

Questions for PHR Panels - GRAHAM

1. What is the problem you are trying to solve with your PHR/service/offering? What is your business objective?

Response:

The Department of Veterans Affairs (VA) views the Personal Health Record (PHR) as a tool for optimizing patient healthcare. VA's PHR, MyHealthVet, started as a trusted source of health information including resources on health issues unique to Veterans. It continues to expand as an online tool providing direct access to information from the VA electronic health record (EHR).

The My HealthVet Program is based on the core belief that knowledgeable patients are better able to make informed health care choices, stay healthy, and seek services when they need them. The overarching goal of My HealthVet Program is to empower Veterans to become more informed partners in their health care by providing them secure, convenient access to their personal health information.

My HealthVet's features include access to trusted patient health education information, links to Federal and VA benefits and resources, a comprehensive personal health journal, health calendar, online requests for VA prescription refills, VA Wellness Reminders and more. The program was released in November 2003; since then VA has continued to incrementally enhance features and services.

2. What is the business model for your offering? Its funding source?

Response:

VA's Personal Health Record, My HealthVet, compliments traditional medical services by expanding Veteran access to healthcare beyond the walls of the healthcare facility. The purpose of MyHealthVet PHR is to maximize Veterans' involvement in their care, foster improved partnerships among members of the Veteran's healthcare team, and support Veteran wellness through prevention and control of chronic disease.

My HealthVet serves as a tool both for communication and delivery medical services. My HealthVet integrates VA business functions within a single portal, providing features such as online refill request functionality for VA prescriptions, and patient-provider Secure Messaging communication. Secure Messaging between patients and care providers potentially could reduce the need in some cases for a traditional office visit, thereby improving overall patient access to healthcare. NOTE: Secure Messaging is currently available at a limited number of VA locations as VA ensures alignment with clinical workflow, solicit feedback from early adopters, and identify needed enhancements to optimize the service for both Veterans and their health care team.

My HealthVet is funded with federally appropriated funds.

3. How do you envision your offerings, as well as the Health IT industry, and patient-facing online services, evolving over the next 5 or 10 years?

Response:

At VA we envision limitless possibilities for the role of the Personal Health Record in patient-centered care. The Markle Foundation's Connecting for Health describes the PHR as follows:

"An internet based set of tools that allow people to access and coordinate their lifelong health information and make appropriate parts available to those who need it. PHRs offer an integrated and comprehensive view of health information, including information people generate themselves" (2003).

Currently, VA's My HealthVet fits this description; the next steps in its evolution will include development of online authentication functionality to reduce user burden of In-Person Authentication, currently required for access to certain features.

VA will further increase access to personal medical and health-related information through development of tools that will enable Veterans to access to additional parts of the electronic health record (EHR). This will include tools that allow Veteran users to delegate access to parts or all of the PHR and to export and import EHR information. Further, VA will expand the potential for patient-provider online Secure Messaging to foster timely communication to improve health, and to increase access.

4. How do you envision the relationships among PHRs, electronic health records, providers, plans, health information exchanges, etc. evolving over the next five or ten years?

Response:

We envision seamless interoperability among PHR, EHRs, providers, plans, exchanges and others to provide enhanced value to the patient as a healthcare consumer. Consumers value the convenience of electronic services and transactions, such as the ability to refill prescriptions, schedule appointments, and communicate electronically with their healthcare providers.

For consumers, medicine and healthcare are local paradigms impacted by personal preferences, and influenced by individual definitions of "value." Some of the ways in which health information exchange through interoperability adds "value" to consumers, is by enabling timely and convenient consumer access to EHR information such as laboratory test results; enabling providers who care for patients access to the full range of data and information about a particular patient (including both data provided by the patient and that provided by other health care providers and organizations); decreasing the need for patients to provide duplicate information at each interaction with the health care system; and avoiding the occurrence of duplicate tests, contraindicated medications, and unnecessary visits.

From the patient's perspective, interoperability is successful from when the patient can connect to accomplish tasks across multiple entities across the healthcare system. For

example: a patient would be able to send a secure electronic message to a primary care provider and obtain a prescription renewal informed by laboratory test results, perhaps from a different health care provider or laboratory, and supported by a comprehensive review of a complete medications list, enabling a prescription refill at the local pharmacy deemed as “covered” by the patient’s health insurance.

