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# Health Information Security and Privacy Collaboration

## Lessons from AccessMyHealth: Consumer Education and Engagement in the Washington State Health Record Banking Project

Prepared for

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# TABLE OF CONTENTS

EXECUTIVE SUMMARY .....	1
<b><u>I. INTRODUCTION AND OVERVIEW</u></b>	
1.A OVERVIEW OF THE HEALTH RECORD BANKING PROJECT.....	2
1.A.1 ROLE OF ACCESSMyHEALTH IN THE HEALTH RECORD BANKING PROJECT.....	3
1.B. ACCESSMyHEALTH MEMBERSHIP AND STRUCTURE.....	4
1.B.1. ACCESSMyHEALTH VISIONS AND GOALS.....	5
<b><u>II. EDUCATING AND ENGAGING CONSUMERS IN THREE PHASES</u></b>	
<b><u>II.A PHASE 1 – DEVELOPING A COMMUNICATIONS STRATEGY</u></b> .....	7
II.A.1 KEY MESSAGING ISSUES AND DISCUSSION.....	7
II.A.2 USING KEY MESSAGES TO EDUCATE AND ENGAGE CONSUMERS.....	10
II.A.3 EDUCATIONAL SURVEYS.....	11
II.A.4 LESSONS LEARNED FROM PHASE 1.....	14
<b><u>II.B. PHASE 2 – THE PRIVACY CONVERSATION AND ENGAGING PROVIDERS</u></b> .....	16
II.B.1 ADDRESSING CONSUMER CONCERNS ABOUT PRIVACY AND SECURITY.....	16
II.B.2. RISKS AND BENEFITS OF USING AN ONLINE PERSONALIZED HEALTH RECORD.....	17
II.B.3. PROVIDER EDUCATION AND ENGAGEMENT.....	19
II.B.4 LESSONS LEARNED FROM PHASE 2.....	21
<b><u>II.C. PHASE 3 – SUPPORTING THE PILOT COMMUNITIES</u></b> .....	22
II.C.1. INITIAL AMH GOALS FOR PHASE 3.....	22
II.C.2. EVALUATION OF THREE HEALTH RECORD BANKING PILOT SITES.....	25
II.C.3. RECOMMENDATIONS FOR PRIVACY AND SECURITY CRITERIA.....	26
II.C.4. LESSONS LEARNED FROM PHASE 3.....	27
<b><u>III. OVERALL LESSONS LEARNED AND FUTURE DIRECTIONS</u></b>	
III.A OVERALL LESSONS LEARNED.....	28

<b>III.B FUTURE DIRECTIONS.....</b>	<b>30</b>
<b><u>IV. CONCLUSION.....</u></b>	<b>30</b>
<b>APPENDICES.....</b>	<b>32</b>

## **EXECUTIVE SUMMARY**

AccessMyHealth (AMH), the consumer and provider education and engagement committee for the Washington State Health Record Banking (HRB) Project, funded by the Washington State Legislature, has been successful in reaching out to individuals, consumer advocates, providers, and other interested parties about online personalized health records. Although all AMH activities were funded by the Washington State legislature and not through the Health Information Security and Privacy Collaboration (HISPC), the HISPC funding allowed AMH to have one paid committee member to assist the Washington State Deputy Project Manager and the AMH Chairperson with planning consumer education and engagement activities. All other AMH committee members were unpaid volunteers. In the past year, AMH has:

- Developed strategies and tactics for engaging consumers about online personalized health records.
- Generated interest among consumers in Washington State about online health records through a marketing and educational grassroots marketing campaign.
- Created a language base for including consumers in the health IT dialogue that can often be complex and fraught with technical lingo and acronyms.
- Surveyed consumers about their desires for health technology features and functionality.
- Developed a knowledge base about consumers' concerns about privacy and security and potential solutions/remedies; worked to address those concerns.
- Created an educational website where consumers can learn more about online health records and access other relevant resources about using the Internet to manage health information.
- Engaged the provider community in thinking about patient activation through access to information.
- Supported the three pilot sites in the education and recruitment of participants.

AMH is proud of its accomplishments, which required hard work and many hours of time on the parts of paid and unpaid volunteers. In the spirit of transparency and sharing, it is the hope of AMH that this Final Report and all of its supplementary resources can help other online health information projects get a head start in educating and engaging consumers.

## I. INTRODUCTION AND OVERVIEW

The primary purpose of this report is to document the consumer education and engagement efforts of AccessMyHealth (AMH), the consumer outreach arm of the Washington State Health Record Banking (HRB) Project. This project was funded by the Washington State Legislature (i.e., marketing campaign and materials, educational surveys, Health Record Banking demonstration sites, etc.), with additional monies from the Health Information Security and Privacy Collaboration (HISPC) supporting staff time for the AMH activities. Captured in this report are the overall strategies and tactics that AccessMyHealth applied in engaging consumers about using technology for health information management, conversations and thinking that shaped key messages, lessons learned, and many of the tools and surveys that were developed as part of this year-long endeavor. Although this report discusses some of the background on how Washington State came to adopt the HRB model and touches upon the technical aspects of health banking, these discussions take place within the context of educating and engaging consumers.

### I.A. OVERVIEW OF THE HEALTH RECORD BANKING PROJECT

The Health Information Infrastructure Advisory Board (HIIAB) was created in 2005 by the Washington State Health Care Authority (HCA) to develop recommendations for the Washington State Health Information Infrastructure (WSHII) (see Appendix A for a complete list of HIIAB members). In May 2007, the Washington State Legislature appropriated more than \$3 million to the HCA to implement the HIIAB's recommendation for the competitive consumer-centric HRB model.

By design, the HRB model provides patients and patient proxies (hereafter known as consumers) access to copies of their health care information through an online personalized health record. With greater consumer access to their health information, consumers are better able to partner with medical professionals and take greater ownership of their health and health care.

The HRB holds a variety of patient health care information, including direct downloads from industry data (i.e., prescription refills and refills from pharmacies, lab results, immunization records), as well as patient-managed information. Patient-managed information includes self-entered data for home monitoring, edit/comment capacity of industry data to validate medication and allergy information, advance directives, and other useful clinical information. HRB

consumers are able to share the health information aggregated in their online records with medical professionals by printing out a copy of their updated information prior to an office visit and presenting it to their providers at an appropriate time in the patient visit workflow (see Appendix B for a diagram of the HRB concept and information flow). The HRB also allows patients to share their health information with family, caregivers, and others entities outside of their direct health care treatment needs as desired.

In July 2008, three communities in Washington State were chosen to receive grant funds totaling \$1.7 million to develop pilot HRB projects. These communities were scheduled to support operational HRB systems from February through June 2009, with some communities expecting to maintain the project through the end of the year. In preparation for the demonstration projects, the HIIAB created several committees to develop the HRB concept: (1) AccessMyHealth, which focused its efforts on educating and engaging consumers about online personalized health records; (2) Privacy and Security Committee, which made recommendations about the technical and privacy standard minimums that should be adopted by HRB pilot sites; and (3) Policy and Governance Committee, which explored the future possibilities of governance structure and financial sustainability for the HRB model.

### **I.A.1 Role of AccessMyHealth in the Health Record Banking Project**

The strong consumer-centric focus of the HRB model led to a general consensus among HIIAB members and the HCA that engaging consumers is of paramount importance to the HRB efforts. The AMH initiative, therefore, played a central role in vetting the recommendations made by the other two committees from the consumer's perspective. This consumer vetting was a particularly imperative component of the recommendations made by the Privacy and Security committee because privacy issues are of critical importance to consumers when considering the option to create an online personal health record. Through the vetting process, AMH assisted in developing key security policies regarding consumer access and control over their HRB account, as well as guidelines for product attributes.

In addition to vetting HRB recommendations made by the HIIAB, AMH's explicit role was to shape the development of the HRB project through its outreach to consumers. This outreach included developing standard messaging for educating patients and providers about the benefits of online personalized health records, creating a website where consumers could learn about

online health tools, providing educational resources for consumers to better understand health information technology (IT), privacy and security, and providing consumers with opportunities to participate in the HRB demonstration projects.

#### **I.B. ACCESSMYHEALTH MEMBERSHIP AND STRUCTURE**

The AMH committee was made up primarily of 10 individuals, representing a variety of backgrounds. The members were chosen not only for their understanding of the significance of information technology in health care, but also their desire to facilitate consumers becoming more engaged and activated in their own care. The committee members included providers, health informaticists, a patient access care coordinator, an employer representative, a quality improvement specialist, and several consumer representatives (see Appendix C for a complete list of AMH committee members).

AMH committee members were sensitive to the fact that the committee lacked “real” consumer representation, as opposed to “professional” consumers/consumer advocates. “Professional” consumers can be defined as people who have had experiences being patients in the health care system, but because of their professional or volunteer experiences, are very familiar with the discussions surrounding health care and IT and would therefore be less likely to view online health records through unfiltered lenses. AMH aimed to recruit into its membership consumers who had less experience thinking about health IT and would be more apt to give unbiased feedback in how to educate and engage consumers about the HRB project. The targeted consumers for AMH membership included parents who organize their children’s immunization records, individuals managing their chronic illness and accompanying medications, or adult children of elderly parents with multiple providers. Unfortunately, because of the time commitment to a project of this magnitude, it was very difficult to recruit “real” consumers to AMH. To fill this gap in information, AMH sought out consumer feedback through the AMH website, <http://www.accessmyhealth.org>, and tried to maintain a well-rounded group of committee members.

In addition to asking consumers directly for feedback about online health records, AMH frequently shared educational materials, committee progress, and plans for consumer engagement with other stakeholders in the HRB project to maintain transparency and facilitate information sharing among the different HRB project committees. The AMH chair and the HCA

Deputy Project Manager reported committee developments back to the executive members of the other two HRB committees on a weekly basis, and to the larger HIIAB group on a monthly basis. The general HIIAB meetings were frequently attended by health IT stakeholders. These interested parties were given the opportunity to comment on committee developments if so desired.

### **I.B.1 AccessMyHealth Vision and Goals**

*“We cannot solve our problems with the same thinking we used when we created them.”*  
—Albert Einstein

The general vision of AMH was to be a credible source of independent information to help consumers understand and compare the diversity of online health information tools available to them. To that end, AMH collected information from consumers to understand and advocate for patients in the domain of health IT while maintaining a commitment to progressive innovation. Underlying this vision was a set of core beliefs that greatly influenced how the AMH approached engaging consumers and consumer advocacy groups in the HRB project. The beliefs were the following:

1. Consumers should have better access to their own health care information. Although health care information is about the individual patient, the patient often is the least likely to have a copy of his or her own records. In the current system, consumers rarely have the opportunity to correct mistakes or update information in their health records when appropriate, leading to potential patient safety issues.
2. Without greater access to their own health care information, patients are hindered from taking a more active role in their health (e.g., interest in and ability to self-manage) and their health care (e.g., co-provision of care through more productive interactions between patients and providers).
3. Doctors already rely on the patient for many types of information including their health history, the medications they are taking (from all prescribers, over-the-counter and alternative medications), and the dates and locations of previously completed

tests and labs because the patient is the only person who experiences all of these health care discussions and treatment regimens.

4. Typically, once health care professionals know there is relevant information about a patient in industry databases, they will invest a great deal of administrative time retrieving the information, which often interrupts or delays the clinical encounter. If patients came prepared to office visits with the needed information in hand, it would allow providers to focus on clinical decision-making rather than gathering information, allowing for a smoother workflow.
5. It would strongly benefit both patients and health care professionals if patient information could be accessed online during an emergency. Unknown patient history can lead to serious patient safety issues, such as delayed treatments, drug interactions, and allergic reactions to medications, among other problems.

Based on their overall vision and beliefs, AMH's main goal was to encourage the use of health IT products that meet doctors' and consumers' unique needs, but also allow the two entities to share and compare information with each other. This goal was intended to create efficiencies in the exam room, motivate patients and doctors around a set of common goals, and ultimately impact cost and quality. The HRB approach adopted by HCA to fulfill this goal was to identify opportunities to copy information from health care organization-owned clinical systems (e.g., Electronic Health Records, pharmacy data, lab results, etc.) and make them accessible to consumers through HRB accounts. This approach was necessary as a strategy to:

1. Assemble a more complete record for each patient that is portable and durable.
2. Use patient control as a more direct method than patient consent to facilitate the authorized flow of clinical information from one node of the health care delivery system to another.
3. Create the possibility for patients to opt in to research, public health initiatives, and other activities that have societal value, but have historically been unachievable without the necessary health information infrastructure to support these efforts.

To lay the groundwork for attaining the vision and goals set forth by AMH, particularly educating and engaging consumers in the HRB demonstration project, the committee partitioned its project into three main phases:

Phase 1: Engage consumers in learning about the HRB project and gather information from consumers to understand their views about online personalized health records, including concerns about privacy and security.

Phase 2: Address consumers' privacy and security concerns about using online records to manage their health information, which begins with an understanding of the risks and benefits of using the Internet for managing any type of personal information. Educate the provider community about the benefits of consumers creating an online personalized health record account.

