



**PREPARED COMMENTS FOR THE
AMERICAN HEALTH INFORMATION COMMUNITY**

**CONSUMER EMPOWERMENT WORKGROUP
HEARING ON PERSONAL HEALTH RECORDS
JULY 27, 2006**

**HUMPHREY BUILDING – ROOM 800
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I would like to thank the co-chairs, Ms. Davenport-Ennis, Dr. Robertson, and members of the AHIC Consumer Empowerment Workgroup for the opportunity to testify on the development and evolution of Personal Health Records, and to make observations and recommendations that will enable consumers to be more actively engaged in their health care through the use of Personal Health Records.

As the mother of a child diagnosed with hydrocephalus, I am acutely aware of the need to have access to critical health information. In 1999, my son Alex, who has two shunts implanted in his brain and who has undergone more than 18 surgeries, arrived at a rural hospital with a severe head injury. The ER staff did not have Alex's history, did not know the type of shunts implanted, and were not aware of his severe and potentially life-threatening allergies to some medications.

As Alex's primary caregiver, I kept copies of his information and records with me in several packing boxes ready for quick retrieval. However, I was not with Alex at the hospital, so that information was not available.

That experience, the fear of not having correct information available in case of an emergency, led to the development of the **FollowMe** personal health record in 1999. As a mother and coordinator of my son's medical care I wanted to make sure that all of his information was stored in one place and available immediately.

Technology is the reason Alex is alive today, and I do not want the LACK of technology to put him or his health in danger.

My hope and continued vision is for better and coordinated care for everyone, using PHR technology as the tool.

Vulnerable Populations

FollowMe was the first of the 1st Generation PHRs when it went live in 2001. Over the past 5 years we have upgraded and customized the FollowMe platform for several special populations. Of these, MiVIA, a PHR for migrant and seasonal workers, is the most notable in terms of serving vulnerable populations.

Launched in 2003, MiVIA (www.mivia.org) now serves thousands of migrant and seasonal workers and their families, providing a bridge to the healthcare system for a mobile population that suffers from chronic conditions such as diabetes and asthma.

MiVIA "members" carry a photo ID emergency information card that lists conditions, allergies, and emergency contact information. This card provides a sense of security for these workers, especially when they are confronted with language barriers in an emergency setting.

MiVIA works because we **engaged** the community to help design a PHR to meet their needs. Using focus groups and consumer advisory committees, we continually upgrade the PHR to

address issues such as condition-specific health information, insurance and coverage issues, worker safety, immunizations, and how to navigate the healthcare system. And we use community outreach workers and *Promotores* (lay workers who come from the community) to explain the PHR to the migrant community. We have thus been able to establish trust between the consumer and their PHR, to learn what features and functions are important, and to upgrade the PHR platform to meet their needs.

Another customization of FollowMe specific to individuals diagnosed with hydrocephalus was launched in 2004, www.Myhin.org. In this PHR, the hospital-based neurosurgery practice enters information including brain scans and critical shunt information, and then, most importantly, turns the PHR over to the patient and/or the patient's family.

As an early pioneer in the PHR space, our hope is that the technology will be allowed to unfold organically, creating a tool to help consumers navigate an increasingly complex and fragmented system. Our fear is that without adequate guidelines and alignment to standards, the tool will be hijacked by third party interests, and consumers will be left in distrust of Health IT and left at-risk of having their personal health information used against them.

Recommendations

We believe there are five key foundations to a successful PHR.

- 1) It is “**owned**” by the consumer - not by healthcare providers, not by employers, not by a government agency, and not by health insurance providers;
- 2) It is **controlled** by the consumer – in particular as to who can input, edit, and access the information;
- 3) It is absolutely secure;
- 4) It is interoperable with EHRs and other consumer health information; and finally,
- 5) The consumer is made aware of these attributes of the PHR.

Increasing consumer awareness and engagement in Personal Health Records

Let's start with this final point: How do we let consumers know what PHRs are and how they can benefit from them?

We believe this is a proper and beneficial role of government, to provide an educational and consumer awareness outreach program that stresses the fact that consumers have a right to their medical information. Many, if not most consumers are simply not aware that they have the right to copies or to review their medical information. An outreach effort could be facilitated through participation with CMS, AHRQ and organizations such as the National Patient Safety Institute and other consumer advocacy groups.

This segues into some of the questions posed by this hearing's organizers: *What are the most important features and functions of a PHR from the patient's perspective, and who, if anyone, should establish a minimum or most important set of PHR elements?*

In our experience working directly with our subscribers and with clinics and hospitals on customized PHRs, we have found that the most important features of the **first** generation PHRs include the ability to:

- Record chronic medical conditions
- Record current medications
- Record allergies
- Provide access to accurate medical information (for example, *Medline Plus*)
- Create an emergency information card

There are dozens of other useful features; most PHRs already offer all of them. We've certainly noticed that almost every feature developed by FollowMe since 1999 has been adopted by the other major PHRs since then!

