Media, Mistrust, and the Genome:

How Media Shapes Public Perceptions of Genetic Data Collection

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As advances are made in scientific technology, ethical fields arise to regulate the new developments. Modern genetics is a relatively young field, with its origins rooted in the 1860s with Mendel's pea plant experiment, which uncovered the fundamental laws of inheritance. Within the short 160 years of the field's existence, grand strides have been made in developing the study of genetics. We have determined the location and structure of DNA, sequenced the human genome in the Human Genome project, developed genetic therapeutics and CRISPR technology, and even have access to direct to consumer genetic testing.

Although the rate of development has been impressive, it does not come without a cost. Genetic research is largely reliant on public participation from human subjects. Without broad and diverse participation, genetic research cannot produce findings that are scientifically robust or applicable to the broader population.

While scientific institutions and ethical review boards oversee how genetic data is collected and used, public willingness to participate is shaped by more than scientific policy alone. The media– mostly journalistic media, social media, and entertainment media– plays a powerful role in informing, or misinforming, the public about genetics research. Social media platforms, political discourse, and entertainment media each frame genetics research in ways that influence how people interpret its risks and benefits. News coverage may highlight breakthroughs in personalized medicine, while films and television often depict dystopian futures shaped by genetic surveillance or discrimination. Concurrently, social media platforms amplify both scientific communication and misinformation, accelerating the spread of narratives that can shape public attitudes toward research participation. Communication scholars describe this process through concepts such as *agenda-setting* and *framing*. Agenda-setting refers to the media's ability to influence which issues the public perceives as important, while framing shapes

how those issues are interpreted. In the context of genetics research, headlines emphasizing either medical breakthroughs or ethical risks can prime audiences to evaluate participation through very different lenses.

Media narratives significantly shape public perceptions of and willingness to participate in genetics research by influencing trust in scientific institutions, public understanding of genetic science, and perceptions of privacy and ethical risk. Through framing effects, amplification of controversy, and the circulation of stories about misuse, media heightens skepticism and influences scientific literacy, public trust, and perceptions of consent and guilt.

Public participation is essential to the success of modern genetics research. Many studies rely on extremely large datasets. Research showed that a simple binary study for a single gene variant would require 4000 cases and 4000 controls to generate a power of 80%. This calculation assumes that disease and genotype were assessed without error and that there is no heterogeneity in disease risk. When taking these factors into account, the required sample size would be closer to 8500 cases and 8500 controls (Burton et al., 2009). Studies looking into polygenic traits and more complex genetic questions will require even larger datasets. Recruiting this many participants is a huge undertaking that requires substantial manpower, time, and money even before considering the potential influence of media narratives on public trust.

Public trust is a fundamental prerequisite for successful genetics research. Participation requires individuals to believe in the research question being asked and believe that scientists will safeguard their personal data and use it responsibly. When trust is strong, people are more likely to contribute biological samples, support large population studies, and participate in clinical trials for things like vaccines.

Larger and more diverse datasets allow scientists to distinguish between genetic and environmental influences and ensure medical discoveries are applicable to people across different populations. As of June 2021, the vast majority of genomics studies have been conducted in individuals of European descent (86.3%) (Fatumo et al., 2022). When research datasets lack diversity, resulting treatments and diagnostic tools may disproportionately benefit already well-represented populations while excluding marginalized communities. Therefore, participation from broad demographic groups is not only scientifically beneficial but also ethically necessary to ensure equitable healthcare outcomes.

Despite the potential benefits of genetics research, the relationship between the scientific community and the public has historically been complicated by ethical failures that undermined trust. One widely taught and discussed example is the Tuskegee Syphilis study, in which low-income African American men in rural Alabama were falsely inoculated against syphilis so researchers could study the natural history of untreated syphilis. The study persisted for 40 years from 1932 to 1972 and researchers withheld treatment for syphilis for participants who contracted it even though treatment was easily available (Centers for Disease Control and Prevention, 2024). The lack of informed consent among participants later raised enduring ethical concerns about exploitation and transparency in biomedical research. Similarly, members of the Havasupai Tribe filed a lawsuit in 2004 against researchers at Arizona State University after DNA samples originally collected for diabetes research were later used to study migration patterns and schizophrenia without their explicit consent (Sterling, 2011). Incidents of informed consent in these marginalized communities creates long lasting mistrust, hinders their participation in future research and further widens the gap in representation among datasets.