Phase 3: Build a participant base of consumers and providers who are engaged in information sharing using online personalized health records, including coordinating with the pilot communities to enhance social marketing strategies.

## **II. EDUCATING AND ENGAGING CONSUMERS IN THREE PHASES**

### **II.A. PHASE 1—DEVELOPING A COMMUNICATIONS STRATEGY**

Phase 1 of AMH project planning focused exclusively on educating and engaging consumers about the HRB concept with the expectation that provider education and engagement would come at a later time. This decision was made because of the strong consumer-centric aspect of the HRB project and the belief that patients' desires to utilize online health records would spur providers' interests in HRB technology and its benefits.

#### **II.A.1 Key Messaging Issues and Discussion**

A vital first step in the efforts to educate and engage consumers was to develop a communication plan and create standard messaging for the targeted audience to ensure message consistency and

promote understanding of the HRB project. Working with rialto communications,<sup>1</sup> a marketing and public relations firm in Seattle specializing in health and technology, AMH worked toward creating key messages. During the process of creating the key messages, AMH and rialto had several noteworthy discussions about the language that would be used for communications with consumers. The first of these discussions was about the use of the term “consumer” itself. This discussion required AMH to clarify who was its intended audience. When the term “consumer” is not clarified, it could be defined as just about anyone who participates in health care activities, ranging from patients to providers to health plans. To avoid confusion, AMH agreed that all consumer-targeted messages would be addressed to patients.

Another discussion about terminology was related to how health care professionals refer to health care providers versus the average patient. While health care professionals may know and care about the difference between various providers’ roles (e.g., provider, cardiologist, medical assistant, RN, etc.), patients primarily refer to most health care providers as doctors or nurses. The messaging would need to reflect this very basic manner of describing health care entities.

AMH also needed to create a term for the project that could be understood by any individual who did not have a background in health IT. While health record banking is the name of the IT infrastructure model and the pilot project, AMH deemed the term “health record banking” to be too esoteric for the average consumer to understand. AMH preferred a term that was more descriptive and would not require any previous knowledge of the health IT options currently available to understand its meaning. The phrase “online personalized health records” was chosen as an alternative to “health record banking” and was used in all of the marketing materials.

Although one of the key project goals was to give patients greater access to their health records, AMH wanted to be clear in the key messages that the HRB technology would allow the patient to view and update a **copy** of his or her health records through downloads from health organization-owned clinical systems. Having a copy of one’s record is distinct and separate from accessing originals that are typically the legal records of health care entities. The goal of the HRB project was not to change the current structure of patient record ownership, but to facilitate the exchange of information between providers and patients by giving patients greater access to copies of their health care information.

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<sup>1</sup> rialto communications is legally spelled with all lower-case letters.

Lastly, AMH and rialto tried to strike a delicate balance between creating targeted messages that were general enough to engage all potential users of the online personalized health record versus speaking directly to the specific audiences that were the most likely to use online technology to manage their health information. A 2008 survey of health care consumers segmented patients into six categories: (1) Content and Compliant (29%; preference for traditional health care, less likely to seek information or value added services), (2) Sick and Savvy (24%; have one or more chronic illnesses, rely more on themselves than their doctors for care-related decisions, and seek information), (3) Online and Onboard (8%; use online tools more than any other segment), (4) Shop and Save (2%; sensitive to health care costs and tend to switch doctors frequently), (5) Out and About (9%; tend to use alternative forms of health care), and (6) Casual and Cautious (28%; healthiest segment and least likely to be engaged about health care issues).<sup>2</sup> The audience AMH targeted for its health IT education and engagement efforts were the 43 percent of patients who show interest in using nonconventional approaches to health care and/or are likely to seek information (i.e., sick and savvy, online and onboard, shop and save, out and about). However, the education would also need to be broad enough that the patients who fall into the other categories depicted by the survey could identify with the message. The issue of creating key messages that can be engaging to all audiences is of importance when considering that most people have not thought about using technology for health information management,<sup>3</sup> but when asked, 60 percent of Americans think that being able to use technology for viewing and refilling prescriptions, getting lab results, and updating mistakes in their health records is a good idea.<sup>4</sup> Consequently, all patients in general, and not just targeted audiences, may see the benefit of online health records with some education.

A general strategy taken by AMH and rialto was to keep the key message language simple and clear so that literacy and education were minimized as barriers. Similarly, the explanation of the benefits of using online health records was described in a straightforward manner, such that the average consumer might be able to relate to and understand its usefulness.

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<sup>2</sup> Deloitte Center for Health Solutions. 2008 Survey of Health Care Consumers. Washington, DC: Deloitte. Available from <http://www.deloitte.com/dtt/article/0,1002,sid%253D80772%2526cid%253D193730,00.html>.

<sup>3</sup> Connecting for Health. Connecting Americans to their Health Care [monograph on the Internet]. New York: Markle Foundation; 2004 July [cited 2006 May 17]. Available from [http://www.connectingforhealth.org/resources/wg\\_eis\\_final\\_report\\_0704.pdf](http://www.connectingforhealth.org/resources/wg_eis_final_report_0704.pdf).

<sup>4</sup> Markle Foundation. Markle Foundation Survey Fact Sheet [monograph on the Internet]. New York: Markle Foundation; 2005 [cited 2006 May 17]. Available from [http://www.connectingforhealth.org/resources/101105\\_survey\\_summary.pdf](http://www.connectingforhealth.org/resources/101105_survey_summary.pdf).

## **II.A.2. Using Key Messages to Educate and Engage Consumers**

The key messages addressed what an online personalized health record is, who is leading the efforts to guide consumers to online health records, why the focus on online health records, and how consumers can participate in the development of the HRB project. The six major points that AMH communicated to consumers were the following (see Appendix D for all key messages):

1. Patients often do not have access to their own health information. Online personalized health records will allow patients to decide what medical information is copied and safely stored in electronic format, to whom that information is released, and when.
2. The online health record project is a joint partnership of patients, doctors, and other Washingtonians, convened by the Washington State Health Care Authority.
3. The focus of having an online health record is so that patients can make better use of their time with their doctors by being better prepared and knowledgeable partners in their own health care.
4. Volunteers are needed to help explore how the online personalized health record could be useful to patients, their families, and doctors on a day-to-day basis.
5. Privacy, security, and convenience are high priorities of this project.
6. AMH wants to ensure that the consumer's opinion is heard. Consumers can give feedback at <http://www.accessmyhealth.org>.

Once the key messages were created, rialto communications prepared these messages in a variety of media for consumer engagement, including fact sheets (see Appendix E), PowerPoint presentations when introducing the project to consumer advocacy groups (see Appendix F), e-mail templates when contacting consumer advocacy groups (see Appendix G), tear off tabs that were placed in a variety of health care settings (see Appendix H), banner ads on Internet sites (see Appendix I), news articles in trade magazines and organization newsletters (see Appendix J for an example), press releases (see

<http://www.reuters.com/article/pressRelease/idUS221001+20-Aug-2008+BW20080820>), posters (see Appendix K), and radio advertisements.

### **II.A.3 Educational Surveys**

In efforts to reach out to consumers, AMH members contacted health care consumer advocacy groups and asked staff from those organizations to share the AMH communication materials (see above) with their stakeholders. The communication materials directed consumers to the AMH website, <http://www.accessmyhealth.org>, which was the major tool by which AMH communicated with consumers about the HRB project and educated them about health IT and associated privacy and security concerns. Consumers who visited the website were asked to take two educational surveys. The first survey aimed to strike a balance between learning about consumers' health care information management needs and understanding consumer concerns about online health care privacy and security. The second survey delved deeper in addressing consumer health IT privacy concerns, while explaining the risks and benefits of using the Internet for any business where personal information is transmitted. The second survey asked questions about consumers' other electronic behaviors that capture personal information, such as using the Internet to shop, pay bills, or use supermarket loyalty cards. These questions were meant to illustrate to the consumer that people typically trade some degree of security for convenience. Both surveys were meant to facilitate dialogue about using online health records, be a starting point for education, and check in with consumers to see how comfortable they would be with the idea of using an online health record. The surveys were not used to gather research or statistical data (see Appendix L for a complete list of survey questions).

Both education surveys were available to consumers from July through October 2008. Survey one received 510 consumer responses and survey two received 71 responses (the low number of responses was because of an unexpected discontinuation in funding for AMH outreach, described in the Phase 3 portion of this report). Survey one asked two open-ended questions. The first was, "Tell us what, if anything, you like about the concept of an online personalized health record?" Some of the representative responses to this question were:

- "We already manage everything else online, why not our health care?"

- “I would like to be able to access my health care records without having to go through my physician.”
- “It would be good to have my medical information available in times of emergency and to inform my adult children of my care.”
- “Being able to track down old information about my health history—the kind of the information that doctors always ask for, but is never at my fingertips.”
- “I think this would be great! As a nursing student, I know what a hassle it was to get all my immunizations together for verification. I had to call and visit many offices to find these records. The ones that could not be found, I ended up having to pay to go the doctor to have them done again.”
- “Yes, this is extremely appealing to me. As a person with chronic health issues.... it would be EXTREMELY useful to be able to go to one single place and access what I need to look at: lab result, x-ray result, chart notes (I always want to know what my doc is really saying about me!), prescription info, etc. Having one universal place to access my info and be able to give that same access to my care providers would be incredible. For all my providers to finally be able to see the complete picture of my health care would be priceless for me.”

The second open-ended question was “Tell us what, if anything, you don’t like or what concerns you about the concept of a personalized health record. What potential risks would you like to see addressed?” Representative responses included:

- “My biggest fear is if any insurance company got access to it. They look for anything to deny or withhold coverage—for life or health insurance. My next concern is that someone hacked into the system and stole my information.”
- “I think the biggest problem is the fact that hackers seem to be able to hack anything and with the rising cases of insurance fraud, it would be a big issue about the security of your personal information once it was put out there. There is also the issue that the

people it would help the most are people who are not very good with computers (aka elderly).”

- “Privacy and security are number 1 and 2 issues. I want the health record to be under the control of the subscribers. I worry about the government and insurance company’s access to these records as well as employers.”

Survey 2 asked the question, “Millions of customers use online banking services every day—they decide that they want their personal financial information accessible on the Internet. When you think of having financial—or health-related—information available to you on the Internet, what worries or concerns do you think of?” Responses included:

- “I am one of the other millions of customers who don’t use online banking services at all, not to speak of doing it every day. However, an online health record system is different. I would try it if I control the access to my records and there is guarantee that people who access my records are truly the ones I grant permission and an imprisonment penalty (not just fine) for accessing the records unauthorized.”
- “Unauthorized access is my main concern. Health information is very sensitive and personal, and patients have the right to privacy.” And “others who are unrelated to the medical field accessing my information (i.e., an employer, insurance carrier, etc.).”
- “The key to getting folks on board is security, being able to decide who sees one’s records and keeping track of who has seen one’s records.”

The first open-ended question from Survey 1 indicates that consumers can see the various benefits of having an online health record, including being able to access one’s own health care information more readily, being able to share one’s health information with health care professionals and family members, and having records available in case of emergency. However, consumers were also very concerned about nonauthorized access to the health records and the (in)ability to view the audit trail of who attempted to view the information. To combat consumer fears about breaches in privacy and security, it was clear that any online health record system would need to give consumers control over who accesses their records and provide robust audit

trails so that consumers can ensure their information was not inappropriately retrieved. In fact, 84 percent of survey respondents stated that they would put their health information online if the record holder had the authority to designate access and another 87 percent would feel comfortable having an online health record if there existed a verifiable audit trail (see Appendix M for a summary of consumer responses to both Surveys 1 and 2).

#### **II.A.4 Lessons Learned from Phase 1**

*“From the errors of others, a wise man corrects his own.”—Syrus*

Listed below are the lessons learned from phase 1 of the AMH project.

1. **Consistent messaging is critical.** The AMH committee started meeting and developing project plans in February 2008. In March 2008, rialto communications won its contract to create marketing materials for AMH and the HRB project. The HRB pilot sites were expected to be operational by February 2009, less than a year after AMH began its consumer outreach efforts, resulting in a very aggressive timeframe for creating key project messages, educating consumers about health IT, getting feedback from consumers about their privacy concerns, and generating interest in participating in a pilot community. Because of the short timeframe and the importance of engaging consumers in the HRB project, AMH members felt compelled to begin their outreach to consumer advocacy organizations as soon as possible, even before key messages and marketing materials were fully developed. AMH created a list of more than 50 health care-related organizations in Washington State with active stakeholders and split the list up among its committee members to start contacting to gauge interest in learning more about the HRB project.

