

Personal Health Records to Improve Health Information Exchange and Patient Safety

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Abstract

The personal health record (PHR) is proposed as an innovative solution to the problems of fragmented communication and lack of interoperability among diverse electronic medical record (EMR) systems. It provides a single source (the patient's PHR) for authentication and remote access of the health information data from all EMR systems. A voluntary survey was offered to selected patients, caregivers, and health providers of the Willmar, MN, PHR project to determine if a PHR was useful to these stakeholders, and if so, what aspects of a PHR would be most helpful in caring for patients. The survey responses revealed nearly universal interest by both patients and health providers in using the PHR regularly for accessing and exchanging health information, including medication and medical history reconciliation and patient education. The highest utilization would result from a community-based PHR implementation that was owned and controlled by the consumer and was portable among providers, plans, and employers.

Introduction

Health information exchange through electronic interoperability of electronic medical records (EMRs) allows a person's health information to be immediately accessed by any approved health provider and would improve the safety and quality of health care, particularly during emergency care. The Institute of Medicine's report, *Preventing Medication Errors 2007*, states that poor communication and exchange of medical information at transition points for patients from one provider to another are responsible for many medical errors and adverse drug events.¹

There are substantial barriers, however, to the exchange of health information through the electronic interoperability among EMRs. Such an exchange would require extended technical and political processes and involve standardization and modification of current information systems. Electronic exchange of health information also raises questions about policies and procedures regarding confidentiality, security, and identity management. Many health providers are reluctant to give up confidentiality of their records, and many EMR vendors have found the process of creating complex algorithms to convert one database to another to be costly and time consuming.

As a result, only limited health information—such as demographics and immunizations—can be accessed through data exchange among information systems available today. To achieve the many benefits of interoperability—such as improvements in quality, safety, and the costs of

health care—new solutions are needed to integrate and exchange health information between different health care providers and consumers.

One solution involves the use of electronic personal health records (PHRs) as the center of a person's health information exchange. PHRs are considered by many to be an important part of this initiative.^{2, 3, 4, 5, 6, 7, 8} A PHR is a personal and secure set of online tools that connect consumers to their EMRs and empower them to manage their health, health care, and health care costs.^{1, 3} Various types of PHRs include those tethered to an EMR or health plan database, as well as those that are nontethered, independently hosted, and owned by the consumer.²⁻⁷ The nontethered PHR is proposed as an innovative solution to the problems of fragmented communication and lack of interoperability among diverse EMR systems by providing a single source for an individual patient (the patient's PHR) for authentication and access to health information data from all EMR systems.

A patient's PHR could include utilities for translating EMR databases into a standard format to allow health providers secure HIPAA-compliant electronic access. It also could include online educational tools and information to help consumers make the best decisions to improve the quality and cost of their own health care. The goal of interoperability of health data and its reconciliation into one source, the patient's PHR, can be achieved with a simple, inexpensive, and expedient process.

However, the PHR is a new concept that has yet to be fully developed and implemented. First-generation efforts have been an important initial step in testing the utility of PHRs, but their adoption by consumers has been slow. For example, despite considerable publicity, PHRs tethered to a health care plan have been used by less than 2 percent of the plan's members.⁷ The low initial utilization by consumers could be explained by several reasons, including slow adoption of new technology by consumers, lack of perceived ownership and transportability by the consumer, concerns about privacy and security issues, and lack of research into the utility and features that engage consumers.

This article discusses the implications and processes involved in using PHRs for health information exchange and presents the results of a study that evaluated the PHR features that drive utilization and improve health care safety and quality.

Methods

This project was initiated with funding from the Minnesota Department of Health, Stratis Health, and Avenet Web Solutions to implement PHRs in a defined population of congestive heart failure (CHF) patients who were involved in a collaborative CHF rehabilitation initiative in the rural community of Willmar, MN. The goals of the project were to improve participating clinics' ability to access patients' medical records through the PHR, improve health information exchange, and provide online education for patients.

A PHR was defined as a nontethered, consumer-owned, personal and secure set of online tools that connect consumers to their health information and provide e-tools to help them manage their health, health care, and health care costs. The study selected for development features of a PHR

that were of interest to consumers and had been studied previously.^{7, 8, 9, 10, 11, 12, 13, 14, 15, 16, 17, 18, 19}

A voluntary survey was mailed to all CHF patients, caregivers, and health providers involved the CHF collaborative, followed by mailed reminders to complete the survey. The participants were asked to determine if a PHR was useful to them, and if so, what aspects of a PHR would be most helpful in their own care. The sampling frame for the health providers included health care providers in the two practices that make up the Affiliated Community Medical Center and Family Practice Medical Center and the hospital health providers who had patients involved in the CHF collaborative. It also included all patients and identified caregivers who were involved in the collaborative between the hospital and clinics. A total of 440 surveys were mailed to patients and caregivers, and an additional 80 surveys were mailed to health care providers for a total sample of 520 surveys.

