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POLICY FORUM

Will the Potential of Personal Health Records Be Realized?

Tara LePage, MPH, and O'Neil Britton, MD

The rapid evolution and advancement of commercially available technology have reshaped the way we do just about everything in our lives. The early days of the personal computer (PC) stimulated the imagination of a generation, but, due to cost considerations, remained inaccessible to many in our society. The introduction of the iPhone by Apple in 2007, followed by the tablet PC, triggered an explosion of widely available and cheap technology with functionality that few could have imagined in prior years [1]. At the same time, traditional brick-and-mortar institutions were pushed by economic forces to embrace the Internet, with its revenue-generating and cost-saving potential as a necessary component of a healthy business model, given the rapid migration of consumers to Internet and mobile platforms.

An enormous amount of choice in our lives is being driven by these same technological advancements. Whether we are online shopping through retail sites such as Amazon, selecting meal and leg-room preferences for air travel through one of the many online travel agents, or even utilizing online banking to apply for a mortgage without ever having to visit a physical bank, the options appear endless. Thus, it was only a matter of time before this phenomenon started imposing itself on the health care system, where patients and advocates began to clamor for access to, control of, and portability of their personal health information. When these advancements were coupled with policy initiatives promoting patient-centric health care, it was no surprise that the preconditions for creating the first personal health records were set in motion, specifically to engage the individual in the management of his or her own health [2]. Technology has become a major facilitator in the development of this model of care, and its rapid advancements are offering innovative tools that are optimizing patient-clinician connectivity more than ever before. From academic medical centers to rural community hospitals, the sophistication of these information systems is now supporting administrative and clinical decision making; information organization, management, and accessibility; and communication across the care continuum.

Types of Personal Health Records

An electronic health record (EHR) is a collection of health information that is both gathered and managed by health care professionals [3, 4]. Much attention has been paid to the promotion and adoption of EHRs in both private and public care settings across the country, driven by government incentives for their "meaningful use." In contrast, personal health records (PHRs)—defined as "an electronic application

through which individual patients can access, manage, and share their health information in a private, secure, and confidential environment" [5]—have been developed to address the growing demand of the patient-as-consumer for health information. With far less regulatory attention and incentives, these records currently represent a more niche industry, largely driven by software entrepreneurs and health care institutions attempting to improve their engagement with patients.

There are three general classifications of PHRs:

- 1. Stand-alone software applications accessible through the Internet or personal storage devices with content solely uploaded by the end user or designee,
- 2. EHR-based patient portals that directly connect to and are governed by the care providers' patient information sources, and
- 3. Complete, patient-controlled records, ideally interoperable with all available information from caregivers across the health care spectrum [3, 5].

In response to the transition towards patient empowerment and patient activism in our health care environment, a number of vendors and institutions have committed to the adoption and implementation of PHRs to engage individuals in the management of their health. The common belief is that patients engaged in this manner generally have better health outcomes, but it remains unclear whether this is a result of selection bias, inasmuch as patients who were quick to seek out and adopt PHRs are particularly motivated to take active roles in their health [4].

In 2007, Microsoft released their web-based PHR model, HealthVault, an example of the PHR described in classification 1 above. With Internet accessibility, anyone is able to register with HealthVault to store, organize, and track personal health information, upload relevant data from home health devices, and search for vetted health and wellness resources [6]. These records provide the patient with a centralized repository for storing, tracking, and managing personal and familial health data that can range from over-the-counter medications, special diets, and exercise programs to symptoms of chronic conditions and progress on personal fitness goals [3]. While this classification of PHRs affords complete patient control of data entry and the desired mobile access, concerns about consistency of reporting and reliability worry those with clinical decision-making roles [4].

The EPIC application My Chart is an example of the second classification: a tethered PHR product that links with the vendor's enterprise EHR [4, 7]. This model allows patients to view selected pieces of their medical records including diagnoses, medications, immunizations, and, most popularly, test results. Additional features allow the patient to request prescription renewals and office visits and recommend updates to particular fields in the chart as necessary [7]. The opportunity for bidirectional communication between patient and clinicians and the subsequent time saved performing routine tasks electronically are the apparent advantages of this interconnectivity. The patient is now equipped with the most relevant medical records and has the ability to share with the physician pertinent information that may have previously been missing from the chart. Epic's newest PHR module, Lucy,

permits all of the functionality described above, in addition to allowing the patient to share and store health summaries from other health care organizations. The governance of the information in this module is entirely under the control of the patient with some built-in restrictions to prevent patients from overwriting the EHR. Of all 3 potential models, this one—the PHR tethered to an EHR—appears to be the option with the greatest potential for traction. The EHR vendors' strengths resources to invest in software development, ability to meet security and compliance standards, and long-term market presence—would make these PHRs attractive.

