

As we entered the new millennium, banking and financial services often were highlighted as models for transforming healthcare. These models have continued to evolve and offer insights for consumer-centered healthcare services. As the automatic teller machine has transformed retail banking, the personal health record (PHR) will be used to build new relationships and new structures that support consumers. For individuals working to improve their health and manage their care, PHRs will reach across time and into every setting, from their homes and offices, to their physicians' office and the hospital. More than seven in ten Americans (72 percent) are eager for the new functionalities PHRs offer.<sup>1</sup> Much of the early work on PHRs has been done by the Markle Foundation, which funds and directs the collaborative known as Connecting for Health and the Personal Health Technology Initiative. According to Zoë Baird, president of the Markle Foundation, "Americans use digital

information technology to manage their finances, pay bills, book flights, and customize the music they listen to, and...they now want to use health information technology to get the best care possible for themselves and be better able to manage their own health.... People realize that if they or those they love are in an accident or disaster, having their medical records available at a moment's notice through secure electronic information exchange could mean the difference between life and death."<sup>2</sup> At the same time, the California HealthCare Foundation, an independent philanthropy, reports that nearly three out of four Americans express significant concerns about the privacy and confidentiality of their personal health information.<sup>3</sup> Clearly, failing to address privacy issues could have major implications for PHRs and efforts to transform healthcare nationwide. Yet 59 percent of those respondents stated they would be willing to share their personal health information when it could result in better medical treatment.<sup>4</sup>

Transformation of any sector requires investment, but can yield benefits. The ATMs transformed how consumers bank and interact with banks. Retail Banking Research Ltd. put the cost at more than \$40 billion to purchase the machines and many times that amount to maintain them.<sup>5</sup> To maximize this investment, the banking industry is creating new services that enable consumers to pay traffic tickets and child support via ATM and employers to issue "plastic paychecks."<sup>6</sup> Originally developed to give consumers access to cash, the ATM has become the leading edge of a movement toward online banking and away from paper checks and paper money. The emergence of interoperable electronic medical records across the country stands to build on this readiness and transform healthcare, at not inconsiderable costs. According to estimates from the RAND Health Information Technology Project, the cost of adoption for the next 15 years totals an average of \$6.5 billion per year for hospitals and \$1.1 billion for physician offices, while combined potential savings reach \$142 billion to \$371 billion, or \$9.5 billion to \$24.7 billion annually.<sup>7</sup> That said, the study authors note that "providers must absorb the costs of EMR systems, but consumers and payers are the most likely to reap the savings" and suggest that "the efficiencies will be used to improve quality rather than to reduce costs."<sup>8</sup> Even so, decisions in healthcare are rarely made according to bottom-line economics alone. James Walker, chief medical information officer at Geisinger Health System, observed that, "We have enough estimates. To enable providers and payers to make serious commitments to implementing EMRs, we need real-world demonstrations of how commercially available EMRs can support improved care processes cost-effectively."<sup>9</sup> Moreover, policymakers need to provide incentives and support services, especially for solo and small group practices, "where more than two-thirds of U.S. physicians work."<sup>10</sup> Healthcare consumers "want their experiences to mirror their expectations as consumers in other areas of their life," and they want "more involvement in deciding what healthcare they want to receive and how they want it delivered."<sup>11</sup> As a panel of U.S. business leaders concluded, consumers "are ready for change as they increasingly seek more healthcare information and choices....and would be the ultimate beneficiaries of health information technology

and the resultant transformation of America's healthcare system, as they have been for previous technological revolutions."<sup>12</sup> In 2004, one in three U.S. residents, or eight in 10 Internet users, went online to find information about a medical problem.<sup>13</sup> In 2005, nine out of 10 who went online for health information confirmed that they had successful searches and found reliable information.<sup>14</sup> They reported finding answers to health-related questions such as diet and fitness (51 percent and 42 percent).<sup>15</sup> Consumers also made growing use of self-management tools, from home surveillance systems to decision support aids, to "manage their health issues outside formal medical institutions."<sup>16</sup> Clearly, consumers in what has been called the "iPod generation" are receptive to using "digital tools,"<sup>17</sup> with revenues for home and portable peripherals expected to reach more than \$2.5 billion in 2005 and annual sales expected to grow at a rate of 8.5 percent.<sup>18</sup> In 2005, nearly three quarters (72 percent) of Americans favored the establishment of a nationwide electronic information exchange.<sup>19</sup> Four in five indicated that, if physicians kept electronic medical records on their patients, healthcare quality would improve and medical errors would be reduced because physicians would be able to retrieve a patient's complete medical history in a matter of seconds.<sup>20</sup> About four in five (81 percent) also believed that EMRs would enable physicians to determine what treatments work best for different diseases.<sup>21</sup>

