

## Personal Health Care Records

By Frost & Sullivan, A Global Growth Consulting Company



## PERSONAL HEALTH CARE RECORDS

As the Hurricane Katrina disaster demonstrated in 2005, the American health care system and the underlying physical and informational infrastructure that supports it is incredibly fragile. In the aftermath of the hurricane recovery operation, paper-based health records were destroyed and proved quite difficult to reproduce. Of all of the evacuees who moved from New Orleans to a new location, the only group of people who did not experience any major disruptions in receiving care was military service veterans who received their medical care through the Veterans Health Administration (VHA). Any veteran who sought care at a different VHA facility in Houston or Atlanta was able to have his or her medical history, including a list of current pharmacy prescriptions, available to their provider instantly. This example demonstrates the value of having a robust health information infrastructure that captures and stores personal health information electronically.

Electronic Personal Health Records were first widely available in the late 1990s when a number of commercial firms began offering them. This really was the first generation of PHR solutions. Most of these companies were startups or niche companies that were founded primarily due to the large amount of venture capital available during the Dot-Com bubble. These companies usually offered a limited range of PHR solutions and experienced limited success. After the Dot-Com bubble subsided in 2001, most of these firms went bankrupt although a small number continued to survive through mergers and acquisitions. In 2006, there are an increasing number of firms offering PHR solutions to customers through various methods.

Americans are increasingly using digital services in their daily lives and broadband acceptance continues to accelerate. Internet connection speeds, computing power, memory capacity, and home networks are removing the barriers to personal health care records. The technical roadblocks have been surmounted to a large degree. According to a December 2006 survey by the Pew Internet and American Life Project, 65 percent of American adult internet users, about 92 million people, use the internet on an average day. This trend has increased over the past seven years as more than 70 percent of Americans now have access to the Internet at home or through their employer. In addition, about 75 percent of Americans now have a personal computer in their home.

In contrast, personal health information has historically been recorded and stored in a paper-based format. This format has a low initial cost and provides a certain degree of reliability but has some very important limitations. Paper-based records can be difficult to access, time-consuming to update, and impossible to share. In addition, paper-based records are generally not very secure and quite vulnerable to destruction. As a way to overcome some of these deficiencies, there has been a great emphasis on the adoption of electronic health records (EHRs).

The U.S. health care system is lagging behind in the investment and deployment of health information technology (HIT) compared to other select Organization for Economic Cooperation and Development (OECD) countries. Other OECD countries have already begun making substantial investments in HIT, although the scope and type of systems vary widely. In addition, the United States did not have a central authority to coordinate HIT efforts until April 2004 when the Office of the National Coordinator for Health Information Technology (ONCHIT) was established.

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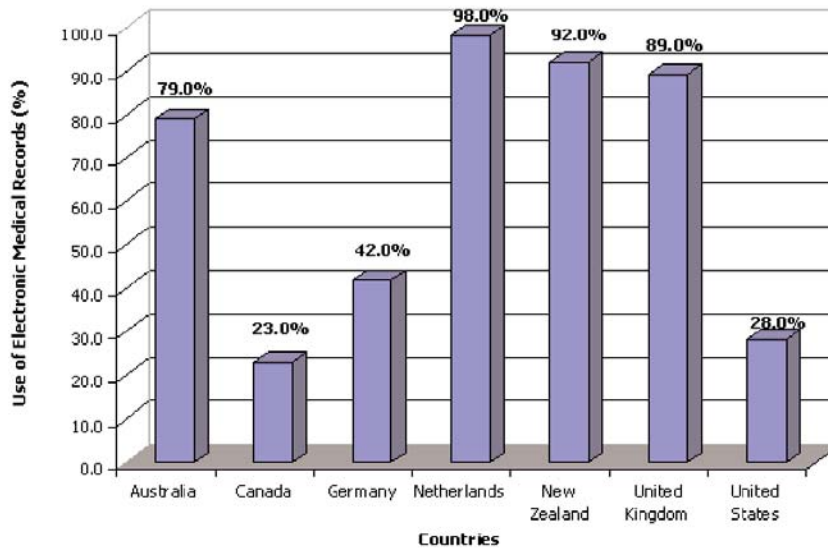
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Chart 2.2

Personal Health Records (PHR) Market:  
Primary Care Physicians Use of Electronic Medical Records (World), 2006



