Connecting for Health...A Public-Private Collaborative

KEY FINDINGS

Connecting For Health is a public-private effort involving more than 100 important healthcare stakeholders, including government, for-profit and non-profit organizations. By acting collaboratively and decisively, Connecting for Health has taken a first critical step toward enabling the best patient care through the use of vital health information.

- 1 Over the past nine months, the Collaborative has successfully built consensus on an initial set of healthcare data standards,
- 2 developed case studies of places where privacy and security practices may provide a model for others and
- 3 advanced our understanding of the consumer's role in an interconnected healthcare system.
- 4 In addition, a demonstration project, the Healthcare Collaborative Network (HCN), involving twenty organizations, which will demonstrate real-world feasibility and benefits of an interconnected healthcare system was developed.

Data Standards Working Group

- The current information transfer problems in our healthcare system undermine the quality of care by making it difficult for patients and providers to get the information that they need when they need it in order to make the best decisions about treatment.
 - 1 The Data Standards Working Group has gained consensus on a core, initial set of data and communication standards and defined the barriers to widespread adoption of those standards specifically the lack of interoperability of systems within hospitals and healthcare organizations.
 - While we do not have a full set of data standards to realize true interoperability, of health care data and knowledge, many standards do exist and their use and broad adoption would dramatically improve the current log-jam of vital health information.
 - 3 Connecting for Health has focused on those standards that are ready for broad adoption and use in its recommendations to date. These are referred to as the "operable" set: HL7 v2.x data interchange standard, the HL7 Reference Information Model, the DICOM standard for imaging, the NCPDP SCRIPT prescription drug

information standard, the LOINC vocabulary for laboratory tests, the IEEE/CEN/ISO 1073 medical device communication standard, the ASC X12 administrative transaction standard, HL7 Data Types, Clinical Document Architecture (CDA), and the HL7 Clinical Context Management Specification (CCOW).

This Group has also developed a proposed migration framework for all participants in the health care system to consider when implementing the recommended standards in electronic communication and data interchange at the local or community level.

Privacy and Security Working Group

- Privacy and security of patient information are critical issues in the discussion of an interconnected healthcare system.
- The Privacy and Security Working Group worked to identify noteworthy privacy and security practices, as and case studies of places where privacy and security practices may provide behelpful for others implementing an information system adopted by healthcare providers.
- The Privacy and Security Working Group will share real-world examples of noteworthy practices for protecting the privacy and security of the healthcare consumer.

• Their findings include:

- 1 Adoption of an electronic health record can enable a great deal of security and privacy if these elements are built into the application and fully implemented.
- 2 Making privacy and security an upfront and integral part of adopting new information technology has the potential to decrease costs and increase the likelihood of successful implementation.
- 3 Organizations adopting new healthcare information technology can achieve high levels of security and privacy.
- 4 Coordination and commitment among internal and external stakeholders enable organizations to agree on common policies and practices and take the steps necessary to implement them.
- 5 Rigorous privacy and security practices enable sharing of clinical information, public health data and research. These same practices need not interfere with a clinician's access to the information needed to deliver patient care.

Personal Health Working Group

- As patients begin to take a much more active role in healthcare treatment decisions, it becomes important to empower them with access to and control over their personal health information.
- The Personal Health Working Group worked to define the characteristics of an electronic personal health record and identify the needs and desires of consumers with regard to using personal health information stored in an electronic format.
 - Connecting for Health's work is enhanced by a survey conducted by the Foundation for Accountability (FACCT) to gain a better understanding of the internet-using public's interest in using computers to manage their healthcare.
 - They found that seventy percent of consumers would be interested in using some or all the aspects of an electronic personal health record.
 - o Forty percent erroneously believe that their doctors already use electronic records.
 - o Seventy-five percent said they would want to email their doctors.
 - Sixty-nine percent said they would want to note mistakes in their medical records.
 - A majority of consumers in this survey also indicated that the privacy and security of their personal health information was very important to them.
- The PHR has several distinct attributes:
 - Each person controls his or her own PHR. Individuals decide which parts of their PHR can be accessed, by whom and for how long.
 - PHRs contain information from one's entire lifetime.
 - PHRs contain information from all health care providers.
 - PHRs are accessible from any place at any time.
 - PHRs are private and secure.
 - PHRs are "transparent." Individuals can see who entered each piece of data, where it was transferred from and who has viewed it.
 - PHRs permit easy exchange of information with other health information systems and health professionals.