More important, is that as the PHR space matures, there are higher expectations and more functions requested. We anticipate that features of the "next generation" of PHRs will include:

- Self management plans
- Decision support
- EOB insurance information
- Secure physician/consumer communication
- Access and Edit audit trails

As we proceed to the next generation of PHRs, consumers, providers and payers need to collaborate to insure the success and effectiveness of the PHR in improving health. For example, as payers search for new and innovative ways to shift healthcare costs off onto patients, it's foreseeable that patients will be more inclined to fulfill the management and administrative tasks that relate to their own care, including record tracking, billing analysis, etc.

We don't believe that a minimum set of elements should be mandated. Consumers should be aware of what features are available to them in a PHR product and should have a choice about which PHRs they want to use.

As consumers become involved in their health care, there will be increased demand for new features. This innovation should be encouraged in an open market.

We do feel there is a role for the government in establishing minimum criteria around **privacy** and **security**.

While hospitals and physician offices maintain systems that focus on practice management and financial transactions, the PHR is the holder of all the patient information, owned and controlled by the consumer. Access is provided by permission. Audit trails and edit trails assure consumers that they are in control and know who has accessed their record.

There is also a role for government in helping to establish **interoperability**, which I'll address in a moment.

What we envision is a patient/consumer centric health record that interfaces with any EHR. Interoperability will be a significant advancement in the next generation of PHRs, allowing information storage and retrieval across multiple platforms and provider access points.

So, in summary on this point, the minimum criteria for the next generation of PHRs, if any, should focus on security and interoperability, with the **flexibility** for companies and organizations to innovate and add features that appeal to their client or customer base.

Achieving interoperability: We define **interoperability** as the ability of any PHR to communicate with any EHR in a fully automated way. A critical first step will be by vendors agreeing to, or being required to adopt a core set of standards such as HL7, CCR, and ASTM.

The ability to interface and exchange data between some EHRs and PHRs is now possible by using technologies such as Web services. Several pilots are underway in our organization to exchange condition-specific data with selected EHR vendors.

Interoperability between all providers of a patient can be accomplished once all participating vendors have adopted the same standards and are using common technologies to exchange data.

Most of us are adopting the standards I've mentioned; the challenge now is a common technology to transfer this standardized data. And the challenge is not the technology itself, but the **business case**, particularly for EHR users. Some vendors are now charging their EHR clients fees and service charges to provide interoperable "access" to other programs, including PHRs and disease management programs.

We will know *Interop* has been achieved when there are no "additional charges" associated with such system integration. This will also enable faster adoption of EHR technology.

However, it is doubtful that any one EHR or PHR vendor would willingly invest to develop this and then share it freely with competitors, so perhaps this is a role for government to step into.

The final question I'd like to address: ***Is certification necessary for privacy and security, interoperability or a minimum set of functionality, and is there a sense of urgency?***

I believe that certification for privacy and security is a good idea, but the critical urgency in the developing PHR industry is not that.

It is with who accesses, who owns, and who controls the information stored in a PHR, and how that information might be used.

Data sharing within organizations or subsidiaries should be highly controlled – for example, an insurance company's risk analysis division should not have access to non-deidentified PHR data. If this isn't feasible, then payers should be barred from hosting and owning the systems behind a PHR.

While we applaud the recent certification efforts by CCHIT for EHRs, we are concerned that high certification fees will inhibit innovation and new development. We would not want to see the PHR space impacted in that way, especially those organizations serving vulnerable populations.

As an example, MiVIA, a PHR for migrant and seasonal workers having a clinician portal, basically serves as a full scope PHR/EHR. MiVIA is customizable for varying migrant populations and needs. Certification fees for each customization would be prohibitive.

Concluding comments and recommendations

To sum it all up, we believe the success of the PHR “market” will be determined by the consumer, but only after resolution of security, privacy, and interoperability issues, along with more comprehensive provider adoption of EHRs.

Personal health data must be able to flow seamlessly and securely from EHRs to PHRs, irrespective of the consumer’s location, employment, healthcare providers, or insurer.

However, as we see greater information sharing, the risks of abuse increase dramatically. Security standards need to include such things as public disclosure of unauthorized data breaches within 72 hours of breach discovery, along the lines of the California Security Breach Notification Law (*California Civil Code Sections 1798.29 and 1798.82*).

Privacy standards should insure that data aggregation is restricted with opt-in functionality and limited to de-identified information only. At-risk populations could otherwise be even more marginalized by this information sharing - and the potential pool of at-risk may grow. If greater information sharing directly results in greater numbers of uninsured, then we have failed to adequately safeguard this developing industry.

Letting corporations alone determine the future of this industry is a disservice because the vast majority of corporations plan for sequential revenue growth and their long-term plans rarely exceed 3 years. For HIT, true long-term planning must be the focus, and we applaud the government’s efforts in this regard.

We appreciate being invited to participate as well. Thank you.