

Personal Health Records: Empowering Consumers

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A B S T R A C T

By empowering consumers, electronic personal health records (ePHRs, more commonly PHRs) will play a key role in the evolving electronically enabled health information environment. Consumers want to be more engaged in their own healthcare and are seeking out information online. Despite intense concerns about confidentiality and security, they have high expectations for electronic health information. The growth of patient self-management tools for remote monitoring will fuel PHR adoption, if tools and standards are developed that make clinical information understandable to and usable by consumers. The value of the PHR will lie in shared information and shared decision-making, as its components support the continuity of care. Efforts in other countries can provide guidance in helping Americans do what they do best—develop and use innovative technology to serve the American people.

K E Y W O R D S

- Personal health records
- Consumer informatics
- Patient empowerment
- Nationwide health information network
- Healthcare transformation
- Electronic health records

By the end of 2005, electronic personal health records had joined electronic health records as a hot topic for the healthcare industry. The fall of 2005 saw a national conference on the PHR¹, several major surveys² on related topics and special reports from key PHR advocacy groups^{3,4}. This activity has advanced the understanding of the PHR and its role in consumer empowerment, and the results are cited later in a discussion of the evolving health information environment and consumer information seeking behaviors,

privacy concerns and expectations that underpin progress toward the PHR.

As an enabling technology, the electronic PHR enables consumers to become actively engaged in their own healthcare and bring “high expectations into healthcare relationships...[that] can improve the way the system interacts with the patient and the way care is delivered.”⁵ As noted elsewhere,⁶ “It is in these interactions that the potential for better quality and improved outcomes lies.... Neither

innovation nor consumer autonomy is 'more important than a relationship with a trusted physician.'⁷

The PHR will transform the physician-patient relationship by empowering the patient to play "an increasingly central role," as envisioned by a national consensus conference held in 2003.⁸ However, the PHR will have a more profound impact on healthcare, much as the stethoscope did two centuries earlier.⁹ As Neil Postman explains in *Technopoly: The Surrender of Culture to Technology* (1992),¹⁰ the stethoscope promoted two key ideas: "Medicine is about disease, not the patient. And what the patient knows is untrustworthy; what the machine knows is reliable." Postman quotes Stanley Joel Reiser to this effect: "The physician in the last two centuries has gradually relinquished his unsatisfactory attachment to subjective evidence—what the patient says—only to substitute a devotion to technological evidence—what the machine says. He has thus exchanged one partial view of disease for another."¹¹

Ultimately, the PHR has the potential to create a more complete and balanced view of the patient. Because it is owned, controlled and managed by the patient, the PHR puts patients back at the center of the healthcare process, where physicians can view them directly rather than through what Reiser calls "a screen of machines and specialists."

A recent Commonwealth Fund survey in Australia, Canada, Germany, New Zealand, the United Kingdom and the United States studied patients' perceptions of the care provided by their physicians. Across the indicators of patient-centeredness (in the four areas of communication, choice and continuity, patient engagement and responsiveness to patient preference), the United States ranked last in the six nations surveyed.¹²

According to a national survey, 87 percent of primary care physicians in the United States support the concept of team-based care and 83 percent favor sharing medical records with their patients. In practice, however, many still experience some problems in the transfer of important patient information. Of those surveyed, 74 percent reported these problems involved the availability of patients' medical records, test results or other information at the time of a scheduled visit.¹³ According to the research team, "While physicians favor patient-centered, only 22 percent scored high in incorporating such techniques into their day-to-day practices."¹⁴

Because health information technology has been given such a prominent role in efforts to redesign and transform healthcare, industry players and consumer groups are focusing on electronic PHRs. Granted, the PHR does not have to be electronic. Only 14 percent of physician offices—usually the larger groups—now have electronic medical records.

