

**Illinois Health Information Exchange
Legal Task Force
Genetic Testing Work Group- Genetic Information
Privacy Act Subgroup
March 11, 2011
Meeting Minutes**

In-Person Attendees:

Mark Chudzinski, Office of Health Information Technology

Attended by Phone:

Monique Anawis, Weiss Memorial Hospital

Vaughn Ganiyu, Office of Health Information Technology

Mary Lucie, Northwestern Memorial Hospital

Maia Thiagarajan, Ingalls Health System

Richard Wagner, Wagner Consulting, LLC

Maia, as co-chair of the work group, welcomed people to the call at 10:04 a.m., hosted by the Office of Health Information Technology at the State of Illinois J.R. Thompson Center in Downtown Chicago with a telephone conference call in number. Notice of the meeting and was 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.

Maia explained that she wanted this subgroup to come together outside of the larger workgroup in order to discuss specific issues related to Illinois' Genetic Information Privacy Act (410 ILCS 513) [GIPA]. Maia then briefly summarized the information covered by the Genetic Counselor Licensing Act subgroup, which met previously to this subgroup.

In preparation for this meeting, Maia circulated an article from the Loyola University Chicago School of Law Annals of Health Law entitled, "*Breaking Down the Federal and State Barriers Preventing the Implementation of Accurate, Reliable and Cost Effective Health Records*" by Stephen J. Weiser. Maia then briefly highlighted the key points of the article with the group.

Next, the subgroup turned its attention onto the genetic testing matrix and began by addressing the initial question: does the law allow, without patient consent, a disclosing entity to disclose genetic information to the HIE for purposes of treatment through the HIE? Maia first analyzed 410 ILCS 513/30(a)(3) and determined that disclosure of genetic information by an agent or health care provider would require authorization. The group found it troubling that GIPA did not further define what type of authorization would be sufficient in this case or if there was implicit authorization.

A group member asked if the group should assume that the IL HIE would be classified as an authorized agent of a health care provider under GIPA? Mark responded that the group could

make this assumption however he emphasized that express language creating an exception listing the IL HIE as one of the entities authorized to receive genetic information would be preferred. After this, Maia and the rest of the subgroup concluded that GIPA was more restrictive in its disclosure requirements than the HIPAA laws regarding disclosure of the protected health information. The group then discussed whether GIPA should adopt the HIPAA approach in regards to treating genetic information in the same manner as HIPAA treats the disclosure of protected health information.

The members of the group then discussed the benefits of adopting the HIPAA approach within the GIPA. Many members agreed that currently providers are taking a very conservative approach in regards to the disclosure of sensitive information due to misinterpreting both the state and HIPAA laws, in turn restricting the free exchange of information. The members of the group reach a consensus that the language as currently written in Section 30(a)(3) needs to be amended to be less restrictive. The group proposed three possible solutions: 1) remove the following language “if the health facility or health care provider itself is authorized to obtain the test results;” 2) create a separate exception specifically for the IL HIE; or 3) adopt the approach taken by HIPAA.

Next, Maia addressed the question on the matrix about how to treat the disclosure of genetic information in an emergency under GIPA. In discussing this issue, the group considered whether to broaden Section 15(b) of GIPA to include for medical emergencies that would require the disclosure of genetic information. A member of the group reiterated that the language amendment proposed by this work group should also be consistent to the similar emergency provision within the Genetic Counselor Licensing Act. After this discussion, the members of the group concluded that there was an opportunity for the language under Section 15(b) to be expanded further to cover emergencies pertaining to genetic information.

The next question discussed by the group was whether the law allows for the disclosure of genetic information to the HIE without patient consent for purposes of payment. The group began this discussion by analyzing Section 20(a) of GIPA. The group was concerned with whether the term “non-therapeutic” within Section 20 is sufficient language to expressly prohibit the use of genetic information for payment purposes. The group also emphasized that it would be important to segregate disclosures pertaining to payment and ones for purposes of underwriting.

A group member stated that it is important for people to continue to benefit from genetic testing without having to worry about the risk of their information being exposed to unnecessary third parties. The group also voiced its concern over what type of access will insurance companies have to the information within the HIE and how much of the HIE will be used for purposes of facilitating payment. Maia ended the discussion by stating that the group may need to consider revising Section 20 of GIPA in regards to clarifying the issues surrounding payment.

At the end of the meeting, Maia reviewed with the group the important topics covered at the meeting and stated that the group still needs to consider more changes to the emergency and payment sections of GIPA.

The next meeting of the subgroup was not scheduled at this time.

The meeting adjourned at 10:57 a.m.