

The Trustworthiness Deficit in Postgenomic Research on Human Intelligence

BY SARAH S. RICHARDSON

Awkward.” “Troublesome.” “Charged.” A queasy lexicon pervades discussions of research on the genomics of intellectual ability. Science writer Nicholas Wade invoked this trope of unease in his 2014 book *A Troublesome Inheritance*, which argued that postgenomic science shows that, contrary to previous consensus, racial, ethnic, and national differences in social behavior have a genetic origin.¹ Wade claims that the full implications of this new science have been avoided by social scientists and geneticists, for whom it uncomfortably challenges cherished ideas of social equality. The first postgenomic dust-up over IQ and genomics occurred in 2005 when University of Chicago geneticist Bruce Lahn claimed that genes for large brain size were more common among Europeans and Asians than in African populations. Lahn implied that this was related to the cultural achievements of non-African populations. Analyzing the fall-out from this episode in a 2011 article, I argued that Lahn’s claim (now debunked) would not be the last of this sort.²

Though rebuked by scholars of race and genetics, Wade’s 2014 book has found a wide audience, sounding another warning of an older accord coming undone.³ In the past work on racial and ethnic variation in brain and behavior was marginalized within genetics. Against the backdrop of genetics’ eugenic legacy, wide consensus held such research to be both ethically problematic and methodologically controversial. But today it is finding new opportunistic venues in a global, transdisciplinary, data-rich postgenomic research environment in which such a consensus is increasingly strained.

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I use the nascent term “postgenomics” here to refer to the period since the completion of the major genome sequencing projects in 2001. In the postgenomic era genomics has become a foundational platform in most areas of life sciences research, proliferating the methods and applications of genomic science. Postgenomics is characterized by deep contestations about what questions can and cannot be answered using DNA sequence data. In *Postgenomics: Perspectives on Biology after the Genome*, Hallam Stevens and I argue that the conditions of scientific knowledge production in genomics are destabilizing shared understandings of what counts as scientific knowledge in this arena. As genomics methodologies become ubiquitous, there is a renewed need for articulation of community standards for research. Yet there is a dearth of venues for sustained conversations that might lead to the establishment of scientific community standards for research in transdisciplinary genomics research endeavors.⁴

The Lahn episode put all of the ethical and epistemic challenges of the postgenomic moment on full display. Researchers professed the importance of academic freedom, condemned racism, and managed media controversy simultaneously to try to ameliorate harms. These approaches focused on the interpretation of the studies’ results, failing to recognize and raise fundamental questions about changing standards for making claims in the postgenomic sciences of human differences in cognition and behavior. As such, they revealed worrying deficits in the fields’ ability to govern and negotiate standards for making postgenomic claims in the transdisciplinary space between human population variation research, studies of intelligence, neuroscience, and evolutionary biology.

Today, researchers at BGI Shenzhen (formerly Beijing Genomics Institute) in China, in collaboration with lead-

ing behavior geneticist Robert Plomin and with prominent figures such as Steven Pinker in advisory roles, are pursuing the genomics of intelligence on a newly grand scale.⁵ They are sequencing large numbers of whole genomes of people considered highly intelligent (by varying empirical and social measures) in the hope of finding gene variants predictive of intelligence. Troubling and at times outlandish futurist claims accompany this research. Scientists involved in this research have openly discussed the possibility of marketing prenatal tests for intelligence, of genetic engineering or selective embryo implantation to increase the likelihood of a high-IQ child, and of genotyping children to guide their education.⁶ In this permissive and contested environment, what would trustworthy research on the genomics of high intelligence look like?

In the fall of 2014, The Hastings Center and the Johns Hopkins Center for Talented Youth (CTY) gathered a diverse group of experts to discuss a request by researchers seeking to study genetic markers associated with high intellectual functioning. The researchers sought access to test score data and contact information for participants in a long-running CTY study known as the Study of Exceptional Talent. As of May 2015, the study included almost 5,500 eligible eighteen-and-over individuals identified over many decades of work at the highly regarded CTY as a part of their ongoing research on the trajectories of people who were identified as highly talented children.⁷

The main question before CTY was whether it should make its data available to these researchers. One view was that it should, as long as the researchers were proposing methodologically sound science that would be subjected to peer review before publication. The problem with this view is that, in the case of genomic research on human intelligence, we lack a trustworthy way to determine that this is the case.

