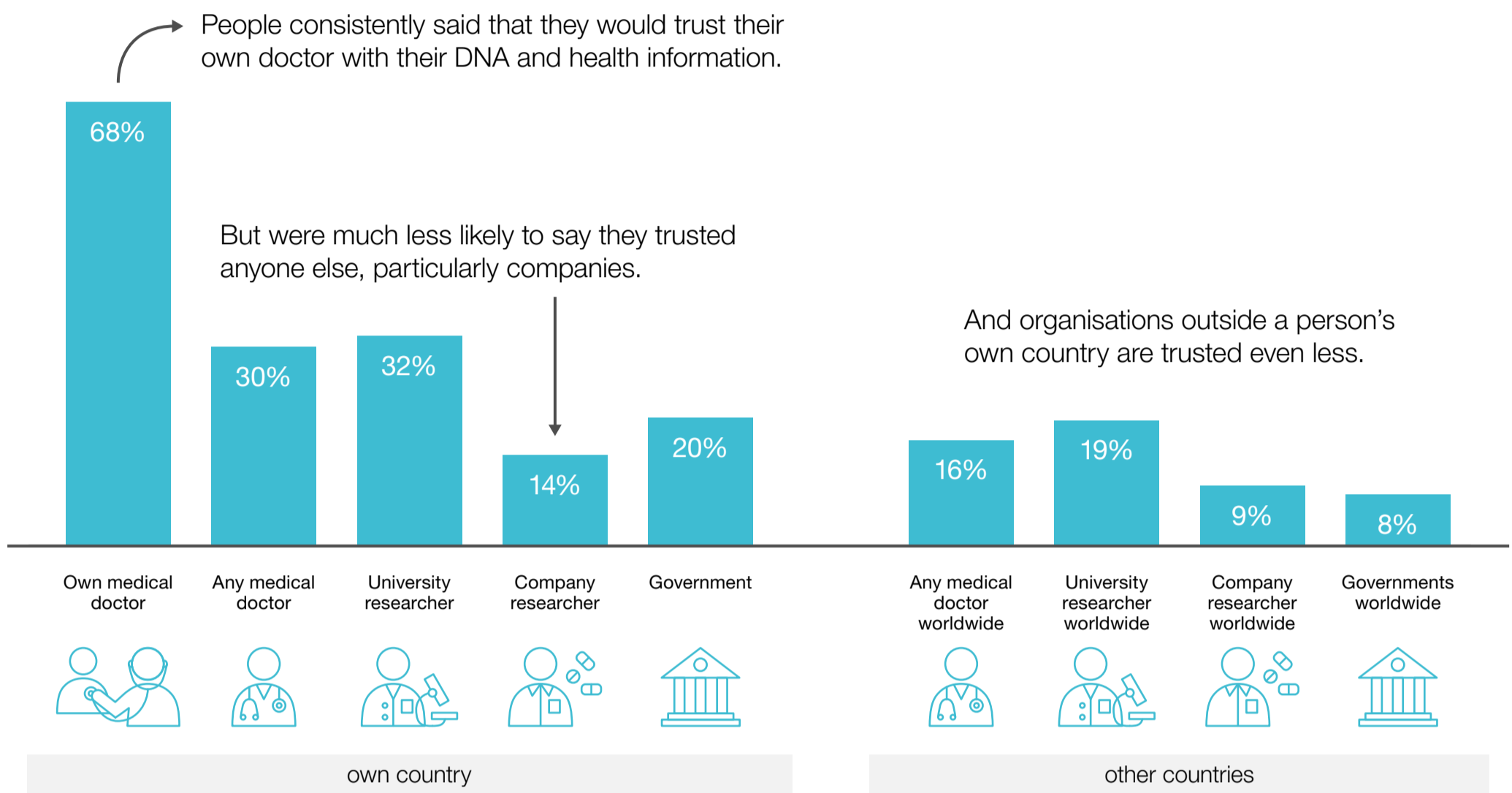