Because AMH had not yet fully developed its key messages and finalized marketing materials at the point when committee members started its outreach efforts, there were some inconsistencies in the manner in which consumer groups were approached about the health record banking project and the message that was initially espoused. For example, organizations that were contacted early on were told to ask interested consumers to send a message to an e-mail address. Once the AMH website was created, consumers were directed to the website instead. Another example is that while organizations contacted early in the outreach process were told about the health record banking project, organizations contacted later in the process were told about online

personalized health records, which was the more descriptive term that AMH had chosen to use in its key messages. In several instances, AMH needed to reconnect with the organizations that had already been contacted at the early stages of the project to give them updated information. Ideally, consumer organizations and health care stakeholders would have been contacted only after the AMH communications package had been developed to prevent rework and avoid consumer confusion.

2. **Use both grassroots and direct marketing efforts.** The strategy taken by AMH for reaching out to consumers was by first contacting consumer advocacy organizations and explaining the goals of the project to personnel, who then either suggested that AMH talk to someone else in the organization to get approval for participating in this project or agreed immediately to print out the AMH consumer fact sheet to give to their membership. Although AMH adopted this strategy because of its desire to get the online personalized health record message out to certain audiences, the consumer organizations were, in essence, a middle man that determined whether the individual consumer received the message or not. In this way, advocacy organizations made the decision for the individual consumer about whether they wanted to pursue information about online health records. A more ideal way to pursue engaging consumers would have been to speak directly to the consumer from the start of the project through press releases, news articles, posters, etc., rather than asking consumer organizations to share information with their membership. Another reason to go directly to consumers is that AMH learned during the course of this project that while people in health care often make assumptions about what consumers want in health IT, asking consumers directly about their desires and concerns often yields new information. Thus, while using patient proxies as a resource for dispersing information and gaining knowledge may be efficient and helpful, it is still important to ask the patient directly for input and treat them as active (versus passive) stakeholders in any health IT project.

3. **Consumer enthusiasm for online health tools.** In talking with various consumers about online personalized health records, AMH was struck by the amount of interest people have in online health tools and how the tools can help individuals become more involved in their own health and health care. There was genuine enthusiasm for the health record banking project, enthusiasm that remained despite concerns about privacy and security.

4. **Targeting early adopters.** While the enthusiasm that many individuals showed for online health records was real, the translation of that excitement into action, through the desire to sign up for a pilot health record banking account, was less apparent. When there is a call to action for patients to try online health records, the focus needs to be on the early adopters who are willing to pave the way for others. It is through the early adopters and the people who follow in those individuals' footsteps that usage of online health tools will reach a critical mass.

## **II.B. PHASE 2—THE PRIVACY CONVERSATION AND ENGAGING PROVIDERS**

Phase 1 was about developing messaging to entice consumers to learn more about online personalized health records. At first, consumer educational activities centered on completing the two surveys available on the AMH website. During phase 2, there was a stronger focus on addressing consumers' privacy and security concerns, as well as integrating providers into the educational mix.

### **II.B.1. Addressing Consumer Concerns about Privacy and Security**

In Survey 2, consumers often mentioned that they were concerned that nonauthorized entities would “hack” into their account and retrieve sensitive personal health care information. On the AMH website, consumers were told that more than anything, protecting one's online health information is primarily dependent on adopting good practices. This means choosing an online health record vendor that meets minimum security standards and has a privacy policy that is readily available and clearly written. In particular, the AMH website suggested that consumers should look for policies that allow the individual health record holder to control access to his or her information. As a supplement to this education, the AMH website provides a link to a fact sheet called “Health Privacy: Know Your Rights,” created by the Health Privacy Project (<http://www.healthprivacy.org/>), which is a consumer advocacy organization that addresses the privacy challenges posed by online exchange of personal health information.

An important aspect of privacy and security for health care consumers is the Health Insurance Portability and Accountability Act (HIPAA) of 1996 Privacy Rule and what it means for patients. Many consumers do not necessarily understand what is indicated when they sign a HIPAA Privacy Rule notice of privacy practices at their doctor's office prior to receiving care. Many consumers are unaware that the HIPAA Privacy Rule permits providers and hospitals to use and/or disclose patients' medical information with other providers to coordinate care, as well

as with the patients' insurer and certain business partners and services without obtaining patients' written consent. Understanding the HIPAA Privacy Rule, along with its safeguards against the inappropriate use and sharing of patient data, gives consumers a more accurate grasp of current data sharing practices. This new domain of patient-provider information exchange will require further development of security and privacy policies and practices that pertain to both health care entities and information technology vendors. For example, the HIPAA Privacy Rule explicitly prohibits health care providers from sharing information with employers, a point that many consumers expressed concerns about in Survey 2. However, not all technology vendors, such as freestanding PHR vendors who offer patients storage and sharing capability of their health information, are required to comply with the HIPAA Privacy Rule. The HIPAA Privacy Rule would only apply to PHR vendors that offer software that is tethered or connected to a health care provider covered by HIPAA. In this scenario, a non-HIPAA covered PHR vendor would not be required to abide by HIPAA regulations.

In the reverse, it is important that consumers understand that once they authorize sharing of their health information from their HRB to a provider, they are not able to override the treatment, payment, and operations (TPO) sharing provisions that a provider is permitted to engage in under the HIPAA Privacy Rule.

### **II.B.2 Risks and Benefits of Using an Online Personalized Health Record**

Before starting the process of addressing consumer concerns about privacy and security, consumers first needed to understand the benefits of managing their health information online. Namely, consumers would be able to aggregate copies of their health information into one place, which is very useful especially for patients with multiple providers for various illnesses or are seeing a new provider for the first time. Consumers would then be able to access a copy of their aggregated health records, update and correct the information if needed, and share that information with whomever, whenever they choose (e.g., primary care physicians, emergency room physicians, family, physicians seen while traveling, etc.). This would allow consumers to play a larger role in their own health care by being active partners in their care rather than passive recipients.

Despite AMH's education efforts, some consumers still responded in Surveys 1 and 2 that they would be uncomfortable with posting their health information online (14% of survey

respondents). In response, AMH worked with the HIIAB Privacy and Security Committee to draft a document weighing the risks and benefits of using an online personalized health record. Some consumers believe that they would not participate in online health records unless they are 100 percent sure that their information is safe. The risks/benefits document explains that there is no risk-free way to store information online, just as there are no risk-free methods to store health information on paper. Only if the benefit of using online health records is greater than the real and perceived risks will consumers use the Internet for exchanging health information. The analogy that was used in the risk/benefit document is that of driving a car. Most people know that driving a car can be dangerous, yet most people of driving age choose to drive and accept the risks because the benefits outweigh the inconvenience of walking, taking public transportation, and so forth. To continue the analogy, people drive the speed limit for safety reasons and wear seat belts because that safety precaution makes it more likely that drivers will be protected in case of an accident. Similarly, the convenience of consumers being able to access all of their health care information in one place and use that information to partner with their providers in improving care may outweigh the concerns. The key is that there is a tradeoff between security and convenience. The more consumers want fail-proof security for using online health tools, the more they will sacrifice convenience. To strike a balance between security and convenience, AMH recommended several safety precautions that consumers can take to safeguard against identity theft. These precautions include making sure that the vendor asks the consumer to sign a sharing agreement, verifies the consumer's identity, and gives the consumer a unique digital ID number. The consumer should also ensure that the vendor allows the consumer to control who gets access to the health record and can display an audit trail that allows the record holder to know who has accessed the records (see Appendix N for the full document).

In addition to educating consumers about the risks and benefits of using online personalized health records, the second phase of the AMH project focused on bringing providers into the conversation and showing them how activated consumers with online health records could assist with the clinical workflow to gather patient information.

### **II.B.3 Provider Education and Engagement**

Providers and their staff spend a lot of time gathering the information they need to make clinical decisions. The necessary information can be stored in a multitude of places including the patient's paper charts or the provider's electronic health record, in other doctors' charts, in

industry databases, or with the patient and his or her caregivers. Gathering information can take a great deal of staff time, is disruptive to workflow, and can postpone treatment. When patient information is not collected or when it cannot be found, patients bear the brunt of the costs. Patients may leave the office without having their medical needs met, receive a delayed diagnosis, or receive treatment that results in a medical error. Within the health care industry, there have been discussions about EHR interoperability, in which providers' EHR systems would be able to "talk" to each other, whereupon physicians would have an alternative to relying on industry databases and patients' memory for information. However, these plans have typically lacked a business model, are expensive to implement, and are hard to scale. The option offered by the HRB project is that the patients store key information in their online health records and bring the information to their office visits, sharing the information with providers at opportune times in the existing workflow of care encounters. This allows providers to focus on answering patients' questions, recommending treatment options, and engaging patients in shared decision-making rather than the administrative task of gathering information.

In the ideal scenario, activated patients would bring to the office visit a validated list of medications that they are taking, a list of immunizations that are needed, lists of screening or chronic disease monitoring tests that are due, and a list of questions about optimal therapies for consideration and discussion during the clinical encounter. The provider in this scenario would use his or her experience and training to review the patient's information, respond to questions, recommend treatment options, and engage the patient in shared decision making for ordered tests, consultations, and interventions.

Providers were asked to join in the HRB/online health record conversation by visiting the provider's page on the AMH website. On the website, providers were encouraged to complete the two surveys developed by AMH and read the provider fact sheet (see Appendix O) on the HRB project. Providers could also partner with AMH by posting an AccessMyHealth participant logo and link to the AMH website from their organization's homepage.

AMH anticipated that providers would have three main concerns: (1) Will the data from the online health record be accurate, (2) Will the provider be legally responsible if the inaccurate information is made a part of the provider's legal records, and (3) Will the provider be

responsible to access and incorporate information that patients make available via their online health record?

Regarding the first issue, understanding that there is a distinction in the source of the information helps to resolve the issue. The HRB account houses a *copy* of the patient record and not the original record, which comes from the provider's patient charts. If patients want to update, revise, or change information in their copy, the source will be noted as the patient so that providers can use it accordingly.

The second issue is valid and remains in uncharted legal territory. However, this potential landmine is rendered a nonissue in the HRB pilots because it is currently not possible for patients to make deposits of the health information contained in their HRB account into a provider's records. Information that the patient brings on paper to the office visit would be given the same weight as the patient's current responses to a provider's questions, but will likely be of a higher quality because the patient has access to copies of clinical information.

The issue of whether providers are responsible to access and incorporate patient information that is available to them via the HRB pilots is addressed by patients bringing in paper copies of their information to the office visit. Providers do not need to log onto another system to gain information because patients will be able to share pieces of their health record with them in an organized manner during the office visit. This topic is of particular importance for HRB vendors to note because successful systems will need to provide patients with better ways to organize and share their information with providers and other designated entities.

In general, provider education focused on helping doctors understand how engaged and activated patients with access to online health tools can actually make their jobs easier. Also, because the HRBs would only house a copy of patients' information, which would not be the legal responsibility of providers or their organizations, the issue of liability was contained.

#### **II.B.4 Lessons Learned from Phase 2**

Listed below are the lessons learned from phase 2 of the AMH project.

1. **Describe risks and benefits in an everyday way.** When prompted to think about online health information concerns, consumers are likely to think only about the risks without weighing the benefits. Describing privacy and security in a way that helps consumers understand the risks/benefits in an everyday way (e.g., driving) makes the concepts more readily digestible and practical. Also, explaining the risks and benefits using a common scenario like driving equates online health record banking with a behavior that most people would not think twice about because it is such an integral part of our society.

2. **Start consumer education with the benefits of online records, not the risks.** Privacy and security are big consumer concerns. However, starting educational efforts off with addressing privacy and security detracts from the main messages, which are the safety and quality benefits of using online health records. The strategy AMH took was to start engaging consumers in why they should participate in online health records before addressing consumers' concerns about privacy and security. If consumers do not know all of the benefits of having an online health record, then any risks associated with managing health information over the Internet will seem like insurmountable barriers. However, knowing and understanding the benefits of online health records will allow the consumer to weigh those against the real and perceived risks.

3. **Hold consumer forums between patients and providers.** An appropriate next step after educating consumers and providers would have been to hold forums where patients and their physicians could discuss the benefits of having online personalized health records and begin addressing the risks and barriers to utilizing online health records as a communication tool. This conversation would have fostered the vision of AMH, which was to facilitate a partnership between activated patients and providers in managing health care. The meeting of patients and providers would have also been an opportunity to clarify the concerns brought up by both groups in the AMH surveys and allow physicians to hear first-hand what their patients have to say about the movement of their health information.

4. **Hold consumer forums for other stakeholders in the community.** Community forums would be helpful in engaging local, regional, state, and possibly national leaders in the future of online health records, and what this future could possibly mean for individuals in the

community. The workshops would be used to generate participation and engagement from medical- and health-related associations (e.g., Washington State Medical Association, Washington State Hospital Associations, etc.), national organizations and public policy organizations focused on health technology (e.g., Markle Foundation, California Healthcare Foundation), and disease population- and consumer-focused organizations (e.g., American Cancer Society, AARP, Susan G. Komen Fund for the Cure). The workshops would feature the pilot participants and the key vendors supporting their pilot efforts (Microsoft HealthVault, Google Health, etc.). They could also feature an open conversation about privacy and security—the elephant in the room. By generating local meetings and activity, there would be an opportunity to create local and regional news, otherwise known as “Earned Media,” which broadens the circle of awareness.

