

February 18th

Monday, February 11, 2019 3:42 PM

Important Reading Due Today: 23andMe guy (Dr. Robert Gentleman) speaking today, so readings about that

Reading Response: https://docs.google.com/document/d/1dRqALigWFefjmf-s_lu0zfIbHGGBbTTI5TCOn_9gLdg/edit

Reading Summary/ Questions

- What is this data going to be used for in the future?
- Will the dataset gathered from this data be biased? Who has access to this data?
- What about misconceptions people have about their genetic results?
- If I discovered a relative who did not want to be discovered without their consent, is that moral?
- Do people have the ability to consent to this? Do they understand the risks associated with giving 23andMe access to their genome (and browser history, etc)?
 - What does the ability to consent to this look like, or informed consent in general? How can we determine who is able and who isn't able to give informed consent.
- Are we obligated to create govt. regulation to regulate the type of things we can decide on? Aka should we be able to give informed consent

Summary of Speaker

Note: No Laptops allowed during talk, so points are summarized here from memory (and are quite brief)

- 23andMe allows people to understand conditions they may be predisposed to, allowing them to take action to protect their own health in the long term
- 23andMe does not just give out their data, it is only for research and is regulated by the FDA
- 23andMe does not have the capability or desire to delete your genetic data entirely from their database, but are willing to flag it as "not to be used". Still, it will always exist in their database (U)
- Conducted like research, opt-in opt-out anytime
- Does not participate in advertising in any way, only approved medical research

Reactions to Speaker

- What!? **You "can't" delete the data even if requested to?** True due to the nature of a hard backup, but does the general public understand that their data is permanent even if they request the sample be destroyed
- His focus and **experience is in the medical/research** side so he is obviously biased towards thinking that there is a lot of good happening in that area. He may be inclined to overlook the circumstances around or beyond that research
- Internal research is **funded by millions from private investors** and contracts to provide individualized or model based data.
- *"Everyone should be able to see their genetic data, without the need for doctors"* Argument was to improve access to that data, yet **the test costs \$200** soooo...
- *"I think more people should tell the truth..."* maybe, but we also have privacy and the truth about what we have said or done can be sensitive and private information *"If you are worried about being exposed, eg your ancestry, then you're parents shouldn't've lied to you about that"* Yet they still have a right to keep that information private, **should I not expect privacy when it comes to my information?**
 - As someone's child, **am I entitled to know** that information or do my parents have a right to keep that a secret?
- *Responsibility to contribute to research analogized to responsibility to vaccinate.* I find this problematic b/c of trolley problem. The choice of vaccination is a choice that is action either way (either doing bad or doing good) while **the decision to contribute research is a choice between action and inaction**, and is therefore inherently different.

Genetic data and other data
used as a means to decide whom
to provide health insurance to
(or other types of insurance)

