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Building Consumer Trust into Health Information Exchange

For nationwide health information exchange to succeed, consumers must trust that their data are being managed responsibly. Regional and other networks that create the nationwide exchange should make consumer trust a priority that is factored into every decision they make. Connecting for Health's Common Framework offers a starting point.

by Carol Diamond, MD, MPH, and Lygeia Ricciardi, EDM

While the technical elements of networks for local and regional exchange of health information can be adapted from other industries, the policy questions on the expanded movement of health data are new, dynamic, and daunting. Nowhere is this clearer than with issues surrounding privacy of personal health information and ways in which it might be handled or used.

According to a survey by the California HealthCare Foundation, 67 percent of national respondents are "somewhat" or "very concerned" about the privacy of their medical records.¹ A survey by the Markle Foundation found that 79 percent of likely voters believe that it should be a high priority to ensure that their medical records can be shared only after they give permission to do so.²

A national approach to exchanging health information electronically must be designed to build consumer trust. That is the view of the 100 members of Connecting for Health, a public-private collaborative led by the Markle Foundation. Connecting for Health includes leaders from across the healthcare system, including privacy advocates, consumers, vendors, professional societies, and hospital groups.

Connecting for Health's members believe that information exchange can take place among very diverse existing and future healthcare networks over the Internet if all participants adhere to a small set of shared rules—a "Common Framework" of technical and policy guidelines that every healthcare organization can adopt. The development of this approach was driven by the desire to leave private health information in the hands of the doctors, hospitals, and others who are trusted by the patient, rather than requiring information be sent or centralized by a third party who has no direct relationship with the patient.

Identifying the Policy Issues That Lead to Trust

In 2005 Connecting for Health working groups teamed up with three communities—Boston; Indiana; and Mendocino County, California—to develop and document a set of policies and technical standards through a working prototype of health information exchange. The goal was to test whether the Common Framework could indeed connect several very different communities with diverse technical approaches and systems.

The success of the prototype is the basis for the Common Framework resources that are now in the public domain (see www.connectingforhealth.org/commonframework). The resources include model policy documents for health informa-

tion exchange, a model contract, and technical interfaces and standards, including implementation guides as well as the actual code and test server interfaces from the prototype.

The approach addresses policy and technology requirements together based on the belief that policy decisions, such as access rules and privacy protections, should be built into and drive the technical requirements of an information system. The model policy documents help communities further enhance trust by addressing key topics such as consent, privacy, security, control, and access. Topics include the following:

Cross-cutting issues

- ▶ What measures beyond those prescribed by HIPAA should be taken to protect patient privacy?
- ▶ What is the right balance between thoroughness in protecting patient privacy and undue burden on healthcare providers?

Obtaining patient notification and consent

- ▶ What should an institution planning to make patients' health information accessible to others do to notify the patients?
- ▶ How and when should an institution offer patients a choice about whether to participate in a health information exchange system?

Appropriate uses of health information

- ▶ Which uses of health information are appropriate or inappropriate?
- ▶ What practical methods are available to help networks and organizations collect and use health data appropriately?
- ▶ When and how should the use of health information be disclosed to patients?

Identifying records that belong to a particular patient

- ▶ How can the likelihood of correctly identifying patient records be maximized and incorrect matches be minimized?
- ▶ How can inadvertent exposure of health data be minimized?

Authenticating the identity of users

- ▶ What are the best ways to verify both the identity of someone who wants to access health information and his or her authority to do so?

Patient access to his or her own information

- ▶ How can patient access to his or her own health information be maximized?
- ▶ How can rigorous security and privacy safeguards be maintained in an architecture that allows patients to access their own information?

Audit trails

- ▶ How can audit systems ensure appropriate technical, physical, and administrative safeguards for information?

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Breaches of confidential health information

› Given that some breaches are inevitable, who should be notified of them, and what actions should be taken?

The Common Framework is a starting point—it helps identify some of the most important issues and decisions that key stakeholders should consider. However, it does require users to adapt it to their own unique circumstances.

No matter what decisions they make, it is essential that they consider the policy questions along with the technical ones. Building consumer trust is a priority that must be considered from the beginning and factored into every decision along the way. ❖

Notes

1. California HealthCare Foundation. "National Consumer Health Privacy Survey." November 2005. Available online at www.chcf.org/documents/ihealth/ConsumerPrivacy-2005ExecSum.pdf.
2. Markle Foundation. "Attitudes of Americans Regarding Personal Health Records and Nationwide Health Information Exchange: Key Findings from Two Surveys of Americans." October 2005. Available online at www.connectingforhealth.org/resources/101105_survey_summary.pdf.

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