** Readings – Privacy of Genomic Data, Thursday week 7**

Contents

[Some interesting videos 1](#_Toc52936361)

[XY Exercise 1](#_Toc52936362)-2

**Some interesting topical videos**

*Please at least read the TLDR for each video, but it is beneficial to watch as many as you have time for.*

* The **benefits of DNA sequencing** on **medicine** <https://www.youtube.com/watch?v=M3SLHhWYxiY>
  + TLDR: Medicine is currently largely reactive, but it is widely known that preventative measures are better. What if we could diagnose and begin treating diseases before symptoms even present? Looking at your genome can help reveal diseases that are rooted in genetics, and considering 9/10 deaths are related to genetic issues, this would be a very valuable preventative measure. So, should we have access to our genome for medical reasons?
* An unbiased look **behind the scenes** of **23andme**, by SmarterEveryDay <https://www.youtube.com/watch?v=U3EEmVfbKNs>
  + TLDR: 23andme never actually gets your DNA sample, nor can they relate it back to you (only to an email address). The labs that sequence the DNA are separate from 23andme and all they have is your sample and a barcode, whereas 23andme uses barcodes and email addresses, therefore allowing them to send the results from the lab with the same barcode to the provided email address. 23andme only sequences a tiny fraction of your DNA (0.02%). If you opt for your sample to be destroyed after being sequenced, then it will be destroyed.
* **What DNA ancestry tests can/cannot tell you**, and **privacy**, a two-part series, by Vox & the Verge:

1. <https://www.youtube.com/watch?v=IIWlatQt4KE>

* TLDR: Certain genetic markers are present in particular parts of the world, with varying probabilities of occurrence among those locations. The percentages (e.g. 86.7% Western Asian) you get on your results are just probabilities, generated from the set of genetic markers that you possess – there’s no way of telling where you actually came from, and the small percentages can be ignored. Furthermore, the location of markers are based off of where they are in the modern world, not where they would have been for your ancestors, and with global travel and multiculturalism becoming more and more prevalent, the real truth about where you came from is becoming more and more hidden. Still, these tests can be useful for getting a general idea, and also for reuniting lost family members.

1. <https://www.youtube.com/watch?v=7q8Oa97a04g>

* TLDR: The Golden State Killer was a serial rapist and murderer who terrorized California in the 70’s and 80’s. Despite never giving his DNA to a company (like 23andme or ancestry.com) he was able to be caught and charged in 2018 after detectives uploaded his DNA (taken from crime scenes) to GEDmatch, a large online DNA database. The database returned ~20 relatives and using this information they were able to create a family tree and narrow down the suspects. After researching the suspects, they were confident Joseph James DeAngelo was the suspect, and after sequencing DNA from a tissue taken out of his trash can, they were certain. Now, whilst catching criminals is great, this is also a privacy concern, because individuals who haven’t uploaded their genome can still be identified, so long as enough relatives have uploaded theirs. A population with common ancestors and be almost completely identifiable by only 2% of the DNA from that population. Privacy is no longer privacy if it’s no longer a choice you have the power to make and protect.

## XY Exercise (breakout group activity)

*The following activity will take place during the seminar – but you may find it helpful to read over this information beforehand.*

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**Consider the following scenarios, and the videos above.**

**Two university students are discussing using a genetic analysis kit that can be purchased online. We’ll call the two students ‘A’ and ‘B’.**

A: Hey, have you heard of this company before? You can order one of these kits and all you have to do is send away some of your saliva – then they tell you all about where your family is from and what diseases you’ll get! Neat, right?

B: You would really do that? Give this company a whole vial of your DNA? Aren’t you worried that they’ll clone you?

A: Well, it says on their site that the DNA is destroyed after they analyse it. And it’s all totally legal. Besides, I have a family history of Alzheimer’s and the site says that it can tell you whether you’ll get it or not.

B: That doesn’t sound right – you can’t tell that for sure. Maybe they can say whether you’re more likely to get it…

A: I’m not sure, they’re not really clear on what the percentages mean. But wouldn’t it be cool to find out all this information about yourself? Besides, it says that this kind of information is really helpful for scientists trying to understand genetic diseases. And it says that in the future medicine will be personalised to our individual genome. Like maybe they’ll be able to tell if you have a penicillin allergy before actually giving you penicillin, or which cancer treatments would be most effective for you…

B: Right, but isn’t it a bit creepy to think about all this data just lying around? What if people can just look this up? Like you’re applying for a job and your employer finds out that you’re 10% more likely to have a heart attack than the average person so they don’t hire you?

A: I’m sure that DNA data is uploaded anonymously.

B: Sure, but you share your DNA with a load of distant relatives. What if someone can identify one of them, and then work out who you are?

A: I know, I know – but this could man that I have better medical care in the future, and it would also help scientific research. If I can help people like this, shouldn’t I try?

\*

As a group, discuss the following questions:

1. As a group, briefly discuss what you think are the most important ethical issues surrounding the privacy of genomic data.
2. Which of the barriers to ethical decision making can apply to privacy of genomic data? Remember that the barriers are
   1. Partisanship
   2. Rationalisation
   3. Implicit/unconscious bias
   4. Ethical blindness
   5. Reasoning with a false equivalency
   6. Ethical scripts
3. What are some positive and negative outcomes of sharing genomic data? How can these outcomes be managed by being ethically cautious?

Remember the principles of ethical caution from the lectures are: considering the ‘precautionary principle’, providing ‘safe exits’, and engaging in ‘defensive driving’.

1. Discuss as a group – would you use a service like 23 and Me? Why/why not?