Personal Health Records: The People's Choice?

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OVERVIEW — *Information technology (IT), especially in the form of an electronic health record (EHR), is touted by many as a key component of meaningful improvement in health care delivery and outcomes. A personal health record (PHR) may be an element of an EHR or a stand-alone record. Proponents of PHRs see them as tools that will improve consumers' ability to manage their care and will also enlist consumers as advocates for widespread health IT adoption. This issue brief explores what a PHR is, the extent of demand for it, issues that need to be resolved before such records can be expected to proliferate, and public-private efforts to promote them.*

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Take control, health care consumers are exhorted. Don't risk having your health information swept away in a storm or unavailable when you are taken unconscious to the emergency room. Safeguard yourself and your family. Become empowered!

The empowered consumer, a stock character in health-reform scenarios, is not so easily identified in real life. There is a range of reasons for this: A given consumer may be sick or injured or cognitively impaired, thus lacking the ability and/or will to exercise choice. He or she may have been conditioned to do what the doctor says without second-guessing. Most commonly, he or she may lack the information that is the coin of empowerment. Some analysts argue that what the consumer needs most in order to secure high-quality health care is control of his or her own personal health information.

The route endorsed by many is the personal health record (PHR), which would allow an individual to see and to manage his or her health history, including test results, diagnoses, medication lists, physicians' instructions, and more. As it has become ever easier to aggregate and move data via the Internet, plans for transforming the way that Americans manage their care have emerged. The vision, as articulated by the Markle Foundation's Connecting for Health collaborative, is this:

> In our fragmented and pluralistic delivery system, the electronic personal health record is an essential tool for integrating the delivery of healthcare and putting each patient at the center of their care. It can support the shift from episodic and acute care toward continuous healing relationships with physicians and healthcare professionals. It represents a transition from a patient record that is physician-centered to one that is patient-centered, prospective, interactive, and complete.[1]

Many Americans already have access to a PHR, either privately purchased or made available by a health plan or a provider organization. Information about how many are actually being used is harder to come by.

WHAT IS A PHR, EXACTLY?

A precise definition of a PHR, meaningful to all stakeholders, is elusive. Is a PHR the data it contains, the mechanism that makes the data accessible, or the applications that allow a consumer actually to use the data? All of the above? It depends somewhat on who is talking and in what context. Some organizations have painstakingly crafted half-page explanations;[2]

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others have declined to be specific. As the National Committee on Vital and Health Statistics (NCVHS) put it in a 2005 report, "NCVHS concluded that it is not possible or even desirable to attempt a unitary definition at this time. However, the Committee believes it is possible as well as useful to characterize [PHRs] by their attributes."[3] Attributes are elements such as the nature of the PHR's contents, the source(s) of the information they contain, and the functions they offer. From the consumer perspective, perhaps the most significant distinctions that can be drawn among different PHR models have to do with the source of health data, who controls the data, and how the data can be made available.

Reduced to simplest elements, a PHR may be no more than a person's paper or home-computer file recording doctor visits, medications, insurance claims, and whatever else an individual might find useful to organize for quick access to family medical history. Such a record is created, updated, and controlled strictly by the individual. A variation is a Web-based PHR offered by a vendor, which may add communication options (such as broadcast e-mail health updates to family and friends) on top of basic record-keeping.

