

Advisory Committee on Genetic Privacy and Research Meeting Minutes — February 1, 2006

Attendees:

Michael Garland (**co-chair**), Jon Zonana (**co-chair**), David Holt, Rose Raymond (guest), Greg Fowler, Emily Harris, Allison Naleway, Amy Thomas, Kara Manning-Drolet, Gayle Woods, Kerry Silvey, Nan Newell, and Naomi Adams

New members have joined the committee. Everyone introduced himself or herself.

PSU Forum Discussion

Greg Fowler brought in one of his students, Rose Raymond, to discuss the PSU forum to be held Monday March 13, 2006 from 2-4pm. The purpose of the forum is three-fold:

1. To help raise awareness about the science of Genetics, i.e. what it can and cannot do;
2. As a vehicle for the community to express concerns, and put forth values they think are important, and;
3. To provide an opportunity for policy makers to come and hear the concerns of the community.

The students have narrowed the discussion down to “direct to consumer” tests. Rose and the other students in Greg’s class want to extend an opportunity to the public as well as some of the committee members to participate in the discussion.

Some committee members expressed concern that the approach the students were taking may have been somewhat negative. It was pointed out that there are very positive things about genetics and genetic research that should be emphasized as well. Greg was asked to help his students clarify the topic and broaden the discussion to include the more positive aspects. Greg also announced another upcoming forum by Speaker James Hughes on improving Humans in the 21st Century.

Committee Membership and Attendance

Kerry Silvey told the group that there are two people interested in becoming alternates for the consumer position. However, a consumer member of an IRB is still needed.

The committee agreed, that there needs to be a commitment made by current members to attend meetings on a regular basis and make an effort to read meeting summaries if they are unable to attend.

Certain committee members felt that Carol Pratt had been such a positive contribution to discussion that a sincere effort should be made to bring her back for a second term.

Outcomes:

Patricia Backlar has agreed to contact Carol Pratt to see if she would like to remain a member of the ACGPR

Education plan update By Kerry Silvey

The OMA wanted to meet to talk about education of healthcare providers. Bob and Kerry will meet with an OMA representative to discuss this issue and are working on a draft to present to the OMA. Bob has made an outline and Kerry will flesh it out this week to at least start something that could be posted on a DHS website but also be available for others to print or adapt. Bob's goal is to create something that is very clear and straightforward such as what the law is, and what changes have been made.

There are 4 target audiences:

1. Consumers
2. Health care providers
3. Researchers
4. IRB members.

Bob believes that a majority of this would be the same info for each target group but there would be differences in how the information was presented.

Emily told the group that Kaiser would be hiring a communications specialist for membership education. This person will also work on clinician education. Emily said this person can be used as a resource for the ACGPR as well, depending on the timeframe set up for having the educational material ready for viewing by the public.

Michael Garland suggested putting together a forum for IRB's to learn about the opt-out provision.

Outcome:

- Allison, Kara, and David will meet individually to discuss organizing an IRB forum. They will talk about what they come up with at the next meeting.
- Kerry and Bob will circulate a draft of the provider education sheet for committee input.
- Next time Kerry will update the committee on a consumer IRB rep.

Framing Discussion

The committee then moved on to a discussion of the rationale for special laws regarding the privacy of genetic information. Michael Garland emailed an inquiry guide to committee members prior to the meeting. The questions presented and structure of the discussion was based on the initial discussion in January.

Key Discussion Points:

1. Structure the problem

2. Evaluate potential solutions
3. Select preferred solution

Definitions of privacy protection for policy purposes

(i.e., circumstances where considerations of justice and common good demand specific legal protections and obligations)

- Is genetic information uniquely private?
 - Privacy for its own sake
 - Privacy for protection from social harms
- What other forms of legally protected health information should we compare with genetic information?
- Map overlap and differences with HIPAA
- Identify consequences of modifying the policy rationale that underlies previous work
 - Can policy reflect a utility gradient for privacy about genetic information?
 - Can society more effectively protect genetic information by grouping it with other forms of personal health information?

The group also briefly discussed SB99 and what they felt went wrong and why.

Next time: Anti –discrimination discussion.

Outcomes:

- Naomi will research the exhibits from the testimony on SB99 and find out how to access the tape-recorded testimony.
- Naomi will send a copy of the 2005 legislative report to all committee members.

Adjourned

Next Meeting March 1, 2006

1:00 p.m. to 3:00 p.m.

Oregon Medical Association

5210 S.W. Corbett Avenue in Portland