



Biased Science

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© 2023 ReferencePoint Press, Inc.
Printed in the United States

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ReferencePoint Press, Inc.
PO Box 27779
San Diego, CA 92198
www.ReferencePointPress.com

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LIBRARY OF CONGRESS CATALOGING-IN-PUBLICATION DATA

Names: Currie, Stephen, author.

Title: Biased Science / Stephen Currie.

Description: San Diego, CA : ReferencePoint Press, 2022. |

| Includes bibliographical references
and index.

Identifiers: LCCN 2022014074 (print) | ISBN

9781678202323 (library binding) | ISBN 9781678202330 (ebook)

Subjects: LCSH: scientific research | Medical
ethics--Juvenile literature. | Medical research

Communicable diseases--Juvenile literature.

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The Tuskegee Experiment and Henrietta Lacks

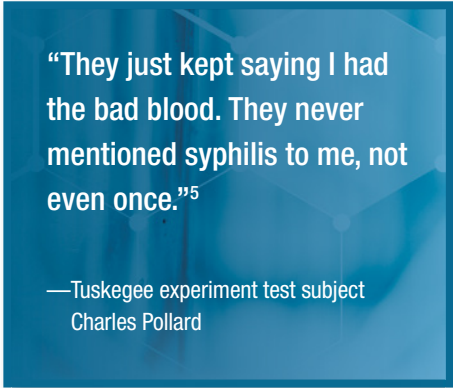
In 1932 a government agency called the US Public Health Service (PHS) organized a medical study involving syphilis, a sexually transmitted disease that can kill those who have it. The study centered on the small Alabama town of Tuskegee and was carried out at a clinic on the campus of a Black college called the Tuskegee Institute. The PHS recruited 600 men from the area to take part in the study. Of these men, 399 had syphilis. All were African American; virtually all were poor and uneducated. Study participants were offered medical care, rides to and from the clinic, meals on days when they were being given examinations, and burial stipends to be paid to their survivors should any of the participants die during the study.

Everyone involved in planning the study knew that the research was not about curing the men who had the disease. At the time, there were no truly effective treatments for syphilis. The only available protocols involved poisonous substances such as arsenic and mercury. These treatments were painful and led to unpleasant side effects. As one expert put it, the

drugs offered “more potential harm for the patient than potential benefit.”³ Nor did researchers aim to find a wonder drug that would provide a cure. Rather, researchers were simply interested in tracking the course of the disease in those it afflicted. There was no expectation that the men who had syphilis would recover.

But that was not what the men recruited for the study were told. Instead, the PHS promised prospective volunteers that they would receive appropriate treatment for what ailed them. Recruitment flyers explained that all volunteer subjects would be given a physical examination. “After [the examination] is finished,” the flyer continued, “you will be given a special treatment if it’s believed that you are in a condition to stand it.” The flyer ended with a veiled threat, printed in all capital letters: “REMEMBER THIS IS YOUR LAST CHANCE FOR SPECIAL FREE TREATMENT.”⁴

Moreover, evidence strongly suggests that the men were not told that the study was about syphilis. Charles Pollard, one study participant, told later interviewers that he had been recruited because he had what researchers called “bad blood”—a catch-all term within the local Black community for ailments both serious and benign. “They just kept saying I had the bad blood,” Pollard reported years later. “They never mentioned syphilis to me, not even once.”⁵ And while some study leaders disputed Pollard’s recollections, other doctors involved in the research backed his account.

