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20,000 international voices share how they want their DNA information used

A project to gather public opinions on how genetic data is used and distributed has gone global

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The Wellcome Genome Campus and Global Alliance for Genomics and Health (GA4GH) have gone global with a project to explore public attitudes and beliefs on the sharing of genetic information. Now available in English, Russian, German, Portuguese and Polish, with French, Icelandic, Arabic, Japanese, Italian, Swedish, Hindustani and Mandarin translations on the way, the film-based survey, called Your DNA Your Say, is on track to gather feedback from more than 20,000 people around the world.

Every day, DNA and medical data are collected at clinics and research labs around the globe. Individuals are asked to give permission for their genetic information to be donated for the purposes of research - both non- and for-profit. Such data are sent around the world every second.

Your DNA Your Say is the largest global survey of public opinion on genomics. The results of the survey will feed into the work of GA4GH, including the development of new policies to address the ethical and moral questions - both personal and political - about how we use people's genetic information.

Dr Anna Middleton, Head of Society and Ethics Research at Connecting Science, Wellcome Genome Campus, who leads the project, said: "As we enter a new era of genomic and personalised medicine, a need to understand the public's views on the sharing of genetic data has become increasingly urgent. This is a very ambitious project, aiming to gather opinions from across the world - we want everyone to take part. There is a huge global evidence gap on this subject. Since we don't have a clear public voice on the issue, there's a risk of inappropriate policy being made about how data are shared."

The survey targets not just the general public, but also patients, research participants, scientists and health professionals.

Professor Barbara Prainsack, who led the German arm of the study, explores the societal aspects of data use for personalised medicine at King's College London. She said: "We use a series of nine short films to illustrate how people's data could be used in different contexts. We deliberately seek to engage people who may not have thought about these aspects before. How would you want your data to be used, by whom, and on what terms? These questions are relevant for all of us as citizens and patients."

Nadia Kovalevskaya of Repositive, a global portal for genomic research data, helped develop the Russian translation. She said: "We think it is fantastic that this survey will be available to members of the public in Russia. We know that genomics research is developing fast across the world, so it is important to study attitudes of the global audience towards these developments."

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Your DNA Your Say:

To access and participate in the survey, visit YourDNAYourSay.org today. Your DNA Your Say was designed by the GA4GH Participant Values Task Team and takes the form of a 'film-survey' experience. First, a series of short films introduces participants to the practical and

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ethical issues of DNA and medical data sharing followed by a survey in which participants are asked to provide their views on whether they would donate their data, for what purpose, and whether they perceive any harms associated with the act of donating.

Selected websites:

Global Alliance for Genomics and Health

The Global Alliance for Genomics and Health is an international, non-profit alliance formed to accelerate the potential of genomic medicine to advance human health. Bringing together over 400 leading organizations working in healthcare, research, disease and patient advocacy, life science, and information technology, GA4GH Members are working together to create a common framework of tools, methods, and harmonized approaches and supporting demonstration projects to enable the responsible, voluntary, and secure sharing of genomic and clinical data. <http://www.genomicsandhealth.org/>

Wellcome Genome Campus Connecting Science

The mission of Wellcome Genome Campus Connecting Science is to enable everyone to explore genomic science and its impact on research, health and society. We connect researchers, health professionals and the wider public, creating opportunities and spaces to explore genomic science and its impact on people. Connecting Science inspires new thinking, sparks conversation, supports learning and measures attitudes, drawing on the ground-breaking research taking place on the Wellcome Genome Campus. <http://www.wellcomegenomecampus.org/connectingscience>

Wellcome Genome Campus Society and Ethics Research

Wellcome Genome Campus Society and Ethics Research uses quantitative and qualitative research methods to investigate the psychological, social and ethical impact of genomics. We are continually asking 'how are people responding to genomics?'. We gather and share data on attitudes that can be used to improve the experiences of the public, patients and their families, health professionals, genetic counsellors and researchers. Wellcome Genome Campus Society and Ethics Research is part of Connecting Science. <http://www.wellcomegenomecampus.org/societyandethics>

The Wellcome Trust Sanger Institute

The Wellcome Trust Sanger Institute is one of the world's leading genome centres. Through its ability to conduct research at scale, it is able to engage in bold and long-term exploratory projects that are designed to influence and empower medical science globally. Institute research findings, generated through its own research programmes and through its leading role in international consortia, are being used to develop new diagnostics and treatments for human disease. The Wellcome Trust Sanger Institute is one of three host institutions of the Global Alliance for Genomics and Health, along with the Ontario Institute for Cancer Research and the Broad Institute of MIT and Harvard. <http://www.sanger.ac.uk>

Wellcome

Wellcome exists to improve health for everyone by helping great ideas to thrive. We're a global charitable foundation, both politically and financially independent. We support scientists and researchers, take on big problems, fuel imaginations and spark debate. <http://www.wellcome.ac.uk>

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