

Personal Health Records (PHRs)

Issue Brief

What is a PHR?

As the Internet has come of age, a new type of health care product has emerged in recent years: the personal health record, or PHR. Personal health records are Internet services to help consumers manage their own health information and care.* PHRs come in many different forms, and people use them in different ways. A PHR can be any of these things:

- A daily online organizer for health care—to e-mail doctors, make appointments, receive test reminders and results, and request prescription refills
- An all-in-one-place repository for an individual's health information, from medical records to over-the-counter medicines to self-tracked data
- A tool for achieving personal goals—losing weight, for example, or controlling high blood pressure or tracking fitness activities
- An aid for managing the health care of another family member, even someone who lives far away

PHRs of various types are available through health plans, personal health management vendors (like OptumHealth and WebMD), medical groups, and hospitals. Consumers also can set up their own PHRs by using online services available to anyone; many such PHRs are free to the user, while others charge a monthly fee. A summary of the different kinds of PHRs and who provides them is included in this brief (see pages 5–7).

* There are PHRs that aren't Web-based, but the focus here is on online services.

Top PHR Features

- Patient-doctor communication including patient information exchange and e-mail
- All-in-one-place health history record
- Patient can check that records are right
- Portability—consumer can transfer data if plan or providers change
- Online viewing of test results
- Service at your fingertips—online prescription refills, appointment scheduling
- Information shared by all of a patient's doctors and caregivers
- No or low cost to consumer

PHRs Today— Opportunities and Barriers

- Consumer demand is growing for the PHR products that are available today through integrated care systems and direct-to-consumer online services.
- Patient data aggregators that offer open systems PHR platforms (e.g., Google Health, Dossia, Microsoft HealthVault) are expanding their services through data interchanges.

BUT...

- Few doctors are connected to PHRs at present—they have no compelling financial incentive to share patient data, and they have a proprietary interest in controlling patient management activities.
- Despite consumer interest, demand is spotty due to privacy concerns, the burden of entering data, and the uneven availability of services.
- Most PHRs lack interoperability; the consumer has to transfer his or her own data as provider, plan, or other relationships change.

What is the Value of a PHR to the Consumer?

A PHR—the health record and its connectivity to data sources—is not an end in itself. Rather, its importance for most consumers is as a springboard to various personal health applications. PHRs have high value for consumers today for the following reasons.

A PHR is a springboard to a variety of personal health applications.

easy access to their health records—and so do their doctors. Centralized record-keeping can prevent unnecessary duplication of treatment or delays in care.

Saving time and money. A PHR makes it possible to schedule appointments, order prescription refills, e-mail a doctor for instructions and advice, and view lab results online. Avoiding trips for supplies or services saves time and money. Getting advice or instructions from a doctor or nurse online costs much less than an office visit, and sharing test results among a patient's doctors online helps avoid the cost and inconvenience of repeat tests.

A PHR makes it possible to order prescriptions, share information with doctors, and view lab results online.

Staying healthy—or living well with illness. A PHR makes it easy to track daily self-care and wellness activities like exercise, diet, and vital signs. Patients with the same health problem can share peer-to-peer care information and support. Vital health indicators, like blood pressure, can be sent to doctors from home by using monitoring equipment.

Caring for a family member. A PHR simplifies the task of helping aging parents or other loved ones with their health needs—using medications correctly, staying on a treatment plan, or adjusting meals and daily

activities to control symptoms. The care organizer can connect with all the involved providers online, so all are up-to-date about the patient's treatments. Payment records, appointment reminders, medication refill requests, and more can be organized online.

The Employer's Role: Four Options

Employers can play any of a number of roles in fostering PHRs, from education to advocacy to implementation. Or an employer can “wait and see” as the PHR market is evolving quickly. The following four options can be pursued separately or in combination.

1. Educate your workforce. Educate employees about PHRs and how a PHR can help to better manage one's health and health information.

Promote the use of PHRs that are already available through the employer's health plans, a personal health management vendor, or direct to the consumer through the Internet.

