Your DNA, Your Say

Trust is important in sharing data

People trust different organisations differently with data

People consistently said that they would trust their own doctor with their DNA and health information.

But were much less likely to say they trusted anyone else, particularly companies.

And organisations outside a person’s own country are trusted even less.

How much trust people place in different organisations varies

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.

How much people said that they trust differed across countries.

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

Your DNA, Your Say:

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

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

Overall, people most wanted to know who would benefit from the use of their genomic data. What was most important to people varied across countries.

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

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.
Return of research results

What results from genomics research to feed back to patients and participants is a persistent question.

Genomics research produces a range of results. Policies diverge on whether to return results to patients and participants, which ones to return and how to do so.

The interest and expectations of participants related to receiving research results is an important factor in this discussion.

Multiple studies have shown that research participants are highly interested in receiving their individual research results.

However, the evidence on public attitudes towards the return of results is dominated by a small number of countries.

And although we know that people are interested in receiving results we don’t know whether this motivates people to donate DNA and health data.

The Your DNA, Your Say study questioned 37,000 people across 22 countries about their views on genomics and data sharing. Across the 22 countries of the study there was no clear effect of return of results on whether or not people would be willing to donate their DNA and health data.

And the Your DNA, Your Say results suggest that the US does not seem to be a reliable guide to attitudes in other countries. The US alone accounts for 65% of studies of public attitudes towards the return of individual research results.

Respondents in almost all other countries were less likely to be wholly influenced in their decision to donate by the return of results than those in the US, and more likely not to be influenced.

GA4GH policy recommends the return of clinically actionable results from genomics research. However, there is substantial global diversity in public attitudes on the importance of return of results in motivating donation.