

# Trust is key to boosting diversity in genetics research

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Gene therapies could one day offer life-saving treatments for diabetes, cancer, sickle cell disease and other illnesses that disproportionately affect ethnic minorities, yet many black Americans have profound reason to be skeptical of genetic research.

"The memory of Tuskegee is ingrained in us," said Patricia McManus, president and CEO of the Black Health Coalition of Wisconsin.

During the Tuskegee syphilis experiment that began in 1932 and ran four decades, federal researchers recruited 600 impoverished Alabama sharecroppers for a clinical study. Of that group, 399 had syphilis, but no participants were told of the diagnosis and no syphilis treatment was provided so that researchers could observe the disease's progress.

UW-Milwaukee College of Nursing professors Aaron Buseh and Sandra Millon-Underwood can't rewrite that shameful history, but they are trying to better understand the legacy of mistrust in order to boost ethnic minorities' participation in potentially life-saving medical research. Backed by a grant from the Wisconsin Genomics Initiative, they conducted a detailed, community-based study exploring perceptions and attitudes about [genetic research](#) among African-Americans and African immigrants in Milwaukee.

Buseh and Underwood asked participants about their knowledge of genetics, their sense of possible benefits and disadvantages of genetic research, and their willingness to provide samples (such as blood and

tissue) to biobanks for use in future research.

"The goal of our study was to get a better sense of their thoughts and experiences in the hope that in the future, more individuals from the black community would at least consider engaging in the research process," Underwood said.

McManus and Fessahaye Mebrahtu, executive director of the Pan African Community Association, partnered with the professors, in part to ensure that their communities aren't left out of potential cures for deadly diseases that disproportionately affect ethnic minorities. "This is a new frontier for medicine, and if we do not understand it, our community may not benefit from it," Mebrahtu said.

The UW-Milwaukee findings may shape how genetic researchers engage minority communities to address health disparities. Boosting awareness of ethical genetic research practices could also lead to strategies that encourage minority populations to participate in future studies – including DNA donation.

## **A community approach**

Mebrahtu and McManus – who earned two nursing degrees and a doctorate in Urban Studies from UW-Milwaukee – said they agreed to take part in the genetics attitudes project because of their long-standing relationships with Buseh and Underwood. Both researchers have spent years studying health disparities in Milwaukee. In a recent project, Underwood focused on improving access to breast cancer information and screening among African-American women. Buseh has studied the experiences and challenges faced by African-American men living with HIV and AIDS. Each uses a community-based participatory research approach.

This makes community collaboration central to their studies. They hold focus groups to ask [community members](#) what research questions are most important to them and share findings with the community once the research is complete. "We do not use a helicopter approach and fly in and fly back out," Buseh said.

This type of collaboration takes extra time and effort. "I tell my students: 'Doing community-based participatory work is not an easy thing,'" Buseh said. But he believes the effort is worth the trust it builds with study participants.

McManus agreed. "The way they do it means a lot, and it goes far within our community."

The genetics attitudes project included focus groups with community leaders and community members, in-depth interviews and a pencil-and-paper survey administered to volunteers. The researchers designed the study with two separate arms: one for African immigrants and another for African-Americans, with 212 people in each arm. Professor emerita of nursing Patricia Stevens joined the team to analyze the data.

## **Their findings**

The study revealed deep concern about genetic testing among African-Americans and African immigrants. To Buseh's surprise, those doubts were voiced even by those with advanced degrees. "The issue of trust reverberated through the transcripts," Buseh said.

Focus group participants wondered what might happen to their genetic samples once they were collected and how genetic information might block their access to insurance. Some expressed doubts that minority communities would benefit from the research after scientists collected the data. African immigrants noted that in their culture, there's a risk

that if a person's genetic defects become public, his or her entire family might be shunned.

"Almost every aspect of 'what if' was raised," Mebrahtu said.

Some of the conversations touched on the story of Henrietta Lacks, subject of a 2010 bestseller. Lacks, an African-American tobacco farmer, was dying of cervical cancer in 1951 when doctors took a sample of her cells without her consent. After her death, her husband and five children, including a 1-year-old son, lived in poverty. Two companies were founded to sell copies of her cells, which led to the development of the polio vaccine among other key medical advances – and tens of millions of dollars in profit. Focus group participants expressed anger that researchers might have profited at her family's expense.

In another focus group, McManus shared the more-recent example of a 1990 Centers for Disease Control study of measles vaccines in infants in Los Angeles, Senegal and Haiti. Researchers failed to tell parents that their babies received an experimental vaccine and then halted the study when they noticed an increased death rate among female infants in Senegal who received a stronger dose of the vaccine.

Buseh says the focus group conversations and other findings underscored for him the importance of scientists being open about the motives and possible effects of their research.

"How can we better educate and engage our health care professionals to have these conversations with patients?" Underwood asked. "How can we help patients better understand how genetics and genomics does indeed impact their health and well-being, and the well-being of the next generation?"

She added that many of the people they surveyed wanted to learn more about genetics research, and some said they would consider donating DNA samples for research. "Many were very interested but had never been asked," Underwood said.

Buseh noted that any conversations about gene therapies must cover their potential limits. "We can't overpromise that once we get your DNA, we can analyze it and figure out what's happening to you now and will happen to you in the future, and you will be fine," he said.

Buseh hopes to host a genetics summer camp for [ethnic minority](#) teens, teaching them about the process of taking a detailed family health history. He wrote an opinion piece in The Scientist, calling for researchers to venture into diverse communities and hold "genetics cafes," in which they sit down with ethnic minorities to describe their work and answer questions.

Finally, he and Underwood are working with Mebrahtu and McManus to expand the study, with the hopes of getting more medical researchers to examine wider [health care disparities](#) affecting black Americans and African immigrants.

"We want to create opportunities for bench scientists and community members to meet in the community," Buseh said. "Building trust starts when the affected people can say that the scientists came to them instead of scientists asking people to leave their community and step into a lab or clinical setting."

Provided by University of Wisconsin - Milwaukee

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