Informed Opinions on Genomic Data Use: Control vs. Money

How much value is there in genomic data donated by the public to companies? How these data might be used? Should providers be compensated somehow? As soon as people become aware of these issues, they start questioning the use and security of their genetic information, shows a recent research.

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The first nationally representative survey to consider DNA collection from both nonprofit and for-profit settings in the U.S. (Briscoe et al. 2020) focused on public attitudes regarding genomic database governance. While in prior research data provision was mainly framed as altruistic donation, in the current work the authors explored how public perception is formed when several growing trends are considered, namely:

- Availability and usage of genomic databases in many sectors besides academic biomedical research.
- Commercial value of these data.
- Emerging additional privacy risks.

The authors conducted the Genomic Data Governance Survey (GDGS) among 2,020 U.S.-based respondents from 27 November to 20 December, 2018. The participants were shown a three-minute video comprising excerpts from mainstream media coverage on genomic databases, and then asked to complete a questionnaire to assess whether they were willing to provide genomic data, if they expected any payment for this, and how they viewed relevant governance policies.

Willingness and Compensation

The results showed that only 234 respondents (11.7%) were willing to freely provide their data. Another 1,022 participants (50.6%) would do this for a compensation, while 764, or 37.8% of participants would not contribute their data even if paid. The authors note that this contrasted with results reported by academic research biobanks, which find consistently higher (over 50%) rates of willingness to donate genomic data.

Interestingly, the median reported value of a desired compensation was €116 ($130) mirroring the sum covered in the pre-survey priming video. This finding suggests that perceptions and responses were influenced by the video.

Governance Policies

The survey also asked how 12 specific policies would affect participants' willingness to provide genomic data. The three policies that increased willingness in data providers the most were:

- The ability to request that their data be deleted.
- Assurance that the data will not be sold or shared.
- Reuse of the data will require specific permissions.

On the other side of the list were policies of:

- Selling database access to pharmaceutical firms
- Providing data to the federal government
- Retaining the data indefinitely.

Although the three groups of respondents reacted differently to various genomic governance policies, a common denominator was a preference for restrictions on sharing or reuse, unless the individual has specifically granted permission. As the current researched showed, when armed with more comprehensive information people expect greater security for their data and to be more in control over them.

References

Briscoe F et al. (2020) Evolving public views on the value of one's DNA and expectations for genomic database governance: Results from a national survey. PLoS ONE, 15(3):e0229044. Available from https://doi.org/10.1371/journal.pone.0229044

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