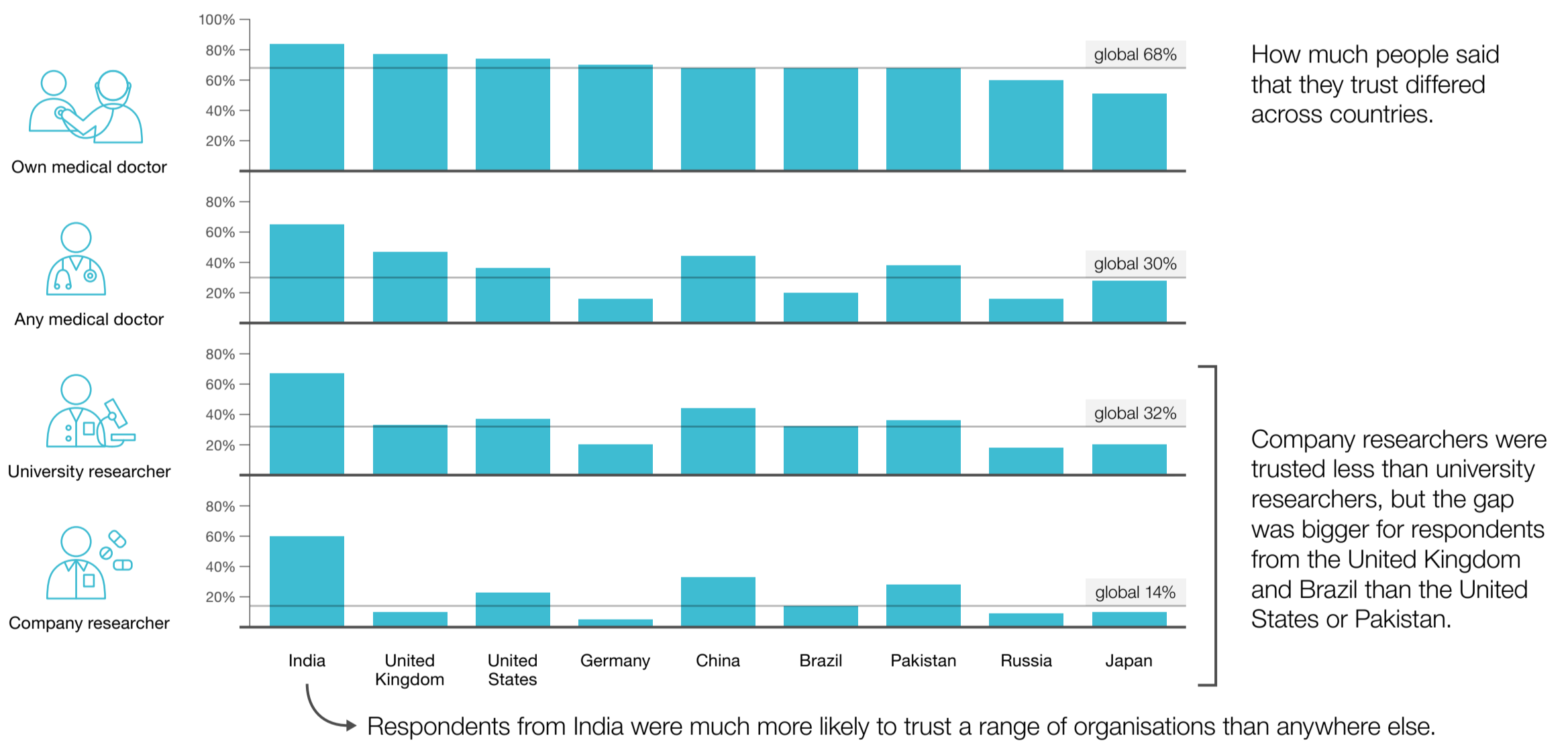


