Illinois Health Information Exchange
Legal Task Force
Patient Consent Management/Forms Workgroup Meeting
July 14, 2011
Meeting Minutes

Committee Members Who Attended in Person:
Abe Arnold, Office of Health Information Technology
Mark Chudzinski, Office of Health Information Technology
Carolyn Metnick, Barnes & Thornburg
Julie Treumann, Ungaretti & Harris

Committee Members Who Attended by Phone:
Rob Connor, Illinois Department of Human Services
Evelyn Hoffmann, Hoffmann, Lerman & Associates
Marcia Matthias, Southern Illinois Healthcare
Renee Popovits, Popovits and Robinson
April Schweitzer, Office of Health Information Technology
Marilyn Thomas, Illinois Department of Healthcare and Family Services
Crystal VanDeventer, Lincoln Land HIE

Marilyn Thomas, as chair of the Patient Consent Workgroup, welcomed participants to the call at 9:08 a.m., hosted by OHIT at the State of Illinois J.R. Thompson Center in Downtown Chicago with a telephone conference call-in number. Notice of the meeting and the agenda were posted on the OHIT website and at the Chicago meeting location no later than 48 hours prior to the meeting. Roll was taken, and the ability of those attending by telephone to hear and participate was confirmed.

The minutes from the 3/14/11 meeting were approved without objection.

Marilyn began the meeting by reviewing the types of consent this workgroup is concerned with specifically consent for information to go into the HIE.

Marilyn then invited Renee Popovits to speak about the confidentiality of substance abuse and the edits her work group has recommended to the consent forms developed by HISPIC based on patient feedback.

Renee reminded the group that state laws as well as federal law govern substance abuse treatment records. She also updated the group on developments with SAMSHA concerning consent forms and offered to send a draft of a model consent form currently under development to Marilyn.

There was agreement within the group that written consent is absolutely needed for treatment but the open question is whether there should be provisions that are more like opt-out instead of opt-in on consent forms? Another important question is whether

consent forms should distinguish between medical records and treatment history? Members of the group seemed to agree that an all or nothing approach is necessary for the HIE. However, on the substance abuse treatment side, there is a distinction to be made between information in the medical record and the very personal information in the lengthy progress notes. In general, patients are not comfortable with the progress notes being included in the HIE.

One group member asked specifically about how consent works when minors consent to treatment without parental consent. Renee confirmed that minors over 12 years old hold the right to decide whether or not to disclose their records even to their parents. Renee noted the need for families to be very involved in the treatment of minors.

The discussion then turned to whether trying to include a research consent within the treatment consent would cause problems? While Renee thought some research may fit into the audit and evaluation section of the CFR she confirmed that research regarding a specific patient would likely cause problems and cause patients to opt-out of the HIE.

The group members agreed that implementation of the HIE needs to be incremental.

The group then discussed issues surrounding re-disclosure. Under 42 CFR Part 2, re-disclosure is not permitted. A group member asked what types of re-disclosures are permitted. The following example was given:

- A provider from treatment facility # 2 sometimes requests the discharge papers of a patient from treatment facility # 1 before admission to treatment facility # 2. Treatment facility # 1 would only forward records created at treatment facility #1 not records that they received from another facility. However, it is important to note that when the information is in an emergency room record it has no 42 CFR Part 2 protections.

The group also discussed whether there was a way for patients to track disclosures that have been made regarding their medical records. Renee agreed to share a patient's rights paper that addresses these issues.

Currently OHIT is developing an RFP for the design of the HIE which includes two types of secondary use: one concerning the collection of measurements with regards to healthcare providers and the second concerning syndromic surveillance in regards to public health. Additionally, the HIE is authorized to create an IRB which will provide additional patient protection.

There are several pieces of legislation of note pending:

- HB 1338- Sent to Gov. on June 10th
- HB 1234- Sent to Gov. June 24th
- HB 2917 – Sent to Gov. on June 15th

Several comments were mad regarding the use of common consent forms. For instance, Kansas has adopted legislation that will utilize a common consent form and default to federal HIPAA regulations and there is an Upper Midwest Group that has drafted a common consent form as well.

The group agreed to meet again in the next 2-3 weeks. Marilyn asked for volunteers to email her directly to volunteer to begin drafting recommendations on behalf of the group.

Marilyn asked for questions and comments from the public and thanked Renee for joining the call.

The meeting adjourned at 10:03 a.m.