

# The Tuskegee Syphilis Study: How Compromised Health Created an Ethical Conflict

Kathleen Grube

Senior Division

Individual Exhibit

Exhibit contains 499 words

Process Paper contains 500 words

My project is on the Tuskegee Syphilis Study and the ethical conflict it created after 40 years of compromised health. I heard about this topic last year when I saw a project on the Tuskegee Airmen, and my mom asked if I had ever heard about the Tuskegee Syphilis Study. I decided to investigate, and I thought it would make an excellent topic for my project.

I started my project by focusing on how the Public Health Service (PHS) maintained the deception for 40 years. After talking with some History Day staff, I was advised to focus my project on how participants' compromised health created an ethical conflict when the study was revealed in 1972. I interviewed Susan Reverby, an expert on the study. She answered some questions and referred me to excellent sources. I also interviewed medical professional Kari Wilhelmi, who is familiar with how Tuskegee Study affects medicine today. The book "Bad Blood" by James H. Jones was my most useful source. It went through the study's developments and brought voice to multiple perspectives involved in the study. National Archives had many letters between PHS officials, and political cartoons after the revelation were useful in illustrating the study, making it clear the public was not going to accept their government conducting studies on their citizens.

This project has inspired me to research twisted stories in history where you wonder "How could this *happen?*". History Day has helped me to become a better writer, while doing a board has taught me to be concise and organized. The colors on my board represent the color of the men's skin and blood.

In 1929, the United States Public Health Service (PHS) began studying and exploring treatment for syphilitic men in Tuskegee, Alabama. Altering their approach in 1932, PHS compromised subjects' health, shifting their focus from treating syphilis to observing its

effects. Revealed in 1972, the study sparked a conflict around medical ethics, leading to new medical standards.

After the Great Depression put halt to the initial 1929 syphilis treatment study, curiosity about race and untreated syphilis drove PHS officer Taliaferro Clark to design a new study in 1932. Intending to study participants' autopsies, PHS deceived Tuskegee men into believing they were being treated in order to garner participation. Treatment was never part of this study. For 40 years, participants' health was **compromised** and treatment was withheld even when penicillin became the accepted cure for syphilis. Only in 1972 did Peter Buxtun, a PHS investigator, blow the whistle that ended the study. This caused a **conflict** in the medical community and public about what medical ethics are. Senator Edward Kennedy held a hearing to gain testimonies from multiple perspectives involved in the study, and made suggestions for guidelines to protect future human subjects from compromised health. His suggestions resulted in 1974 legislation that require informed consent from all participants in a study, and created a panel to review and enforce medical protocol, ensuring a "Tuskegee" never happens again.

# Primary Sources

## Letters

Clark, Taliaferro. "Outline of the Study." Received by Dr. M.M. Davis, *Rediscovering Black History: Records of the African-American Experience*, The National Archives, 29 Oct. 1932.

This is a letter from Senior PHS officer, Taliaferro Clark to Dr. M. M. Davis of the Julius Rosenwald Fund. In this letter, Clark outlines the experiment and mentions what he hopes to achieve in his time frame of at least six months. Clark hopes to discover how untreated syphilis affects the "human economy among people now living and engaged in their daily pursuits." Clark states that he picked this group of syphilitic men because they have not previously received treatment. In five bullet points, Clark outlines the experiment from getting volunteers, to health examinations, to physical exams that include X-Rays and spinal taps. Clark states that he is confident that the results of this experiment will "attract worldwide attention." This letter was really useful in my build up when I was trying to figure out Clark's motives and intentions behind the experiment.

Duval, Merlin K, and Assistant Secretary of Health. "Memorandum Terminating the Tuskegee Syphilis Study." Received by Director Center for Disease Control, 16 Nov. 1972.

This letter was written shortly after the Ad Hoc Panel came out with their findings on the ethicality and the amount of justification of the Tuskegee Experiment. Part of what the Panel was deciding on was whether the experiment should continue or be terminated. This letter was written to the director of the CDC demanding the study must be terminated. Not only that, but all the participants must receive all the appropriate medical care as a part of the "close-out" phase of the project. This letter was used in my impact when I talk about the termination of the study and the decisions of the Panel. This was really helpful to understand that the men were supposed to immediately receive medical attention and care.

Wenger, O. C. "Wenger to Clark ." Received by Taliaferro Clark, 9 Jan. 1933.

This is a letter from the PHS surgeon O. C. Wenger to Senior PHS officer, Taliaferro Clark. In this letter, Wenger reports on the treatment centers in Macon County, Alabama from November 1, 1932 to December 31, 1932. Wenger calls attention to the number of cases of Syphilis uncovered, versus the percentage of subjects that return for their examination. It is stated that some didn't return because they live too far away from the clinic, or because of bad weather, but are expected to report later. This letter was useful to know what the first blood tests uncovered, and how many people actually came back for their examination. I used this information in my build up when I talk about men testing positive for syphilis and returning for physical examinations.

