Local Health Information Networks Share Data

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SAN DIEGO — A few pioneering health care organizations have set up local information networks to share electronic health data, and there are interesting lessons to be learned from these examples, according to Gordon J. Apple, a health lawyer based in St. Paul, Minn., who spoke at the annual meeting of the American Health Lawyers Association.

He compared the Santa Barbara Care Data Exchange with the Indianapolis Network for Patient Care, two projects that have similar goals but are using very different technologies and organizational structures.

The Santa Barbara project developed as a public/private collaboration, and today is organized as a nonprofit with a "community stakeholder" board of directors, including physicians, chief financial officers, chief operating officers, a chief information officer, and a consumer and business advocate.

It uses peer-to-peer Internet technology, the same method college students use to share music files. "This is a pointer system," Mr. Apple said. It can identify where data are stored within the system, and "it provides the physician with a patient-centered view of both clinical and administrative results. However, it is not an electronic medical record."

Efforts like these are expensive, and the Santa Barbara project has run into problems. Insufficient grassroots support has been an issue, Mr. Apple said. The data exchange received a $10 million grant from the California HealthCare Foundation and $400,000 from the federal government. Although it started development work in 1999, it is expected to be up and running this summer.

The Indianapolis Network for Patient Care has been functioning for more than 7 years. "Five hospital systems that at one time were probably fierce competitors are now cooperating," Mr. Apple said.

Indianapolis started with a small project, one everyone could agree was really needed. At first, when a patient came into the emergency department, physicians could access limited data from participating hospitals. This effort was originally funded through a National Library of Medicine grant, but when the grant expired, the participants chose to continue the project.

Today, the much-expanded Indianapolis network can be used for any treatment purpose. With the patient's permission, physicians can access a complete medical history, including all previous care.

Indianapolis uses a data warehouse system. Each institution stores its data in a separate database, but all the databases use the same structure and the same coding processes. The system can pull out and combine information as needed.

The Regenstrief Institute, a nonprofit affiliated with Indiana University, Indianapolis, manages the network. Indianapolis didn't set up a separate entity to deal with these issues; instead, the network is governed by a contractual agreement signed by all users. "Regenstrief acts as the hub of the wheel," Mr. Apple said.

Before it went into effect, this draft agreement was reviewed and approved by clinicians, compliance officers, lawyers, risk managers, and information system personnel in a cooperative, consensus-building process. "That's the most important point," Mr. Apple said. "This wasn't something where the information technology folks said, 'let's put this out and make the doctors use it.' They actually spoke with the physicians and looked at all the issues before rolling this out."

He pointed out a second key difference: The Santa Barbara network allows doctors to pull up computer files so they can access each other's information, but the information is unstructured. Physicians are, in effect, accessing copies of paper files. In Indianapolis, the data are entered in a structured format, so it's possible to search for and compare key data items. Test results are tagged so that other computers in the network can recognize them.

Neither network offers a truly interoperable electronic health record, and Mr. Gordon told this newspaper that it will be years before we get one: "When you get all the different players in a community together, you see just how difficult it can be to reach agreement. Do we want to drive a Porsche or a VW?" Some hospitals and health systems will seek more robust technology, storing larger amounts of data with higher levels of security. Others will say they can't afford that level of sophistication. ■