The features identified in the survey were then used to develop the PHR that best fit the needs of these stakeholders. Survey development was based on the results of focus groups with patients and providers and was approved by the University of Minnesota institutional review board (IRB) for research with human subjects. The purpose of the survey was described in a letter, which also asked participants to complete the survey and to answer questions about the features and functions of the myHealthfolio[®] PHR from Avenet Web Solutions (Figure 1).

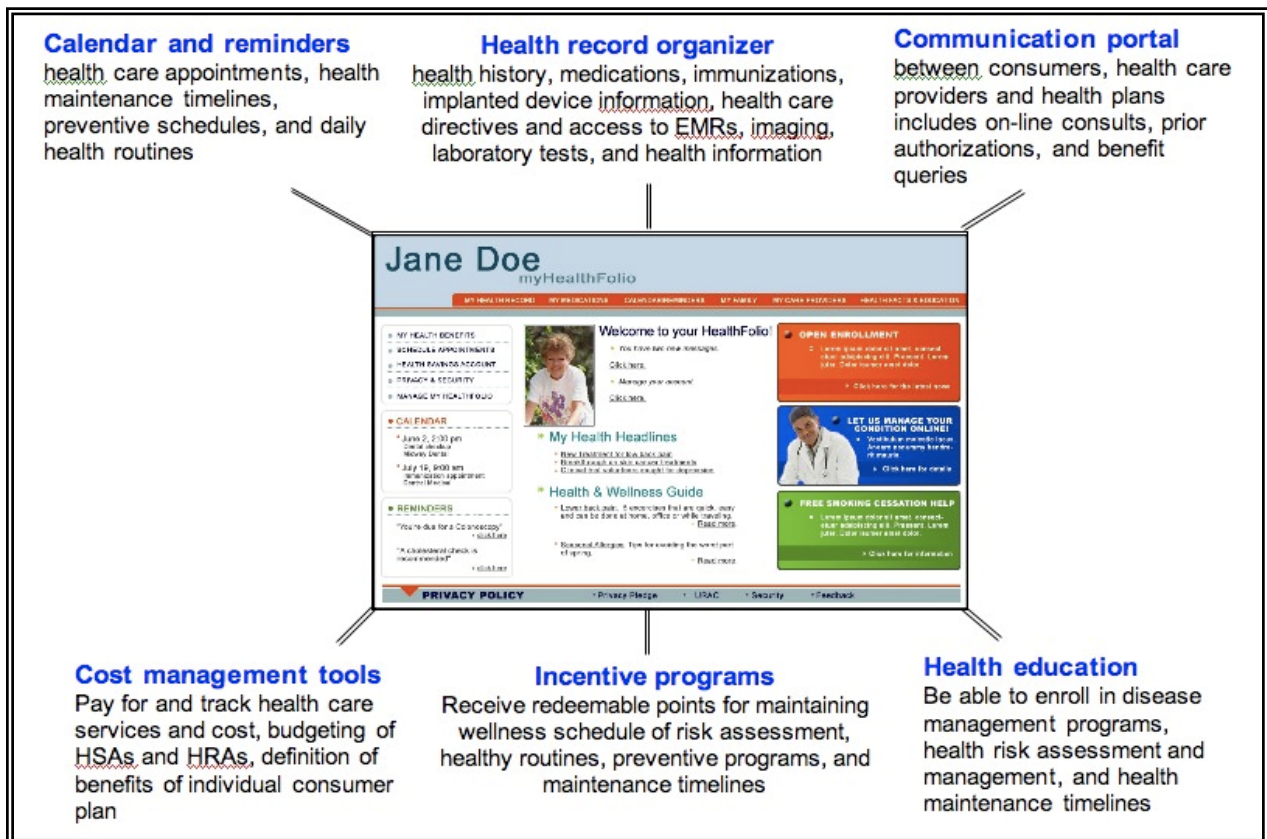


Figure 1. Summary of features and functions of the myHealthfolio[®] PHR from Avenet Web Solutions. (Reproduced with permission from Avenet Web Solutions, St. Paul, MN.)