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A second PHR type is created by a health plan or an employer, populated with claims data (which may include laboratory and pharmacy information) and typically available to the consumer through a secure Web portal. Research conducted by America's Health Insurance Plans (AHIP) indicates that at least 70 million Americans have access to a PHR offered by their health plan.[4] Some hospitals have made clinical information available via Web portals to patients (or parents of young patients) with certain diagnoses.
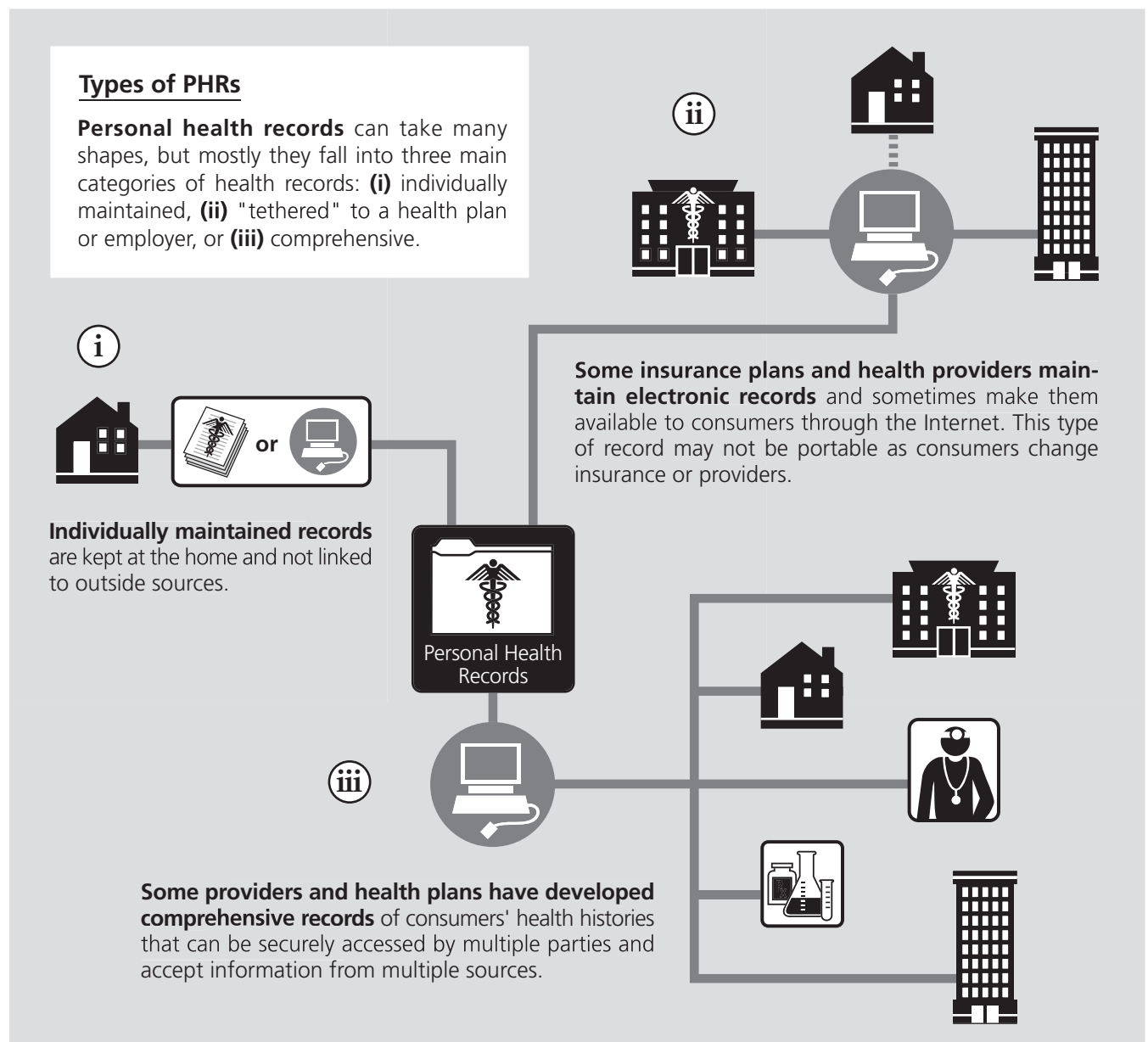
A more sophisticated PHR is available to some consumers as part of an electronic health record (EHR). An EHR typically is maintained by a provider or provider organization, such as a physician, hospital, or integrated delivery system (such as Kaiser Permanente or the Veterans Health Administration). It is designed to be a full repository of clinical information on a patient and to accept information from a variety of sources, including physicians, laboratories, and consumers. A PHR capability allows the consumer access to some portion of his or her clinical data, under rules set by the provider; it may also allow secure e-mail messaging, access to condition-specific medical information, appointment scheduling, transmittal of children's immunization information, and other functions. Any electronic PHR, whether Web- or provider-based, may also incorporate the ability to download to a digital device such as a USB (universal serial bus) drive on which a person can store and carry essential information.

