



Study Investigates Trust in Genomic Data Sharing Initiatives to Inform Future Efforts

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NEW YORK – Results of an international online survey have shown that trust in genomic data sharing efforts varies across countries, age, gender, educational level, and religiosity. Regardless of various demographic characteristics, though, those surveyed expressed the greatest amount of trust in their own medical doctors and the lowest in others, especially companies and governments.

The ongoing effort — called [Your DNA, Your Say](#) — based its results on responses from nearly 9,000 people from the US, UK, Canada, and Australia. The findings were [published earlier this month](#) in the journal *Human Genetics*.

Anna Middleton, chief investigator of the YDYS study, said that the project has collected 35,000 surveys from 22 countries since it commenced in 2016 and that the current study, which is focused on English-speaking countries, is just one of several to come.

"The trust paper, which explores views from the English-speaking public, will be expanded shortly to consider the views of public audiences who speak Urdu, Arabic, Japanese, Mandarin, Swedish, German, plus many other languages," said Middleton, who is head of the Wellcome Genome Campus Society and Ethics Research Group in Cambridge, UK, and corresponding author on the paper.

The YDYS study has its roots in the Global Alliance for Genomics and Health, an international organization that aims to set policy and standards for genomic data sharing initiatives. A team of GA4GH's regulatory and ethics group tasked with looking at participant values decided to organize the survey to gauge public attitudes toward genomic data sharing in a way that could be used to compare data across languages and between countries and cultures. Investigators involved in the study previously [described the survey](#) in a paper last year.

For the recently published study, researchers examined a dataset of 8,967 English-speaking respondents who were randomly recruited by email by Dynata, a Plano, Texas-based market research company. Participants received a small financial reward for taking part, roughly £1 (\$1.2), and were asked to respond to 29 questions online.

Those who took part in the survey were queried about what factors would influence their decision to donate their DNA and medical information, including questions about familiarity with genetics and concerns about data security. They were also asked to indicate if they would trust certain actors, including medical doctors, university researchers, company researchers, and their government with their data. In addition, the investigators collected data about their age, relationship status, whether or not they had children, ethnicity, education, and religiosity.

The researchers were able to break respondents down into three groups: those with high trust in data sharing efforts; those with variable trust, depending on the situation; and those with low overall trust. Sixteen percent of respondents fell into the high-trust group, meaning they tended to trust actors — from

medical doctors to their government — with their data, while 43 percent fell into the variable group. This group expressed a high level of trust in their medical doctor but moderate trust in university researchers and low trust in companies and their government. Forty-one percent of participants had low trust in all of the categories.

Those in the high-trust group tended to be men from the US younger than 50 with children, more educated, and have had a personal experience with genetics. They were also more religious, and they were the most likely to be willing to donate their genomic and health data for clinical and research uses.

Those in the variable group tended to be from the UK, and the low-trust group was similarly more likely to be from the UK, while also being single, widowed, or divorced. This group was also less reassured than other respondents by laws preventing exploitation of donated information.

Issues of trust

Barbara Prainsack, a professor for comparative policy analysis at the University of Vienna and a coauthor on the paper, said it was the first study to delve deeper into the issues of trust in a large-scale sample of English-speaking people across the UK, US, Canada, and Australia.

"We have known for a while that trust is a really important factor that can determine whether people are willing to share their data, and with whom," she said. "But there has been hardly any evidence so far from large-scale studies on what factors are associated with higher or lower trust, and who people trust."

According to Prainsack, these kinds of studies help to better understand how trust works. She said that trust is often seen as an unchanging factor, rather than one that can fluctuate. "We need to shift from a static view of trust to one that treats trust as a living and breathing relationship, where both sides do things to earn, maintain, or lose trust of the other," Prainsack said.

People dislike when organizations know more about them than they do about those entities, Prainsack noted. She cited a [2016 report](#) prepared for the Wellcome Trust that dubbed this effect, the one-way mirror.

"Both our research and our policy needs to pay much more attention to how we can build and maintain institutions that deserve the trust of people," said Prainsack. "This paper is the first step to understanding better what characteristics people have who have high trust, and what and whom they trust," she added. "This is the first step in building better institutions."

Prainsack said she is currently working with other researchers to prepare a paper focused on results from participants surveyed in German-speaking countries.

Susan Kelly, a professor of medical sociology at the University of Exeter in the UK, said the YDYS study was "pretty unique" given the effort's scope and size. She said she would like to see the findings of the current paper replicated in non-English-speaking parts of the world and would like to see the results replicated in a non-genetic exposed population. She also suggested the survey results could be followed longitudinally.

"That it is a snapshot in time is noteworthy in that it captures what people's experience online is just now, which may change as people have more experience," said Kelly.

Kelly has studied the role of trust in data-sharing projects extensively. In 2015, she and her coauthors [published a study](#) in *PLOS One* that evaluated the consent preferences of 2,309 volunteers from the Twins UK Registry. For that paper, the researchers asked respondents to complete an online survey about their views on the consent process for use of their DNA and medical information in research.

Kelly said the new YDYS paper is likely to be of interest in genomics as well as in clinical medicine. She called the study "interesting and impactful," but didn't speculate about how exactly it might be used. "That is a difficult question," she said, "but issues of trust online, not just having to do with DNA, are important."

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