

Advisory Committee on Genetic Privacy and Research

Meeting Minutes — November 3, 2004

Attendees

Gwen Dayton (Co-Chairperson), Emily Harris (Co-Chairperson), Ted Falk, Paul Newton, Bob Koler, Gayle Woods, Bob Nystrom, Astrid Newell, Nan Newell, Kerry Silvey, Kara Manning, Andrea Meyer, Margaret Everett, Mike Becker, Trish Backlar, Barry Anderson, Laura Zukowski

Introduction and Announcements

- Welcome and Introductions — Everyone introduced himself or herself.
- Review of Draft Minutes from Last Meeting (October 6, 2004) — Draft minutes from October 6, 2004, had been circulated in the e-mail prior to this meeting. No one has requested any corrections.

Outcome: *Co-Chair Emily Harris directed that the minutes from October 6 were approved with the understanding that they may be corrected. Contact Laura Zukowski (laura.a.zukowski@state.or.us or 503-731-4021) if you would like to request changes.*

- Meeting dates for 2005 were scheduled in the Oregon Medical Association. The committee will continue to meet in the same room, every first Wednesday of the month, 1:00 to 3:00 p.m. All of the 2005 meeting dates are listed at the end of these minutes. The Political Affairs Department of the OMA is sponsoring the room during 2005.
- Updated rosters were distributed. There are several new members.
- Review of Agenda —

Outcome: *The committee will discuss the use of genetic and family history information at the December 1 meeting. Committee members are neither decided nor in full agreement over whether there is truly a barrier for the seeking of genetic services or the full disclosure of family history, or whether consumer perception is the barrier. Not all members are resolved on whether the current law protects from discrimination in insurance underwriting and employment those individuals who seek genetic counseling. Also to be discussed is whether the law should protect from discrimination individuals who seek genetic counseling.*

- Gayle Woods reported that she had talked with Lewis Littlehales about the committee's concerns over the proposed replacement of the Oregon Standard Health Statement. Question 52.a., as currently drafted, would require an applicant to report any "medical advice, diagnosis, care, or treatment" within the last five years, which would include genetic services. In response to this concern, Insurance Division staff has proposed adding a notice on the Oregon Standard Health Statement that informs an applicant that s/he is not required to report genetic testing, genetic information, or genetic counseling. This same notice would appear on the Insurance Division website, also.

Recommendation: *The committee recommends that DHS post the Insurance Division’s notice on their Genetics Program website and also link their website to the Oregon Insurance Division’s notice that health insurance applicants are not required to report any genetic testing, genetic information, or genetic counseling on the Oregon Standard Health Statement. Gayle Woods will contact Laura Zukowski when the notice is posted on the Insurance Division website, so that Laura Zukowski can post the notice on the DHS Genetics Program website and link the Genetics Program website to the Insurance Division’s notice. Also, Gayle will request that Insurance Division staff set a link on the Insurance Division page to the DHS Genetics Program website.*

Oregon’s Employment Statutes and Genetic Discrimination

Gwen Dayton reported on her review of the state employment code in terms of protection against discrimination based on genetic and family history information. She distributed copies of ORS 659A.300 through 659A.306, which is entitled “Miscellaneous Unlawful Employment Discrimination (Prohibited Testing).” The statute prohibits an employer “from obtaining, seeking to obtain or using genetic information” of an individual or an individual’s blood relative; however, ORS 659.300(5) does permit the exception that an employer may administer a genetic test to an individual with the individual’s consent and “solely to determine a bona fide occupational qualification.” Definitions for genetic test, blood relative, genetic information, and other terms reference ORS 192.531 (definitions section of the genetic privacy statute).

This discussion did not result in a decision on whether or not to proceed with a legislative concept or a recommendation on whether additional legislation is needed. Some members expressed discomfort with being uncertain of the full implications of banning occupational testing for genetic propensities; others expressed discomfort with the “bad science” behind Burlington Railroad’s genetic testing for carpal tunnel syndrome. Someone suggested the Americans with Disabilities Act (ADA) might offer some protection of an individual who was “perceived as having a disability,” although in fact this is an interpretation of an administrative rule, which could change. Also questioned was the effectiveness of the use of informed consent (as a protection) in the context of a pre-employment physical examination.

