



Online Ethics Center  
FOR ENGINEERING AND SCIENCE

# Selected Issues in Depth - Genetic Data and Privacy

## Year

2014

## Description

As part of unit 7 of the [Course on Genomics, Ethics and Society](#), this page includes a number of short clips from Dr. Bennet Greenspan and Dr. John Mendelsohn discussing issues around genetic data and privacy.

## Body

For this, our final unit, we have a 20 minute TED video, and a bunch of short clips from two speakers. Our speakers are Dr Bennett Greenspan, a pioneer in genetic genealogy, currently managing partner of *Gene by Gene* and the CEO of *Family Tree DNA*; and Dr John Mendelsohn, former President of the MD Anderson Cancer Center in Houston. Here's a link to Bennett Greenspan's Wikipedia page:

[http://en.wikipedia.org/wiki/Bennett\\_Greenspan](http://en.wikipedia.org/wiki/Bennett_Greenspan) and to Dr Mendelsohn's page at MD Anderson: <http://www.mdanderson.org/about-us/facts-and-history/md-anderson-s-past-presidents/john-mendelsohn-m-d-/md-anderson-s-past-presidents-john-mendelsohn.html>

However, before looking at these clips, we'd first like you to watch a TED talk by Wendy Bonython from the School of Law at the University of Canberra, Australia, filmed in in December 2013, on genetic privacy.

Bonython provides us with some background here by talking about the changes in genomics that have led to concerns about genetic privacy, then moves on to discuss direct to consumer genetic tests, in particular the company 23&Me. (You can find the website for 23&Me here: <https://www.23andme.com/>) She argues that even if worries about what the tests tell us about disease risks could be resolved, questions about genetic privacy remain. What happens to genetic data obtained by direct to consumer companies? How is this genetic data protected in cyberspace? And what about genetic data obtained by our doctors? In Australia, it's legal for doctors to tell other family members about relevant genetic information obtained from us, even if we have not consented: their "right to know" she says trumps our right to privacy. (This is a particularly interesting case of potentially conflicting rights).

Bonython also raises some interesting questions about what rights we have with respect to our genetic data; and not only us as individuals, but our families and future generations. She argues that we need better laws offering much more protection for our genetic data, and that - since we all have a genome - we are all stakeholders in working together to create such laws.

Our first clip here is from Dr Bennett Greenspan. In this first clip, he describes how he (Bennett Greenspan) can be identified by the genetic repeats that he has inherited from his father:

In this second clip Dr Greenspan explains what such genetic repeats can tell us. In a well-known case, he discusses whether a Jefferson male (perhaps Thomas Jefferson) had fathered a child with Sally Hemmings. Looking at the Y-chromosomes he says, tells us for sure that a Jefferson male did indeed father a child with Sally Hemmings. However, the DNA test can't tell us which of four possible Jeffersons was involved: all we can tell from the DNA is that it was one of them; we would need other kinds of historical records to work out who was where when, and which male was involved.

This case shows us what DNA tests can reveal - and how powerful genetic information can be. Now, as chair of a DNA testing and preservation company, Dr Greenspan is asked about how he stores other people's genetic samples, what happens to these samples, and who access access to them. Although his account suggests that there's not much to worry about here, and that it's very useful for the consumer to have continuing access to their preserved DNA, the concerns raised in Bonython's talk should not be forgotten:

Our second speaker here is Dr Mendelsohn. He's speaking from the perspective of medical research in a large hospital, rather than from a direct to consumer testing service; and he begins by addressing a rather different problem about the broadcast of genetic information: *hoarding* rather than *sharing* data. In the medical world, he points out, huge amounts of data is stored (very expensively). This data is hoarded because it might include intellectual property in it from which money can be made; and the prospect of making money prevents data from being shared in ways that could promote research (although not necessarily protect privacy).

Dr Mendelsson goes on to argue that - in terms of medical research at least - restrictions to protect patient privacy are having the effect of slowing down research - an argument that looks, in essence, like a claim that the general gains to health from medical research outweigh (in certain forms at least) a patient's right to privacy. (This looks very different from Dr Wendy Bonython's position). Dr Mendelsson also argues that if medical records, presumably including genetic data, were standardized and available for transmission between hospitals, individuals would also benefit, since if they were injured or ill away from home, all the records from their home hospital would be immediately available to the physicians treating them elsewhere.

Finally, Dr Mendelson considers a particularly difficult case of an "incidental finding," one of the really tricky kinds of cases here. Someone is tested genetically for one disease - say, colon cancer - and they are found to have a BRCA1 mutation which increases the risk of breast and ovarian cancer. This has nothing to do with the colon cancer. But should the patient be told? By whom? And what about the patient's family - the patient's daughter, for instance, since BRCA1 mutations are inherited? What should offspring be told about genes they may have inherited that increases their risk of disease? Dr Mendelson argues for sharing, though recognises that this raises both practical and ethical issues; as you'll recall, Dr Bonython was much less enthusiastic about doing so.

Bonython's TED talk, and these clips, then, raise a number of significant questions about genetic privacy, in the context of direct to consumer testing and the storage and transmission of data; in the context of sharing genetic data for medical research; and in terms of informing patients and families of the results of genetic

tests. These issues are likely to become much more widely discussed, and (eventually) to form the basis for a new round of legislation on genetic privacy.

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## **Resource Type**

Instructor Materials

Multimedia

## **Topics**

Privacy and Surveillance

Informed Consent

Human Subjects Research

## **Discipline(s)**

Genetics and Genomics

Life and Environmental Sciences