A PHR maintained and controlled by a health plan, employer, or provider organization is referred to as "tethered." Its chief disadvantage is a lack of portability; the individual who changes jobs or insurance companies loses

access. In response to this concern, AHIP and the BlueCross BlueShield Association (BCBSA) have undertaken an initiative to adopt standards for the essential data content of PHRs as well as for messaging among them in order to make PHR data transportable among health plans.[5]

In a report for AARP, researcher Carol Cronin examined PHRs commercially available to the public, that is, not tethered. She identified 24 products, a mix of Internet- and PC-based, some including portable devices. Consumers enter information into all these models and thereafter control

Types of PHRs

Personal health records can take many shapes, but mostly they fall into three main categories of health records: **(i)** individually maintained, **(ii)** "tethered" to a health plan or employer, or **(iii)** comprehensive.

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Some insurance plans and health providers maintain electronic records and sometimes make them available to consumers through the Internet. This type of record may not be portable as consumers change insurance or providers.

Individually maintained records are kept at the home and not linked to outside sources.

or

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Some providers and health plans have developed comprehensive records of consumers' health histories that can be securely accessed by multiple parties and accept information from multiple sources.

access to it. A potential weakness of this consumer-generated record—beyond the basic uncertainty as to whether the individual will get around to entering the data—is the degree to which the information is trusted by other parties, including physicians. (In some products, the consumer may authorize access by one or more physicians, who are then permitted to enter data as well.)

The question of who supplies information to a PHR has clinical and legal ramifications. Physicians have expressed concern that they could be held liable for basing diagnoses and treatment decisions on inaccurate information supplied by a patient, though how this risk differs from relying on information conveyed orally by a patient is not clear. In fact, once entered, information in a PHR would not be subject to the loss of clear memory a patient may experience as time goes by. Nevertheless, accuracy of data is a concern, with respect both to what is entered into the record and to what is missing. The mechanisms by which errors of omission and commission can be corrected, or differing opinions flagged, vary across PHR products.

Struggles over control of patient information can also arise simply from physicians' concern about losing power in the doctor-patient relationship. Some analysts would prefer to see the tussle over "ownership" retired in favor of attention to the flow of information between a patient-controlled PHR and a physician-generated medical record.

WHO IS ASKING FOR IT?

Various researchers have found that the PHR concept is new to people, who in the main have not given much thought to the state and location of their medical records. In a survey by Health Industry Insights released in May 2006, 52 percent of respondents said the reason they had never used a PHR was because they had never heard of one.[6] Adoption of the products reviewed by Cronin has not been dramatic. In contrast, enrollment for access to the PHR portion of a provider-maintained EHR—through programs such as Epic Systems' MyChart or the Veterans Health Administration's My Health*e*Vet—is growing. This may be true because more information and instruction are provided by EHR sponsors. Focus groups conducted by AHIP revealed that consumers were attracted to the convenience of PHRs but had concerns about the security of their information.[7]

Research by Corey Angst and colleagues at the University of Maryland demonstrated that attitudes about PHRs varied considerably, depending on who was sponsoring them. The choices of trusted sponsors presented by researchers can be seen to influence that variation, however. The Angst study found that primary care physicians were significantly favored over employers by their survey respondents. BCBSA found that respondents preferred an insurer to the government or a third-party vendor.[8]

Vendors or sponsors of PHRs have developed common messages to potential enrollees, calling on them to take control, save time, and protect

their safety.[9] A 2003 online survey by the Markle Foundation's Connecting for Health project found that, while consumers' responses were fairly consistent across demographics such as age and income, those with chronic illness and those caring for elderly parents reported the highest and most urgent interest in PHRs.[10] A Whatcom County, Washington, consortium that developed a PHR as part of an Robert Wood Foundation (RWJF) Pursuing Perfection project implemented in 2002 found that chronically ill patients also became a PHR salesforce, enlisting friends and family members to participate.

PHRs are an element in the health information technology (IT) enthusiasm of the Bush administration, evident in actions from the President's 2004 call for all Americans to have EHRs in place within a decade to the appointment of a national coordinator for health IT to Secretary of Health and Human Services Mike Leavitt's personally presiding over a group known as America's Health Information Community (AHIC). A part of AHIC's current focus is PHR development and deployment.