**Diverse Banking Models** In 2000, Ramsaroop and Ball described the concept of the individual "banking on health," using PHRs in the same way as one would use a personal bank or credit cards to withdraw and deposit information at ATMs. The PHR would give consumers worldwide access to a secure vault for storage, account updates, and services.<sup>22,23</sup> Ramsaroop and Ball suggested that the e-commerce model then evolving in banking "provides multiple applications for both consumers and institutions and lays the groundwork for the formation of alliances with providers of other types of services, such as healthcare."<sup>24</sup> Significantly, they noted that PHRs "would not replace the physician's or the institution's records; rather, they would function as personal records that consumers could control and share, all or in part, with whom they choose, and when, where, and how they choose."<sup>25</sup> Their Bank-of-Health concept went beyond "static information consolidation" to support a wide array of consumer services, such as "electronic verification of immunizations and physical exam summary information," within "a highly sophisticated network" potentially capable of providing consumers with a "one-stop-shopping" business model.<sup>26</sup> Three more recent models for health record banking exemplify the diversity of thought regarding the use of banking systems for assembling and protecting the personal health record. These include Shabo's non-centric Independent Health Records Bank, Yasnoff's eHealthTrust, and Gold's Health Record Bank. Shabo presents a non-centric Independent Health Records Bank system, one in which lifelong medical records are deposited and maintained in independent repositories mandated through legislation.<sup>27</sup> The key to Shabo's concept is the shift from each provider being responsible for the storage and maintenance of their portion of the healthcare consumer's records to an IHRB that will be legally responsible to gather and warehouse all providers' records, as shown in Figure 1. Multiple competing IHRBs will be owned privately and independently of healthcare providers, health insurers, government agencies, and health consumers, thus avoiding conflicts of interest. Shabo's model is neither "government-centric," because it does not focus on national repositories for citizen EHRs, nor "provider-centric," because provider records are forwarded to external custody, nor "consumer-centric," because patients do not own or maintain copies of their own records. This model concentrates on the "objective and independent service of sustaining individual EHRs, much like financial banks are perceived with regard to certain financial assets."<sup>28</sup> It also solves the need for a nationwide unique patient identifier, which poses privacy concerns in countries such as the United States. eHealthTrust, Yasnoff's proposed central repository for patient information, will be paid for and controlled by the consumer, as shown in Figure 2. Financial incentives, paid for by the consumer, will reimburse the provider for the use of a standard electronic record for each patient encounter. Because HIPAA

regulations require holders of patient data to make this information available to the consumer upon request, the additional financial motivation given the physician will help make this system sustainable. Patient access and control of the data remain key elements to this model, as does physician incentives to utilize an electronic health record and comply with use of a standard form.<sup>29</sup> In contrast with the previous models, Gold envisions a Health Record Bank that will enable the consumer to store all personal health information in a secure virtual “account,” or PHR, and possibly, similar to a financial bank, could pay its owner a dividend for this with appropriate permissions from all concerned.<sup>30</sup> As shown in Figure 3, the HRB will include information from a wide range of healthcare sources, along with that added by the consumer, such as treatment directives and living wills. These records, or PHRs, will be owned and controlled by the consumer, who will direct who has access to which parts of the record over what period of time, and who can deposit information in the record. With the consumer’s permission, the HRB can lease access to de-identified data in databanks for use by pharmaceutical and medical technology companies, insurance companies, research institutions, universities, and government agencies. Through its Bank Association Data Exchange, possibly a division of a RHIO, a consumer’s leased de-identified health data could be released according to prearranged agreements to provide a dividend to its owner. Legislation, similar to that governing financial banking institutions, will define consumer and bank controls, establish regulatory committees, and protect the consumer against loss, as the Federal Deposit Insurance Corporation does for financial accounts. These models propose systems in which individual consumers place their health information in a bank that is part of a larger networked system. Critical issues common to all health record bank models are the standardization of data entry and sharing interoperability, stakeholder acceptance, medico-legal definitions and legal mandate, information security, HIPAA standards for privacy and confidentiality, accountability and auditability, business incentives and considerations, and operating speeds. Thus, these concepts map to the PHRs and regional health information organizations that we are focusing on.