Engaged patients who maintain paper-based records,

including lists of medications and allergies along with other vital information, can walk into any office with confidence their paper records can be read and understood. That is not the case for the electronic PHR on a disk, CD or memory stick. Even some of their advocates admit they print out copies of their electronic records to take to appointments. Yet the initiative to create an interoperable Nationwide Health Information Network (NHIN) is bringing the electronic PHR front and center.¹⁵

The Evolving Electronic Environment

In *Crossing the Quality Chasm: A New Health System for the 21st Century*,¹⁶ the final report in that groundbreaking series, the Institute of Medicine identified six goals—safety, effectiveness, patient-centeredness, timeliness, efficiency and equity. These goals are guiding the national initiative to adopt electronic health records and build a NHIN.

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As Paul Tang and David Lansky pointed out in *Health Affairs*,¹⁷ "the IOM's (Institute of Medicine's) worthy aims will not be achieved unless we build a system in which patients share information and control with professionals. The mere installation of electronic health records (EHRs), even with comprehensive interoperability, will not sufficiently engage patients in the health system." In their view, PHRs are "the missing link" needed to bridge "the patient-provider health information gap."

A recent white paper published in the *Journal of the American Medical Informatics Association* by Paul Tang and colleagues¹⁸ summarized the findings of a 2005 symposium on the PHR held by American Medical Informatics Association's (AMIA's) College of Medical Informatics. They noted, while all levels of government and the private sector have encouraged EHR adoption in the past few years, PHR systems have not received the same level of attention. However, there was consensus among symposium participants PHRs have the potential "to transform patient-provider relationships, especially when integrated with EHR systems."

Defining the PHR as "health information managed by the individual" and the EHR as "the clinician's record of patient encounter-related information...managed by the clinician or the healthcare institution," AMIA symposium participants envisioned a future "environment in which health information about an individual can flow seamlessly among systems used by authorized health professionals, caregivers and the patient, when the patient authorizes such sharing."

The integration of EHRs and PHRs is implicit in the

1. Individuals should be able to access their health and medical data conveniently and affordably.
2. Individuals should be able to authorize when and with whom their health data are shared. Individuals should be able to refuse to make their health data available for sharing by opting out of nationwide information exchange.
3. Individuals should be able to designate someone else, such as a loved one, to have access to and exercise control over how their records are shared.
4. Individuals should receive easily understood information about all the ways that their health data may be used or shared.
5. Individuals should be able to review which entities have had access to their personal health data.
6. Electronic health data exchanges must protect the integrity, security, privacy, and confidentiality of an individual's information.
7. Independent bodies, accountable to the public, should oversee local and nationwide electronic health data exchanges. No single stakeholder group should dominate these oversight bodies, and consumer representatives selected by their peers should participate as full voting members.

Source: The Markle Foundation, www.markle.org

Table 1. The Seven Patient and Consumer Principles Endorsed by the Markle Foundation's Personal Health Technology Council.

vision of an electronic health information environment that empowers individual patients, consumers and caregivers to take an active role in their healthcare. In October 2005, the Markle Foundation's 43-member Personal Health Technology Council¹⁹ endorsed a set of patient and consumer principles to guide system design "within organizations or networks designed for electronic patient data exchange between healthcare institutions." Realization of these seven principles, shown in Table 1, is predicated on the adoption of PHRs within a robust national health information network that includes EHRs for clinicians and institutions, electronic data exchanges and oversight bodies.

In describing the architectural foundations for MyHealthVet, the PHR of the Veterans Health Administration, James Demetriades²⁰ noted "the goal of empowering individuals to manage their health information and data easily outdistances all other goals," which he identified as the longitudinal composite health record, record accessibility, security and privacy of information and data, and interoperability of records with shared semantic meaning. As a goal, individual empowerment "gives rise to and is intertwined with (these) other key goals," he added.

In September 2005, the federally chartered commission known as the American Health Information Community (AHIC) formed workgroups on biosurveillance, chronic care, EHRs and consumer empowerment. The workgroups were charged with developing recommendations to AHIC that will produce tangible and specific value to the health-care consumer within a two- to three-year period, while preparing the way for long-term transformation.

