Quick Take

- The majority of human DNA is identical regardless of race or nationality, but differences in our ancestors’ social and environmental conditions have contributed to the development of unique genetic variants that can influence our physical and mental health.
- To date, more than 80% of genetics research has involved White participants, meaning that genetic risk scores for many conditions are less accurate for BIPOC individuals.
- Prioritizing training and funding for genetics researchers from understudied populations can help prepare these scientists to lead future genetics studies.
Researchers can help recruit more BIPOC participants by acknowledging past abuses and pursuing projects of interest to understudied populations.

Partnering with communities and ensuring participants are equipped to provide fully informed consent can help empower people to approach genetics studies on more equal footing.

Building researcher capacity • Building trust with participants

Since the first human genome was sequenced in 1990, the field of genetics has exploded with potential.

“Behavior genetics is a field that has experienced rapid advancement the likes of which are unparalleled, with the exception of advances in computer science,” wrote Danielle M. Dick (Rutgers Robert Wood Johnson Medical School) in a 2022 Current Directions in Psychological Science article. “If the first 50 years of the field were dedicated to demonstrating that a wide range of human behavior is genetically influenced,” she wrote of the period leading up to that 1990 breakthrough, “the next 50 years will surely be consumed with mapping the relevant genes and applying this newfound knowledge.”

But not without considerable change. For everyone to benefit equally from these advances, the field of behavior genetics needs to take significant steps to include more racially diverse participants and perspectives. Currently, more than 80% of participants in genetics studies have been White, Dick noted. According to the U.S. National Human Genome Research Institute, although more than 99.9% of human DNA is identical regardless of race or nationality, notable genetic variations exist within certain populations because of the different social and environmental conditions experienced when humans migrated out of the continent of Africa to populate the world. Thanks to these variants, genetic risk scores for many physical and mental health conditions based on studies using participants from only one racial group or geographic location are less accurate for people with a different ancestral background and may miss genetic risk factors unique to some ancestries entirely.

**Understanding Genetic Risk**

In the early 20th century, people generally believed that behavioral disorders were caused primarily by environmental factors, researcher Danielle M. Dick explained in a 2022 Current Directions in Psychological Science article. It has since become clear that our genes powerfully influence everything from our personalities to our risk for mental health conditions. Although there is no one gene “for” traits like outgoingness or conditions like anxiety and alcoholism, Dick stressed, our genes do influence our behavioral tendencies, which in turn shape how we interact with and react to our environments.

Having a gene associated with a certain condition also doesn’t necessarily guarantee that the condition will develop. As Susan C. South (Purdue University) and colleagues stated in a 2021 Clinical Psychological Science article, an individual at increased genetic risk for a condition like generalized anxiety disorder may be more likely to experience that condition only when they are under significant
stress, such as prolonged marital conflict.

Psychological scientists’ rapidly advancing understanding of how genetic risk factors interact with our socioeconomic environment to influence our health has the potential to improve mental health care through preventative precision health care, Dick wrote.

In one 2021 *Clinical Psychological Science* study, for example, Brian M. Hicks (University of Michigan) and colleagues explored how genetic risk factors related to smoking might contribute to the risk for antisocial behavior in adolescents. The researchers computed a polygenic score (PGS) for ever being a regular smoker by analyzing the genetic data of 3,225 participants from the Minnesota Twin Family Study. On the basis of clinical interviews and teacher ratings, adolescents with higher smoking PGS scores were found to be less conscientious and less agreeable—and more likely to have oppositional defiant disorder and externalizing problems such as inattention, impulsivity, and aggression.

“Hopefully, PGSs will eventually have practical value by identifying persons at greatest risk for experiencing negative outcomes,” allowing them to access interventions before more serious problems arise, Hicks and colleagues wrote.

In practice, this means that genetic risk scores are generally less accurate for individuals who are Black, Indigenous, and people of color (BIPOC). This is because the majority of genetics studies have been done with participants of European descent.

