

Chapter 3

Personal Health Records: Status–Quo and Future Perspectives

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ABSTRACT

Consumers, industry, and government have recently focused attention on the potential of personal health records to empower patients in the health care process, improve patient-provider relationships, facilitate patient access to health information, and improve the quality of health care. A Personal Health Record (PHR) is a private and secure digital record that is created, managed, and owned by an individual, and contains the owner's relevant health information. The benefits of PHRs have not yet been widely realized due to several significant challenges in their adoption, including the need for privacy, security, and interoperability, and the lack of accepted standards. Although many players in the healthcare arena are beginning to offer partial solutions, none have adequately addressed the full range of challenges. The adoption of PHRs can be significantly accelerated by the development of Open Source software that enables an individual to collect, create, organize, and manage his or her own private and secure PHR, using a standardized format and controlled vocabulary.

INTRODUCTION

Healthcare today is facing many critical challenges. One of the biggest is the lack of electronic health information. Studies suggested that over 80% of the doctors in the US manage healthcare information on paper. In other words, individual health information is housed independently by doctors or care

providers. Therefore, access to individual's health information is difficult, especially in the event of an emergency. The concept of the *electronic* personal health record (PHR) has been suggested as a significantly improved method for collecting and using personal health information.

Recent surveys suggest that the general public wants PHRs. The Markle Foundation commissioned a survey of 1,003 Americans in November 2006, examining public opinion toward PHRs

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(Markle Foundation, 2006a; Markle Foundation, 2006b). The survey found that 79% of the public believes that PHRs would provide major benefits to individuals in managing their health and 46.5% of the public expressed an interest in having a PHR. Eighty-four percent said it would be important to have electronic copies of health records if changing doctors or moving to another city. Similar percentages said they wanted access to their medical information to ensure that it is accurate, and to check for errors. However, most of those surveyed were very concerned about the potential that their personal health information might be misused or accessed without their authorization. Nearly 57% of the public express concern over the privacy and security of their data and more than 90% felt that their expressed consent should be required for each use of their information. Three quarters of those surveyed said the government has a role in establishing privacy and confidentiality protections for electronic personal health information.

PHR Benefits

There are many benefits to PHRs. In general, PHRs allow a greater patient access to a wide variety of health information, best medical practices, and health knowledge. Instead of several paper files locked away in various doctors' offices, all of an individual's medical records are in one place and fully accessible by that individual. A number of authors have recently described the benefits of PHRs and PHR systems (Endsley, S., Kibbe, D.C., Linares, A., & Coloafi, K., 2006; Tang, P.C., Ash, J.S., Bates, D.W., Overhage, J.M., & Sands, D.Z., 2006; U.S. Department of Health and Human Services, 2006). The key benefits include:

- **Improved quality of care:** PHRs can provide the opportunity for automated analysis of an individual's health profile, and identify potential improvements to health-care based on an analysis of drug-drug

interactions, current best medical practices, identification of gaps in the current medical care plan, and identification of medical errors. Patients with chronic illnesses will be able to track their diseases in conjunction with their providers, promoting earlier interventions when they encounter a deviation or problem.

- **Reduced healthcare cost:** In a recent study titled *The Value of Personal Health Records* (The Center for Information Technology Leadership, n.d.), the Center for Information Technology Leadership at Partners Healthcare System stated that adopting interoperable PHRs could save the United States more than \$19 billion annually after expenses. The financial estimate is based on making the PHRs available to 80% of the population in a 10-year rollout period. The initial start-up costs are \$3.7 billion and the annual maintenance costs are \$1.9 billion. Primary sources of cost savings include sharing test results and medication lists, monitoring chronic disease conditions, visit support, automated medication renewals, electronic appointment scheduling, and administration of pre-visit questionnaires.
- **Better provider and patient relationship:** PHRs improve communication between patients and clinicians, allow documentation of interactions with patients and convey timely explanations of test results. PHR-mediated electronic communication between patients and caregivers can free clinicians from the limitations of telephone and face-to-face communication or improve the efficiency of such personal contacts (Tang, P., Ash, J., Bates, D., Overage, M., Sands, D., 2006).
- **Empower patient control:** A PHR provides continuity in healthcare records as an individual obtains medical services from multiple healthcare providers in different

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