

Chapter 8.7

Personal Health Records: Patients in Control

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ABSTRACT

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. Despite increasing public access to PHRs via employers, insurance companies, healthcare providers, and independent entities, it is unclear whether the PHR will be successfully implemented and adopted by the public. 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.

INTRODUCTION

The ongoing transition toward the electronic medical record (EMR), initially referred to as computerized patient record or electronic patient chart (Tang & McDonald, 2001), was spurred by concerns over medical errors and rising costs in healthcare. As EMR systems became more robust, they proved themselves to be beneficial to healthcare providers in many ways. The EMR reduced information duplication (Ewing & Cusick, 2004), improved

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utilization of lab and radiology results (Ewing & Cusick, 2004; Wang, Middleton, Prosser, Bardon, Spurr, Carchidi, et al., 2003), increased the efficiency of coding and billing (Menachemi & Brooks, 2006; Schmitt & Wofford, 2002), and provided healthcare personnel with quicker access to patient records (Sandrick, 1998; Wang et al., 2003).

Yet, patients and their caregivers share EMR benefits only indirectly. Patients continue to be viewed by EMR developers as passive participants who should not have direct access to or control of health data that are contained within the EMR. At the same time, patients want to be more engaged in their own healthcare and are seeking information online (Ball, Smith, & Bakalar, 2007). Use of the Internet to gather information about healthcare has increased substantially in recent years (Clark, Williams, Clark, & Clark, 2002; Gerber & Eiser, 2001; Lenhart, Horrigan, & Fallows, 2004), and the Pew Internet & American Life Project estimates the number of Americans searching for online health information at 113 million (Fox, 2006). As a result, patients have been undergoing a role change that is facilitated by Internet technology. The traditional paradigm of the patient as a passive recipient of physician diagnosis and instruction is evolving toward the patient becoming the driver of healthcare relationships. Patients have more options for receiving care, such as newly-created “store front” clinics being offered by major retailers to provide basic care (Wal-Mart, 2007). In addition, the Internet has greatly improved access to health information (Greenberg, D’Andrea, & Lorence, 2004), allowing patients to explore new treatments, to access current research journals, and to utilize increasingly sophisticated interactive and individually tailored programs through the Internet and Internet-enabled devices for health behavior change and chronic disease management (Ahern, 2007).

The personal health record (PHR) has emerged as a mechanism for patients to participate directly in the benefits of electronic records and integrated

e-health delivery. Proposed benefits of the PHR include secure online access, comprehensive personal health history, means to become one’s own health advocate, benchmarks and prompts for health maintenance, fluid communication between patient and provider, and automatic data entry (Morrissey, 2005). As patients manage their own personal health records using a PHR, it is hoped that this will help them make more informed choices about available options and give them the ability to exercise greater control over their own healthcare (Tsiknakis, Katehakis, & Orphanoudakis, 2002), in effect converting patients from passive information recipients to proactive consumers and generators of health information.

Leading health informatics groups in the U.S.—the American Health Information Management Association (AHIMA) and the American Medical Informatics Association (AMIA)—note that PHRs empower patients by providing a means for collecting, tracking, and sharing important, up-to-date health information for them or those in their care (AHIMA, 2006). Additionally, PHRs can promote patients’ health management by providing cues for health issues (e.g., weight control or diabetes management), delivering reminders for medical test scheduling, and supporting entry of information—such as blood pressure or blood glucose levels—that may increase compliance to treatment protocols.

Patients have increasing opportunities to use a PHR, but many current initiatives offer only a partial PHR solution, are difficult to use, or raise privacy concerns. Typical offerings by employers and national insurers implement partially complete PHR designs that are limited in the scope of information that is readily included. For example, the PHR offered by Aetna, Inc. primarily provides information that is found in insurance records, such as billing and coding (Havenstein, 2007), and Kaiser’s PHR contains only limited types of medical information (Hines, 2007). Although third-party PHRs have the potential to contain more complete

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