

**Patients' Perspectives on Personal Health Records:  
An Assessment of Needs and Concerns**

Barbara M. Wildemuth, Ph.D., Catherine L. Blake, Ph.D.,  
Kristina Spurgin, M.L.S., Sanghee Oh, M.L.I.S., & Yan Zhang, M.S.I.S.  
School of Information & Library Science, University of North Carolina at Chapel Hill

**Background.** Personal health records (PHRs) have the potential to empower people in managing their long term healthiness and in communicating effectively with their health care providers.<sup>1,2,3</sup> However, currently we have only anecdotal data concerning how and why someone might use a personal health record. This study was intended to identify the potential uses and concerns related to acceptance of PHRs.

**Methods.** Forty-three semi-structured interviews explored frustrations with existing PHR's, the range of uses for which people would create and maintain PHRs, the types of data they would keep, and the privacy and security issues that are most important. Study participants were purposively recruited from four specific groups that are likely to be early adopters of PHRs: parents with young children, adults with chronic illnesses, adults caring for older parents, and older adults.

**Results.** Most of the participants currently keep health records of some kind – primarily their health-related financial records. However, they have little confidence in their ability to find and use particular records when needed, and difficulties in sharing records between health provides often resulted in repetition of tests or medical procedures. As expected, participants would like their "ideal" PHR to include lab test results (tracked over time), medications (names and dosages, the doctors who prescribed the medicines, prescription numbers, refills, etc.), appointments with health care providers and the outcomes of those appointments. They would most like to view their PHR to prepare for an upcoming physician visit and to monitor and investigate trends over time; in addition, they would like emergency health care providers to have access to their PHR. While most participants were comfortable with their care provider viewing and editing their PHR, they were very wary of other people, not directly involved in their health care, having access to their PHR (e.g., insurance companies or government agencies). While the participants were not universally comfortable with any external entity holding their records, most were uncomfortable with taking on the responsibility of holding their records for themselves.

**Conclusions.** The results of this study have identified a number of features that need to be included in a PHR to ensure its acceptance by a broad range of potential users. While there is good consensus about the content of a PHR and the ways in which it might be used, there was little agreement about who should hold and maintain the records of an individual. If PHR systems are to be sustainable over the long term, we must also understand the level and type of commitment needed to maintain them.

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<sup>1</sup> Cognetti, G., & Cecere, L. (2003). E-oncology and health portals: Instructions and standards for the evaluation, production organisation and use. *Journal of Experimental & Clinical Cancer Research*, 22(4), 677-686.

<sup>2</sup> Ueckert, F., Goerz, M., Ataian, M., Tessmann, S., & Prokosch, H.U. (2003). Empowerment of patients and communication with health care professionals through an electronic health record. *International Journal of Medical Informatics*, 70, 99-108.

<sup>3</sup> Wald, J.S., Middleton, B., Bloom, A., Walmsley, D., Gleason, M., Nelson, E., et al. (2004). A patient-controlled journal for an electronic medical record: issues and challenges. *Medinfo*, 11, 1166-1170.