Public Attitudes for Genomic Policy Brief

Genetic exceptionalism

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Global Alliance for Genomics & Health

Understanding how individuals view their genetic information — whether they see it as unique when compared with other medical information, and what consequences this might have on their views about how their DNA should be stored, accessed, and shared — will assist in informing future policy choices.



What is genetic exceptionalism, and why does it matter?

A person's DNA can be uniquely identifying, it can also link the person to their relatives, and it can provide information about their past, current, and future health.[1] Whether or not these features make genetic information somehow "special" when compared with other types of medical information is widely discussed and contested in ethical and legal discourse.[2] Genetic exceptionalism refers to the idea that genetic information is uniquely powerful and uniquely personal, meriting unique protection.[3] Concerns about privacy have driven much of the debate about this need for special treatment.[4]

[1] Patricia A. Roche, "Protecting genetic privacy" (2001) 2 *Nature Reviews Genetics* 392-396.
[2] See, for example, Mark A. Rothstein, "Why treating genetic information separately is a bad idea" (1999) 4(1) *Texas Review of Law and Politics* 33-37; James Evans and Wylie Burke, "Genetic exceptionalism: too much of a good thing?" (2008) 10 *Genetics in Medicine* 500-501; Daniel Sulmasy, "Naked bodies, naked genomes: the special but not exceptional nature of genetic information" (2015) 17(5) *Genetics in Medicine* 331-336.
[3] George J. Annas, Leonard H. Glantz, and Patricia A. Roche, P. A. (1995). "Drafting the genetic privacy act: science, policy, and practical considerations" (1995) 23 *The Journal of Law, Medicine & Ethics* 360-366.
[4] Radhika Rao, "A veil of genetic ignorance? Protecting genetic privacy to ensure equality" (2006) 51 Villanova Law Review 827-840.

Genetic exceptionalism is currently recognised in legislation in some countries, but not others.[5] For example, the USA's Genetic Information Nondiscrimination Act 2008 regards genetic information as unique — warranting increased protection. In Australia, in contrast, an attempt to introduce similar legislation failed, and instead the legal requirements relating to the collection and use of genetic information are the same as for other medical information.[6]

It is important to understand how individuals view their genetic information — whether they see it as unique when compared with other medical information, and what consequences this might have on their views about how their DNA should be stored and shared, and who should be able to access it. This is especially important given that research to improve our understanding of the role of genetic factors in health and disease is dependent on the involvement of a large number of individuals from diverse populations. Understanding the factors that influence the decisions of individuals about whether or not to participate in genomic research will assist in informing future policy choices.

What do we know about genetic exceptionalism, and how it affects willingness to donate?

The Your DNA, Your Say (YDYS) study is the largest international study of attitudes towards the collection of genetic and medical data. It collected survey responses from 37,000 people across 22 countries. The survey asked a number of questions about the factors that might influence willingness to donate DNA and medical information, including whether DNA was viewed as being different from other types of medical information.

Overall, 53% of respondents across all 22 countries viewed genetic information as being different from other types of medical information, but the percentage of respondents sharing these views differed substantially between countries.[7] For example, over 65% of respondents in Mexico and Italy viewed genetic information as being different from other forms of medical information, whereas only 31% of those in Russia did.[8] The reasons for these differences in views between countries have not yet been fully explored, and warrant further analysis.

Views on genetic exceptionalism were not found to be correlated with decreased willingness to donate genetic or other medical information in any country. There was either no association or, in some instances, a positive association. Across the sample, participants who were unwilling or

[5] Lawrence O. Gostin and James G. Hodge, "Genetic privacy and the law: an end to genetics exceptionalism" (1999) *Jurimetrics* Fall:21-58.
[6] Australian Law Reform Commission and Australian Health Ethics Committee, *Essentially yours: the protection of human genetic information* (2003), particularly 137-146.
[7] Anna Middleton et al., "Global public perceptions of genomic data sharing: what shapes the willingness to donate DNA and health data?" (2020) The American Journal of Human Genetics 107.
[8] Anna Middleton et al., "Global public perceptions of genomic data sharing: what shapes the willingness to donate DNA and health data?" (2020) The American Journal of Human Genetics 107.

unsure about donating their medical and DNA information were less likely to express genetic exceptionalist views.[9]

A more detailed analysis was undertaken of the aggregated survey data relating to genetic exceptionalism in the UK, USA, Canada, and Australia. This analysis revealed that genetic exceptionalist respondents were substantially more likely to accept that their "anonymous" DNA and/or medical information should be donated for research purposes (65.3% of genetic exceptionalist respondents versus 47.1% of non-exceptionalist respondents). Genetic exceptionalist respondents were also more likely to be influenced in their decisions about whether or not to contribute their genetic information to research by the prospect of receiving a personal readout of their DNA (50.6% versus 30.2%) and by knowing there are legal protections in place to prevent exploitation (63.9% versus 47.2%).