The survey had two specific goals:

1. Ascertain the general level of interest and support from patients, caregivers, and health providers in using a PHR.
2. Determine which features would best motivate regular use of the PHR by this group.

The questions in the survey described each potential feature in the myHealthfolio and asked questions designed to elicit information about the following issues:

- Whether participants would use the feature.
- How often myHealthfolio would be used and, if not used, why not.
- General comments and concerns about myHealthfolio.
- Demographic and computer use characteristics of the survey participants.

Results

Of the 520 surveys mailed out, 182 were returned, including 84 patients, 49 caregivers, and 49 providers, for a response rate of 35.1 percent. The mean ages of respondents were 75.7 years for patients and 67.9 years for caregivers.

The Willmar survey results showed overwhelming interest in the use of the PHR by all groups, including the senior population (Tables 1 and 2). Health providers indicated the strongest interest, with 96.7 percent indicating interest in at least monthly use, and 67.4 percent indicating they would use it every week; 83.8 percent of caregivers and 78.1 percent of patients indicated they would use it at least monthly (Table 2).

Table 1 identifies the specific features of myHealthfolio in which respondents expressed the greatest interest. In general, respondents showed strong interest in PHR features, with interest in use ranging from 33 to 93 percent. The general features in which respondents indicated the most interest included:

- Organizing health records, including medication reconciliation (91 percent).
- Availability of online calendars and reminders (74 percent).
- Personalized health education (71 percent).
- Access to community services (69 percent).
- Online health communication with providers and health plans (60 percent).
- Health care cost management (57 percent).

All three groups expressed high interest in accessing and exchanging health information, including accessing doctor, laboratory, and hospital records (90.6 percent); organizing current health history, immunizations, registration, and health plan information (91.2 percent); and organizing medications (90.5 percent). This interest was across the board, with doctors, patients, and caregivers all expressing strong interest in accessing health information. There were no significant differences among the groups.

Table 1. Percent of patients, caregivers, and doctors/staff who indicated interest in using various PHR features

Would you use or recommend use of this PHR feature?	% (95% CI) responding "Yes"			Total
	Patient	Caregiver	Doctor/staff	
Order prescriptions from online pharmacies	42.9 (0.3, 0.6)	33.3 (0.2, 0.5)	65.2 ^a (0.5, 0.8)	47.1 ^a
Most current medication list that has been reconciled by the patient and doctors	85.3 (0.8, 1.0)	94.9 (0.8, 1.0)	91.3 (0.8, 1.0)	90.5
Check adverse effects, safety, and medical history conflicts of medications	78.5 (0.7, 0.9)	81.6 (0.7, 0.9)	73.3 (0.6, 0.8)	77.8
Access doctors' summary, imaging, and laboratory reports, and hospital records for a specific patient	87.9 (0.8, 1.0)	92.3 (0.8, 1.0)	91.5 (0.8, 1.0)	90.6
Access patient's most current health history, registration, and health plan information	88.1 (0.8, 1.0)	92.1 (0.8, 1.0)	93.3 (0.8, 1.0)	91.2
Give new doctors permission to access medical records	83.1 (0.7, 0.9)	92.1 (0.8, 1.0)	68.2 ^a (0.5, 0.8)	81.1 ^a
Health directives, e.g., end-of-life care, living wills	79.1 (0.7, 0.9)	76.3 (0.6, 0.9)	69.6 (0.5, 0.8)	75.0
Confidential doctor-patient e-mail, including online consultations	52.3 (0.4, 0.6)	58.8 (0.4, 0.8)	45.5 (0.3, 0.6)	52.2
Doctor-finder with contact information and background	70.8 (0.6, 0.8)	81.1 (0.6, 0.9)	43.2 ^a (0.3, 0.6)	65.0 ^a
Communicate with health care plans about claims, eligibility, benefits, and prior authorization	75.8 (0.6, 0.8)	78.9 (0.6, 0.9)	52.3 ^a (0.4, 0.7)	69.0 ^a
Online patient support groups for health issues	42.9 (0.3, 0.6)	37.8 (0.2, 0.6)	41.8 (0.3, 0.6)	40.9
Receive e-mail about health, drug, and implanted device alerts	51.6 (0.4, 0.6)	59.5 (0.4, 0.8)	59.1 (0.4, 0.7)	56.7
Health care fees for clinics, hospitals, and procedures, e.g., MRI scans, surgeries	67.2 (0.5, 0.8)	59.0 (0.4, 0.7)	45.7 (0.3, 0.6)	57.3
E-mail reminders for when and why to complete important preventive tests and conduct regular health care routines	84.8 (0.7, 0.9)	92.3 (0.8, 1.0)	45.7 ^a (0.4, 0.7)	74.3 ^a
Online self-management action plans for specific illnesses	75.8 (0.6, 0.8)	71.8 (0.6, 0.8)	67.4 (0.5, 0.8)	71.7
Online community services available for patients	73.8 (0.6, 0.8)	64.1 (0.5, 0.8)	69.6 (0.5, 0.8)	69.2
Frequency of using online resource for health information in the past year?	19.4 (0.1, 0.3)	46.2 (0.3, 0.5)	87.5 ^a (0.8, 1.0)	51.0