**PHR Definitions** In *Connecting Americans to Their Healthcare*, the Markle Foundation defines the PHR as “an electronic application through which individuals can access, manage and share, their health information in a secure and confidential environment. It allows people to access and coordinate their lifelong health information and make appropriate parts of it available to those who need it.”<sup>31</sup> Thus, it differs from the EHR, which is “an electronic version of the patient medical record kept by physicians and hospitals. The data in the EHR are controlled by and intended for use by medical providers.”<sup>32</sup> Another attempt at definition, by HIMSS Analytics, uses the older term, EMR, to refer to the legal record owned and used by the healthcare facility to document and manage encounters, refers to the record shared across institutions as the EHR and makes no mention of the PHR as such.<sup>33</sup> During the transition to a national health information network, it may be helpful to define three interdependent entities. Within this construct, the EMR is the basic building block, the source of information that feeds the EHR; the EHR is the longitudinal record made possible by RHIOs and interoperability across care delivery organizations; and the PHR is the record owned, accessed, and managed by the consumer. The interdependencies are clear. Without linkages to the EMR, the PHR depends on the consumer to manually input vital data, like laboratory results. Without an EHR, the PHR cannot accept information from multiple providers. In short, the PHR belongs in the domain of the individual, while the EHR is in the domain of the provider. The EMR is the legal health record in the domain of the provider. It is important to note that, as a standalone accounting of personal health information, the PHR has limited value; as an interactive account with the healthcare system as a whole, it offers a wide array of benefits. Ultimately, the PHR and the environment that supports it can transform healthcare to the patient-centered model advocated by the Institute of Medicine. The PHR is further defined by the information it contains, something that discussions of the electronically enabled PHR, the focus of this paper, do not generally address. The American Health

Information Management Association (AHIMA) characterizes the PHR as “a collection of important information about your health or the health of someone you’re caring for, such as a parent or a child, that you actively maintain and update.”<sup>34</sup> AHIMA details what that information should include, regardless of the record’s medium, as shown in Table 1.<sup>35</sup> The 2003 report of the Markle Foundation’s Personal Health Working Group identified attributes common to the different forms of the PHR. In short, the PHR is a lifelong and comprehensive record, controlled by the individual, accessible anywhere and anytime; private and secure, it facilitates information exchange across the healthcare system; transparent, it enables the individual owner to see who has entered and viewed data.<sup>36</sup> The report defined the PHR as an enabler that “connects each of us to the incredible potential of modern healthcare” while it “gives us control over our own information.” According to the report, the PHR provides an integrated and comprehensive view of information, “self-generated as well as from physicians, pharmacies, and insurance companies,” and serves as a communications hub that can be used to e-mail physicians, transfer information to specialists, receive test results, and access educational and decision support tools.<sup>37</sup> In 2005, the Markle Foundation’s 44-member Personal Health Technology Council, including “leading consumer and privacy advocates, medical professionals, informatics experts, payers, technologists, federal policymakers, bioethicists, and researchers,” endorsed seven patient and consumer principles. Framed to guide the development of electronic information exchange in the public and private sectors, these principles reflect critical issues associated with the evolution and acceptance of interoperable PHRs.<sup>38</sup>

