Advisory Committee on Genetic Privacy and Research
Final Minutes

June 6th, 2012
1:30 – 3:00 pm

Room 221
Portland State Office Building
800 NE Oregon Street, Portland, OR 97232

Attendees

Members: Hillary Booth, Kara Drolet, Laura Zukowski, Patricia Backlar, Steve Nemirow (phone), Stuart Kaplan

Alternates: Becky Straus

Staff: Bridget Roemmich, Summer Cox

Guests: Bob Shoemaker, Peter Jacky (phone)

Not Present

Members: Anne Greer, Jenny Franks, Katrina Goddard, Ken Gatter, Gayle Woods

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

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1. Approval of minutes for April 2012

2. Review of Stakeholder Impact summaries from 2007/2008
    a. It has been 4-5 years since these data were collected. People may now be more familiar with OGPL, have some sense of GINA, etc. It may be time to check in with some informants and learn about their experiences with the state and federal laws.
    b. We need specific questions to bring to their consideration. (Use questions from today, from past minutes, from Shannon O'Fallon's work to review the OGPL, etc)
    c. We need a list of possible stakeholders (hospitals, researchers, employers, etc). BOLI (employment), clinic, labs, research,

insurance, public health lab.

3. Identification of top issues with the Oregon Genetic Privacy Law (guided by minutes from April 4th meeting)
    a. Intent: Notification process was meant to inform people that their sample might be used in the future and allows them to opt-out and remove their samples from (or have them not enter) the research pool. We have concerns that the committee's intent was not fully realized in the law. We would like to understand how the current Oregon Genetic Privacy Law (OGPL) affects pathologists, hospitals, clinicians, labs, researchers, employers, insurance agencies, the public health lab, and possibly consumer and commercial interests.
        - Clinicians: Do clinicians generally find the OGPL to be confusing? What exactly is it in the OGPL that causes confusion? How are the retention and destruction requirements of the OGPL handled in clinical settings? Do they have any suggestions on specific ways to revise the law to reflect their practices and precautions better?
            - Gwen Dayton could connect us with providers who have feedback about the law.
        - Hospitals: How are samples generally handled by hospitals in routine situations? Are they used for testing other than the original test/reason was collected for? How are the retention and destruction requirements of the OGPL handled in clinical settings? How are OGPL retention and destruction requirements balanced with CLIA (and other laws covering retention/destruction). What other laws do you use in setting retention & destruction policies?
        - Healthcare Systems: How have you interpreted the law? How you go about the process of notifying patient? How is the notification process working for your organization? What is your percent of opt-out? Have any of your procedures changed? Do you face any challenges or barriers because of the law?
        - Research: Does the OGPL inhibit research? In what ways? Are there suggestions on specific ways the law could reflect research practices and precautions better?

- IRB: Historically, healthcare settings conducing research have had difficulty getting studies through the IRB, due to IRB interpretation of OGPL. Kaiser staff especially have voiced this (SLC to check in with Katrina, we would like to hear from her & others about their IRB experiences as well as other issues that may effect researchers).

- Employers: check in with BOLI for employment issues & interests.

b. <u>Education</u>: Can we do a better job of educating public, providers, etc, about what the law means, how to work within it, etc?

4. Brainstorm on next steps in resolving issues, where we need more information, which people we should invite to the table
    a. Need to have clear, concise questions to ask stakeholders
    b. Need to ensure that the 'right' people are being asked the 'right' questions
    c. Need to have enough people answer the questions
    d. We could ask a broad range of people questions via survey monkey and then narrow down to some follow-up/discussion questions and invite some of those who answered the survey
    e. Possible hypothesis: The OGPL is confusing to providers and researchers, making it more difficult to ensure protection of the genetic privacy of Oregonians.

5. Prioritize Next Steps
    a. Everyone is welcome to contact their own connections with about coming to speak with us about the OGPL. (Gwen, Ken, Katrina, Anne, Bill Noonan?)
    b. SLC to draft questions and draft list of who we might be asking them of (or who may be able to connect us with others). Build/send a survey monkey survey with list of questions, ask if willing to come in to discuss further for an in-person discussion (focus group or round table discussion).
        - Include familiarity with GINA, HIPPA, etc, in survey.
    c. Next session to go over draft survey & list of key informants.

6. Brief review of revised invited guest and general public participation policy
    a. Guest guidelines accepted with a few edits from Trish
    b. Agreed that in the future the guidelines will be placed (with a sign of explanation) near other handouts
7. Other
    a. Do we want to consider having a journal club-like session? Review 2-3 papers and discuss... Possible for a future ACGPR meeting.
8. Adjourn

Next Meeting
August 1, 2012
1:30 – 3:00