Privacy and security also are of paramount importance to consumers, and this highlights the need for interoperability to address authorization and access in ways that are clear and meaningful for patients. As we progress in the areas of interoperability and health information exchange, care must be taken to also develop this “content” so that it is easily understood by patients and leads to actionable interpretations.

5. How does information come to reside in the product or service you are offering?

Response:

VA’s PHR includes Veteran self-entered information, information from the VA electronic health record, and access to trusted health information resources including evidence-based health information libraries.

6. What information do you give participants when they sign up?

Response:

My HealthVet incorporates government and industry standards for security and privacy, including:

- *a state-of-the-art technical infrastructure*
- *systematic testing to ensure system security*
- *software monitoring tools to detect any unusual activity*
- *requirements for complex username/password combinations*
- *access-auditing that generate a historical record of changes*

My HealthVet has received multiple awards and has been recognized for its safety and security measures.

The My HealthVet Pilot began in 1999, providing VA practical experience with the demand and benefits of identity proofing and user authentication. As a result, VA has continued to actively contribute to development and evolution of these standards. Recognizing the great need for privacy and security of health information, VA developed authentication guidelines to meet emerging standards by which authentication and identity management can be assured.

Identity proofing and user authentication is addressed in the My HealthVet Personal Health Record in a Health Insurance Portability and Accountability Act (HIPAA)-compliant tiered model that aligns increasingly rigorous requirements with increasing levels of access to information.

- **Web site visitors may access patient health education content through the site's evidence-based health information libraries without registering or logging in.**
- **Web registration is required to utilize additional program features such as self-entered health journals and health e-log. Initial registration via the website is accomplished by the completion of a web based form and complex passwords are required in order to safeguard user information.**
- **In Person Authentication, a one time process of "face-to-face proofing", is required to enable features that include personally identifiable health information from the EHR. The In Person Authentication process involves the following steps:**
 - *Veterans must present at a VA facility or VA designated location and display two forms of photo ID or a new Veterans Identification Card (VIC). Valid photo ID may include a driver's license, passport, or other government ID.*
 - *This initiates an electronic transaction to match the user's information with the VA Master Patient Index (MPI) using the Social Security Number and other data elements as a key identifier. This matching is critical to connect the patient to functions like prescription refill and health information extracts.*

7. What are you most concerned for them to understand about what you're offering?

Response:

The VA My HealtheVet PHR is based on a foundation of trust in which the Veteran user's privacy and security is paramount. It is important for Veterans to understand their rights and obligations in maintaining this trust relationship, for example by safeguarding their username and password information. From a practical perspective, VA is committed to ensuring that PHR "content" is easily understood by patients and leads to actionable interpretations and health-promoting behaviors.

8. What kinds of privacy protections and policies are you building in to your product/service?

Response:

MyHealtheVet data is securely stored in a VA Data Center behind VA firewall protections. User access to individually identifiable information through MyHealtheVet requires In Person Authentication. Synchronization ensures that key data elements are standardized.

9. Do you reserve the right to change those policies? Have there been any changes to date?

Response:

Yes, VA reserves the right to change specific privacy protections and policies built into MyHealtheVet. For instance, as technology evolves VA anticipates transitioning to an

online authentication model to replace In Person Authentication. In the past, we have updated the My HealtheVet PHR Terms and Conditions as needed when, for example, different data sources have become via extracts from the EHR.

10. What kinds of issues have you grappled with as you develop privacy policies?

Response:

As we began to release portions of the electronic health record through our PHR we grappled with several challenges:

- *Determining if certain health information should be immediately available or if there should be a structured delay to enable time for clinicians to convey results to patients first. And, if there is such a hold, determining how long should it be (one, two, five or, seven days for example?), and if the hold should be longer for information such as abnormal laboratory results?*
- *Following existing VA policies regarding release of specific results such as HIV test results, which by policy require pre- and post counseling of patients.*
- *Applying research protocol. Initially VA did not have a provision in the Privacy Act System of Record notice for My HealtheVet to allow access for research that will be important to optimal development of the program. This is being revisited at this time to enable informed opportunities for Veterans to participate in My HealtheVet-related research if they choose to.*
- *Ensuring that privacy policies convey rights and responsibilities in clear language that is easily understood by Veteran users.*

11. What is your experience of the public's questions or concerns with these policies?

Response:

Some Veterans find the In-Person Authentication (IPA) process to be burdensome.

