

# Positive framing of genomics met with skepticism in some communities

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New research published in *Human Genetics and Genomics Advances*

reveals the difference between "what we say" and "what people hear" when engaging underrepresented communities around genomics and health care.

Genomics datasets, which underpin the ability to interpret all genetic tests, are known to consist of DNA from predominately white, Northern European populations. As genomics becomes an increasingly important part of everyday health care, barriers to diverse participation must be overcome so that everyone can benefit from genomic medicine, not just the privileged few.

The research shows that conversations that lead by positively framing genomics around [potential benefits](#) were met with cynicism and skepticism, due to socio-historical inequalities and misinformation that result in widespread mistrust of the health care system, private companies, and government.

Researchers from Wellcome Connecting Science, Genomics England, and language strategy firm maslansky+partners leveraged framing theory and [behavioral science](#) to develop alternate ways to connect with traditionally disengaged audiences and then conducted focus groups with 100 people from British communities of varying backgrounds.

The groups were mixed in age and genders, and had limited familiarity with genomics. The individuals self-identified as belonging to communities with Black African, Black Caribbean and Pakistani ancestries, as well as people of various ancestral heritage who come from disadvantaged socio-economic backgrounds—all groups identified as missing from genomic datasets.

The groups were presented with short phrases of genomics for non-expert public audiences, framed by what genomics is and what it can offer, such as personal and scientific benefits. The phrases were based

on typical text in patient and participant information leaflets used by the NHS and in research studies, and were delivered by an actor—a Black British woman.

In response to the narratives that lead with the positively-framed scientific and [health benefits](#), the participants expressed clear mistrust and cynicism.

In explaining their reactions, some participants cited examples of racism in science, including historical injustices, as well as present-day issues and personal experiences, such as a lack of diversity in clinical trials and unequal access to, and quality of health care. Others evoked controversial applications of genomics, such as cloning, gene editing or mentions in dystopian fiction.

Some participants expressed suspicion around claims that genomics would benefit everybody, suggesting people like them can be excluded from studies and clinical trials.

Other reasons behind participants' skepticism around the benefits of genomics included lack of trust in those who should deliver these benefits, including private companies and governments, scientists and the NHS. Others believed these positive phrases were over-promising and perceived as disingenuous, due to the limitations of current genomics knowledge and lengthy clinical trials.

The researchers suggest a more successful approach is to begin conversations by directly and overtly acknowledging and validating their questions and concerns before introducing details about the science. This means recognizing and articulating that inequalities exist for people from marginalized communities. As genomics becomes part of everyday health care, these realities must be talked about and addressed if diverse public groups are to confidently access genomic medicine equally.

Professor Anna Middleton, Wellcome Connecting Science and Director of the Kavli Center for Ethics, Science, and the Public, University of Cambridge, said, "Our research has demonstrated that everyday talk about genomics currently, used by researchers and clinicians alike, has the potential to alienate already disengaged public audiences."

"We interpret our findings, not in terms of illiteracy about genomics, but as illustrative of the very real socio-historical inequities and inequalities that exist for people from marginalized communities. The conversations about genetics that led with the science and its benefits were triggering for participants—this revealed itself as cynicism and mistrust. And thus continuing to frame our science, only through its benefits, however well-meaning, has the risk of doing harm. Moving forward, we will incorporate the results of this research into the tools and training we offer scientists."

Keith Yazmir, Partner at language strategy firm maslansky+partners, said, "It's human nature to communicate in ways that you want to be communicated to. But effective communication is based on meeting your audience where they are—not where you are. This is particularly important when connecting on complex topics like genomics and emotional ones like [health care](#). Based on our philosophy that it's not what you say, it's what they hear, we were honored to partner with Wellcome Connecting Science and Genomics England on this groundbreaking work."

Vivienne Parry OBE, Head of Public Engagement at Genomics England, said, "This is a very important piece of research with far reaching implications. We now need to make it widely available and act on its findings. This will help ensure that everyone benefits from genomic medicine, with no-one left behind."

**More information:** Anna Middleton, The Legacy of Language: What

we say, and what people hear, when we talk about genomics, *Human Genetics and Genomics Advances* (2023). DOI: [10.1016/j.xhgg.2023.100231](https://doi.org/10.1016/j.xhgg.2023.100231). [www.cell.com/hgg-advances/full ... 2666-2477\(23\)00063-5](https://www.cell.com/hgg-advances/full-servlet/S0266-2477(23)00063-5)

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