

Advisory Committee on Genetic Privacy and Research

Meeting Minutes — February 2, 2005

Attendees

Emily Harris (Co-Chair), Gwen Dayton (Co-Chair), Kara Manning, Bob Koler, Paul Newton, Ted Falk, Gayle Woods, Stuart Kaplan, Jon Zonana, Michael Garland, Kiley Ariail, Patricia Backlar, Bob Nystrom, Michael Becker, Laura Zukowski, Naomi Adams

Introduction and Announcements

- Welcome and introductions: Everyone introduced himself or herself. Naomi Adams was introduced the group as the new staff support replacing Laura Zukowski. Laura was thanked for her service.
- Review of draft minutes from last meeting on January 5, 2005.

Outcome:

1. Co-Chair Emily Harris directed that the minutes of January 5, 2005 were approved with the provision that they were still correctable. Contact Naomi Adams (naomi.adams@state.or.us or 503-731-4021 xt: 537) if you would like to request changes to the January minutes.
2. Gayle Woods, Department of Consumer and Business Services, distributed the revised Oregon Standard Health Statement. Please contact Gayle directly if you have any input on this form. (gayle.woods@state.or.us)

Insurance and Employment: Draft Legislative Language

There was a general discussion about proposed legislation on discrimination and genetic testing. The discussion came to be centered on ORS 746.135 section 4. Gwen Dayton thought the language should be fixed to say that insurance should not be denied based on the genetic history of the applicant or a relative (i.e. parent). Michael Becker and others voiced concerns about excluding information about actual care received and actual diagnoses as a basis for underwriting insurance policies. Gwen agreed to redraft the legislative language and solicit email comments. It was decided that for consistency, the revision should use the language from the revised Standard Health Statement.

Outcome:

1. Gwen Dayton will redraft the legislative language to incorporate concerns voiced by Michael Becker and others. The revision will make explicit that information about actual care received and actual diagnoses are not excluded as a basis for underwriting insurance policies. The revision will use the language from the revised Standard Health Statement to describe the terms of insurance underwriting. Gwen will also re-structure portions of Section 1 for clarity.
2. There will be an email vote. Committee members will be asked to review the revised legislative language and indicate whether or not they support seeking legislative

sponsorship of the draft bill. Gwen agreed to redraft the language by Friday morning. The vote will end on Tuesday. Naomi Adams will tally the votes at that time.

3. Gwen Dayton will approach Senator Devlin or Representative Richardson about introducing the draft legislation.

The Legislative Report

A legislative report needs to be submitted to the Legislature. The committee discussed what the report should say. Michael Garland recommended that it be said that the committee did not have enough time to discuss all assigned issues.

Outcome:

1. Kiley Ariail reported that the draft report is due at the time SB99 is heard in committee. This hearing will be scheduled on February 10. In the worst possible case, the hearing could be scheduled with a few days of February 10. To meet this uncertain deadline, the draft report will be completed in the upcoming week and circulated for review.
2. Michael Garland will give some additional text to Kiley Ariail to include in the Public Education and Input section. Kiley will integrate Michael Garland's comments then circulate the complete draft.
3. Other committee members should submit comments and suggestions to Kiley Ariail (kiley.ariail@state.or.us).
4. The Committee revised and reordered the policy issues for the next biennium. The # 1 policy issue will be genetic exceptionalism and related issues, followed by monitoring Oregon genetic privacy law for unanticipated effects, informed consent for minors and other special populations, and supporting efforts to elicit consumer and public input on genetic privacy and research issues.
5. Kiley Ariail will revise the report to incorporate the re-ordered agenda for the next biennium. She will also complete the draft by incorporating the outcomes of today's research subcommittee report conversation. The co-chairs will review the report, then Kiley will send the report out for review by the full committee, by Monday 2/7 if possible.

Research: Subcommittee Report

The committee discussed whether to pursue this legislation during this session or defer consideration until 2007. Also discussed was whether there is support for the concept of changing consent requirements under certain conditions. The section Y exemption is only for HIPPA covered entities. Kiley Ariail noted that blanks cannot be filled in on the legislative report until the committee decides whether to pursue research legislation. If the committee waits it may not be able to get it submitted to the Legislature. If the committee decides to move forward, there won't be enough time to do everything.

Outcome:

1. The committee voted whether to endorse and move forward with this session with Version #1 of the draft language provided by Ted Falk. Nine members voted in favor, and one member abstained. There were no votes in opposition.
2. Gwen Dayton will investigate methods of getting Version #1 introduced as a bill separate from SB99.
3. The committee agreed there is a need to learn how the ACLU will stand on this issue. Stuart Kaplan will talk to Andrea Meyer and find out her position on this issue.

Adjournment

Meeting Schedule

March 2	August 3
April 6	September 7
May 4	October 5
June 1	November 2
July 6	December 7

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