

Advisory Committee on Genetic Privacy and Research

Meeting Minutes — August 4, 2004

Attendees

Emily Harris (Co-Chairperson), Gwen Dayton (Co-Chairperson), Ted Falk, Margaret Everett, Bob Nystrom, Michael Garland, Patricia Backlar, Kerry Silvey, Kiley Ariail, Jon Zonana, Nan Newell, Bob Koler, Kara Manning, Robb Moses, Ron Marcum, Laura Zukowski

Introduction and Announcements

- Welcome and Introductions — Everyone introduced himself or herself.
- Review of Draft Minutes from Last Meeting (July 7, 2004)
Draft minutes from July 7, 2004, had been circulated in the e-mail prior to this meeting. No one present had any requests for corrections or additions.
Outcome: *Bob Koler moved that the draft minutes of July 7, 2004, be approved. Jon Zonana seconded the motion. There were no objections. Minutes from July 7 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 changes.*
- Margaret Everett has had an article about genetic privacy published in the August 2004 issue of Genetic Counseling.
Outcome: *Margaret will share an electronic copy of the article with the committee.*
- Trish Backlar requested volunteers to help with publicity for the symposium on genetic testing, privacy, and race, which she is organizing through Portland State University.
Outcome: *Laura Zukowski will circulate a request for volunteers to help with publicity for the forum. Patricia Backlar will write the request and send it to Laura to circulate through e-mail.*

Action Item Review: Legislative Appointees

Nan Newell is working with DHS Intergovernmental Liaison Katy King to identify legislative appointees to the committee.

Outcome: *Kiley Ariail will contact former member Astrid Newell to determine if any representatives, either from the House of Representatives or the Senate, were identified before she left DHS.*

Update: DHS Legislative Concept

Gwen Dayton reported that she had met with Holly Robinson from Legislative Counsel since the last committee meeting to discuss the DHS legislative concept. Holly stated that the concept should be woven into the existing genetic privacy statute, rather than have it

exist as a standalone statute, and would like to exclude health insurers from the change. Justifications for Holly's decisions include that: the DHS concept would make existing statutes more complex to interpret (since health insurers are governed by additional statutes, which do not govern health care providers); she is unconvinced that health insurers are having difficulty complying with the existing statutes; concern that the changes would give insurers broader access to genetic information.

Several people present at this meeting disagreed with Holly's approach for several reasons. One of the lawyers present pointed out that individual doctors and health systems are the same entities in some situations and that HIPAA maintains the same standards for providers and insurers.

Holly will be drafting the language for the proposed legislation within the next few weeks. The committee will have the opportunity to review Holly's draft. Also, the legislation may be amended after it is introduced.

Outcome 1: Ted Falk will e-mail Gwen Dayton a summary of his concerns about excluding health insurers from the change. Gwen will forward the concerns to Holly Robinson.

Outcome 2: Gwen will contact some colleagues with ties to the health insurance industry and request their input on the family history and underwriting issue.

Outcome 3: The committee recommended that the legislative concept include "health care service contractors." Gwen will inform Holly Robinson about the results of this discussion.

Discussion: Proposed Changes to Trade Practices and Anti-Discrimination in Employment Language

Jon Zonana, Kiley Ariail, and Kerry Silvey reported on their work on the proposed legislative concept addressing the use of genetic and family information in health insurance and employment. The proposed concept would prohibit employers and insurance companies from using genetic data, which would include family history, occurrences of disease or disorders that had been diagnosed without genetic testing, and the act of seeking genetic services, in decisions about health insurance and employment. The proposed changes would also broaden the definition of "family member" to include a spouse and adoptee. When they researched similar statutes in other states, they found that the definition of genetic data in Oregon's proposed concept would be broader than the language all but four other states' definitions. So far, they have also been unable to locate or identify any instances of complaints or backlash against this type of legislation in other states where similar legislation has been proposed and/or adopted.

Discussion of the concept revealed disagreement and many questions and concerns among participants of this meeting. Specific concerns and issues included:

- the breadth of the definition of "genetic data";
- difficulties in underwriting family health insurance policies without being able to consider the medical history of family members who would be covered;

- the fact that ORS 746.135 is governed by the Insurance Division and not DHS.

There did appear to be agreement that defining “genetic information” to include only the results of genetic testing is too narrow.

Outcome: This discussion will continue at the next ACGPR meeting on September 1. The committee will devote a large portion of the agenda to a discussion of the concept of anti-discrimination and will avoid trying to draft. The chairs and/or DHS will invite insurance representatives to the September 1 meeting.

Other Business

Michael Garland reported that Market Decisions has field tested the public input survey and will begin the actual data collection on August 9. The first tabulations should be ready on August 27 and could be discussed at the September 1 meeting.

Adjourn

2004 Meeting Schedule

September 1

October 6

November 3

December 1

First Wednesday of each month

1:00 to 3:00 p.m.

Oregon Medical Association

5210 S.W. Corbett Avenue in Portland