12. How have you attempted to address concerns presented by members of the public?

Response:

VA is actively testing alternative means of accomplishing authentication including online authentication for My HealtheVet, in conjunction with the Veteran enrollment process and Veterans Identification Card issuance. . Trying to support maximum access, VHA's Health Information Management office is also evaluating the practice of allowing visiting nurses to perform the in person authentication as well

13. In what ways is the model notice proposed by HHS helpful to you, or not helpful? How would you modify it to be more useful to your business?

Response:

We believe the model notice proposed by HHS would be helpful in efforts to standardize and simplify the language of notices, and this would directly benefit the consumer.

14. What challenges do you find in managing individuals' authorizations and consumer-directed access to their PHRs?

Response:

Challenges to managing individuals' authorizations and consumer-directed access to their PHRs include a lack of understanding on the part of consumers of the current requirements for In Person Authentication. The geographic restrictions inherent in this policy represent a significant challenge.

15. Should data subjects be able to add to, change, or amend their records in a PHR? Can yours?

Response:

Under the HIPAA Privacy Rule and the Privacy Act, Veterans have had the right to request amendments to their health record, both in the paper and in the electronic world. Instructions on how to request such an amendment are available on the My HealtheVet Website. Veterans are not allowed to change, edit, or amend the VA- provided electronic health record data that is part of the My HealtheVet PHR for VA patients who have been authenticated. Veterans may request an amendment to their electronic health record as the data source, and subsequent PHR extracts will reflect these changes.

Veterans are allowed to add to, change, or amend all portions of their self-entered data within the PHR.

16. What were the areas that you had to focus on to ensure that you had adequate consumer support for your product/service?

Response:

VA enlisted the support of the National Veterans Service Organizations from the initiation of the My HealtheVet Program. VA utilizes Veteran and clinician focus groups to maximize PHR usability and to assess the most desired functionality. An industry-standard customer satisfaction survey tool (the American Customer Satisfaction Index) has been used since October 2007 in order to track satisfaction and to solicit Veteran needs and preferences. We ensure that a help desk is available to provide assistance to Veterans and to respond to questions as they arise. Trends are examined in order to develop strategic and responsive approaches, such as the development of an online password reset tool. We ensure that the site architecture is scalable and have strong technical and process provisions to ensure continuity of operations. VA also has a named coordinator in each of our Medical Centers so that the Veteran has an individual with whom to interact.

17. How are you dealing with particularly sensitive categories of information?

Response:

VA is incrementally providing access to electronic health record data in MyHealtheVet; beginning with pharmacy and the enabling of pharmacy refill functionality. We are in

the process of adding laboratory and radiology results as well. We have piloted Veteran access to provider progress notes with 7,500 testers to identify the challenges and consequences associated with release of progress notes within the PHR. One of the challenges we anticipate with progress notes is the interpretation, and we are examining work being done by Group Health and others to provide a more easily understood summary of the visit.

We are also piloting delegation within the PHR and in this model the Veteran can delegate access to a family member, caregiver, or non-VA clinician, for example. Granular control is desirable, and in this pilot, a Veteran can specify the type of information shared, and the duration of this access.

18. As a vendor, are there any type of medical records that your company will not include in a PHR? For example, will your PHR seek or accept records subject to the HHS Substance Abuse rules and the strict re-disclosure regime that it imposes on recipients (even those who obtain records with patient consent)?

Response:

We do not consider release of information to the Veteran patient to be a disclosure. The existing disclosure protections are to assist the patient with control of the disclosure of information, not to keep information from the individual.

We have incrementally enabled access to electronic health record information in My HealtheVet to gain experience as we explore areas such as mental health, substance abuse and other areas that may require additional review.

19. To what degree are patients actually using the PHR that you offer? Do they use some features more than others, and, if so, why do you think that is so?

