

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

April 5 -6,2011

Possible discussion topics derived from registrants' opinions on what is needed and what impedes sharing, preservation and reuse of The EHR

Breakout session 3: Institutional Policy of Sharing Preserved Electronic Health Records_

Question 1: What Needs to Be Done in the Policy Arena to promote Sharing and Preservation of EHR?

About one third of the responses to this question identified issues that entail action in the policy domain. They addressed both what policy should be and its implementation. Issues include:

- Creating a “policy and resources landscape” that supports sharing, preservation and re-use and embodies “sound and workable” approaches;
- Assuring the accuracy, validity, and integrity of the original source record (data) so that it is worthy of primary use and, thereafter, appropriate secondary uses;
- Defining business process to support the authenticity, integrity, reliability and usability of the records;
- Legal issues, governance;
- Assigning specific responsibility for sharing and preservation and making the responsible persons accountable for finding the information;
- Managing data consent and;
- Implementing effective records management;

Some responses identified policy issues that go beyond individual institutions. Some of these cross-cutting issues need to be addressed at the institutional level; for example,

- Policies on privacy and security should be consistent across institutions, accepted by the general public, and implemented in information exchange;
- Institutions need to agree on open source formats for EHR and the various stakeholders need to communicate and agree on next steps towards open source formats;
- Health data exchange requires patient identifiers that are unique and persistent across systems;

Some responses identified policy issues that need to be addressed in concerted or even national level action:

- Data sharing policies should be coordinated or reconciled across governmental and private entities in order to preserve patient confidentiality, maximize research utility and minimize bureaucratic roadblocks;
- Sharing and preservation should become a national requirement for all health care organizations;
- A standard for recording the metadata of the EHR record should be adopted nationwide and it should address both informational content and security/privacy aspects.

Discussion:

- *Are there other important policy issues that should be addressed to enable or facilitate sharing of the EHR for health care?*
- *Are there other important policy issues that should be addressed to enable or facilitate preservation and reuse of the EHR for research?*
- *Are there specific actions that could be taken in the immediate future to promote the development and implementation of appropriate policies?*

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

30 of 92 responses identified policy issues as the single greatest obstacle. In these 30 responses, the types of policy obstacles most frequently cited (19) were policies on privacy or privacy and security. Laws and rules in these areas are seen as very complex, lacking in clarity, and difficult to implement. These difficulties are compounded by liability issues and lack of clarity over who owns the information. One respondent felt that privacy policies need to “protect both patient and clinician” but do not. Managing patient consent is seen as difficult, including patients’ consent to subsequent release of data for their own health care, and managing the records of deceased persons to protect the privacy of their descendants appropriately. Within the federal government, information security law is seen as making it easy for federal agencies to acquire health data from private sources, but difficult to release such data to the private sector even for the care of the individual subject of the record.

Other areas where policy is seen as a major obstacle include:

- the lack of policies promoting sharing;
- policies that fail to clarify what should be preserved and shared and how these things should be accomplished; and
- policies that fail to “show how preservation and sharing work while meeting privacy and access control needs.”

Discussion

- *Do you agree that policy constitutes the single greatest obstacle to either sharing or preservation and reuse of the EHR?*
- *Are there policy obstacles that were not cited in responses to the registration questions?*
- *What could be done now to remove or reduce policy barriers?*