

Advisory Committee on Genetic Privacy and Research

October 2, 2002

Attendees

Ted Falk (Co-Chairperson), Astrid Newell (Co-Chairperson), Bob Koler, Kara Manning, Emily Harris, Michael Garland, Kerry Silvey, Patricia Backlar, Marc Marengo, Lisa Sardinia, Andrea Meyer, Peter Jacky, Kathy Walsh, Donalda Dodson, Laura Zukowski

Welcome and Introductions

Everyone present introduced himself or herself. Guest visitors included Lisa Sardinia, from Pacific University, and Donalda Dodson, Administrator of the DHS Office of Family Health.

Review of Minutes from September Meeting

Bob Koler motioned that the draft minutes of September 4, 2002, be accepted with no changes. Andrea Meyer seconded the motion.

Outcome: Draft minutes of September 4, 2002, were accepted with no changes or discussion.

Update — Public Outreach and Education

1. Fred Friendly Seminars/*Our Genes, Our Choices* — Michael Garland announced that the OHSU School of Nursing is interested in hosting outreach sessions in connection with the Fred Friendly broadcast series, *Our Genes, Our Choices*. He shared a draft proposal for the \$10,000 outreach grant, offered through OPB, that would help promote the series. Key aspects of the proposal include: small allocations to each of the six OHSU School of Nursing campuses around the state to help offset costs of outreach sessions (\$1,500); expanded promotion of the series through print and commercial radio advertising (\$2,500); a coordinator/project manager (Oregon Health Decisions) to handle detailed arrangements before, during, and after the broadcasts and the OHSU outreach sessions (\$4,000); and development of interactive materials for the Geneforum website that would relate to promotion and follow-up of the broadcasts (\$2,000). In addition, Michael has identified substantial in-kind support (\$12,500 to \$14,500) that would supplement the proposed grant.

There was also discussion about outreach to additional groups, such as science teachers and the faith community. Community meetings should target these additional groups and include opportunities for education about issues and resources, and dialogue and feedback with different sections of the larger community. This committee expects to receive usable feedback and insights, but no hard data from the meetings.

The first broadcast of the Fred Friendly series will be about privacy. No date is set yet, but the broadcast time will be in the evening, and so the community meetings will probably occur separately from the actual broadcasts.

Outcome 1: Please direct any feedback or suggestions about these plans to Michael directly, e-mail mdgar@teleport.com or phone (503) 236-1293.

Outcome 2: Marc Marengo will send Laura Zukowski details about a November 4 talk planned by the Ecumenical Ministries of Oregon. Laura will circulate the information to the rest of the group.

2. The request for match dollars from the Collins Medical Trust was not funded.

Legislative Report Draft Review

The committee began reviewing the draft legislative report. For the sake of efficiency, Ted Falk or Astrid Newell requested that grammar and spelling edits be submitted to them outside of this meeting (red ink markups on hard copies, please). The main objective was to review the body of the document through page 24, with special emphasis given to the section on genetic research.

The following bulleted list and the list of outcomes summarize the discussions, recommendations, and agreements that occurred during the review.

- Page 3/Overview—Section D. Insert “whether to modify” within the first sentence of the Clinical Issues bullet point. The sentence should read, “Clinical Issues: charged with addressing issues related to privacy of genetic information obtained through means other than through a genetic test, privacy of persons seeking genetic services, and whether to modify the opt-out provision for anonymous research.”
- Pages 3 & 4. Clarify the many references to “committees.” There are several committees mentioned, and they become muddled in places, especially where pronouns are used.
- Page 4/Confidentiality. In the second and third sentences, define the terms “concept of property,” “concept of confidentiality,” “possessor of genetic information,” and “DNA samples.”
- Page 4/Confidentiality. Insert after the third paragraph a summary of the work completed by the Advisory Committee on Privacy of Medical Information and Records. Perhaps Gwen Dayton could write it?
- Page 5/Informed Consent. Insert into the second paragraph, second sentence, the phrase, “as well as using samples.” The sentence should read, “First, the term “informed consent” is used for authorizing the release of information, as well as using samples, rather than its traditional use for authorizing . . .”
- Page 5/Genetic Exceptionalism. Insert a few paragraphs describing concepts underlying why genetic information is defined as exceptional, and then present a few key arguments against these concepts. Trish Backlar agreed to prepare this or have someone else prepare it for her, by October 15.
- Page 7/Genetic Exceptionalism. Include more detail about HIPAA rules. See the bullet points listed.

- Page 8/Privacy of Persons Who Seek Genetic Counseling or Testing. The final paragraph should read, “We recommend that Oregon’s genetic privacy law be extended to protect the privacy of the fact an individual has sought genetic counseling, genetic evaluation, or genetic testing.” The group wanted the recommendation to be broader, so that privacy extended to clinical exams.
- Page 9/Genetic Research—Section 1. There was a lengthy discussion around recommendations relating to informed consent for genetic research. No agreement was reached. See Outcome 8 in the next section below.
- Page 10/Genetic Research. In the list that follows, “We recommend,” link make numbers 1 and 2 one item. Also, place the word “and” between items a through e, so that all of these requirements must be met.
- Page 10/Genetic Research. There was discussion about the date of June 25, 2001, which is listed in item number 2. No agreement was reached about including or excluding this date.
- Page 10/Genetic Research. Recommendation number 3 generated disagreement, and no agreements were reached. See Outcome 8 in the section below.
- Page 10/Guidelines for Coded or Encrypted Genetic Research. At the end of the title, add the phrase “to Guide Institutional Review Boards in Their Reviews.”
- Page 11/Guidelines for Coded or Encrypted Genetic Research. There was a lengthy discussion concerning Options A and B, with no resulting resolution.

Outcome 1: In addition to DHS reviewers, Emily Harris volunteered to have technical editors at Kaiser Permanente review the legislative report before it went to the Legislature.

Outcome 2: Astrid Newell will invite DHS Legislative Liaisons, Lisa Joyce and Katy King, to attend the November 6 meeting. Since they will be reviewing the report before it is submitted to the Legislature, it could be helpful to them to listen to discussions about the document.

Outcome 3: Place all recommendations in boxes to emphasize them and make them easier to locate. The text boxes should clearly say whether there is a change or no change recommended. Also, list all recommendations from the entire report together at the end of the document.

Outcome 4: Emily Harris will locate a table she prepared in the past, which summarizes the different approaches to research, for inclusion in the report.

Outcome 5: There will be a recommendation in the report that the Legislature and the committee need to watch for genetic privacy issues that may emerge around disclosure of family history, as it relates to insurance, employment, and criminal databases. There was concern expressed about the different standards for privacy of genetic information in clinical and research settings.

Outcome 6: No recommendations about insurance will appear in this year’s report; however, insurance issues will be flagged for next year’s report. One such issue concerns insurance companies’ being prohibited from denying coverage based on family history but being allowed to deny coverage based on the results of genetic tests.

Outcome 7: The report will include the exact date the statute went into effect.

Outcome 8: There will be a special work session scheduled before the November 6 meeting to allow more discussion around the three types of consent for research. Astrid Newell will send out an invitation to the full advisory committee. The meeting date chosen will allow attendance the attendance of Emily Harris and representative(s) from the ACLU.

Next Full Advisory Committee Meeting*

Wednesday, November 6, 2002

1:00 to 3:00 p.m.

Oregon Medical Association

5210 S.W. Corbett Avenue

*Subcommittee Working Session immediately follows full committee meeting, from 3:00 to 4:00 p.m.