Response:

- *779,799 Registered users since launched in November 2003 (88% Men, 12% Women and 74% of these registrants are VA patients)*
- *118,945 of these registrants have been in person authenticated (IPA)*
- *More than 28 Million visits since November 2003*
- *More than 9.8 Million Prescription Refills processed since launched in August 2005*

Over the past year, VHA has used the American Customer Satisfaction Index (ACSI) to measure and monitor satisfaction; and to better understand the characteristics, needs, and preferences of My HealtheVet users. As part of the My HealtheVet Performance Evaluation Program, the ACSI is an industry standard tool which offers a random selection of site visitors an opportunity to participate in a brief online survey. The ACSI data reveals that the majority of My HealtheVet users are male (91%), between the ages of 51-70 (68%), served in the Vietnam War (60%), and are in good or fair health (67%). Satisfaction with My HealtheVet is high (8.3/10.0), and users are both highly likely to return to the site (8.6/10.0) and to recommend the site to others (9.1/10.0).

Understanding what users are trying to accomplish when they visit the site is an important factor in prioritizing portal features to meet user needs. For My HealtheVet, pharmacy-related features currently represent users' top objectives, although all portions of the site show significant use. Most Veterans currently visit the site to order VA prescription refills (75%), access their VA prescription history (24%), and look up information about a medication (18%). When asked about which additional features are desired: 87% wish to view upcoming VA appointments, 74% want to be able to schedule or change their VA appointments, 73% want to view information from their VA medical record, and 64% would like online secure communication with their doctor. Plans are underway to make each of these most highly ranked features available.

VA views these additional features as tipping points in the adoption and use of the PHR.

20. To what degree do you anticipate providers accessing patient information through the PHR?

Response:

We have examples today of providers interacting with their patients using the electronic health record and My HealtheVet to monitor chronic disease and enhance communication. These complementary tool enable providers to empower patients to improve health by facilitating direct correlations between lifestyles changes and improvements in their health.

We see My HealtheVet, and the PHR in general, as a tool that can be widely used for continuity of care activities such as medication reconciliation, which can be accomplished within My HealtheVet through the dynamic generation of printable summaries for the Veteran to provide to their VA and non-VA providers. We anticipate that delegation will be an important addition to support bidirectional information sharing.

21. Do you intend for your offering to be a “source record” for medical information? How have physicians’ practices or relationships with patients changed with the advent of PHRs?

Response:

VA recently added an indicator to its electronic health record that informs the clinician that a Veteran patient has an authenticated My HealtheVet account. This enhances interaction between the patient and providers; the healthcare team can direct the Veteran to My HealtheVet information, tools, and extracted electronic health record information, which further empowers the Veteran to participate in healthcare. We anticipate that the PHR will become an integral tool to enhancing current practice, and to enhance patient-provider relationships by enabling robust information sharing and communication.

22. How should we evaluate whether PHRs are successful?

Response:

PHRs should be evaluated through a combination of consumer satisfaction monitors and a robust performance management evaluation system. VA has adopted the American Customer Satisfaction Index (ACSI) to monitor satisfaction and to identify My HealtheVet PHR user characteristics, needs and preferences.

Background: Consumer research reveals high interest in use of PHRs, yet adoption remains relatively low. Both adopters and nonadopters represent important perspectives from which to understand this paradox.

Objective: This study focuses on direct feedback from adopters obtained using the ACSI survey on the My HealtheVet PHR portal (<http://www.myhealth.va.gov>) of the Veterans Health Administration (VHA). The results represent a source of direct feedback with which to better understand Veterans' needs and preferences.

Methods: The ACSI Survey was implemented in October 2007 to measure satisfaction and solicit information about characteristics and preferences of My HealtheVet PHR adopters. The data represent a continuous random sample of site visitors who have navigated at least four pages on the site. A total of 100,617 surveys were completed (representing a response rate of 17.2%).

Results: Satisfaction with My HealtheVet is high (8.3/10.0), and users are highly likely to return to the site (8.6/10.0) and recommend the site to other Veterans (9.1/10.0). The majority of system adopters are male (91%), between the ages of 51-70 (68%), served in the Vietnam War (60%). Most Veterans currently visit the site to utilize pharmacy-related features.

In conclusion, VHA has used the ACSI to monitor satisfaction, and better understand the characteristics, needs, and preferences of early adopters. The data provide an important source of direct feedback to inform program optimization. Future research will include monitoring the impact on satisfaction of new features, and conducting additional research with nonadopters to identify barriers to adoption and use.

VA has also adopted the RE-AIM framework.

