

**Illinois Health Information Exchange  
Legal Task Force  
Genetic Testing Work Group- Genetic Information  
Privacy Act Subgroup  
March 28, 2011  
Meeting Minutes**

**Attendees by phone:**

Maia Thiagarajan, Ingalls Health System  
Mary Lucie, Northwestern Memorial Hospital  
Vaughn Ganiyu, Extern  
Lindsay Kessler, Extern  
Richard Wagner, Wagner Consulting, LLC  
Ann Mahalik

**Introduction**

The meeting began at 9:06 a.m.

Maia opened the meeting by apologizing for the change of the meeting date. Maia asked if anyone had a questions, comments, or changes to the meeting minutes. There was a motion to approve, Richard seconded. The group approved the meeting minutes from the previous session.

**Matrix Review**

The group continued with the rest of questions on the matrix, which was attached in the email for the group to reference. The matrix review began on page 8.

**Healthcare operations.** GIPA 30(a)(5) is the relevant section. Group members suggested that GIPA is narrower than HIPAA and then discussed possible justifications to make the language more broad – either for purposes of the HIE or to align with HIPAA. Other states, like Missouri, have done this to ease the facilitation of new information and to align state and federal law. The group decided this was a good starting point, and the next steps would involve carving out exceptions for more sensitive information.

The group agreed that the language should be broadened to align GIPA with HIPAA. In terms of the actual verbiage, the group looked at how this would be possible. One member suggested this could be done by cross-referencing and incorporating HIPAA by reference. Then another member pointed out that the group needs to be careful not to do anything that would be contrary to GINA (for example, by adopting HIPAA , would need to carve out an exception for underwriting).

**Disclosures per 45 CFR 164.512.** The matrix states that GIPA has allowances for disclosures similar to those outlined in 45 CFR 164.512, but the permitted disclosures seem to be narrower than those outlined under HIPAA. A member stated that at first glance the disclosures within section 15(b) are narrower than HIPAA's currently allows it. However, members agreed that 45 CFR 164.512 under the HIPAA Privacy Rule is initially broader.

Next, the group considered the value of disclosing genetic information to law enforcement, and agreed this was limited to identification purposes. Members discussed whether they felt comfortable with law enforcement officials having this type of information, and contemplated why they might need genetic information other than for identification purposes. None were identified.

Worker's comp is also covered by GIPA and HIPAA. A member posed the question of whether GINA allows for the 45 CFR 164.512 disclosures and at first glance seems to be slightly more restrictive. GINA-Title 2 covers this and the group pointed out that proposed language should not be contrary to GINA.

The group agreed that section 15(b) pertaining to confidentiality when a person is inflicted with a disease at the time of the test is very vague. This is an area more research needs to be conducted, looking into why this particular language was used.

Then, members looked at whether legal proceedings would necessitate broadening the language to make genetic tests relevant. A member considered the scenario of an individual with a certain genetic condition being placed in a population – i.e.: a transgendered person being incarcerated. Another member pointed out that the definition of “genetic information” under GINA and GIPA specifically excludes information about age or sex.

The group also pointed out that GIPA has no clause addressing public health.

In general (Illinois has the newborn screening act) and it is very narrow. Overall, members agreed that the language in GIPA needs to be broader for section 15 in regards to confidentiality.

**Research.** GIPA does not really address this issue besides section 25 for the employer employee relationship. GIPA allows for monitoring of biological issues in the workplace, but restricted to notice, written consent by the employee, monitoring is compliant with OSHA, and information that is not disclosed once info is relayed to the employer. Overall this is far more restrictive than HIPAA, and may not even address the use for research.

The question of whether a genetic test can be de-identified was brought up and Mary said the Research/Public Health workgroup co-chair, Maria Pekar, was contacted with a similar question from the Genetic Counselor Licensing Act subgroup and might be a source of information.

The main issue related to research involves obtaining consent. A group member asked if GIPA needs an exception similar to HIPAA, which allows research without consent pursuant to an IRB

process. Additionally, this workgroup should collaborate with the research subgroup and find out their approach to Illinois law.

The remaining matrix questions are De-identification and Limited Data Set.

### **Conclusion**

Maia concluded with determining that the next steps should be to have one more GIPA subgroup meeting and then have a joint meeting with the research group. Finally, an entire Genetic Testing workgroup meeting (including both subgroups) should be scheduled to provide recommendations to the executive committee.

### **Meeting Date**

The next meeting date was not set at this meeting.

### **Other Business/Public Comment**

There was no public comment offered in response to the chairman's invitation for public comment.

The meeting adjourned at 10am.