Illinois Health Information Exchange
Legal Task Force
Genetic Testing Work Group- Genetic Counselor
Licensing Act Subgroup
March 18, 2011
Meeting Minutes

In-Person Attendees:
Mark Chudzinski, Office of Health Information Technology
Maureen Smith, Northwestern University

Attended by Phone:
Kelly Carroll, St. Louis University
Vaughn Ganiyu, Office of Health Information Technology
Mary Lucie, Northwestern Memorial Hospital
Claudia Nash, IDPH
Maia Thiagarajan, Ingalls Health System

Mary, as co-chair of the work group, welcomed participants to the call at 11:31 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 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.

Mary welcomed everyone to the call and announced that the previous subgroup's meeting minutes would be distributed to the group members shortly after this meeting. Mary then briefly outlined with the group the topics that would be discussed during the meeting, including discussing the disclosure of genetic information as it relates to healthcare operations, reviewing use cases, and reviewing the provisions of the HIPAA Privacy Rule at 45 CFR 164.512.

After outlining the agenda with the group, the group turned its attention to reviewing the questions on the matrix. The first question the group analyzed was whether the law allows without patient consent, a disclosing entity to disclose genetic information to the HIE for purposes of health care operations? The group began by reviewing the definition of health care operations under HIPAA.

The group members all agreed that Genetic Counselor Licensing Act (GCLA) along with the Mental Health and Developmental Disabilities Confidentiality Act (MHDDCA) by reference are more restrictive than HIPAA. The group also noted that the HIPAA definition of health care operations is not incorporated into the GCLA. Therefore, the group concluded that it would recommend in its report to the Executive Committee that the HIPAA language pertaining to

health care operations be incorporated into the GCLA, with the exception of language related to underwriting. This approach would be consistent with the Proposed Rule at 74 FR 51698 to amend HIPAA consistent with the federal GINA, as outlined on the work group matrix. A group member also suggested that the issue could be addressed by drafting language in the GCLA that cross references to the Illinois Genetic Information Privacy Act as another possible solution.

The next question the group reviewed was whether the GCLA addresses disclosures for the purposes outlined in 45 C.F.R. § 164.512., such as public health, health oversight, and law enforcement. After reviewing the public health disclosures permitted under HIPAA, the group concluded that the GCLA does not currently address the issue of public health. The group members then discussed during what context a person would utilize the disclosure of genetic information for purposes related to public health. After speaking with practicing genetic counselors, the group determined that the GCLA does not contain provisions related to disease monitoring or conducing public health surveillance. The group members concluded that it would recommend that Section 90 of the GCLA incorporate language outlining disease monitoring and public health surveillance, which could also give genetic counselors better clarification on this issue.

Next, the group briefly discussed disclosures related to judicial or administrative hearings. By incorporating the provisions of the MHDDCA by reference, the GCLA requires a process for in camera inspections of records and protective orders for situations where the patient or provider contests the release of records.

The group then turned to analyze disclosures for purposes of research as well as de-identified information. It was noted that currently the MHDDCA allows for the disclosure of information to two specific organizations for research purposes. However, the GCLA is largely silent in regards to research. The group briefly discussed how HIPAA treats the disclosure of information for research purposes, but it did not reach any final recommendations for how the GCLA should be amended.

At the end of the meeting, Mark encouraged the group to reach out to Maria Pekar, the co-chair of the Public Health work group, in an effort to discuss in more detail the legal issues regarding research and de-identified information. Additionally, a member of the group suggested that it may be helpful for the Genetic Information Privacy Act subgroup to look at Michigan's bio bank, as an example of how to de-identify genetic information.

Mary closed the meeting by stating that the GCLA subgroup may meet one more time to discuss workers compensation and that she would reach out to Maria Pekar to further discuss issues related to research and de-identification.

There was no public comment offered.

The meeting adjourned at 12:40 p.m.