Consumer Identity and Privacy Come First

Public Input to AHIC Consumer Empowerment Workgroup July 27, 2006

Thank you for this opportunity to provide input into the AHIC/Consumer Empowerment Workgroup. I represent MedCommons, a company founded to commercialize independent banking of personal health information.

Personal Health Records may not grow from the same roots as Electronic Health Records. The good news is that PHRs will be market-driven and evolve much faster than the institutional components of the national health information network. The reason is simply that each interaction between a consumer and a caregiver is an opportunity for the consumer to express their PHR communication preference. As soon as a consumer chooses a PHR, their caregivers must respect the choice, even if it means processing paper.

Why do consumer identity and privacy come first? Assume an institution attempts to drive the process by giving the consumer a PHR. If that PHR does not give the user full control over their health care identity and an absolute privacy guarantee then the next time the consumer visits a physician, a lab or a pharmacy they may decide to avoid their first PHR. If their reluctance leads to another caregiver and another identity and another PHR the consumer will behave as they do now with merchant credit cards or Web chat group asking for an email. A consumer with two identities and two PHRs will choose between them once again on each successive encounter.

It is likely that consumer behavior in a nationally connected health information network will be similar to their behavior on other global networks like the Internet or cell phones or email. Inadvertent disclosure of personal health information accessible on a national health information network is no different from malicious "phishing" for identity theft or spam for commercial gain. Technology and standards are already well underway by consumer-oriented companies offering Web services. These technologies help consumers manage their networked ID and ensure privacy without having to rely on federal mandates or the benevolence of service providers.

MedCommons believes that a successful national health information network will require a very high degree of trust on the part of consumers lest patients and physicians avoid putting information on-line rather than risk unforeseen or unintended consequences. PHR services, like other consumer banks, will engender trust as they compete with each other on the basis of consumer trust and consumer service. PHR networks will achieve global interoperability just as credit card and ATM networks did before them.

MedCommons has participated in the Consumer Empowerment Technical Committee (CE-TC) to provide input from the consumer privacy perspective on standards for identifying and indexing health information and technical systems to ensure informed consent and avoid unintentional disclosure ("phishing") of health information. Until now, the CE-TC has focused on the provider perspective and has not considered patient identity and informed consent technologies as core to consumer empowerment.

We therefore suggest:

Public input, in the form of written testimony, is sought on the following issues:

• What is needed to increase consumer awareness and engagement in Personal Health Records (PHRs)?

A healthy commercial PHR banking system can arise if PHR banks are allowed to compete to maintain the privacy and provide disclosure services for patients and their caregivers without undue interference from provider and payor interests that currently dominate RHIO projects and the standards harmonization discussions.

• What are the most valuable features and functions of a PHR from the patient perspective? Please summarize the real world   experience or evidence to support this part of the testimony.

The PHR should be:
1. Private - Access to a patient's PHR should be private and only accessible subject to the informed consent of the patient or her/his health care proxy. Indexing of patient identifiers and the names of labs, pharmacies, clinics and caregivers should be subject to informed consent by the patient to the same extent that the test results and consultation results themselves are subject to informed consent. The information in PHR should not be subject to automatic indexing in regional or national databases where it might be required as a condition of employment, insurance or treatment.
2. Up to date – with prescriptions, lab results and reports added to the PHR as soon as they become available.
3. Subject to Disclosure Consent – by enabling the patient to seek testing anonymously with the result deposited in their PHR prior to any disclosure if they so choose.
4. Authoritative - with individual elements signed in a non-repudiable manner by the labs, institutions and physicians responsible for each element.
5. Complete and Accessible – such that second opinions and alternative care can be sought without asking permission from the labs, institutions and physicians responsible for each test result or consultation note.

6. Emergency-Ready - with the option of having a secure copy on some portable device, such as their cell phone in case of disaster or emergency as well as at some remote site such as the PHR service website.

7. Competitive and Voluntary - so that the patient can choose among PHR service providers the way phone number portability allows them to choose telephone services.

• Would a minimum set of PHR elements ensure that consumers have the features and options most important to them when   choosing a PHR?

The PHR should have whatever information labs and caregivers want to communicate across institutions. As long as lab-to-provider, provider-to-provider and provider-to- payor communications pass through the patient's PHR account the way financial transactions pass through the patient's bank account market forces will drive toward the clearest and most useful PHR elements. A combination of modern privacy technologies and legal mandates can prevent the transfer of health information beyond the informed consent of the patient the same way that fraud and kickbacks are controlled in financial transactions.

• Who should identify the most important elements of a PHR?

Doctors are the best equipped to determine the information they require for treatment. A number of national primary care practice organizations have already collaborated to establish the ASTM-standard continuity of Care Record (CCR). MedCommons believes the CCR is a good foundation for an authoritative PHR but we recognize that consumer communities and market forces will cause the PHR elements to evolve. Once a patient chooses to use a PHR service their labs and caregivers will specify the elements of the PHR just like they do with today's communications but subject to the practices of the PHR service. If the lab or caregiver finds the PHR service inadequate they could suggest alternatives to the patient or refuse care.

• If applicable to your testimony, please comment on how health and HIT literacy needs should be addressed through PHRs.

No particular level of health or HIT literacy should be required of the patient. For example, an elderly patient might choose a PHR service that updates their PHR to a cell phone or internet storage account even though the patient does not have routine access to the Internet or has no interest in or need to see the content of the PHR. Such a PHR would be valuable in case of a disaster such as Katrina and would be readily accessible to the patient's heath care proxy if they became incapacitated or incompetent.

• How can interoperability be achieved between PHRs and electronic health records (EHRs)? Please also comment on when this could be accomplished.

Interoperability will be achieved when a patient can require that a caregiver update their chosen PHR. Market forces will work to favor PHRs that are able to combine caregiver information most effectively and caregivers that respond to leading PHR interfaces.

• How can interoperability be achieved between PHRs and all of the providers from whom the patient receives health care services? Please also comment on when this could be accomplished.

Interoperability between PHRs and providers is already required. Patients can bring paper or CCRs or passwords to a web site and, within reason, most providers are required to honor their PHR format. As digital PHR Services come to market they will compete on the basis of how well they support interoperability just as ATM networks and credit cards do today. Providers and payors that do not support the leading PHR Service offerings will be at a disadvantage in the marketplace. This could be accomplished within 5 years as providers and insurance companies are driven to compete on a national and international basis.

• Should the market be left alone for innovation or could vendors compete around a minimum criteria set for PHRs?

The market should be left alone for innovation. Internet standards and sophisticated consumer privacy technologies are already in place and evolving much faster than any standards organizations and vendor consortia can control. Vendors that do not bring consumer-focused products and services to market and rely on mandated standards and regional barriers to competition do so at great risk to their long-term survival.

• If you think certification is necessary for privacy and security, interoperability or a minimum set of functionality, is the   timing important and is there a sense of urgency given the diversity, complexity and mobility of today's population and the   demand for availability of PHRs at the point of care?

As currently implemented, the current certification commissions and standards organizations are dominated by institutional interests and have not been able to take up privacy and informed consent from a consumer perspective. Either these certification efforts should be adjusted to make privacy and informed consent their primary focus or the result risks being ignored by PHR services and the providers that choose to use them.

Submitted by: Adrian Gropper, MD
                  Chief Science Officer
                  MedCommons, Inc.
                  agopper@medcommons.net