

EDUCATOR RESOURCES



The Tuskegee Syphilis Study

The Tuskegee Syphilis Study was a clinical trial (study) conducted by the U.S. Public Health Service (USPHS) from 1932 to 1972. The study enrolled impoverished African American men to research the natural progression of untreated syphilis. This study is commonly used to showcase unethical research practices. Many African Americans cite the Tuskegee Syphilis Study as a main reason for distrusting the medical system¹, along with other factors, including prior experiences of racism, concerns about privacy and general mistrust of institutions^{2, 3, 4}. It is important to know the background of this study and some of the common barriers and misconceptions you may encounter when encouraging your audience to seek medical care. The majority of African Americans are aware of the Tuskegee study, but many believe some common misconceptions (untrue beliefs) of the study details.

Study Details

In 1932, the USPHS recruited 600 Black men in Tuskegee, Alabama — 399 of which had syphilis and 201 who did not have the disease. Study participants were given incentives that took advantage of their low socioeconomic status, including:

- Free medical exams
- Transportation to medical appointments
- Free meals on exam days
- Treatment for injuries or disease
- Paid funeral and burial expenses in the event of their death

The men with syphilis were never informed of their diagnosis and were instead told they had “bad blood,” which was a local term that could include several illnesses. One of the reasons the study is so controversial is that the men were not treated for the disease even after penicillin was introduced as the standard treatment in 1947. Information about the effectiveness of penicillin was kept from the men. They were denied treatment and were told they could not leave the study to seek treatment elsewhere.



This Tuskegee study was performed on African American men. The misconceptions listed below are attributed to U.S. born African Americans. Thus, Black populations are not discussed in this resource.

NOTE

The purpose of this resource is to help you to be prepared for any questions or feedback you may receive about the Tuskegee Syphilis Study. This resource will help you respond with information about the protections that are put in place for the safety of study participants and patients seeking health care.

In 1972, a panel of members of several federal agencies found that the Tuskegee Syphilis Study was not ethical and forced an end to the study. The study was found to be unethical because researchers did not:

- Tell the men all the important details of the study (informed consent),
- Tell them the purpose of the study,
- Inform them of how the treatments used would affect their health, or
- Allow them to receive penicillin when it became available.

In 1996, President Clinton, on behalf of the U.S. government, formally apologized to the surviving members of the study and families of the deceased for the emotional, medical and psychological damage from the study⁵.

Many African Americans are aware of the Tuskegee experiments, but for some, the history is unclear and there is some confusion. The content below will help you be aware of these common myths about the Tuskegee Syphilis Study and provides ideas about how to respond. Increasing knowledge about the Tuskegee Syphilis Study can begin to dispel misconceptions and reduce barriers to accessing care.

Myths ^{6, 7}	Possible Responses
“The government injected the men with syphilis.”	The government did not inject the men with syphilis. The men already had syphilis at the beginning of the study.
“The study was kept completely secret, especially to African Americans.”	Information about the Tuskegee Syphilis Study was publicly available throughout the study period. The ethical violations were exposed in 1972, causing the study to end.
“The study ended when penicillin became available.”	The study did not end when penicillin became accepted as the standard of care to treat syphilis. This is one of the ethical violations recognized in 1972.
“The doctors in the study were not affiliated with the government.”	The doctors in the study were employed by the United States Public Health Service, which was a government agency. They were not independent physicians.
“The men in the study were falsely told they had syphilis when they didn’t.”	The men included in the study had syphilis before the study began and were diagnosed accurately. The men were told they had an illness, but not specifically syphilis.
“Studies like this still happen.”	This study is one of several unethical studies that lead to the creation of Institutional Review Boards (IRB), which approve and monitor all formal research on human participants. The IRB approval process ensures that rights and safety of participants are protected.

Institutional Review Boards protect the rights of human study participants by requiring researchers to show proof of the following⁸:

- **Informed Consent:** Researchers must get written consent from participants before beginning the study. Informed consent means that participants are given information about the study, including the procedures, the purpose of the research, risks and benefits and other therapies that are available.
- **Comprehension:** Information provided to participants must be provided at an appropriate reading level and in ways that participants can understand the material.
- **Voluntariness:** The decision to participate must be voluntary. Researchers cannot pressure participants into taking part in the study.
- **Withdrawal from Study:** Researchers must tell the participants that they may ask questions or withdraw from the study at any time.
- **Risk/Benefit Assessments:** Researchers must balance risks and benefits of the research. Studies that involve cruel treatment of humans are not approved.
- **Fair Participant Selection:** Participants may not be selected out of convenience, vulnerability, or because the researcher does not like a certain group.

Without confirming these protections are in place, IRBs will not approve a study. Researchers cannot conduct a study using human participants without IRB approval.

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- 1 Ma, M., Kibler, J., Vigil-Otero, A., Sarpong, D., Lally, M., and Mayer, K.H. "Correlates of Willingness to Participate in Microbicide Research Among African Americans," *Journal of Health Psychology*, 18, no. 1 (2012): 65-74.
 - 2 Brandon, D., Isaac, L., and LaVeist, T. "The legacy of Tuskegee and Trust in Medical Care: Is Tuskegee Responsible for Race Differences in Mistrust of Medical Care?" *Journal of the National Medical Association* 97, no. 7 (2005): 951-956.
 - 3 Jacobs, E. A., Rolle, I., Ferrans, C. E., Whitaker, E. E., & Warnecke, R. B. "Understanding African Americans' Views of the Trustworthiness of Physicians," *Journal of General Internal Medicine* 21, no. 6 (2006): 642-647.
 - 4 Gamble, V. N. "Under the Shadow of Tuskegee: African Americans and Health Care," *American Journal of Public Health* 87, no. 11 (1997): 1773-1778.
 - 5 "About the USPHS Syphilis Study," National Center for Bioethics in Research and Health Care, last modified 2015, http://www.tuskegee.edu/about_us/
 - 6 Ma, M., Kibler, J., Vigil-Otero, A., Sarpong, D., Lally, M., and Mayer, K.H. "Correlates of Willingness to Participate in Microbicide Research Among African Americans," *Journal of Health Psychology*, 18, no. 1 (2012): 65-74.
 - 7 Green, B.L., Li, L., Morris, J.F., Gluzman, R., Davis, J.L., Wang, M.Q., and Katz, R.V. "Detailed Knowledge of the Tuskegee Syphilis Study: Who Knows What? A Framework for Health Promotion Strategies," *Health Education & Behavior* 38, no. 6 (2011): 629-636.
 - 8 "Institutional Review Board Guidebook," United States Department of Health and Human Services, Office for Human Research Protections, last modified 1993, http://www.hhs.gov/ohrp/archive/irb/irb_introduction.htm