**Public Attitudes for Genomic Policy Brief**

# Trust and Trustworthiness

31 August 2022

Global Alliance for Genomics & Health

In situations where data misuse is possible, such as in interactions between patients or publics and genomics researchers, trust is essential. In this guest blog post, the Public Attitudes for Genomic Policy subgroup from the GA4GH Regulatory and Ethics Work Stream delves into the importance of building trust for genomics research.



*This guest blog post launches the start of a new series on Public Attitudes for Genomic Policy. This subgroup aims to disseminate the findings from the* ***Your DNA Your Say study*** *and other public attitudes studies into a series of blog posts and accompanying infographics. Touching upon a range of themes, these will inform the Global Alliance for Genomics and Health and external audiences on public attitudes towards genomic research and how policy and research should be designed to address these views.*

## What is trust and why is it needed?

Genomics research has great potential to contribute to improved human health for all by adding to our understanding of the complexities of the human genome and leading to improved diagnosis, treatments, personalized medicine and public health. The success of

genomics relies on (1) access to large and diverse sets of individuals' genomic and health data, and (2) the ability to share this data with other researchers in some form – potentially internationally. However, in making genomic and other health information available, individuals and communities may become vulnerable to the misuse of these data – whether intentional or not.

In situations where data misuse is possible, such as in interactions between patients or publics and genomics researchers, trust is essential. While definitions of trust vary, for the purposes of this document, we define trust as an attitude that enables an individual to rely on another to take a specific action. It is an attitude that arises within, and is fostered by, meaningful relationships between individuals and communities, and that relates to the perceived qualities of the person or organization being trusted.

Trust is especially essential when those providing data might already be considered vulnerable and when there is uncertainty about the future. In the case of genomics, people cannot generally be informed about all of the potential future uses of their data at the time at which those data are collected, because these uses may currently be unknown to researchers themselves. It may also be difficult to specify at the outset by whom data may be used. The potential negative consequences associated with the misuse of genomic data may be greater for individuals and communities who continue to face historical and contemporary injustices and inequalities associated with genomics, medical research and healthcare. Concerns about the use and potential misuse of data may also arise in relation to some users of data (e.g. commercial entities).

It is thought that public trust is an essential underpinning of willingness to engage with and support genomics initiatives, including donating data and facilitating public funding for genomic research. Where trust is absent, genomics initiatives may struggle to fulfill their potential because they cannot attract public support and engagement or secure future public funding.

## Whom do people trust with genomic data?

There is a growing literature on the importance and distribution of trust related to the donation of genomic data. In this brief, we concentrate on the findings of *Your DNA, Your Say*, a questionnaire survey that includes responses from 37,000 individuals across 22 countries. It explores levels of trust in the individuals and institutions collecting genomic and health data. The study found that overall levels of trust are highest among respondents in China, India, the UK and Pakistan and lowest among respondents from Egypt, Russia, Germany and Poland. Among the variety of data stewards presented, personal doctors were consistently the most trusted with DNA and health data. Across the countries, less than half of all respondents report trusting someone other than their own doctor. Respondents generally reported trusting researchers from non-profit research organizations substantially more than researchers from for-profit organizations. It was also found that all organizations within the same country were trusted more than the equivalent organizations outside a respondent's own country. This reflects previous findings (see for example references 3 and 9) that commercialisation can reduce trust and that trust may decrease when data moves across borders.

In addition, the findings from *Your DNA, Your Say* demonstrate the importance of trust in individuals' decisions about donating genomic data, and thus for the future of genomic medicine. Across the study, respondents who trusted more were substantially more likely to be willing to donate their genomic and health data for research than those who trusted less. Those who trusted an organization were also more likely to donate data for use by that organization than those who did not.

## How might genomics research obtain and sustain trust?

While public trust appears to be important, it is less clear how it can be obtained and sustained by genomics initiatives. A more tractable approach is to ask what genomics initiatives can do to be seen as worthy of trust by the wider public? The *Your DNA, Your*

*Say* study explored a range of options that may foster trust, from transparency about data use, to direct interactions with data gatekeepers, to details about sanctions. It examined how these different options were rated by respondents across the 22 countries studied. The most important thing that respondents said would enable trust was transparent information about who would benefit from data access (the most selected option in 17 countries). This was followed by the option to withdraw data and to be provided with information about who is using data, and for what purpose. In contrast, providing websites about data access, biographies of researchers, and enabling direct communication with gatekeepers were seen as less important. Respondents in a few countries diverged significantly from this general pattern. For example in Japan the most important factor seen as enabling trust was knowing what sanctions would be in place in the case of data misuse.