## Newspapers

A.B, *Philadelphia Inquirer*, Letter to the editor, July 30, 1972.

This was a letter to the editor shortly after the study was revealed to the public. The quote I got from this letter was simple: "If this [study] is true, how in the name of God can we look others in the eye and say: 'This is a decent country'". I really liked this quote and learned a lot from this as it is simple but powerful. In such a proud, patriotic country, how can we live with pride with the knowledge that our own government compromised the health of so many innocent men without their consent? I think a lot of people like this author had to rethink their morals and values after this study was revealed and this was an excellent source to get a feel for what people in this country were thinking through after the study became public knowledge.

*Afro-American*, August 12, 1972.

This was an influential Black Newspaper at the time the study was revealed. In here were many quotes from people responding to the revelation of the study. Many were furious as there was yet another unethical study using only Black subjects who could not do anything about it. I got a quote from here that talked about how condescending and void the claims are that race had nothing to do with the study, when all of the participants were Black. This person feels like federal officials think they can do anything where Black people are concerned. This was really helpful to hear this perspective. I used this in my impact when I talk about the outcry after the study was revealed.

"AIDE QUESTIONED SYPHILIS STUDY." *New York Times (1923-Current file)*, Aug 09, 1972, pp. 43. *ProQuest*.

This newspaper was written a few months after the revelation of the study. I learned a bit about whistleblower Peter Buxtun's history with the study. I learned that he tried to blow the whistle earlier in 1966, but was told nothing could be done for the participants in Tuskegee. I learned that the decision to not treat participants was done because of their age. PHS believed they were, to an extent, doing the men a service by withholding treatment. Penicillin has some awful side effects and the participants' syphilis was believed to be dormant. Treatment was believed to do more harm than good, according to an Aide. This information was useful in my impact and main event when I talk about the revelation of the study, and about whether penicillin should have been given to the participants when it became available in the 1940s.

"AT LEAST 28 DIED IN SYPHILIS STUDY." *New York Times (1923-Current file)*, Sep 12, 1972, pp. 23. *ProQuest*.

This newspaper article was written after the Syphilis Study was revealed to the public, but before the Ad Hoc Panel reviewed the ethicality of it. This article goes into detail about the deaths caused by the study and about how they determined 28 men died as a direct result of untreated syphilis from studying the men's autopsies. I learned that not

ALL men died directly from the disease. There were also side effects of the disease including effects to arteries, abnormalities to the lymph nodes, loss of vision, and the shortening of their lifespans. It was very interesting to learn about all the side effects that the PHS allowed to happen without offering treatment. I also learned about the Civil Rights Lawyer Fred D. Grey and how he sought financial compensation for the men. This information was used in my main event when I talk about how many men died from the disease, as well as my impact when I talk about the aftermath of the study.

*Birmingham News*, July 27, 1972.

This article was published very shortly after the study was revealed. I got a quote from this article that showed that not everyone had the same appalled views at the revelation of the study. Dr. Ira L. Myers was quoted saying when the study began, there was no treatment, and participation was volunteer. Nobody was denied care. He believes somebody is trying to make a mountain out of a molehill. This take was interesting to me. Even in 1972, when there *was* effective treatment, and after it was revealed what the PHS was actually doing to the men, there were still people who had no problem with it, and believed PHS were the "good guys". This was helpful to illustrate even the conflict in the public about whether the study was justified or not or ethical or not. I used this quote in my impact when I talk about the public outcry.

"Blacks in U. S. Syphilis Program Settle their Suit Out of Court." *New York Times (1923-Current file)*, Dec 17, 1974, pp. 20. *ProQuest*.

This article was from 1974 and announces the out of court settlement that was reached between for the participants. From this source, I learned the exact amount of money each participant received, which was \$37,500 from the Government. I learned this was not their original goal of money, which was \$3 million dollars each. I learned that of the 600 men that originally were a part of the study, only 100 were still alive to receive the money. I learned that no matter if the men were syphilitic, non-syphilitic (controls), alive or dead, they would all receive some compensation. This newspaper was really useful in my impact when I talk about the out of court settlement, and how the men finally received compensation.

"Doctor Says He was Told Not to Treat Men in V.D. Experiment." *New York Times (1923-Current file)*, Aug 08, 1972, pp. 16. *ProQuest*.

This article gave me a lot of insight into how the study was conducted and how the PHS gained interest, trust, and willingness to participate from the participants in Alabama. I learned the doctors were to not treat the syphilis patients. One of the doctors speaks out about his experience on the study and says that if any of the men sought treatment, they would be dropped from the study, and none of the men wanted that to happen because the study offered them benefits that were luxuries to them. I also got some insight into Dr. Heller and his plea of ignorance during the study. He claims he had no idea the men were not being treated. This information was useful in my impact when I

talk about the study's revelation and helped me to understand what the men were being told and what they were not being told about the study.