Other ideas on how to proceed included redefining the term “genetic information” in ORS 192.531 to include information from a genetic test *and family history*, and then adding “family history” to the definitions. The definitions could be written to exclude genetic research, because including family history as part of the definition of “genetic information” could potentially make every study qualify as genetic research. Currently, the employment and insurance statutes are in synchronization with each other, and the research and general statutes are in synchronization. More than one person present expressed the opinion that if the statutes are made any more complicated, they could become indecipherable.

Additional concerns that prevented the group from reaching a decision on these issues involved doubts about the timing with the 2005 Legislative Session and concerns about the relating clause's being opened up to anyone's input or the possible repeal of existing statutes. If this legislation were introduced, the committee would need to be prepared to explain why the legislation is being introduced, what harm could result from not adopting the proposed legislation, and what would be the intended (and unintended) consequences of adopting the proposed changes.

Outcome 1: Kerry Silvey will send Laura Zukowski a web address for circulation that contains a detailed discussion of the proposed federal genetic anti-discrimination legislation.

Outcome 2: Gwen Dayton will compose an e-mail for the voting members of the committee. The e-mail will ask members to vote on whether the committee should proceed with legislation that proposes additional protections in the insurance and employment codes. Specific proposed changes would address family medical history, the act of seeking of genetic counseling or services, and non-blood relatives who are immediate family members. The e-mail will have members vote separately on each issue, will cite the exact statutes for proposed changes, and require a vote within a short timeframe.

Legislative Report

There is general agreement among the committee to prepare a shorter legislative report than what was written for the 2003 session. The report is due in January. It is possible to write the 2005 report as an addendum to the 2003 report. This approach would be less time consuming to prepare and would entail comments on existing recommendations and updates on outcomes.

Outcome 1: The 2005 Legislative Report will be introduced at the presentation on LC 298.

Outcome 2: Laura Zukowski will send Gwen Dayton an electronic file of the 2003 Legislative Report.

Outcome 3: Gwen Dayton will review the 2003 Legislative Report and decide what to include and what to delete. She will parse out various sections of writing or begin drafting the report herself.

Research Subcommittee

Emily Harris opened this discussion with the statement that she has been considering the issue (of making researchers in Oregon subject to HIPAA and other federal regulations only, by exempting them from state genetic privacy regulations) from the perspective of historical tissue samples and not from the perspective of new tissues samples. She stated that the discussion needed to be broadened to include collection of new samples, research performed by entities not covered under HIPAA, the role of IRB review, and other considerations.

A few members objected strongly to the committee's bringing forward legislation that would alter consent requirements for genetic research. Other members did not express opposition or support for the concept. A few members expressed support for the idea and stated they believed a few minor changes in the genetic privacy statute would create the desired result.

Objections to pursuing this type of legislation were based on concerns, which included Oregonians' losing the chance to opt out of genetic research, the lack of time before the start of the upcoming legislative session, the fact the IRBs do not review all genetic research and therefore offer limited protection, and a lack of clarity about how the statutes would be altered and what the consequences could be for these types of changes. Statements were made that the committee reached agreement around consent requirements after extensive discussion during the 2003 session, and that a great deal of time and work were invested to reach those agreements, which included consideration of HIPAA. One non-member suggested basing protection laws on the tissue sample itself, rather than the information that is derived from the sample.

Outcome 1: Emily Harris will send Laura Zukowski a document to circulate. Everyone should read this document and come to the December 1 meeting prepared to discuss it.

Outcome 2: Emily Harris and Kara Manning will draft a brief summary of proposed changes to the privacy laws that affect genetic research. They will cite the statutes affected and propose language. Changes are expected to be minor, with no major conceptual changes.

Meeting Schedule

December 1, 2004	July 6, 2005
January 5, 2005	August 3, 2005
February 2, 2005	September 7, 2005
March 2, 2005	October 5, 2005
April 6, 2005	November 2, 2005
May 4, 2005	December 7, 2005
June 1, 2005	

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