All but a few privileged actors are necessarily dependent on—and therefore must trust—the investigators leading any particular scientific endeavor because they lack the knowledge or access to check their claims. “Trustworthiness” is an epistemic-ethical feature of scientific work that allows us to rely on its findings even when we cannot witness them or do not have the tools to independently audit them. We find scientific projects “trustworthy” when we have good reasons to believe that they in fact do what they say they are going to do. As philosopher of science Naomi Scheman has influentially argued,

The trustworthiness of scientific methods derives, in practice, from the effective working of those institutional structures; and justified belief in that trustworthiness arises from the justified belief that those institutions do in practice what they are supposed to do in theory: ground knowledge claims that are acceptable to all of us,

not just to those of us with certain forms of privilege, who see the world through certain lenses, from certain biased perspectives.⁸

From this perspective, the trustworthiness of the results of basic science is—and should be—entangled with the trustworthiness of the social processes that produce, disseminate, and use those results. Trustworthiness offers a valuable framework for thinking through the mangle of ethical and epistemic considerations provoked by proposals to research the genomics of individuals identified as highly intelligent.

If we begin to probe the researchers’ request for access to CTY’s data, some troubling opacities emerge. For example, when asked by CTY, the researchers said they were not interested in racial or group differences in intelligence. They also promised to donate ten dollars to a scholarship fund for minority students for each participant who agreed to send a cheek swab to the study. However, it was known that the eligible study group within the Study of Exceptional Talent is 70 percent male and 94 percent of white or Asian ancestry. This skew in the data set could affect data interpretation and the scope of the findings due to sex- and population-based variation in genomic architecture. How would the researchers address this issue in the design, interpretation, and communication of the results of the study?

As another example, the researchers revealed no commercial interests. However, the research team has proposed that genetic testing could be used in schools to individually tailor educational programming that would involve the marketing of “gene chips” to school systems. One of the researchers is a principal in the BGI Cognitive Genomics project, a for-profit enterprise with open ambitions of marketing genetic tests for intelligence. The exact role of BGI in the study was not clarified, although researchers said that the genome sequencing itself would not occur at BGI. Would the CTY data be pooled with data supporting the controversial BGI Cognitive Genomics project? Did the researchers envision commercial applications utilizing the CTY participants’ genomic data? What checks would the researchers put in place to reduce potential biases introduced by their own intellectual, institutional, and possible financial investments and interests?

I invite the reader to take the standpoint of communities most historically open to harm from this kind of research: poor African American communities—one of which, it should be noted, surrounds CTY and Johns Hopkins in Baltimore, Maryland. There are well-motivated reasons for this community to perceive genomic research on high-intelligence individuals as lacking trustworthiness. These reasons are documented in Aaron Panofsky’s recent book *Misbehaving Science*. They include a history of excessive focus on group-based racial differences in intelligence,

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contributing to the stigmatization of racial minorities; stonewalling of well-motivated methodological and ethical critiques; and grand but ultimately unrealized claims about the explanatory power of genetics to account for human behavioral variation.⁹

I would add three further considerations related to the specific conditions of the postgenomic sciences. The first is the portability of genomic data. Once sequenced and tagged, genomic data is in a digital form that can be instantly transmitted and infinitely parsed. Generally speaking, the genomics community expects researchers to share and pool genomic sequence data. Without severe restrictions (and even sometimes in spite of them), sequence data can be taken up and used by other researchers, potentially in perpetuity, for any purpose they see fit. Second and related is the commercial context in which much genomics research is taking place, including visions of clinical and recreational uses of genetic tests as part of a repertoire of educational counseling and prenatal embryo selection. A third consideration is the context of scientific illiteracy and media hype that characterizes public discussions of genomic findings pertaining to human behavior.¹⁰