DR.R.A.VONDERLEHR; LED DISEASE CENTER." *New York Times (1923-Current file)*, Jan 31, 1973, pp. 44. *ProQuest*.

This newspaper announces the death of Raymond. A. Vonderlehr, who was the head of the Tuskegee study after Taliaferro Clark. This article talks about Vonderlehr's life and accomplishments and his work in the venereal disease department. What this article did not mention however, was his work with the Tuskegee Study. The people who read this article in 1973 did not know him for his work in a study that was dominating the news and ethical conversations. They remember him for his work to combat communicable diseases, and his effort to bring the issue of venereal diseases to the attention of the public. This information was useful in my impact when talking about the aftermath of the revelation.

"EX-CHIEF DEFENDS SYPHILIS PROJECT." *New York Times (1923-Current file)*, Jul 28, 1972, pp. 29. *ProQuest*.

This article had a very different tone and topic than many of the articles that came out during the time of the revelation. This article was about Dr. John R. Heller, who was the ex-chief of the study. He wholeheartedly defends the study and what it did. He finds nothing was unethical or unscientific about the experiment. Heller believes that all the participants received at least some form of treatment from private doctors during the study. This article, that came out only a few days after the study was revealed, cites only seven men died directly from the disease, which means they discovered the number was actually higher later. There was a Black physician who was also interviewed who worked on the study as an intern during the 1930s. He reveals that not even the interns were fully informed of the true goals of the study. This information was used in my main event when I talk about the revelation of the study and the public outcry it produced.

Heller, Jean. "Syphilis Victims in U.S. Study Went Untreated for 40 Years." *New York Times*, 26 July 1972.

This is the newspaper article that Jean Heller wrote that exposed the Tuskegee Syphilis Study to the public. Peter Buxtun was the person who told Heller about the study and she then reported it. Heller reveals that the participants were denied treatment even though an effective treatment was widely available (penicillin), and states, "the study was conducted to determine from autopsies what the disease does to the human body." This article was really useful in my main event when I write about Buxtun revealing information to the press and the public. This was helpful to get first hand knowledge about the immediate reaction to the study as well as the efforts to compensate the participants.

NANCY H. "REGULATION URGED IN HUMAN TESTING." *New York Times (1923-Current file)*, Mar 21, 1973, pp. 30. *ProQuest*.

This article was written shortly after the Ad Hoc Panel came out with their decision of the ethicality of the Tuskegee Syphilis Study. Instead of reporting on the ethical decision made by the panel, this article focuses more on moving forward with better laws and protections of human subjects in medicine. From this article I learned that it was the DHEW that appointed the 9-member Ad Hoc Panel, as well as the action the panel suggested moving forward. I learned that the lack of a uniform policy for protection leads to confusion and denies some people the protection they deserve. A National Humans Investigation Board was suggested to regulate federally supported research. This information was really useful in my impact and legacy when I talk about the panel and the legacy of the experiment.

"NEGRO NURSE HONORED." *New York Times (1923-Current file)*, Apr 19, 1958, pp. 8. *ProQuest*.

This was an article announcing that Nurse Rivers of the PHS was awarded the United States Welfare Award. This award is given to the outstanding employee of the department. Nurse Rivers was awarded this because of her outstanding work in the "successful study of syphilis" in Tuskegee Alabama. This was useful to know that in 1958, the study was known, and even seen as a "success". Rivers won an award for her work on this study that, less than 20 years later caused a huge ethical debate and caused a lot of outcry. This information was useful for my main event when learning about what was acceptable during those 40 years of studying syphilis.

"Plaintiffs are Narrowed in Syphilis Research Suit." *New York Times (1923-Current file)*, Jul 14, 1974, pp. 40. *ProQuest*.

This was a newspaper article published in 1974, two years after the revelation of the Syphilis Study to the public. This article came out around the time that the men were seeking compensation with their attorney Fred D. Grey. This article announces that plaintiffs were narrowed to include only the men physically affected by the disease. I learned that the men were seeking a three million dollar out of court settlement. I also learned that the men were asking that the class action include the surviving participants as well as the families of all the participants alive or dead. This article was useful for my impact when I talk about the lawsuit and helped me understand what the men were asking for.

Special to The New, York Times. "H.E.W. WILL STUDY SYPHILIS PROJECT." *New York Times (1923-Current file)*, Aug 25, 1972, pp. 40. *ProQuest*.