Trust is important in sharing data

People trust different organisations differently with data



How much trust people place in different organisations varies



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

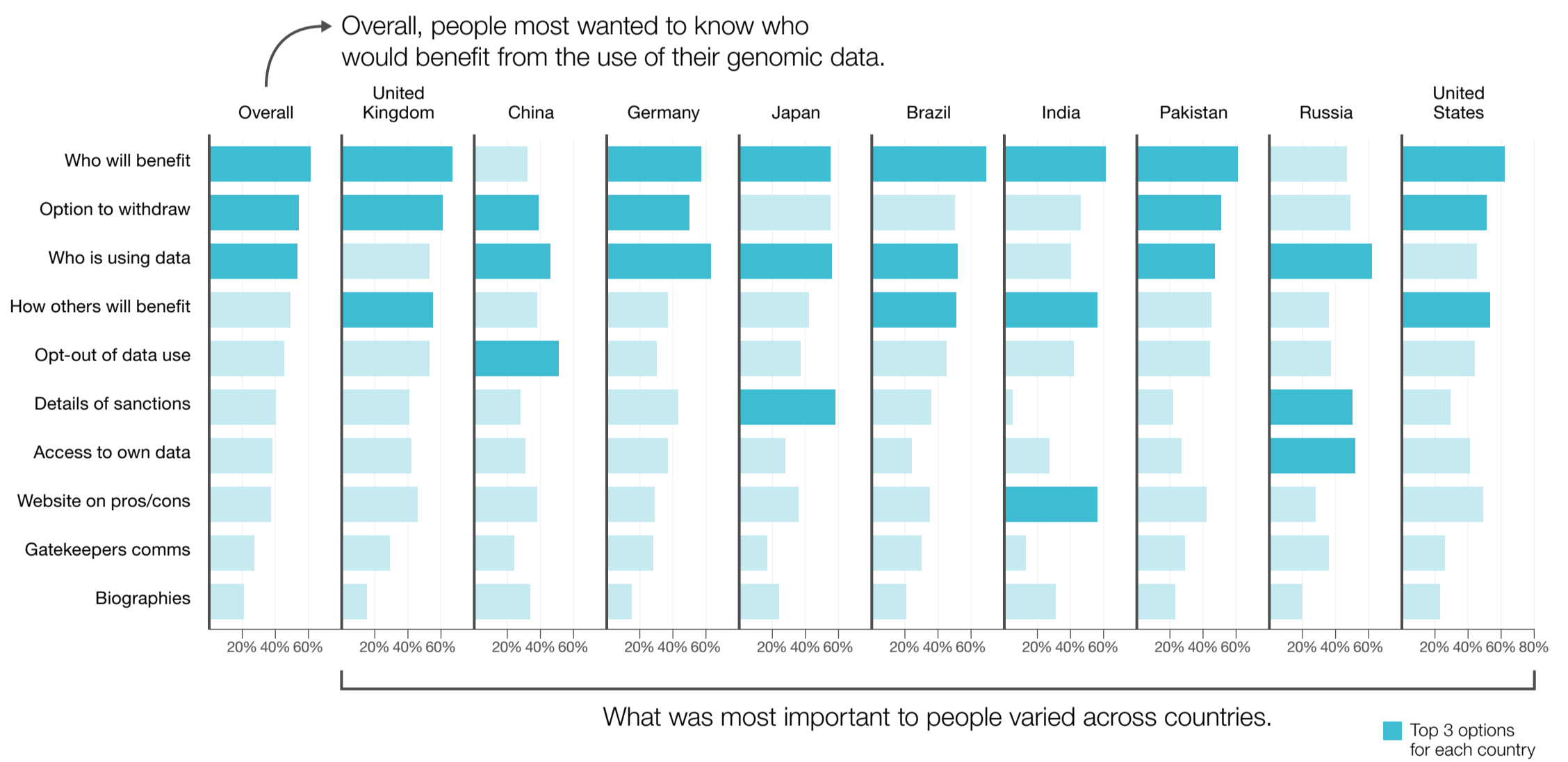
Middleton A, Milne R, Atutornu J, Costa A, Morley, K.I, Patch C, Roberts L, Roberts J, et al (2020) Global public perceptions of genomic data sharing: what shapes the willingness to donate DNA and health data? American Journal of Human Genetics, vol. 107, issue 4, pp 743-752.
 Milne, R., Morley, K.I.,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

What might help people trust?

