

NATURE | RESEARCH HIGHLIGHTS: SOCIAL SELECTION

# Should DNA donors see their genomic data?

Geneticists discuss on social media the pros and cons of giving genome results to study participants.

Rachel Becker

03 December 2015

Geneticist Charles Danko turned to Twitter this week to ask for help in convincing his institutional review board (IRB) at Cornell University in Ithaca, New York, that he should be allowed to let his study participants download their genetic information. He tweeted:



**Charles Danko**  
@charlesdanko

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Writing IRB amendment to give subjects their genomic data. IRB does not like. Suggested reading to make the case? CC: @erlichya @dgmacarthur

Several scientists responded to Danko's request, including computational geneticist Yaniv Erlich at Columbia University in New York, who pointed out that direct-to-consumer (DTC) genetics companies such as 23andMe already give people their data.



**Yaniv Erlich**  
@erlichya

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.@charlesdanko @dgmacarthur Another argument is that ~2 million people have access to their raw genetic data through DTC (e.g. 23andMe) 1/n

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**Yaniv Erlich**  
@erlichya

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**@charlesdanko @dgmacarthur** No adverse events have been reported so far due to access to raw data. Other research projects do the same 2/n

Researchers, regulators and companies have long debated how much genetic information people should receive. Some say that raw data could be misinterpreted because of the difficulty of accurately predicting disease risk on the basis of genetics. After two years of review, in October the US Food and Drug Administration allowed 23andMe, based in Mountain View, California, to offer a limited number of health-related genetic tests to the public. A June study in the journal *Public Health Genomics* noted that customers generally understand such genetic results. However, a paper in the *Journal of the American Medical Association* reported that even clinicians can find it difficult to interpret whole genome scans.



Nature's snapshot of science on social media

Danko and his group want to investigate how differences in human DNA sequences in regulatory regions affect the timing and levels of gene expression. The protocol they submitted to their IRB for approval included a provision to share genomic data with people who donate their DNA. He says that research subjects have the right to see their own data. But Danko felt that the IRB approval was taking too long, so he withdrew the protocol and resubmitted it without the data-sharing provision. He hopes to eventually add it back as an amendment, and used Twitter to ask for information that he could use to bolster his case for data sharing.

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"The objection to data sharing that I see come up often is that incidental findings from a patient's data set may tell them something about their susceptibility for disease. In some cases, participants may not want to know," Danko says. "However, I am not convinced that the risk outweighs a subject's right to access their own data."

Erlich shares Danko's scepticism about the potential risks of sharing genetic data with patients, and says: "I'm not aware of any case that someone — basically, just by having access to the raw data — suddenly did something, or suddenly freaked out." In October, Erlich launched a crowdsourced database called DNA.LAND, to which people can submit their genome data for research.

Danko also reached out on Twitter to the Genomes 2 People research programme directed by Robert C. Green, a medical geneticist at Brigham and Women's Hospital in Boston, Massachusetts. The programme had a few concrete suggestions for him, such as tailoring the presentation of personal test results by test type.



[@charlesdanko](#) [@dgmacarthur](#) Consider how subjects will understand, perceive and make decisions based on returned info [genomes2people.org/wp-content/upl...](http://genomes2people.org/wp-content/upl...)

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Green added in an interview that the most ethical way of releasing raw genetic data to study participants is still not clear. A concern is that people “who may not be aware of all of the incredible complexity involved in our current, early efforts to interpret genome information could make themselves very confused and could misinterpret the raw information,” Green says. “At this moment in history, we should allow it, but we should be very transparent about the limitations of interpreting raw data.”

*Nature* **528**, 167 (10 December 2015) doi:10.1038/528167f

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