

Advisory Committee on Genetic Privacy and Research
Meeting Minutes – February 8, 2008

FINAL

Phone Attendees:

Andrea Meyer, Susan Hayfield (OHSU)

Attendees:

Terry Crandall (alternate), Ted Falk (alternate), Bob Nystrom (DHS), John Anderson (DHS), Kara Manning Drolet, Ron Marcum (alternate), Steve Nemirow, Gayle Woods, Pierre LaChance (Kaiser), Carey Bush (Legacy), Kate Morris (Legacy), Gwen Trieu (DHS), Nan Newell, Marilyn Hartzel, Patricia Backlar, Allison Naleway

January Agenda overview:

1. Agenda approval
 2. Approval of Minutes for December 2007
 3. Announcements
 4. Input on Oregon Genetic Privacy Law – discussion with lab managers
 5. Continue discussion on definitions
 6. Adjourn
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1. Agenda approved

2. December 2007 minutes approved

3. **Announcements:**

- Mary Pat is no longer with DHS and will be returning to Kaiser as GC
- John Anderson starts job rotation as RA, Feb. 11
- Gwen Trieu will support committee
- Nan Newell will job rotate into Mary Pat's position
- Funding gap of 3-4 mo before states are awarded
- Problem in filling in for Mary Pat due to circumstances

4. **Input of Oregon Genetic Privacy Law**

.. discussions with genetic researchers and IRB administrators

Susan Hayfield (OHSU)

- Operational issues from investigators
 - Complaints are not about the laws
 - Everything seems to be working well
 - Opt out seems to allow research to be done more freely but no significant changes
 - High info sensitivity awareness
- 10.6% opt out rate- lower vs. other institute
 - Patient samples are compared to the opt out list and notified of who is eligible
 - Patient is automatically opted in if not opted out

- Many coded research projects are being conducted
 - Some are being extended
 - A lot is in the pipeline
- Annual cost after 1st year is over a few hundred for mailing and data entry

Kaiser

- Standardized indentifying special for genetics
 - 11% - 12% opt out rate
 - Spent 40K+ 1st year
 - Time consuming: cost to go through letters, data entry and dealing with angry people
- Ability to exclude people
- Virtual data base between Kaiser and OHSU
- Annual cost after 1st year is minimal

Legacy

- 30-40% opt out rate as of 09/07
 - 44k opt in – 20k opt out
 - In patient: 4300 opt in/1800 opt out
 - Lots of meetings
- No current research that is affected by the law
- Annual cost after 1st year is still at 20-40k
- Cost were enormous but value compared to cost is questionable

5. Begin discussion on definitions

- Need strong governance rules about how to share data
- Genetic test to guide treatments may not be covered by the privacy acts.
- Only undefined definitions
- Different procedure for research, treatment
- Narrow the law to situations
- Refine genetic test
- Public education to understand the research and to get more cooperation
- Opt-out makes bio-banking easier
- What is covered under the definitions?
 - If we could step back, we talked about the burden to comply with the Oregon Genetic Privacy Act re what is covered.
- Can DHS by rule declare inheritable? What about drug response? Should it be excluded?
 - Expand overview on disease management.
 - Different steps on providing genetics info between providers.
 - Need high level summary of genetics information.
 - Need uniform procedure for all consumer w/simpler fashion in a modern time.
 - Need newer tool and be cautious on making distinctions too precise.
 - Consider the public's perceptions on genetic tests are different.
 - Use rules to exempt certain things without having to go back to legislative?

6. Adjourn