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Building a better PHR paradigm: Lessons from the discontinuation of Google Health™



Richard Brandt*, Rich Rice¹

Texas Tech University, TTU Department of English, Lubbock, TX 79409-3091, USA
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Abstract

The growing complexity and increasing volume of healthcare information is currently overwhelming many healthcare professionals and patients within the U.S. healthcare system. The federally mandated digitization of physician-generated electronic medical records (EMRs) may facilitate the expedited adoption of the patient-controlled personal health records (PHRs) as the majority of Americans want to be more involved in their own care. The world's greatest purveyor of information gathering and organization, Google Inc., attempted to facilitate a comprehensive PHR paradigm but the project was discontinued after experiencing limited success. PHR adoption rates among U.S. citizen-patients remain low. Most research offers a simplified, one-size-fits-all checklist of generalized PHR problems that need correction or compare Google's efforts to those of other companies. Unfortunately, low PHR implementation rates cannot be framed within, or assisted by, a widely cast call-to-action and a generic solution. In an effort to combine academic research and industry-based grey literature, this article explores various databases and search engines (i.e. EBSCO, JSTOR, Texas Tech University's OneSearchSM, Google Web Search, and Google Scholar), and relates a list of 22 potential deficiencies that may have contributed to the discontinuation of Google Health™. Findings are itemized and presented in an attempt to help refine healthcare communication and documentation protocols, and to reinvigorate the imagination of scholars, clinicians, and health informatics professionals.

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Introduction

The complexity and volume of medical information continues to increase, and less than perfectly imagined data management may continue to contribute to inflated healthcare administrative costs [27], increased clinician

workload [40], and compromises in patient safety [24]. It is clear that “health professionals are overwhelmed by information” ([6], p. 6). And it is also clear that the systematic digitization and restructuring of this information in order to create more efficiencies, as well as to standardize dissemination and data exchange into clinically relevant protocols and practices, will enhance provider services and patient care.

Patient-organized personal health record (PHR) systems are such e-health companion products to physician-generated electronic medical records (EMRs) [26]. While PHRs have been nationally implemented in Germany, Australia, and

*Corresponding author. Tel.: +1 817 704 4777.

E-mail addresses: richard.brandt@ttu.edu (R. Brandt), rich.rice@ttu.edu (R. Rice).

¹Tel.: +1 8 1 806 319 5894.

the Netherlands for years, industry penetration in the U.S. is likely to have been obfuscated by government-imposed EMR and Meaningful Use mandates (i.e. HITECH Act). Other barriers to PHR adoption include costs, interoperability, security, and new privacy requirements. While the technology and legislation may be new, the struggle for patient agency and record-control has been ongoing for some time ([22,28]; Segal, 2005 [43]). The struggle has been documented in recent scholarly literature, such as Archer, Fevrier-Thomas, Lokker, McKibbin, and Straus [3] in *Personal Health Records: A Scoping Review*. Still, the widespread adoption of medically based Internet queries, and the abundance of accessible information have fortified a renewed interest [1]. The top-down, physician-controlled dissemination of healthcare knowledge and patient data is increasingly being supplemented in the form of bottom-up, patient-controlled personal health records and Web 2.0-based information searching.

Despite potential and well-documented benefits, “The PHR market remains an elusive, challenging market to understand and predict its future outcome” ([26], p. 247; [37], p. ii). Most research offers a simplified, one-size-fits-all checklist of problems that need correction. Unfortunately, technological powerhouses have not been able to sustain a PHR protocol. In order to more fully leverage the multifocal benefits of integrated PHR usage by patients, providers, hospitals, and healthcare systems, we as scholars, developers, and clinicians must examine specific reasons for the lack of medical adoption through early attempts, such as Google’s first PHR project. Why was the world’s greatest purveyor of information gathering and organization unable to sustain a PHR system for the U.S. healthcare industry, an industry labeled as the “most inefficient information enterprise” ([24], p. 1103)? Several scholarly articles have focused on Google Health™ [12,20,33,45], but most academic publications only mention the popularized comparison of Google Health™ and Microsoft HealthVault™. In *The Demise of Google Health and the Future of Personal Health Records*, Mora [36] states that “very few evaluations can be found in the literature” (p. 367).

In order to fulfill a largely unaddressed area of research, this article focuses on the efforts of one company through the lens of popular layperson culture most represented in the grey literature of technology and consumer health web articles, blogs, interviews, and news feeds. We have included scholarly literature, as well, to develop the context. Many tech-based journalists, however, have held good access to industry insiders and stakeholders during these events.

Background

In February 2009, the American Recovery and Reinvestment Act was signed into U.S. law. It included the Health Information Technology for Economic and Clinical Health Act (i.e. HITECH Act), provisioning \$19.2 billion (USD) to ensure the complete digitization of all American medical records by January 2014 ([4,5], 2009). This federally mandated and nationwide transformation of medical record keeping and health information exchange protocols is currently materializing into a variety of medical record platforms (e.g. EMR, EHR, PHR) as well as brand-specific, proprietary products which are collectively

encompassed under the rubric of electronic medical records (EMRs). Our focus, the personal health record (PHR), is an individual’s electronic record of personal health information (PHI) that incorporates nationally suggested interoperability standards. It can be accessed and reviewed from multiple sources, and it is constantly organized, controlled, and disseminated by each individual patient [definition adapted from a NAHIT report, 2009 [23]]. Information can be comprised of self-produced data (e.g. daily blood sugar readings), clinician-generated medical office visit notes (e.g. EMR notes), laboratory printouts (e.g. blood work results), and diagnostic imagery (e.g. X-rays). This digitized health folder can be stored on an individual’s computer, laptop, mobile device, or encrypted and password-protected web-based server. Regardless of storage and delivery, individual patients may strictly control which part of their personal health record (PHR) is seen, and by whom. The server model (cloud-based centralized data collection) enables various providers to consult on a case simultaneously in disparate locations. Moreover, this approach enables adult children to access and monitor the health of aging family members. And this approach allows patients to take a comprehensive medical record with them wherever they may relocate or travel.

Despite the low national adoption of this protocol, it is clear that U.S. patients want to be more involved in their healthcare. In a 2008 Deloitte survey of healthcare consumers, 78% of respondents reported interest in having online access to medical records and test results provided by doctors, and 76% were interested in online access to an integrated medical record system (Deloitte Executive Summary, p. 10 [9]). Perhaps based in part on similar data, Google’s Internet-based PHR service, Google Health™, began development in 2006 as an XML-based Continuity of Care Document (CCD) system that enabled users to manually compile separate personally constructed health and physician-generated medical information into a centralized packet. Following two months of live testing with 1600 patients at the Cleveland Clinic, the Google Health™ Beta Edition was released to the public in May 2008. Further upgrades and iterations continued, but on June 24, 2011 Google announced its discontinuation effective January 1, 2012. Registered patients were given until January 1, 2013 to retrieve and transfer their files to their computers, other PHR vendors, or to their physicians.

Although an exact reasoning or detailed explanation for Google’s decision to discontinue Google Health™ was never given, as such a reason is likely confidential and proprietary in nature, a great deal of speculation and debate continues amongst technical communication scholars and health informatics professionals. Theorizing weaknesses of this system through categorizing a review of relevant literature may help us work to design, develop, and implement better iterations of Google Health™ or other PHR systems.

Literature review

Our goal was to offer a qualitative itemization and categorization of the potential and multi-faceted reasons that the Google Health™ platform underperformed and was discontinued. Moreover, we were more concerned with compiling a master list of addressable causes than with the pedigree of our sources. As such, the review includes scholarly

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