Reinforce the value of personal responsibility for one's health by informing employees about using PHRs to manage their health and medical care.

2. Advocate and act for universal PHR services. Join with other employers to advocate for a universal data set of personal health information, available to individuals regardless of where they are employed, who their providers are, or what health plans they belong to.

Integrate self-funded medical data into personal health information repositories that are available to employees.

Collaborate with health vendors to integrate workforce data into personal health information repositories; focusing especially where waste is rampant and savings opportunities greatest—avoiding duplicate lab tests and imaging, for example.

Identify PHR “must-haves”—key PHR features that the employer can use in purchasing criteria, vendor negotiations, and employee communications.

3. Change your benefits program to encourage PHR use. If a PHR is fee-based, subsidize its cost for employees as a component of their health benefits package.

Implement health benefits changes that encourage the use of PHR services, such as the following:

- E-visit copays to reduce the need for in-person visits
- “Value-based benefits” that use PHR services to efficiently deliver care that’s been proven to work, such as home monitoring of vital health indicators
- Wellness services that take advantage of PHR services like online smoking and weight-loss programs
- E-prescribing to reduce errors and use cost-effective medication therapies

Identify employee health management needs that aren’t

PHR users were 10 times more likely to fill out a health assessment.

being addressed well by providers, health plans, or the employer. Assess the feasibility of providing PHR services to fill these gaps.

4. Defer PHR action for the present. Postpone consideration of PHR activities for now but identify milestones for later PHR consideration. Milestones could include:

- The PHR is a lifetime product with widespread market portability
- A critical mass of physicians is exchanging information with patients online
- Online care monitoring and support systems are connected to homes anywhere

How Does a PHR Fit with Your Health Benefits?

Employers need to weigh a number of criteria—company values as well as the PHR market environment—when assessing whether active PHR support is a good fit.

Among the aspects to consider:

1. *The benefit to employees.*

Given their present capabilities, PHRs are of significant value to a relatively small number of employees, though they include people who have critical health needs. A PHR offers high value for these consumers:

- People with specific health needs that are well served by an existing PHR (like thesmartphr.com, for cancer patients and special needs children)
- Those with the motivation and ability to provide their own health information to support self-care activities (like users of sensi.com, a weight-management PHR)
- Those who particularly value the control and peace of mind realized through organizing and maintaining a consolidated family health record
- Active patients of providers who already use PHRs for online patient care communications

2. *Role of the employer in promoting common care management services for employees vs. assisting employees who seek care management support outside of employer-sponsored services.*

- How important is it to the employer to channel employees to contracted health services versus supporting options for them to create their own support services?
- What is the employer’s tolerance toward “unmanaged PHR health support services” that may include elements considered intrusive or offensive to certain employees (advertisements, data harvesting, product sales, etc.)? Does the employer have a role in filtering out unwanted elements?

In one study, PHR users were twice as likely to get cancer screenings.

3. The strength of an employer's health plan PHR services.

- Most health plans provide few personal health management services through their PHR offerings. The focus is on member convenience and access to health information rather than self-care or treatment support.
- Some health plan PHRs complement their disease/health improvement services by channeling reminders and alerts through the PHR as an example. And health risk assessment data can be automatically populated in the PHR to support health improvement activities.
- Consumers may not trust employer or health plan-sponsored services that involve personal health information.
- As health plan PHR capabilities improve, they will bring greater value to the consumer. But a number of plans probably will continue to populate their members' PHRs with health plan data rather than provider-based data and may continue to limit the portability of the PHR.

Eight in ten consumers are concerned about identity theft and unauthorized use of personal data.

Who Owns and Controls Personal Health Data?

For the early PHRs, the control of personal health data is expressed in the following two broad categories.

Patient-controlled PHRs. In patient-controlled PHRs, the consumer decides which data to enter or which automated data services to connect to the PHR—and which data can be shared with health professionals or other people.

