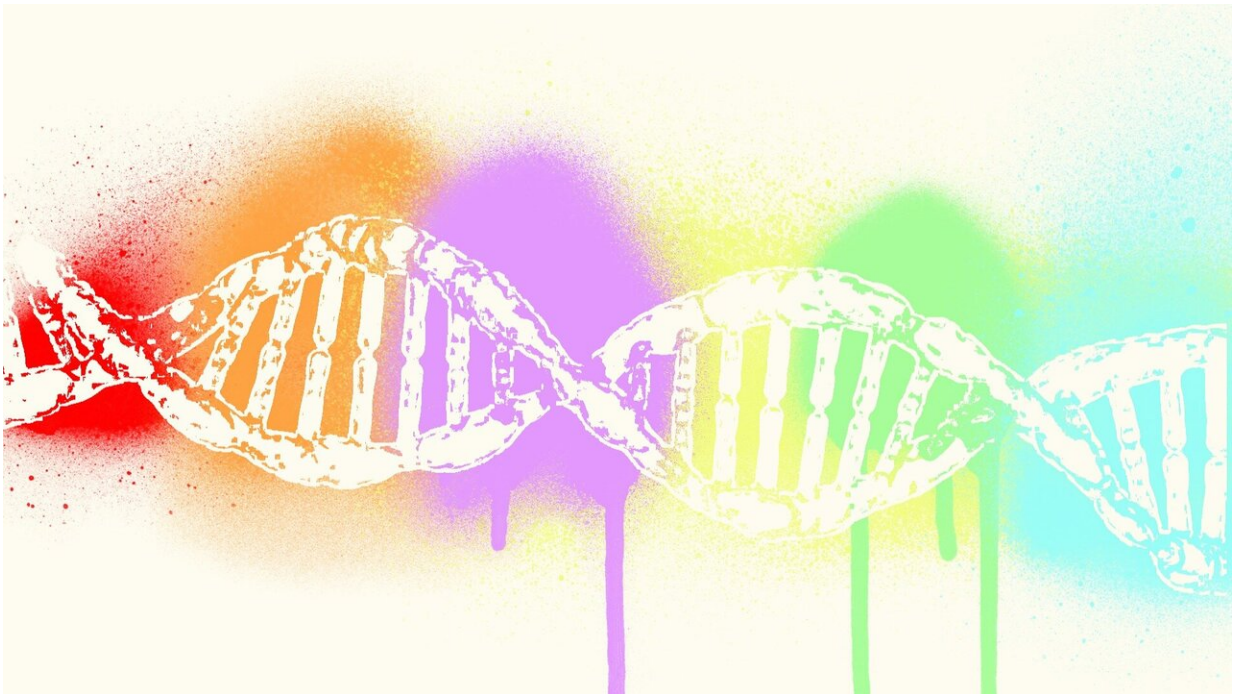


More than half of Americans want money, control in exchange for genetic data

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As people become more aware of privacy concerns and the ways in which genomic database companies are profiting from their data, their expectations for compensation and control may increase, according to researchers at Penn State and Cornell University.

"As human genomic data collection rises, the organizations responsible

for managing these data are developing and refining their internal policies and protocols related to data end uses, transparency and security, for example," said Forrest Briscoe, professor of management and organization, Penn State. "In a survey of more than 2,000 people, we found that the majority of respondents clearly prefer a more transparent and participant-centric governance approach that gives them more control, confidence and compensation."

The researchers created a survey based on in-depth field interviews with officials and employees who were involved in genomic governance at 12 different organizations. They recruited 2,020 participants—representative of the U.S. population—through Qualtrics to participate in the survey and provided them with mainstream media coverage of genomic database companies. The results will appear on March 11 in *PLOS ONE*.

Next, the team provided participants with a scenario:

"Imagine that today you are presented with an opportunity to provide your DNA data to Genetic Data Inc. [one of five similarly named fictitious companies], to be used in a biomedical research program. They can obtain your DNA data if you provide them with a small saliva sample. Genetic Data Inc. is a U.S. for-profit technology corporation. Based on this information, and what you have just learned about DNA data, how willing would you be to provide your DNA data to Genetic Data Inc.?"

The four response options were: "Willing as a charitable donation," "Willing if I'm paid at least a certain amount of money," "Unwilling, at least for now" and "Unwilling, now or ever". Those who were willing to provide their data if they were paid were asked how much they would expect to be paid. All of the participants were also asked how much they would pay the company to obtain a report containing information about

their ancestry and forecasting their risk for 20 different genetically based [health conditions](#).

The team found that 11.7% of respondents were willing to altruistically donate their data, 50.6% were willing to provide data only if they were financially compensated and 37.8% were unwilling to provide data regardless of compensation. For the altruistic donors, the median net expected payment—after subtracting the amount they were willing to pay for a personalized report—was -\$75, while the median net expected payment for respondents who wanted to be compensated for their data was +\$95.

"Our results suggest that as public awareness grows regarding the commercial aspects and privacy issues of genomic databases, individuals' expectations for compensation in exchange for data provision may rise," said Briscoe.

The researchers also asked participants questions about how willing they would be to provide genomic data to companies given 12 different governance policies.

The three policies that increased willingness the most were:

- ability for [data providers](#) to request that their data be deleted
- assurance that providers' data would not be sold or shared beyond the organization collecting it
- assurance that companies' re-use of provider data would require specific permissions

The three policies that decreased willingness the most were:

- selling database access to pharmaceutical firms
- providing data to the federal government

- retaining data indefinitely without a specified date for destruction

"A common denominator across our governance policy findings is a preference for restrictions on sharing or reuse, unless permission is specifically granted by the individual," said Briscoe. "These preferences appear to pose a challenge for the goals and business models of many commercial and public database-owning organizations, which often envision that their databases will serve multiple scientific and commercial purposes through access arrangements with multiple outside partners."

Yet, Briscoe added, technological solutions are being pursued that might give individual data providers more control over who accesses and uses their data and what their data are used for, while also allowing data sharing to meet the needs of health care, academic and industry communities. For example, DNA blockchains can enable people to have their genomes sequenced and then rent or sell access to them at their own discretion.

"Our findings offer a forward-looking window on individual preferences that can be useful for institutions of all types as they develop governance approaches in this area of large-scale [data](#) sharing," he said.

More information: *PLOS ONE* (2020). journals.plos.org/plosone/article?id=10.1371/journal.pone.0229044

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