These variations are, however, of significant potential importance for making policy around the development of genomics initiatives. There are some cases where the strength of variation may flag potential challenges associated with international standard setting and policy making. In the *Your DNA, Your Say* study, this was the case for responses from China, Japan and Russia, which differed substantially from those of respondents from other countries in the perceived value of measures to enable trust. However, even where variation is less pronounced, policy should be attentive to the local contexts in which trust is established, to the work involved in establishing trusting relations and with historically underserved or excluded communities.

## Conclusion

The findings of the *Your DNA, Your Say* study on public attitudes regarding genomic and health data sharing show that trust is an important factor in the willingness of members of the public to donate DNA and health data. However, respondents' attitudes of trust varied in relation to different organizations using data. There is also considerable variability in attitudes of trust among respondents from different countries. Doctors are

generally trusted the most, commercial entities the least, and data users outside an individuals' own country trusted less than domestic users. These findings reflect the wider literature on trust.

These findings on trust highlight the importance of building relationships of trust for genomics research. This can help people feel that their trust is justified, and that it is placed in those who are worthy of it. The findings of *Your DNA Your Say* suggest that important features of demonstrating trustworthiness include being transparent about the goals and benefits associated with genomics, allowing individuals to exert control over the inclusion of their data, and, in some contexts, strong enforcement regimes.

## Authors

This brief was prepared by Richard Milne, Maili Raven-Adams, Dianne Nicol and the Public Attitudes for Genomic Policy Subgroup, Regulatory and Ethics Work Stream, GA4GH.

## Your DNA, Your Say

More information on the *Your DNA, Your Say* study can be found here and in the publications below. The full dataset is available for download at https://osf.io/px3gb/

Middleton, Anna, Richard Milne, Mohamed A. Almarri, Shamim Anwer, Jerome Atutornu, Elena E. Baranova, Paul Bevan, et al. "Global Public Perceptions of Genomic Data Sharing: What Shapes the Willingness to Donate DNA and Health Data?" *The American Journal of Human Genetics* 107, no. 4 (October 1, 2020): 743–52. https://doi.org/10.1016/j.ajhg.2020.08.023.

Milne, Richard, Katherine I. Morley, Heidi Howard, Emilia Niemiec, Dianne Nicol, Christine Critchley, Barbara Prainsack, et al. "Trust in Genomic Data Sharing among Members of

the General Public in the UK, USA, Canada and Australia." *Human Genetics* 138, no. 11 (December 1, 2019): 1237–46. https://doi.org/10.1007/s00439-019-02062-0.

Milne, Richard, Katherine I. Morley, Mohamed A. Almarri, Shamim Anwer, Jerome Atutornu, Elena E. Baranova, Paul Bevan, et al. "Demonstrating Trustworthiness When Collecting and Sharing Genomic Data: Public Views across 22 Countries." *Genome Medicine* 13, no. 1 (May 25, 2021): 92.https://doi.org/10.1186/s13073-021-00903-0.

## Further reading

1. Bussey-Jones, Jada, Joanne Garrett, Gail Henderson, Mairead Moloney, Connie Blumenthal, and Giselle Corbie-Smith. "The Role of Race and Trust in Tissue/Blood Donation for Genetic Research." Genetics in Medicine 12, no. 2 (February 2010): 116–21.https://doi.org/10.1097/GIM.0b013e3181cd6689.
2. Carter, Pam, Graeme T. Laurie, and Mary Dixon-Woods. "The Social Licence for Research: Why Care.Data Ran into Trouble." Journal of Medical Ethics 41, no. 5 (May 2015): 404–9. https://doi.org/10.1136/medethics-2014-102374.
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4. Dive, Lisa, Christine Critchley, Margaret Otlowski, Paul Mason, Miriam Wiersma, Edwina Light, Cameron Stewart, Ian Kerridge, and Wendy Lipworth. "Public Trust and Global Biobank Networks." BMC Medical Ethics 21, no. 1 (August 15, 2020): 73. https://doi.org/10.1186/s12910-020-00515-0.
5. Kraft, Stephanie A., Mildred K. Cho, Katherine Gillespie, Meghan Halley, Nina Varsava, Kelly E. Ormond, Harold S. Luft, Benjamin S. Wilfond, and Sandra Soo-Jin

Lee. “Beyond Consent: Building Trusting Relationships With Diverse Populations in Precision Medicine Research.” The American Journal of Bioethics: AJOB 18, no. 4 (April 2018): 3–20. https://doi.org/10.1080/15265161.2018.1431322.