Source: Frost & Sullivan based on information from The Commonwealth Fund

A 2006 survey by the Commonwealth Fund highlighted some key differences in HIT adoption rates among six OECD nations such as Australia, the Netherlands, New Zealand, United Kingdom, Canada, and the United States. The Commonwealth Fund survey did not present any specific information on the adoption or usage of personal health records (PHRs) but did report on the usage of electronic medical records (EMRs) by primary care physicians. Only 28 percent of primary care physicians in the United States reported that they utilized an EMR system. This is in contrast to 98 percent of primary care physicians in the Netherlands and 89 percent of physicians in the U.K. Only primary care physicians in Canada reported a lower percentage of 23 percent than the U.S.

All six countries reported that integrating and coordinating care represented a challenge, yet there were some responses that highlighted where the U.S. really lags behind. Forty percent of primary care physicians in the United States reported that records and clinical information were often or sometimes not available at the time of an appointment. Only physicians in Canada reported a higher percentage (42 percent). Furthermore, only 33 percent of U.S. physicians reported that they received information back after referring a patient to another physician or specialist. This percentage was dramatically lower than in any other country. The closest was the Netherlands which was 61 percent.

In the United States, both PHRs and EMRs are both elements of EHRs. This view contrasts slightly with other countries where there is no real effort to make a distinction between a PHR and an EHR. For example, in Australia, there is no separate definition for a PHR. A PHR is just considered part of any shared EHR. In the U.S., EMRs have been the focus of a lot of attention from both the government and the private sector. Widespread interest in PHRs is just starting to emerge.

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## Definitions for Personal Health Care Records

Currently, there is some confusion regarding EMRs, PHRs, and EHRs. In the United States, PHRs and EMRs are both considered to be elements of EHRs. The EHR represents the ability to easily share medical information among various stakeholders and to have a patient's information accompany him or her through the various modalities of care engaged by that individual. The EHR contains patient input across episodes of care and across multiple health care systems. In an EHR, the patient controls access to the information as opposed to the EMR where the provider controls access. EHRs are proposed by the government to be part of the national health information network (NHIN).

EMRs are a more clearly defined concept than a PHR. An EMR is the legal record created in hospitals and ambulatory environments that is the principal source of data for the EHR. A fully functioning EMR is described as one that includes a clinical data repository, controlled medical vocabulary, computerized provider order entry, clinical documentation or charting, pharmacy management, electronic medication administration record, major ancillary systems (for example, laboratory, diagnostic imaging, cardiology, and so on.) and picture archive and communication systems (PACS).

PHRs are still an evolving concept and there is no accepted universal definition of a PHR in the market or government. The key features of a PHR are that it is under the control of the patient or customer and that at least some portion of the information that it contains has been entered by the patient or customer. The biggest confusion lies in the fact that some health care stakeholders believe that a PHR must be separate from an EHR if it is to meet the requirements of patient ownership and enable patients or consumers to create, enter, maintain, and retrieve data; however, this is not entirely necessary. This is because a PHR can have exactly the same type of record architecture as an EHR and still meet the aforementioned requirements of a PHR.

This lack of consensus around a PHR definition makes it difficult to coordinate the efforts around sharing data among PHRs and defining what data elements should be included in a PHR. Two PHR definitions or models that have attracted a lot of attention are the Markle Foundation and the American Health Information Management Association (AHIMA).

The Markle Foundation's 'Connecting for Health' collaborative is a public-private endeavor that is working toward establishing an interoperable health information infrastructure for the U.S. health care system. The Markle Foundation advocates for a networked PHR solution that is defined as:

*'An electronic application through which individuals can access, manage, and share their health information and that of others for whom they are authorized, in a private, secure, and confidential environment.'*

Perhaps, the most widely-acknowledged definition of a PHR is from the American Health Information Management Association (AHIMA). AHIMA PHR's definition is:

*'The personal health record is an electronic, universally available, lifelong resource of health information needed by individuals to make health decisions. Individuals own and manage the information in the PHR, which comes from health care providers and the individual. The PHR is maintained in a secure and private environment, with the individual determining rights of access. The PHR is separate from and does not replace the legal record of any provider.'*

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Finally, HL7, an accredited standards development organization that creates standards for the exchange, management, and integration of health information in the clinical and administrative domains, established a PHR working group in 2004. This working group has not attempted to develop a definition of a full PHR. Instead, this working group reviewed existing definitions and it is working on developing a list of glossary terms for PHRs (For example, authorized PHR user) to help draw clear distinctions.