Additionally, this case highlights how new methods of data storage allow samples to be used for many years following collection for unpredictable research questions.

In response, some institutions have adopted stronger consent policies, but public willingness to participate in genetics research depends on more than regulatory safeguards alone. While evolving consent frameworks aim to address ethical concerns surrounding data reuse and transparency, their effectiveness ultimately depends on whether the public understands and trusts these protections. Individuals often form their understanding of genetic science and its potential risks through media narratives rather than through direct engagement with scientific institutions. Consequently, examining the role of media in shaping perceptions of genetics research is critical to understanding how trust or the erosion of trust evolves.

Different forms of media shape public perception through distinct mechanisms. Traditional journalism often functions as an agenda-setting institution, determining which scientific issues receive public attention. Social media, by contrast, amplifies emotionally engaging content through algorithmic recommendation systems that reward controversy and simplified narratives. Entertainment media operates differently again, shaping long-term cultural imaginaries about genetics through fictional storytelling rather than direct reporting. These differing mechanisms mean that media does not influence public trust in a single uniform way, but through overlapping channels that affect how individuals interpret scientific information.

Getting scientific information from social media is appealing to many because it is presented in a digestible, attention-grabbing manner. However, media representations often simplify complex scientific findings, sometimes exaggerating the influence of genetics on human behavior or health. Instagram user “healthylifesage” has 1.4 million followers and posts videos wearing scrubs with AI-generated audio, giving health tips. In one video, he lists ten genetic

traits that are inherited from a person's father including athleticism, sense of humor, and height potential. The video amassed over 90000 likes and 3000 comments with no mention of environmental influences and no citation of reputable sources or evidence. This phenomenon, known as genetic determinism, portrays genes as the primary driver of traits such as intelligence, personality, or disease susceptibility. When media narratives emphasize deterministic interpretations of genetics, the public may misunderstand the probabilistic nature of genetic risk and the importance of environmental factors. These misunderstandings can contribute to exaggerated fears or unrealistic expectations about genetic technologies.

Social media platforms further amplify these dynamics by accelerating the spread of emotionally charged content. Algorithms on platforms like Instagram and TikTok tend to prioritize posts that generate strong engagement, including outrage or controversy. While some of these concerns are grounded in legitimate ethical debates, others rely on exaggerated fears that portray genetics research as a form of governmental or corporate control. As a result, misinformation or shocking interpretations of genetic research can spread faster than accurate scientific explanations. Correcting misinformation is extremely difficult, moves more slowly than viral social media posts, and sometimes is not believed or well-received. Consequently, the speed of misinformation spread frequently outpaces that of scientific correction.

Political discourse also shapes how genetics research is interpreted. In recent years, scientific topics ranging from vaccines to climate change have become increasingly politicized. Genetics research can similarly become entangled in political debates, particularly when discussions intersect with topics such as racial identity, national security, or genetic privacy laws. When scientific issues become politicized, individuals may interpret genetic research not through scientific evidence but through partisan identity.

The bankruptcy of 23andMe, a direct to consumer genetic testing business, in 2025 immediately triggered widespread political debate about who owns and controls genetic data collected through research and consumer DNA testing. Lawmakers and privacy advocates were worried that this highly sensitive data could be sold as a corporate asset during the bankruptcy process which would unveil national security concerns and uproar from genetic data donors. Political commentators and policymakers can create the impression that genetic data is inherently unsafe. This perception can discourage participation in future research endeavors for fear that their data will not be adequately protected. Commentators are able to shape public perception by choosing to frame genetics research as a valuable public investment or as a potential threat to civil liberties. These competing narratives can influence whether individuals view participation in genetic research as a civic contribution or a personal risk.

