

Roundtable Discussion

Personal Health Records: Federal Agencies' Leadership Role

A personal health record (PHR) ideally should serve as a “guardian angel,” watching over the individual patient to make sure preventive measures occur at optimum times and providing a consolidated narrative of tests and procedures, in the process enlightening and guiding both patient and provider and transforming health care from a disease-oriented to a health-oriented enterprise.

While this ideal has been articulated and is being attempted in many forms in both the federal and private sectors, it has yet to be realized. Numerous issues, from uncertainty as to who should “own” the PHR, to privacy concerns, to confusion about just what constitutes a PHR, confound current attempts to attain one.

The most successful effort to date, it was agreed during a roundtable discussion held by the nonprofit U.S. Medicine Institute for Health Studies, is the MyHealth₂Vet program of the Veterans Affairs Department. Launched as a pilot program in 2000, MyHealth₂Vet is available to veterans who wish to access it — though all the functionality of the pilot program is not yet available systemwide — and now has more than 5,000 registered users (www.myhealthvet.va.gov).

USMI's roundtable was attended by representatives from federal agencies, Capitol Hill, academia, patient

groups and professional associations. With only 14% of providers in the private sector having electronic-record systems that meet minimum standards, it will be years, if not decades, before integration of all health data into a personal record can be accomplished, some roundtable participants cautioned.

There currently are more than 100 “players” in the private-sector PHR market, “but none of them is doing well,” it was noted.

Some in the group made a fervent plea that efforts toward a PHR proceed as an open-source process, with minimum specifications, allowing the PHR to evolve and adapt, much as the World Wide Web has done. “No one, when the Web was begun, anticipated the creation of Google or E-Bay.”

The best approach, it was suggested, might be to “give up trying to anticipate every problem” and instead to just move forward. “There is more benefit in the information than there are phantom problems.”

Additional issues addressed during the roundtable include:

- *There is tension between public health imperatives and individual privacy, and resolving it is not simple.* Individuals need assurance that any data collected for public health purposes will not allow them be personally identified. Trust is essential here and must be cultivated; without it, crucial data

Discussion Highlights

- **Who owns the personal health record remains unclear.** HIPAA (Health Insurance Portability and Accountability Act) says the individual has the right to a *copy* of his or her record, but the question is, who has the right to *access* it? “We need to establish the individual’s ability to have a say over how the data flow.”
- **There currently is no agreed-upon definition of a personal health record.** The Office of the National Coordinator for Health Information Technology is releasing a document for public comment as a means of building such a definition. If it attains the desired level of specificity, there likely are programs currently on the market that “just won’t fit.”
- **Similarly, there is no commonly agreed-upon definition of quality.** So, what does it mean to say PHRs will improve quality? How is that measured?
- **Internet access remains limited in rural areas.** For example, only about 20% of residents on Indian reservations have such access — a “digital divide” that serves as a barrier to the PHR.
- **If the medical record is to become patient-centric, with the patient in charge, then it is essential to increase the health literacy of the U.S. populace.** “They need the ability to be able to seek new opinions about the data they have.”
- **The resources for a “revolution” toward patient-centered care exist in the federal sector.**

about disease incidence or progression may be lost.

- *Should patients be allowed to edit the data in their personal health records?*

Again, this is a difficult issue: Missing data could compromise effective treatment, yet on the other hand, some personal data could lead to discrimination. VA attempts to address this issue in MyHealth_{Vet} by allowing veterans to appeal items in their records. Subject-matter experts review the appeal to make sure the requested change would not compromise care in future.

- *VA and the Defense Department are working to integrate their electronic records, but much remains to be done.* Fifty percent of military beneficiaries and forty percent of veterans receive care outside their respective systems, making integration of data a challenge. Further, DoD has concerns about security of medical records containing information related to combat or combat-readiness.

- *Is a new paradigm needed for the PHR?* Some in the roundtable group urged moving away from today's language of disease — for example, CPT codes that deal in the intricacies of illness and “exist for physicians, not for patients” — toward a “language of health” that would focus on wellness and prevention and help overcome the fragmentation that underlies the health care system.

Further, it was pointed out that the burgeoning era of genomics will change the way medications are prescribed and place emphasis on the requirements of each individual, rather than disease groups.

The Value of Transparency

Patients Like Me, an organization designed to help patients share

their experiences and learn from others with the same syndrome or disease, eschews concerns about privacy and security — and collects data in numbers larger than most clinical trials can capture.

Users are required to share “every piece of information” they deem relevant to their conditions (though not to attach their names to it). This then is captured into a database that can be shared with hospitals and providers.

Transparency is the guiding rule of Patients Like Me: “We are unwilling to pretend that data can be truly anonymous.” At the same time, the organization maintains a legal team to tackle any cases of discrimination or other problems that may occur through the openness of its data (www.patientslikeme.com).

Nationwide Health Information Network (NHIN)

The Office of the National Coordinator for Health Information Technology is working to build a network of standards and information that can flow between various health care sectors, breaking down current “silos.”

An innovative step in this process is a \$5 million grant from the Department of Health and Human Services to the Brookings Institution and LMI Consulting to privatize the current American Health Information Community (AHIC) into a self-sustaining public-private partnership that requires participants to work together to help develop the NHIN, with no one group exercising control.

PHRs undoubtedly will be on the menu of this new organization. The current thinking in HHS is that MyHealth_{Vet} will serve as the model

for a broader PHR. An interim step will be to merge DoD, VA and the Indian Health Service into a joint PHR by December of 2009.

The goal for the NHIN is to stream data. “As we confirm what works, it will grow in volume of data and in the number of entities “ using it (www.hhs.gov/healthit).

Issues being addressed include: the level of security needed, the level of privacy that consumers should control, and how to achieve interoperability, so that all players can “come together.”

Participants in this roundtable: Madhulika Agarwal of the Veterans Health Administration; Michael Andrews; Dave Baker of Humana Military Healthcare Services; Marion Balsam of the National Institutes of Health; Cynthia Bascetta of the Government Accountability Office; Karen Bell of the National Health IT Office Dan Blum of the Telemedicine and Advanced Technology Research Center; S. Ward Casscells of the Defense Department; Guy Clifton of the New America Foundation; Patrick Conway of the White House; Theresa Cullen of the Indian Health Service; Dolores Dunn of the House Veterans Affairs Committee; Maria Gaboury of DefenseWeb Technologies; James Heywood of Patients Like Me; Robert Kolodner of the National Health IT Office; Kim Lipsky of the Senate Veterans Affairs Committee; Alanna Miller of the Office of Rep. Jon Porter; Chitra Mohla of the National Health IT Office; Orie Mullen of Humana Military Healthcare Services; Tom Munnecke; Kim Nazi of the Veterans Health Administration; Arnauld Nicogossian of George Mason University; Hon Pak of the Telemedicine and Advanced Technology Research Center; Ray Pryor of Humana Military Healthcare Services; Wayne Rawlins of Aetna Government Health Plans; Dan Rode of the American Health Information Management Association; Cathy Wiblemo of the House Veterans Affairs Committee

The roundtable was moderated by Phillip Longman of the New American Foundation. USMI Managing Director is Nancy Tomich (www.usminstitute.org). The roundtable was sponsored by Humana Military Healthcare Services.