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# *Socialising the Genome: Communications, Public Trust and Engagement*

**Public Policy Projects Virtual Webinar  
Session Report  
Tuesday, 15 June 2021**



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This virtual webinar focusing on the need to ‘Socialise the Genome’ through the harnessing of engagement and trust amongst the disengaged, addressed the following key topics and themes:

- Empirical research has shown a direct relationship between a global lack of public awareness of genomics, a mistrust of those using genomic data, and a disinclination on the part of the public to participate in research;
- According to the British Science Association, the majority of the public are either disinterested in science or choose to actively disengage from science;
- Despite years of investment in communications and engagement strategies, these only reach public audiences who actively choose to engage with them and thus this investment has not shifted broader public perception; and
- Not enough is being done currently to engage and harness trust between the public and the relevance of genomics.

Without broader trust and engagement, the ability of genomics and genetic medicine to deliver their full potential benefits to a more diverse population will not be fully realised. This will further exacerbate health inequalities.

To engage the disengaged the ‘elephant in the room’ must first be acknowledged by the scientific community - there are core and historic reasons explaining lack of engagement by certain communities. These will not be corrected by another programme of “education”.

Communications must be delivered in language and through platforms that are familiar to disengaged communities and should be developed in conjunction with those with the specific creative experience of how to reach such audiences. We need to explore utilising creative health campaigns, social media strategies and, essentially, creative story-telling delivered via film, documentaries and TV.

There are excellent examples of many individual initiatives that are seeking to engage multiple communities but to really effect change we need to do something much bigger with a collective strategy building on the evidence we have collated.

The time to act is now.

On Tuesday 15 June 2021, Public Policy Projects (PPP) convened an audience from over 30 jurisdictions to discuss and share their experience with regards to socialising genomics. The webinar included presentations from Professor Anna Middleton (Founder and Head of Society and Ethics Research at Wellcome Connecting Science) and Vivienne Parry (Head of Public Engagement, Genomics England). A recording of those presentations can be accessed here:

[Global Genomics - Public Policy Projects](#)

### ***Socialising the Genome***

Genomics, genetics, and genomic sciences are the here and now of medicine and they are also the future. Ensuring the public is engaged with such fields of science will be essential. Without public trust and engagement, the ability of genomics to reach its full potential will be inherently limited.

The challenge does not lie with those who have engaged with genetics and genomics. The evidence is strong that once people have engaged, they are keen to understand more. The challenge lies with engaging with the audience who do not yet know why they need to care and who are actively turning away.

The pandemic has taken ‘variant sequencing’ and ‘genomics’ into mainstream media. And the public is seeing, in real time, the benefits of genomics and of data sharing. In 2018 the NHS launched the Genomic Medicine Service. Direct to consumer genetic tests are widely advertised. Yet even so, public awareness of genomics is very low and whilst people probably know more than they think, they do not feel confident in speaking about it. This helps fuel mistrust about the use of genomics, and who benefits from it. This is particularly marked in minority and disengaged populations.

Since 2016 there have been ‘urgent’ calls for public engagement about genomics, with a recognition that without public trust in the science, the potential for public backlash is considerable. However, despite a recognition that publics need to be on board, and years of public engagement delivery by individual organisations, awareness of genomics is still very low. New tactics are essential. A joined-up commitment is needed; there is too much work to be done for individual organisations to try to tackle alone and no agreement as to the key messages.

In the same way that global publics have now at least heard of Climate Change, even if they do not understand the science in depth, we need to shift awareness levels of genomics. Why? Because even if we have not had any level of genomic testing ourselves, we will be biologically related to someone who has, even distantly. Therefore, the ethical issues linked to data sharing, data storage, privacy, trust, discrimination, and governance are now relevant to all of us. There have been repeated calls for the involvement of society in decision making about genomics, but this is impossible if the word alone is enough to disengage people from even starting a conversation.

The largest ever public attitudes survey to document awareness and familiarity with genomics, “Your DNA, Your Say”, explored the views of 37,000 people from 22 countries in 16 languages and showed

that outside of the USA,<sup>1</sup> familiarity with genomics and the data-sharing process that underpins research is very low. This work has also shown a direct relationship between a lack of awareness of genomics, a mistrust of those using genomic data, and a disinclination on the part of the public to participate in research.

The question is therefore posed as to how do we better engage with the public about the benefits of genomics? If the science and technology behind genomics is to be regarded as the ‘nuts and bolts’, then public trust and engagement must be considered as the ‘hearts and minds.’ Engaging the hearts and minds of the population, is essential.

