Chapter 8

Personal Health in My Pocket: Challenges, Opportunities, and Future Research Directions in Mobile Personal Health Records

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ABSTRACT

Consumers' access to their health records is increasing, and one of the ways they can gain access and potentially contribute to their records is by using a mobile Personal Health Record (mPHR). mPHRs emerged as a combination of mHealth and Personal Health Records (PHRs). Despite the current shortage of evidence supporting mPHR use, these systems are already being deployed, and examples of currently available mPHRs are provided. mPHRs have an array of potential uses and different target user groups, but there are also several challenges impeding their success. The physical constraints of mobile devices, health literacy, and usability all create obstacles for mPHRs. However, mPHRs create opportunities due to the affordances of mobile devices and the potential to integrate consumer mHealth applications. The challenges and opportunities of these nascent systems are outlined in this chapter, as they inform research topics with respect to mPHRs.

INTRODUCTION

There are a number of important changes occurring in healthcare today. Perhaps foremost among these is a greater move towards involvement and empowerment of consumers (i.e., citizens and patients) in the self-management of their health. Indeed, over the past decade the concept of consumer access to their

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records has moved from a pilot in the late 1990's (Cimino, Patel, & Kushniruk, 2002), when electronic access by consumers to their health data via the worldwide web (WWW) was being explored, to the current access by millions of patients and citizens to their own institutional health data today over the Internet (Halamka, Mandl & Tang, 2007; Protti, 2008). This movement has stemmed from a desire of consumers to have access to their own data, with the first manifestation of this appearing as the "standalone Personal Health Record (PHR)" (Tang, Ash, Bates, Overhage & Sage, 2006). This movement has included access by patients to health data contained in their own PHRs and it has also included a move towards increased access to their own data stored in hospital and even national databases. The objective of this chapter is to introduce the reader to the concept of mPHRs, provide examples of these systems, outline potential users and use environments, and discuss the challenges, opportunities and directions for future research.

What is a PHR?

According to the Medical Library Association (MLA) / National Library of Medicine (NLM) Joint Electronic Personal Health Record Task Force, a PHR is

a private, secure application through which an individual may access, manage, and share his or her health information. The PHR can include information that is entered by the consumer and/or data from other sources such as pharmacies, labs, and health care providers. The PHR may or may not include information from the electronic health record (EHR) that is maintained by the health care provider and is not synonymous with the EHR (Jones, Shipman, Plaut & Selden, 2010, p. 244).

In the past decade, several models for providing consumers with personal health have emerged. PHRs are available in three basic types based on their connectivity or integration with other health information systems. PHRs under the sole control of the consumer and which do not connect with any other health information systems are called stand-alone PHRs (Tang et al., 2006). In contrast, tethered PHRs allow patients to access their own personal information contained in their health provider's health information system (Tang et al., 2006). For example, the Epic health information system (used by many hospitals in the United States) has included in many implementations a component called MyChart that allows patients to access parts of their electronic record remotely. Interoperable PHRs are ideal, because they allow a variety of different health information systems to exchange data and thus, offer the most financial benefits (Kaelber & Pan, 2008) and utility (Tang et al., 2006). Yet another model for consideration are national portals, which allow citizens read-only access to their health data that is interconnected across regions and even nationally. This approach has emerged over the past ten years and examples include the Sundhed.dk patient portal in Denmark, which allows all Danish citizens to access their own health data over the Internet (Protti, 2008).

What is mHealth?

Concurrent with the trend towards PHRs has been a staggering increase in the use of mHealth applications (i.e., health applications running on mobile devices). mHealth is the use of mobile devices for healthcare, or "mobile computing, medical sensor, and communications technologies for health care" (Istepanian, Jovanov, & Zhang, 2004, p. 405). mHealth is revolutionizing the way health data is collected

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