The third classification speaks to the ideal PHR; a hub-and-spoke model that would capture the entirety of health care services (spokes) encircling each individual patient (hub) [6]. For patients, whose personal health information is held by a variety of constituents including many care providers, employers, health plans, insurers, and even family members [8], having the architecture and functionality to import, export, manage, and share relevant information from all sources would yield the greatest value. Successfully achieving this seamless flow of data would require an infrastructure of nationally recognized interoperability standards to regulate the building and maintenance of these technology systems and tools [8].

Implementation

The main barrier to achieving widespread use of PHRs has been achieving interoperability between the EHRs of multiple health systems and other organizations, made more difficult by the fact that EHR vendors are vying for the same customers. But the promulgation of integrated value-based care may reduce these challenges by decreasing the number of health systems from which patients seek care. A secondary barrier to widespread PHR use is varying levels of computer competency and health literacy among patients. Efforts to increase health care understanding among patients will be instrumental in making access widespread and equitable [4, 7, 8].

For patients to adopt any version of PHRs, they must be convinced of the value the technology has for them. Framing that value in a way that actively engages patients as collaborators in their health care management will not only empower the individual but improve patient-clinician relationships overall [9]. For some patients, the value may be control of or immediate access to their information, while others will be most enthusiastic about features such as self-scheduling of exams and social media connections to lifestyle-modification support groups. These concepts of transparency, flexibility, and connectivity reflect the desired participatory model of care, where patients will be welcome to join their clinicians at the table and take ownership of decisions regarding their health [9].

Benefits. Working to lower the barriers to adoption and making PHRs available on user-friendly and affordable mobile devices will allow more patients to access PHRs. And, as more engage with the tools, there will be greater opportunities for scholarly evaluation of patient-reported outcomes and patient behaviors, as well as instrumental feedback on desired functionality for future development [7]. Over

time, assessments of robust data sets will more clearly show PHRs' impacts on quality of care, safety, efficiency, and overall patient satisfaction [6].

Risks. On the other hand, widespread EHR adoption could compound the effect of threats to information security, leading to unlawful access to patient information and fraud related to misuse of patient accounts, as well as, possibly, to crippling clinician productivity with exponentially increased workloads. The clinician's perception of risk may also be increased if clear rules or policies regarding importation of patient reported information into the "official" medical record are not established. This may be exacerbated by any poor clinical outcome and would be likely to lead to deterioration of the patient-clinician relationship.

Conclusion

It is clear that personal health records represent a significant investment in greater patient engagement—offering unprecedented access to personal health information and encouraging shared patient-clinician decision making to improve clinical outcomes. In a time of broad transformation of the health care system, technologic advances are undeniably providing opportunities to embrace patients as partners in their health care management [8].

References

- 1. West J, Mace M. Browsing as the killer app: explaining the rapid success of Apple's iPhone. *Telecomm Policy*. 2010;34(5-6):270-286.
- 2. Agarwal R, Anderson C, Zarate J, Ward C. If we offer it, will they accept? Factors affecting patient use intentions of personal health records and secure messaging. *J Med Internet Res.* 2013;15(2):e43.
- 3. Tang PC, Lansky D. The missing link: bridging the patient-provider health information gap. *Health Aff (Millwood)*. 2005;24(5):1290-1295.
- 4. Tang PC, Ash J, Bates D, Overhage JM, Sands D. Personal health records: definitions, benefits, and strategies for overcoming barriers to adoption. *J Am Med Inform Assoc.* 2006;13(2):121-126.
- 5. Pagliari C, Detmer D, Singleton P. Potential of electronic personal health records. *BMJ*. 2007;335(7615):330-333.
- 6. Kaelber DC, Jha AK, Johnston D, Middleton B, Bates DW. A research agenda for personal health records (PHRs). *J Am Med Inform Assoc*. 2008:15(6):729-736.
- 7. Halamka JD, Mandl KD, Tang PC. Early experiences with personal health records. *J Am Med Inform Assoc*. 2008;15(1):1-7.
- 8. Kahn J, Aulakh V, Bosworth A. What it takes: characteristics of the ideal personal health record. *Health Aff (Millwood)*. 2009;28(2):369-376.
- 9. White A, Danis M. Enhancing patient-centered communication and collaboration by using the electronic health record in the examination room. *JAMA*. 2013;309(22):2327-2328.

Tara LePage, MPH, is a recent graduate of Boston University School of Public Health with a concentration in health policy management. Her career interests include providing strategies to improve the quality of life of nursing home residents and analyzing the barriers to adoption of health information technology by the elderly population.

O'Neil Britton, MD, is the chief health information officer of Partners HealthCare in Boston. He is a senior clinician in the Department of Medicine at Brigham and Women's Hospital and former chief medical officer at Brigham and Women's Faulkner Hospital. His career pursuits have focused on clinical operations, quality improvement and patient safety, and the education and mentoring of trainees and students.

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