## **II.C PHASE 3 – SUPPORTING THE PILOT COMMUNITIES**

AMH did not make it quite as far as Phase 3. At the end of Phase 2, Washington State was faced with a budget crisis. In response to the deficit, many of the state-funded activities and projects were vastly reduced or cut completely. Funding for the AMH communications and outreach plan was discontinued, as were monies to support any other AMH activities. In the face of the budget cuts and the dissolution of AMH, the AMH chair, the HCA Deputy Project Manager, and the HISPC representative continued to support the pilot communities in their efforts to engage and recruit patients, although on a much smaller scale.

### **II.C.1. Initial AMH Goals for Phase 3**

The following describes what AMH had planned to do in phase 3 had its funding continued.

As described earlier in this report, three communities in Washington State were the grant recipients of funds totaling \$1.7 million, made available by the Washington State Legislature, to develop pilot HRB projects. These three communities were:

- 1. Inland Northwest Health Services (in partnership with Google Health)**
  - a. Community location: Spokane, WA
  - b. Grant award: \$583,377.00
  - c. Recruitment Approach: Targeting patients seen in 3 clinics in Eastern Washington, representing more than 240 health care providers.

- d. Consumer Engagement Strategy: Materials will be placed in the waiting and exam rooms and will be sent to the patients via the clinics' normal communications channels, including e-mails and newsletters. Enrollment fairs and mass marketing techniques (e.g., press releases, news stories, etc.) will also be used.
- 2. St. Joseph Hospital Foundation and the Critical Junctions Institute (in partnership with Microsoft HealthVault)**
- a. Community location: Bellingham, WA
  - b. Grant award: \$598,352.00
  - c. Recruitment Approach: Targeting seniors and their caregivers, pregnant moms and their newborns, moms with young families, family caregivers, and individuals concerned about disaster preparedness and medical care during emergencies. Enrollment will occur in the following venues: Childbirth and Parenting Classes, OB clinics and Hospital OB Dept, Primary Care Clinics, Childbirth Centers, Senior Facilities, Fire Stations and Emergency Medical Services.
  - d. Consumer Engagement Strategy: Through traveling road shows, kiosks for sign up, scheduled registration sign up times, videos, display boards, links to emergency preparedness, link to [Accessmyhealth.org](http://Accessmyhealth.org).
- 3. Community Choice Healthcare Network (in partnership with Microsoft HealthVault)**
- a. Community location: Cashmere, WA
  - b. Grant award: \$551,448.00
  - c. Recruitment Approach: Four counties will be part of the recruitment: Chelan, Douglas, Grant, and Okanogan. Within these communities, the patient populations that will be targeted include mothers, seniors, migrant/Spanish speaking, engaged patients, staff/employees.
  - d. Consumer Engagement Strategy: Staff and providers at health care partners will sign patients up for a health record banking account. Additionally, an ongoing outreach and enrollment campaign will occur with public school partners, enrollment events at public library sites, and other project partners.

For phase 3 of their work, AMH made initial plans to support these three pilot communities in recruitment and enrollment efforts that included five major components:

1. Facilitate focus groups with targeted patient groups, with the intention of fielding questions and helping them to understand user agreements and the identity management process. AMH would also help develop and review user agreements and privacy policies to ensure that it is readable to the average consumer and that it addresses the issue of access control and information release.
2. Coordinate among the pilot sites the communications of standard messaging to targeted audiences, including using common language and branding, relaying information to news outlets, and sharing progress with stakeholders. Using a standard brand, such as the AMH logo, would facilitate the perception that the three pilot sites are involved in an overall project, rather than promoting activities of just one community.
3. Patient recruitment support, including messaging templates and other marketing support.
4. Serve as a consumer advocate/Ombudsman, including helping patients learn which pilots are available to them, understanding the differences between the three pilots (cost, level of access control, security), and routing patients to pilot sites' help desks to resolve user issues in using the HRB. In the event that a consumer has an unresolved dispute with a pilot site vendor, AMH would triage the issues for resolution by the HCA.
5. Evaluate consumer experience of the HRB pilots through surveys that address (a) usability and utility of health record, (b) user metrics (i.e., how often and in what way did patient access their information), and (c) perceptions of privacy and security, patient activation, and customer service (e.g., were issues resolved in a timely manner to the consumer's satisfaction?). Evaluation criteria for providers included (a) patient activation (e.g., Did you notice more activation in the patient?), (b) workflow integration of the patients' HRB information, (c) value

perception, (d) success of the vendor’s HRB promotion to patients, e) barriers to use, (f) value creation, and (g) capture suggestions for other functionality that would be of value of their participants.

In reality, AMH was only able to support the pilot sites in the evaluation of their products, make recommendations about what should be included in pilot sites’ privacy policies, and review pilot sites’ user agreements and privacy policies for consumer readability and ease of comprehension.

### **II.C.2 Evaluation of Three Health Record Banking Pilot Sites**

The pilot sites agreed that there needed to be a set of common evaluation questions that would be asked of participating consumers both at the beginning of enrollment into the project, and at the end of the project 6 months later. At enrollment, patient participants would be asked five questions that tap into two key concepts: (1) learning about the patient and his or her preferences and (2) how easy/difficult was it to sign up for an account (see Appendix P for a complete list of enrollment questions). Additionally, enrollees would be asked to answer 13 questions related to their current view of their role in health care. This survey tool is called the “Patient Activation Measure” (PAM) and was designed and tested by Judy Hibbard and her colleagues from the University of Oregon.<sup>5</sup> Questions such as “Taking an active role in my own health care is the most important factor in determining my health and ability to function” and “I am confident that I can take actions that will help prevent or minimize some symptoms or problems associated with my health condition” are answered on a 4-point Likert scale, ranging from strongly disagree to strongly agree with an option for not applicable (see Appendix Q for a complete list of the PAM).

At the end of the 6 months, enrollees would be asked to evaluate their experiences with health record banking on another set of questions. In addition to responding to demographics and population characteristics, enrollees would be asked questions relating to their HRB use (e.g., “How many times have you logged into and looked at your online health record?” and “What information have you added to or updated in your online health record?”); satisfaction with features (“Having an online health record has been helpful in the following ways” and “Which

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<sup>5</sup> Hibbard, JH, Mahoney E, Stock R, Tusler M. (2007). Do Increases in Patient Activation Result in Improved Self-management Behaviors? *Health Services Research*, 42(4):1443-63.

type of health information did you use/need most?); ease of use (e.g., “Updating my online health record is easy to do” and “It was easy to share information from my online health record with those who need it”); and privacy and security (e.g., “I feel in control of the information coming into and leaving my online health record” and “It is clear to me who I have given permission to see my online health record and what parts of the information they have access to”) (see Appendix R for a complete list of post-pilot questions). Enrollees would also retake the PAM to measure any shift in their perceived role or “activation.”

These surveys would be available to enrollees both online and on paper, depending on preference. The survey responses would be aggregated to determine whether participating in health record banking results in more activated patients, and understand what features of the HRB pilots were most valued/used.

### **II.C.3. Recommendations for Privacy and Security Criteria**

AMH also played a role in recommending and reviewing privacy and security policies for the pilot sites. Under security, AMH recommended that pilot sites authenticate the identity of enrollees and others using the system, and offer binding agreements for vendors signing up participants, the consumers, and providers that access the health record information. AMH also recommended that enrollees be given a unique user name and digital code to initiate their accounts and that this information be provided to the consumer via the postal service, in person, or in a manner that could not be intercepted.

For privacy criteria, AMH recommended that the privacy policy should be easily accessible to consumers, be clearly written and understandable, cover all downstream entities and vendors that may have access to the health information, describe who and when others may have access to the information, and state that others who can access the information are also in binding agreements with the HRB pilots to follow the privacy and security policies. Following the advice that was given to consumer in phase 2 about safeguarding one’s identity, AMH also recommended that privacy policies include notifications about consumer obtainment and control over their data, including any limitations that exist, and ensure immutable audit trails. Lastly, AMH recommended that pilot sites disclose if they are collecting nondemographic data and specific uses of those data to participants.

AMH reasoned that consumers who know, understand, and agree with their health IT vendor's privacy and security policies are more likely to trust in online health record banking.

Transparency is key to gaining consumer confidence and transitioning into an environment where patients use online tools to become more activated patients.

#### **II.C.4. Lessons Learned from Phase 3**

At the time this final report was being written, the HRB pilots had just begun and patients were still being recruited for enrollment in the demonstration projects. The lessons learned from phase 3 are incomplete because the timing of this report did not completely overlap with the work completed by the pilot sites. Regardless, the following sums up the lessons learned up to the point of this report.

1. **Use of the Clinical Activation Measures.** Pilot sites agreed to use the PAM to evaluate the impact of the HRB project on patients' perception of their role in their own health (care). There was some discussion to also employ the Clinician Activation Measure (CAM), currently being pilot tested by Judy Hibbard and colleagues, as a complement to the PAM. The CAM is a 13-item questionnaire that measures the extent to which providers feel it is important that patients are engaged in their own health care. Although the pilot sites ultimately chose not to implement the CAM, future projects that measure patient activation may want to also utilize the CAM to measure provider receptivity to a more active role for patients.

### **III. OVERALL LESSONS LEARNED AND FUTURE DIRECTIONS**

Common themes in engaging consumers emerged during the course of this project. These common themes may significantly impact future engagement of consumers in health information technology and health information exchange.

#### **III.A. OVERALL LESSONS LEARNED**

Often enough, efforts to engage consumers start and end with consumer advocacy organizations. While this method of outreach to consumers has certain benefits, it should not replace efforts to speak directly to the average consumer. "Real" patients, as opposed to "professional" patients, may have different perspectives on issues. For example, early in the life of AMH, a consumer not affiliated with health care was asked to attend a meeting. In that meeting, AMH learned that the term "health record banking" did not bring up any meaning for the consumer. AMH learned

then that to “hook” consumers into learning about online tools, the terminology used needs to be somewhat recognizable to consumers immediately. Because most of the AMH members had been working with the HCA and the HIIAB in thinking about health record banking for over a year, they did not question the usage of the HRB term for marketing purposes.

Similarly, to develop a sustained business plan for online health records, it would behoove future projects to ask patients directly about what they want and need from online health tools.

Educating and engaging patients, providers, and other health care entities about using online health tools is a big shift away from the traditional paradigm in medicine. It takes a good deal of time and effort to educate all types of consumers about the uses and benefits of health care technology for the purposes of care quality, patient safety, and streamlining clinical processes. It also takes time and effort to bring those different types of consumers together so that a shared understanding of the value of online health tools can emerge. In the course of outreach to patients and providers about online personalized health records, it became apparent that there currently exists a gulf between patients and providers in terms of the desire to give patients more access to their health care information. Patients find it fairly reasonable that they should be able to see their own health care information, correct that information if needed, and share it with whomever they want whenever they want. Providers, on the other hand, are less likely to see the benefits of this model. For consumers to engage in online health tools, in which both patients and providers are actively working with one another to improve health care, there needs to be buy-in from both sides. Educating and engaging patients and providers in silos is less likely to result in a mutual understanding about why online health information sharing is beneficial for both parties than if patients and providers talk to each other. This can be accomplished through consumer forums, focus groups, and other mechanisms for community discussion.

Education in whichever mode, whether it is directed at patients, providers, both patients and providers, or other health care entities, is the key to consumer engagement and acceptance. Education helps consumers recognize that providers would benefit from patients bringing key health information to office visits because gathering information is time consuming. Consumers are also usually unaware that quality can be increased and costs can be decreased if providers’ records regarding tests, results, and medications are updated and corrected with the patient’s help. Additionally, consumers may need prompting in thinking about how online management of

health information could be very important in the event of an emergency, or during a health care visit while traveling.

Providers need a robust educational program to alleviate providers' concerns about risk and liability when patients have access to their own information. Because HRBs house a copy of patient records, the provider's originals, either on paper or electronic, are still the legal property of the provider. At this point in the pilot's current models, providers are only responsible for acting on patients' HRB information when it is brought to them as part of a clinical care encounter. In contrast to additional risk and liability, the HRB model may actually help clinicians with workflow issues because it makes gathering and organizing information about patients much more efficient. The provider does not have to do anything additional to collect this information; rather, the patient presents a paper copy of his or her health record to the provider at the appropriate time in the workflow. With the information already gathered and organized, the provider can focus on making clinical decisions with the patient and developing processes for implementing those decisions. In addition to concerns about risk and liability, providers need to be reassured that the ability to access more patient information does not translate into more administrative burden.

Provider concerns need to be addressed, whether it is risk and liability or additional administrative burden. All concerns that make providers less likely to support patients in accessing and sharing their own health information will have the potential to dampen patient enthusiasm for and usage of using online health tools, because patients typically report that the opinions of their providers are likely to sway their health actions.

Fully engaging consumers about online health tools is just one piece of the puzzle; actually getting consumers, patients and providers, to access and use the information is the next crucial step. To accomplish this feat, patients, and providers will need tangible evidence that their use of online health tools directly benefits them and incentives to bolster participation rates. On the flip side, patients and providers also need to understand how not using online health tools can place them at a disadvantage, in both emergency and ambulatory care situations.

