Embracing a Health Services Research Perspective on Personal Health Records: Lessons Learned from the VA My Health*e*Vet System

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BACKGROUND: Personal health records (PHRs) are designed to help people manage information about their health. Over the past decade, there has been a proliferation of PHRs, but research regarding their effects on clinical, behavioral, and financial outcomes remains limited. The potential for PHRs to facilitate patient-centered care and health system transformation underscores the importance of embracing a broader perspective on PHR research.

OBJECTIVE: Drawing from the experiences of VA staff to evaluate the My Health*e*Vet (MHV) PHR, this article advocates for a health services research perspective on the study of PHR systems.

METHODS: We describe an organizing framework and research agenda, and offer insights that have emerged from our ongoing efforts regarding the design of PHR-related studies, the need to address PHR data ownership and consent, and the promotion of effective PHR research collaborations.

CONCLUSION: These lessons are applicable to other PHR systems and the conduct of PHR research across different organizational contexts.

KEY WORDS: personal health records; health information; health services research; PHR.
J Gen Intern Med 25(Suppl 1):62–7
DOI: 10.1007/s11606-009-1114-6

INTRODUCTION

Recent advances in information and communication technologies have enabled the development of comprehensive tools intended to support greater consumer participation in their healthcare.[1–3] The personal health record (PHR) is one such tool that has potential to dramatically shape the contemporary healthcare landscape. Whereas electronic health records (EHRs) and systems (EHR-S) are collections of health information that are managed by healthcare providers, PHRs are designed to address the health information needs of consumers. Although there is variability in functionality across systems,[4–11] most PHRs share a basic goal: "to give patients better access to their own healthcare data and enable them to be stewards of their own information."[12]

According to the American Health Information Management Association (AHIMA), the PHR is "an electronic, lifelong resource of health information needed by individuals to make health decisions. Individuals own and manage the information in the PHR, which comes from healthcare providers and the individual. The PHR is maintained in a secure and private environment, with the individual determining rights of access. The PHR does not replace the legal record of any provider."[13] Currently there are more than 200 PHR systems available.[14] Many early PHRs were "static repositories,"[15] but more recently there has been a shift towards web-based PHRs that are integrated with or "tethered" to an EHR-S.[11] Tethered PHRs can bring together data created and stored by the individual with that from the EHR, thus offering a range of functionality.[11,16,17]

The enthusiasm surrounding the development of PHR systems can be attributed to the anticipated value that PHRs hold for consumers, healthcare providers, financers, and other stakeholders;[5,11,12,14,18] however, such perceived benefits extend beyond what is currently known about their use and effects. The perspectives of healthcare providers suggest both excitement over the potential benefits of PHRs and concerns surrounding their impact.[4,5,12,19–22] Trends in consumer survey research reflect limited access to electronic PHRs but suggest growing interest in using them.[23–26] Despite this expressed interest, it remains difficult to anticipate the manner in which different communities of users may ultimately choose to adopt PHRs.

Initiatives undertaken to inform the course of PHR development[27,28] and to articulate important architectural and policy recommendations[29] represent a foundational response to persistent calls for more substantive PHR research;[30] yet, the lack of research demonstrating the value of PHRs to stakeholders poses a threat to their long-term viability and sustainability.[16] Research regarding the effects of PHR use on patient and provider experiences, behavior, costs, and clinical outcomes remains underdeveloped.[11,16] Studies that move beyond a technical focus to embrace a broader health services research perspective on PHR systems are needed to promote further adoption, enhance patient-centered care, and realize the anticipated potential for health system transformation. Health services researchers are in a unique position to address this gap in the evidence base, but doing so will require careful attention to the formulation of research questions and study designs, the prioritization of research areas, and an accounting of the unique factors inherent in PHR research.

In 2003, the Department of Veterans Affairs (VA) introduced My Health*e*Vet (MHV), a web-based PHR intended to complement traditional services, improve co-managed care, and empower patients and their families to play a more active role in veterans' health. Below we describe the MHV PHR and efforts to evaluate the impact of its use on veterans and the VA healthcare system. Drawing upon the VA experience, we describe salient PHR research questions and potential study design issues. We identify important factors inherent to PHR research that we have thus far identified, and offer lessons learned that can inform research and evaluation efforts surrounding PHR systems across different contexts.