A partnership between genomics and humankind must be developed and built so everyone feels involved. Genomics will play a central role in future health-care methods and approaches, but the pressing and present issue is that a substantial portion of the population feels excluded and as a result is mistrusting of the field. We therefore need to bring them into the conversation and socialise genomics. The nature of the social contract between the public and the health system needs exploring to understand how to be worthy of public trust and how to gain that trust. Genomics is currently not resonating with the public even though genes contain the human story in all its messiness, and even though everyone may look different on the outside, on the inside they are not all too dissimilar.

Whilst building trust essential, it is also fragile. Recent lack of trust as illustrated by the opt-out approach to NHS data sharing rather than asking for consent may have set the ability to gain the required trust back years.<sup>2</sup> As in the 1990s, with neither understanding nor support for genetically modified food, the negative public reaction to the science (and especially “Frankenfood” style reporting) was so considerable that it halted that research for a decade. It also led to the creation of legal restrictions across Europe preventing the development of gene editing techniques. We want to avoid this happening again. Genomics offers the potential for much improved care for individuals and populations but without trust, this genomic healthcare future could falter and fail at the very point that it is most needed.

According to the British Science Association, currently, 76 per cent of the British public (around 49 million people) are either not interested in science (and thus genomics) or will make no effort to actively engage in science. The levels of engagement are so low, to the extent that within existing research, members of the public participating “often assume there might be a mistake in pronunciation, asking helpfully: ‘Did you mean to say gnome when you said genome?’”<sup>3</sup> This creates an incredibly pressing problem. However, it must not be regarded as a lost cause. Once people have engaged through becoming a patient, they are often interested to learn more and remain engaged, nonetheless this occurs predominately within clinical settings. The audience that needs to be engaged is the one which is inherently distrusting of science and isolated from the clinical setting.

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<sup>1</sup> Middleton A, Milne R, Atutornu J, Costa A, Morley, K.I, Patch C, Robarts 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

<sup>2</sup> Medina IA, (The Conversation, June 2021) ‘UK Government plans to collect and share NHS data are hugely concerning – here’s why’ Available at: <https://theconversation.com/uk-government-plans-to-collect-and-share-nhs-data-are-hugely-concerning-heres-why-162699> (accessed 17 June 2021).

<sup>3</sup> Parry V and Anna Middleton, ‘Socialising the genome’ [2017] The Lancet 389:10079, 1603.

### ***Recognising historical trauma: Reasons for disengagement***

In the webinar, early work from Maslansky was presented – commissioned by Wellcome Connecting Science and Genomics England. This social sciences research engaged with disengaged groups, including British members of the public with lower socio-economic background as well as Caribbean, West African and Pakistani British publics. Their findings demonstrated that traditional appeals as to the benefits of genomics, either personal, societal, or scientific were not being heard. The research clearly demonstrated that mistrust prevented messages being received. For them to be received, first their history had to be acknowledged, language calming concerns had to be used and choice and control had to be emphasised. In exploring and eventually adopting novel approaches that use this evidence, the fundamental and core reasons for why such levels of mistrust, distrust and lack of engagement must be recognised and addressed. One of the key sentiments expressed by disengaged communities is that “a lot of our choices have been stripped from us with regards to our own health and how we live our lives”. It is thus vital that the power be placed back in the hands of the people to enable for them feel as though they are in control. We need to create a shared notions of: ‘it’s your choice, you can choose to be involved or not.’

Disparities within science are often linked to the history of colonialism, fuelling such levels of mistrust and a lack in willingness to engage with science, and more specifically medicine and genomics. This is not a problem found uniquely within the UK and is recognised highly within other jurisdictions. In Canada for example, concern and mistrust is found between indigenous communities and the healthcare and genomics systems as they do not feel as though they have ownership or control over the data they provide and contribute. In creating a communications methodology to spark interest in engaging with, and hopefully ultimately trusting, genomics and genetics, the self-defined goals, aims and desires of those respective communities must be taken into consideration.

In doing so, it will be crucial to acknowledge and recognise that the reasons behind such scepticism will vary between different communities. It also feeds into a more widespread issue of distrust in both government and other forms of authority. Taking this into consideration, the idea of ‘it’s not what you say, it’s what they hear’ reverberates strongly. It should encourage the development of a strategy that resonates with the desired audiences. This should include consideration of the best means of communication for a particular group, rather than obliging them to take the communication methods of choice for the scientific and medical community. Inviting disengaged communities into the conversation will be crucial. Forcing them to take part will only cause further frustration and damage existing and already feeble relationships.

