

NCVHS Personal Health Records Public Testimony of Michael Stokes, Director of Policy and Compliance for Microsoft Corporation's Health Solutions Group.

**What is the problem you are trying to solve with your offering? What is your business objective?**

**Dynamic, Personalized, Consumer-Driven Healthcare.** At Microsoft, we have a powerful vision for how technology can improve healthcare, much broader than simply the use of electronic medical records. We envision a connected health ecosystem, allowing patients as consumers, physicians as knowledge workers, and creating a dynamic, learning healthcare system. In order to accomplish this vision, we must maintain clear focus on results and outcomes. We believe that this focus requires solutions that are fundamentally very patient-centric, especially enabling consumers to become very active participants of their health, wellness and fitness. If we become overly prescriptive on certifications and interoperability standards geared primarily to provider-centric healthcare, we might limit the ability for consumer participation and stifle innovations that empower consumers. For consumers to get the full benefit of the Health IT investment, we should ensure that Meaningful Use, includes allowing consumers to exchange data with their providers into a consumer controlled personal health record.

**Empowering Consumers to Access, Consolidate, and Share Their Health Data**

For consumers, we launched HealthVault, a consumer-controlled, privacy and security-enhanced data storage and sharing platform. People can use HealthVault to manage copies of their health records from providers, plans, pharmacies, schools, government, or employers; upload data from home health devices like blood glucose monitors and digital scales; manage, at a granular level, the data they share with health care providers, coaches, and trainers; and access products and services to help improve their health.

**How do you envision your offerings, as well as the Health IT industry, and patient-facing online services, evolving over the next 5 or 10 years? How do you envision the relationships among PHRs, electronic health records, providers, plans, health information exchanges, etc. evolving over the next five or ten years?**

We envision personal health management systems that

- cater to the needs of the “family health manager” – the person most often responsible for a family’s health care,
- contain data from many different sources, including EMRs, lab, pharmacy, and payor data; ,
- give people total control over their data and enable them to add their own information, such as progress on a fitness plan or self-management of chronic conditions,
- seamlessly connect to the workflows of multiple provider and payer systems, as opposed to simply being tethered to one provider or payer system,
- offer secure, programmatic access to these data and processes, to enable the development of new kinds of tools and services,
- make it possible for people to search for (and share) relevant health information, knowing this information is credible and actionable.

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

As described in our privacy principles below, consumers control what information comes to reside in their record. In other words, no data comes into HealthVault or leaves HealthVault without the explicit control and consent of the consumer. This can be done by a one-time push/pull or establishing continuous synch with various data sources.

**What information do you give participants when they sign up?**

We do not populate the consumer health record with health information. As described by our privacy principles below, the consumer controls what information is put into or taken out of their record.

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

How our service can help them manage their own family health and fitness more effectively and efficiently. Providing an environment of trust continues to be a critical foundational requirement.

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

"Our HealthVault Privacy Principles

- You control the Microsoft HealthVault record you create.
- You decide what goes into your HealthVault record.
- You decide who can see, use and share your information.
- Microsoft won't use your information in HealthVault to personalize ads or services without explicit permission."

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

Below is the relevant text from our published Privacy Statement.

"We may occasionally update this privacy statement. When we do, we will also revise the "last updated" date at the top of the privacy statement. Details of such changes to date are provided below. For material changes to this privacy statement, we will notify you either by placing a prominent notice on the home page of the HealthVault Web site or by sending you a notification directly.

Changes from September 2008

- Updated description of HealthVault Connection Center to include Version 2

Changes from June 2008

- Clarified that separate health records should be set up for each individual
- Clarified that Programs include systems that may not have an online portal accessible to consumers (such as clinical systems)

- Clarified use of aggregated data to improve Service
- Added link to HealthVault Code of Conduct
- Added reference to contact information for feedback
- Clarified e-mail sent by the Service is unencrypted
- Added description for direct editing of information in the Service account
- Added Health On the Net Foundation (HONcode) certification

#### Changes from October 2007

- Added OpenID sign-in
- Clarified data storage location
- Revised data disclosure requirements for Programs operated by healthcare providers, insurers, and other entities covered by laws governing use and disclosure of healthcare information
- Removed strong password security requirement
- Clarified Program access
- Emphasized recommendation to read Programs' privacy statements
- Removed statement that data can be moved from an old, closed account to a new account"

#### **What kinds of issues have you grappled with as you develop privacy policies?**

In designing and delivery HealthVault, we have worked with several consumer advocacy organizations to grapple with issues such as data ownership, government access, easily understandable privacy statement language, data governance for service effectiveness and aggregation, trusted user experiences especially in sharing authorization situations, ecosystem partner obligations and commitments among many other issues.