### **III.B. FUTURE DIRECTIONS**

There have been several national health information technology organizations (e.g., CCHIIT, AHIC) that have stated the value of patients being activated in their own care, and recommended that patients be given the necessary online tools to manage their health information. Given these recommendations, it is likely that new projects focusing on consumer access and control to health information will be developed in the near future. In addition to educating and engaging consumers and providers about online health information exchange and management, AMH believes that it is essential for there to be a consumer Ombudsman role to assist consumers in making the transition from being passive recipients of health care to active participants. The Ombudsman would help consumers navigate online health information or serve as a resource for resolving disputes between consumers and technology vendors. This role will contribute to the understanding of needs for policy and additional laws to protect consumers and their health information.

### **IV. CONCLUSION**

The outreach to consumers completed by AMH resulted in greater learning about consumer needs and concerns about online health records and health record banking. In the past year, AMH developed a communication strategy for engaging different types of consumers, facilitated emergent consumer conversations about online personalized health records, and has begun to test the field for consumer interest and participation in online health tools. While AMH has made significant progress in educating and engaging consumers in the last year, there is also the recognition that much more needs to be done and that the recent efforts have just scratched the surface. AMH further appreciates the current paucity of resources available for engaging consumers in health record banking. Without consumer demand for online health information and actual consumer participation in using online health tools, health IT projects are not likely to thrive, to the detriment of patients and providers. It is the desire of the AMH committee that future health IT projects using a consumer-centric model can utilize the work and lessons learned from this project to bolster their consumer outreach efforts, and with the success of those efforts, help consumers become more activated in their health care using online tools.

## APPENDIX A

### Washington State Health Care Authority/Health Information Infrastructure Advisory Board Members (HIAB)

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**Wendy Anne Carr, Access Coordinator**, Whatcom Alliance for Healthcare Access

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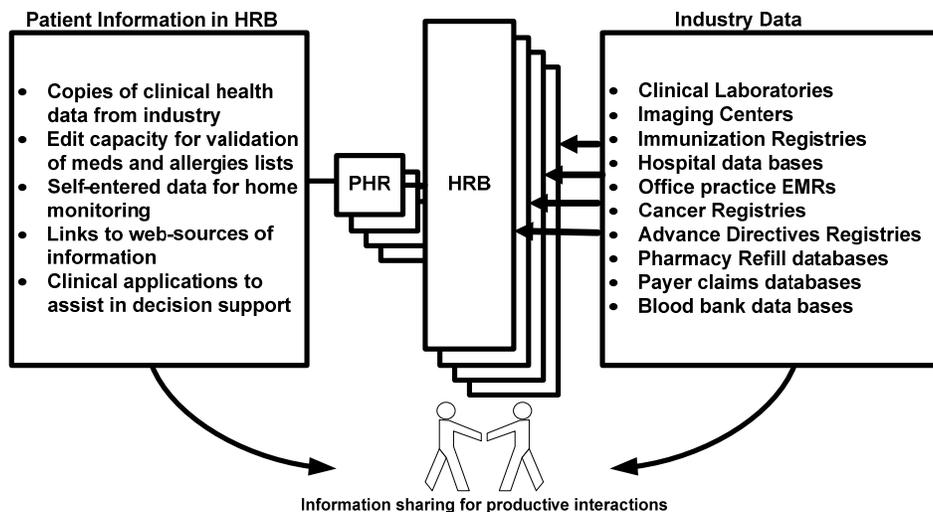
**Juan Alaniz**, Project Manager

**Kelly Llewellyn**, Deputy Project Manager

**Annette Burgin**, Project Assistant

## Appendix B

Visual of the HRB concept and the flow of information:



- **The activated patient brings:** A printed validated list of medications being taken, a list of immunizations needed, and when fully operational, lists of screening or chronic disease monitoring tests that are due, as well as prompted questions about optimal therapy organized to assist in making clinical decisions.
- **The doctor and proactive practice team bring:** The experience and perspective to review the patient's information, answer the patient's questions, recommend treatment options, and the ability to engage the patient in shared-decision-making for ordering tests, consultations and interventions.

## APPENDIX C

### AccessMyHealth Committee Members

#### Chair

**Wendy Anne Carr, Access Coordinator**, Whatcom Alliance for Healthcare Access

#### Committee Members

**Ed Singler, JD**, Former President, AARP Washington, Retired

**Gil Thurston**, Former Elementary School Principal & Consumer Advocate, Retired

**Chris Thayer, MD**, Family Practice, Group Health Cooperative

**George Rice, MD**, OB-GYN Practitioner, Retired

**David Deichert, ND**, Naturopathic Medicine, Institute of Complementary Medicine

**Jeffrey Hummel, MD, MPH**, Medical Director for Clinical Informatics, Qualis Health

**Maggie Lohnes**, Administrator, Clinical Information Management, MultiCare Health System

**Peggy Evans, PhD.**, Quality Improvement Consultant, Qualis Health

**Sandra A. Rominger**, Program Manager, Integrated Defense Systems, Boeing

#### Washington State Health Care Authority Staff

**Juan Alaniz, Project Manager**

**Kelly Llewellyn, Deputy Project Manager**

**Annette Burgin, Secretary**

#### Communications Team

**Peter Summerville**, Consultant, rialto communications

**Megan Aukema**, Consultant, rialto communications

**Linda Blankenship**, Consultant, rialto communications

#### Project Consultant

**Howard Thomas, MBA**, Consultant, Thomas & Associates Consulting, LLC

## APPENDIX D

### KEY MESSAGES

#### ONLINE PERSONALIZED HEALTH RECORDS FOR ALL WASHINGTONIANS

- **AccessMyHealth.org is a partnership of Washingtonians—patients, doctors and others—that will be exploring ways to improve patients’ access to their personal health information.**

The AccessMyHealth.org partnership, convened by the Washington State Health Care Authority, is supporting the concept of secure online personalized health records to help patients gather and store their health information to share with their doctors, family members and others.

- **With an online personalized health record, patients will have the ability to view and share a copy of their medical record as they choose.**

Patients often do not have ready access to their own health information. An online personalized health record will provide a place to store information from your healthcare visits as well as health information you want to add and the ability to share both kinds of information with your doctor, family members and others.

- **Our focus is on helping patients make great use of the time spent with their doctors.**

At the heart of this project is the goal that patients would have better and more convenient access to their medical information so that they can be more knowledgeable partners in their own care.

- **We are looking for volunteers to help us explore how an online personalized health record could be useful to patients, their families and doctors.**

To deploy an online record that truly meets the needs of Washingtonians, we want to hear firsthand from the people who will use it. Are you interested in having access to your personal health information in one place? If so, what information is most important to include, and how would you use the online record? These are just a few of the questions we’re looking for you to help answer.

- **Privacy, security and convenience are our highest priorities.**

Personal health information is near and dear to everyone – and must be protected. Help us define what privacy and security mean to you! What can be designed into the online record so that it ultimately offers convenience while still meeting your privacy expectations?

- **Make sure your opinion is heard!**

Prior to testing the functionality of an online personalized health record in early 2009, we are looking for volunteers to tell us what they want to see in an online record and how they might use it. We encourage all Washingtonians to share their thoughts.

AccessMyHealth.org will be looking for organizations interested in working with us to gather opinions from their members, constituents and employees. We are also looking for individuals interested in giving us direct input. You can participate at any level: answer a brief survey, take a telephone poll, eventually test the functionality of the online personalized health record, or something in-between. Learn more—or sign-up to give us feedback—at our home on the Internet: <http://www.AccessMyHealth.org>.

# # #

### VOCABULARY

Preferred Terms	Terms to Avoid
Patient, family, in some cases consumer	Chronically ill, children with special needs
Washingtonian	Citizen, resident
Online personalized health record * Online health record Online record	PHR Personal Health Record Health Record Bank HRB EMR EHR
Doctor	Physician Provider Healthcare provider Nurse practitioner PA Pediatrician
Copy of information Copy of health care information	Medical record
Test	Pilot test
Patients can work with their doctors to better manage their own care. Maximize time with your doctor Make great use of time patients spend with their doctors	Making visit with your doctor more efficient and effective
Safely stored	Private, secure and confidential
Patient owned personal health record Share	Patient owned HRB Control (as in “patient-controlled”)

## APPENDIX E

# Facts for getting involved: AccessMyHealth.org

## Online personalized health records for all Washingtonians

**In a nutshell.** AccessMyHealth.org is a partnership of Washingtonians — patients, doctors and others — that will be exploring ways to improve patients' access to their personal health information.

The AccessMyHealth.org partnership, convened by the Washington State Health Care Authority, is supporting the concept of secure online personalized health records to help you gather and store a copy of your health information to share with your doctors, family members and others.

### **We're looking for volunteers now!**

We are looking for volunteers to help us explore how and when an online personalized health record could be useful to patients, their families and doctors. We encourage all Washingtonians to share their thoughts.

**A few of the questions we're looking to answer.** Are you interested in having access to your personal health information in one place? If so, what information is most important to include, and how would you use it? What's most useful to parents, seniors or people with certain medical conditions? What is the most useful health information from the doctor's perspective?

**Will this benefit the patient or the doctor? Both.** The patient and doctor will reap benefits from an online health record: patients will have the ability to view, share and update a copy of their medical information; doctors will get more reliable information from their patients, such as accurate medication lists.

### **We're looking for good ideas.**

By working in partnership with people of all walks of life, we expect to learn what features and benefits are most valuable. At the heart of this project is the goal that patients would have better and more convenient access to their health information so that they can be more knowledgeable partners in their own care. Done correctly, this concept could lead to a robust online health record that helps to:

- + Give patients access to the tools and information they need to improve their health
- + Give doctors and patients the ability to compare information
- + Make it easier for patients to securely gather and store a copy of their health information to share with doctors, family members and others.
- + Create a copy of each patient's health record that is portable, easily accessible, and comprehensive

### **What about privacy and security?**

Privacy, security and convenience are our highest priorities. Personal health information is near and dear to everyone—and must be protected. Help us define what privacy and security mean to you! What can be designed into the online record so that it ultimately offers convenience while still meeting your privacy expectations?

### **How does the Washington State project stand out from other efforts?**

Across the country, patients, doctors and many health care entities are working on online health records. The Washington State initiative is different from other efforts in a crucial way: we are focused on the patient and the patient's relationship with his or her doctor, not just on sharing health information among doctors and healthcare providers. We're working to provide multiple opportunities for patients to participate and inform our process.

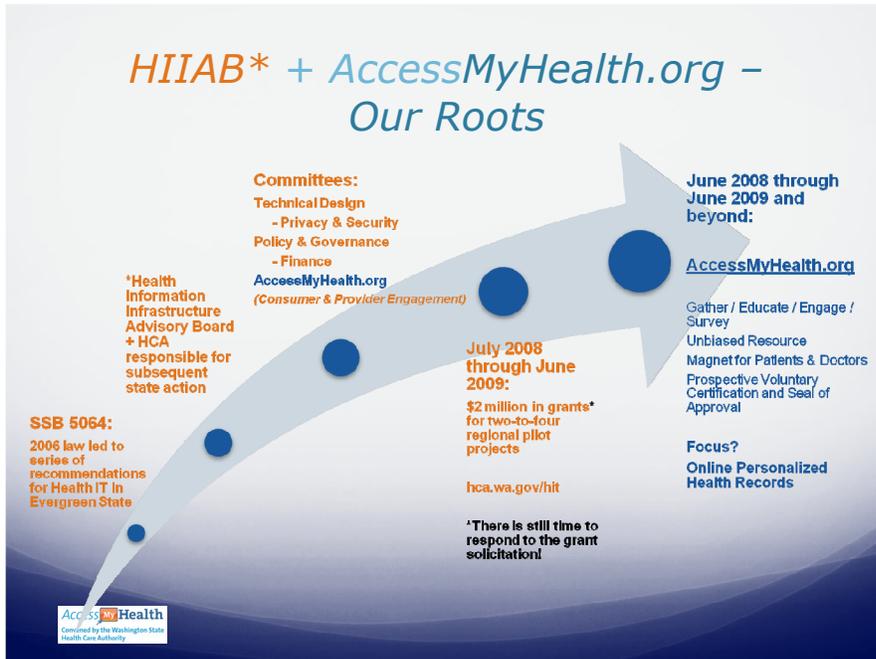
**AccessMyHealth.org needs the input of as many Washingtonians as possible. Sign up to participate by going to AccessMyHealth.org.**

**AccessMyHealth.org c/o Washington State Health Care Authority** P.O. Box 42682 Olympia, WA 98504-2682

We will protect the privacy of your personal information to the fullest extent of the law. We will not share your e-mail or other personal information with any other party for commercial purposes.

## APPENDIX F

### AMH PowerPoint Presentation (6 Slides)



## AccessMyHealth.org – Our Elevator Pitch

**AccessMyHealth.org** is a partnership of Washingtonians – patients, doctors and others – that will be exploring ways to improve patients' access to their personal health information.