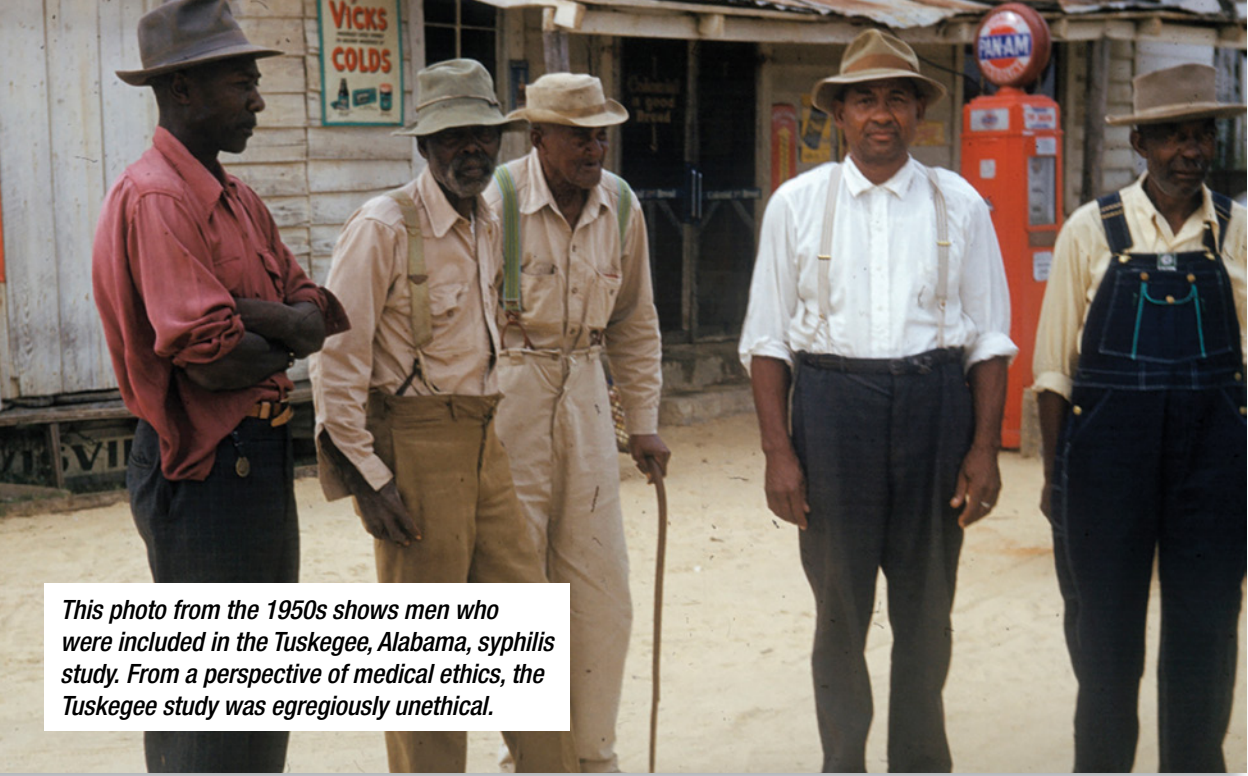


“They just kept saying I had the bad blood. They never mentioned syphilis to me, not even once.”⁵

—Tuskegee experiment test subject
Charles Pollard

Tuskegee and Medical Ethics

From a perspective of medical ethics, the Tuskegee study was severely flawed. Principles of medical ethics state that studies should only be performed on people who have given informed consent—that is, people who know what the study is about and what their role in it will be. The Tuskegee syphilis study failed



This photo from the 1950s shows men who were included in the Tuskegee, Alabama, syphilis study. From a perspective of medical ethics, the Tuskegee study was egregiously unethical.

to provide enough information to subjects to ensure that they could make an informed decision about whether to participate. Moreover, by not identifying syphilis as the focus of the study, the researchers helped spread the disease through the community. Study participants did not know that they could infect their wives—and their unborn children, since syphilis can be transmitted to a fetus if the mother has the disease—and so dozens of women and children became syphilitic as well.

Matters grew considerably worse in the early 1940s, when penicillin, an antibiotic, was used to treat syphilis for the first time. It soon became evident that penicillin cured the disease and carried few negative side effects. But those in charge of the Tuskegee study decided not to dose the men in their care with penicillin. Instead, the study continued as before, with doctors recording the inevitable health declines of the subjects who had syphilis. “I hope that the availability of antibiotics has not interfered too much with this project,”⁶ commented Raymond Vonderlehr, one of the study’s directors, in 1952—making the goal of the experiment clear.

No one knows how long the study might have continued. But in 1972 reporter Jean Heller published a story about the study. Heller's account was met with shock and horror. For decades a government health agency—an agency dedicated to promoting health—had lied to these Black men about their medical condition and denied them treatments known to be effective in fighting their disease. Though study organizers initially tried to downplay the immorality of the experiment, most observers remained aghast. Journalist Harry Reasoner wondered how the PHS could be “only mildly uncomfortable” with using “human beings as laboratory animals in a long and inefficient study of how long it takes syphilis to kill someone.”⁷