These conditions are extenuated by what science studies scholar and historian of genomics Mike Fortun refers to as the “promissory”—a label that describes a particular feature of twenty-first-century genomics discourse, namely, a reliance on continuously renewed but rarely fulfilled promises of providing therapeutic and technological breakthroughs.¹¹ The promissory mode is characterized by a rhetoric of forward-looking, speculative statements that are attractive because they are optimistic and open to possibilities but are also unsettling because they are not about what is true or responsible. Like speculative markets that lead to bubbles, they are driven by haste and speed and people’s perception of value within a space of risk and uncertainty. Akin to Stephen Colbert’s concept of “truthiness,” these discourses produce ambiguity, controversy, hype, and ignorance. As Fortun argues, the promissory mode places decision-makers in a condition of undecidability rather than uncertainty. With uncertainty, we can seek to ameliorate our condition by gathering more knowledge. With undecidability, we simply have to decide and then take responsibility for our decision. This promissory mode has implications for the possibility of ethical debate about the genomics of high intelligence because it makes uncertain possibilities seem to be already foregone conclusions, restricting the discussion

to questions of what should be done to manage risk rather than broader questions of fundamental values and what we want to happen.

Each new development in genomics technology, methodology, and the institutional milieu renews this promissory mode, and behavior genomics is not immune from it. In 1998, Robert Plomin predicted routine DNA testing in clinical psychology practice within a few years: “DNA is coming to a neighborhood near you. I predict that by the turn of the century, psychologists will routinely use DNA in research and perhaps even in clinical practice.”¹² Whereas biometric and classic gene-hunting methodologies predominated in the 1980s and 1990s, now behavior geneticists hope to sequence thousands of whole genomes and use technologies of “big data” mining to locate genomic signs that help to explain behavior and cognition. In his 2003 *Behavioral Genetics in the Postgenomic Era*, Plomin renewed his optimism: “The future for behavioral genetics looks brighter than ever in the dawn of the postgenomic era.”¹³ Plomin’s 2013 book *G is for Genes*, written with Kathryn Asbury (who has contributed an essay to this special report),¹⁴ continues this promissory message. Asbury and Plomin project high confidence in our knowledge of genetic proclivities. They imply it will lead to reform of educational and social policies. They even imagine a future in which “learning chips” documenting genetic tests for intelligence are used to guide children’s educational development.¹⁵

These claims are strongly dissonant with recent genomic studies showing that a large number of gene variants are required to account for even a tiny sliver of the purported heritability of intelligence.¹⁶ The burgeoning fields of epigenetics, microbiomics, and studies of chimeric and monoallelic gene expression in the human genome similarly challenge the notion that DNA sequence itself will be highly explanatory of normal variation in human behavior.¹⁷ This state of contestation belies any sort of strong claims about the power of gene sequences alone to explain the emergence of human behavior. There is, in fact, little consensus about what constitutes meaningful questions, study design, data interpretation, and translation to human practices in the postgenomic study of the genetics of human behavior.

Under such conditions, what would it take for a request to study the genomics of high-intelligence individuals to meet ideals of trustworthiness? Note that trustworthiness

does not require the promise of *no harm*, nor does it require that research guarantee the reportage of *true* findings. Rather, it is an achievement standard that assesses the degree to which research is conducted according to how researchers promise that it will be conducted. Moreover, trustworthiness is not a quality that accrues to individual researchers, who are almost surely good-hearted, justice-loving people, but to institutions and processes. To what extent could the epistemically dependent stakeholder, whether we imagine that as CTY, the cheek swab donor from the pool of exceptionally talented individuals, or the historically under-resourced African American community in Baltimore, have trusted that the system of scientific research would function as promised in this case?

The establishment of trust in the functioning of scientific research methods is a social process. I have argued that such trust is created and maintained through wide-open dialogue concerning a scientific community's standards for research. Borrowing from Helen Longino's concept of "transformative criticism," I call these "transformative conversations." Transformative criticism addresses a scientific community's shared standards that set the conditions for what counts as maximally trustworthy scientific knowledge in a particular study area.¹⁸ Transformative conversations invite rigorous critical dialogue about the standards of research in a field and generate the conditions for the reception and uptake of transformative criticism within a field. The key elements of a transformative conversation are that fundamental issues of standards for research are up for discussion, that all well-motivated perspectives can be heard, and that there is a genuine possibility that criticism could lead to transformation in a scientific community's research practices. Transformative conversations involve continued dialogue and clarification of key issues. They need not lead to consensus among all parties. They are ongoing and diffuse rather than discrete and one-time events. All parties may not be satisfied at any particular moment, but in transformative conversations, the conditions are maintained for open dialogue and for potentially transformative criticism.