Principle 1. “Individuals should be able to access their health and medical data conveniently and affordably.” As to access, the report, “Consumers in Health Care: The Burden of Choice” documents that American consumers want to be more involved in their healthcare. Nine out of 10 want to be an active and involved partner with their physician (Hart Research 2004). More than half (52 percent) want to make final treatment decisions for themselves or a family member, and 38 percent want to make those decisions together with their physician (Rand 2005).<sup>39</sup> Convenience and affordability are other matters. Studies cited in The Burden of Choice document notable differences related to age, gender, education, economic status, and ethnicity.<sup>40</sup> Older Americans are less likely to go online (Kaiser 2004), as are households with lower incomes, lower educational levels, and less Internet experience (Pew 2005). Principle 2. “Individuals should be able to authorize when and with whom their health data is shared. Individuals should be able to refuse to make their health data available for sharing by opting out of nationwide information exchange.” Six out of 10 (59 percent) consumers view their PHRs as information they can choose to share in exchange for some benefits (such as access to care or discounts); around half (53 percent) regard their PHRs as information they own and have a duty to share to advance healthcare or as information they own and control (49 percent).<sup>41</sup>

Enabling individuals to opt out of nationwide information exchange addresses opposition to a mandatory, providing telehealth capabilities, with six major hospitals serving as hubs and stakeholders planning for electronic health data exchange.

- PeaceHealth, an integrated delivery network in the Pacific Northwest, serving Oregon, Washington, and Alaska, offering technology services and access to a comprehensive community health record. As its first case study, the white paper<sup>1</sup> presents HealthBridge as an example of collaboration, not boundaries. Launched in the mid-1990s by large employers in the area in an attempt to control costs, HealthBridge is an independent not-for-profit corporation, with providers and payers represented on the governing board. Founded with seed money from stakeholders, it was intended to sustain itself from revenues. Results delivery service now funds all of its projects, and provider organizations save money by participating. For example, St. Elizabeth Medical Center estimates that having HealthBridge deliver diagnostic test results saves \$500,000 per year and reduces phone calls for results by 40 percent. HealthBridge offers a single standard community interface; more than 50 clinical applications are available on its password-protected portal, which currently runs at around 46,000 information requests per month

from approximately 4,000 active physicians. As its second case study, the white paper described PeaceHealth as “managing the health of an entire community.” Launched in the early 1990s to connect six community hospitals, outpatient medical groups, regional laboratories, and pharmacies, this not-for-profit corporation serves medium-sized and rural communities. PeaceHealth serves the 340 physicians employed at its ambulatory clinics and 1,700 independent physicians through a community health record used in both inpatient and outpatient settings. Since 1996, when the CHR went live, PeaceHealth has collected records for 1.5 million individuals, creating a data warehouse that populates data marts focused on chronic diseases that can be searched in a matter of seconds. This capability was used in 2004, when Vioxx was recalled, to identify patients who had been prescribed the drug. The third study looks at CalRHIO’s efforts toward “building a business model for health information exchange” in the nation’s most populous state. Fewer than 10 percent of the state’s physicians and 25 percent of its hospitals have functioning EMRs. Begun as a project of the Health Technology Center in January 2005 and slated to become an independent not-for-profit in January 2006, CalRHIO first inventoried health information exchange projects in the state and now is developing a list of recommended standards for providers. Providers, payers and other stakeholders from more than 60 health-related organizations are involved in CalRHIO working groups. Based on stakeholder input, CalRHIO has selected five projects: emergency department linking, infrastructure, administrative efficiencies, medication management, and personal health records. It seeks to provide leadership and foster incremental change. The fourth case study reviews the Indiana Network for Patient Care and “the interface between technology and policy.” Now about a decade old, it was created to serve as an operational community-wide patient record system. A joint project of the Indiana Health Information Exchange and the Regenstrief Institute, the network demonstrates the feasibility and benefits of a community-wide electronic health record system. It includes 21 hospitals in five major hospital systems and serves as a referral center for the entire state. Its architecture is that of a federated consistent database; data are received primarily as HL7 messages and then standardized according to rigorous requirements. The INPC database contains 7 million registration events, 48 million orders, 45 million radiology images with 8.8 million radiology reports, and 25 million prescriptions. The system is accessed more than 3 million times a year, and peak usage exceeds 10,000 hits per hour. According to an economic model developed by the Center for Information Technology Leadership, savings for central Indiana could potentially reach \$560 million. The fifth model described in the white paper is the Nebraska Statewide Telehealth Network, exemplifying “strong partnerships delivering a statewide health information infrastructure.” In a public-private partnership, providers own the Telehealth Network and the state government maintains the technical infrastructure. By the end of 2005, 95 percent of its connections were live. Rural hospitals pay \$100 a month to access videoconferencing. The network plans to build on this culture of collaboration, possibly by using the existing network to transmit patient data, such as diagnostic test results and images, and by supporting broader adoption of EHRs. In addition, the program SimplyWell, a combination of PHRs and disease prevention developed at the Nebraska Medical Center, makes patients “their own health manager.” Based on claims reductions so far, SimplyWell could potentially reduce costs by 20 percent. These five case studies describe exemplars of solutions to barriers in the areas of financing, health management, privacy and security, technical infrastructure, and cultural change. PHR Working Models Like RHIOs, PHRs come in a multitude of forms and are developed by different entities with different philosophies to meet different needs. These differences are reflected in their PHRs, which are working models that are in place today. For these reasons, they do not fully reflect the health record banking models set forth by Shabo, Yasnoff, and Gold, which are conceptually dependent upon the capabilities provided by RHIOs. One PHR model is that of the Veterans Health Administration’s MyHealtheVet. Its power was demonstrated in the aftermath of Hurricane Katrina, when physicians and patients throughout southeast Louisiana,