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Trying to heat up the still largely lukewarm (or just uninformed) response of most consumers are some committed PHR proponents. The NCVHS and the Office of the National Coordinator for Health Information Technology (ONC), in pursuit of a national health information network, consider PHRs an integral component. RWJF introduced in July 2006 an initiative called Project HealthDesign: Rethinking the Power and Potential of Personal Health Records. It is designed to stimulate innovation in the design of PHR systems through the following actions:

- Supporting design and prototyping efforts that focus on the needs, preferences, and living environments of individuals

- Promoting a systems approach to PHRs, in which an array of personal health applications can be built on a common platform of core data elements and technical utilities[11]

Project designers want to emphasize that the existence of a record does not have transformative potential; rather, it is the use of tools that draw on the record to help people make decisions that can bring about change. Or, putting it the other way around, standardization and open programming interfaces at the level of the record ideally will allow great diversity of application to individual situations and preferences.

Some PHR enthusiasts have more explicit aims. The American Academy of Family Practice (AAFP) has long supported the concept of a continuity of care record (CCR), a standardized presentation of basic patient data designed to ensure at least a minimum standard of transportability when a patient sees a new provider. AAFP has worked with the Massachusetts Medical Society, the Health Information Management and Systems Society, and standards-development organization ASTM International to make

the CCR a fully balloted and published standard. The CCR is also compatible with other PHR/EHR standards, such as the National Council for Prescription Drug Programs' SCRIPT standard for transmitting prescription information electronically. AAFP reports working with some 40 IT vendors to get the CCR standard integrated into their systems.

In response to critics who suggest that the CCR is not geared to recording data on variables such as cognitive status, quality of life, or severity of chronic symptoms over time, AAFP's David C. Kibbe, MD, readily concedes that the CCR does not have everything. However, he says, it is the first attempt to mobilize data from a variety of existing digital sources.[12]

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The "it's a start" mentality seems characteristic of consumer-focused PHR proponents. As more than one has pointed out, getting consumers to see the value of quick access to accurate health information is probably an easier sell than getting many doctors enthused about EHR systems; a majority of the latter still are not prepared to make information available by e-mail and may see maintaining a PHR interface as yet another unreimbursed service. As some PHR proponents have observed, why make consumers wait for physicians to get on board and for interoperability to manifest? As consumers become accustomed to the convenience of electronic records, the thinking goes, they will put pressure on providers to adopt compatible technology.

WHAT IS AT ISSUE?

In trying to determine whether any constituency is opposed to the adoption and diffusion of PHRs, one is forced to wonder whether the widespread lack of awareness of their existence might preclude opposition. With respect to those more in the know, David Lansky, executive director of the Markle Foundation's Personal Health Technology Initiative, explains that, in the abstract, nearly everyone supports the idea of a PHR. "But any way that you operationalize it, you make some group of people uneasy."[13] While different stakeholders have different discomfort points, there is general agreement on a series of issues that need to be resolved to clear the way for widespread PHR use. (It should be acknowledged that these issues are relevant to EHRs as well.)

Standards

It is self-evident that a PHR accessible only to an individual would have limited utility. To serve the ends of patient safety, improved quality and efficiency of care, and consumer empowerment, a PHR must be able to accept information from a variety of sources and to be read by physicians and others to whom the individual grants access. To make this possible,

standards for data field definitions, a common core data set, and standards for electronic transmission must be agreed to. At a basic level, the Markle Foundation has pointed out the alarming gap that exists between the clinical terminology used by health care practitioners and the lay language understood by most patients.[14] The Health Information Technology Standards Panel, a public-private group under contract to the American National Standards Institute, has proposed an initial set of standards in three priority areas to AHIC working groups.[15]

Opt In or Opt Out

Some consumers will never be comfortable with the whole idea of digital records, as witness the writer of a letter to the editor of *Modern Healthcare*: "Just wait for the electronic health record…all information regarding most patients will be readily available to just about anyone."[16] Most PHR proponents are willing to give consumers a yes or no decision about participating. If the PHR in question is entirely under an individual's control, those who object to the idea can simply refrain from keeping a notebook or opening a computer file. Where a PHR is sponsored by an employer, health plan, or provider, there is much discussion about whether it is better to require those who want to participate to sign up or to include everyone except those who go on record as refusing. The latter is easier administratively, but the opt-in approach may be more readily adapted to allowing patients something between yes and no; that is, a patient may be given the opportunity to block certain categories of information.