The relationship between media coverage and public trust becomes particularly visible when ethical controversies emerge in genetics research. One recent example involves a consortium study that has a site at UCLA. The Adolescent Brain Cognitive Development (ABCD) Study, funded by the National Institutes of Health (NIH), is an ongoing 10-year longitudinal study that collects brain imaging and genetic data from more than 20,000 children across the United States. Mike McIntire, a two-time Pulitzer Prize-winning journalist at the New York Times, published an article in January 2026 strikingly titled “Genetic data from over 20,000 U.S. children misused for ‘Race science’” which called out the ABCD study for not properly protecting participants’ identities and not ensuring responsible use of their data. McIntire claims that a small group of researchers accessed the ABCD dataset and produced papers promoting controversial and widely discredited claims about genetic differences between racial groups. The

publications circulated online and were cited by fringe communities promoting pseudoscientific theories about race and intelligence.

This was shocking to the principal investigator, Mirella Dapretto, overlooking the UCLA site for ABCD. All data was de-identified and she was upset that an ill-intentioned researcher used our data to make racist claims. The parents of the participants were notified of the New York Times article. However, it later was revealed that the data used in these research studies did not come from ABCD at all but from the Philadelphia Neurodevelopmental Cohort. The NIH is currently drafting a letter to the New York Times to correct this misinformation, but the damage has already been done. Not only was McIntire alerting the public of bogus science, but he also cited the wrong dataset, potentially damaging the future of ABCD research. If even an esteemed investigative journalist like McIntire can be misled, how is the public supposed to discern truth from falsity?

Stories about the ABCD controversy spread through news coverage and social media discussions, contributing to broader public concerns about whether genetic data can truly be protected from misuse. When such incidents receive significant media attention, they can shape public perception of genetics research more broadly. Headlines emphasizing ethical breaches or pseudoscientific misuse, like McIntire's, can lead audiences to conclude that the entire field is vulnerable to exploitation or bias. Even when the majority of researchers follow strict ethical guidelines, highly publicized controversies can undermine confidence in the institutions responsible for managing genetic data.

Entertainment media also shapes public imagination about genetics. Films, television series, and novels frequently depict dystopian futures where genetic information determines social status or enables intrusive surveillance. Movies like *Gattaca* portray societies in which

genetic profiling dictates employment opportunities and social mobility. While these plotlines can stimulate important ethical discussions, they may also create lasting associations between genetic science and social control or discrimination.

Importantly, these different media forms often interact with one another. Memes referencing dystopian films may circulate on social media while political commentators invoke fictional scenarios to support policy arguments. In this interconnected media environment, movie tropes, political narratives, and viral social media content collectively shape how the public interprets real world genetics research.

In response to these challenges, many scientific organizations have developed strategies to rebuild public trust. Outreach programs aim to communicate the goals and safeguards of genetics research more clearly, often partnering with community organizations to address historical concerns about exploitation. Associate professor at the Institute of Society and Genetics at UCLA, Nanibaa Garrison, PhD, is a leader in establishing healthy relationships between Native Americans and scientific research. Garrison promotes ethical, community-based research and the strengthening of tribal governance over data to foster trust through education. She helps Indigenous populations engage in research on their own terms and aims to prevent Indigenous populations from being taken advantage of like the Havasupai Tribe. These efforts illustrate how rebuilding trust in genetic research requires not only transparency, but also meaningful power-sharing with the communities whose data are being studied. By prioritizing community control and culturally informed collaboration, researchers can begin to address past harms and create more equitable models of scientific participation.

Additionally, ethical controversies have prompted ongoing reforms on how consent and data access are managed. Traditional informed consent frameworks were designed for studies

with relatively narrow research goals in which participants' data was only used within a specific project. However, the rise of large genomic databases has created new challenges. Data collected today may be analyzed by researchers around the world or decades later, raising questions about how to obtain meaningful consent for future research that has not yet been imagined. By adopting stronger consent frameworks that encourage more active participant engagement, instances of inadequate consent procedures can be reduced. In turn, this can help prevent high-profile controversies that fuel public mistrust and negative discourse.

Many research institutions have since implemented stricter safeguards for accessing genetic datasets. Some databases now require researchers to complete ethics training and credential verification before gaining access to sensitive data. Others employ tiered access systems that restrict certain categories of information or require review by independent oversight committees. These measures aim to prevent misuse while still allowing legitimate scientific inquiry.

