

Researchers explore legacy of Tuskegee syphilis study today

January 9 2017, by Beth Duff-Brown



Stanford sophomore Javarcia Ivory (left) and Dr. Owen Garrick compare notes outside a clinic where volunteers receive medical checkups. Photo by Nicole Feldman.

It's been more than 40 years since the revelation of the Tuskegee syphilis

study sent shockwaves across the country. The subsequent mistrust of the medical community among African-American men appears to have spread far beyond the Deep South, where the infamous public health project took place.

Six hundred African-American men were chosen for the "Tuskegee Study of Untreated Syphilis in the Negro Male," launched during the Great Depression. They were told they had "bad blood," and many underwent painful spinal taps and other medical procedures. Of those 600 men, 399 had syphilis.

Even after the U.S. Public Health Service in 1945 approved penicillin to treat the disease, the study that began in 1932 would continue until 1972 without the men being treated – all in the name of medical research.

Stanford sophomore biology major Javarcia Ivory remembers hearing this medical horror story growing up in neighboring Mississippi. He vowed to become a doctor and help revive the lost trust in public [health](#) in the Deep South.

When Ivory learned about a Stanford-led research project in Oakland, CA—one that would dig deeper into this legacy of mistrust stemming from Tuskegee—he jumped.

"As an African-American and someone who aspires to one day become a doctor, I just knew I had to get involved," he said.

Lower life expectancy

"The [Tuskegee] study's methods have become synonymous with exploitation and mistreatment by the medical community," write Stanford Health Policy's Marcella Alsan and her colleague Marianne Wanamaker at the University of Tennessee.

The two have found that the disclosure of the study in 1972 is correlated with increases in medical mistrust and mortality among African-American men. They published their findings in a working paper for the *National Bureau of Economic Research* last year.

Using publicly accessible data, the researchers estimated life expectancy at age 45 for [black men](#) fell by up to 1.4 years in response to the disclosure, accounting for about 35 percent of the 1980 [life-expectancy](#) gap between black and white men.

Alsan and Wanamaker used data on medical trust, migration and health utilization from the General Social Survey and the National Health Interview Survey, as well as morbidity and mortality data from the Centers for Disease Control and Prevention.

Their paper touched a nerve among some prominent African-Americans, some of whom praised the work as a model for understanding [medical mistrust](#) today.

"The story that Alsan and Wanamaker uncovered is even deeper than the direct effects of the Tuskegee Study," wrote Vann R. Newkirk II in [The Atlantic](#).

"Their research helps validate the anecdotal experiences of physicians, historians and [public health](#) workers in black communities and gives new power to them," Newkirk wrote. "These findings are also useful in framing health care debates and discussions of [health disparities](#) today."

Health disparities run deep

African-American men today have the worst health outcomes of all major ethnic, racial and demographic groups in the United States. Life expectancy for black men at age 45 is three years less than their white

male peers, and five years less than for black women.

In the years following the disclosure of the Tuskegee trials, medical researchers have repeatedly pointed to the U.S. Public Health Service experiment as one reason African-Americans remain wary of mainstream medicine and health care providers.

"Mistrust may function as a tax on the price you pay to see a doctor," said Alsan.

To further test this hypothesis beyond their data research, Alsan launched a pilot project in Oakland this summer to evaluate the willingness of black men to seek preventive medical screenings.

The Oakland Health Disparities Pilot Project partnered with Owen Garrick, president and COO of Bridge Clinical Research, an organization based in Oakland that helps clinical researchers find patients from targeted ethnic groups.

Alsan and Garrick worked alongside students from Stanford and the University of California, Berkeley, as well as recent emergency medical technician students from the Oakland community to help run the project.

"We believe that even if you remove all the obstacles – transportation, access to health care and insurance – if you don't trust the provider, you won't follow their advice," said Garrick, a physician whose mission is to get more people of color involved in clinical trials.

"But if you can push through this issue of mistrust, then you really begin to reap the benefits of the wealth of our health care system, and then take advantage of the things that we as Americans have been afforded," he said.

Oakland barbers in predominantly black neighborhoods partnered with the researchers and the barbershops served as recruitment sites. Uber also donated rides to the clinic for screening services.

Some 200 men filled out a medical survey; of those, 60 then agreed to clinical care.

Chris Colter, a manager for Station 33 Barber Shop in downtown Oakland, was pleased to participate in the pilot.

"It feels good that we're helping out the community and that we're instrumental in helping black men with health issues," said Colter.

The pilot results are encouraging, Alsan said, given the high number of those who took up the offer for medical screenings. The team is hoping to scale up the research if they secure additional funding.

Ivory spent his summer in the Oakland barbershops urging patrons to fill out the surveys and get the free checkup.

"I was really surprised at how easily they opened up with me and how interested they were that I went to Stanford," said Ivory, who intends to go to medical school and return to rural Mississippi to practice medicine.

African-American men have a 70 percent higher risk of developing heart failure than white men, prompting Ivory's desire to become a cardiologist.

"Working in the barbershops really gave me an in-depth understanding of how important diversity and inclusion in medicine are for some American populations," said Ivory. "Medical mistrust does not have to dissuade black men from seeking [health care](#) in contemporary America – but it does. And this has galvanized my passion for wanting to become

a doctor."

A presidential apology

Herman Shaw was one of eight Tuskegee survivors invited to a White House ceremony in 1997, to meet President Bill Clinton, who formally apologized for one of the most macabre clinical trials in American history.

The last of the Tuskegee survivors, Ernest Hendon, died in 2004 at the age of 96.

"The wounds that were inflicted upon us cannot be undone," Shaw said at the White House ceremony, after being helped to the podium by Clinton. "I'm saddened today to think of those who did not survive and whose families will forever live with the knowledge that their death and suffering was preventable."

The valedictorian of his 1922 high school class had wanted to go to college to study engineering, but his father insisted he stay back to run the family farm. Shaw died in 1999 at the age of 97.

Two years earlier, at the White House ceremony, Shaw still found it in his heart to say it was never too late to "restore faith and trust."

"In order for America to reach its full potential," Shaw said, "we must truly be one America – black, red, white together – trusting each other, caring for each other and never allowing the kind of tragedy which has happened to us in the Tuskegee study to ever happen again."

More information: Tuskegee and the health of black men:
www.nber.org/papers/w22323.pdf

Provided by Stanford University

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