Mississippi, and the Florida panhandle struggled without access to paper patient records, and more than the 38,000 veterans and their physicians did not.<sup>55</sup> VA physicians and patients had “access to information those outside the VA are dreaming of: up to 20 years of lab results and six years’ worth of X-rays, scans, physicians’ notes, and medication records.”<sup>56</sup> After logging in at the VA’s portal, [www.myhealthvet.va.gov](http://www.myhealthvet.va.gov), registered users have access to information in their own accounts, which includes details on benefits and services, health information, and a health assessment tool. Functions include access to a personal health journal, which includes demographics, contact information, provider names, and more; Health eLogs to record blood sugar, blood pressure, pain levels, and other information; and room for self-entered information such as military history and drug records for prescriptions, over-the-counter medications, and herbal preparations. Veterans can use their PHRs to arrange for prescription refills online, create a family health history, and print wallet-sized identification cards. In late 2005, for My HealtheVet’s second anniversary, the VA released three new health journals to help veterans monitor their health. These include a Food Journal for recording daily food intake, an Activity Journal, to record daily exercise routines, and Pulse Oximetry to help monitor the usefulness of oxygen therapy. Help features include a virtual tour, My Care, explaining important tools and features. According to Jonathan Perlin, MD, the acting undersecretary for health at the VA, MyHealtheVet “recognizes a person has interests in how his care is managed”<sup>57</sup> and is “available 100 percent of the time for 100 percent of the VA patients.”<sup>58</sup> There are several models of PHRs in the private sector, including those put in place by healthcare institutions to better serve their patients. One that has received significant attention is PatientSite. Launched in 2000 by CareGroup information systems and Beth Israel Deaconess Medical Center, PatientSite provides patients with services, education, and their own PHR. Enrollment reached 11,000 patients and included 120 physician users in 40 practices as of February 2003.<sup>59</sup> Available at <http://www.patientsite.org>, the PHR offers services, such as e-mail, prescriptions, appointments, referrals, links and account statements; records and a personal profile; and help features. When registered users sign on, they see a list of appointments, providers, and e-mail. The success of PatientSite has introduced controversial and interesting issues. According to Sands and Halamka, these include, “Should patients have full electronic access to their record, or should certain types of data be restricted? Is it necessary for physicians to review results before patients can view them? Should patients be permitted to use PatientSite to view their record if their physician does not use PatientSite? What happens to patient-entered information in the personal health record? Should physicians be able to view the patient’s personal health record? Should they be required to do so?”<sup>60</sup> Two institutions in the private sector are among the early leaders in installing vendor-developed PHRs. (For a partial listing of these vendors, see Table 2.) Cleveland Clinic offers the PHR developed by Epic Systems at eCleveland Clinic MyChart at <https://mychart.clevelandclinic.org>. Adult patients of primary care physicians can review past appointments, manage prescription renewals, make or cancel appointments, and access reliable health information on topics that interest them. Using the PHR developed by Cerner, IQHealth, Winona Health Online offers “consumer patients” who register a personal health profile, health assessment, online prescription refills, drug information, and the ability to receive lab and test results through secure messaging. According to [www.winonahealth.org](http://www.winonahealth.org), “This free service allows you to actively manage your own health and the health of your loved ones,” and it is “a secure site...safer than online banking or as safe as using your ATM card.” Another PHR model is payer-based, not institution-based, made available to employees on their employer’s or health plan’s Web site. A major force in the commercial sector, WebMD’s PHR also attracts unique visitors to [www.webmd.com](http://www.webmd.com) every month, promising even greater PHR access.<sup>61</sup> The current version of WebMD’s PHR offers services, including personalized health and benefit information, benefit and treatment decision support, and targeted clinical messages. It integrates self-reported and professional data, including medical and medication claims, to create a