Data-only aggregators, like Google Health and Microsoft HealthVault, are the foundation of one type of patient-controlled PHR. In this approach, the PHR data repository is an open system that connects to any data sources or health applications that establish interfaces with the PHR platform.

A second approach is represented by the PHR services that cater to condition-specific online communities or offer other niche services. For these PHRs, the health record applications are customized to the communities' interests. Examples include Diabetes Mine for diabetes patients and PatientsLikeMe for online communities ranging from depression to Parkinson's patients.

Sponsor-controlled PHRs. Most PHRs are controlled by a sponsoring organization—a provider, a health plan, or a health information company. The sponsor determines the data sources and the consumer's right to enter or remove data. The sponsor also determines the extent of any portability—if and how a consumer can move data to another health record application. Generally there is little or no portability in today's sponsor-controlled PHRs; the consumer cannot readily transfer his or her data to another application except by printing it out and re-entering it elsewhere.

Is Data Connected Across the Marketplace?

Most PHRs at present are “information islands” with limited connections among the many personal health information sources.

Medical group/physician and hospital PHRs draw consumers' personal health information from the clinical and administrative systems operated by the providers. Information from other clinical systems—prescriptions, medical records from other providers, radiology results, and patient self-report/monitoring data—usually is not available.

Health plan PHRs draw consumers' personal health information from the administrative systems operated by the plan. Information from provider clinical systems (medical records, patient registries, patient self-report/monitoring data) usually is not available. Plan-sponsored PHRs generally don't interface with provider administrative systems and don't support some of the transactions most valued by consumers, such as online appointment scheduling and prescription refills.

However, several major health plans are beginning to work with PHR data aggregators to give their members options to connect to additional data from sources other than the health plan.

Direct-to-consumer PHRs often rely heavily on the consumer to self-enter health information. Some health information business sponsors with more expansive PHR services, like WebMD and OptumHealth, also draw data from certain centralized sources, including national labs and pharmacy chains.

Data-only aggregators of personal health information—Google Health, Dossia, and Microsoft Health-

Vault—are open systems that interface with centralized sources such as national labs and pharmacy chains. They are regularly expanding their connections to new data sources. However, the PHR customer—be it a company offering specialized patient care

applications, an employer, or another PHR sponsor—must take additional steps to utilize software that standardizes data for integration into the PHR.

Most PHRs today are information islands with little connection between different health data sources.

The PHR Marketplace

Some PHRs are sponsored by health plans, medical providers, or personal health information vendors, while others are available directly to consumers on the Internet. Still another category includes “data aggregators” that provide services to collect and maintain health information from a number of sources.

Health plan PHRs. All the national health plans offer their members some form of PHRs. Typically the member’s lab results, medications, and medical services are automatically entered, but little or no provider-information exchange occurs—physicians and other providers are connected in only a few areas.

Health plans with integrated care systems, like Kaiser Permanente, are more likely to offer PHR services that include patient-doctor e-mail messaging along with appointment scheduling. However, Kaiser members have no control over their information—they cannot enter data into the record.

Aetna, in collaboration with Microsoft HealthVault, is one of the first plans to enable members to transfer PHR data into and out of an open systems PHR repository.

For summaries of health plan PHR services, go to http://www.pbgh.org/programs/consumer/documents/PBGH_PHR_PlanComparison.pdf

Health Plan PHRs	
Strengths	Weaknesses
Member information such as prescriptions, lab values, and medical services can be entered automatically.	Consumer information is limited to health plan sources and doesn't include clinical data. The PHR isn't portable when the consumer changes plans/employers.
Care management resources such as educational information, health trackers, and diaries are available online.	Lack of provider connectivity limits care management capabilities—and without physician engagement, it is much more difficult to attract patients to PHR applications.
Some transactions can be done online—medication refills, for instance.	The most desired services typically aren't available: online test results and appointments, patient-provider messaging.

Provider PHRs. A few medical groups in selected areas offer PHRs to their patients. As an example, half a dozen groups in the San Francisco area and a similar

number in the Los Angeles basin provide PHRs—but most of the more than 250 California medical groups do not offer such services.