Some observers worry that opt-out power may prove illusory, if health plans or employers say a beneficiary must authorize creation of a PHR in order to be eligible for benefits. They fear that a new enrollee could be forced to make a pre-existing PHR available to a new carrier, which could then use health history for underwriting or exclusion purposes.

Privacy and Security

Quite naturally, even consumers eager to opt in to a PHR program are concerned with keeping information about their health private. As a longitudinal record, the PHR may preserve (and at the same time make vulnerable) information that might otherwise have disappeared when Dr. Smith retired or the hospital purged its old films. As noted above, some of this concern can be addressed in design, by giving an individual the means to specify that only certain other parties be given access to PHR information or that certain categories of information are off-limits. Encryption of data and secure Internet connections for remote access offer a defense against accidental (or malicious) record access.

The Health Insurance Portability and Accountability Act of 1996 (HIPAA) sets minimum standards for the use and disclosure of personally identifiable health information by "covered entities" that routinely deal with

health information, such as health plans, data clearinghouses, providers, and their agents. In the case of a PHR offered by a health plan, HIPAA standards would apply. However, a PHR vendor offering services directly to consumers is neither a covered entity nor an agent; hence, HIPAA offers no protection.

Researchers Mark Rothstein and Meghan Talbot point out in a June 2006 *Journal of the American Medical Association* article that "privacy analyses have centered on computer security issues and whether to provide individuals with some level of control over the content of their health records," while "little or no attention has been given to mechanisms to prevent the disclosure of sensitive health information with no current clinical usefulness when third parties compel individuals to disclose their health information."[17] They cite employment screening processes; applications for life, health, and disability insurance; worker's compensation and veterans' disability claims; and personal injury lawsuits among the instances in which authorization to disclose health information (often to parties not covered by HIPAA) is required. Information so disclosed may be far in excess of what is needed to make an employment decision or even a mortality projection, particularly when it is all collected in a longitudinal electronic record.

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To combat the potential threat to privacy, Rothstein and Talbot endorse a concept they call "contextual access criteria," which would limit the scope of disclosures for nonmedical purposes based on the type of information actually needed by the third party. They note, however, that this concept is not yet an available technology.

Authentication represents a significant subset of security issues. It is critical to ensure that patient information is accessible only to authorized persons. From a clinical perspective, it is equally critical to be sure that information used to populate a PHR pertains to the right patient. While use of the social security number is fraught with identity-theft fears, PHR proponents stress that there must be some mechanism for ensuring that the person requesting health information is who he says he is. The Markle Foundation has outlined three methods of verification: the individual provides something that he knows (such as a password or personal identification number), has (such as a smart card), or is (such as a retina scan). The first is the easiest and weakest; as with all passwords, a person may choose something obvious like a child's birthday or, in the case of a more complicated choice, write it down on a card in his wallet. The third method is near to foolproof but expensive and unavailable to most PHR sponsors and participants.

NCVHS (among other groups) has proposed security standards, including giving consumers a full audit trail of access to their record and the

ability to control access to subsets of the PHR. RWJF, in recognition that technical fixes only go so far, will provide its Project HealthDesign grant- ees with the services of a consulting team on the ethical, legal, and social implications of their PHR projects.

With respect to consumer fears, some analysts observe that the many people who have conquered their trepidation about paying bills online will get used to online health records as well. Consumers might respond that it is easier to get money returned to an account than to restore a privacy, once violated. Evidence that fears are well-founded continues to come to light. The Government Accountability Office found that in 2005 fully 40 percent of federal Medicare and TRICARE contractors and state Medicaid agencies surveyed reported that they had experienced a recent privacy breach involving personal health information.[18] Another AHIC workgroup has been established to wrestle further with privacy issues.