**AccessMyHealth.org** is supporting the concept of secure online personalized health records to help you gather and store your health information to share with your doctors, family members and others.

**AccessMyHealth.org** does not offer a personalized online health record, but helps consumers and patients safely explore the great opportunities around online health information.

## AccessMyHealth.org – *What is our focus?*

### **We want to:**

- Give patients access to the tools and information they need to improve their health
- Give doctors and patients the ability to share and compare information
- Make health information sharing more efficient and secure
- Help reduce the unnecessary hassle and cost of duplicative medical tests
- Create a copy of each patient's health record that is portable, easily accessible, and comprehensive

### **Our current efforts**

- Establish communications materials
- Create a Web presence for educating and engaging
- Create opportunities to learn from consumers – through online surveys



## AccessMyHealth.org – *Three Surveys / Future Vision*

### **Three online surveys:**

- 1) Consumer focused. June 1st
- 2) Privacy & Security focused. Late July
- 3) Survey Results. September

### **Future Vision:**

- 1) Help patients become knowledgeable partners / advocates
- 2) Ombudsman role: provide unbiased / impartial information
- 3) Education role: teach the benefits of informed patients partnering with doctors
- 4) Be the magnet for & about online health records in WA
- 5) Provide voluntary certification / seal of approval



## *AccessMyHealth.org – For Anyone that is Interested:*

Sign up at [AccessMyHealth.org](http://AccessMyHealth.org)

Take the surveys during June-August 2008

Stay tuned for more information

If possible, be a participant in one of the 2009 pilot projects that are being funded mid-July 2008



## *AccessMyHealth.org – Key Audiences*

Patients and consumers

Doctors – Especially in terms of what we are hearing and learning from patients

Grant recipients

Opinion leaders / public policy experts – state and national

Regulatory and Legislative Leadership



## Appendix G

### E-MAIL TEMPLATE PATIENT ORGANIZATION FOCUSED



TO: **e-mail address to be determined by the sender**

SUBJECT: Empowering people with their health information

**[Dear \_\_\_\_\_ ],**

Knowing of your work related to Washingtonians' access to health care, you are getting this e-mail because we – a group of doctors, patients, consumers and others – are interested in explaining an emerging project to members of your organization.

**In a nutshell ...** here are **three things** we want you to know, and one action we would like to accomplish:

- 1.** During early 2009, a partnership of patients, doctors and other Washingtonians will be testing ideas for an online personalized health record that will help patients gather and store their health information to share – at their discretion – with their doctors, families and others.
- 2.** We are calling this effort: **AccessMyHealth.org**. The work is convened by the Washington State Health Care Authority.
- 3. We're looking for volunteers now!** We are looking for volunteers to help us explore how an online personalized health record could be useful to patients, their families and doctors on a day-to-day basis. This work will be initiated beginning in June 2008 – it is not too early to sign up! I've attached a two-page Microsoft Word document titled "Facts" with more details – including ways that your members can learn more and sign up.

**Our actionable request:** We want **[organization name]** to help us get the word out about this project, and to help us find individuals that want to volunteer to help inform our work over the next 12-plus months. Online surveys, focus groups, opinion polling, concept testing and other activities will begin soon – our early success hinges on getting solid ideas from patients across Washington State.

Please let me know if you have any questions. I have attached a number of documents that further explain our work – including a fact sheet and two brief articles that you can use for your organization's newsletter. If I can help in any way to communicate information to your members about AccessMyHealth.org, I would be happy to assist.

Thanks very much for your consideration,

**[Your name]**

## Appendix H

### Tear Offs

Access **My** Health | Governed by the Washington State Health Care Authority

**Knowledge  
is power.**

Take control of your health information.  
Take control of your health. Visit  
[www.AccessMyHealth.org](http://www.AccessMyHealth.org) to find out  
more about secure online personalized  
health records for Washingtonians.



# APPENDIX I

## Banner Ads



## APPENDIX J

### Sample Newsletters

#### VERSION #1: (398 words, with headlines)

Secure and Convenient Online Personal Health: Pipedream or Reality?  
***AccessMyHealth.org is Working on Answers***

Have you ever wished you had better and more convenient access to your personal health records? If so, you're not alone. AccessMyHealth.org, a partnership of Washingtonians – patients, doctors, consumers and others – is exploring ways to improve patients' access to their personal health information. The AccessMyHealth.org partnership has been convened by the Washington State Health Care Authority. Everyone is invited and encouraged to participate.

With an online personalized health record, you can gather and store your health information to share with your doctors, family members and others. Here's an example of how it might work: If you talk to most doctors, especially those in emergency rooms, they will tell you that an accurate list of medications is the most important information they need to effectively treat someone. They will tell you too much time during a visit is spent trying to collect or recreate this information, and that it's not always complete. What if patients had a simple, easy-to-use tool to keep track of their medications so they could share it with any doctor who needs it? An up-to-date list of the prescribed, herbal and over-the-counter medications you are currently taking could make all the difference in your care.

AccessMyHealth.org is requesting your help. Before this concept can become a reality, it needs to be tested. They need firsthand input from the people who will ultimately use an online personal health record; that's all of us. They know the basic requirements: personal health information needs to be safely stored, easy-to-use, patient-owned and web-based. But they need input before they can go further.

This is your chance to weigh-in at the outset. Here are just a few of the questions that need answers:

- Are you interested in having access to a copy of your personal health information in one place?
- Will you use it to work with your doctor to better manage your care?
- What information is most important to include from your point of view?
- Are you ready to be a more knowledgeable participant in your own care?

Participation at any level is welcome. Maybe you only have time for a short survey, or perhaps you'd like to eventually test an online personalized health record. Every bit of input helps.

If you'd like to learn more, please sign up at [www.AccessMyHealth.org](http://www.AccessMyHealth.org).

# # #

**VERSION #2: (226 words, with headlines)**

Secure and Convenient Online Personal Health: Pipedream or Reality?

***AccessMyHealth.org is Working on Answers***

Have you ever wished you had better and more convenient access to your personal health records? AccessMyHealth.org, a partnership of Washingtonians – patients, doctors, consumers and others – is exploring ways to improve patients' access to their personal health information.

The AccessMyHealth.org partnership is convened by the Washington State Health Care Authority. The idea is to give patients better and more convenient access to a copy of their health information, so that they can be more knowledgeable partners in their own care. Everyone is invited and encouraged to participate.

AccessMyHealth.org needs firsthand input from the people who will ultimately use an online personal health record; that's all Washingtonians. They are requesting our help to answer questions such as:

Are you interested in having access to a copy of your personal health information in one place?

Will you use it to work with your doctor to better manage your care?

What information is most important to include from your point of view?

Are you ready to be a more knowledgeable participant in your own care?

If you'd like to learn more, please sign up at [www.AccessMyHealth.org](http://www.AccessMyHealth.org). Participation at any level is welcome – from taking a ten-minute online survey, to eventually testing an online personalized health record. Every bit of input helps.

#

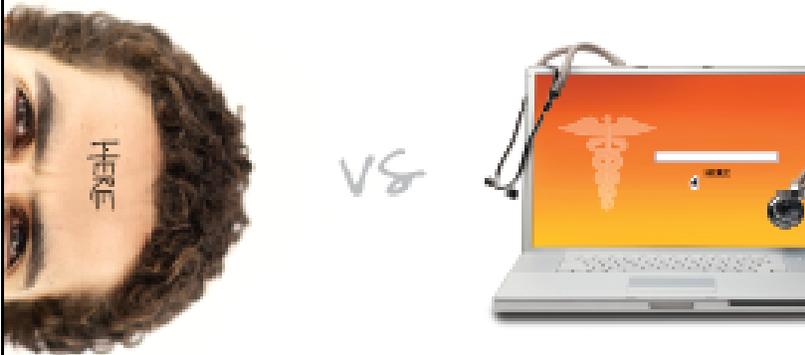
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## APPENDIX K

### AMH Poster 1

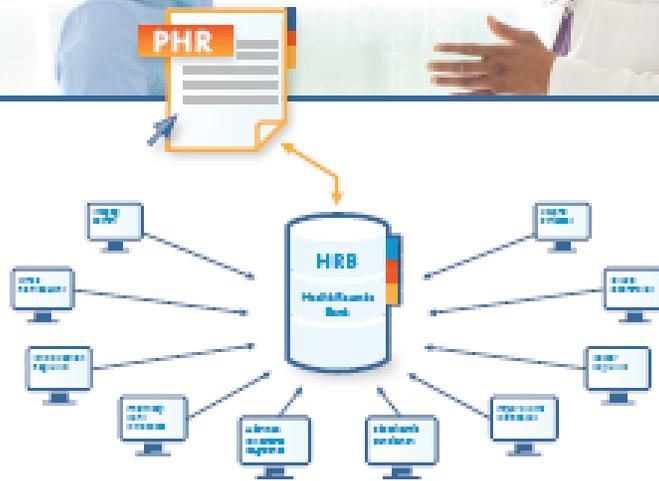
Choose the best place to store  
your health information



Join the movement. Join the conversation.  
[www.accessmyhealth.org](http://www.accessmyhealth.org)

## \*PHRs: Better information means better patient conversations.

Better data, better knowledge, better diagnosis, better efficiency.  
It's better when you get to patients and us.



\* Personal Health Records

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## Appendix L

### AccessMyHealth Survey #1

1. **Are you male or female?**
  - a. Male
  - b. Female
  
2. **What is your Age?**
  - a. 17 or younger
  - b. 18-29
  - c. 30-49
  - d. 50-64
  - e. 65 or older
  
3. **What is your zip code?**
  
4. **Do you work in health care industry?**
  - a. No
  - b. Yes, in direct patient care
  - c. Yes, in office administration
  - d. Yes, as a health care vendor or consultant
  - e. Yes, in another role
  
5. **Do you have a chronic condition or disease (such as diabetes, heart disease, depression, asthma or other)?**
  - a. No
  - b. Yes
  
6. **Do you care for someone who has a chronic condition or disease?**
  - a. No
  - b. Yes, a spouse
  - c. Yes, a child
  - d. Yes, a parent
  - e. Yes, a friend or other family member
  - f. Yes, as a paid caregiver
  
7. **How many people, including yourself, do you coordinate care for (please count children, parents, spouse, or partner, etc)?**
  - a. 1 person
  - b. 2 people
  - c. 3 or more people
  
8. **During the last 12 months, approximately how many times have you or someone you arrange care for, received care at a doctor's office or hospital?**
  - a. 0

- b. 1-3
  - c. 4-10
  - d. 11-20
  - e. 21 or more
9. **How many medications (prescription and non-prescription) are you, and the people you care for, regularly taking? Please check all that apply.**
- a. Myself (0, 1-3, 4-10, More than 10)
  - b. Person #10 (0, 1-3, 4-10, More than 10)
  - c. Person #2(0, 1-3, 4-10, More than 10)
  - d. Person #3 (0, 1-3, 4-10, More than 10)
10. **How much do you agree or disagree with the following statements (strongly disagree, disagree, neither agree nor disagree, agree, strongly agree)?**
- a. When all is said and done, I am the person who is responsible for managing my health.
  - b. I feel comfortable questioning my doctor about a recommended course or treatment
  - c. I almost always follow my doctor's recommendations
11. AccessMyHealth.org is exploring ways to securely compile online health information in one place, so that patients can work with their doctors to better manage their own care. An online personalized health record would allow patients to electronically view, share, and update a copy of their medical information so that all the information – from different doctors, pharmacies, etc – would be readily available in one place.

**Would you be interested in showing a copy of some or all of your information to any of the following people (Yes, No, Maybe, No Opinion)?**

- a. My spouse/partner
  - b. My grown children
  - c. My caregiver or a trusted friend
  - d. My regular doctor or doctors
  - e. Emergency Room doctors
  - f. Other healthcare providers
  - g. The person with my durable power of attorney
  - h. My health insurance company
  - i. My pharmacist
  - j. Public Health
  - k. Anyone else
  - l. Please specify
12. Patients do not always have easy access to their own health information. An online personalized health record would allow patients to decide what medical information is copied and safely stored in electronic format, to whom that information is released and when?

**Please rate the value of the following capabilities (not valuable, somewhat valuable, valuable, very valuable, no opinion)**

- a. Tracks medication history and gives an up-to-date list of all medications
  - b. Provides a record of drug, food, and other allergies and drug reactions
  - c. Tracks and gives access to immunization records
  - d. Provides access to advanced directives, including Living Wills and Durable Power of Attorneys
  - e. Provides access to lab results and lab test information
13. With an online health record, health information remains accessible to you and continues to be collected even if you change doctors, change insurance, or move to another state.

**Please rate how valuable you believe an online personal health record would be in the following situations? (not valuable, somewhat valuable, valuable, very valuable, no opinion)**

- a. If I, or someone I care for, is brought to the emergency room
  - b. When traveling
  - c. Before a visit to my doctor or specialist
  - d. Before visiting a new doctor
  - e. To store information for future use
  - f. In another situation (please specify)
14. Privacy and security are big issues for people when it comes to their health records.