Working on behalf of the Office of the National Coordinator for Health Information Technology, AHIC identified three categories for potential breakthroughs. The

first of these, consumer empowerment, is defined as helping "individuals manage their healthcare and advocate for themselves as they use healthcare services." The category is further defined as including "My Personal Health Record," "My Medication History," "My Health Record Locator" and "My Registration Information." The second category, health improvement, is focused on physicians and

"American consumers want to have their own electronic personal health records."

hospitals, and the third concentrates on public health protection. With funding from the Department of Health and Human Services, four NHIN vendor consortia were charged with developing prototypes to focus on key issues.

According to Tang and Lansky,²¹ creating PHRs to empower consumers addresses the 10 design rules for the health system of the 21st Century identified by the IOM,²² most specifically the first four—care based on continuous healing relationships; customization based on patients' needs and values; the patient as the source of control; and shared knowledge and the free flow of information.

Surveying Consumers

American consumers want to be more involved in their healthcare.²³ One survey indicated 90 percent want to be an active and involved partner with their physician, while only 9 percent want their physician to manage their care and make decisions for them.²⁴ More than half (52 percent) want to make final treatment decisions for themselves or a family

member, and 38 percent want to make the decision together with their physician.²⁵

In addition, American consumers want to have their own electronic personal health records.^{26, 27} In the fall of 2005, 60 percent of Americans said they favored the creation of a secure online PHR service for their own use. They believed PHRs could improve safety and offer convenience. Some 69 percent of respondents said they would use it to check for mistakes in their medical records, and 68 percent said they would use PHRs to check and fill prescriptions. Another 58 percent said they would use PHRs to get results over the Internet, and 57 percent would turn to PHRs to conduct secure and private e-mail communication with their physicians.

On a national online survey,²⁸ Americans with greater health needs reported highest interest in PHRs. People with chronic illness, frequent healthcare users and people caring for elderly parents had the greatest interest in having PHRs. Of consumers who had not visited the physician in the past year, only 57 percent were interested in PHRs, compared with 66 percent of those with one to six visits and 71 percent of those with seven or more visits. Those with chronic illnesses were more likely to be interested in making immediate use of at least one PHR feature than those without chronic illness (66 percent vs. 58 percent).

Today, a majority of American consumers are online.²⁹ In 2004, 79 percent of Internet users searched online for information on at least one health topic, most often a specific disease or medical problem (66 percent) or a certain medical treatment or procedure (51 percent). However, the information they are seeking is changing. Compared with 2002, they were significantly more likely to search for information about physicians and hospitals (28 percent vs. 21 percent), experimental treatments (23 percent vs. 18 percent), health insurance (31 percent vs. 25 percent), prescription or over-the-counter drugs (40 percent vs. 34 percent), fitness (42 percent vs. 36 percent), and nutrition (51 percent vs. 44 percent).³⁰

A 2004 consumer survey that was not just limited to Internet users reported 51 percent of all adults had looked for health information online at some point in 2004, representing 111 million Americans, a significant increase from 54 million in 1998.³¹ In another 2004 survey, 12 percent had researched health providers' cost or quality online in the previous year.³² Consumer demand for quality measures has continued to grow. A 2006 online survey of 2,123 adults found 47 percent believe it would be "fair" for health plans to measure and compare the quality of medical groups using electronic medical records and other tools, and 69 percent said it would be fair to measure quality using patient satisfaction surveys.³³

A 2005 study of non-elderly commercially insured consumers who visited their health plan's Web site provided details on their use of online decision support tools.³⁴

These consumers used tools to track healthcare expenses (47 percent), estimate costs of common office visits or procedures (43 percent), compare prescription drug costs (43 percent) and compare the cost of different physicians or hospitals (40 percent). In the area of quality, 45 percent used the Web site to research the side effects of prescription drug side effects or compare efficacy; and 42 percent used it to conduct comparisons of physician or hospital quality.

With one in 10 healthcare dollars now spent on prescription drugs,³⁵ the ability to compare and manage those costs is critical for consumers, and, as more seniors increasingly have prescriptions coverage, for healthcare payors. For consumers, this means access to information to guide them in making decisions that affect their health as well as their pocketbook.