Ranking of what might help people trust

- Information about **who will benefit** from the data access
- The **option to withdraw** your data
- Knowing **who is using your data and for what purpose**
- Information about **how others will benefit** from the data access
- The **option to opt out** of having your data accessed by other researchers
- Details about sanctions** if your data is misused
- The **ability to access your own data**
- A **website** that explains the pros and cons of data access
- Being able to **communicate directly with gatekeepers** of your data
- 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, Roberts 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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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.



clinical research setting

73%-95% of the public is **interested** in individual research results

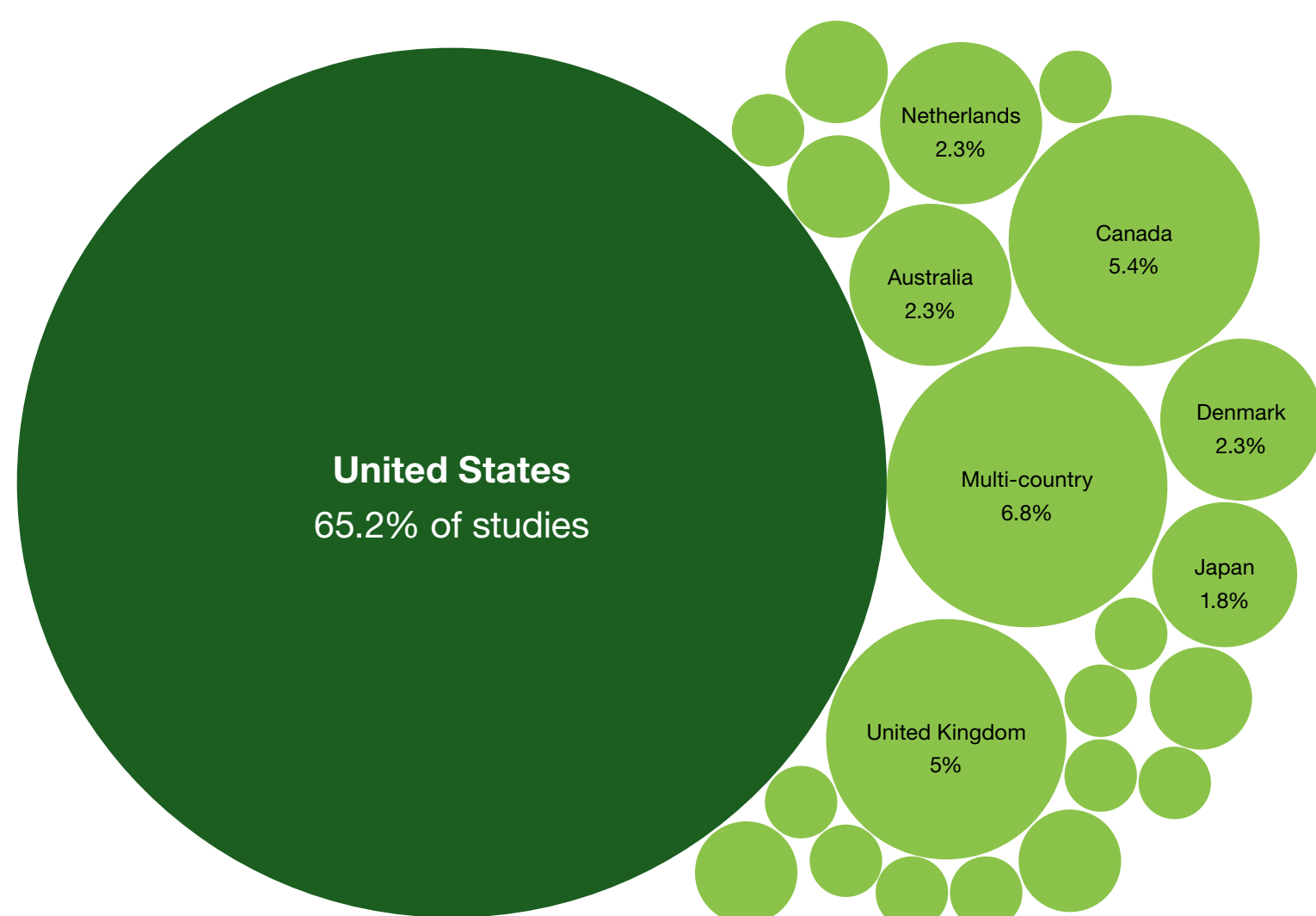


biobank setting

91%-98% of the public is **interested** in individual research results

Data: Danya Vears et al, 'Return of Individual Research Results from Genomic Research: A Systematic Review of Stakeholder Perspectives' (2021) PLoS ONE 16(11).