BACKGROUND

My HealtheVet System Overview

My Health*e*Vet (http://www.myhealth.va.gov) is an integrated PHR that includes health information entered by Veterans, data from VA's unified EHR-S, health education information, health management tools, and links to other resources.[31–36] The system represents collaborative work between multiple offices in VA. The Veterans and Consumers Health Informatics Office (V/CHIO), a division of the Chief Health Informatics Office (CHIO), identifies strategic priorities, coordinates with policy experts, and translates MHV goals into business, functional, and technical requirements, based on veteran and consumer needs and preferences. Other offices perform the technical lifecycle tasks of requirements management, system development, testing, and run-time operations. Hereafter, we refer to this partnership as the MHV Program Office, a functional model that represents the full range of strategic and technical activities. The MHV Program Office is advised by a multidisciplinary Clinical Advisory Board (MHV CAB). From an organizational perspective, this approach yields multiple benefits, including the direct alignment of program goals and resultant PHR design and development strategies with the overarching objectives of VA and its partners.

There are three levels of MHV access, with a progressive increase in functionality (see Table 1). First, portions of MHV can be accessed by anyone with an Internet connection. Second, veterans can create an account by performing an online registration, which provides them with functions not available to the general public. Third, veterans who choose to complete a onetime in-person identity verification at a VA medical center, referred to as "in-person authentication" (IPA), can also view a growing array of additional information extracted from the VA EHR-S. As of July 2009, MHV has been visited over 28 million times, more than 810,000 people have registered (16.3% of veterans currently receiving VA healthcare services), and over 130,000 veterans have completed the IPA process.[37,38] Veteran feedback obtained through the American Customer Satisfaction Index (ACSI) Survey, an industry standard tool for measuring satisfaction and prioritizing improvements,[39] is used to guide system redesign and the addition of new features.

Developing an Evaluation Approach for MHV

The MHV Program Office is working to pursue a robust PHR evaluation program that moves beyond studies focused solely on technological or system concerns to those that reflect a broader health services perspective. Inherent in this shift is a fuller accounting of the social, clinical, and organizational contexts in which PHRs are used. Each of these dimensions is important to identifying optimal PHR features and assessing system impact. Several MHV-related projects initiated by members of the VA research community were not formally designed as part of the Program Office's evaluation effort, but together reflect commitment to an encompassing approach. For example, the MHV Program Office has partnered with the Stroke Quality Enhancement Research Initiative (QUERI) to create age-appropriate, culturally relevant materials for caregivers

Table 1. My Health*e*Vet Personal Health Record Features

My Health*e*Vet Personal Health Record feature key: V = all site visitors R = registered users A = authenticated users (IPA)	V	R	A
General information and resources: Access information about Federal and VA benefits and resources, VA-related news and events. Link to additional resources	X	X	X
Research health: Browse and search collections of evidence-based health information including Healthy Living Centers, Condition Centers, and medical databases. Access health screening tools, mental health resources, and articles	X	X	X
My HealtheVet Learning Center: Take online courses to promote mental health	X	X	X
Personal information: Store and maintain contact information including emergency contacts. Manage account profile, preferences, and options		X	X
Get care: Store and maintain information pertaining to caregivers and providers, treatment facilities and locations, and health insurance coverage		X	X
Health information card: Print selected personal and medical information on a pre-formatted wallet card for a convenient reference		X	X
Personal health history: Record important health history information and events		X	X
Family health history: Record family member's health history and events that may affect health		X	X
Military health history: Record important events from military service including assignments related to health history, potential exposures, and treatments		X	X
Personal health summary: Select information to print out as a personal health summary report to share with providers		X	X
Health eLogs: Track and graph common health measures (blood pressure, blood sugar, cholesterol, body temperature, weight, heart rate, pain, pulse oximetry, INR)		X	X
Allergies: Record allergies by date, severity, reaction, diagnosis, and add comments		X	X
Immunizations: Record the immunization, date, method used, and any reactions		X	X
Tests: Record tests by test name, date of test, location where the test was performed, provider's name, results, and add comments		X	X
Medical events: Keep track of illnesses, accidents, or other events by logging the date, treatment prescribed, and any comments regarding the event		X	X
Food and activity journals: Record food intake to monitor diet or control weight, and keep track of exercise routines. Print journal worksheets for easy tracking		X	X
Health calendar: Add events, set reminders, utilize a to-do list		X	X
Medications, over-the-counter drugs, herbals, and supplements: Record the name, starting and ending date, prescription number, and dosage		X	X
Prescription refills: Request refills for VA prescriptions online (authenticated users can view medication names when ordering refills)		X	X
VA prescription history: View a record of all VA prescriptions			X
My complete medications: View and print a complete summary of both VA and self-entered medications to support medication reconciliation			X
Wellness reminders: View customized reminders for preventative care and screens			X
Secure messaging: Exchange secure electronic messages with your healthcare team for non-urgent needs (currently available at 8 sites with further expansion planned)			X

of stroke survivors.[40] Other research studies are currently underway, including studies focused on usability testing,[41] use of MHV as a communication tool for health screening,[42] development of a MHV Healthy Living Center dedicated to spinal cord injury,[43] and the integration of evidence-based tools to assess heart failure care according to published VA guidelines.[44] As we discuss below, close working relationships between PHR system providers and researchers can be instrumental in sustaining such efforts.