Privacy, Confidentiality and Security

Two-thirds of American consumers express serious concerns about the privacy of their personal health information, and 52 percent of all consumers are concerned information they provide to insurers on claims might be seen by an employer and used to limit job opportunities, an increase from 1999, when only 36 percent expressed similar concerns.³⁶ More precisely, in light of the fact consumers already have agreed to share such information, their concerns are about confidentiality, or the ability to control access to information.

Those most concerned about employer misuse of their personal health information are racial and ethnic minorities—61 percent of minorities have this concern, compared with 46 percent of those not in this category—and those with chronic diseases—55 percent of those with chronic conditions said they were concerned about confidentiality, compared with 48 percent of those who do not have a chronic disease.³⁷ Such concerns have led one in eight consumers to ask a physician not to record a problem, go to another physician to avoid telling their regular physician about a condition, personally pay for services such as tests, procedures or counseling rather than submit a claim, or decide not to be tested for fear others would find out the results.

Chronically ill patients are twice as likely to engage in such behaviors,³⁸ yet more than half of chronically ill consumers would likely share their personal health information if doing so could benefit them. Chronically ill patients would share information with physicians not involved in their care for better coordination of medical treatment (60 percent), enhanced coverage/benefits (59 percent), access to experimental treatment (58 percent), for current information on medical developments (54 percent) or financial incentives (52 percent).³⁹

Privacy and confidentiality concerns will affect consumers' choice of media for a PHR.⁴⁰ "It shouldn't be

one-size-fits-all,” Lansky said. “Young people might prefer to keep their PHR online, while others might be concerned about identity theft or hacking and will carry their data on a universal serial bus (USB) key in their pocket. Medicare members, who are older, might feel more comfortable carrying a paper copy of their records.”

However the information is stored and shared, consumers need to understand the Health Insurance Portability and Accountability Act of 1996 (HIPAA) covers only PHRs provided by covered entities, such as health plans, healthcare clearinghouses and healthcare providers who “choose to conduct certain financial and

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administrative transactions electronically.” Determining whether an entity is covered or non-covered can be difficult, as the 12-page Covered Entities Flowchart at www.cms.hhs.gov demonstrates.

Security issues are of some concern to consumers, although seemingly less than privacy. Only 24 percent of consumers were aware of specific incidents compromising the privacy of personal information. Two-thirds of those who were aware, however, reported having heightened concerns.⁴¹

Despite concerns about privacy, American consumers have high expectations for electronic health information. Eight in 10 believe electronic medical records will improve healthcare quality, and six in 10 believe they will reduce medical errors and decrease healthcare costs.⁴² Almost all believe computerization will give physicians and nurses quicker, easier access to patient information (93 percent) and increase communication between hospitals, physicians’ offices or plans (88 percent).⁴³

According to a 2005 privacy survey, almost all Americans are willing to share their personal health information with the physician they see most often, and almost as many (92 percent) are willing to share it with other physicians or professionals involved with their care.⁴⁴ Consumers envision using the PHR to designate others with whom their information can be shared, for example, a husband, wife or partner (90 percent), or close relatives, such as parents or children (87 percent). They are much more reluctant to

share their personal records with their employer (37 percent), other physicians or health professionals not involved in their care (30 percent), drug companies (27 percent) or governmental agencies (20 percent).⁴⁵

Consumers view their personal medical records as information their physicians have a right to use (69 percent) or as information they can choose to share in exchange for some benefits, such as access to care or discounts (59 percent).⁴⁶ Yet somewhat surprisingly, only 49 percent believe personal health information is “information I own,” a view that is foundational to the PHR concept. Still fewer agree it is information researchers (43 percent) or the broader medical community has a right to use (33 percent),⁴⁷ which are activities essential to the public health benefits of the NHIN and, most immediately, to biosurveillance.