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

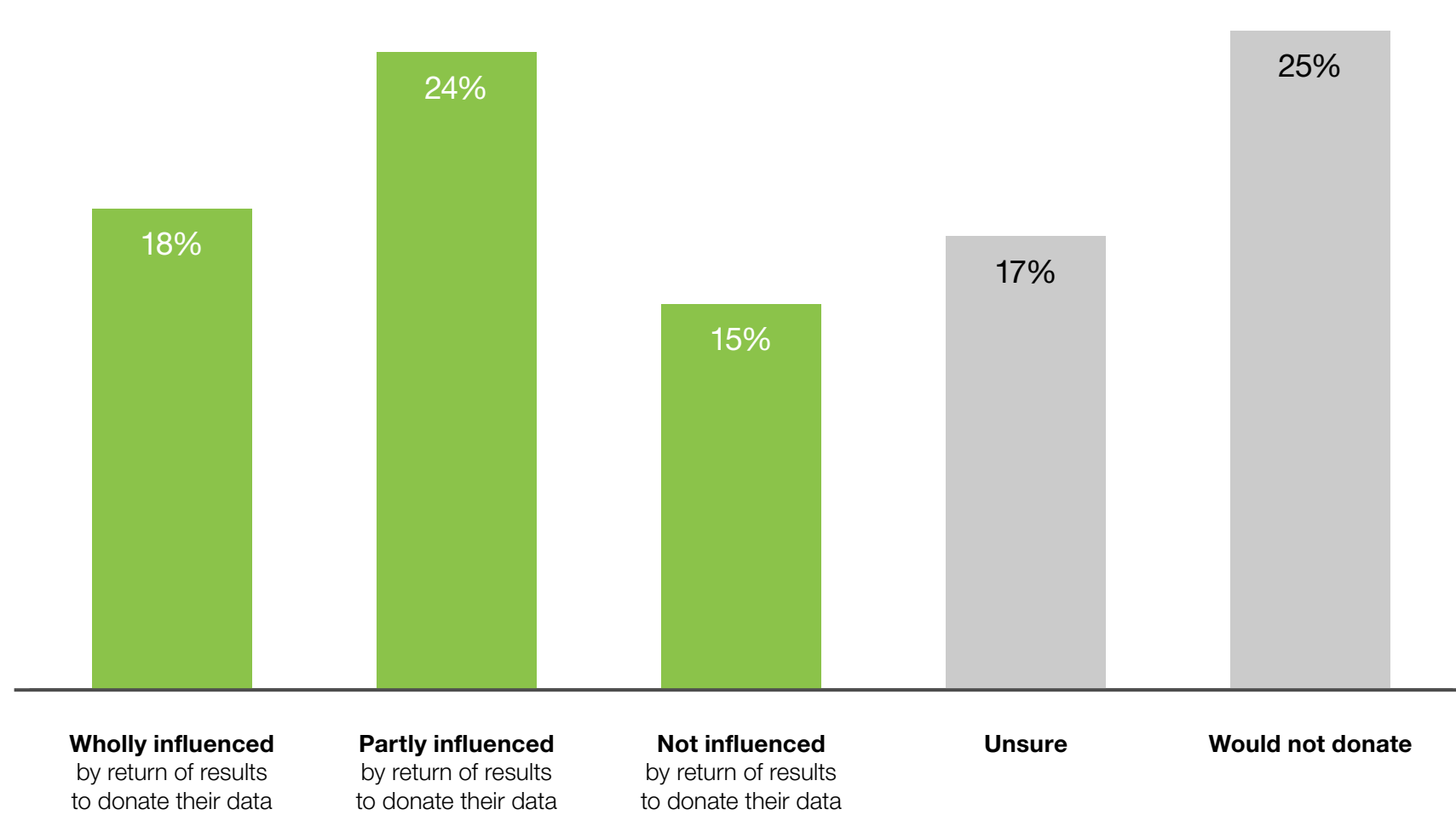


The US alone accounts for 65% of studies of public attitudes towards the return of individual research results.

