

Advisory Committee on Genetic Privacy and Research

Meeting Minutes – June 3, 2009

FINAL

Attendees:

Members: Patricia Backlar, Kara Manning Drolet, Katrina Goddard, Marc Marengo, Steve Nemirow, Nan Newell

DHS staff: Bob Nystrom, Gwen Trieu

Alternate: Ted Falk, Stuart Kaplan

June Agenda overview:

1. Review of agenda and approval of minutes for May 2009
 2. PSU Student Project – follow-up PSU report – finalize questions we may want to ask the students and discuss what to do with the report
 3. Legal intern: OSU may have a 0.5 FTE legal intern for the summer who may be interested in helping the legal sub-group on analyzing GINA vs. OR genetic privacy law.
 4. Other Business
 5. Adjourn
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1. Brief intro and May minutes approved

2. PSU Student Project

- Project as it stands is not publishable and some additional information from the students is important in order to be able to move forward
 - i. Kara will send the students the following questions:
 1. What are the titles & departments of the interviewees from each organization?
 2. What is the code for the hospital and clinic names?
 3. Can you clarify the methodology used, including which numbers are actual and how the estimates were calculated?
 4. Can you describe the sources of the variability of the numbers?
 5. Can you include bios for John Silvey & Bonnie Russell?
 - ii. This project is a success in that it will inform our thinking about this issue going forward
 - iii. The ACGPR will pursue gathering more information on this project if there is funding or if additional students want to take it on.
 - iv. The 2011 legislative report will include a summary of this project, including why we did the study.
 - v. It appears that the higher the per patient spending, the higher the opt-out.
- Other issues for continuing the project:
 - Need to understand confidentiality issues with the organizations.
 - Need to get better numbers for calculations; new patients/year or unique patients/year rather than patient visits/year
 - Recheck figures after getting names of hospitals & may have to correct

headers on fact sheets.

- Need to have better information on the cost/benefit of the opt-out provision.

- Trish to discuss with professor Goldstein

- Request no to publish on their website before determine flaws
- Suggest the possibility of taking on another student group to get cleaner info

3. Legal intern

- OHSU may have a 0.5 FTE legal intern for the summer who may be interested in helping the legal sub-group on analyzing GINA vs. OR genetic privacy law
 - Maggie Frances
 - ◆ From Boston University
 - ◆ 2nd year law student
 - ◆ Arriving next week
 - ◆ Kara will figure out her interest

4. Grant Application to RWJ Foundation for “PH Law”

- Brief proposal submitted May 19, 2009
- Will be notified by July 13, 2009 if invited to submit full proposals
- Have 4 weeks turn around to submit full proposal
- Still looking for committed legal contributor
- Ted can help formulated the issue
- Suggested to put together an oversight legal team comprised of a few ACGPR members to help write the proposal and advise the contracted attorney
- Trish to contact Bill Noonan about his ideas for legal help if we do get the RWJF grant.

5. Adjourn

Tentative July Meeting – July 1
Definite August Meeting – August 5