Institutions are now also using other forms of consent such as broad, blanket or dynamic consent. Broad consent allows future research within defined ethical boundaries or specific fields. Blanket consent is unrestricted, allowing for any future use. Dynamic consent is a more adaptive form of consent that allows participants to update their consenting preferences over time through an online portal. This model aims to address the concern of unpredictable future uses of genetic data by providing genetic data donors with an interactive platform where they can have more autonomy over their participation in research. A workshop by the University of Oxford and the COST Action CHIP ME gathered clinicians, researchers, ethicists, lawyers, and research participants to discuss experiences of using dynamic consent. They concluded that dynamic consent offers positive impacts for research by providing practical solutions for

participant recruitment, collection of informed consent, participation retention, and consent management (Budin-Ljøsne et al., 2017). Dynamic consent technology can also address privacy concerns by implementing security expectations similar to requirements for electronic health records.

There are limitations to the dynamic consent model, however. Since this model is an online platform, some populations who do not have consistent access to the internet may not be able to reap the benefits. Concerns have also been raised about “consent fatigue”. A personalized consent process can become lengthy and requiring participants to re-consent for all new uses of their data can cause disengagement among some participants. A study also revealed that some individuals who used dynamic consent felt that the system did not provide enough information on data management procedures (Lee et al., 2024). These issues will all need to be addressed in order to encourage more widespread usage of dynamic consent.

As these improvements are being made, it is important to acknowledge that representation of genetics research in the media is not always bad. Media institutions can also play a constructive role in communicating the societal benefits of genetic research. News stories have the ability to present genetic research as a revolutionary path toward personalized medicine, emphasizing breakthroughs in disease prediction or treatment. For example, an article from BBC highlighted the story of a woman who was empowered by genetic testing. She was able to undergo a preventative double mastectomy after discovering she was a carrier for the BRCA2 gene that dramatically increases risks for breast, ovarian, and prostate cancer (BBC News, 2026). Articles like these highlight the positive outcomes of genetic technology and bolster public opinion and trust in research.

Overall, media coverage has played an important role in accelerating consent reforms and data safeguards. Investigative journalism often brings ethical lapses to public attention, prompting policymakers and funding agencies to respond with stronger regulations. Public outcry generated by media reports can create pressure for greater transparency and accountability in scientific research. Historical cases such as the dispute involving the Havasupai Tribe demonstrate how legal action and public visibility can influence the development of consent policies.

However, significant challenges remain. Media narratives about genetic research are often fragmented, with different outlets emphasizing different aspects of a controversy. Striking headlines may attract public attention but fail to explain the complex regulatory structures governing modern research. As a result, the public may perceive genetics research as either dangerously unregulated or overly restrictive, depending on the media sources they encounter.

Strengthening public confidence in genetics research requires coordinated efforts from scientists, media organizations, and policymakers. For research institutions, proactive engagement with the media is essential. Scientists should communicate clearly about how genetic data is protected, how ethical oversight functions, and what steps are taken when breaches occur. Transparency about both successes and failures can help build credibility with the public.

Media organizations also have a responsibility to report on genetics research with accuracy and nuance. Responsible reporting should include consultation with qualified experts, contextualization of controversial findings, and skepticism toward fringe claims that lack scientific support. Balanced reporting can help audiences understand the difference between legitimate scientific debate and pseudoscientific speculation.

Ethics boards and policymakers should continue refining consent models to reflect the realities of modern science. Adaptive consent models like dynamic consent allow participants to update their preferences and provide greater flexibility while maintaining ethical safeguards. Policies requiring researchers to disclose data misuse and inform participants when breaches occur could also strengthen accountability and trust.

Genetics research offers enormous potential to improve medical knowledge, personalize treatments, and deepen understanding of human biology. Yet the success of this research depends fundamentally on the willingness of individuals to share their genetic data and participate in studies. Media narratives play a powerful role in shaping this willingness by influencing public perceptions of risk, trust, and scientific credibility. When coverage emphasizes misuse, controversy, or dystopian possibilities without sufficient context, it can erode public confidence and discourage participation. Sustaining ethical and effective genetics research therefore requires more than scientific innovation alone. Innovation must be accompanied by responsible media reporting, transparent data protections, and consent practices that empower participants. Through collaboration between scientists, journalists, policymakers, and participants we can begin to rebuild the trust necessary for continued public participation in the scientific exploration of human genetics.

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