Efforts are underway to evaluate the impact of the My HealtheVet Personal Health Record on Veterans' health care. My HealtheVet Performance Evaluation Goals are ambitious and reflect a primary focus on VA's mission. The goals of the evaluation program are to:

- *optimize the My HealtheVet program to improve Veterans health care*
- *generate evidence-based knowledge to support clinical adoption*
- *meet agency requirements*
- *foster new collaborative relationships with VA Researchers*
- *engage and inform external partnerships*
- *contribute to the field of health care informatics*

The Performance Evaluation Workgroup of the My HealthVet Clinical Advisory Board uses an extension of the RE-AIM framework as a model for evaluating the impact and effectiveness of the My HealthVet Program on the Veteran population. Each RE-AIM dimension (Reach, Efficacy/Effectiveness, Adoption, Implementation, and Maintenance) encompasses important indicators of how the program is making a difference in VA health care. The extended model (figure 1) defines metric categories to distinguish between metrics of interest for program evaluation, program management, and research. Multiple evaluation strategies support performance evaluation including use of the ACSI Survey to measure and monitor user satisfaction, prioritize areas for improvement, and improve understanding of user characteristics, needs, and preferences.

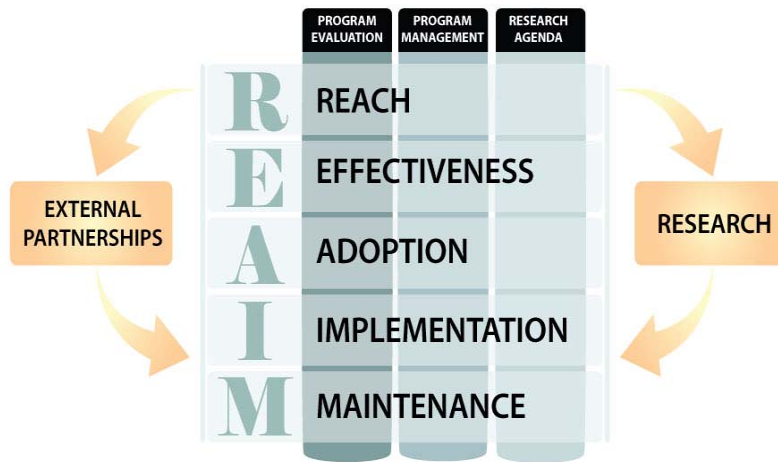


Figure 1: Extended RE-AIM Model

23. How will PHRs affect health care costs?

Response:

We see significant potential for the PHR in reducing health care costs. Some areas of potential cost reduction include: 1) the ability for patients to manage their own appointments will reduce the number of no-shows thus freeing up appointment slots and reducing wait times 2) administrative overhead will be reduced in areas where online functions are utilized; for example online prescription refills reduce pharmacy-related phone calls 3) direct access to electronic health record information will reduce the release of information costs associated with printing and mailing responses to Veteran requests for health information.

There are other examples in the continuity of care that is enabled by the PHR that have yet to be fully realized.

24. What will happen in five years if providers, employers and plans discover that PHRs don't save money?

Response:

“Not everything that can be counted counts and not everything that counts can be counted.” Einstein

Convenience and patient empowerment are difficult to quantify, but are valuable concepts to the patient, clinician, and organization. VA recognizes that the benefit of the PHR may be more evident in a closed system such as ours where both the organization and the patient benefit from continuity in the provision of care. While VA recognizes the potential for associated cost savings and improved utilization management, we also place high importance on offering increased value. The monetary savings may be difficult to isolate when patients are provided a continuum of care supported by both an electronic health record and a PHR, however the savings in the general health of the patient are evident.

25. Do you favor federal rules for PHRs or 50 different state rules?

Response:

Federal rules should be applied. The PHR should be seen as a comprehensive tool, blind to state or country boundaries, operating in a globally-connected society. Even within the VA healthcare system, Veterans often receive care across these boundaries. Application and enforcement of state rules would be complex and increasingly problematic.

26. Should PHRs be subject to HIPAA privacy and security rules?

Response:

Yes, VA has a responsibility to not only treat our veterans but also safeguard their protected health information. This is done by applying the existing privacy and security provisions to the ongoing development of My HealthVet.

27. How do the changes to HIPAA in the Recovery Act affect your work with PHRs?

Response:

The changes to HIPAA in the Recovery Act are in line with current VA practice. We use a user-specific audit trail, maintain an accounting of disclosures, and have planned for practice notification in the event of a breach.