**Please rate how much you agree or disagree with the following statements about privacy and security (strongly disagree, disagree, neither agree nor disagree, agree, strongly agree).**

- a. A system that is secure as online banking would be adequate
  - b. I would want to know that there were stiff penalties in place for anyone who breached the system
  - c. It would be important to me that certain data (like mental health problems, abortion, drug use) be held in a special compartment that only I can access and make available if I wish
  - d. Authorization for distributing any health information from my online health record about me would be completely up to me
15. Had you heard about personal health records before taking this survey
- a. No
  - b. Yes
16. Patients do not always have easy access to their own health information. An online personalized health record would allow patients to decide what medical information is copied and safely stored in electronic format, to whom that information is released and when.

**Have you heard of, or are you using any of the following? Please select all that apply (I've never heard of, I've heard of, I have used, I am currently using).**

- a. My insurance company's online personal health record (like Aetna®)
  - b. My doctor's online personal health record (like MyGroupHealth®)
  - c. Web MD Health Manager
  - d. Microsoft's Health Vault
  - e. RealAge
  - f. MyPHR.com
  - g. Google's PHR
  - h. Other (please specify)
- 17. Tell us what, if anything, you like about the concept of an online personalized health record. Does it sound appealing to you? Please describe.**
- 18. Tell us what, if anything, you don't like or what concerns you about the concept of a personalized health record. What potential risks would you like to see addressed?**

**AccessMyHealth Survey #2**

- 1. Are you male or female?**
  - a. Male
  - b. Female
  
- 2. What is your Age?**
  - a. 17 or younger
  - b. 18-29
  - c. 30-49
  - d. 50-64
  - e. 65 or older
  
- 3. What is your zip code?**
  
- 4. Do you currently use an online banking service to check account balances?**
  - a. Yes
  - b. No
  
- 5. Do you currently use an online banking service to pay bills?**
  - a. Yes
  - b. No
  
- 6. Have you ever purchased products and services online?**
  - a. Yes
  - b. No
  
- 7. Do you use a grocery store or supermarket loyalty card or discount card?**
  - a. Yes
  - b. No
  
- 8. Have you ever been the victim of identity theft as a result of online activity?**
  - a. Yes
  - b. No
  - c. possibly
  
- 9. Do you work in the health care industry?**
  - a. No
  - b. Yes, in direct patient care or health administration
  - c. Yes, as a health care vendor or consultant
  - d. Yes, in another role
  
- 10. Do you have – or do you care for someone who has – a chronic condition or disease (such as diabetes, heart disease, back pain, depression, asthma or other)?**
  - a. No
  - b. Yes

**11. Had you heard about personalized online health records before visiting AccessMyHealth?**

- a. No
  - b. Yes
12. You may have seen newspaper articles or TV news stories in which an aspect of medical privacy or a breach related to medical records is featured. AccessMyHealth is interested in learning what you think would work best to protect the privacy of your online personalized health record.

**Please tell us how much you agree or disagree with the following statements (strongly disagree, disagree, neither agree nor disagree, agree, strongly agree).**

- a. A one word password is convenient, easy to use and would get the job done
  - b. A password and multiple identification questions, like some financial institutions now use, would work for me.
  - c. The best way to keep my online health information private is for me to have 100 percent control over who can view my health information and which information they can see.
  - d. There is no solution to the privacy risks that would make me willing to have my personal health information online.
13. We are living in the digital age and share an increasing amount of personal and financial information online. The concept of creating an online personalized health record is now being considered. That means medical information would be available, along with other types of data already accessible on the Internet. If you weren't already paying attention to the privacy and security of your online information, this is a great time to start.

**Please tell us how much you agree or disagree with the following statements (strongly disagree, disagree, neither agree nor disagree, agree, strongly agree).**

- a. If my personal health information is accessible to doctors when it is needed (e.g. in the emergency room)
  - b. I'm willing to put it online as long as it is kept from prying eyes
  - c. Put my health information online as long as I have the authority to designate the individuals who can view my personal health information
  - d. Put my health information online as long as there are strong penalties for illegal use of, or access to, my information
  - e. Put my health information online as long as there is a verifiable audit trail of everyone who accesses my information
  - f. Under no circumstances do I want my personal health information to be online
14. Dr. Henkle was seeing a patient, Mary, who suffered from diabetes, obesity and eczema. Mary described how she had been feeling depressed due to present circumstances and thought maybe she should go back on the antidepressant medication she used to take. Dr. Henkle agreed that restarting the anti-depressant was probably a good idea, and started to write out the prescription. Then Mary said, "By the way, wasn't there a blood test that was abnormal a couple of years ago, something with a 'c' that you told me we should keep an eye on?" Dr. Henkle looked back through the records and found an elevated calcium test from three years ago. Since this can contribute to feelings of depression, he

ordered a repeat test and this time the test came back markedly elevated. Because Mary brought up the test, Dr. Hinkle was able to find the root cause and order a more appropriate course of treatment.

This real-life example shows what can happen when a patient and their doctor partner to arrive at the best course of action together. Online personalized health records are an important way that a patient and doctor can share and compare information that lead to these powerful conversations.

**Please tell us how much you agree or disagree with the following statements (strongly disagree, disagree, neither agree nor disagree, agree, strongly agree).**

- a. Patients with personalized online health records can be more engaged in their own care - and contribute to their care in important ways, especially when it comes to helping their doctor with the complex job of compiling all the details of their health that may come from many sources.
- b. Doctor-patient communications would be enhanced with personalized online health records.
- c. It is my primary care doctor's responsibility to store and review my health information from previous visits and other doctors. I don't see a role for myself in managing my health information.
- d. Other (please specify)

**15. Millions of customers use online banking services every day – they decide that they want their personal financial information accessible on the Internet. When you think of having financial – or health-related – information available to you on the Internet, what worries or concerns do you think of?**

16. Imagine the following happening: a major earthquake has hit the Evergreen State. You have been displaced miles from your home, and you require urgent medical attention at an out-of-town emergency room or medical facility. To give you the best care, the attending doctor needs to know your medical history.

**Please rate how much you agree or disagree with the following statements (strongly disagree, disagree, neither agree nor disagree, agree, strongly agree).**

- a. The quality of my care would be better and more efficient if the attending doctor could access the information in my online health record
- b. The quality of care would be better if the doctor can access my online health record
- c. Having an online personalized health record available to my doctors would be worth dealing with some privacy and security risks
- d. Considering the privacy and security risks of having my health information online, I would prefer that the attending doctor rely on current methods like phone and fax to get the health information that he/she needed to treat me.

**17. There are many potential benefits of having and using a personalized online health record. Please indicate which of the following benefits you would consider of importance – check the two that are most important to you.**

- a. I get to decide and chose: to whom, what and when my personalized health record will be shared
- b. An easy place for storing and printing my health information for school, camp, or a new doctor
- c. Ability to look at my own health information or test results to make sure they are correct and up to date.
- d. In case of a catastrophe or public disaster, there is an electronic backup of my online health records
- e. I have my own reason for wanting to have my health record online.
- f. Here's what I think:

**18. Now that you have read a little bit more about online health records, are you getting more or less comfortable with the concept?**

- a. More comfortable
- b. Less comfortable
- c. Neither

**19. Do you have any questions or comments you would like to add?**

**20. Based on what you now know about online personalized health records, would you want to use an online health record if it became available to you or your community on a trial basis?**

- a. Yes
- b. Yes, if my doctor is involved.
- c. No
- d. Why or Why not? (please specify)

**21. How did you hear about AccessMyHealth.org and this survey?**

## **APPENDIX M**

### **Survey One Results As of Sunday September 7, 2008**

1. There were 510 respondents. (33 more since the last report 8/20)
2. 77% of respondents provided their e-mail address at the beginning of the survey. Another 130 have provided their e-mail at the end of the survey. (This may include duplicates.)
3. Respondents to date are 70% women and 30% men. (male respondents increased)
4. 45% identified themselves as being between the ages of 50-64, 34% identified themselves as being between the ages of 30-49 and 14% 65 or older. (less 50-64 and more 65 or older)
5. 62% said “yes” to the question “Do you work in the health care industry?” (down from last report)
6. 55% indicated they did not have a chronic condition
7. 67-82% of respondents rated all features in question 13 (listed below) as ‘Very Valuable’
  - Tracks medication history and gives an up-to-date list of all medications
  - Provides a record of drug, food and other allergies and drug reactions
  - Tracks and gives access to immunization records
  - Provides access to advanced directives, including Living Wills and Durable Power of Attorneys
  - Provides access to lab results and lab test information
8. 83% felt it would be very valuable “If I or the person I care for is brought to the emergency room”.
9. In question 15 regarding Privacy and Security, 71% strongly agree with stiff penalties for breaches, 73% strongly agreed that authorization should be completely up to them.
10. 82% of respondents indicated they had heard of a personal health record.
11. 158 people have provided their name (30%) (down from last time)
12. 70% of respondents wrote in positive comments about the online personalized health record under “Tell us what, if anything, you like about the concept of an online personalized health record.”
13. 68% of respondents answered the question “Tell us what, if anything, you don’t like or what concerns you about the concept of a personalized health record. What potential risks would you like to see addressed?” 99% of the write in comments are about privacy and security concerns.

### **Survey Two Results As of September 7, 2008**

Survey Two started July 21, and after 48 days 71 people have taken the survey. (an increase of 29)

- 40% are between the ages of 50-64
- 73% are women
- 70% use an online banking service to check balances and 44% to pay bills online
- 96% purchase online
- 86% use a supermarket loyalty/discount

- 59% do not work in healthcare

Question 12 asked for feelings about passwords, access and security

- 14% of respondents indicated (agree or strongly agree) that there is not a solution to the privacy risks that would make them willing to put their health information online.
- While 52% felt a one word password would work, 69% preferred a password and multiple identity questions
- 82% agreed or strongly agreed that the best way to keep information private is to have 100% control over who can view their information

In question 13

- 87% agreed to put their health information online as long as there is a verifiable audit trail
- 84% agreed to put their health information online as long as there are stiff penalties for illegal use or access
- 84% agreed to put their health information online as long as they have the authority to designate who can view it
- Only 5% said “under no circumstances do I want my personal health information online”

In Question 16

Over 80% felt care would be “better and more efficient” or “quality of care would be better if my doctor can access my health record”

Question 17 asked for the two most important benefits. The top two selections are:

- 73% - getting to chose to whom, what and when my record will be shared
- 60% - ability to look at my health information and test results to be sure they are correct and up to date.
- 50% said they were more comfortable after the survey and 40% said they were neither more or less comfortable
- 51% want to use a personal health record if it becomes available in their community, 29% said yes if their doctor is involved. (81% want to use one.)
- How did they hear about AMH? One heard about us from an Internet ad and one through Community minded, Wendy Carr, Ed Singler, others said friends or co-workers. 96% provided their e-mail address

## APPENDIX N

### Risks/Benefits Document

#### HIIAB Privacy and Security Subcommittee Language for Consumer Pilot Participants DRAFT – 05/26/08

- Prepared at the request of the Subcommittee chair, this document is an attempt to summarize the key elements of the pilot privacy and security specifications that are relevant to the average consumer user.

We are all living in the digital age and share an increasing amount of personal and financial information online. Now, you're thinking of creating an online personalized health care record and adding your medical information to the mix. If you weren't already paying attention to the privacy and security of your online information, this is a great time to start.

As the potential owner of a personalized online health record, the first thing to know is there is no such thing as "perfect" security nor can anyone "guarantee" your privacy. Keeping your health records on paper carries privacy risks, keeping your records online also carries privacy risks. There is no risk free way to store health information. Like many other areas, information security is all about tradeoffs. For example, if you drive a car you have a risk of getting hurt in an accident. You can avoid or reduce this risk by not driving a car, driving a car with a seatbelt, driving a car with a helmet, or only driving a tank. Most people elect to drive and accept the risk because it is convenient; most people also wear seatbelts but avoid the helmet and the tank because the latter are expensive and uncomfortable. Storing your personal health information online is similar. You are going to accept some risk in sharing health information online because it improves your health, simplifies your interaction with the health care system or makes life more convenient. So, what's the equivalent of the seat belt? How do you reduce your privacy and security risk while still enjoying a system that is usable, convenient and cost effective?