### ***Building a bridge between genomics and the disengaged***

The key take-away from both the webinar presentations as well as the research presented is that a bridge between disengaged communities and genomics must be built. How that bridge is built, however, is the challenge with which the genomics and genetics communities are now faced. Tried and tested messages regarding collective good did not work, therefore new approaches must be explored and adopted.

Messaging and communications around genomics need to adopt existing communication methods that are most used by the disengaged, for instance community radio, local TV, or WhatsApp. Language, tone, style, and presentation should be familiar to communities and resonate with them. In the battle

for hearts and minds, the need to reach hearts is paramount as it is the heart where the stories within genomics will resonate most fully.

In adopting new approaches, it will be crucial to explore different avenues from those currently used. There is also an opportunity to learn from other industries. For example, harnessing and building engagement and trust in genomics shares many similarities with the challenges posed and overcome with regards to vaccine confidence.

Other fields to explore include finance, creative industries, tech, and software, amongst others, as their learnings, both positive and negative, can only inform the approaches adopted by genomics and genetics.

### ***Call to action***

It is important to note that the themes being addressed resonate across the globe and are not just UK centric. The need to emerge from the silos created in this field was one echoed by many attendees. Even though there are many individual pockets of excellence, to genuinely make a difference in driving this agenda forward, a collaborative, national, regional, and global approach must be adopted. For example, a framework for use of language best suited to tackling this agenda and shifting it forward, would be a positive step in the right direction. The key take-aways are these:

- We need to “go big”. Individual initiatives will not achieve change at the required scale;
- We need to accept that existing Communications and Public Engagement strategies are not reaching disconnected audiences on a big enough scale to affect a change in perception;
- Firm, evidence-based, communication bridges need to be built with specific disengaged public audiences who do not trust science or scientists;
- Scientists do not have the skills to deliver large, scalable communication campaigns;
- Large scale funding is required alongside a clear communications strategy to reach disconnected public audiences;
- Multidisciplinary partnership is required across genomics, communications, and creative industries.

The issues addressed in this report and during the webinar are pressing, and time will run out on the ability to engage with disengaged communities. The time is now. The evidence, research and opinions are evident. It is time to put the gathered knowledge into active use and begin building new methods of communication utilising an alternative approach to engagement which is not “educating” the disengaged but recognises that we need to approach these communities in a way which understands and accepts the reasons for their disengagement. Without a new approach we cannot expect to have a different outcome and we cannot expect to encourage greater diversity in engagement with genomics which will mean we will not be able to bring the benefits of genome sequencing to everyone.

Thank you to the following for their contributions and presentations:

***Kate Orviss, Session Chair, Senior Advisor, Global Genomics, Public Policy Projects***

Kate joined Public Policy Projects (PPP) after 25 years at international law firms Linklaters and Pinsent Masons. When at Pinsent Masons, Kate set up and led the Global Healthcare Projects Team, bringing together healthcare and life sciences specialists from across their global network. She also most recently worked on healthcare projects in a range of jurisdictions including Egypt, India, The Gambia, Uzbekistan, China, and the UK/ Kate's background is in major projects in a range of sectors including transport, housing, education, healthcare, and energy. She brings to PPP the benefit of her significant, global network and understanding of the commercial drivers affecting all participants in pursuing complex opportunities. Kate brings together the unique combination of a market leading, independently recognized legal background with a strategic vision to support global discussions on key issues of the day and a desire to further change.

***Professor Anna Middleton, Founder and Head of Society and Ethics, Research, Wellcome Connecting Science and Faculty of Education, University of Cambridge***

Prof Anna Middleton is the founder and Head of Society and Ethics Research at Wellcome funded Connecting Science in Cambridge. She is an entrepreneurial research leader who delivers high impact social science and engagement around the ethics of science. She leads a team that sits within the Wellcome Sanger Institute, which is a non-profit academic world leader in genetics research, currently identifying variants of Covid for UK Public Health agencies and delivering cutting edge research on the genetic basis of disease. The focus of her group is to understand how public audiences make sense of the impact of genetic information. She is particularly interested in how to engage disengaged audiences and how trust is authentically communicated. She has led the largest study of public attitudes in the world on genomic data sharing involving 37k people from 22 countries, study delivered in 16 languages.

***Vivienne Parry OBE, Head of Public Engagement, Genomics England***

Vivienne Parry has been Head of Public Engagement at Genomics England since its foundation, ensuring that the organisation both earns and maintains public trust and confidence in the use of genomic data. She combines this role with her career as a science broadcaster, journalist, and author. She also has an extensive commitment to public service, serving on the boards of UCL, the MRC and UKRI.

## Contacts

If you are interested in hearing more about the work Public Policy Projects' is undertaking in Genomics, please feel free to get in touch with a member of the team:

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