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Privacy is key to interoperability

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Privacy should not be considered an “obstacle” to patient data sharing and it is not a trade-off for electronic records, according to speakers at The Road to Interoperability conference held in Boston last week.

“Privacy is clearly a critical element in dealing with a national health information network,” said William Yasnoff, MD, PhD, managing partner, NHII Advisors. “Quality healthcare requires complete information. We need EHRs and privacy. This is not a tradeoff.” Because health information today is so scattered, current information sharing in not effective. Yasnoff called for the creation of an institution dedicated to the issue. “If no one is responsible, it doesn’t get done.”

One of the biggest challenges, he said, is that 13 to 17 percent of consumers admit to information-hiding behavior, such as not letting one provider know that they are seeing another, or using alternative treatments. He said that the true number is probably higher than those willing to admit the behavior. That is why complete information with patient consent should be the goal and no less should be expected.

Yasnoff discussed the valuable role that health record banks can play. He envisions a system solution similar to safe deposit boxes at banks, where the bank operates the infrastructure but do not own the contents. Health record banks would allow for value-added services and enables trust and privacy. Yasnoff said that the communities that have successfully implemented a health information infrastructure all have a central repository for patient data.

Judah Thornewill, acting director of the Center for Complexity and Health at the University of Louisville, discussed efforts to study health record banks and fund them. In Louisville, all the stakeholders have been at the table and agreeing to a health record bank, he said. “The vision is a nationwide HRB network of probably 300 banks.

Thornewill discussed a multi-step plan to get to that point. First is engaging the coordinating bodies—the four Ps—purchasers, payers, practitioners and providers. “Any one of them can derail the process at any point. Next steps include obtaining purchaser commitments to sponsor community revenue streams and forming consumer value propositions. The team is currently conducting “a robust series of focus groups and other research” to find out what consumers want at each stage of life. A successful

implementation also includes defining open standards, engaging the private sector and linking HRB service providers to legacy data.

When asked about including medical images in an HRB, Thornehill said that there is not advantage to having HRBs store images because they are not needed immediately and are not searchable. “The gaping hole is ambulatory care when 80 percent of healthcare occurs.”

Janlori Goldman, director of the Health Privacy Project, said that the industry should stop talking about privacy as a barrier to health information exchange. “It’s not an either-or proposition,” she said. “Privacy promotes healthcare.” She cited studies that have found that almost 20 percent of people practice privacy-protective behavior—leaving information about their health out of discussions with providers because of their fear of stigma or discrimination.

“We need national leadership urgently,” Goldman said. She said that the uniformity of state regulations should be increased and that attention to privacy should be increased without eliminating existing laws. The current standards need a privacy impact test, she said. She called for a more engaged private sector and more efforts to educate and engage patients and consumers. “The price of good care shouldn’t be privacy,” she said.

Mark Leavitt, MD, PhD, chair of the Certification Commission for Healthcare Information Technology (CCHIT) and medical director of HIMSS, described CCHIT as a market-based mechanism to drive standards. The group is entering the third of a three-year, $7.5 million project for the federal government.

CCHIT accelerates HIT by making it less risky, ensuring interoperability, enhancing availability of adoption incentives, and protecting privacy, Leavitt said. In 2006, the commission began certifying ambulatory EHRs, in 2007, inpatient EHRS and plan to start certifying networks or RHIOs in 2008. The group doesn’t stand still, he said, and continually updates criteria for existing domains. Meanwhile, several other sectors have asked for a certification process, including long-term care and behavioral health.

Certification seems to be having a positive impact on the industry, Leavitt says. The process has been endorsed by major medical associations and payers are using certification as a qualifier. There was concern that the process would wipe out small vendors and limit innovation but Leavitt says it has “created a level playing field and fostered competition.” Forty percent of vendors who have applied have gotten their product certified and 17 percent of them have less than $1 million in revenue.

David Bates, MD, MSc, medical director, Clinical and Quality Analysis, Partners Healthcare System, compared the situation in the United States with that of other countries. He said that the United Kingdom has seven practitioners in total that are not computerized. In Australia, electronic records went from 20 percent to 80 percent penetration among general practitioners in three years. These were paid for via

pharmaceutical ads which pop up while physicians are using the systems. This and other problems such as little decision support mean the system isn't ideal, Bates said.

He discussed the strengths and weaknesses of the certification process. CCHIT has a great set of experts, a good mix of stakeholders and specifically addressed interoperability and security. However, just because a product passes a criterion doesn't mean it does that task well, he pointed out. CCHIT has a heavy reliance on volunteers and the group is still learning which items are really important. "The bar will go up with time but we need to decide how far up it will go."