

Advisory Committee on Genetic Privacy and Research

Work Session Minutes — April 2, 2003

Attendees

Astrid Newell (Co-Chairperson), Ted Falk (Co-Chairperson), Michael Garland, Patricia Backlar, Greg Fowler, Marc Marengo, Kara Manning, Laura Zukowski

Welcome/Introductions

Request for Practical Information for Implementation of Genetic Privacy Laws/HIPAA Regulations

Astrid Newell reported that she has been receiving calls on a regular basis from hospitals and health systems that are looking for guidance on how to implement genetic privacy laws. The questions touch upon a range of systems within the clinical setting, everything from consent procedures for genetic testing, to billing practices, to release of information for referral of laboratory specimens. She has received feedback from several individuals that the different levels of privacy requirements for diagnoses obtained through genetic tests versus through clinical observation make no sense. Clinicians have pointed out that discrimination can happen on the basis of a diagnosis, regardless of how it is obtained. There seems to be confusion among doctors and clinical staff regarding legal requirements. Many clinical sites seem to handle genetic material routinely without following any special procedures, and Astrid suspects that many doctors may not regard certain information as “genetic information,” which state law would classify this way.

There seems to be a need for training for clinicians, members of IRBs, and other groups in health care and research.

Outcome 1: This issue will be included on the May meeting agenda. Astrid will continue to compile the requests for information and clarification on genetic privacy requirements that she receives. Representatives from Kaiser, OHSU, etc., will be invited to participate in the May meeting discussion, also.

Education and Outreach Subcommittee

Subcommittee chairperson Michael Garland reported on plans for the community forums and focus groups scheduled in Bend (May 13), Salem (May 14), and La Grande (possibly May 19 or 20). ***[Note: the La Grande forum is scheduled for May 22.]*** The community forums will be held in the evening; a focus group will follow each forum the following morning and will include 8-12 participants from the forum the evening prior. The group discussed a draft schedule for the community forums and gave feedback on the plans that the subcommittee has developed.

Purposes of Focus Groups (Why)—Focus groups will guide the committee’s formulation of the future survey and help structure its future educational efforts; generate qualitative information to the committee regarding the public’s level of understanding, beliefs, and values around genetic policy; gauge the current social environment (ignorance level, worry level about genetic issues) for the Legislature. The mix of participants in the community forums and focus groups will not be representative of Oregon’s population at large, but will provide feedback on the how public views genetic policy issues.

Questions for Focus Group Participants (What)—The group continued its discussion about content areas that the focus groups will cover. Among the eight topic areas identified during the brainstorming session of March 5, these four were considered for inclusion in the focus group: genetic exceptionalism; insurance issues; surrogate consent; protections around the seeking of genetic counseling. Forum audiences will view the clip from the Fred Friendly broadcast “Who Gets to Know” that relates to denial of insurance coverage based on genetic test results and genetic testing as a pre-employment screening tool.

Outcome 2: Topic areas for the focus groups will be genetic exceptionalism, insurance issues, and protections around the seeking of genetic counseling.

Suggestions for Respondents/Participants (Who)—

- Native Americans
- someone from agribusiness industry (where the focus is on non-human genetics)
- persons affected by genetic condition/disease (self or a significant other in life)
- post-secondary students
- members of various ethnic groups
- K-12 science teacher/educator
- professor in a non-scientific field, such as Humanities
- representatives from the insurance industry (agents, health insurers, life insurers, purchasers of life and health insurance)
- nurse who works in a non-genetic clinical setting, such as a primary care clinic
- someone from law enforcement
- science reporter or media person

Discussion brought out concerns about having focus groups with respondents who are too diverse in comparison to one another. One suggestion was to separate the “opinion leaders” from other respondents.

None of the community forums or focus groups will be taped. Focus group hosts will use another method to capture data.

Outcome 3: Michael Garland will circulate a summary of the above discussions and request feedback on the community forums and focus groups.

Outcome 4: The title for the community forums will be—“Genetic Privacy in Oregon: Who Gets to Know? A Public Conversation.”

Outcome 5: Ted Falk and Astrid Newell will adapt the PowerPoint presentation that was developed for the Legislature, so that it shown as part of the community forums. They will drop the emphasis on changing Oregon’s genetic privacy law and shorten the presentation to around 10 minutes. The ELSI video clip will remain. The presentation will include a brief introduction to Oregon’s genetic privacy law, will describe this committee and its function, and try to generate some interest among the audience in being part of the public process of policy development. Someone suggested that the tone of the forum overall should walk a balance between raising fear in participants and lulling participants into believing that Oregon law fully protects them.

Future Full Committee Meetings

First Wednesdays—

May 7

July 2

September 3

October 1

November 5

December 3

1:00 to 4:00 p.m.

Oregon Medical Association

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