

To make history, a major study on black heart health looked beyond the lab

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A quarter-century ago, the foundations were laid for the Jackson Heart Study, one of the most significant research efforts in the history of heart health.

As the largest single-site study of Black people's heart health ever undertaken, it would eventually spawn more than 800 [scientific papers](#) and provide critical insights on genetics, prevention and more, based on examinations of thousands of Black men and women living in and around Jackson, Mississippi.

But before the study could make scientific history, it had to confront issues that went far beyond the lab, say people who shaped the study.

"We did focus on much more than looking through a microscope at something," said Frances Henderson, who started working with the study in 1997, during its design phase, and held multiple positions with it over the decades, including deputy director.

The need for research into the cardiovascular health of Black people was clear, said Dr. Herman Taylor, the study's founding director. "There was a huge gap in terms of death and disability between the Black and white populations in Mississippi. And that was reflective of a gap that could be found across the country."

But Black people had historically been left out of research studies. Taylor, now endowed professor of medicine and director of the Cardiovascular Research Institute at the Morehouse School of Medicine in Atlanta, pointed to the example of the Framingham Heart Study, which established the very concept of risk factors for heart health. The participants in that seminal project, which began in 1948, were 98% white.

Better data on Black men and women clearly was needed. But, Taylor

said, the history of all-Black, government-backed studies in the Deep South was problematic. The infamous Tuskegee study, which withheld lifesaving penicillin from Black men so scientists could chart the progress of syphilis, may be the best-known example of how Black people were exploited in the name of science, but it's far from the only one.

The Tuskegee study was shut down in 1972, but Henderson said the history of it and other "horrible things" done in the name of medical research lingers in the minds of many Black Americans.

Many think, "I don't want to be a guinea pig," she said. "And I don't want them to find something and not tell me, so they'll let me die."

Broader than the issue of how Black people were treated in medical research, Taylor said, was suspicion and mistrust of a system "that was deeply discriminatory for much of the lives of the people we were seeking to recruit."

Jackson Heart Study designers worked to overcome that legacy by making partners of participants.

"They had to have ownership in the study and feel they were a part of it," Henderson said. "We didn't have them under a microscope, looking at all the things that were wrong with the population and then going back to California somewhere. We were a part of the community."

Study designers listened to Jackson residents' frustrations with the medical system. Some had lived through the era when Black patients had separate, unkempt waiting rooms and were seen only after white patients had been treated.

Henderson, who is retired but continues to serve as a consultant for the

study, said trust was fostered in many ways. Potential participants were consulted to make sure language on consent forms was clear. For people who might have trouble reading, videos were recorded. A "council of elders" was made part of hiring decisions. People were promised that lab results would be shared with their primary care doctors.

The Jackson Heart Study did not invent the idea of such community engagement, Henderson said. But designers embraced the concept, which since has been used by many others.

The idea was controversial. "Epidemiological purists" might have said sharing information changes what you're doing from a study into an intervention, Taylor said, but ultimately, designers found that sharing information "was not only not a contradiction to scientific inquiry, but in fact, there was a moral obligation to do so."

The study began enrolling participants in 2000. It eventually recruited more than 5,300 people whose participation would lead to important findings related to the genetics of heart disease, links between discrimination and [high blood pressure](#), the significance of social factors in heart health, and more.

By design, the study's goals went beyond understanding [heart](#) disease and into the world of education. Part of this was out of necessity, Henderson said. Jackson lacked experts in [public health](#), so "we had to build our own cadre of health researchers."

So the study created ways to make sure high school students were ready for college and provided career mentors for older students. "That was unusual" for such a study, Henderson said. But it did develop medical experts. Not all of them ended up staying in Jackson—but some did, Henderson said.

It also meant collaborating with some very different educational institutions. Jackson is home to two historically Black colleges: the small, private Tougaloo College, which has educated many of the state's Black health care professionals; and the larger, public Jackson State University, a former teachers college later designated "the Urban University of the State of Mississippi." The city is also home to the University of Mississippi Medical Center. UMMC, part of "Ole Miss," is the state's only academic medical center but didn't graduate a Black doctor until 1972.

Diversity among physicians and researchers can directly benefit Black health, and Henderson said the study helped forge ties that bolstered all three institutions.

"It was not easy to do," she said. "But it worked."

To Taylor, the study's broad goals meant it had been, and continues to be, "truly audacious, truly ambitious."

Researchers, of course, have not closed the racial gap in [heart health](#). A 2022 study in the American Heart Association journal *Circulation* showed that between 1999 and 2019, cardiovascular age-adjusted mortality rates declined significantly for both Black and white adults, but Black women and men continue to experience higher cardiovascular mortality rates.

"Research is a slow enterprise," Taylor said. "Way too slow." Participants often say, "As I'm doing this, I realize it may not help me. But I want to do it for the future, and my children."

But even as he considers the Jackson Heart Study to be "landmark" in terms of understanding Black health, Taylor said it has been more.

"It is also a source of expanded [health](#) literacy in a large Black community," he said. "It is a transgenerational intervention to expand diversity and inclusion of young Black learners into the pipeline of researchers and providers. It is the hub of an international network of scientists of multiple disciplines to better understand human biology as it operates in an environment marked by adverse social and political circumstances. And it is a gift to the world from the Black community of Jackson, Mississippi."

Because ultimately, he said, "discoveries made in Jackson will transcend race and geography—just as they have in Framingham."

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