

**Illinois Health Information Exchange  
Legal Task Force  
Genetic Testing Work Group  
April 15, 2011  
Meeting Minutes**

Attended by Phone:

Kelly Carroll, St. Louis University  
Vaughn Ganiyu, Office of Health Information Technology  
Mary Lucie (Co-chair), Northwestern Memorial Hospital  
Richard Wagner, Wagner Consulting, LLC  
Maureen Smith, Northwestern University  
Maia Thiagarajan (Co-chair), Ingalls Health System

Mary, as co-chair of the work group, welcomed participants to the call at 1:05 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 welcomed everyone to the call and gave an updated status report to the Work Group on the most recent Executive Committee meeting. Mary stated that the Executive Committee requested updates from each individual work group on the status of their analysis. Mary and Maia stated that in regards to this Work Group, adding comments to the matrix grid would be the best option for the formation of the Work Group's report. The group agreed to update the grid using information from previous meeting minutes that include recommendations related to genetic testing issues involving the HIE. While the chairs work with the rest of the group to update the matrix, the chairs are waiting to receive more feedback from the executive committee regarding the format of the expected report.

Next, the group turned its attention to discussing issues related to research. The group first addressed the issue of research from a general perspective in order to determine what type of recommendations it would make in regards to genetic research. The group focused on how HIPAA treats research and also compared it to other states' laws regarding genetic research, such as Missouri. One member stated that Missouri maintains an opt-in system, where genetic information is bundled together with all other sensitive information. The group agreed that any recommendations it offers would be made independently and not based on a particular opt-in or opt-out protocol.

The group decided that it would rely on the established framework set by HIPAA in making its recommendations on changing current state laws addressing research as well as de-identified information. Members of the group suggested that relying on HIPAA as a framework could be useful to maintain consistency in the laws that relate to the privacy and security of protected health information. Mary then asked members of the group about the process of de-identifying genetic information for research purposes and the difficulty associated with that process. After a brief discussion, the group determined that it would be difficult to maintain the research value of genetic information if it was restricted to limited data sets or aggressively de-identified.

This discussion prompted the group to discuss which entity would be in charge of the source information and what responsibilities that would entail. The group then debated the need for the HIE to potentially have an independent review board if it was given the responsibility of maintaining the source information for de-identified research information. A member of the group stated that there could indeed be great public concern over how their identifiable information may be used by companies, such as insurance companies and thus demand limitations be placed on what types of organizations could access the HIE for research purposes.

After discussing the issues related to research and de-identified information, Mary stated she would speak with Maria Pekar from the Public Health workgroup concerning the research questions raised by members of this group. Additionally, Mary stated that Maia and herself would continue to work with the interns to update the matrix and begin to add the member' comments to it in preparation of drafting the Work Group's report. .

There was no public comment.

The meeting adjourned at 2:02 p.m.