

Last time

- Who found statistical associations in their processed datasets?
- Stay skeptical, but ways to improve predictive power:
 - experiments
 - redo statistics on independent sample

Ethics of direct-to- consumer genetic testing

- <http://www.geneticsandsociety.org/article.php?id=7975>
- <https://www.youtube.com/watch?v=43gAIBzXzsw>

- GINA 2008 makes it illegal to discriminate based on genetic information (remember the case of the devious defecator?)
- But what about the ethics of having access to your own genetic information?

1. If an outcome of a genetic test will tell you whether you will die from an untreatable illness in the next ten years, would you get the test done?

2. If there's a chance you'll discover you have family members you never thought you had, would you get the test done?

3. If your genetic data might in the future be purchased by a drug company that profits from your data, would you get the test done?

I. Regulation of direct-to-consumer genetics testing for health-related results

- A warning letter to 23andMe from the FDA: <http://www.fda.gov/ICECI/EnforcementActions/WarningLetters/2013/ucm376296.htm>

- Note:
 - Ancestry carries out essentially the same genotyping procedure, but does not report health results
 - ‘Device’ not the raw genotype report, but 23andMe’s interpretation given to the customer
 - the stern tone of the letter may have been more the result of 23andMe’s uncooperativeness than the legality of their product

Two extremes

- Paternalism
- Libertarianism

Somewhere in-between

- *‘but how many people can there be who (1) know enough to seek out a genetic testing product, but (2) know so little that they’d rely on a cheap and vastly underpredictive consumer product to make health or reproductive decisions?’ - John Conley, Genomics Law Report*

In 2015, FDA permits marketing of carrier status reports

- <http://www.fda.gov/newsevents/newsroom/pressannouncements/ucm435003.htm>
- after all, less than 1% of the population are consumers of DTC genetics testing

2. What your DNA can say about your family

- “*your genetic information should be controlled by you*” - a core value of 23andMe
- But in reality, your genetic information can say a lot about your immediate relatives - who controls what?
- In fact, both 23andMe and AncestryDNA use this fact to offer information about family genealogy and ancestry



for adoptees

The largest DNA ancestry service in the world

sign in

register kit



welcome

ancestry

how it works

buy

search

help



<http://www.vox.com/2014/9/9/6107039/23andme-ancestry-dna-testing>

<http://www.vox.com/2014/9/9/5975653/with-genetic-testing-i-gave-my-parents-the-gift-of-divorce-23andme>

“When you check that [close relatives] box it should have a bunch of stars and bells and whistles around it. Because there are plenty of people who click boxes. Nobody reads their iTunes agreement. That's how I feel about the family finder thing: you just check all the boxes, just keep doing it, and never put a whole lot of thought into the possibilities.”

"I Would Want A Warning Saying, 'Check This Box And Fyi: People Discover Their Parents Aren't Their Parents And They Have Siblings They Didn't Know About.'"

23andMe terms of service

- *‘Once you obtain your Genetic Information, the knowledge is irrevocable’*
- *‘You may learn information about yourself that you do not anticipate. This information may evoke strong emotions and **has the potential to alter your life and worldview.** You may discover things about yourself that trouble you and that you may not have the ability to control or change (e.g., **your father is not genetically your father**, surprising facts related to your ancestry, or that someone with your genotype may have a higher than average chance of developing a specific condition or disease). These outcomes could have social, legal, or economic implications.’*

3. How your DNA is used by the DTC company



Bloomberg

Markets

Tech

Pursuits

Politics

Opinion

Businessweek

23andMe Turns Spit Into Dollars in Deal With Pfizer

<https://www.technologyreview.com/s/601506/23andme-sells-data-for-drug-search/>

- *‘By submitting DNA to AncestryDNA, you grant AncestryDNA and the Ancestry Group Companies a **perpetual, royalty-free, world-wide, transferable license to use your DNA**, and any DNA you submit for any person from whom you obtained legal authorization as described in this Agreement, and to use, host, sublicense and distribute the resulting analysis to the extent and in the form or context we deem appropriate on or through any media or medium and with any technology or devices now known or hereafter developed or discovered. You hereby release AncestryDNA from any and all claims, liens, demands, actions or suits in connection with the DNA sample, the test or results thereof, including, without limitation, errors, omissions, claims for defamation, invasion of privacy, right of publicity, emotional distress or economic loss. This license continues even if you stop using the Website or the Service.’ — AncestryDNA terms and conditions*

- *‘Waiver of Property Rights. As stated above, you understand that by providing any sample, having your Genetic Information processed, accessing your Genetic Information, or providing Self-Reported Information, **you acquire no rights in any research or commercial products that may be developed by 23andMe or its collaborating partners.** You specifically understand that you will not receive compensation for any research or commercial products that include or result from your Genetic Information or Self-Reported Information.’ — 23andMe terms of service*

I. If an outcome of a genetic test will tell you whether you will die from an untreatable illness in the next ten years, would you get the test done?

For now, there are very few diseases like this.
E.g. Huntington's disease, about 7 in 100,000.

2. If there's a chance you'll discover you have family members you never thought you had, would you get the test done?

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3. If your genetic data might in the future be purchased by a drug company that profits from your data, would you get the test done?

A lot of tech companies already make money from user data. Difference is DTC genetic testing consumers pay for their tests.

Other approaches: Personal Genomes Project is entirely voluntary.

Further reading

- Follow the links in these slides
- Read on your own, **but please make sure your sources are credible**
 - opinion vs fact
 - objective vs subjective
 - trashy tabloids vs real journalism
 - amateur vs professional reporter