6. Lemke, A A, W A Wolf, J Hebert-Beirne, and M E Smith. “Public and Biobank Participant Attitudes toward Genetic Research Participation and Data Sharing.” Public Health Genomics 13, no. 6 (2010): 368–77. https://doi.org/10.1159/000276767.
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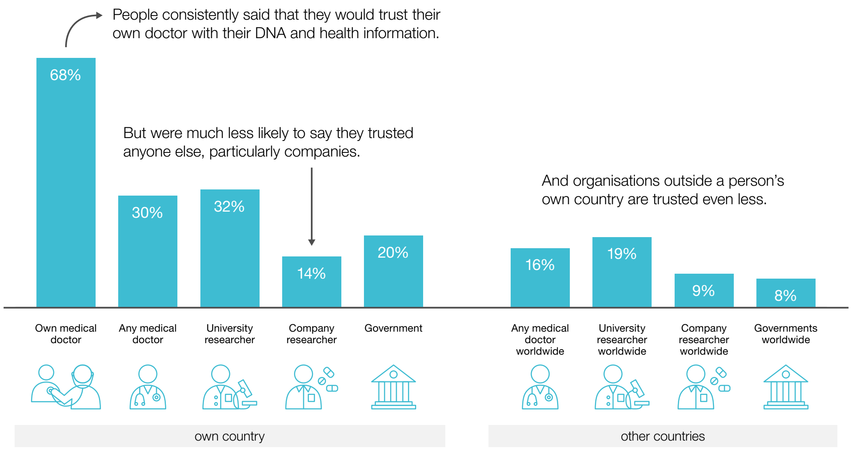
8. McGuire, Amy L., Mary A. Majumder, Angela G. Villanueva, Jessica Bardill, Juli M. Bollinger, Eric Boerwinkle, Tania Bubela, et al. “Importance of Participant-Centricity and Trust for a Sustainable Medical Information Commons.” The Journal of Law, Medicine & Ethics: A Journal of the American Society of Law, Medicine & Ethics 47, no. 1 (2019): 12–20. https://doi.org/10.1177/1073110519840480.
9. Nicol, Dianne, Christine Critchley, Rebekah McWhirter, and Tess Whitton. “Understanding Public Reactions to Commercialization of Biobanks and Use of Biobank Resources.” Social Science and Medicine 162 (2016): 79–87.
10. Passmore, Susan Racine, Amelia M. Jamison, Gregory R. Hancock, Moaz Abdelwadoud, C. Daniel Mullins, Taylor B. Rogers, and Stephen B. Thomas. “‘I’m a Little More Trusting’: Components of Trustworthiness in the Decision to Participate in”

*This brief is part of the Public Attitudes for Genomic Policy blog series, developed by the GA4GH Regulatory & Ethics Work Stream (REWS).* ***Visit here*** *to read the past brief.*

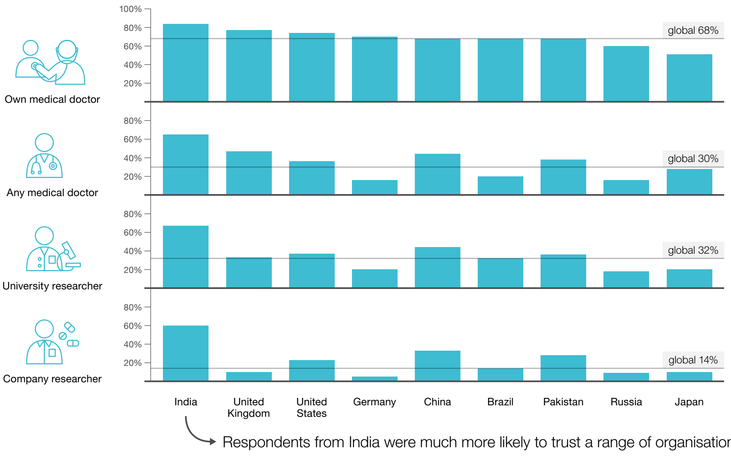
Your DNA, Your Say

# Trust is important in sharing data

## People trust different organisations differently with data




## How much trust people place in different organisations varies




How much people said that they trust differed across countries.

Company researchers were trusted less than university researchers, but the gap was bigger for respondents from the United Kingdom and Brazil than the United States or Pakistan.

Respondents from India were much more likely to trust a range of organisations than anywhere else.