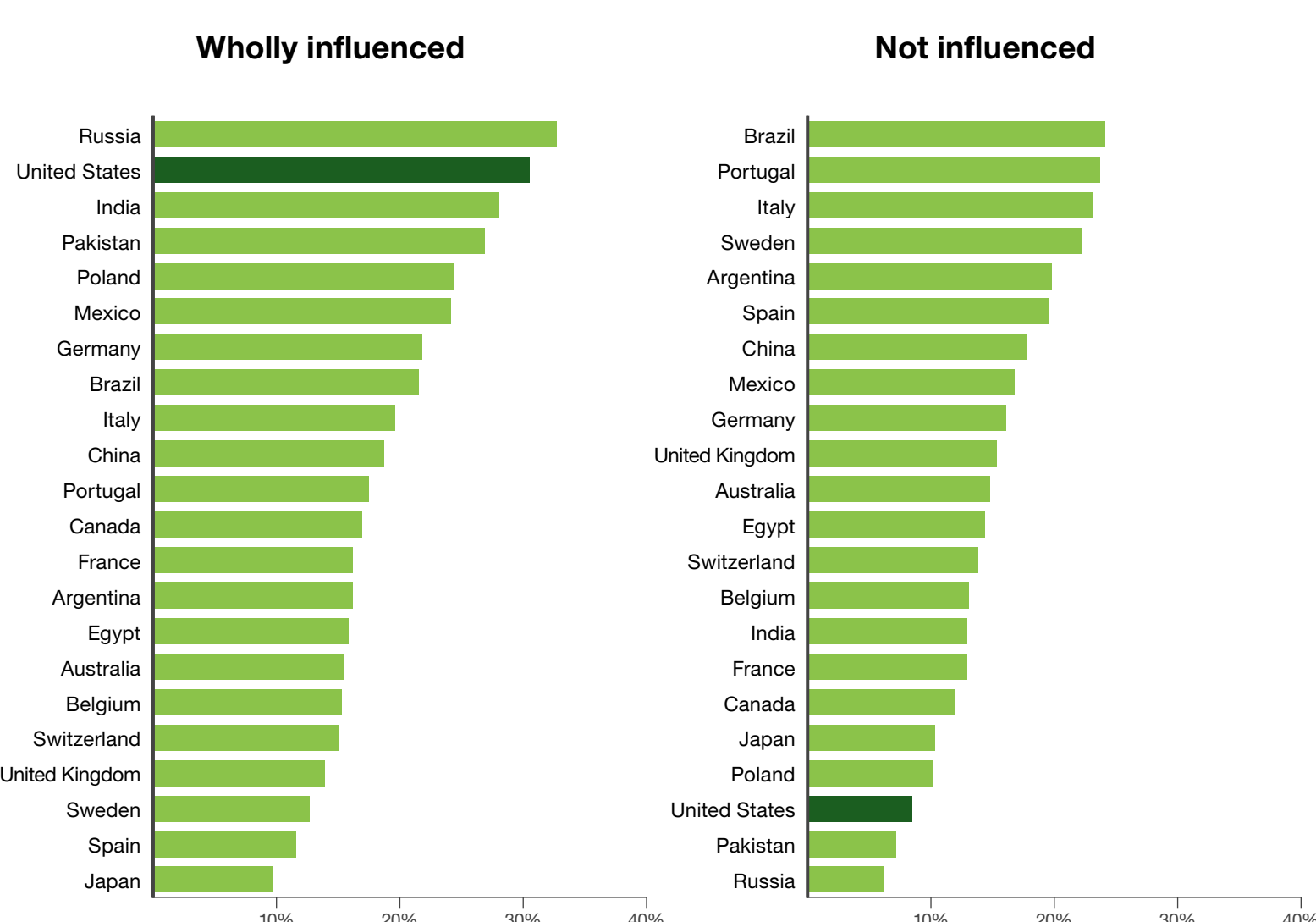
Data: Danya Vears et al, 'Return of Individual Research Results from Genomic Research: A Systematic Review of Stakeholder Perspectives' (2021) PLoS ONE 16(11).

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



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.

Milne R, Morley KI, Almarri MA, Atutornu J, Costa A, Howard HC, Patch C, Roberts L, Roberts J, Middleton A et al (2022) Return of genomic results does not motivate intent to participate in research for all: Perspectives across 22 countries. Genetics in Research [Online] 1-10.