

**Illinois Health Information Exchange
Legal Task Force
Genetic Testing Work Group- Genetic Counselor
Licensing Act Subgroup
March 4, 2011
Meeting Minutes**

In Person Attendees:

Mark Chudzinski, Office of Health Information Technology
Vaughn Ganiyu, Office of Health Information Technology

Attended by Phone:

Kelly Carroll, St. Louis University
Mary Lucie, Northwestern Memorial Hospital
Claudia Nash, IDPH
Maureen Smith, Northwestern University
Maia Thiagarajan, Ingalls Health System

Mary Lucie, as co-chair of the work group, welcomed participants to the call at 3:05 p.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 explained that the reason this group formed was to review the Genetic Counselor Licensing Act (GCLA, 225 ILCS 13590) in more detail and to start addressing some of the major questions outlined in the genetic testing matrix. Mary then briefly went through the materials she emailed the rest of the subgroup members in preparation for this meeting, including various use cases and a pending Senate bill, SB1234, which proposes changes to the Mental Health and Developmental Disabilities Confidentiality Act (MHDDCA, 740 ILCS 110/11). Since the MHDDCA is incorporated into the GCLA, Mary noted that SB1234 would be pertinent to this subgroup's discussions.

The first question the group discussed was to what extent does the current statute allow, without patient consent, a disclosing entity to disclose genetic information to the HIE for purposes of treatment through the HIE? Mary first noted that the GCLA addressed this issue in Sections 20(b) and 90(a)(1). Additionally, Section 9 under the MHDDCA also contains provisions referring to the disclosure of information.

Mary asked are there additional treatment uses or potential uses of genetic counselor services, records, or tests that aren't contemplated within the relevant current statutory framework that would be needed to fulfill the purposes of the HIE? A member noted that genetic counselors provided limited information to labs in the course of care.

Mary also asked the group for their thoughts about potential uses for a genetic counselor's reports and genetic tests for treatment purposes to an interdisciplinary care team. While the GCLA allows a counselor to share information with their colleagues and consultants who share professional responsibility in Section 90(a)(1), the question was raised as to whether counselors seek out specific authorization in practice if the disclosure is to anyone but the referring physician. A member responded that if they had authorization they would release information to relatives or to release information to another clinician who was not the referring physician. Should an exception be made in regards to the HIE for facilitating the exchange of information between providers such that the authorization requirement be required or should an exception be carved out?

The group considered whether an exception should exist for patient emergency treatment. It is unclear whether the disclosure allowed to protect any person from a clear risk in Section 90(a)(4) would cover a medical emergency of an individual who is the subject of genetic testing. Later during the call, Mary pointed out the emergency provision incorporated into the GCLA by way of the MHDDCA(740 ILCS 110/11(iii)). There was discussion about whether a specific exception for medical emergencies within the GCLA should be considered.

As noted on the matrix, re-disclosure is prohibited under Section 9 of the MHDDCA so further authorization is needed once the medical record was released containing genetic information. That the comment was made that the collection of patient authorizations seems to have become common practice among health care providers to enable requesting information from other institutions. However, a concern was expressed as to the variability of health care provider resources and the uniformity of industry best practices.

In the course of the discussions, a member suggested that genetic information overall should be more available for treatment purposes, and not limited to just the providers articulated in the statute, since such data is not that totally different from other types of medical information.

The group discussed the specific language of section 90(a)(1) in comparison to the language in the HIPAA Privacy Rule for treatment, payment, and health care operations. These provisions were also compared it and contrasted it with similar language found in both the Genetic Information Privacy Act and in the AIDS/HIV Confidentiality Act. A member noted that the statutory language in GIPA relating to health care operations might be too broad if it were incorporated into the GCLA.

The group discussed Senate bill SB1234, which changes the Mental Health and Developmental Disabilities Confidentiality Act (740 ILCS 110/11) to allow for the disclosure for treatment purposes of patient pharmaceutical records without prior patient consent.

After the discussion of the implications that SB1234 could have in regards to its incorporation within the MHDDCA on the HIE, the group discussed various use cases as outlined in the diagrams provided to the subgroup prior to the meeting. In regards to the disclosure of genetic information for treatment purposes, the group acknowledged that there may be a need for a specific exception for the HIE incorporated within the GCLA. Another avenue that could be looked into is the interagency disclosure provision under the MHDDCA (740 ILCS 110/7.1, 9.2) and how the HIE may be characterized under that provision.

The issue of prospective access of payers to genetic testing data through the HIE was raised. A member also asked whether Title 1 of the Federal Genetic Information Nondiscrimination Act would give the group more commentary on use of genetic information for payment.

A member indicated that overall the language of Illinois' GCLA is more restrictive than the national model related to genetic counselor licensure that exists currently. Mary agreed to follow up with another member of the group to get access to the general national model and other information as it relates to genetic counselor licensing acts in other states.

It was proposed that in the next meeting the group should pick up on discussing health care operations on page 8 of the matrix. Additionally, the group will begin to focus on issues related to law enforcement, public health reporting, and research.

There was no public comment offered.

The meeting adjourned at 4:04 p.m.