VIEWPOINT

Personal Health Records
More Promising in the Smartphone Era?

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As health care delivery organizations shift from implementation of electronic health records to optimization of these systems, the persistent problem of patient data interoperability is becoming increasingly relevant. Interest in accessing medical information from hospital records and databases and providing convenient patient-controlled portable records is increasing. Technology companies are seeking to develop innovative solutions to meet these demands.

Interoperable personal health records are not a novel concept; unsuccessful attempts to collect digital patient records have been pursued by several major technology companies. As 1 of the first 12 health care organizations to integrate one company's next-generation approach (Apple Health Records) into a patient portal, UC (University of California) San Diego Health is assessing whether this new functionality can overcome prior challenges and catalyze systemic change toward meaningful patient-controlled interoperability.[1]

Personal health records, which are distinct from patient portals tethered to health system electronic health records, are repositories of clinical data managed and maintained by patients.[2] These records can contain many of the same types of data as hospital medical records including medical history, diagnostic test results, and clinician documentation. Paper repositories have transitioned to digital platforms that are accessible by personal computers or mobile devices over the internet.

More recently, standards have been developed to ensure that patients can connect their personal electronic devices to health care organizations by using application programming interfaces to automate both the retrieval of health record data from those organizations and the communication of clinical information (such as blood glucose levels from wearable devices) to those organizations. Next-generation personal health records are promising to expand from collecting and organizing clinical data to providing the patient with streamlined record portability, analytics derived from patient-generated medical data, and access to third-party tools such as cost information.

Understanding the initial reactions of patients to any new platform is important. In a brief (3 question) anonymous online survey sent to the first 425 patients at UC San Diego Health who activated the personal health record feature in 2018, the 132 survey respondents indicated that they could easily connect their mobile devices to the platform (96%), that they were satisfied with using the feature (78%), and that the smartphone solution improved their understanding of their own health, facilitated conversations with their clinicians, or improved sharing of personal health information with friends and family (90%); however, less than half (48%) reported improvement with all 3 of these outcomes. As of fall 2018, UC San Diego Health has hundreds of personal health record users who have downloaded thousands of clinical results and other pieces of medical information though the platform.

As with many other new products and solutions, such enthusiasm is common from early adopters. The platform will need to prove that it is useful, sustainable, scalable, and actually improves health outcomes. The key questions are whether this personal health record will improve patient outcomes and lower costs while also increasing quality. Why might this time be different? Three key developments may contribute to success: the ubiquity of mobile technology, the maturation of health data communications standards, and the widespread use of mobile software distribution platforms.

When Microsoft introduced HealthVault (2007) and Google launched Google Health (2008) personal health records, the first iPhone and Android devices had just been released. The newly launched Android Market and iOS App Store offered just hundreds of apps to download compared with the millions of apps available today. Thousands of apps on these devices are related to health or fitness. Since that time, smartphones have become the de facto standard for communication for consumers.

The universal adoption of mobile technology has led consumers to expect simple and intuitive software applications on their devices that can be used anywhere. Bringing health-related mobile applications to consumers in an already mature smartphone market allows patients to conveniently access new features and functionality with the devices they use every day. By incorporating these features into the core smartphone operating system, device manufacturers can widely disseminate these applications with a simple software update, and could possibly seamlessly push features to millions of patients.

Advances in internet-connected consumer devices have allowed patients to continuously collect biometric and other clinically relevant data with electronic sensors found on virtual assistants, smartphones, and wearable devices such as smart watches. For example, electrocardiographic and fall detection information have recently been added to the collection of other health-related data such as heart rate, activity, nutrition, and sleep pattern monitoring on some smart watches produced by companies like Samsung, Apple, and Fitbit. Developers in partnership with Amazon have built health software using the virtual assistant product (Alexa) to collect symptom descriptions, track blood glucose measurements, and enhance patient engagement and education.

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Electronic personal health records are now well positioned to facilitate the flow of this potentially powerful clinical data to health care delivery organizations and application developers. If these innovations can lead to other uses, such as successful integration of home monitoring data into the electronic health record, clinicians could access multiple types of patient-generated clinical data to better inform care.[3] Adding biometric data to the medical record and empowering patients with easy access and control of their data may help improve engagement and understanding of their medical information.

Early adopters of the first generation of commercial personal health records experienced limited accessibility and variety of features, and most importantly, a lack of meaningful integration with hospital data. Adoption of the first wave of personal health records was quite limited. For example, a 3-year venture by Google Health into an interoperable personal health record relied largely on older and less standard interfaces, resulting in integration with less than a dozen health systems when the product was discontinued in 2011.[4] These standards had variable and uneven implementations among different health care systems, resulting in an inability to integrate records into a meaningful patient-accessible format.

Records were often missing, incomplete, or indecipherable jumbles of meaningless text, which ultimately negatively affected the patient experience and limited adoption.[5] Some implementations that were technically successful still failed because the system displayed test results already available on a hospital patient portal and did not offer other features, such as secure communication with clinicians or online scheduling. Such challenges are now easier to overcome given the more robust ecosystem of apps ready to use the data with patient consent and improved integration with major electronic health records.[6]

This latest attempt to enable interoperable personal health records has largely been driven by the adoption of a new health data standard called FHIR (Fast Healthcare Interoperability Resources),[7] which uses web-based programming protocols to simplify interoperability and connect health care organizations into the standard framework that powers the internet. Such efforts align with the meaningful use stage 3 requirement effective January 1, 2019, to give patients the ability to connect third-party applications to electronic medical records via an application programming interface. The ability to integrate clinical data on patient demand into health records reflects the power of these standards and has allowed 1 recent personal health record to be adopted by more than 130 major health systems in less than 1 year.[8]

Beyond building mobile and desktop devices, technology companies often manage the software that consumers install on such devices through their app stores. By building a common discovery and distribution platform, the Google Play application store is an example of how this approach can create profitable mobile software distribution platforms. By combining mature software developer networks with standard health software programming tools such as Apple HealthKit or Google Fit, technology companies are likely to drive developers to build health-related applications that consumers will use, pay for, and integrate into their lives, as envisioned almost a decade ago.[9]

Improvements in mobile hardware and sensors, digital communication standards, and accessible software have changed significantly since the initial efforts at creating personal health records. Although it remains too soon to draw firm conclusions, the continued development of patient-facing health care technologies by well-established technology companies suggests that the digital health care landscape may now be sufficiently mature to foster the broad adoption of personal health records. Whether these technological advances ultimately improve patient outcomes, lower costs, and improve quality remain the most important unanswered questions.

ARTICLE INFORMATION

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