

Advisory Committee on Genetic Privacy and Research

Meeting Minutes - Oct 3rd, 2007

Attendees:

Ron Marcum (alternate), Ted Falk (alternate), Terry Crandall (alternate), Mary Pat Bland (DHS), John Anderson (DHS), Kara Manning Drolet, Steven Nemirow, Allison Naleway, Stuart Kaplan (alternate), Nan Newell, Mark Loveless

September Agenda overview:

1. Agenda approval
2. Approval of Minutes for October 2007
3. Announcements
4. Continued Genetic Exceptionalism Discussion – walk through two examples of tests. How are they currently protected?
5. *if time allows* Plans for obtaining input on Oregon Genetic Privacy Law – Mary Pat Bland
6. *if time allows* Direct to Consumer Genetic Testing in Oregon – Mary Pat Bland
7. Adjourn

1, 2 - Outcome:

- Agenda was approved. Minutes were approved, with the following corrections: in the summary, HIPAA has no requirement for informed consent. Oregon law contains oral consent.
- Future corrections to minutes can be directed to john.a.anderson@state.or.us.

3. Announcements:

The ACGPR group needs a consumer representative. For example, someone who has tested BCRA 1 & 2 positive but is asymptomatic would be a good choice.

3 - Outcome:

- Group members will look for a potential consumer representative.

4. Continued Genetic Exceptionalism Discussion

KMD – We'll have a line-by-line comparison of the two diseases.

HIPAA covers many protections for asymptomatic Hep C and Huntington's, and extra protection for Huntington's (for example, a 90 day expiration for individual insurance).

KMD – Why is this the case?

TF – Only 7% have individual insurance. It's a smaller issue than what people think. Predictive tests should be treated differently than non-predictive.

RM – The ability to predict outcome is one measure, social stigma is also part of the picture.

SK – Operationalize potential harm to the person, the risk of stigma etc. we can think of potential harm as the trigger.

ML – The degree to which a specific test can predict an outcome is a measure, but HIV was about stigma (in terms of exceptionalism).

TF – HIV and genetic discrimination are based on current symptomatic status.

KM – If a patient applies for health insurance with asymptomatic cancer that is terminal in six months, that person can be discriminated against.

TF – Such things as blindness and race can't be discriminated against, but those things that are actuarially sound can be.

ML – AIDS has changed, intervention is now possible. Genetic diseases with no treatment are most susceptible to health care access discrimination. We have one class of well-defined outcomes with no intervention vs. less well defined outcomes that have treatment available.

RM – This relates to the issue of harm. The treatments are a moving target in regards to discrimination and the law.

KMD – Should there be a federal non-discrimination act?

RM – Is the idea fewer columns, and more yeses? *[in the chart]*

[numerous] - Yes.

MPB – If GINA passes, what do we want to retain?

TF – There as a conscious effort to separate life and disability insurance from health insurance. It was a compromise with the insurance industry. What might deter a consumer from getting predictive genetic testing, fear of losing health insurance? Perhaps losing life/disability insurance is not as big an issue?

MPB – No, that too.

TF – For employment insurance, it is practically impossible to conduct genetic testing except for bona fide work qualifications.

ML – Testing employees for things that will make them ill in their specific work environment is a future possibility.

MPB – Federal law is more inclusive.

KMD – We might have identified some issue where exceptionalism applies, but they may also be non-genetic issues.

Predictability and the ability to perform interventions are important considerations in relation to discrimination in insurance, as opposed to considering only whether or not a test is genetic. The hypothetical situation is a patient who has no symptoms, does not have a genetic condition, but has undergone a predictive test.

What does Oregon law do that other laws don't? Mainly, some additional minimal protections. If GENA passed, there would be some minimal additional protections in the areas of life and disability insurance. Otherwise the laws are duplicative.

4 - Outcome:

- The discussion will continue at the next meeting.

5. *if time allows* Plans for obtaining input on Oregon Genetic Privacy

MPB – We can use group representatives as contacts for presentations to the group. For example, genetic counselors or lab managers might tell us what's working and what isn't. Other ideas?

SK – A survey, survey monkey?

MPB – Terry has good access.

TC – Survey monkey should be short.

SK – The survey can be used to defend conclusions against charges of selective use of input.

MPB – The survey coordinator can run ideas by the committee.

SN – We can keep the survey in reserve as a test of validity of issues identified.

MPB – More ideas?

AN – The rigorous approach is Steve's.

RM – Talking with genetic counselors could clarify issues first.

RM – Jim McLoury of OHSU (pathologist, lab head) is a source.

TC – It's important to get some lower-level individuals for input.

KMD – Continued discussion can generate more names.

TF – Panel discussions would be good. Surveys have been difficult to use in practice regarding wording of questions. Panels would bring people to the committee.

KMD – Individual members may be charged with organizing this.

5 - Outcome:

- Email names/categories of potential presenters to the committee.

6. if time allows Direct to Consumer Genetic Testing in Oregon – Mary Pat Bland

DCM has had lots of press lately. Internet companies are able to circumvent Oregon law. We will see more of this in the future...there is a federal push to deal with it.

ML – “Medical tourism” is growing, genetics will be embedded in that process.

RM – People who are participating in TM should be aware of Oregon TM laws.

SK – What is our mandate here?

MPB – DCM is FYI at this point.

TK – We have a broad mandate which could extend to DCM. We might want to do some preliminary exploration.

NN – Results reporting has to go through a licensed person.

6 - Outcome:

- The group’s charge is with the law – if the group continues after work on that, we might consider DCM.

7 Adjourn