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

We have been pleased with the public response to our current policy positions, but strive to improve them continually.

#### **How have you attempted to address concerns presented by members of the public?**

As noted in the change details of our privacy statement, we continue to implement improvements based upon concerned presented by the public.

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

In our discussions with consumers, consumer advocates and policy makers, we remain concerned that any prescriptive standard or certification will limit innovation. Here are two minor examples among many others we have discussed; a) the model notice does not provide dynamic capabilities for consumers to

better understand the notice details, b) this model does not provide links to source of information independent of the vendor or government. If the model notice is required, it could stifle more informative and innovative solutions by becoming the regulatory ceiling as well as the floor. We encourage HHS to not be too prescriptive and to encourage positive innovations and better practices that go beyond any regulatory floor.

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

We continue to focus on and improve the challenge of providing a trusted user experience in which the user provided deeply informed decisions in their best interest with a clear understanding of all of the short and long term consequences of those decisions. Among other tools, we currently support informed consent, explicit authorization and limited use rules in combination with dynamic and evolving user interface experiences that strive to support the advantages of information sharing used in combination with privacy and security management controls. In addition, we continually strive to make it easier for consumers to aggregate their data from many disparate, siloed data sources. We have made great progress here with lab and pharmacy data – but it has been slower to get interoperability with provider data systems. That is why we believe it is so critical that the Meaningful Use standards in the ARRA legislation, include data interchange with consumers.

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

We continue to focus on enabling consumers to easily manage their family health issues. This means focusing in two areas (a) making it easy for consumers to get an electronic copy of their data from the many silos of data that exist (pharmacy, lab, provider, and payer data); AND (b) working with application developers to ensure there are robust experiences on HealthVault for consumers to interact with their data. This includes offerings, such as the Mayo Family Health Manager, Heart 360 from the American Heart Association, work out applications from companies such as Pod Fitness,

**How are you dealing with particularly sensitive categories of information?**

We believe all of our consumer health information is very sensitive and strive to treat it accordingly. The consumer control model allows consumers to best manage the sensitivity around particular pieces of data – they can choose which information to share and have the ability to modify, annotate or delete information.

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

We continue to have many encouraging and positive discussions with providers that view patient access through PHR as a critical component of improving their provider/patient relationship and improving the patient health outcomes. Providers are very interested in receiving lab, pharmacy, procedure, and device data from consumer's HealthVault accounts to allow them to deliver better care. In many cases, this data is sequestered in a separate part of the providers EMR allowing the doctor to choose which pieces to pull into the full record. In addition, we provide digital signature support for data elements to help provide provenance information in support of the consumer provider relationship. We remain concerned that current legislation and rules could inadvertently limit useful access by consumers if it becomes overly prescriptive on certification.

**Do you intend for your offering to be a "source record" for medical information?**

As outlined above, providers are finding value in the data they are receiving from consumers via HealthVault. HealthVault is consumer controlled and not a replacement for the provider's record, however, it can provide some useful information and context to deliver better care.

**How have physicians' practices or relationships with patients changed with the advent of PHRs?**

We are beginning to see evidence of these relationships growing stronger, increasing in trust and improving outcomes as consumers choose to share some of their HealthVault information with their healthcare provider of choice.

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

The language in the Recovery Act has introduced some ambiguity concerning how Covered Entities should interact with consumer-controlled personal health records. We encourage HHS to clarify the Recovery Act with clear rules as soon as possible. We are working to provide specific examples in current public comment requests from HHS, FTC and CMS.

**How do you think PHRs affect health care costs?**

We believe when consumers are provided effective solutions to manage their family health and fitness, it will lead to more informed lifestyle and healthcare choices, which will improve health outcomes and thus increase cost efficiencies overall.

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

We have consistent been in support of comprehensive federal privacy regulations.

**Should data subjects be able to add to, change, or amend their records in a PHR?**

Yes, HealthVault provides consumers control of the information in their PHR to add, change, amend, delete, and to restrict and account for access, use and disclosures by others.

**to PHR vendors: Are there any type of medical records that your company will not include in a PHR? For example, will your PHR seek or accept records subject to the HHS Substance Abuse rules and the strict redisclosure regime that it imposes on recipients (even those who obtain records with patient consent)?**

We view our service as the consumer's copy of their health information. Thus any information that is restricted from being provided to consumers cannot be provided to our service. Disclosure or sharing from our service is controlled by the consumer.

**How should we evaluate whether PHRs are successful?**

We think that the best metric is evidence that consumers, along with their care providers, are engaged in more effectively managing their health and wellness..

In conclusion, I would like to thank NCVHS for the kind invitation to provide this testimony. We encourage keep in mind that the core value of a PHR should be based on the health outcomes consumers and providers continually strive to achieve.