Provider PHRs	
Strengths	Weaknesses
Patient information—medications, lab values, services—can be entered automatically.	Consumer information is limited to a particular provider's data sources; data from other providers is missing. The PHR is not portable when the consumer changes providers.
Clinical information in the PHR facilitates patient-doctor care information exchange, self-care support, and better point-of-care decisions; there's potential for remote patient care via home monitoring devices.	Scant patient care management applications are operating today—the focus is on transaction services.
Highest-demand services are offered: test results, patient-provider messaging, appointment scheduling.	Availability of transactions like medication refills and appointments is highly variable among provider PHRs.

Direct-to-consumer PHRs. A number of PHRs are available free online. Most require users to gather and enter their own health information rather than have it copied automatically from electronic health records or administrative data feeds—a major deterrent to widespread successful adoption. But some patient segments

are highly motivated to use such PHRs, given the help they seek for a particular medical condition or health improvement effort. In addition, specialized PHRs offer services that range from managing medications to organizing care for family members or others who live elsewhere.

Direct-to-Consumer PHRs	
Strengths	Weaknesses
The consumer controls the PHR, and it is portable with job, plan, or provider changes.	The consumer must self-enter the health information; some PHRs' revenue sources may be intrusive (advertisements, patient data uses).
An extensive array of online care applications is available, including patient communities and expert resources. Peer exchange services are particularly appealing—patients tend to trust one another.	Self-care and treatment support are largely consumer based; lack of provider connectivity limits doctor-patient information exchange and clinical management capabilities.
The consumer can set up a PHR that matches personal needs ranging from remote care for a family member to condition-specific self care.	Highest-demand services typically are not available: online test results and appointments, patient-provider messaging.

Data-only PHR aggregators. Data-only aggregators of personal health information include Google Health, Dossia, and Microsoft HealthVault. These systems offer the greatest portability for the consumer and the opportunity to integrate the widest array of data sources, as they do not rely on a specific employer, payer, or provider client. They do not charge the consumer or health data sources but rely on revenues generated through search and other advertising services.

Using data-only aggregators requires that the employer or other sponsor hire additional vendors to integrate the desired data sources (e.g., medical providers, labs, pharmacies or other ancillary services, and health plans), standardize the data, and contract for end-user applications. These applications include software for patient-doctor information exchange, self-care, and other patient activities.

Data-Only PHR Aggregators	
Strengths	Weaknesses
Consumer information is automatically entered across a spectrum of data sources.	Physician clinical data and transaction services aren't widely available yet, as few practitioners are connected to aggregator products.
An extensive array of online care applications and resources can be offered, including patient communities and expert resources.	Self-care and treatment support are largely consumer based; lack of provider connectivity limits clinical management capabilities.
Some key services are increasingly available, including online prescription refills and lab results.	Some high-demand services typically aren't available (like patient-provider messaging and appointments).
The consumer controls the PHR—it is portable with job, plan, or provider changes.	Technology is still emerging for mapping data from myriad sources to create and update a standard patient record.

Improving Health and Reducing Costs—the Evidence

PHR users are more likely to get preventive care, studies show.

The PHR promise of improved health is rooted in several studies in which patients who received Web-based support showed better health outcomes than those with usual office-based care. An intervention using Web services, home blood pressure monitoring, and online pharmacist consults resulted in proportionately more patients achieving target blood pressure levels. Similarly, more diabetes patients lowered their blood sugar levels when the care included online access to their doctors and medical records.

