

**MINUTES OF THE AUGUST 17, 2012 MEETING
OF THE DATA SECURITY AND PRIVACY COMMITTEE OF THE
ILLINOIS HEALTH INFORMATION EXCHANGE AUTHORITY**

The Data Security and Privacy Committee (“Committee”) of the Board of Directors (“Board”) of the Illinois Health Information Exchange Authority (“Authority”), pursuant to notice duly given, held a meeting at 2:30 p.m. on August 17, 2012, at the offices of the Illinois Office of Health Information Technology (“OHIT”), 100 West Randolph Road, Suite 2-201, in Chicago, IL and at the offices of the Illinois Department of Healthcare and Family Services, 201 South Grand Avenue E., 3rd Floor, in Springfield, IL, and with webinar participation capabilities.

<u>Appointed Committee Members Present in person:</u> <ol style="list-style-type: none">1. Elissa J. Bassler2. David Carvalho3. Nicholas Panomitros, Chair4. Gerald DeLoss5. Harry Rhodes	<u>OHIT Staff Present:</u> Mark Chudzinski; Krysta Heaney; Cory Verblen <u>Invited Guest:</u> Sonia Desai Bhagwakar
<u>Appointed Committee Members Present electronically:</u> <ol style="list-style-type: none">1. Leah Bartelt2. Carl Gunter	

Call to Order

Mark Chudzinski, Secretary of the Authority and General Counsel of OHIT called to order the meeting of the Committee. Prior to calling roll, Mr. Chudzinski reported that the most recent meeting of the Committee was held on August 13, 2012 and minutes from that meeting would be forthcoming.

The next scheduled meetings of the Committee are Thursday, September 6, 2012 and, if necessary, Friday, September 7, 2012 to finalize the Committee’s privacy, security, and consent management recommendations for submission to the Board on September 19, 2012.

Mr. Chudzinski provided an overview of the documents distributed to the Committee prior to the meeting: 1) a written overview of the “opt-out” consent model discussed by the Committee at the August 13, 2012 meeting; and 2) several graphics illustrating two-stage HIE use cases.

Roll Call

Mr. Chudzinski welcomed the appointed Committee members present in person and electronically, and confirmed the presence of the Committee members noted above. There were no objections from the members of the Committee to the participation by electronic means of Leah Bartelt and Carl Gunter who had advised the Secretary in advance of their attendance by electronic means necessitated by business or employment purposes.

Deliberations Regarding ILHIE Privacy and Security Policy Questions

Mr. Chudzinski presented and explained graphics prepared by OHIT depicting six use cases of the two-stage “opt-out” HIE model that was discussed by the Committee at the last meeting on August 13, 2012.

The Committee discussed the issue of requiring “opt-in” consent for sensitive personal health information (“PHI”) at Stage 1. It was determined that, because an effective screening process is not feasible for providers, an all-or-nothing approach would be suitable. If a patient with sensitive PHI did not “opt-in” for that provider, the patient’s entire record located at that provider/facility (both sensitive PHI and general PHI) would be kept inaccessible to the HIE.

The Committee was advised that if a patient “opts-out entirely”, the available technology would allow for a patient to request override consent for one provider to access her health information through the HIE (similar to how providers can access the HIE pursuant to a “break the glass” exception).

The Committee contemplated how other states are implementing or considering granular “opt-in” consent. It was concluded that, while vendors may claim their technology allows for granularity, there is no evidence that they can perform this service effectively. It was suggested that a consent model include that providers not be held liable for technology failures.

Committee members relayed concern that the sensitive PHI of a patient would become part of the patient’s medical history and would, therefore, become part of most, if not all, of her provider’s records. The effect would be that every provider’s medical records for this patient would be inaccessible if “opt-in” consent was not obtained. Some committee members expressed concern that a number of patients, even if a small percentage of the patient population, would be completely excluded from ILHIE even if they only wanted one item of sensitive health information such as an abortion excluded from exchange. Committee members set forth that advocacy groups such as many of those that testified at Committee hearings would not hesitate to be vocal with the General Assembly to speak on behalf of this small percentage of individuals.

The participating Committee members overall advocated for an evolutionary process for ILHIE - as technology develops and implementation becomes more feasible, granularity options should be introduced. However, Committee members felt the granularity options should be available for certain sensitive health information but that the options to exclude data should be a limited set and not overly broad. The Committee agreed that consent forms should not be too complex or burdensome. The consent form should be easy to track for the consumer and for the HIE to track the consumer’s selections.

The Committee contemplated whether a two stage “opt-out” HIE model would be necessary once technology allows sequestering of limited categories of PHI. It was discussed that once EMRs evolve to allow break up of a health record, there should be uniformity across EMRs. The members further discussed whether, once Illinois’ privacy laws are changed, all PHI could get in

the HIE and remain sequestered there unless a patient gives consent for it to be accessed or a “break the glass” exception is triggered.

Committee members brought up security concerns. It was set forth that data does not actually go in the HIE, and the concern should be with who might view the data that is sent by the HIE. There was concern that a physician’s credential to access the HIE could be compromised, and the consequence of the wrong person obtaining the information could be significant. The members discussed that consent is one way to limit access to records, and another method is to require authentication of the requesting party.

The Committee agreed that the Office of Health Information Technology (“OHIT”) should investigate risk mitigation strategies and that it do a security study to determine what security concerns exist.

A discussion ensued about changing state law to conform with HIPAA and further that, even if the law is changed, new legislation should also give OHIT regulatory authority to allow sequestering of data and write regulations for granularity at whichever point the technology will allow it.

The Committee took note of the difficulty in getting bills out of the House Committee at the General Assembly, let alone being passed into law, unless it is confirmed that groups such as the ACLU does not oppose it. It was agreed that passing legislation requires support of consumer groups.

The Committee then focused on whether the technology would allow a patient to participate in the HIE but exclude one provider, such as a provider where an abortion was performed, from releasing its records to the HIE. It was discussed that this likely could be done currently or could be one of the first granularity choices that could be offered in the future.

The Committee briefly addressed consent management. Members suggested that an opt-out form be given at an initial visit with a provider; the individual could make the selection there or could use a website to “opt-out”; that selection would be available to other providers so the process does not have to be duplicated. A consent directory at the HIE was suggested. The Committee agreed that the consent process and operational implementation would not be addressed in detail by the Committee at that time and that it may be helpful to have practicing physicians involved with operational decisions.

By the conclusion of the meeting, a consensus of the majority of participating Committee members was reached in recommending: 1) the two stage “opt-out” consent model discussed during the meeting with the introduction of granularity options in the future as the technology allows for it and 2) that OHIT determine the safeguards needed for authorized access to the HIE.

Public Comment

There were no comments offered from the general public.

DRAFT 8/30/2012

Adjournment

The meeting was adjourned at 4:45 p.m.

Minutes submitted by:

Sonia Desai Bhagwakar