Any nationwide information exchange would have to address privacy concerns to win consumer acceptance.⁴⁸ Some 91 percent of consumers place high priority on the system’s ability to confirm the identity of anyone using the system to prevent unauthorized access or mistaken identity, and 81 percent want to be able to personally review who has had access to their personal health information.

Meeting Consumer Needs

Harvard Business School marketing expert Clayton Christensen and colleagues state, “The job, not the customer, is the fundamental unit of analysis.” In their analysis for a fast food chain, “knowing how to improve the product did not come from understanding the ‘typical’ customer. It came from understanding the job.”⁴⁹

In an April 2006 interview on the PHR, David Lansky⁵⁰ observed “we’re seeing the most interest...in products that provide high value to certain groups of people” with specific sets of needs for specific types of services. As an example, he mentioned the consumer with diabetes who uses a blood sugar monitoring device at home and wants a product that “knows how to read that signal and manage it and add value to it.”

The popularity of remote patient monitoring devices is growing, driven in part by increased coverage by insurers.⁵¹ One estimate puts annual sales of such devices at more than \$2.5 billion in 2010, up from \$461 million in 2005.⁵² *The Wall Street Journal*⁵³ reports providers are beginning to use remote devices to offer more efficient care. A \$3,500 vital sign monitor includes a glucometer, a blood pressure cuff, a finger sensor and a video function; Montefiore Medical is using bathroom scales that plug into phone jacks to monitor patients at home with congestive heart disease. Also driven by the demands of aging baby boomers for more convenient care, the use of remote monitoring is likely to increase even more, once the technology is proven clinically and financially effective.⁵⁴

A 2005 study of patient self-management tools character-

izes them as straddling “the healthcare and consumer sectors.”⁵⁵ Designed to be used and owned by consumers in their roles as patients, these devices add the greatest value when they are interfaced to the PHR and the information entered by the patient is interpreted and acted upon by the physician or other clinician in collaboration with the patient. The increasing use of such devices will help fuel PHR adoption.

One potential barrier to PHRs received little attention prior to the 2005 publication of *Lost in Translation* by the California HealthCare Foundation.⁵⁶ This report observed, “Consumers who go online to choose or manage their own care often encounter clinical information and technical jargon that they are unable to decipher because it is presented in a format that reflects the provider’s point of view (diagnosis, treatment and option).”⁵⁷

Making information understandable to consumers is a thorny issue. First, there is no single standard language for health professionals. The Unified Medical Language System developed and maintained by the National Library of Medicine currently lists 143 “dictionaries,” and the nursing profession alone has 13 different terminologies.⁵⁸ With such wide variability in the terminology used by professionals, it is difficult to imagine how to translate health information in ways that consumers—far from a homogenous group—can readily understand.

Although many consumers understand the term “acute lateral wall myocardial infarction” means a heart attack, they would not be familiar with the specific meaning of each word.⁵⁹ Clinicians rely on the granularity of the term in its entirety to diagnose and treat patients, while, “at the same time, patients need everyday language to understand the ramifications of their health condition.”

Although the amount of online health information for non-healthcare professionals has grown during the past few years to cover a wide range of topics, it tends to be general information focused on particular diseases or diagnoses. Because it is not patient-centered, it does not help individual consumers understand the nature and implications of his condition, or how to manage and treat it. Creating patient-centered, consumer-understandable information is a major challenge.

The California HealthCare Foundation (CHCF) report stresses the need for tools and standards that help consumers retrieve, translate, integrate and manage their personal health information from across the healthcare continuum. “To be relevant and useful, the information patients retrieve must take into account their demographics (such as age and gender), health risks and other medical conditions. Consumers also need to know how a decision at any one moment of care, such as choosing a treatment, might affect other aspects of care, such as paying for it.”⁶⁰ Helping consumers address payment issues will be a simpler task than helping them understand the clinical

dimensions of their conditions and the implications of treatment options.

