

# **Workshop on Long-term Preservation & Management of Electronic Health Record**

April 5 -6,2011

*Possible discussion topics from registrants' opinions on what is needed and what impedes sharing of The EHR*

## **Breakout session 1: Interchange of Electronic Health Records.**

When they registered for this workshop, individuals were invited to respond to two questions:

Question 1. What is the single most important thing that needs to be done to enable preservation and sharing or re-use of EHR?

Question 2. What is the single greatest obstacle to preservation and sharing or re-use of EHR?

Many of the responses identified actions and obstacles related to sharing or exchange of EHR. The responses can be used to stimulate discussion in the break out session. Responses are grouped under general subject areas below.

## **Standards**

Many individuals who registered for this workshop identified standards as the most important area of action to enable sharing of EHR. Particular areas identified as in need of standards development to facilitate sharing include:

- standards for EHR interchange and for interoperability among EHR systems;
- a “universal exchange language” and open source formats for EHR;
- standard definition and structure of the EHR as a whole, and standardization of ontologies, semantics, data, and metadata, including privacy and security as well as content;
- a standard for globally unique patient identifiers; and
- privacy and security standards.

Many registrants cited lack of standards as the greatest obstacle to sharing. Aspects of this obstacle that were mentioned include lack of a fully functional National Health Information Network and conversely the existence of multiple standards that each cover part of the need, but do not constitute a coherent or comprehensive set. Inconsistent data standards, including data definitions and encoding, were also cited, as were failure to implement existing standards, instead implementing proprietary approaches. It was also suggested that absence of government enforcement of standards compliance is a major impediment to sharing.

## **Discussion**

- *Do you agree that there is an important need for standards development and implementation in these areas to support data sharing? Would you add any others?*
- *Do you agree that lack of standards, incomplete and inconsistent standards, and failure to implement standards constitute a great obstacle to sharing?*
- *What could be done in the immediate future to address these issues?*

## **Implementation**

Registrants identified many things that should be done at the practical or operational level to promote sharing of EHR.

One of them was the “development and application of principles of data stewardship.” Several other suggestions can be considered as identifying elements of data stewardship:

- the accuracy, validity, and integrity of the original source record (data);
- accurate attribution of data provenance;
- a managed approach to keeping or deleting data;
- documentation of business functions in different organizations to facilitate sharing
- consistent, reliable, and secure identification of patients across systems and providers;
- ensuring accessibility of data as technology changes;
- implementing the ability to export from proprietary to general, open standard formats;
- establishment and communication of standard operating processes throughout organizations;
- communication among stakeholders to develop agreement on implementation; and
- effective training of staff and other users.

Many individuals also cited implementation or operational issues as constituting the greatest obstacle to sharing. Human shortcomings were frequently cited, including

- general resistance to change;
- “user blinders to the long term implications of data exchange;” and
- conflicts between system requirements optimized for an episode or encounter of care v. those that address longitudinal care.

Other practical obstacles are at the institutional level, including:

- lack of institutional commitment
- absence of incentives to encourage interoperability;
- business models that impede sharing of information;
- restrictions on data;
- focus on process rather than effective problem solving;
- vendor focus on selling their particular solutions;
- absence of dialogue among relevant federal agencies
- lack of collaboration;
- reactionary policies at state and federal levels; and

- varying interpretations of privacy, security and similar policies.

Technology is also seen as presenting great obstacles at the operational level, especially de facto lack of interoperability among systems. It was also pointed that existing, “historical” architectures make it difficult to implement interoperability. The difficulty of exchanging raw data was also highlighted.

## Discussion

- *Are there other actions you see as necessary for data stewardship?*
- Do you agree that issues at the level of current activities, operations and implementation pose major obstacles to sharing?
- What do you think of the specific difficulties mentioned in the human, institutional and technological spheres?

## R&D

In response to the question on what is most important for sharing and preservation of the EHR, registrants cited the need for development of the Health Information Exchange and more generally of a common ecosystem for health information. More specifically, individuals indicated the need for continuing research in capabilities for sharing electronic records and for improvements in clinical data intelligence and analytical methods.

## Discussion

- Are there other areas where research is needed to enable or facilitate data sharing?
- How would you prioritize research needs?