Earlier work also shows the potential of PHRs to spur gains in wellness efforts. In a 2007 pilot study, Aetna compared a PHR intervention group with a control group and found that the PHR users were:

- 10 times more likely to fill out a health assessment
- 1.7 times more likely to have preventive visits
- Twice as likely to get cancer screenings

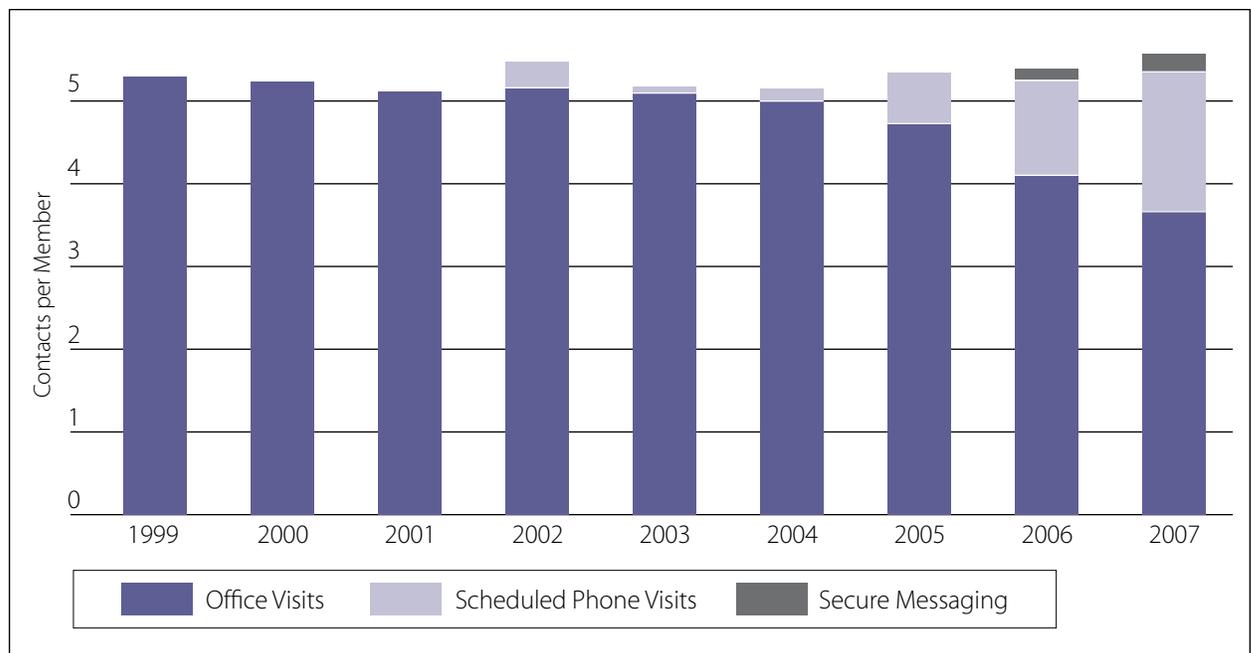
To date, only a few such “engaged consumer” studies have been done, mostly in integrated care systems. This early work is promising but has not yet been replicated on a large scale.

Savings projections. A 2008 study by Partners Healthcare System in Boston projects annual savings of more than \$20 billion when interoperable PHRs become available to 80% of the United States population. Major anticipated sources of savings:

- Avoided repeat testing as results are shared among involved providers
- Monitoring and follow-up of sickest patients, such as those with heart failure
- E-visits replacing some office visits
- Electronic prescription refills preventing errors and substituting lower-cost drugs
- Smoking cessation management yielding higher quit rates than the usual care

A shift in services. Kaiser Permanente Hawaii conducted an eight-year study of the shift in patient care contacts with the introduction of online services that include scheduling, secure patient-provider messaging,

Distribution of Patient Contacts Over Time Among Kaiser Permanente (KP) Hawaii Members, 1999–2007



SOURCE: Authors’ analysis using data from the Kaiser Permanente Hawaii Data Warehouse and secure messaging database.

and medication refill ordering. Some key results:

- A 26% reduction in patient office visits
- An 8% increase in contacts per member with the addition of scheduled phone visits and e-mail
- Unchanged quality performance—no significant change in HEDIS quality scores
- Very high satisfaction among users of the online services

