Public Attitudes for Genomic Policy Brief

Familiarity

12 September 2023

Global Alliance for Genomics & Health

As genomic data become more widely available and used in healthcare, familiarity with genomics or genetics is likely to be important in shaping how people engage with the collection and use of their data in research and care.



Why does familiarity matter, and what is it?

As genomic medicine projects and services expand, the availability of genomic and genetic data across populations is vital to developing knowledge about genetics and its relation to health and disease, and to informing diagnosis and treatment. As genomic data become more widely available and more widely used in healthcare, familiarity with genomics or genetics in some form is likely to be important in shaping how people engage with the collection and use of these data in research and care. In this brief, we concentrate on the role of familiarity in shaping public attitudes towards genomics.

By familiarity, we mean the extent to which genomics or related terms (such as DNA and genetics) mean something to people. For example, familiarity could be gained through

personal experience, professional practice, or through awareness derived from popular culture or the media rather than (or in addition to) knowledge and expertise. Here it is important to distinguish familiarity from technical knowledge about genomics. It can often be assumed that increased knowledge leads to greater uptake, and that consequently, it would be good to encourage the wider public to know more about genetics and genomics. By using "familiarity," we make two points. The first is that the link between knowledge and attitudes has not been consistently shown empirically. Indeed, the nature of the relationship between knowledge and public attitudes has been a persistent question in efforts to understand how members of the public relate to science more broadly. This is further complicated by the range of contexts in which people may encounter genomics and the challenge of consistently measuring knowledge. Second, if the goal is to encourage people to engage meaningfully with the implications of genomics for their lives and those of their families, detailed knowledge of the technical content of genomics might neither be sufficient, nor indeed necessary, to enable engagement with, and inform decisions about, participation in genomics research and healthcare.

What do we know about familiarity?

The Your DNA, Your Say (YDYS) study is the largest international study of attitudes towards the collection of genetic and health data. It collected survey responses from 37,000 people across 22 countries. The survey asked people whether they were familiar with DNA, genetics, and genomics. Such familiarity could be a result of popular culture, media, or education. Alternatively, familiarity may come from personal experience with genetics. This might come from being a patient or parent of a patient with a genetic condition, being a participant in research, having a family history of disease, or working as a genetic health professional or genetic scientist.

The study found that most participants in most countries surveyed are not familiar with the concepts of DNA, genetics, and genomics. While familiarity with these concepts varies across the countries in the study, Italy and the USA were the only countries studied where more people claimed to be familiar, rather than unfamiliar.

How does this impact genomics?

Across the 22 countries studied in YDYS, familiarity with genomics was consistently associated with a willingness to donate DNA and medical information for research. Respondents who reported being familiar with genetics through personal experience — being a patient, having a family history of an inherited condition, or working in genetics — were substantially more willing to donate genetic data. Conversely, a lack of familiarity with genomics was found to relate to hesitancy about donating data.

Familiarity is clearly an important factor in shaping how people engage with genomic data, and a detailed analysis of YDYS data from the UK, Australia, Canada, and the USA suggests that increasing familiarity may result in those people who are currently unsure about donation becoming willing to donate. However, this analysis also suggested that increasing familiarity may not shift attitudes on donation, particularly given potential concerns about privacy, potential discrimination, and the future use of data.

What can we do?

As a field, there is a need to focus on familiarising the public with genomics with the purpose of genomic research and the importance of data sharing. This should not simply involve communicating information about what genomics is and its benefits and risks, but also why and how genomics is done and its potential applications. Here policy-makers might usefully develop innovative engagement approaches to openly communicate about genomics in ways that are familiar and meaningful to individuals and communities. They might also openly acknowledge that like other health data, genomic data are

sensitive, provide transparent information about how data are used, and demonstrate how they manage the risks of data being misused. This includes meeting people where they are, to invite public discussion and debate on the development of global genomics research and data sharing, and how this is relevant to everyday life and the future of healthcare.

Conclusion

Familiarity with genomics is important in shaping attitudes towards genomics and genomic data. A focus on familiarity allows genomic medicine to be grounded in existing knowledge and understandings that can help people consider its implications for them. For some, this may make genomics less threatening or more accessible, while for others, it may link it to wider concerns about the nature of healthcare or connect to questions of mistrust.

Further reading

- Middelton 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
- Haga, S.B., Barry, W.T., Mills, R., Ginsburg, G.S., Svetkey, L., Sullivan, J., Willard, H.F., 2013. Public Knowledge of and Attitudes Toward Genetics and Genetic Testing. *Genetic Testing and Molecular Biomarkers*17, 327–335. https://doi.org/10.1089/gtmb.2012.0350
- Allum, N., Sturgis, P., Tabourazi, D., Brunton-Smith, I., 2008. Science knowledge and attitudes across cultures: a meta-analysis. *Public Underst Sci* 17, 35–54. https://doi.org/10.1177/0963662506070159

- Kerr, A., Cunningham-Burley, S., Amos, A., 1998. The new genetics and health: mobilizing lay expertise. *Public Underst Sci* 7, 41–60. https://doi.org/10.1177/096366259800700104
- Middleton, A., Milne, R., Thorogood, A., Kleiderman, E., Niemiec, E., Prainsack, B., Farley, L., Bevan, P., Steed, C., Smith, J., Vears, D., Atutornu, J., Howard, H.C., Morley, K.I., 2019. Attitudes of publics who are unwilling to donate DNA data for research. *Eur J Med Genet* 62, 316–323. https://doi.org/10.1016/j.ejmg.2018.11.014
- Middleton et al, Attitudes of Publics Who are Unwilling to Donate DNA Data for Research (2019) *European Journal of Medical Genetics* 62:5

Authors

Richard Milne, Dianne Nicol, Maili Raven-Adams and the Public Attitudes for Genomic Policy Subgroup, Regulatory and Ethics Work Stream, GA4GH. The YDYS study was designed and led by Anna Middleton.

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.*