complete profile of health history and health status. Corporations now offering WebMD's PHR to their employees include IBM, Verizon, Intel, Pepsi-Co, and Ford<sup>62</sup> among many others. The extent of activity within the healthcare industry is reflected by the number of PHR vendors. In November 2005, HIMSS Executive Vice President Carla Smith offered a list of more than 30 PHRs currently available, as a snapshot in time, with the caveat that the list is incomplete (see Table 2).<sup>63</sup> Clarifying the Vision Work being done under NHIN contract is expected to clarify how the PHR will evolve and operate. At this time, use cases are being developed in biosurveillance, the electronic health record, and consumer empowerment, identified in 2005 as "breakthrough areas" by the Health and Human Services' American Health Information Community. Currently, the Office of the National Coordinator, David Brailer, MD, PhD, is completing the "harmonization" of input from the four NHIN consortia—IBM, Accenture, CSC, and Northrup Grumman—and three other working groups representing clinicians and clinical practices. The use cases addressing consumer empowerment will guide efforts to involve consumers in actively managing their own healthcare. Focused on the short term, these will set forth first steps and lay the framework for gaining wide adoption of consumer-centric PHRs that are easy to use, portable, longitudinal, and affordable. This framework will specify policies and mechanisms involved in such areas as consumer and physician access and business functionalities. It also will identify obstacles and necessary conditions. A Time for Transformation

The vignettes in the new report, *Ending the Document Game*, highlight the experiences of patients coping with chronic conditions and terminal diagnoses, along with statements from physicians, dentists, pharmacists, and nurses. All point to the need for transformation. As the Commission on Systemic Interoperability drives home in *Ending the Document Game: Connecting and Transforming Your Healthcare Through Information Technology*, "There is no single step that, if taken, would create a connected nationwide system of health information."<sup>64</sup> Rather, there are multiple steps, which the commission, a federal health information technology initiative, organizes into three categories: adoption, interoperability, and connectivity. PHRs and other extensive transformational changes, like the use of health record banks and RHIOs, have multiple success factors. These include the establishment of a NHIN, re-education of the public, attention to the security and privacy of health information, the willingness to change the way practitioners work in healthcare, and still others not touched upon here. Change is not an easy task, but the use of models, like those summarized in this article, can help facilitate the process. Adoption requires public awareness. For the healthcare technology and informatics community, this means making the benefits of networked interoperable PHRs apparent to consumers and clinicians. Consumers are concerned about the healthcare that they and their families need, not about technical features. Clinicians are focused on delivering care, not on acquiring or using electronic record systems, which are in place in only 15 percent to 20 percent of physicians' offices<sup>65</sup> and in only 20 percent to 25 percent of hospitals in the U.S.<sup>66</sup> Consumers using PHRs in an environment supported by RHIOs will bring "high expectations to healthcare relationships. These expectations can improve the way the system interacts with the patient and the way care is delivered."<sup>67</sup> As Ball and Costin state in their contribution to the 2006 HIMSS proceedings, "As a standalone accounting of personal health information, the PHR has little value; as an interactive account with the healthcare system as a whole, it offers a wide array of benefits."<sup>68</sup> Just as personal ATMs derive their utility from their interface with the world of banking and financial services, so too will PHRs realize their potential when they are part of a health information network that spans the whole of healthcare. Only then will healthcare become truly patient-centered.

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