High patient interest. According to a nationwide study sponsored by the Markle Foundation, consumers would like online access to their medical information to ensure its accuracy, to improve doctor-patient communications, and to help prevent medical errors. And, 68% of those surveyed believe personal health records would give them greater control over their health care. Among the findings:

- 91% say it's important to review what their doctors write in their chart
- 88% say online records would help reduce unnecessary or repeated tests and procedures
- 82% want to review test results online
- 84% would like to check for errors in their medical record

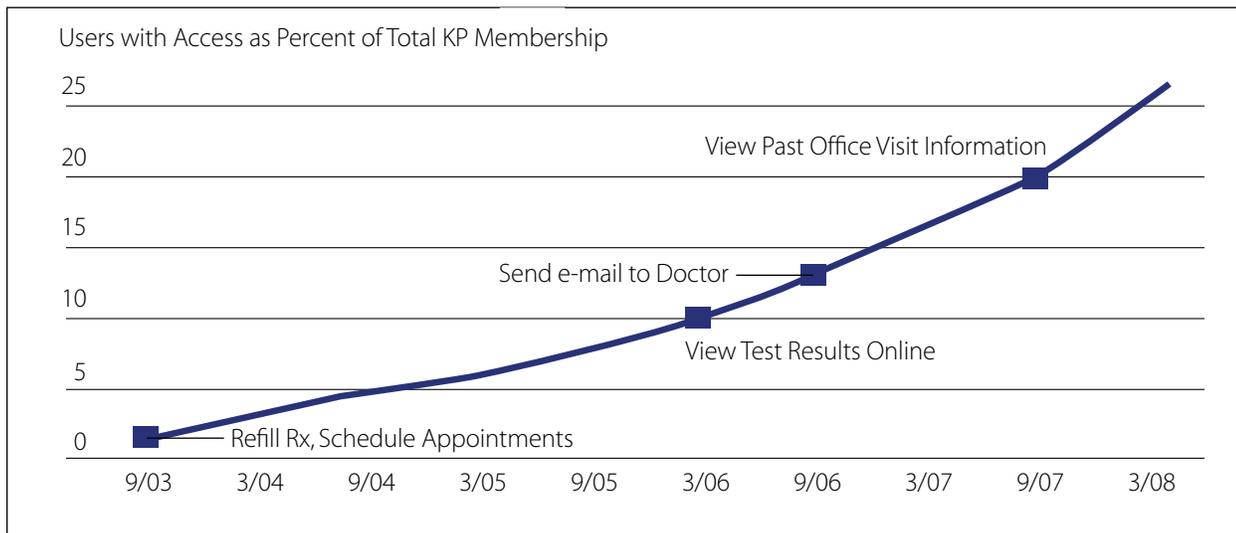
- 90% say it would be important to track symptoms or health changes online
- 83% of parents would be interested in tracking their children's health information like immunizations

However, the same study also indicates that people are very concerned about the confidentiality of their information: eight in ten say they are concerned about identity theft or fraud and the possibility of personal data being used by marketers without their permission.

User satisfaction. Studies by Kaiser Permanente and Group Health Cooperative show very high patient satisfaction among users of their online services. In a 2005 Group Health study, 94% of surveyed patients said they were satisfied/very satisfied with the plan's online services. Test results, medication refill ordering, after-visit summaries, and patient-provider clinical messaging were identified as the most valued features.

As Kaiser has added new online capabilities, its clinical management services have become the most frequently used functions. The highest demand is for test results, prescription refills, and patient-to-provider messaging. Kaiser's facility directory, health encyclopedia, and online appointment scheduling are other regularly used features.

EXHIBIT 1: Changes in Kaiser Permanente (KP) Member Registrations on KP's Member Web Site Over Time, with Various Secure Site Features, September 2003–June 2008



SOURCE: Member registration data from KP's member Web site.

NOTES: Labeled items indicate that as of this point, more than 80 percent of site members had access to the feature. Does not include information from the Colorado Springs region, which has a network and not a group health delivery model.