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

September 1, 2017

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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,

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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."

Explore further: [Closing the evidence gap on public attitudes toward genetic data handling](#)

More information: surveys.genomethics.org/survey/yourdnayoursay?_=1

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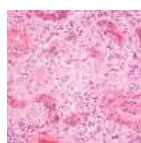
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