Transformative conversations concern a scientific community's standards for research. As such, they are of a metascientific nature. Metascientific debate about values and standards in scientific research engages basic questions about the foundations of knowledge in a field. Such questions may transcend traditional boundaries, melding "ethical" and "epistemic," "external" and "internal," or "social" and "scientific." Starting questions for a transformative conversation include these:

- What are the standards for an empirically adequate claim in this research field?
- What social and intellectual conditions are required to produce empirically adequate research in this field?

- What questions can be asked or answered using scientific methodology within the area of study, and which cannot?
- What kinds of evidence are relevant to testing hypotheses?
- Who counts as an authoritative knower or expert in the scientific field?
- Should this research be done?
- To whom are scientific researchers in this field accountable?

The Hasting Center's 2014 workshop, the articles in this special issue, and earlier projects that produced *Intelligence, Genes, & Success: Scientists Respond to "The Bell Curve"* (published in 1997) and *Wrestling with Behavioral Genetics: Science, Ethics, and Public Conversation* (2008) invite transformative conversations by posing questions such as these: What questions can be asked or answered given the theoretical and empirical constraints of genomics and the study of human behavior? What conditions would be required to produce trustworthy research on individual and group (race or sex, for example) differences in IQ? For whom and for what purposes is knowledge on the genomics of high-intelligence individuals produced? Ideally, transformative conversations are initiated by practitioners, are structured into the ongoing work of the field, and include a wide range of stakeholders at the table: potential research participants, populations who may stand to gain from the research, members of communities historically harmed by such research, and the researchers themselves.

Is this too stringent a benchmark to ask human behavioral genomics research on individuals regarded as highly intelligent to meet? No. Not only are there prior models, noted above, within the field of behavioral genomics itself, but we also have an excellent example of transformative conversations at work in the history of at least one other case of perpetually and highly controversial genomics research: human population variation genetics. In the 1990s, the field was nearly taken to its knees by controversy over the Human Genome Diversity Project, which came to be seen as an insensitive, extractive, neocolonialist, and racist enterprise and was ultimately halted.¹⁹ Sociologist Catherine Bliss's 2012 book *Race Decoded: The Genomic Fight for Social Justice* documents how an antiracist, multiculturalist consensus became a socializing, regulating ethos and identity among elite genome scientists at the turn of the twenty-first century.²⁰ Today, the field shows the fruits of major steps taken to respond to these criticisms and reframe its approach to research on human genetic diversity.

As a research community, human population genetics has built trustworthiness by engaging in constant, open, and responsive conversation with the many stakeholders in

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the science and by seeking, with insights from that conversation, to mitigate harms that could be caused by the science.²¹ Today training and socialization in human population genetics involves introduction to the history, philosophy, and ethics of scientific work on racial difference. Scientists regularly participate in interdisciplinary conversations and initiatives with social scientists and humanists.²² They engage in educational efforts to ensure community consent and involvement in ongoing research in vulnerable populations. As Bliss shows, the field has drawn a newly diverse population of scientists who mobilize their own histories and ethnic identities, using the tools of population genetics to study their own populations. Leading scientists in this field participate as experts in a broad civic platform in the debunking of conventional racial stereotypes. The field is able to exert ongoing vigilance surrounding the direction of research that could lead to the entrenchment of harmful conceptions of racial difference. For example, leading human population geneticists recently rebuked Wade's *A Troublesome Inheritance* in a public letter signed by 140 scientists, sending a forceful message of the field's ability to regulate its own standards for claims-making about the genetics of human racial and ethnic differences.²³

