

Advisory Committee on Genetic Privacy and Research

Meeting Minutes — June 2, 2004

Attendees

Emily Harris (Co-Chairperson), Gwen Dayton (Co-Chairperson), Ron Marcum, Bob Koler, Michael Garland, Paul Newton, Bob Nystrom, Kerry Silvey, Jon Zonana, Patricia Backlar, Kiley Ariail, Margaret Everett, Kara Manning, Carol Pratt, Nan Newell, Ted Falk, Marc Marengo, Andrea Meyer, Laura Zukowski

Introduction

- Welcome and Introductions — Everyone introduced himself or herself.
- Review of Draft Minutes from Last Meeting (May 5, 2004)
Draft minutes from May 5, 2004, had been circulated in the e-mail prior to this meeting. No one present had any requests for corrections or additions.

Outcome: *Michael Garland moved that the draft minutes of May 5, 2004, be approved. Andrea Meyer seconded the motion. There were no objections. Minutes from May 5 were approved with the understanding that they may be corrected. Contact Laura Zukowski (laura.a.zukowski@state.or.us) if you would like to request any changes.*

Genetic Privacy Protection in the Clinical Setting

Gwen Dayton provided a draft document that outlined possible revisions to Oregon genetic privacy statutes for clinicians in a clinical setting (not clinicians performing research). Her draft would exempt HIPAA-covered entities from genetic privacy requirements for purposes of treatment, payment, and health care operations. State and HIPAA requirements for clinicians performing research would remain in effect.

Discussion revealed that this draft (unintentionally) removes anti-discrimination clauses for clinicians. Other points of discussion included whether to continue to allow private right of action against clinicians who violate genetic privacy laws, the perception that there is an easy crossover of samples from the clinical realm into the research stream, the fact that institutional review boards are only required to review federally funded research, the consideration that HIPAA allows a provider to talk to a patient (even a patient who is not his or her own patient) during recruitment for a study and may disclose the identity and other PHI of patients/potential research subjects to third parties who are involved in recruitment, concerns about whether there are sufficient protections against redisclosure of genetic information, and whether or not the definition of genetic information should be changed.

Outcome 1: *Gwen Dayton will look up Oregon child abuse reporting statutes to examine the section(s) that address(es) redisclosure of confidential information.*

Outcome 2: *Gwen Dayton volunteered to draft another set of revisions to Oregon’s genetic privacy law that will reflect consensus reached during this meeting. She will reference exemptions for covered entities and will address treatment, payment, and health care operations only. In addition, she will include a reminder that HIPAA protections and anti-discrimination protections would still apply to covered entities. This draft will not include any reference to the issue of responding to a subpoena and will not redefine the term “genetic information.”*

Definition of Genetic Information: Is Change Needed?

During the prior discussion about genetic privacy protection in the clinical setting, members and participants decided to set aside the question of whether or not to change the definition of genetic information. Including family history and clinical diagnosis in the definition of genetic information continues to come up during discussions, especially in relation to broadening anti-discrimination protection.

Outcome: *The group will postpone discussion of the definition of genetic information.*

Research Workgroup/Plan for Next Month

Nan Newell reported that DHS Intergovernmental Liaison Katy King has requested a decision from the committee by the end of July about whether or not the committee will support the DHS legislative concept. Katy has said that the committee may make suggestions for changing the language of the legislative placeholder. The committee also has the option of submitting its own draft bill.

Outcome 1: *Emily Harris will convene a workgroup to prepare a recommendation to the committee about whether researchers should be included (along with clinicians) in the legislative concept. Volunteers for the committee are Emily, Patricia Backlar, Kara Manning, Paul Newton, Carol Pratt, and Andrea Meyer. The workgroup will meet before the next meeting on July 7 and will bring a recommendation to the July 7 meeting.*

Outcome 2: *The Research Workgroup will consider other states’ approaches to protections around genetic information. The National Council of State Legislatures website may be a resource for this information.*

Outcome 3: *Kerry Silvey will contact staff at the Public Health Laboratories to clarify what are their concerns around the genetic privacy statute’s definition of a genetic test and the newborn screening test for PKU (phenylketonuria).*

Announcements

- Marc Marengo will be out of the country on sabbatical for several months this fall. He would like his colleague from the Pacific Institute for Ethics and Social Policy, Lisa Sardinia, to attend committee meetings in his absence.

Outcome: *The committee welcomes Lisa to attend meetings.*

- The Portland State University public forum about genetic privacy went well. Students from the senior capstone are writing up a report of the event and will circulate it or present it to the committee.
- Values (Public Input) Survey
***Outcome:** Michael Garland will circulate the final draft of the survey to the committee one last time before it goes to the vendor for fielding this summer. Any feedback should be directed to Michael, mdgar@teleport.com . The committee should expect to hear the results of the survey around late summer.*

Adjourn

2004 Meeting Schedule

July 7 October 6
August 4 November 3
September 1 December 1

First Wednesday of each month
1:00 to 3:00 p.m.
Oregon Medical Association
5210 S.W. Corbett Avenue in Portland