# Data Synch: Aligning US Data Exchange Initiatives

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*by Donald T. Mon, PhD*

A number of health information infrastructure, electronic health record (EHR), personal health record (PHR), and health-care data exchange initiatives are happening all around the world. As is common in healthcare, these initiatives are being implemented independently of each other and are in different stages of completion. For example, building a consensus in the United States on the national health information infrastructure (NHII) is still in its infancy.[1,2] Canada, on the other hand, is farther along with a similar project, having already published a blueprint for an interoperable, national electronic health record system.[3,4]

Regarding the EHR, Health Level 7—the standards development organization accredited by the American National Standards Institute—released the EHR functional model and draft standard for trial use in March for ballot voting.[5-7] In Australia the *open*EHR project has been publishing formal specifications for communicating electronic health information for some time now.[8]

Countries are also working on ways to exchange health information between providers when patients are referred from one institution to another. The United Kingdom has been testing such information transfer via their General Practitioner to General Practitioner project.[9] In the United States, the American Society for Testing and Materials Committee on Health Informatics released its Continuity of Care Record specification in November 2003.[10]

Finally, several PHR projects are under way, such as one by Connecting for Health, whose working group released its final report in July 2003.[11]

Though these independent projects reflect the styles of their national healthcare systems, they share the following common threads:

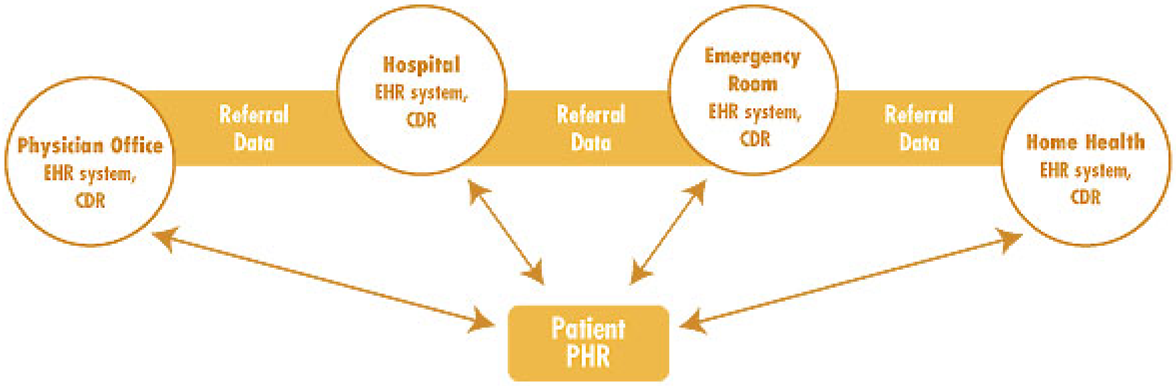
- An information infrastructure need not be a central database of medical records.[12,13]
- EHRs and PHRs are key components of an information infrastructure.[14]
- The longitudinal health record can be implemented as a set of distributed EHRs.
- The data exchanged when patients are referred from one institution to another are a subset of that found in an EHR.
- When longitudinal health records are implemented as a set of distributed EHRs, the glue holding them all together is the PHR.

## The NHII, EHR, and the PHR Must Work Hand in Hand

When the concept of a national health information infrastructure was bandied about in the industry years ago, many thought that a central database of medical records would serve the purpose well. Send the data to a central database and we wouldn't have to worry about interoperability, the reasoning went. However, over time, that concept has proven to be unworkable. First, it would be challenging to implement a database for hundreds of millions of citizens, aliens, and others who receive healthcare services over the years. Second, there would be major privacy and security issues with this model. Third is the question of who would fund this implementation.

A more feasible concept emerging in the industry is one reflecting the common threads above. In this concept (see "The Longitudinal Record," below), a patient over the course of a lifetime could receive health services at his primary care physician's office on one or more visits; be admitted to one or more acute-care facilities for an episode of care; receive emergency services outside his community (while on a trip, for example); and finally, receive home health services in his later life. In this scenario, each institution would use an EHR system that conforms to a standard, one that contains functions and data to support direct care, research, and public health, among other things.

### The Longitudinal Record



In the course of a lifetime, a patient may receive care from many different providers. In this model, providers maintain independent electronic health record (EHR) systems that conform to data exchange standards. The patient's personal health record (PHR) contains, among other care data, a history of encounters that will link future providers to the clinical data repositories (CDRs) of providers where previous care has been delivered.

