

**Illinois Health Information Exchange
Legal Task Force
Patient Consent Management/Forms Work Group Meeting
September 8, 2011**

Committee Members Who Attended by Phone

- Rob Connor, Illinois Department of Human Services
- Anne Mahalik, Illinois Department of Human Services
- Marcia Matthias, Southern Illinois Health Care
- Carolyn Metnick, Barnes & Thornburg
- Eric Swirsky, University of Illinois Chicago
- Marilyn Thomas, Illinois Department of Healthcare and Family Services
- Crystal VanDeventer, Lincoln Land HIE

Office of Health Information Technology

- Mark Chudzinski, General Counsel
- Melissa Tyler, Legal Intern

Marilyn Thomas, as chair of the Patient Consent Workgroup, welcomed participants to the call at 11:08 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 for July 14, 2011 were approved without objection.

Marilyn began the meeting by suggesting that the group condense its discussions and work on making its recommendations to the Legal Task Force. The group should also provide some potential revision to the consent form and notice of privacy practices developed by the HISPC, (2007) legal work group. She suggested that the group break into smaller workgroups to focus on recommendations and/or consent forms. These smaller groups would have several longer meetings, about two hours to work on recommendations. Some individuals could also work on revisions and circulate them among the smaller groups. Then the group would get back together as a large group to discuss the work. The group agreed that this was a good idea.

Marilyn invited Mark to discuss how other workgroups have approached their recommendations. He explained that the approaches vary, but the general approach is to identify barriers under

Illinois law for the development and implementation of an HIE. Once the barriers have been identified, then to suggest potential ways of addressing them. The suggestions are then pulled together into some form of a white paper to present and justify to the body that needs to adopt the recommendations (the Authority or the General Assembly). Mark explained that this work group is unique because of the HISPC work product that exists from 2007. The group should look at this prior work product and update it.

Mark explained that OHIT is now selecting a vendor to provide the core services of the ILHIE. The ILHIE core services will include: master patient index, provider index, public health directory, payer directories, record locator service and privacy and consent management service. At the state level, users of the ILHIE will have to get through the privacy and consent management service before they can obtain patient records. The system will be as flexible as possible to accommodate changes in legislation and policy. He explained that there is evidence that if you make the collection of patient consent too complex you detract from the amount of information going into an HIE. He provided a brief overview of how the patient consent service may operate.

Mark suggested projects for Melissa Tyler, legal intern, to undertake that would assist the group in making its recommendations:

1. Pull together information on states decision on opt-in v. opt-out;
2. Pull together the consent forms that HIEs are using – consent/notice of privacy practice; and
3. Create a table of statutes that require a state-wide model consent form (e.g. Florida & Minnesota). The group should consider whether or not to suggest a common consent form.

In the ensuing discussion, it was noted that timing needs to be considered if new legislation is to be proposed to the General Assembly for the 2012 term. Marilyn suggested that either the Task Force or OHIT find a sponsor, such as a hospital group or medical society to support any legislative initiative.

The group discussed SB 1234, which was passed last year, and amends the mental health confidentiality act. There is no information currently available concerning whether the exception to patient consent for disclosure for Medicaid patient data may be expanded to cover all of the patients PHI.

Mark noted that it is likely that the federal government will issue an NPRM on the governance of the national HIE (NWHIN), which may contain new requirements regarding patient consent for

disclosure of PHI through an HIE. He believes the NPRM will include proposals recommended by the “Tiger Team.”

In the ensuing discussion, a concern was raised regarding due regard to patient privacy rights in the design of any PHI data collection system. It was suggested that the group look at the legislative history of the relevant statutes in states that have addressed “opt-in/opt-out” to see what issues they dealt with.

Mark noted that there is empirical evidence that with an “opt-in” approach, less data comes into the system, with negative patient treatment consequences. To foster physician trust that records obtained from an HIE are complete, some HIEs have adopted an “all-in-or-all-out” approach.

There were no public comments in response to the chairman’s invitation.

Marilyn said that she will send e-mails around to the group identifying meeting dates for subgroups and identifying what areas they want to work on. Additionally, she will send out a meeting date within a week or two.

Meeting adjourned at 11:40 a.m.