Personal Health Records

As a tool for consumer empowerment, the PHR must provide information that is useful to individuals caring for their health. However, it also must be useful to the provider as well because its value lies in shared information and shared decision-making. If the provider chooses not to consult the PHR or input information into the PHR, its value is diminished. “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.”⁶¹ Already beset by consumers acting on televised advice to “Ask your doctor if this drug is right for you,” physicians will likely need to be convinced PHRs can be of help to them as they practice medicine.

Patient empowerment. “Health dashboards” provided by PHRs support patients in managing chronic conditions along dimensions identified by best practices, quality measures and health status scores. The dashboard increases medical situational awareness. For example, the patient sees a display, much like his automobile’s “check engine” light, indicating it is time to have a cholesterol test; or, in cases where the patient is using a glucometer that interfaces with his PHR, the dashboard display warns him and perhaps even alerts his physician that his diabetes control needs adjustment.

By ensuring consumers have vital information about their medical condition, PHRs empower them to participate with their providers in making informed decisions about their health. By helping consumers understand the implications of treatment, PHRs help improve patient compliance and no doubt will play a key role in informing consumer choices as cost sharing continues to develop as a practice among healthcare payors.

Continuity of care. Advocates of PHRs stress the importance of portable records that can go with consumers as they move across and within the healthcare system. For the most part, current PHRs do not offer this capability. When consumers leave their health plan or employer, they generally leave their PHR behind. Inoperability requirements for the NHIN must address this deficiency if the PHR is to live up to its full potential. However, PHRs can help bridge some of the gaps within the current system. For example, the average consumer on Medicare has about six providers, but patients with five or more chronic conditions often have 14 or more.⁶²

Hurricane Katrina highlighted the benefits of electronic health records, particularly records systems that featured off-site data backup. The value of such records extends to contingency preparedness in all categories of events, from natural disasters to terrorist attacks, and infection disease pandemics such as avian flu.

Features and Functionalities	Phase 1. Baseline Health Digital Data Aggregation and Capture	Phase 2. Advanced Health Context with Import/Export Secure Access	Phase 3. Enhanced Integrated Decision Support with Automated External Interface Capabilities
<i>Data Source</i>	Patient/consumer, provider, or other designated health professional (health record curatory) submits manually, can scan or e-fax paper-based information into the digital document library while capturing structured data to allow searching and tagging items for categorization ...can track, store and query structured data in the PHR (e.g., blood pressure, weight, etc.) and conduct and self-report health risk assessments...	...and in this phase can import pre-registered digital healthcare claims and episode-of-care transactions that include summarized health data ...integrate direct digital inputs from electronic health records, designated pharmacy, laboratory, and claims data systems...	...and in this phase can designate pre-registered automated data source inputs to and outputs from a secure Health Information Exchange to populate selected data fields after each episode of care ...and can validate data inputs, submit time/date stamped personal health data and external health fitness data when available
<i>Information Content</i>	Demographics, categorized trusted-source digital document library, health risk appraisal, summary of medical claims reports, decision support tools...	...with an extended digital document library...	...and extended demographics, digital health record including an enhanced contingency patient health summary, patient care plans
<i>Collaboration</i>	Via secure email, print, fax...	...by digital media, e.g., smart card, memory stick...	...and augmented by service modules, e.g., appointment scheduling, electronic renewal of prescriptions
<i>Access Control</i>	Defined globally by the consumer...	...with ability to add clinical categories...	...and extend to surrogates including designated family members

Source: Work by Richard S. Bakalar

Read across each row in the Table to arrive at a full picture of the feature of functionality at the end of the phased implementation process.

Table 2. Roadmap to Phased Implementation of PHR Features and Functionalities.

Potentially, when an interoperable NHIN is in place, the PHR will give consumers access to routine telemedicine or telehealth services at home, at work, on vacation or in shopping areas at private health kiosks and "Minute Clinics." They will give healthy consumers access to personal health and fitness tracking and benchmarking with age matched reference groups as they work out at their gym or pursue personal exercise programs. This latter capability will be a giant step toward realizing the concept

of wellness, something the current healthcare system does not fully support.

