Last modified: 7/26/2006

Statement of Dr. David McCallie, Vice President of Informatics and Chief Scientist
Cerner Corporation

Written Testimony on Personal Health Records for the
American Health Information Community Consumer Empowerment Workgroup

Thursday, July 27, 2006

Summary

As the Federal government considers the model for building a National Health Information Network (NHIN), policy-makers should spend considerable time on patient-centric approaches, including the use of personal health records. One example that has not been thoroughly explored is the idea that new players in the healthcare arena – independent health record banks (IHRBs) – should operate and maintain lifetime electronic personal health records. IHRBs would offer member-owned accounts that would put consumers at the center of the decision-making process regarding their health. This distinction answers one of the more important questions in the debate regarding ownership of information.

Congress is already exploring this concept. During Health IT Week the Independent Health Record Bank Act (S. 3454 and H.R. 5559) was introduced. The Heritage Foundation has also provided thorough analysis on the subject as evidenced by the release of their Web memo "Healthcare Information Technology: Getting the Policy Right." The idea of personal health banks fosters a market-driven approach to building a NHIN and is consistent with my comments as outlined in this testimony.

Workgroup Areas of Focus

Increasing consumer awareness and engagement in personal health records (PHRs)

PHRs are not likely to see widespread use if consumers have to self-populate the record with their own data, or if the PHR data is not independently owned and controlled by the consumer. PHRs should function like a personal bank account into which the consumer's medical information is electronically and automatically "deposited" via standards-based interfaces from payer and provider systems. Based on this approach and on the noted analogy to the nation's electronic banking network, one may refer to a PHR as an "Independent Health Record Bank" (IHRB.) This member-owned account has one focus – the patient.

Even with the availability of IHRB accounts many consumers may not take the initiative to "open" an account unless encouraged to do so by the entities that stand to benefit most from the improved care coordination and cost savings that widespread usage of IHRB accounts would ensure. Therefore, insurers, self-insured employers, and government agencies (CMS, state Medicaid

Author: Dr. David McCallie Publication number: 200607261

programs) should take the lead and sponsor these accounts on behalf and with the express permission of their members. The accounts would still be under the control of the consumer/member, but the sponsorship (and initial awareness) should be driven by those employers and insurers who stand to benefit most from the cost-savings that personal health record accounts can create.

Widespread adoption of interoperable PHRs will be inhibited unless consumers understand that the data in the PHR is under their own control, and that rigid data confidentiality and security standards will be met by all PHRs. PHRs must allow the consumer to control who can access their health data. Consumer trust in the security and privacy of PHR data will be essential for widespread acceptance.

Success of PHRs will depend on a guarantee that the consumer can take the data with him, no matter where he lives or from whom he receives care. I am referring to this as the "portability" of the PHR data. A consumer must have the ability to readily move data to or from the PHR/health bank of his or her choice. In short, personal health banks and the accounts held must not have geographic boundaries.

Valuable features and functions of a PHR for the patient

The automatic population of a consumer's healthcare data into his or her "health bank account" is the single most important feature of a PHR system. Cerner's experience with systems which rely on consumer-entered content is that usage of a manually-maintained PHR is limited. On the other hand, we have seen strong usage and clear benefits from our "community health record" (CHR) projects which we have deployed in Tennessee and Kansas for the Medicaid populations. Our CHR product is automatically populated by data feeds from payers and pharmacy benefit claims (PBMs), and in the afore-mentioned states has been deployed on behalf of the Medicaid population. This project has initially targeted physician users, but it is an example of a health bank that serves a specific group and could build out to a larger population.

Initially, the PHR/IHRB can be populated by existing health data feeds such as medical and PBM claims. These claim feeds can be run through a clearinghouse where the data is cleansed and normalized to standard vocabularies. From there, the clearinghouse feeds the claims into the consumer's account.

As office-based EMR systems proliferate, and as interoperability standards mature, we expect most routine office encounters to result in a data summary (of the encounter) being automatically sent to the PHR, using these existing clearinghouses or perhaps direct-to-PHR interfaces (from the office-based EMR system.)

Of course, the interoperability need is two-way, so that a physician's electronic medical record (EMR) can download medical information from the patient's PHR/IHRB, assuming the patient has granted this physician access to his medical data.