This smaller analysis revealed further associations between genetic exceptionalism and other factors that might influence willingness to donate.[10] As a starting point, respondents holding genetic exceptionalist views were substantially more likely to think that linking personally identifying information to their genetic information could potentially harm them in some way (49.5% of genetic exceptionalist respondents, compared to 35.2% of respondents who did not hold exceptionalist views).[11] The three potential harms most commonly selected by respondents across the four countries were: "my DNA being copied and then planted at the scene of a crime"; "health or life insurance companies using the information to discriminate against me"; and "marketing companies targeting me to sell me products." Analysis of a Costa Rican YDYS sample similarly emphasised the predominance of concerns about the use of genetic information by insurance companies or for employment discrimination.[12]

In summary, the aggregated survey data from the UK, USA, Canada, and Australia revealed that those respondents who held exceptionalist views were the most likely to be willing to donate their DNA and medical information to research, while also being the most likely to understand linking DNA to personal information could cause harm.[13]

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[9] Voigt, T.H., Holtz, V., Niemiec, E., Howard, H.C., Middleton, A., Prainsack, B., "Willingness to donate genomic and other medical data: results from Germany" (2020) European Journal of Human Genetics 28, 1000-1009. https://doi.org/10.1038/s41431-020-0611-2

[10] Anna Middleton et al., "Members of the public in the USA, UK, Canada and Australia expressing genetic exceptionalism say they are more willing to donate genomic data" (2020) European Journal of Human Genetics 28.

[11] Anna Middleton et al., "Members of the public in the USA, UK, Canada and Australia expressing genetic exceptionalism say they are more willing to donate genomic data" (2020) European Journal of Human Genetics 28.

[12] Chavarria-Soley, G., Francis-Cartin, F., Jimenez-Gonzalez, F., Ávila-Aguirre, A., Castro-Gomez, M.J., Robarts, L., Middleton, A., Raventós, H., "Attitudes of Costa Rican individuals towards donation of personal genetic data for research" (2021) Personalized Medicine 18, 141-152. https://doi.org/10.2217/pme-2020-0113

[13] Anna Middleton et al., "Members of the public in the USA, UK, Canada and Australia expressing genetic exceptionalism say they are more willing to donate genomic data" (2020) European Journal of Human Genetics 28.

What can we do?

We are only just starting to understand the ways in which genetic exceptionalist/non-exceptionalist views might affect perceptions of the potential harms arising from linking genetic information to other health information, and attitudes towards participation in genomic research. It is important to better understand these factors, given that over half of the respondents surveyed in YDYS expressed genetic exceptionalist views. In addition, although the YDYS survey revealed differences in the percentages of respondents expressing exceptionalist and non-exceptionalist views between countries, we do not yet have a good understanding of the reasons for these differences. For instance, we do not know whether the existence of genetic exceptionalist legislation might have any bearing on the views of respondents towards genetic exceptionalism. Nor do we have detailed analysis of the differences between countries in respondents' views about the potential harms of linking genetic data with other health data. Clearly, more analysis is needed to better understand the views of the public in this regard.[14]

Conclusion

The YDYS study revealed that more than half of the respondents to the study had genetically exceptionalist views. However, this proportion varied substantially between countries. Because genetic exceptionalist respondents are more likely to donate their DNA and medical information than other respondents, it is particularly important to understand the local factors that might influence their willingness to participate. The fact that they are more concerned about potential harms than other respondents has policy relevance. For example, detailed analysis of aggregated data from the UK, USA, Canada, and Australia showed that misuse, discrimination, and direct marketing are all relevant concerns, illustrating the importance of developing robust infrastructure measures and appropriate legal protections to deter such activities.

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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 past briefs.*

[14] Anna Middleton et al., "Members of the public in the USA, UK, Canada and Australia expressing genetic exceptionalism say they are more willing to donate genomic data" (2020) European Journal of Human Genetics 28.