

Topic: Personal Health Information Management

Pratt, W. Unruh, K., Civan, A. and Skeels, M.M. (2006). Personal health information management. *Communications of the ACM*, 49(1): 51-55. [Available online](#).

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Pratt, Unruh, Civan and Skeels discuss the challenges of personal health information management (PHIM) in a complex healthcare environment. Their work at the University of Washington focuses on the PHIM activities of breast cancer patients, but returns findings that parallel findings in personal information management (PIM) and that illustrate needs of patients in a variety of settings. Through a scenario-based example, the authors discuss the challenges and needs of individuals related to managing personal health information and selectively integrating health-related information with personal information management and communication tools while maintaining privacy.

The complexity of the healthcare environment is due to a combination of factors, including distributed health services; complex insurance policies; the growing role of the patient in managing the details of personal health care; and abundant and diverse health information. There has been a reduction in the amount of time providers are available to individual patients; services are increasingly performed on an outpatient basis; and patients must often coordinate care among several providers and settings. Patients must prepare for consultations, communicate with providers, and record, organize and store health information. Additionally, Health information is encountered and shared in many forms in online and offline environments.

This article provided context for a lively discussion that was enhanced by the variety of perspectives represented, including a patient care professional from a local health care system, a SILS Bioinformatics Faculty member actively engaged in PHR research, a graduate student who had worked to develop a PHR system interface prototype, and others with personal and professional experience in related topic areas. From the patient care perspective, we learned of the challenges faced by health care providers that arise from balancing the need to minimize cost of care with varying levels of needs of patients. While

the increasingly complex environment provides health care workers opportunities to develop and provide additional care services that may be highly effective and valued by segments of their patient populations, it is often necessary to develop these services with grant funding. Once the grant funding runs out, providers are faced with the challenge of paying for the programs.

Of particular interest to our discussion group was the development of systems such as a personal health record (PHR) system that will address the challenges of managing personal health information. We developed an inventory of the types of information a PHR should contain, the functionalities such a system should have, and the politics of PHR management.

The politics of health care information management are centered on questions of who should be trusted to manage personal health information and the benefits and risks associated with potential systems management scenarios. The current direction in PHR systems is to offer online PHRs, which is inline with current trends in the management and storage of other types of personal information. While there are privacy concerns associated with most network systems, privacy is of particular importance to the development of personal health information systems because of the high risks and potential harm to individuals – and groups – if personal health information is inappropriately shared or exposed. In the health care environment, these risks should be of particular concern because of the competing interests of stakeholders and the high economic value of information.

At an individual level, inappropriate exposure of personal health information could be devastating. Among the personal and social consequences related to the exposure of sensitive health information are how this could impact an individual's job security, access to health care, insurance coverage, and the potential for other types of discrimination. At a group level, the potential for discrimination, especially in relation to health care access and insurance coverage are also of high concern. In addition to these privacy concerns, it is necessary to consider the potential for misappropriation of personal health information and its consequences.

Other foci of our discussion related more directly to system functionalities, interfaces, and needs of special user groups, including the elderly. We engaged in expanded discussions of health care information visualization, taxonomy and labeling, and system

interoperability. Systems interoperability is a concern at many different levels in the development of PHRs. As discussed in the article, there are potential benefits for individuals in terms of efficiency and ease of use if we are able to selectively integrate PHIM data with other PIM technologies such as scheduling and communication systems currently in use. Likewise, there are potential benefits of selectively sharing PHIM data across systems such as those used by pharmacies, insurance organizations and health care providers. Though there have been some advances in the development of standards for electronic health records (EHRs) and calendaring systems, EHR standards are still under development and calendaring system standards have yet to be widely adopted.

Health care information visualization and system taxonomies and labeling directly affect how an individual accesses and interacts with their personal health information, and can also impact individual understanding of personal health and health care. Current initiatives in PHR research include examining the needs of special user populations and the development of PHR components and systems that cater to their needs. The challenge to develop PHRs that have both the potential to gain wide spread use and that are able to cater to the needs of special populations promises to continue to offer many research opportunities.