Generally, there are slight variations between all of the current PHR definitions but the most critical aspects are patient or customer ownership of the record and his or her ability to access and update the information.

In June 2004, the HHS issued a major report, “The Decade of Health Information Technology: Delivering Consumer-centric and Information-rich Health Care, Framework for Strategic Action,” which outlined the framework for private and public collaboration along four principal goals.

Goal 3 calls for personalized care with consumer-based health records and better information for consumers. One of the strategies to achieve this goal calls for the creation and use of PHRs. The American Health Information Community (AHIC), a 17-member advisory group, was formed by HHS in October 2005 to further these goals and help direct the country’s HIT efforts. AHIC has formed four work groups that correspond to the four goals outlined in the HHS’s Framework for Strategic Action report. The AHIC Consumer Employment workgroup was formed to help achieve Goal 3. Since they first meet in March 2006, the AHIC Consumer Employment workgroup has helped to coordinate the private sector and federal government efforts around PHRs by holding a series of monthly meetings.

A number of federal agencies are also pursuing efforts to integrate or utilize PHRs. Both the VHA and the Department of Defense’s TRICARE program currently have PHR solutions available to their members. The VHA’s PHR tool, MyHealtheVet, will soon be linked to a veteran’s EMR. The PHR has been popular, as indicated by the more than 284,000 registered users who have access to the portal’s full range of features, and the more than 7.5 million total visits to MyHealtheVet since it was launched on November 11, 2003. The Center for Medicare and Medicaid Services (CMS) is also interested in PHRs for Medicare beneficiaries. Recently, CMS awarded contracts to ViPS and Capstone Government Solutions to test the feasibility of populating clinical information in PHRs from Medicare claims files. The two companies are also expected to examine the security and privacy issues associated with the creation of Medicare PHRs. CMS is also planning a series of pilots for 2007 to provide the necessary elements for automated enrollment and use of a pre-populated Medicare PHR.

**Offering a PHR Solution to Consumers as Part of an Organization’s Competitive Strategy**  
While overall customer awareness of PHRs remains low, surveys show that customers generally support having electronic access to their personal health information. Organizations that are currently offering a PHR solution to their constituency view this as a key part of their competitive strategy although for slightly different reasons. Health care providers (For example, hospitals, medical groups, and so on) and health insurers are offering a PHR solution as a way to differentiate themselves from their competitors. Health care providers are looking to provide their patients with convenient access to specific

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information and services. They are also looking to improve quality and safety through avoiding duplicate tests and adverse events for prescriptions. Health insurers have a similar focus for offering a PHR solution to their customers in the hopes of improving customer service and providing additional information and education.

Employers have a slightly different reason for offering a PHR solution. They also hope to increase employee satisfaction and improve workforce productivity and reduce sick days. As different organizations increasingly offer a PHR solution to their constituency, it will become more critical for an organization to offer a PHR solution to their constituency even if the value of such a solution remains limited.

### **Gradual Transition of the Patient from a Passive to an Active Role in the Care Process**

Traditionally in health care, the doctor-patient relationship has been one of paternalism. Patients were expected to abide by a physician's diagnosis and treatment regimen for a medical ailment. There was little room for a patient to present additional information or discuss potential treatment alternatives. Baby Boomers and younger Americans are challenging this model by being more proactive in the care process.

The principal manner in which Baby Boomers and younger Americans are changing the doctor-patient relationship is by becoming more educated about their medical conditions. They search for health information on the Internet in overwhelming numbers. According to a 2005 survey by the Pew Internet and American Life Project, over 8 in 10 Americans (82 percent of Americans aged 50-64 and 81 percent of Americans aged 30-49) with Internet access looked online for information on at least one of 16 health topics. Besides looking for information on a specific medical procedure or condition, Americans are also gradually increasingly using the Internet to look up information on their health insurance and on a particular doctor or hospital.

As consumers increasingly gather more and more information, it is likely they will look for a solution to help them store, organize, and prioritize their personal healthcare information. As more consumers take advantage of a digital lifestyle, this will create an opportunity for PHR solutions if they are positioned to meet the consumer's needs.

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