Components of the PHR

Electronic PHRs are envisioned as patient-centric, life-long repositories that provide a wide array of capabilities using the infrastructure provided by an interoperable NHIN. As defined by David Lansky and Patricia Flatley Brennan,⁶⁵ the fully realized PHR will provide consumers with:

- A clinical summary of all episodes of health services and patient care encounters.
- Health status parameters, such as exercise, nutrition and spiritual well-being.
- Periodic risk assessment survey results.
- Decision support tools, risk management and professional advice.
- Consumer-focused health information and education.
- Benefits and financial management resources.
- Environmental exposure and community health monitoring information.
- Optional living will and organ donation preferences.

Getting to a fully functional PHR takes time.

Implementing a technology that changes processes and roles—in other words, that is disruptive—requires a phased approach to resolve technical concerns and the more difficult human issues discussed in this article. The Veterans Administration's experience implementing its PHR demonstrates a phased approach. Since MyHealtheVet was launched, the VA has added more features each year on Veterans' Day.

Convinced waiting to have everything right and implementing a full-blown PHR is a considerable risk, some consumer advocates are calling for starting with demographic information, a list of medications and allergies, and little else. However, most PHRs now emerging in the marketplace tend to offer more than a medication list while proceeding in a phased manner.

For example, the three-phased approach shown in Table 2 begins with baseline health data capture and aggregation, moves on to provide advanced health context with import/export secure access, and finally offers enhanced integrated decision support with automated external interface capabilities. Each phase adds new capabilities and features to the existing base.

Phased implementation enables the alignment of incentives and the development of business models designed to address security and cost sharing, as well as the capture, storage, display and distribution of medical information. Such models can eliminate duplicative services while improving the quality and lowering the cost of health services; they also can give other consumers of healthcare, including government, payors, pharmaceutical companies and researchers, access to new and larger data pools for faster and lower cost data analysis.

Next Steps

There are many issues involved in increasing the use of PHRs, particularly as a variety of vendors and providers enter the field. Some health plans and employers are offering PHRs as marketing differentiators; some vendors are struggling to achieve market share with this young technology. The reality is clear electronic personal health

records are one of the tools that will transform our health-care system.

As this process continues, it must be understood consumers of medical information and services are far from a homogenous group. Discussions of health records use the term "consumer" to underscore the fact such records are no longer the sole property of the physician's office or the hospital. Today, payors, including health plans and employers, are principal consumers of healthcare today on behalf of their patients and employees.

As the NHIN makes it possible to share information from health records in context, there will be other "consumers." In the near future, with the transition to health record banks⁶⁴ and consumer-directed health payment accounts, individuals will take on new roles as consumers, managing the clinical and financial aspects of their care. In time, when health record banks offer valuable data repositories and protection for the privacy of individuals, government agencies will use the information to ensure drugs on the

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market are actually safe and to support global monitoring for potential biological threats, such as avian flu. Pharmaceutical companies and medical researchers in various settings will use information to inform their work, ease clinical trials and support drug discovery.

In a transformation of this magnitude, the healthcare and information technology professions and the associations that represent them have demanding roles to play. The American Health Information Management Association, American Medical Informatics Association, Healthcare Information and Management Systems Society and other professional associations must join with academia, private companies and key government and legislative entities. Collaboration across all sectors is crucial to ensure developments serve the consumer, the vendor, the healthcare institution and the American people. Addressing sticky issues such as privacy and security, and serving consumer needs and desires require efforts that cross multiple sectors and require careful response to the consumers those sectors serve. Without collaboration and concerted efforts in private and public entities, the PHR will be another well-intentioned attempt that fails to deliver on its promises.

Although this could be the case, it need not be so. Health information technology has evolved to a point that it can transform healthcare in the United States, as it is doing

in other countries around the world. There is no reason, other than the lack of shared will, why the United States should fail to match and surpass Australia, Canada, Germany, New Zealand and the United Kingdom in using health information technology. These countries can provide valuable lessons in helping Americans do what they do best—develop and use innovative technology to serve the American people.

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