
Consent Implementation Subcommittee April 3rd, 2012 Meeting Summary

Meeting Objectives: Develop a concrete understanding of data storage and access in Direct, and CCO basics related to data sharing and HIE. Determine whether to affirm or revise this Subcommittee's recommendation for implementing the consent policy.

Workgroup Members Present: Bob Thomson, Ronald Marcum, Anne Greer, Bob Brown, Gwen Dayton, Lynn Shoemaker (by phone), Mark Schwebke (by phone), Scott Seibert (by phone), Chas Horner (by phone), Glendora Raby (by phone)

Workgroup Members Absent: Thomas Yackel, Jason McNichol, Jerry Cohen, Tim Timmons

Staff Present: Carol Robinson, Kahreen Tebeau, Tom Wunderlich, Chelsea Hollingsworth, Mindy Montgomery

Meeting Date: April 3rd, 2012, 2 pm – 4 pm, 900 SW 5th Ave, Portland, OR

Meeting Overview: The Subcommittee reviewed questions from the Consumer Advisory Panel and staff responses on data storage and access in Direct Secure Messaging, received an update on the evolving national and state context for patient consent in HIE, and discussed their recommendation to HITOC in light of the new information.

Discussion Highlights:

- The group walked through each of the questions asked by the Consumer Advisory Panel (refer to meeting materials handout).
- A downstream recipient of an amended medical record should receive any amendments. An HIE system that is simply a conduit should not make requirements of users for amendment behavior.
- The consumer is not aware of the technical details, but they should be guaranteed security nonetheless.
- If the bulk of a physician's patients are consenting to HIE but a few are not, those patients might cease to be a financially viable population for the physician to treat.
- Some PIN language, including the phrase, "beyond what is required for an initial transaction," is vague.
- The opportunity to opt-out should apply to whether data is going into a database, rather than what happens once the data is in a database.
- Technological limitations suggest that access rights are the only way to parse information in a queryable database. The complexity required to granulize information once it is in a database is not technically plausible.
- The more entities that have access to a database, the greater the risk for breach. A patient should be able to decide the threshold of risk that he or she wants to participate in, but that may create a barrier to care coordination.
- Currently insurance companies have aggregated databases and probably know more about a given patient's health than their doctor does; the patient needs to recognize the current state and the value of having a fully-informed doctor.

Meeting Outcomes:

- Policy-making groups in Oregon should be focused on the goals of CCOs right now. This group should not impose any additional rules that may impede care coordination and the other goals of CCOs (lowering costs, improving outcomes, etc.).
- Current HIPAA policy provides a regulatory framework for HIE; any additional policy needs identified would need to be specific to the additional technology.

Next Steps:

- This group's recommendation to not implement additional requirements for patient consent for HIE at this time, beyond what is already required by existing state and federal law, will be presented by staff to HITOC at its April 5th meeting.
- This group should have a final meeting to hear the opinions of members who were not present, and to allow for any additional feedback to HITOC.

Challenges/Opportunities:

- The needs of CCOs, the privacy & security mandates of HIPAA, and the guidance on patient consent from the ONC PIN are at a crossroads. It is difficult for this group to move forward to implement an opt-out policy for HIE given the needs of CCOs, the existing technical limitations, and federal policy ambiguity.

Other Workgroup Interdependencies:

- None.

Public Comment:

- None.

Out of Scope, But Needs Attention:

- None.

Input to HITOC:

- HIPAA provides an adequate regulatory framework for patient consent for the CareAccord services and meets the ONC PIN requirements for Oregon's State HIE Program.
- The goals of CCOs, technical limitations, and ambiguity in federal policy suggest that we should not implement additional HIE consent requirements at this time.