We recognized the need for a broader organizing framework in order for VHA to utilize its significant research expertise to optimize the MHV system. The Performance Evaluation Workgroup of the MHV CAB, whose task it is to guide system evaluation efforts, is currently using an extension of the RE-AIM (Reach, Efficacy/Effectiveness, Adoption, Implementation, and Maintenance) framework[45] as a model for assessing the impact of MHV on the veteran population. This framework supports a comprehensive evaluation effort and has resulted in the identification of a number of high priority research areas as shown in Table 2. These range from extending the reach of the program in the veteran population to examining cohorts of users with respect to utility, outcomes, and cost. Ongoing efforts to evaluate the MHV PHR have revealed a number of insights that can inform similar work regarding other PHR systems. In the remainder of this paper, we discuss these lessons and offer examples from our work with MHV, as appropriate.

LESSONS LEARNED FROM A HEALTH SERVICES RESEARCH PERSPECTIVE ON PHRS

Posing Research Questions and Designing Studies

Our experiences underscore the point that many kinds of research questions can be posed in relation to PHRs. Organizations that provide PHRs are generally interested in knowing who is using the system and for what purpose(s), how the design affects use, and whether the content has perceived value. Health services and other researchers, however, are likely to also be interested in additional aspects, including how PHRs can be used to improve patient outcomes, eliminate health disparities, and deliver interventions.

PHR-related studies may entail designs that require engaging PHR users as study participants, or, with their consent, accessing the data that they store in their PHR (e.g., blood pressure readings) as a means of monitoring outcomes. Delineating between research for the purpose of PHR evaluation and studies that utilize the PHR in the course of an intervention is critical. Each approach requires different methodologies and types of collaboration to ensure that goals are clearly identified, and that adequate safeguards are applied to support user needs and expectations. In the case of MHV, the Program Office has thus far emphasized research on users, expecting to address the issue of delivering evidence-based interventions through the system in the future. The scenarios

Table 2. MHV PHR Research Agenda by RE-AIM Domain

RE-AIM domain	MHV program goal	Research priorities
Reach: the number, proportion, and representativeness of individuals who utilize the MHV PHR	Increase enrollment of the veteran population served by the MHV program	• Assess level of awareness in the veteran population and identify effective improvement strategies • Characterize users in comparison with the veteran and VA patient populations • Identify target populations who can most benefit from use
Effectiveness: the impact of MHV PHR utilization on users, outcomes, performance, and organizational systems	Utilize MHV to enhance access to services, improve behavioral and health outcomes, improve quality, increase satisfaction, and enhance system efficiency	• Validate and extend initial analytic findings from user surveys • Examine cohorts of users to evaluate impact on utilization management (access), behavioral and clinical outcomes (quality), cost (value), and satisfaction • Identify how MHV can enhance access to services for rural or special populations • Evaluate impact on workflow, workload, VA performance measures, and organizational processes
Adoption: use of the MHV PHR by veterans and their caregivers, healthcare providers, and healthcare teams	Increase adoption of MHV by veterans, providers, and healthcare teams	• Elicit perceptions of veteran and provider nonadopters • Identify barriers to adoption and develop strategies to address • Examine the current authentication process and identify ways to improve
	Increase levels of engagement and activation with MHV among patients and providers	• Demonstrate clinical utility of MHV components • Compare clinical adoption across settings • Identify communication and process strategies for integration of MHV within clinical practice
Implementation: the efforts and costs involved in implementing the MHV Program	Implement the MHV program nationwide in the most equitable, effective, and efficient manner; enhance program value	• Examine how to prevent further health disparities by exploring issues of access, health literacy, and computer literacy • Evaluate cost/benefit impact of MHV use • Identify optimal implementation strategies
Maintenance: the long-term effects of MHV PHR use and program sustainability	Utilize MHV to enhance and sustain desirable long-term outcomes	• Track long-term impacts on targeted outcomes (access, quality, value, satisfaction) • Identify effective engagement strategies to support sustained MHV use • Explore program enhancements (usability) and expansion (interoperability) • Analyze MHV program sustainability

provided in Table 3 illustrate different ways that a PHR could be employed in intervention studies, either as a vehicle through which to deliver an intervention or as the intervention itself.

A related and particularly challenging issue that warrants mention is that most PHRs are “live systems” with corresponding populations of users. As such, researchers must develop innovative study designs to investigate continually evolving PHR systems and contexts of use. In the time it takes to publish study results, a PHR may have undergone significant changes in terms of content and functionality. Using a PHR to deliver an intervention may also have the effect of making the system even more dynamic and difficult to characterize.

