

Advisory Committee on Genetic Privacy and Research
FINAL Minutes

April 4th, 2012
1:30 – 3:00 pm

Room 918
Portland State Office Building
800 NE Oregon Street, Portland, OR 97232

Attendees

Members: Hillary Booth, Kara Drolet, Stuart Kaplan, Gayle Woods,
Laura Zukowski

Staff: Summer Cox, Robert Nystrom, Bridget Roemmich

Guests: Bob Shoemaker (phone), Peter Jacky (phone), Becky
Straus

Members Not Present

Members: Anne Greer, Jenny Franks, Katrina Goddard, Ken Gatter,
Patricia Backlar, Steve Nemirow,

Alternates: Allison Naleway, Beth Crane, Eran Klein, Gregory Fowler,
Karen Cooper, Paul B. Dorsey, Rhonda I. Saunders-
Ricks, Terry Crandall

1. Introductions
2. Approval of minutes for March 2012 – all in favor, no revisions
3. Review of remaining member concerns regarding legislative concept
 - a) Becky summarized her 4/03 email: ACLU does not support the repeal of ORS 192.537(3)-(9).
 - b) ORS 192.537 statute is written to apply to non-research areas (such as clinical) as well as research. When not specific, the statute is speaking in general terms to all areas.
 - c) With the draft changes expected in the common rule, members are not sure if the OGPL will become redundant or unnecessary, at least in parts.

- d) Acknowledgement that the current law is:
1. Confusing to the point that it is difficult to enforce
 2. Not providing a clear separation of clinical, research, insurance and employment requirements
 3. Potentially redundant when common rule changes are adopted
 4. Using confusing/misleading definitions of 'biological specimen' and 'DNA sample', when a more correct wording may be biological tissue 'for the purpose of'...

4. Decision on legislative concept

- a. Committee is not asking the OHA to move forward with this as a legislative concept at this time, next opportunity would be in the 2015 long session.
- b. OHA legislative liaison has recommended this not be carried by the OHA, but carried directly by a legislator if moved forward.
- c. OHA legislative liaison will work on getting the ACGPR legislative representatives.
- d. Committee's formal decision.
 1. Motion approved
 - "The committee recognizes problems in the current legislation, but did not reach consensus, and has decided to not move forward with either of the draft legislation for the 2013 legislative session."
 - Motion made by Ken Gatter and seconded by Gayle Woods, unanimous approval by a quorum of members.
 - Motion will be published in biennial report to the legislature in 2013.
 2. Follow-up to motion
 - Problems with current legislation include, but are not limited to, uncertainty about the definition of DNA sample, the requirement of informed consent, and other laws that apply to use and retention of samples and information obtained in clinical settings.

- Agreement that we need consensus on the recommended changes and need to make sure they would meet our goal of simplifying and clarifying the law before going to the legislature.
 - After further discussion, committee may be ready to support draft legislation in the 2015 session or when the common rule changes are finalized.
 - Committee members recommend keeping an awareness of how the concept of genetic exceptionalism can shape our decisions as a committee. As more and more genetic tests enter into the clinical setting, we may need to formally lay down the concept and/or draw a clear line in the Oregon statutes between medical tests and research tests.
5. Big thanks to Shannon O'Fallon for the drafting of the reconciliation and selective repeal legislation and helping the committee discuss the statutes
6. Brief discussion of possible new invited guest and general public participation policy
- a. This policy arose from a suggestion that the ACGPR consider following a model of operations more similar to other committees.
 - b. We are a relatively low-visibility committee, but we are required to post this meeting on-line as a regular, formal, public meeting.
 - c. This 'formalized' policy is about creating a structure for appropriate participation and allowing the committee to share their expectations to public participants.
 - d. Chair already has the authority to call on members of the committee first; this protocol provides support for them.
 - e. Committee would like it to: 1) be less formal, 2) be used as a handout during meetings for guests 3) be used at Chair's discretion, and 4) include a reminder that guests do not vote.
 - f. Co-chair requested that members & alternates send a note to the Genetics Program when guests are invited (which will be shared with co-chairs and alternate chairs), so we can

anticipate their participation. Member should be prepared to briefly introduce the guest during introductions.

- g. Summer will send out a reminder to all the committee reminding people to alert the Genetics Program when guests will be invited.
 - h. Stuart Kaplan invited Peter Jacky and Bob Shoemaker to be invited guests whenever the Oregon Genetic Privacy law is under discussion. Both will remain on our email list as “interested parties”.
7. Unanimous vote to approve new committee member Becky Straus, as the alternate committee member to “Organizations Advocating for Privacy of Medical Information”
- a. Summer will make sure that Laura Z. (and Becky S.) receives an appointment letter from Katherine Bradley.
8. Next Steps
- a. Continue the conversation around Oregon Genetic Privacy legislation, discuss related issues as they present themselves, and include stakeholders and informants to further our understanding.
 - 1. Hospital participants: what samples are being collected for only short-term use? What happens to the samples after the designated use? How does the OGPL affect processes and protocols? What exactly is the difficulty in using/interpreting the law (Rick Press?)
 - 2. Researchers: to provide information on how they are affected or constrained by current law. What exactly is the difficulty in using/interpreting the law?
 - 3. Employer representatives: How incorporate GINA into employee data collected? What kind of genetic information could/do employers collect or have access to? How is genetic information used? Check with BOLI (Bureau of Labor and Industries) for a broad perspective
 - 4. Summer will dig out summaries compiled from stakeholder meetings (labs, hospitals, etc) and other documents raised in this discussion. What have we done in the past?

- b. Educational activities – such as Community Conversations
1. Genetic Program staff will continue to provide direct committee support. However, any educational/outreach work must be sustained by committee members (not the Genetics program) due to budget constraints, staffing commitments and the fact that there are no dollars given to staff to carry out the legislative directive to staff the ACGPR
 2. Discuss possible educational outreach with Jacky Shannon (sp?) and/or Rick Press
 3. Insurance Division is doing some interesting work around rate review and health insurance premium rates. Public hearings, Legislative Town Halls, and working with schools. Committee could make use of webinar and video streaming equipment, which would allow for archiving so people can watch when convenient for them. Science classes may be interested in on-demand webinars, etc
 4. Interest in creating a brief updated handout to educate public and providers
 - Check out Coalition for genetic fairness – “GINA and You”
http://www.geneticalliance.org/sites/default/files/ks_c_assets/publicpolicy/gina_information_sheet052710.pdf

9. Adjourn

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| <p>Next Meeting June 6, 2012 1:30 – 3:00</p> |
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