

Advisory Committee on Genetic Privacy and Research

Meeting Minutes — September 1, 2004

Attendees

Gwen Dayton (Co-Chairperson), Emily Harris (Co-Chairperson), Ted Falk, Margaret Everett, Patricia Backlar, Nan Newell, Andrea Meyer, Justin Delaney, Paul Newton, Kiley Ariail, Kerry Silvey, Marilyn Hartzell, Jon Zonana, Gayle Woods, Jann Goodpaster, Representative Dennis Richardson, Mike Becker, Kara Manning, Michael Garland, Margo Neufeld, Laura Zukowski

Introduction and Announcements

- Welcome and Introductions — Everyone introduced himself or herself.
- Review of Draft Minutes from Last Meeting (August 4, 2004)
Draft minutes from August 4, 2004, had been circulated in the e-mail prior to this meeting. No one present had any requests for corrections or additions.

Outcome: *Gwen Dayton moved that the draft minutes of August 4, 2004, be approved. Nan Newell seconded the motion. There were no objections. Minutes from August 4 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.*

“Genetic Testing, Privacy, and Race”

Trish Backlar reminded everyone that she is recruiting volunteers to help with publicity for the symposium on genetic testing, privacy, and race, which will be held at Portland State University on the evening of March 31. She is looking for volunteers to help advertise the event. Multiple committee members are serving as panelists or presenters at this event.

Outcome 1: *Anyone who is interested in helping out with this event should contact Trish directly (backlarp@pdx.edu).*

Outcome 2: *Nan Newell, Kara Manning, Andrea Meyer, and Kiley Ariail volunteered to help advertise the event.*

Outcome 3: *Laura Zukowski will send Trish’s e-mail request to guests Justin Delaney and Mike Becker.*

Action Item Review: Legislative Appointees and Other Vacancies

Kiley Ariail updated the group on membership.

- Senator Richard Devlin will serve as the member representative for the Senate President; there will be no alternate member. Representative Dennis Richardson will

serve as the Speaker of House's Representative; Representative Gordon Anderson will serve as the alternate member.

- Gayle Woods will serve as the member representative for the Oregon Department of Consumer and Business Services; Jann Goodpaster will continue to serve as the alternate member.
- DHS staff is still working to identify an alternate member for the health care consumer slot and pharmaceutical industry slots.

Outcome: Kara Manning will send Kiley Ariail one or more suggestions for appointees to represent the pharmaceutical industry.

Clarification: The State of Oregon regulates only three out of the four categories of health insurance plans. The categories are health insurance, health care contractors, and the less than fully insured. (The federal government regulates Employee Retirement Income Security Act (ERISA) plans, which one attendee estimated to be 25-40% of policies held by Oregonians.) Members could decide to recommend to the Oregon Legislature the addition of insurance industry representation to this committee.

Update: DHS Legislative Concept

Gwen Dayton led a discussion of Legislative Concept (LC 298), which Holly Robinson of Legislative Counsel drafted from the DHS legislative concept. Holly wove the concept into the existing statute, rather than having it stand alone as a new statute, and excluded the state health plan and health insurers from the exemption. DHS staff e-mailed LC 298 to the committee's members and interested parties prior to this meeting.

Discussion touched on many different issues. This portion of the meeting ended with a formal polling of members and an agreement to continue the discussion at the next meeting with additional representatives from the insurance industry for more information about the meaning of "health care operations" in the context of a health insurance company.

Polling of members on LC 298 as drafted by Legislative Counsel:

- Michael Garland: Would like to exempt health care providers and health insurers from the genetic privacy statute and believes that there should be an explicit carve-out for insurance underwriting that includes all health insurers.
- Margaret Everett: Would like the committee to proceed with LC 298, but believes that it should state clearly that genetic information may not be used for health insurance underwriting. Does not think it is possible to separate health insurers from health care providers, so both should be included in the exemption.
- Nan Newell: Would like to proceed with LC 298, but thinks that it should include all health insurers (including those that are not federally qualified under HIPAA). Is interested in returning to the discussion of genetic information, family history, and employment.
- Andrea Meyer: Is concerned about the meaning of "health care operations" and would like more information about what this term includes. Is concerned about future

changes getting away from the original meaning and intent of the genetic privacy statute.