## People who are more trusting were more willing to donate their data

People who trust
**only one organisation or none**



**34 out of 100 people**
will be willing to donate their DNA and medical information

People who trust
**more than one organisation**



**66 out of 100 people**
will be willing to donate their DNA and medical information


Middleton A, Milne R, Atutornu J, Costa A, Morley, K.I, Patch C, Robarts L, Roberts J, et al (2020) Global public perceptions of genomic data sharing: what shapes the willingness to donate DNA and health data? American Journal of Human Genetics, vol. 107, issue 4, pp 743-752.

Milne, R., Morley, K.I., Almarri, M.A. et al (2021). Demonstrating trustworthiness when collecting and sharing genomic data: public views across 22 countries. Genome Medicine [Online]. Volume 13, Article 92.


Your DNA, Your Say:
societyandethicsresearch.wellcomeconnectingscience.org/project/your-dna-your-say

Public attitudes for genomic policy brief:
ga4gh.org/product/public-attitudes-for-genomic-policy-blog-posts

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Global Alliance for Genomics & Health

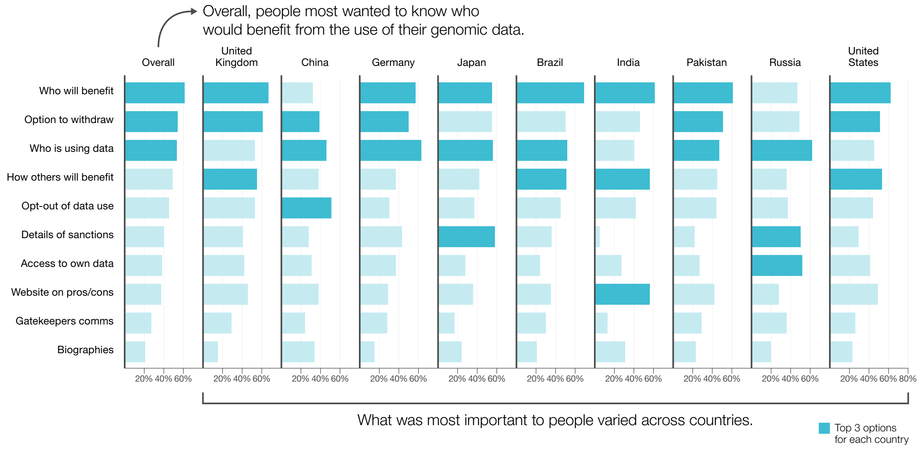
## Your DNA, Your Say

# What might help people trust?

## Ranking of what might help people trust

1. Information about **who will benefit** from the data access
2. The **option to withdraw** your data
3. Knowing **who is using your data and for what purpose**
4. Information about **how others will benefit** from the data access
5. The **option to opt out** of having your data accessed by other researchers
6. **Details about sanctions** if your data is misused
7. The **ability to access your own data**
8. A **website** that explains the pros and cons of data access
9. Being able to **communicate directly with gatekeepers** of your data
10. **Biographies and photos** of researchers who would access the data

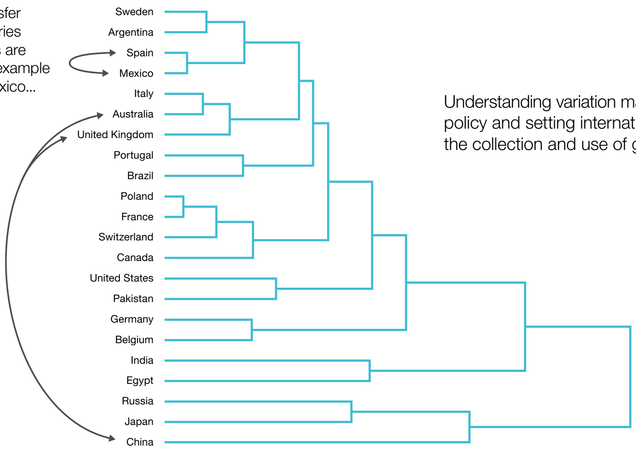
## But people in different countries see different measures as important




## And what people say is important is more alike in some countries than others

It may be easier to transfer policies between countries where similar measures are seen as important, for example between Spain and Mexico...

and less easy where differences are greater, for example between the United Kingdom or Australia and China.




Understanding variation may help when making policy and setting international standards for the collection and use of genomic data.


Middleton A, Milne R, Atutornu J, Costa A, Morley, K.I, Patch C, Robarts L, Roberts J, et al (2020) Global public perceptions of genomic data sharing: what shapes the willingness to donate DNA and health data? American Journal of Human Genetics, vol. 107, issue 4, pp 743-752.

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