The Tuskegee study ended soon after Heller's account appeared. But the effects lingered. The federal government put together a panel of experts to review the study; unsurprisingly, the panel concluded that the research was “ethically unjustified.”⁸ A lawyer sued the government on behalf of the men in the study and their families, eventually settling for more than \$10 million. In 1997 then-president Bill Clinton apologized to the few surviving research subjects and to the families of all who had participated. “We can stop turning our heads away,” Clinton said. “We can look at you in the eye and finally say on behalf of the American people, what the United States government did was shameful, and I am sorry.”⁹

Henrietta Lacks

The Tuskegee research project is unfortunately far from the only example of an unethical medical study. Another example is the case of Henrietta Lacks. Born in Virginia in 1920, Lacks was African American and poor. One of ten children, she was raised mainly by her grandfather and attended school through only the sixth or seventh grade. After she was married, she moved to Baltimore, Maryland. According to friends and relatives, Lacks enjoyed cooking, adored her five children, and loved to dance. As one of her cousins put it, “We'd just get out there [on the dance floor] and shake and turn around and all like that.”¹⁰

Denying Treatment in Tuskegee

As time passed, doctors both in and outside of the Tuskegee study realized that they were not permitted to treat the subjects of the experiment in any meaningful way. Since the purpose of the study was to examine the effects of syphilis, providing medication to combat the men's symptoms was forbidden, even for doctors not involved in the study, because it might interfere with the study results.

Dr. Reginald James, who worked with syphilis patients as part of public health programs in the Tuskegee area from 1939 to 1941, remembered a nurse named Eunice Rivers who told him to ignore the medical needs of study subjects. "He's under study and not to be treated," James recalled Rivers saying when he wanted to offer treatment to the men. James did not have much effective medication to offer; still, he found Rivers's attitude deeply distressing.

Similarly, after penicillin became available, the men were not told that it might be helpful, which might have allowed them to leave the study and seek effective medical care elsewhere. Throughout the experiment, researchers made it abundantly evident that the validity of their study took precedence over the health of their subjects.

Quoted in James H. Jones, *Bad Blood*. New York: Free Press, 1981, p. 6.

In 1951, however, Lacks began experiencing acute abdominal pain and bleeding. She went to Johns Hopkins Hospital in Baltimore—one of the most prestigious hospitals in the country, and one of the few in the Baltimore area that would treat Black people—where she was told that she had cervical cancer. Lacks told her family members that there was nothing to worry about. "Doctor's gonna fix me right up,"¹¹ she assured her husband and children. She was treated with radium, a radioactive element that despite serious side effects was known to kill cancer cells. However, Lacks died on October 4, 1951, less than a year after her diagnosis.

But even though Lacks was dead, some of her cells were still alive. During her visits to Johns Hopkins, doctors had taken samples of Lacks's malignant cells and given them to medical researcher George Gey. George and his wife, Margaret Gey, were attempting to grow cancerous cells outside the human body. If they could find a way to do so, they would be able to run experiments

SOURCE NOTES

Introduction: Scientific Bias

1. Quoted in Peter Galison et al., eds., *Science in Culture*. New York: Routledge, 2017, pp. 161–62.
2. Quoted in John Horgan, “Darwin Was Sexist, and So Are Many Modern Scientists,” *Cross-Check* (blog), *Scientific American*, December 18, 2017. <https://blogs.scientificamerican.com>.

Chapter One: The Tuskegee Experiment and Henrietta Lacks

3. Quoted in James H. Jones, *Bad Blood*. New York: Free Press, 1981, p. 7.
4. Quoted in Harriet A. Washington, *Medical Apartheid*. New York: Doubleday, 2006, p. 163.
5. Quoted in Jones, *Bad Blood*, pp. 5–6.
6. Quoted in Washington, *Medical Apartheid*, p. 166.
7. Quoted in Jones, *Bad Blood*, p. 10.
8. Quoted in Tuskegee University, “About the USPHS Syphilis Study,” 2022. www.tuskegee.edu.
9. Bill Clinton, “Apology for Study Done in Tuskegee,” White House, May 16, 1997. <https://clintonwhitehouse4.archives.gov>.
10. Quoted in Rebecca Skloot, *The Immortal Life of Henrietta Lacks*. New York: Crown, 2010, p. 43.
11. Quoted in Skloot, *The Immortal Life of Henrietta Lacks*, p. 31.
12. Quoted in Skloot, *The Immortal Life of Henrietta Lacks*, p. 41.
13. American Medical Association, “Informed Consent,” Nevada Legislature, 2013. www.leg.state.nv.us.
14. Ta-Nehisi Coates, “Henrietta Lacks and Race,” *The Atlantic*, February 3, 2010. www.theatlantic.com.
15. Cary Funk et al., “Black Americans Have Less Confidence in Science to Act in the Public Interest,” Pew Research Center, August 28, 2020. www.pewresearch.org.