* Significant difference between groups, $P \leq 0.05$

Table 2. Estimated frequency (%) of personal health record use of selected features by survey participants

	Daily	Weekly	Monthly	Never	Total
Patient	4.7	20.3	53.1	21.9	64
Caregiver	5.4	21.6	56.8	16.2	37
Doctor	37.0	30.4	28.3	4.3	46
Total	15.0	23.8	46.3	15.0	147

Note: Selected features are identified in Table 1.

The feature of second highest interest to participants was patient education and empowerment. All groups expressed strong interest in receiving information on how to self-manage using personalized action plans for a specific illness, such as heart disease (mean, 70.1 percent). Patients and caregivers also indicated strong interest in receiving reminders for important diagnostic tests, medical checkups, and health routines (88 percent); doctors expressed significantly less interest in this feature (45.7 percent, $P < 0.05$).

All groups also expressed interest in having access to medication safety information (77.8 percent); documenting personal health directives, such as end-of-life care and living wills (75.0 percent); and accessing online information about community services available to patients (69.2 percent). Patients and caregivers indicated significantly more interest than health providers and doctors in online communication with patients or caregivers, health plans, or referring doctors ($P < 0.05$).

Discussion

Although the respondents represented a population of patients, caregivers, and health providers who were self-selected and most likely had more interest in health information than the broader population, the survey identified those features of the PHR that have the best potential to engage interested patients, caregivers, and health providers. Despite the fact that less than 50 percent of the population had ever accessed online health information previously, 85 percent had interest in doing so; accessing their own health records with their own PHR was the feature with highest interest.

These results support the conclusions of the two earlier PHR studies commissioned in 2003 and 2006 by the Markle Foundation and other PHR research.^{2, 20, 21} In a 2003 survey of a broad profile of 1,246 consumers, only 1.5 percent of respondents managed their health records on a computer, and 0.5 percent of respondents maintained their records online.² However, over 60 percent of respondents were interested in using at least one feature of an online medical record database now or sometime in the future. Additionally, 35 percent of respondents said they would use a complete online medical record (i.e., using 7 or more of the suggested 15 tools) if it were available to them.

A study of patients with irritable bowel syndrome found that the usefulness of patient-based information and communication technology had a theoretical framework that included promotion of a sense of illness ownership, patient-driven communication, personalized support, and mutual trust.²⁰ The authors state that simply providing access to electronic medical records has little usefulness on its own, but integrating this information into a patient-centered framework, such as the PHR, would go farther toward improving health care quality and health outcomes.

The 2006 Markle study²¹ of 1,003 adults nationwide using random digit dialing (RDD) probability sampling demonstrated continued interest in PHR and the ability to access consumers' own medical records. Two-thirds of respondents (65 percent) were interested in accessing their own personal health information electronically. Most respondents (88 percent) said that online records would be important in reducing the number of unnecessary or repeated tests and procedures they undergo; 90 percent said it would be important for them to be able to track their symptoms or changes in health care online. However, respondents also expressed strong concern that their information could be used for purposes other than their own care, including identity theft or fraud (80 percent) or the possibility that their information might get into marketers' hands (77 percent).

Despite privacy concerns about keeping medical records online, studies show that consumers still recognize the benefits of having medical records online so they can access medical information and improve safety and quality of care. One of the most commonly cited needs by health care providers and patients alike in the Willmar project involved the need for accurate medication and medical history reconciliation. This refers to identifying the most accurate list of all medications a patient might be taking at any point in time—including the name of each drug, dosage, frequency, and route—and using this list to provide correct medications for patients anywhere within the health care system. Reconciliation involves comparing the patient's current list of medications against the physician's or other health provider's orders.

