

Advisory Committee on Genetic Privacy and Research

Meeting Minutes — May 4, 2005

Attendees

Emily Harris (Co-Chair), Gwen Dayton (Co-Chair), Nanette Newell, Mike Garland, Paul Newton, Bob Nystrom, Kiley Ariail, Jon Zonana, Marc Moreco, Kara Manning, Gayle Woods, Stuart Kaplan, Ted Falk (By Phone), Naomi Adams, and Representing Regence, Lisa Murphy,

Introduction and Announcements

- Welcome and introductions: Everyone introduced himself or herself.
- Review of draft minutes from last meeting on April 6, 2005.
- Lisa Murphy of Regence was introduced. She attended to the meeting as an interested party.
- Jon Zonana pointed out that Paul Newton also spoke at Trish Backlar's Symposium but this had not been indicated in last month's minutes. Naomi will update the minutes with this information.
- Kiley Ariail announced that phone numbers at DHS had changed and that the roster had been updated to reflect this.

Outcome: Naomi will update the minutes as per Jon Zonana's suggestions. Contact Naomi Adams (naomi.adams@state.or.us or 971-673-0242) if you would like to request further changes.

SB99 Update

Gwen opened with an update of activity on SB 99. Gwen reports that there has been some resistance to the bill over privacy concerns. The Senate Judiciary Committee was concerned that SB99 would allow the inappropriate use of genetic information. Senator Burdick suggested that the bill be revised to allow disclosures of diagnostic and treatment information but not test information or test results, a revision that would satisfy Judiciary Committee members' concerns about disclosure (this provision is contained in the -2 amendments).

Judiciary Committee members were also concerned with the employment provision of the -1 amendments (known in the ACGPR as the anti-discrimination provisions). Judiciary Committee members fear that it might give employees or applicants for employment additional grounds to sue employers. Health insurance carriers are also concerned about the insurance provision and are saying they will oppose it.

Senator Burdick is willing to work the ACGPR to make the –1 amendments more acceptable to the Judiciary Committee. Gwen and Betsy Earls of Kaiser Permanente fear that the opposition to the –1 amendments as currently written is strong enough that the bill will not leave committee. Both Gwen and Betsy think that because of timing (late in session), this bill needs to be passed the next time this goes to committee or it will die.

As a final action, and in interest of saving SB-99, the –1 amendments were abandoned and SB-99 is currently composed of the original bill plus the –2 amendments.

Bob Nystrom noted contextually it was interesting that the Judiciary Committee had great concerns about existing employment law. The fact that there was so much focus and such a long discussion on this matter during the last hearing indicated in his eyes that they might not completely understand what the law actually says.

Jon Zonana was not present at the hearing but listened via computer. He thought the –2 amendment was not fully understood. Committee members didn't seem to understand what genetic information is, and that only test information that is covered in the bill.

Jon Zonana stated that he did not think the –2 amendments accomplish what the ACGPR intended. Others agreed, noting that the –2 amendments do not minimize the problems providers experience when using genetic information. As written, the –2 amendments would require black-lining of some, but not all, information from medical records. Jon was concerned that SB99 had become too complex and questioned whether adding more language to the law would make it even more confusing. He also felt that consumers could potentially be harmed by the new language and that there can't be proper quality review, or exchange of information, but people could still be stigmatized and discriminated against.

Mike Garland asked committee members if they thought the bill made things better or worse for consumers, saying that if things were even marginally better, then going ahead with the bill and trying to secure its passage was justified. However, Jon Zonana thought the bill was a big step backward, and that the new provision would only benefit hospitals and health insurers. Jon stated that he would not support the bill in its current form. He argued that the current law protects consumers, but the new law removes protections. He moved to withdraw SB99 as amended by the -2's, saying that he felt it fair to go back and tell the Judiciary Committee that the ACGPR no longer found it acceptable. Mike Garland seconded the motion.

Several suggestions for making the legislative process more effective were proposed. Gwen suggested that in the future, the ACGPR needs to clarify its legislative intent earlier in the term, to facilitate individual work with legislative

committee members before hearings start. Nan proposed lobbying our state representatives who support the Federal Genetic Information Non-Discrimination Act for support of state proposals. Kara Manning reminded the group that the existing genetic privacy laws passed with the support of Sen. Peter Courtney. She suggested soliciting similar support when the committee reconvenes in two years while Nan Newell felt that the committees best chance lay with the drafting of a whole new law.

Gwen suggested putting SB 99 aside and re-writing the bill for the 2007 session. She noted that Kaiser has been actively advocating for SB 99 and suggested, as a courtesy, letting Kaiser representatives (i.e., Betsy Earls) have a say in the matter. However committee members were not supportive of this idea, pointing out that Emily Harris holds Kaiser's vote in the ACGPR. The committee agreed to vote with the provision that should Kaiser have any comments that the committee felt were important, the vote could be amended.

The group then took a vote. Of the nine voting members present, 8 were in favor. Emily Harris abstained.

Outcome

- **SB99:**
 - **The -1 amendments have been withdrawn.**
 - **The committee voted to withdraw support for SB-99 as amended by the -2 amendments. Gwen is going to talk with Betsy Earls, who has worked on the bill on behalf of Kaiser. The ACGPR continues to support the original, unamended version of SB-99.**
 - **Language as dictated by Jon Zonana: "The Committee reaffirms their support of SB99 as originally proposed but upon further examination we feel that we cannot support the -2 amendments."**

SB 1025

Ted Falk informed the committee that he had concerns about 1025 because the bill has taken on a number of features that he feels unable to support. Ted feels reluctant to go into wholesale revisions of the bill without adequate time to think it through, and he would prefer to abandon SB 1025 rather than push it through without adequate forethought. He noted that the most recent proposed redraft of SB 1025 was not brought to the committee for review in time for the meeting.

Gwen reviewed recent activity on SB 1025. In a recent meeting, the ACLU expressed opposition to SB 1025 as originally drafted. Gwen had a follow-up discussion with ACLU representatives. The ACLU seeks a compromise that maintains the current opt-out for anonymous research and adds an opt-out for

coded research. Stuart Kaplan corrected Gwen, saying that ACLU President David Findanque favors an "Opt-in," but Gwen understood Findanque as saying, "Opt out." The matter was not immediately settled. However, it was clear that the crux of the issue was how to give a subject/patient the opportunity to say whether they would agree to have their personal information or medical specimens used for genetic research. A discussion of how to make an opt-in or opt-out meaningful followed. Gwen pointed out that the option to opt out would not apply to the deceased as stipulated by Federal Common Rule, and that authorization by next of kin would not be required.

Outcome

- **No decisions were made on SB1025. The ACGPR is willing to consider an up-front opt-out that will be presented along with HIPAA notice of privacy practices.**
- **Gwen asked for review of the drafted amendments and input on whether she removed too much of 192.547.**
- **Gwen will take feedback on the amendments.**

Adjournment

Next Meeting June 1st, 2005
First Wednesday of each month
1:00 to 3:00 p.m.
Oregon Medical Association
5210 S.W. Corbett Avenue in Portland