Chapter Two: Scientific Fraud

16. Healio, “Wakefield Study Linking MMR Vaccine, Autism Uncovered as Complete Fraud,” February 1, 2011. www.healio.com.
17. Quoted in Public Health Seattle & King County, “MMR, Autism, and Wakefield—Responding to Vaccine-Hesitant Parents,” *Issue Brief*, February 2011. <https://kingcounty.gov>.
18. Quoted in Jonathan D. Quick and Heidi Larson, “The Vaccine-Autism Myth Started 20 Years Ago. Here’s Why It Still Endures Today,” *Time*, February 28, 2018. <https://time.com>.

FOR FURTHER RESEARCH

Books

Nicolas Chevassus-au-Louis, *Fraud in the Lab: The High Stakes of Scientific Research*. Cambridge, MA: Harvard University Press, 2019.

Barbara Diggs, *Racial Bias: Is Change Possible?* San Diego, CA: ReferencePoint, 2023.

Caroline Criado Perez, *Invisible Women*. New York: Abrams, 2019.

Jennifer L. Eberhardt, *Biased*. New York: Penguin, 2019.

Stuart Ritchie, *Science Fictions: How Fraud, Bias, Negligence, and Hype Undermine the Search for Truth*. New York: Metropolitan, 2020.

Angela Saini, *Inferior: How Science Got Women Wrong—and the New Research That’s Rewriting the Story*. Boston: Beacon, 2017.

Sara Wachter-Boettcher, *Technically Wrong*. New York: Norton, 2017.

Internet Sources

Julia Angwin et al., “Machine Bias,” ProPublica, May 23, 2016. www.propublica.org.

Johana Bhuiyan, “Facial Recognition May Help Find Capitol Rioters—but It Could Harm Many Others, Experts Say,” *Los Angeles Times*, February 4, 2021. www.latimes.com.

DeNeen L. Brown, “‘You’ve Got Bad Blood’: The Horror of the Tuskegee Syphilis Experiment,” *Washington Post*, May 16, 2017. www.washingtonpost.com.

Chris McGreal, “Big Oil and Gas Kept a Dirty Secret for Decades. Now They May Pay the Price,” *The Guardian* (Manchester, UK), June 30, 2021. www.theguardian.com.

Nature, “Henrietta Lacks: Science Must Right a Historical Wrong,” September 1, 2020. www.nature.com.

Ritu Prasad, “Eight Ways the World Is Not Designed for Women,” BBC, June 5, 2019. www.bbc.com.

Jonathan D. Quick and Heidi Larson, “The Vaccine-Autism Myth Started 20 Years Ago. Here’s Why It Still Endures Today,” *Time*, February 28, 2018. <https://time.com>.

Scientific American, “Clinical Trials Have Far Too Little Racial and Ethnic Diversity,” September 1, 2018. www.scientificamerican.com.

Websites

American Civil Liberties Union (ACLU)

www.aclu.org

The ACLU is dedicated to ensuring individual rights and liberties. The group’s activities, many of which occur in courtrooms, focus frequently on racism and sexism. Its website includes position papers and information about racism in artificial intelligence.

American Medical Association (AMA)

www.ama-assn.org

The AMA is the nation’s largest organization representing physicians. By typing “medical ethics” into the search bar, visitors will be directed to the organization’s code of medical ethics and other articles that discuss this topic.

US Food and Drug Administration (FDA)

fda.gov

The FDA is a federal agency responsible for protecting and promoting public health and safety in connection with drugs, medical devices, food, cosmetics, and more. Its website offers information on new drugs and medical devices and the processes they go through in order to be approved, especially as it pertains to human subjects.

Gendered Innovations

<http://genderedinnovations.stanford.edu>

Gendered Innovations tracks and works for greater inclusion of women in scientific studies. The website includes discussions and examples of its work and the reason for it.

National Highway Traffic Safety Administration (NHTSA)

nhtsa.gov

The NHTSA is a federal transportation safety agency. Its website focuses on vehicle safety, including information about crash test dummies and how they are used to determine how safe a vehicle is, given certain types of crashes.

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