Poor communication of medical information at transition points is responsible for as many as 50 percent of all medication errors and up to 20 percent of adverse drug events.¹ Each time a patient moves from one clinic or setting to another, clinicians need to review previous medication orders alongside new orders and plans for care and then reconcile any differences. If this process does not occur in a standardized manner that is designed to ensure complete reconciliation, medication errors could lead to adverse events and patient harm.

Although medications are ordered through physicians and noted in a patient's medical record, and prescriptions are filled by pharmacies, patients ultimately are the final source of information about which medications they are currently taking (including prescribed and over-the-counter drugs), which health care providers have prescribed them, and which pharmacy filled the prescriptions. Thus, the PHR can play an important role in medication reconciliation, particularly, if medication data from multiple EMR sources can be transferred and integrated into the patient's PHR and then reconciled by the patient.

Once stored in a PHR database, medication lists can be integrated and patients can periodically review them to determine the status of their medications at any point in time. This reconciled

medication list in the PHR also can be viewed by health care providers to confirm and update the status of specific medications. The same process can occur with medical history items.

There were problems in the deployment of the PHR in our study. For example, the policy issues of determining which health information from EMRs should be routinely available to patients and how best to secure that information were controversial. Although many physicians acknowledged the importance of patient access to health information, they indicated a greater interest in routinely sharing laboratory, imaging, and medication data but not progress notes or consultation reports. EMR vendors' reluctance to share the costs of developing common health information exchange interfaces with a PHR was a financial obstacle that would need to be overcome. Finally, the lack of use of the computer by 80 percent of the patients became an issue as implementation progressed. However, in most cases in this study, the burden of collecting, conveying, and using health information was often seen as the responsibility of health care providers and caregivers, thus explaining the stronger interest in these groups in the use of the PHR.

Deployment of a PHR has great potential for improving health education, personal health empowerment, health and wellness for consumers, and ultimately lower health care costs.²² For this reason, the Minnesota e-Health Initiative has a stated goal for Minnesota that all residents will have access to a personal health record that is secure, portable, standards-based, and consumer controlled by 2015.²³

The processes associated with developing and selecting features of the PHR are critical to whether it will be successful in engaging consumers sufficiently to improve their health and reduce health care costs. Although first-generation efforts have been an important beginning in testing the utility of PHRs, their adoption by consumers has been slow. The low initial utilization by consumers might be attributed to several reasons, including:

- Slow adoption of new technology by consumers.
- Lack of ownership and transportability by the consumer.
- Privacy and security issues.
- Poor application of health literacy principles in consumer interfaces.
- Lack of research in the utility and features that engage consumers.
- Inclusion of features that do not engage consumers.
- Low ease of use with low level of intuitive and personalized features.
- Little inherent motivation and incentives.
- Lack of interoperability with medical records and use by health providers.

There are several options for facilitating wide use and broad implementation of PHRs. The results of this study suggest that a community-based implementation that allows the PHR to be owned and controlled by the consumer and be portable among providers, plans, and employers would be better utilized. Other characteristics that are attractive to both patients and health providers included:

- User-controlled access to the PHR, including which parts of the PHR can be accessed, by whom, and for how long.
- A permanent lifetime health information portal that is interoperable with electronic medical and dental records from all providers.
- Tools to improve health decisionmaking regarding care and cost by the consumer.
- Privacy, security, and HIPAA compliance.
- “Transparency,” i.e., possible to see who entered each piece of data, where it was transferred from, and who has viewed it.
- Ease of use, personalized, and intuitive with an appropriate level of health literacy.
- Community-based efforts to support a regional health information organization that permit easy exchange of information with other health information systems and health providers as approved by the owner.
- Accessible from any place at any time.
- Training on how to maximize its use.
- Incentives to use the PHR to improve consumer health and health care costs.

Conclusion

This study demonstrates overwhelming interest in the use of PHRs by patients, caregivers, and health providers alike. It also identified the features that have the best potential to engage patients, caregivers, and health care providers, and it supported previous research in the field. There was nearly universal interest in using the PHR regularly for accessing and exchanging health information, including medication, medical history reconciliation, and patient education and empowerment. It is recommended that a community-based implementation allow the PHR to be owned and controlled by the consumer and be portable among providers, plans, and employers to create high utilization. Future research is needed to determine the impact PHRs might have on actual health behaviors and health care costs and to address larger questions regarding financial issues of implementation and use, including documentation of cost savings and expenses related to PHR use.

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