**Building researcher capacity**

Segun Fatumo (London School of Hygiene and Tropical Medicine) and colleagues addressed this problem directly, along with potential solutions to it, in a 2022 *Nature Medicine* article. In order for genomics research to reflect the world’s true diversity, studies need to be done not just on diaspora populations located in the United States and the United Kingdom, but also on people living in Africa, Asia, and South America.

“Increasing diversity in genomics is critical to ensure that translation of genomic screening strategies improves health outcomes for all and does not exacerbate health disparities,” Fatumo and colleagues wrote. This is particularly important because research has shown that scientists are more likely to study participants who share their racial background, they added.

Many projects and initiatives have begun to make progress in this area, Fatumo said in an interview with the Observer. For example, the Latin American Genomics Consortium has collected 100,000 samples from people of Latin or Hispanic descent for use in psychiatric genetics studies and is gearing up to create a biobank of samples from people located outside of the United States. Meanwhile, the Pakistan Alliance on genetic RisK factors for Health (PARKH) is collecting data from 30,000 psychiatric patients and 15,000 control subjects to investigate genetic risk factors for depression, schizophrenia, and bipolar disorder.

Work is still needed to equip more local researchers to take on leadership roles in genomics studies,
For instance, funding requirements can be a significant barrier for researchers in low and middle-income countries (LMICs), which may not have government funding earmarked for genomics research. Fatumo and colleagues noted that the PARKH studies, for example, receive funding from the European Research Council and the U.S. National Institute of Mental Health, but the projects are eligible for these funds only because they are run by scientists based in the United States and the United Kingdom, in addition to Pakistani researchers.

“Given the immense and wide-reaching benefits of increasing diversity in genetic research, funders should reconsider such restrictions,” Fatumo and colleagues wrote. Setting aside funding specifically for studying diverse populations could also help researchers from LMICs build the experience and research infrastructure necessary to be competitive applicants for larger international funding opportunities.

Preparing local students and researchers to study genomics by providing additional training and hiring them to work on existing projects is another important aspect of capacity building in LMICs, Fatumo and colleagues wrote. In addition to conducting research on genetic risk factors for blood disorders, hypertension, and numerous other health conditions, the H3Africa Bioinformatics Network, for example, hosts an annual Introduction to Bioinformatics course and other training workshops for researchers online and in classrooms across Africa. H3Africa also funded Fatumo’s postdoctoral research at the Sanger Institute and the University of Cambridge in the United Kingdom. This research, in turn, prepared him to lead the analysis of the Uganda Genome Resource and other related studies, including the first study of genetic variants related to kidney function conducted with people of African ancestry.

“We need that kind of training to empower people to be leaders. It’s only when they have the possibility of a leadership position that they will be able to create their own agenda,” Fatumo said.

**Building trust with participants**

Generating more racially diverse genetics research also requires scientists to build trust with communities that have been subjected to unethical and even inhumane research practices in the past.

“Mistrust of scientists may be a dominant barrier for individuals of previously excluded communities participating in neuro-psychiatric and behavioral genomics research,” wrote Olivia P. Matshabane and colleagues Calandra G. Whitted and Laura M. Koehly (National Human Genome Research Institute) in a 2022 *Frontiers in Genetics* article.

In the United States, the Havasupai Tribe case and the Guatemala and Tuskegee syphilis studies are two poignant examples of exploitation in the name of science that have led many BIPOC individuals and members of other marginalized groups to question whether scientists always have their best interests in mind, Matshabane and colleagues explained. In the first case, which began in 1990, Native American tribe members’ blood samples were used for genetics testing without fully informed consent, leading to research that some Havasupai felt undermined the tribe’s traditional origin stories. During the Guatemala and Tuskegee syphilis studies of the 1940s, researchers funded by the U.S. government infected Guatemalan and African American people, including prisoners and psychiatric patients, with
sexually transmitted diseases to develop more effective treatments for American soldiers stationed abroad. Many of these “participants” were ultimately left untreated and went on to suffer dire health outcomes.