Trustworthiness is never achieved once and for all. Moreover, it does not make a field immune to criticism. Nor does it prevent controversy. Bliss, for example, argues that despite many transformations in the field, many scientists in human population genetics still “fashion an activism that often neglects the core causes of racial injustice, such as institutional racism and structural inequality. Although scientists are responsive to criticisms of biological determinism, they nevertheless build genomics as a special expert science of race on the basis of its superior knowledge of biological ancestry.”²⁴ Transformative conversations are never permanently achieved but involve contestation between diversely situated actors. They are constantly in the process of actualization. What is important in the assessment of well-founded trustworthiness is the continued engagement of a field in conversations that demonstrate the ability of the scientific community to negotiate and regulate standards for research and the possibility that the field can take up criticism and transform its practices in light of it.

How can scientists operating in a rapidly expanding postgenomic environment marked by unprecedented uncertainty and contestation manage new and charged research on human genomic variation associated with behavior and cognition? Many individual behavior geneticists, including those who participated in The Hastings

Center meeting that led to this special report, have long been committed to conversations with diverse stakeholders in behavioral genetics research. Their efforts form a foundation for field-wide trustworthiness-building exercises in behavioral genetics. Behavioral geneticists might also look to practices in other fields, such as human population variation genetics, for exemplary models of the cultivation of trustworthiness through transformative conversations.

Having unresolved questions and concerns, CTY ultimately did not participate in the proposed study of the genomics of high-intelligence individuals, but if the center had extended an invitation to its alumni to submit cheek swabs to the researchers, it would have conveyed that it found such research trustworthy, meaning some version of the following: We believe that this study is worth your time and ours. We trust that your DNA will be used for good. The study will meet the highest standards of science. The benefits outweigh the harms. People in our communities who may not be able to independently evaluate the science or who historically or in the present have been victimized by this kind of science are unlikely to be harmed by it. This study conforms both to our values and yours (see the essay by Elaine Tuttle Hansen, Stuart Gluck, and Amy Shelton in this special report).²⁵

Wade and others contend that resistance to genomics research on behavior and cognition is a result of “politically correct” queasiness about research that might show some people, and some populations, to be more genetically endowed with socially valued cognitive traits than others. They also suggest that such resistance reflects misunderstandings of the science and its aims. Here I have offered a different view. Resistance to such research is due to sometimes well-founded distrust of researchers' claims that such research can be done well. Genomic approaches to the study of human intelligence are deeply contested within the science of genomics. Additionally, the proposed transnational research project on the genomics of high intelligence involves researchers and institutional actors who have publicly defended research on race-based group differences in intelligence (such as that presented in *The Bell Curve*),²⁶ have advanced genetics-based agendas within the politically charged arena of “choice”-based education reform,²⁷ and are interested in the possibility of proprietary commercial applications. In this context, trustworthiness emerges as a perceptive ethical-epistemic framework for understanding concerns about whether this research should be done.

An ethical practice of the genomics of human behavior and cognition requires addressing perceptions of a trust-

worthiness deficit derived from the concerns of those most likely to be harmed by such research. Meeting these standards requires “contexts in which scientists might engage in vigorous and open debate about community practices, values and standards,” an approach I call “transformative conversations.”²⁸ Such conversations primarily concern the research standards of a scientific community but also, because they edge into metascientific terrain, invite engagement with other communities, including intersecting scientific fields and stakeholder communities such as research participants, patients, or groups subject to downstream harms.

Research on the genomics of high intelligence is rightly resisted unless and until scientists articulate research standards that exhibit trustworthiness. Trustworthiness can be earned by a scientific community’s demonstrated and ongoing engagement in wide-open conversations about the standards for scientific research in ways that show the possibility of uptake of transformative criticism. It is possible that transformative conversations could lead to conditions under which this research can and even should be done.

Trust is gained through social processes. Institutions, such as public and private funders, research centers, and academic journals, can play a key role. As The Hastings Center and CTY have demonstrated in this instance, institutions can spur transformative conversations by creating venues to scaffold and support their continued cultivation. Even when the necessary conversations are at times awkward, troublesome, and charged, critics are well motivated in demanding postgenomic research on human intelligence that is not only methodologically sound but also trustworthy.

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