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VIEWPOINT PAPER

The personal health future

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Personal health records; electronic health records; E-health; Technology adoption; Diffusion

Abstract

Despite several personal health record (PHR) product offerings from major technology sector players over the past years, the notion of tracking and maintaining one's personal health information electronically has failed to takeoff among consumers. Accordingly, we explore factors potentially shaping use of PHR applications. Adopting a qualitative interview approach, we examine underlying potential end-user motivations that might drive use of PHRs, focusing on two prominent market solutions in addition to the notion of a generic electronic personal health record. Our work reveals that relevance, or the utility, of PHRs may present a major challenge to widespread adoption of such systems as potential end-users struggle to see benefits. Furthermore, despite favorable perceptions of system and service quality, potential users lack the requisite trust in vendors and see significant risk in storing personal health information with such firms.

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Introduction

A personal health record (PHR) is an individually maintained electronic record for tracking and managing one's personal health information in a secure environment. PHRs can draw on a diverse set of original data sources including an individual's own healthcare providers, health and fitness-related tracking devices, and personal history, among many others. Apple Computers recently announced its launch

of HealthKit [1], an app-based service for tracking and maintaining a wide range of health and fitness-related information. Interestingly, Apple has partnered with the renowned Mayo Clinic to integrate provider data, a process commonly referred to as "tethering", into the iPhone/iPad-based PHR app. Apple also plans to offer the app as a "stand alone" service offering to those outside Mayo Clinic health plans. This is, however, not the first attempt by a tech giant to venture into the PHR marketplace. Both Google and Microsoft pursued Web-based PHR solutions, with the former abandoning its efforts and the latter struggling to achieve sufficient market share.

While the notion of individual's maintaining their own personal health records is hardly novel, with vendors

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offering a number of different solutions to the market, widespread adoption has seen little success. Furthermore, we do not have a clear understanding of what it will take to make such information system (IS) solutions viable. That said, Sunyaev [2] presented a framework for evaluating PHRs based on functionality, subsequently adopting their model to evaluate both Google Health and Microsoft HealthVault. The posited framework, however, does not lend itself to evaluating a service from the end-user perspective, nor has it or any other effort explained the failure of PHRs to achieve widespread adoption. Accordingly, the current study takes an end-user view of this adoption dilemma, employing a validated qualitative approach to match diverse quantitative measures.

We first studied Google Health, which offered users the opportunity to manage their own health information. Introduced in 2008 and retired at the start of 2012, Google Health failed to capture widespread adoption, achieving only very limited use [3]. Second, we examined Microsoft HealthVault, which started in October of 2007 as a platform to store and maintain health and fitness information. With its launch, Microsoft's Craig Mundie noted that the corporation, "wanted to see what Microsoft could do to anticipate the changes in healthcare and introduce technology that makes it more graceful to move from the old model to a data driven model". Third and finally, we conducted a study with a general PHR as the focal product, not mentioning any specific firm's offering.

The next section discusses existing research efforts related to PHRs, highlighting gaps within the existing literature. We subsequently provide an overview of the research method employed within our research, followed by an analysis of data collected. We conclude with a discussion of implications and limitations of this work.

Personal health records

Personal health records (commonly referred to simply as PHRs) offer users a variety of advantages aimed at patient empowerment. These applications can create a more balanced and complete view for users, when compared to existing health records maintained by each individual provider an individual might be a patient of [4]. Furthermore, PHRs offer additional features and functionality such as making online appointments, supplemental information specific to illnesses, information about different healthcare providers, and options for self-care opportunities, among others [5].

With a personal health record, each individual patient maintains and controls their health record [6]. Information recorded in a PHR often includes allergies, medical history, prescriptions, treatment regimens, and so on. Noteworthy, differences exist between a PHR and an electronic health record (EHR), or electronic medical record (EMR). While one or more healthcare providers hold the latter two, an often cited definition for a personal health record, provided by the Markle Foundation¹ notes that a "personal health record

(PHR) is an Internet-based set of tools that allows people to access and coordinate their lifelong health information and make appropriate parts of it available to those who need it" [7].

Unfortunately, within the existing literature, few clinical trials and systematic reviews focusing on the effects of providing patients with the option of using and maintaining PHRs, particularly standalone applications, exist. A query of PubMed resulted in only a handful of relevant publications. Specifically, Tenforde, Jain, and Hickner [8] found limited evidence of the value of PHRs, identifying only three randomized trials in their research. Furthermore, the authors note these trials were plagued by "study limitations that obscure a clear interpretation of their results," with inconsistent results reported in original works reviewed [8]. Another recent publication reports on a pilot study comparing Google Health and Microsoft HealthVault, when tethered to an advanced EHR application maintained by the United States military [9]. Noteworthy, the study context, namely, a highly tethered system within a large centrally maintained comprehensive healthcare network that includes the full spectrum of primary care and specialty providers, laboratory and diagnostic facilities, and so on, undermines our ability to gain a greater understanding of the PHR adoption challenges in other more fragmented contexts or as applicable to the general population. On a related note, Collins et al. [10] found such highly tethered PHR applications limited to healthcare institutions with "sufficient financial, intellectual, and human capital resources" capable of supporting large-scale initiatives fostering adoption within such environments. Accordingly, given systems not limited to a specific user population, exploring the challenges to standalone PHR adoption constitutes an important pursuit.

Archer et al. [11] purport several reasons for maintaining a PHR:

1. Patient-Provider communication: The benefits of, and satisfaction with, PHR applications include easier access to test results and faster communications with healthcare practitioners.
2. Education and lifestyle changes: In addition to personal data and data from the provider, a PHR can store other data on, for instance, social status, family history, and work environment. Moreover, lifestyle related data, like diet, exercise, smoking, and weight, can be stored.
3. Health self-management: Patient health self-management can be supported by PHRs that allow end-users to record, edit, and retrieve their healthcare data, including, as an example, blood glucose and blood pressure measurements, weight and activity logs, and stress scales. Frequent monitoring can lead to early detection of critical situations and timely intervention.
Another potential benefit not named by Archer and colleagues, but a recurring theme within the literature, includes:
4. Patient empowerment: Maintaining even limited information about their own health status, finds patients empowered to make more informed decisions with their providers. Closely aligned with the notion of empowerment, Collins et al.'s [10] telephone survey of 17 organizations with tethered PHR applications notes increased patient engagement.

¹The Markle Foundation is a charitable organization situated in the United States and works to "realize the full potential of information and information technology in order to address critical public needs, particularly in the areas of health and national security" (Markle, n.d.).

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