Addressing Issues of Data Ownership and Consent

In contrast to EHR systems, which are predominantly owned and operated by the system provider, PHRs are based on consumer control and management of their own data. In the

Table 3. Potential Scenarios for Research Involving PHRs

Study type	Description
1. Accessing data stored within the PHR	A researcher would like to link information from the PHR with patient medical records. In particular, he is interested in looking at blood pressure rates over time, as entered by patients into the PHR, with patient consent, and linking this information to pharmacy and laboratory data for particular medications with the goal of relating patient outcome (blood pressure control) with medication use
2. Delivering an intervention through the PHR	A researcher is interested in improving patient self-management of diabetes through a healthy diet, regular exercise, and regular monitoring of blood sugar. She wants to provide a series of self-help exercises and educational materials through the PHR
3. Utilizing the PHR as an intervention	Through the use of secure messaging, the PHR could be used to facilitate adherence with requirements for elective surgery (e.g., details for arrival check-in, preoperative instructions such as stopping certain medications)

case of MHV, the overall system is managed by the VA, but the content of the PHR is the property of the veteran. Privacy and security are paramount, and researchers who design studies that include access to PHR data must explicitly obtain the informed consent of consumers. These consent processes must recognize the PHR user as the data owner, protect the integrity of PHR data, and still offer PHR users the opportunity to participate in research intended to enhance the system, improve user experience, or strengthen positive outcomes based on effective use.

Engagement of PHR users in research must also ensure that participation is voluntary and that participants have a clear understanding of the level of data-sharing expected. Organizational policy development must include a review of formal agreements between PHR providers and PHR users regarding the maintenance and protection of data, including the PHR terms and conditions, privacy policy, and system of records. From a technical perspective, the development of standardized processes to support access to data is crucial for future research efforts. For example, analysis of application activity logs could reveal patterns of activity independent of user identity, facilitating key insights about PHR usage. For studies that involve PHR users as consenting participants, user delegation of access to specific PHR data may allow researchers to draw upon patient self-reported data and link it to patient data from medical records and other sources to evaluate outcomes. At VA, this delegation functionality has been successfully piloted with an earlier prototype; however, it is not yet available in the national MHV PHR.

Promoting Effective Working Relationships

Efforts to foster PHR research reveal the importance of multidisciplinary collaboration. Processes and policies must attend to the varying objectives, needs, and requirements of PHR providers and researchers to enable effective collaboration. To the extent possible, approaches to collaboration should leverage existing institutional research policies, structures, and processes rather than recreating or duplicating them, accounting as necessary for nuances specific to PHRs. Development of a research agenda to identify high priority areas of study, similar to that shown in Table 2 for MHV, is one way to address this issue. Additionally, an organizational infrastructure is necessary to develop sustainable research collaborations. Such infrastructure can help guide and support research in ways that align with the vision of system designers and stakeholders while preserving the trust of PHR users.

Discussions with VA researchers have also identified practical tools which can further support research, such as the incorporation of a survey engine within MHV to efficiently host survey research. The development and dissemination of a standardized data dictionary has also been proposed. Such a tool would describe relevant data elements important to PHR research, along with any data-specific constraints. A study currently funded by VA is identifying the data elements and technical infrastructure needed to support MHV research.[46] For each type of PHR data, formal processes must be established in order to enable appropriate access for Institutional Review Board (IRB)-approved studies.

CONCLUSION

Significant further work is needed to understand the use of PHRs as integrated tools that complement traditional care, and to identify the impact of their use on patients, providers, organizations, and healthcare systems. In particular, identifying the effect of PHRs on clinical, behavioral, and financial outcomes will be critical in fostering the cultural transformation and uptake needed to make PHRs an integral part of the fabric of healthcare. These interests are well aligned with health services research. Organizations that offer a PHR or intend to develop one will benefit from elucidating specific PHR research priorities, identifying and addressing research barriers, and finding pragmatic ways to support research efforts.

The lessons that we have thus far learned from our efforts to study MHV are not unique to the system itself or to the VA as an institution. PHRs are new tools intended to support patient-centered healthcare. As such, priority must be given to issues inherent to PHRs, including data ownership, access, privacy, and confidentiality. Organizational policy development must be guided by emerging national privacy policy frameworks, provisions, and laws.[47,48] Technical solutions to foster effective research programs must be driven by organizational policy that ensures adequate protection for users while enabling rigorous investigations. Collaborative approaches that connect PHR system providers with the skills and expertise embodied in research communities are essential to support studies that will optimize PHRs and their use. At the center of this work is the PHR user. As researchers and PHR providers, we must offer clear information about data management policies, privacy and security policies, analysis procedures, and opportunities to participate in research, all while maintaining the integrity of consumer trust. Only in this way can we enable a deeper understanding of the PHR as a contemporary tool and a potentially transformative force in health care.

Conflicts of Interest: *None.*

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