- Jon Zonana: Would like to go forward with LC 298 and would like to include health insurance underwriters in the exemption.
- Gayle Woods: Would like to include all health insurers in LC 298, so that insurers receive timely payment and consumers receive medical care in a timely manner. Is comfortable with current health insurance underwriting practices. Reminded the group that consideration of genetic information is permissible in life insurance underwriting.
- Ted Falk: Would like to include all insurers in LC 298, because of the tradition of managed care in Oregon and because he believes it is in the best interest of consumers to include all health insurers. Supports a carve-out for insurance underwriting. Pointed out that “health care operations” is used in the state, because it was copied from HIPAA. Would like the committee to review the HIPAA usage and the Federal Register fully; otherwise, should include all health insurers in the exemption.
- Rep. Dennis Richardson: Agreed with Margaret’s statements earlier about keeping in mind the public’s concerns and values, but otherwise abstained from the poll. Questioned why LC 298 was drafted as an emergency clause and would like there to be a normal time limit to allow the public a chance to comment. (*Note: the committee did not request this. Legislative Counsel added it.*)
- Gwen Dayton: Would like to include all health insurers in the exemption, but is concerned about the full meaning of “health care operations”; therefore, would like the committee to spend some time exploring the concept.
- Emily Harris: Would like to include all types of health insurers and would like to highlight in the statute that consideration of genetic information is not permissible in insurance underwriting. Would also like to include “health care operations” in the exemption, but thinks the committee needs to take another look at the HIPAA definition.

Outcome 1: Discussion of LC 298 will continue at the October meeting. Members will invite representatives from the insurance industry in order to obtain input about what types of disclosures are routine and necessary for underwriting and “health care operations.”

Outcome 2: Guest Mike Becker (of Regence Blue Cross/Blue Shield of Oregon) will invite colleagues from the medical affairs area of his company to attend the October 6 meeting.

Outcome 3: Margo Neufeld will invite colleagues who are knowledgeable about the “health care operations” of Kaiser Permanente to attend the October 6 meeting.

Outcome 4: Gwen Dayton will check in with Legislative Counsel to determine if LC 298 could be edited before the formal amendment phase (to include health care contractors) and to alert Legislative Counsel that amendments are likely.

Discussion: Use of Genetic and Family Information in Health Insurance and Employment

The group discussed some simply worded statements provided by Kerry Silvey and Kiley Ariail. These statements summarized the concepts underlying proposed legislative

concepts that would prohibit the use of genetic and family information in health insurance underwriting and employment. At the last few meetings, the committee had reviewed draft legislative concepts that were based on Senate Bill 1053. In an effort to determine whether there is agreement for the underlying concepts, the statements were used as the basis for the discussion.

These points were raised during the discussion:

- When faced with choices over whether to pursue genetic testing or when receiving diagnoses of genetic conditions, patients often express fear over discrimination in employment and health insurance, both for themselves and their families. They rarely mention fear of loss of privacy. Various attendees expressed concern that fear of discrimination in employment and health insurance can be a barrier to a patient fully divulging family history or seeking genetic services. At least one attendee felt these types of fears are unfounded and addressing them should be an educational issue, not a legislative issue.
- More than one member has stated that the language of the legislative concept should be based on the language of the proposed federal legislation.
- There was concern that legislation of this type might create a burden to the health insurance industry. Medical insurers need access to diagnoses and treatment information in order to conduct routine business.
- A national association of actuaries has stated that using family history in health insurance underwriting is not of great value to health insurers, because it typically has little impact on the immediate future. Since consumers change health insurance policies so frequently, insurance underwriters do not feel the impact of family history.
- Individual policyholders are the most vulnerable to discrimination in underwriting. They have the least protection. Insurance underwriters may not reject or raise rates for group policies based on individuals' health or their family members' health, but anyone currently covered under group health insurance may become an individual policyholder in the future.
- Insurance underwriters require applicants to fill out a standardized medical history form, the content of which is regulated by the state. Underwriters are allowed to request medical records that relate only to any conditions or diseases revealed by a "yes" answer on the form. In practice, medical providers may send whole records with information that goes far beyond the request. Whatever information an insurer receives may be used in underwriting, regardless of whether the information should have been released.

Outcome 1: Discussion about genetic and family information in health insurance and employment will continue at the October 6 meeting. Issues under consideration include whether current laws have gaps in protection of consumers, particularly for consumers applying for individual policies or in situations when insurance underwriters receive information that should not have been released to them.

Outcome 2: The October 6 meeting will begin one hour earlier than usual. The meeting will start at noon and last until 3:00 p.m.

2005 Legislative Report

The committee is charged with submitting a written report to the Legislature at the start of the 2005 Session, which convenes on January 10. The report will update the Legislature on the committee's activities and present any results from studies conducted by the committee. It will also contain any recommendations for legislative changes related to the committee's assigned content areas.

Other Business

Update on Public Input Survey: Michael Garland circulated copies of the actual questions that Market Decisions Corporation will use in the random phone survey. The questionnaire contains some notes to the interviewers on how to respond to requests for clarification on the meaning of certain terms.

Outcome: Attendees should address any feedback on the public health input survey's questionnaire directly to Michael Garland, mdgar@teleport.com.

2004 Meeting Schedule

October 6

November 3

December 1

First Wednesday of each month

1:00 to 3:00 p.m. *****October 6 meeting is from 12:00 to 3:00 p.m.*****

Oregon Medical Association

5210 S.W. Corbett Avenue in Portland