Transferring a subset of health information from one institution to another would be more efficient, since each provider organization would use standardized data. Moreover, as the illustration shows, the longitudinal health record is not a central database maintained by a government agency or healthcare organization. It is instead a set of federated and distributed EHR systems.[15]

However, in this scenario one key element is still missing—how do you know which providers are storing health information on that patient? A provider needing health information on a patient's previous episodes of care at other facilities could issue a query to the databases at various facilities, but that would be highly inefficient as there would be many more misses than hits to the right databases. This is where the PHR plays an important role.

Granted, the PHR still needs a system standard much like the EHR, but assume for now that it contains among other things demographic, insurance, allergy, and history data. As it relates to finding patient data at facilities where previous care was provided, the PHR would also contain encounter data (e.g., the facility, diagnosis, procedures, and encounter dates). Each time a patient receives care, the provider would transfer the requisite data to the patient's PHR. (The PHR might be stored on a smart card, a USB memory stick, or a service provided over the Web.) The next provider could then access the PHR, find all the previous encounters, and query only those databases and records. Thus, the PHR is the glue binding health information across encounters.

Where does the national healthcare information infrastructure come into play? An excellent role for the NHII is to be the organizing force in building consensus in the industry about interoperability standards, just as Canada Health Infoway is doing for that country ("Canada Hits the Infoway", *Journal of AHIMA*, May 2004). It could also provide program incentives to build the actual infrastructure itself (e.g., the high-speed networks).

The common themes arising from these initiatives are gaining greater acceptance for a number of reasons. Each facility would be tasked with managing its own data and need not worry about the privacy and security, cost, and competitive issues of a central database. Transferring data from provider to provider and from provider to public health agency would be more efficient. Consumers would not be asked to maintain clinical data from all of their encounters, enabling them to manage the volume, privacy, and security of data in their PHR. All the while, quality, payment, research, and surveillance can be supported from data collected at the point of care.

These initiatives appear to be on the right track for the potential and practical benefits that can be derived. The next steps—defining data content, as well as data and interoperability standards—will be even more crucial to their success.

## Notes

1. Department of Health and Human Services. “Developing a National Action Agenda for NHII.” Conference, Washington, DC, June 30–July 2, 2003. Available online at www.nhii-03.s-3.net.
2. Rippen, Helga, and William Yasnoff. “Building the National Health Information Infrastructure.” *Journal of AHIMA* 75, no. 5 (2004): 20–26.
3. Canada Health Infoway. “EHRS Blueprint: An Interoperable EHR Framework.” Available online at www.canadahealthinfoway.ca.
4. Shaw, Patrick. “Canada Hits the Infoway.” *Journal of AHIMA* 75, no. 5 (2004): 38–42.
5. Health Level 7. HL7 EHR System Functional Model and Draft Standard for Trial Use. March 2004. Available online at www.hl7.org/ehr.
6. Rhodes, Harry, Donald Mon, and Michelle Dougherty. “The Drive for an EHR Standard Picks up Speed.” *Journal of AHIMA* 75, no. 1 (2004): 18–22.
7. Mon, Don. “Setting the Right Expectations for the EHR Standard.” *Journal of AHIMA* 75, no. 3 (2004): 52–53.
8. Beale, T., S. Heard, D. Kalra, and D. Lloyd. “The *open*EHR Technical Roadmap.” 2003. Available online at www.openehr.org.
9. NHS Information Authority. “GP-GP Record Transfer: Project Initiation Document.” 2001. Available online at www.nhsia.nhs.uk/gp2gp.
10. ASTM International, Massachusetts Medical Society, Health Information Management and Systems Society, and American Academy of Family Physicians. “Continuity of Care Record: The Concept Paper of the CCR.” Available online at www.astm.org/COMMIT/E31_Concept Paper.doc.
11. Personal Health Working Group. “Final Report.” Connecting for Health, 2003. Available online at www.connectingforhealth.org.
12. Department of Health and Human Services. “Developing a National Action Agenda.”
13. Rippen and Yasnoff. “Building the National Healthcare Information Infrastructure.”
14. Ibid.
15. Department of Health and Human Services. “Developing a National Action Agenda.”

***Donald T. Mon*** *(donald.mon@ahima.org) is AHIMA’s vice president of practice leadership.*

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