Using a minimum set of PHR elements to ensure that consumers have the features and options important when selecting a PHR

As noted above, the PHR/IHRB must be able to leverage existing data feeds as a starting point. This implies that standard claims data, including both encounter claims and PBM claims, should be the starting point for PHR/IHRB data elements.

Beyond support for claims data, the PHR/IHRB should focus on patient safety. This would imply that allergies (using a yet-to-be-standardized clinical nomenclature) should always be included, as well as a way to capture and display all currently active medications (to support drug-interaction checking.) In addition to these core elements, a codified problem list, as well as a "visit history" listing all previous encounters (date and location of visit, provider, reason for visit, diagnosis), should be included. As soon as hospital feeds come into the network, the patient's discharge summary will prove to be a very valuable and easy to get data element.

Cerner believes that the data content defined by the ASTM CCR (Continuity of Care Record) represents a good starting point for standardization of the rest of commonly captured clinical information. HL7 has independently defined a care summary record, using the Version 3 CDA format. Cerner would prefer that ASTM and HL7 work together to create a single standard in this space.

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

As noted above, the HL7 and ASTM standards bodies should collaborate to define a standardized structure for the coded medical data that is automatically populated into the PHR/IHRB.

In addition, we believe that the personal health bank account should be able to catalog and store all common types of unstructured data, such as dictated discharge summaries, office notes, referral letters, and medical images, including x-ray, ECG, etc. We propose that the PHR support the most common MIME types in usage on the Internet (such as PDF, JPG, HTML, etc.) DICOM should also be supported for medical images that come directly from imaging devices.

Interoperability between PHRs and electronic health records (EHRs)

As previously noted, existing standards such as the ASTM CCR and the HL7 CDA can be leveraged to quickly create data interoperability standards for the

PHR/IHRB. The ONCHIT-endorsed work being done by ANSI HITSP to create standards for Regional Health Information Organizations (RHIO) can be readily applied to the PHR/IHRB when you consider that this account is really just a RHIO with one member – the consumer.

Cerner supports the HITSP process for RHIO, but we believe that it is critical for HITSP to address the PHR/IHRB use-cases in addition to the NHIN/RHIO use-cases. In particular, to make the PHR/IHRB network feasible, standards will need to be addressed to facilitate the **automatic routing** of data from producers (payers, EMRs) to the account. There are numerous approaches to facilitate existing Internet standards (such as the Distributed Naming Service) to create paths for secure routing of PHR data, but they are beyond the scope of these comments. Cerner believes that more work needs to be done in this area.

We believe that sufficient standards to achieve first-phase interoperability of a PHR could be achieved by mid-2007.

Interoperability between PHRs and providers

Given that it may be at least five years before the majority of physician offices have full-featured EMRs in place, PHR/IHRB integration must proceed in stages.

As previously noted, stage 1 is based on claims uploads, which does not require any change to physician office practices. For physician access to the patient's PHR record in stage 1, we believe a simple Web-browser would be sufficient.

Stage 2 should allow for simple document and/or fax uploads into the patient's PHR from the physician's office, or from the patient's home computer. The PHR can offer a private 1-800 fax number to make the upload secure and convenient, or the PHR can simply let the patient or physician's office staff upload a scanned copy of the encounter summary or lab data. Likewise, the patient can simply print out critical summary documents and bring them to the physician's office as a stop-gap until the physician has implemented a compliant EMR.

Stage 3 would permit transparent uploads and downloads between a compliant office EMR and the patient's PHR/IHRB. Vendors will need to incorporate the PHR interoperability standards into a reasonable office workflow so that physician time is not adversely effected. Additionally, national PHR data routing standards will need to be identified by stage 3.

Criteria for market competition

Cerner strongly believes in market competition as an efficient way for compelling PHR/IHRB products to emerge. However, we recognize that the value of widespread deployment is too great to leave to purely market forces. Therefore, we endorse the adoption of core interoperability and data privacy/confidentiality standards which all PHR/IHRB systems must meet. We believe that given a solid set of core standards, the market will create competitive products with innovative and competitive value-add services to attract consumers, employers, and other payers to join a particular health bank.

PHR/IHRB can have as profound an effect on the quality and cost of care delivered in America as the widespread deployment of EMRs. We applaud President Bush's goal of widespread EMR deployment by the year 2010, and we believe that a robust PHR/IHRB network can and should be deployed in a similar timeframe.

Author: Dr. David McCallie Publication number: 200607261