Clearly, PHR proponents take privacy and security concerns seriously. Unfortunately, no one can feel entirely safe from ingenious hackers, care- less clerks, or the thief who steals the laptop that should not have left the office in the first place.

Family Access

Adolescents pose a particular challenge to PHR sponsors. At what point does their right to privacy trump their parents' right to know? Hospitals and health plans with PHR capability have wrestled with age cut-offs, in some cases allowing adolescents full control over access to their records from the age of 13. Consideration must be given to other interfamily ac- cess issues; for example, what privileges should spouses have with re- spect to one another's records?

Long-Term Record Maintenance

If, as many proponents hope, the PHR is to serve as a lifelong health re- source, maintenance as well as original adoption becomes an issue. Some analysts look to regional health information networks, such as MA-SHARE or the Indiana Health Information Exchange, to draw local residents into a community-wide record system. Such regional bodies have to make their own decisions about where data are to be housed; several have chosen to provide a regional patient index that contains no clinical data but does contain "pointers" to sites where a patient has received care.[19]

Some members of the financial community have suggested that it would make sense to build a nationwide health information network on top of the banking system's existing electronic infrastructure. Other commercial in- terests, including IT vendors such as Cerner, are supporting legislation that would create independent record banks—and allow them to contract with vendors for various services. Introduced by Sen. Sam Brownback (R-KS) and Rep. Paul Ryan (R-WI), S. 3454/H.R. 5559 envisioned the "creation

and storage of lifetime individual electronic health records for individuals that may contain health plan and debit card functionality and that serves the interests of all healthcare entities," maintained by a nonprofit organization covered by HIPAA. Such an entity would be entitled to charge user fees and to sell (under prescribed conditions, including the consent of the individual) nonidentifiable and partially identifiable health information for research purposes. The bills come down squarely on the side of the individual as the owner of information.

The fact that technology certain to change is a long-range maintenance issue. As the successors to today's software packages and gadgets emerge, so does the prospect of transferring information. As now, this data migration likely will proceed differentially in different organizations. One thing that can be said of paper is that—barring fire and flood—it remains readable over time.

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WHAT NEXT?

AHIC has a consumer empowerment workgroup whose task is to make recommendations to the community so that, within one year, a prepopulated, consumer-directed, and secure electronic registration summary, with a linked medication history, is available to targeted populations.[20] The workgroup is considering consumer education strategies, including a social marketing model already employed in some communities. For example, leaders of the Whatcom County initiative described earlier present their PHR as a community resource along the lines of a public utility and market it through senior centers, churches, emergency medical systems, and schools.[21]

The U.S. Department of Health and Human Services (HHS) has awarded a contract to RTI International to work with the ONC and the Agency for Healthcare Research and Quality to identify barriers to PHR adoption and suggest resolutions. ONC has also contracted with the National Governors Association to develop a State Alliance for e-Health, a collaborative body that will provide a forum through which governors, elected state officials, and other policymakers can work together to identify inter- and intrastate-based health IT policies and best practices.[22]

Legislation (H.R. 6289) was introduced by Rep. Patrick Kennedy (D-RI) to establish financial incentives for physicians to cooperate with their patients in maintaining and using PHRs. In addition to giving patients accurate and timely information, improving their compliance with prevention and treatment, and offering a direct communication channel in the event of emergency, one of the bill's objectives was to build public confidence in systems that place medical data online by ensuring that individuals have full control of information so placed in their PHRs.[23]

The Centers for Medicare & Medicaid Services is testing the feasibility of integrating Medicare claims data with personal health records.[24] As on other quality-improvement fronts, Medicare has the clout (and the captive audience) to drive PHR availability. Many PHR (and EHR) supporters wish that HHS would also take on the task of establishing and then mandating adherence to standards, for security and confidentiality as well as for data and interoperability.

To make real the claims of transformative potential, PHRs need to be defined, designed, and deployed in a way that the consumer—who in effect plays both transformer and transformee—can appreciate and will use. The pockets where such use now occurs may be read as encouraging portents but have yet to acquire critical mass.

ENDNOTES

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