An African American male is tested and treated during the Tuskegee Study of Untreated Syphilis in the Negro Male. According to the Centers for Disease Control and Prevention, the study began in 1932 when U.S. Public Health Service medical personnel conducted these tests without the benefit of patients’ informed consent. Centers for Disease Control and Prevention, Public domain, via Wikimedia Commons

Given this history, how can the field of genetics recruit more diverse participants and researchers? A starting point is to acknowledge how psychology has been weaponized against various groups and take action to steer it in a new direction, according to clinical psychologist Evan Auguste (University of Massachusetts Boston). In a 2023 Perspectives on Psychological Science article, Auguste and colleagues documented the anti-Black history of psychology and changes the field can make to better support African American participants and researchers.

“There is a very long history of genetic testing being used in support of White supremacist eugenics practices,” said Auguste in an interview with the Observer. “So much of what continues today in practice, in theory, extends from the initial anti-Black construction of the field of psychology.”

It’s easy for many people to recognize the scientific racism baked into the psychological theories of the more distant past, Auguste said. As he and colleagues noted in Perspectives, physician Samuel A. Cartwright’s 1851 assertion that Black people who wished to escape slavery suffered from a fictitious mental illness known as “drapetomania” is one such example of how early psychologists used the cover of science to justify their existing racist beliefs.

This history didn’t end with the abolition of slavery in the United States, however. Between 1892 and
1947, Auguste and colleagues wrote, 31 presidents of the American Psychological Association also led eugenics organizations. These organizations openly pursued the forced sterilization and institutionalization of Black people, along with other people of color, Jewish people, and people with disabilities, in order to create a more genetically “superior” society by preventing “unfit” people from having children. More recently, Auguste said, the label of “protest psychosis” was used to indefinitely confine African American men in psychiatric institutions during the Civil Rights movement of the ’60s and ’70s.

This legacy of racism also carries over into the study and practice of psychology today, which remains intertwined with the overpolicing and mass incarceration of Black Americans, according to Auguste and colleagues.

For example, Auguste explained, Black people continue to be disproportionately diagnosed with psychotic disorders, and these diagnoses have been found to increase public support for the use of police violence and institutionalization against these individuals. By contrast, White people with similar symptoms are more often diagnosed with mood disorders, which are perceived as less threatening to public safety. Meanwhile, numerous modern researchers have put forward genetics, IQ, and “bad parenting” as primary factors driving involvement with the criminal justice system and reduced educational attainment in Black communities, ignoring the systemic socioeconomic causes of these outcomes.

In light of these and other examples of bias, Auguste said, researchers have to do more than simply acknowledge how historical and continuing racism have shaped psychology. Researchers attempting to recruit more Black participants for genetic risk testing will need to give potential participants a reason to believe that future studies will actually be of benefit to them.

“This study trying to recruit people might be attractive to funding agencies, but is it attractive and appealing to the people you want to work with?” Auguste asked. “Are they interested in those questions, or is the researcher the primary person who will benefit through funding and prestige?”

In addition to increasing the field’s diversity, pursuing research informed by Black theory and scholarship could help researchers engage with this work in a way that is less likely to reproduce the anti-Black harms of the past, Auguste added.

In their 2022 *Frontiers in Genetics* article, Matshabane and colleagues pointed to the NeuroGAP network, which studies genetic risk factors for schizophrenia, bipolar disorder, and neurodevelopmental disorders in South Africa, Ethiopia, Uganda, and Kenya, to illustrate examples of steps scientists can take to pursue more ethical genomics research. These include partnering with participants through community advisory boards, adapting studies to local cultural considerations, and using studies as an opportunity to train and mentor scientists from the population being studied. It’s also important to promote genomic literacy among participants not only by explaining a study but by assessing participants’ understanding of that explanation to ensure that they are able to grant fully informed consent, the researchers added.

“Empowering communities through equipping them to confidently engage and negotiate with researchers is an important step towards creating more equitable partnerships and leveling power
dynamics in scientific research.” Matshabane and colleagues wrote.

Through partnering with understudied communities, research on genetic risk factors offers a path forward to better physical and mental health outcomes for everyone.

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References


