maintain the privacy and security of patient and provider data, which could be compromised by increasing accesses to HIS. Significant labor expenditures will be necessary in order to interconnect HIS with e-health, and it may be difficult for providers to identify ways that these expenses can be offset by increased income. Furthermore, access to HIS is frequently blocked structurally by disparate storage and communication formats among various proprietary systems. Lack of access to the provider's HIS or to specific parts, such as medical records and test results, leaves patients with relatively little to control, as the e-health application will not be able to offer direct interaction with key functions, such as billing and appointment scheduling. Therefore, it is important to develop strategies that can economically enhance access to HIS without compromising security or establish alternatives to direct access (e.g., by applying a data warehouse model where only duplicated data is accessible to patients). It also is key to promote among physicians and clinical staff the ideal that patients have the right to play a central role in their own healthcare decisions.

Principle 5 emphasizes that interaction with outside parties is essential for creating effective patient-centered e-health. Technical approaches can be important to achieve interoperability, as demonstrated by Wilson and Lankton (2003) in their proposal of a guided-mail system as an alternative to e-mail for patient-physician communication. However, social issues should not be overlooked in achieving interoperability, as these may be even more important than technical aspects in motivating outside parties to participate. For example, patients embrace the idea of having access to their own medical records, yet physicians are skeptical that patients would benefit from access and worry that their workload would increase if records became available (Ross et al. 2005).

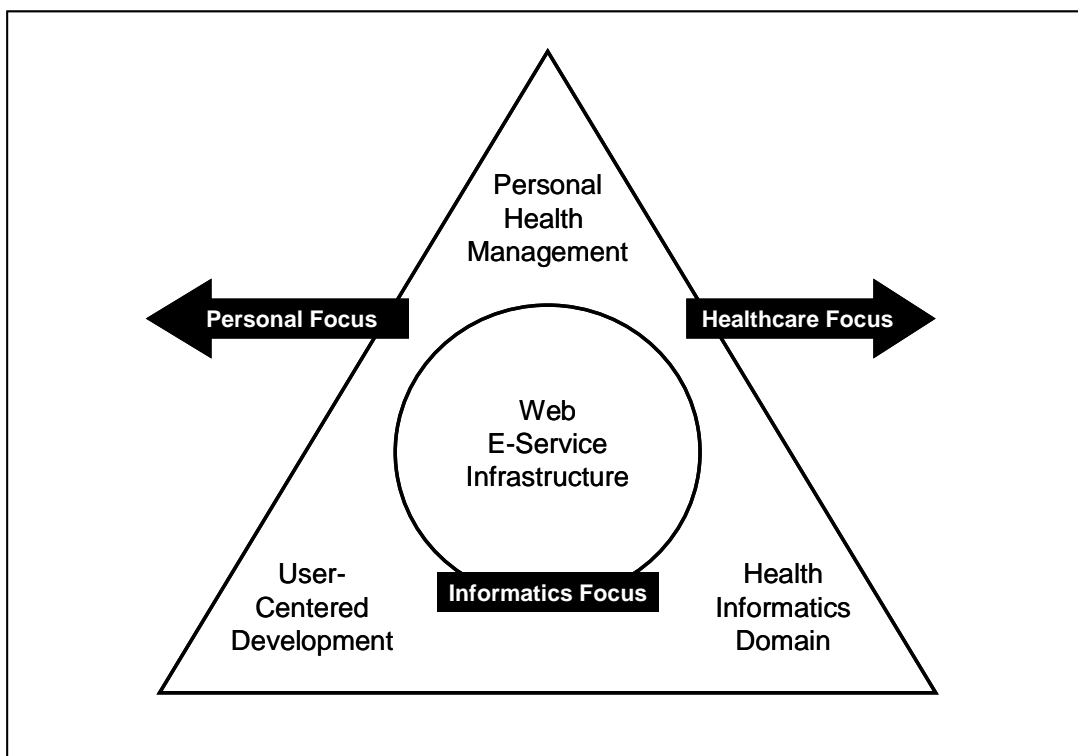
By addressing these five principles, developers can work to create e-health that is centered on patients' needs, accessible, and meaningful in its capabilities. It may be anticipated that other design principles will also apply, (e.g., requirements arising from privacy and security regulations). However, care should be taken to ensure that these do not unnecessarily obstruct any of the five principles of patient-centered e-health that are enumerated above.

## **PERSONAL HEALTH INFORMATICS AND PATIENT-CENTERED E-HEALTH**

Creating effective patient-centered e-health is an important goal but, as discussed previously, this goal faces numerous obstacles, including fears of financial disincentives and reduced work quality for outside parties who are called upon to participate. Key to these concerns is the current lack of a focused discipline in which creation

of patient-centered e-health is a core responsibility. It will remain difficult to champion patient-centered e-health initiatives until such a discipline coalesces through establishment of training programs, identification of best practices, and development of a shared identity.

One approach that satisfies the major goals and guiding principles of patient-centered e-health is the Personal Health Informatics (PHI) agenda proposed by Wilson (2006a). PHI incorporates the knowledge, skills, practices, and research perspectives necessary to develop patient-centered e-health. As shown in Figure 1, four essential content areas support PHI, and these are applied within three focal areas. Web e-service infrastructure describes the hardware, software, and networking capabilities that support e-health functions. In recognition that e-health is primarily service-oriented, the informatics focus in PHI centers on infrastructure that is specialized for e-service presentation and delivery. Personal health management and user-centered development make up the personal focus that PHI presents to patients. User-centered development methods provide tools for eliciting user needs, designing solutions, and evaluating the utility of these solutions in meeting patients' needs. Personal health management addresses patients' individual practices as well as psychological, social, and cultural aspects of their management of personal health information. Personal health management and the health informatics domain combine in the healthcare focus of PHI. Content drawn from the health informatics domain addresses the skills and knowledge necessary to interface with HIS and related healthcare systems.



**Figure 1. Conceptual Model of Key PHI Structural Components (Wilson, 2006a).**

Development of a PHI discipline in which personnel train in these four essential content areas and share a joint focus on patients, healthcare, and informatics would provide substantial leverage toward achieving effective patient-centered e-health. This does not necessarily require development of new academic programs; these content areas can be incorporated relatively easily as a concentration within existing IS programs (Wilson 2006b). Patient surveys consistently show a groundswell of desire for e-health applications that meet their specific needs, including electronic support for managing personal health information (Taylor 2004), patient-physician communication (Taylor & Leitman 2002), and high-quality online health information (Krane 2005). Approaches

such as PHI will be essential in concentrating the skills, knowledge, and patient-centered perspective that are necessary to meet these growing patient demands.

## CONCLUSION

The emergence of e-health has been overwhelmingly beneficial to patients, who already conduct many types of transactions and information searches on the Internet and strongly wish to be able to access healthcare services and information in the same manner. Patients comprise a large and growing constituency of e-health users whose interests would be served by creation of e-health that is guided by the patient's perspective. The guiding principles outlined herein take important steps toward achieving patient-centered e-health. However, a need remains to develop an academic and professional discipline in which patient-centered e-health constitutes a core responsibility, as represented by the PHI agenda. Once these foundations are in place, it will be possible for patient-centered e-health to move beyond the status of a desirable objective.

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