When most people think about online security they tend to think about hackers and technological tools to keep these bad guys out. In reality, it's less about fancy technology and more about good practices. Making sure you buckle your seat belt reduces the risk of injury in a car accident; following good security practices has the same effect on reducing the risk of your information being compromised. This means the most important part of your health information security system is YOU. You and the practices you follow are the best safeguard of your online privacy. Here are some specific practices you should consider:

The operator of your online health record must meet minimum specifications and have a privacy policy. Check with \_\_\_\_ (assumes there will be some type of resource or ombudsman to check with) to make sure he operator has meet minimum specifications. The policy should be readily available and clearly written. Make sure you understand and agree with what it says, if not ask \_\_\_\_\_. The key part of the policy should state that you control access to your online information. As you review the policy, here are a few key things you should look for:

1. While this sounds silly, since you control access to your health information, it is really important when you go online that you are who you say you are. In other words, you don't want

someone who is not you, to spoof your identity and sign up as you. To protect your identity, the operator should do three things:

- **Make you sign an information sharing agreement of some type.** At a minimum the agreement should require you to be truthful in registering, use the system properly, follow all relevant laws and promptly report any security violations you become aware of.
- **Verify your identity.** This may make you a little uncomfortable because identity verification can involve some intrusive questions. However, this is for your protection and if your identity isn't verified in a trusted manner all the rest of the security protections are suspect.
- **Give you a unique digital ID.** Every person should have a unique digital ID (most commonly a password or user ID, though there are many types of digital IDs). Sharing a digital ID with someone else is just as bad an idea as sharing a seatbelt. **DO NOT SHARE YOUR DIGITAL ID.**

2. What's good for you is equally good for anyone else who gets access to your online information; they should go through the same three steps. They should sign an agreement, their identity should be verified and they should have their own, unique digital ID, NOT share yours.

3. No one should get to see your information unless you approve it. You should be able to control who gets to see your record. In some cases you may even have choices about limiting access to specific sections of your online record to specific people.

4. You should have ready access to a list of all the people who looked at your online health information. This is your health record you have the absolute right to know who viewed it.

Asking to periodically view the audit records of who accesses your health information is a good idea for two reasons. First, you can find out if anyone you didn't approve had access, if so, report this to the operator and insist on corrective action. Second, you may want to ensure the people you want to view your records are doing so. If not, give them a call and see what's up.

Safeguarding your information is mostly about what YOU do. Even if you do everything right, there is always some risk. However, by checking the policy, following good practices, asking questions and making sure the operator meets minimum specifications, you can keep that risk to a minimum.

## Appendix O

# Facts for Providers: AccessMyHealth.org

## Advantages of online health record-keeping – partnering with patients – being promoted by state partnership

**AccessMyHealth.org is a partnership of Washingtonians – patients, doctors and consumers – that is exploring ways to securely compile personal health information in one place, so that doctors have the advantages of working with more fully engaged patients.**

The AccessMyHealth.org partnership, convened by the Washington State Health Care Authority, is supporting the concept of online personalized health records to help patients gather and store their health information.

**When patients share their online personalized health record, doctors will get more and better information about a patient’s health status, including adherence to treatment regimens.**

The AccessMyHealth partnership believes physicians can provide better care and know more about a patient’s adherence to treatment regimes when patients take greater responsibility for their own health information; outcomes can be improved.

**Online tools for health information can meet doctor and patient needs for sharing and comparing health data – creating efficiencies from registration to exam room to payment.**

A more complete health record managed by patients – that is portable and durable and more fully accessible by the patient – could improve the flow of clinical information from one clinical source to another, while it could lessen-the-load for patients’ HIPAA consent requirements related to sharing information.

**Online personalized health records work without requiring doctors to adopt new technology or software in their offices.**

An online personalized health record is a copy of a patient’s health information, securely accessible to patients anytime, anywhere. It is a great leap forward to have an online and organized way for patients to gather and maintain their own health information, and bring this information to their appointments. AccessMyHealth.org is interested in learning what steps can be taken by doctors and patients – without new technology, software or administrative burdens required in the clinic.

**We are looking for volunteers to help us explore how an online personalized health record could be useful to doctors, patients, and others on a day-to-day basis.**

To deploy an online record that truly meets the needs of Washingtonians, we want to hear firsthand from the people who will use it. Are you interested in having access to your patients’ personal online health information? Do you see advantages? Disadvantages?

**Privacy, security and convenience are our highest priorities.**

Personal health information is near and dear to everyone – and must be protected. Help us define the privacy and security standards needed. What can be designed into the online health record so that it offers ultimate convenience while still meeting strong confidentiality expectations?

**Make sure your opinion is heard!**

Prior to testing the functionality of an online health record in early 2009, we are building consumer interest, conducting research with organizations and individuals, and coalescing support. You can help by providing us feedback about the prospective requirements and potential uses of the online record. We welcome all Washingtonians – doctors and patients – to weigh in with their ideas.

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AccessMyHealth.org is looking for health-, consumer- and employer-focused organizations interested in working with us to gather opinions from their members, constituents and employees. We are also looking for individuals interested in giving us direct input. You can participate at any level: answer a brief survey, take a telephone poll, eventually test the functionality of the online personalized health record, or something in-between. Learn more – or register to give us feedback – at our home on the Internet: [www.AccessMyHealth.org](http://www.AccessMyHealth.org).

## APPENDIX P

### Enrollment Questions common to all three pilot sites



### HRB Patient Participation Survey Questions

Pre-pilot Questions used by all HRB pilots from “go live” until mid-June.

#### Common Enrollment Questions (5 questions)

1. How did you hear about this online health record? Select all that apply.
  - a. Doctor, clinic, or pharmacy
  - b. A website, letter or other communication from my doctor or clinic
  - c. Friend or family
  - d. Media or advertisement
  - e. Health fair or other community event
  - f. Presentation
  - g. Local library
  - h. School
  - i. Community organization (For example: Headstart, AARP)
  - j. Other (please specify): \_\_\_\_\_
  
2. How did you register for the online health record? Select all that apply.
  - a. Online/I used the Internet
  - b. Completed a paper form myself
  - c. Faxed/mailed a paper form
  - d. Through a series of e-mails
  - e. Someone helped me register
  - f. I did part on paper and the rest online
  
3. How easy was the process of signing up for your online health record? Select one answer that best describes your experience.
  - a. Very easy
  - b. Easy
  - c. Difficult. How could it be made easier? \_\_\_\_\_
  - d. Very difficult. How could it be made easier? \_\_\_\_\_
  
4. How would you prefer to sign up for an online health record? Select one answer that best describes your preference.
  - a. Online
  - b. Fill out and mail a paper form
  - c. Face to face with help from an enrollment specialist
  - d. Other: \_\_\_\_\_

5. Who most often manages your online health record? For example: entering information, accessing the account, setting permissions. Select one answer that best describes your experience.
  - a. I do - as the account holder
  - b. I do - for a child(ren) in my household
  - c. A family member (examples: adult child, spouse)
  - d. A caregiver or friend

**Patient Activation Measure (PAM) (13 questions – See Appendix Q)**

**Demographic Questions – About You (4 questions)**

1. Gender  
Male Female
2. Where do you live?  
Bellingham area  
Spokane area  
Wenatchee area
3. Age  
Under 25  
26 – 35  
36 – 45  
46 – 55  
56 – 65  
66 & Up
4. In general, my overall health is:  
Poor  
Fair  
Good  
Very good  
Excellent

## APPENDIX Q

### Patient Activation Measure

Please indicate how much you agree or disagree with each statement below. If the statement does not apply to you, select N/A. **(Answered on a scale, strongly agree to strongly disagree)**

1. When all is said and done, I am the person who is responsible for managing my health condition.
2. Taking an active role in my own health care is the most important factor in determining my health and ability to function.
3. I am confident that I can take actions that will help prevent or minimize some symptoms or problems associated with my health condition.
4. I know what each of my prescribed medications do.
5. I am confident that I can tell when I need to go get medical care and when I can handle a health problem myself.
6. I am confident that I can tell a doctor concerns I have even when he or she does not ask.
7. I am confident that I can follow through on medical treatments I need to do at home.
8. I understand the nature and causes of my health condition(s).
9. I know the different medical treatment options available for my health condition.
10. I have been able to maintain the lifestyle changes for my health condition that I have make.
11. I know how to prevent further problems with my health condition.
12. I know how to prevent further problems when new situations or problems arise with my health condition.
13. I am confident that I can maintain lifestyle changes, like diet and exercise, even during times of stress.

## APPENDIX R

### Post-pilot Survey Questions



### HRB Patient Participation Survey Questions Post-Enrollment

#### Population Characteristics (17 questions)

Please select the multiple choice answer that best describes your experience.

1. In the last year, how often have you seen a healthcare professional for preventive care (immunization, wellness checkup, mammogram, and colonoscopy)?
  - a. I haven't seen a healthcare professional for preventive health care in the last year
  - b. Once-twice a year
  - c. 2-12 times a year
  - d. More than 12 times a year
  
2. In the last year, how often have you seen a healthcare professional for health problems like being sick or injured (visited the ER, clinic, doctor's office)?
  - a. I haven't seen a doctor or other healthcare professional for any sickness or injury in the last year
  - b. Once-twice a year
  - c. 2-12 times a year
  - d. More than 12 times a year

#### (PAM is included in Pop Characteristics – see Appendix Q)

Please select one answer that best describes your experience.

3. In an average month, how often do you use a computer to go on the Internet or check e-mail?
  - a. I sometimes don't access the Internet/e-mail for a whole month
  - b. Once a month
  - c. 2-5 times a month
  - d. 5-30 times a month
  - e. More than 30 times a month
  
4. Where do you access the Internet/e-mail most often?
  - a. My home computer
  - b. At work
  - c. At a friend or family member's house
  - d. At a public library
  - e. At an Internet café or other commercial access
  - f. Other (please specify): \_\_\_\_\_

## HRB Use (6 Questions)

Please select the multiple choice answer that best describes your experience.

1. How many times have you logged on to look at your online health record?
  - a. Never
  - b. 1-3 times
  - c. More than 3 times
  
2. What information have you added to or updated in your online health record? Select all that apply.
  - a. I haven't added or updated any information.
  - b. My demographic information (name, date of birth, address, etc.)
  - c. My health indicators (blood pressure, blood sugar, weight, etc.)
  - d. My health history (family health history, dates of surgeries or procedures, etc.)
  - e. My current list of medications
  - f. My immunization information
  - g. Other (please specify): \_\_\_\_\_
  
3. What sources of information did you use to add data to your online health record – not including what was uploaded automatically? Select all that apply.
  - a. My records from my doctor/clinic
  - b. My medications from Walgreens, Longs, the hospital or another source
  - c. My immunization record from the doctor/clinic
  - d. Information from a health device that I can plug into my computer (heart monitor, blood pressure cuff, etc.)
  - e. Lab information like test results
  - f. I did not use other sources of information to create my online health record.
  - g. Other (please specify): \_\_\_\_\_
  
4. Who do you share your online health information with? This could be by printing out pages to share or by authorizing someone to have a password to view all or part of your online health record. Select all that apply.
  - a. A family member
  - b. A caregiver
  - c. My regular doctor or someone in his/her office
  - d. A new doctor I was seeing for the first time
  - e. A doctor or other personnel at the emergency room
  - f. Other (please specify): \_\_\_\_\_
  - g. I did not share any of the information from my online health record with anyone.
  
5. If an audit feature is available to you, do you use it to see who looked at your online health record? Select all that apply.
  - a. I am not aware of an audit feature as part of my online health record
  - b. I've never used this feature
  - c. I use the audit feature to see who looks at my online health record

- d. I use the audit feature to see if anyone I don't know looked at my online health record.
  - e. I use the audit feature to see if the list of people with permission to see my online health record is accurate.
  - f. Other (please specify): \_\_\_\_\_
6. If you had any specific questions or concerns with your online health record – was it resolved to your satisfaction?
- a. I haven't had questions/concerns at this point.
  - b. Yes, they were resolved. How and by whom? \_\_\_\_\_
  - c. I had questions/concerns, but didn't talk to anyone about them. (Please describe the problem/question \_\_\_\_\_.)
  - d. I voiced my questions/concerns but they were not resolved to my satisfaction. (Please describe the questions/concerns and what steps were taken by you and others to resolve them? \_\_\_\_\_.)

### **Satisfaction with Features (9 Questions)**

Please indicate how much you agree or disagree with each statement below. If the statement does not apply to you, select N/A.

My online health record...

- 1. helps me use my local health care system more effectively
- 2. helps me communicate more effectively with health care professionals
- 3. helps me share information from one doctor with other health care providers
- 4. helps me better organize and keep track of my medications
- 5. allows me to use more of the health-related tools and programs available on the Internet
- 6. helps me understand my choices and make better decisions about my health
- 7. makes me feel more confident when interacting with the health care system
- 8. Other: \_\_\_\_\_
- 9. What would you like the online health record to help you do in the future?
  - a. *Free text response*

### **Online Health Record "Ease of Use" (4 questions)**

Please indicate how much you agree or disagree with each statement. If the statement does not apply to you, select N/A.

- 1. I can quickly find the information I need in my online health record.
- 2. It's easy to update my online health record.
- 3. Adding information into my online health record from other (online) sources was easy to do.
- 4. It's easy to share information from my online health record with those who need it.

NOTE: add note to N/A in this section "I haven't shared my online health record"

### **Privacy and Security (3 Questions)**

Please indicate how much you agree or disagree with each statement below.

1. I control the information coming into and leaving my online health record.
2. I know who I authorized to see my online health record.
3. I understand the privacy and security policies I agreed to as part of the enrollment process for my online health record.