This newspaper article came out about a month after the revelation of the study to the public. This article announces the appointment of a panel to review the ethicality of the study. In here, I learned about the person who appointed the panel as well as the issues the panel was tasked with deciphering. These issues included whether the study was justified when it began in 1932, and whether it was justified to continue after

penicillin became widely available in the 1950s. The last thing I learned was that the study did not end right away when it was revealed. Part of the panel's task was to find out whether the study should continue or be terminated. I originally thought it was terminated upon revelation. I also learned that five of the nine members on this panel were Black. This information was extremely useful for my impact when I talk about the panel, its findings and the ethical debate.

"SYPHILIS EXPERIMENT TERMED UNJUSTIFIED." *New York Times (1923-Current file)*, Mar 29, 1973, pp. 54. *ProQuest*.

This newspaper article from March 1973 talks about whether the study was justified and discusses what standards to hold the study to, 1973 standards or 1932 standards, because they were very different. This newspaper suggests that in 1932 when the study began, there may have been some scientific validity; however, the panel overall found the study unjustified even by their standards. I learned from this article that at least 28 to 107 men had died directly from untreated syphilis. This newspaper was very useful when writing my impact when I was researching the findings of the panel, and this was useful in my main event when I was talking about how many men had already died from the disease.

"Syphilis Study Went on After its Apparent Success." *New York Times (1923-Current file)*, Sep 13, 1972, pp. 30. *ProQuest*.

This newspaper article came out within months of the revelation of the Tuskegee Syphilis Study to the public. This article goes back to the beginning of the study and claims that after 4 years of observing the participants, the researchers had gained the scientific knowledge they had initially sought. But instead of ending the study then, PHS continued the study to include the examination of autopsies "just to be sure" of their findings. This article also goes into how the participants believed they were a part of a special club for being treated by government doctors and getting treated for their bad blood. It was a mark of distinction for the men to get to ride in Ms. Rivers' big nice station wagon and to have promised free burial. This article was really useful in my main event when I talk about the revelation of the study. Also, I got some good information here that helped me with my build up and building a timeline for those 40 years of observation.

"U.S. Syphilis Study Called 'Ethically Unjustified'." *New York Times (1923-Current file)*, Jun 13, 1973, pp. 21. *ProQuest*.

This newspaper article from 1973 announces the result of the Ad Hoc Panel review of the Tuskegee Syphilis Study. The panel was reviewing whether the study was justified even in 1932, whether and when penicillin should have been administered, and whether the existing regulations protecting human subjects are adequate. I learned the Panel's conclusions to these questions were: The study was not justified, even by 1932 standards, penicillin should have been administered when it became widely available in 1953, and the existing regulations were inadequate, and newer protections were

suggested. This article was really helpful in my impact when I talk about the panel's findings.

*Washington Post*, July 31, 1972.

This was a newspaper article right after the study was revealed to the public. After that, the newspapers were full of fiery opinions on the study and the ethicality and the amount, or lack of justification it deserved. This newspaper clip was of the perspective that experiments are ethically justified if the guinea pigs are fully informed that they are in fact guinea pigs. This means they are fully aware of the facts, risks and dangers. That was not the case in the Tuskegee Syphilis Study, so therefore it was not ethically sound or justified. This was a really helpful source that supported that there was an outcry in the public who believed that ethics need to be rethought and revised if the United States will allow a study like this to happen.

WOOTEN, JAMES T Special to The New York Times. "Survivor of '32 Syphilis Study Recalls a Diagnosis." *New York Times (1923-Current file)*, Jul 27, 1972, pp. 18. *ProQuest*.

This article was written shortly after the revelation of the study. Here, I learned all about Charlie Pollard who was a participant of the Tuskegee Syphilis Study for 40 years. It was fascinating to hear his words and realize just how little he knew about the study and its goals, although he was a part of it for so long. I learned there were only 74 survivors out of the original group. I learned that in return for participation in the study, men were promised free hospital care, free burial, and \$100 for their survivors. Mr. Pollard was only told that he had "bad blood" and went for routine examinations without much more thought. Syphilis was never mentioned to him once. This was really useful information as I learned just how secretive and deceptive this study was. For 40 years the men had never even heard the term "syphilis" being used, let alone know they had the disease. This information was used in my main event and impact when I talk about the revelation of the study, and it helped me understand how the study was structured.

### Journal Articles

Carter, R. Brundenell. "Medical Ethics." *International Journal of Ethics*, vol. 11, no. 1, 1900, pp. 22–46. *JSTOR*, JSTOR, [www.jstor.org/stable/2376431](http://www.jstor.org/stable/2376431).

This article was written in 1900: 32 years before the start of the infamous study. This gave some excellent background on the basic, accepted ethics at the time the study began. To understand what was acceptable at the time helps you to see this event in another perspective. This included the "code of ethics", and lists out the accepted rules of the time. Through these rules, I gained knowledge about the role of the practitioner, and what was acceptable for them to do, as well as the role of the patient. I learned a bit about their relationship. This source was very useful for my background section, It was extremely helpful to learn what was the 1900s view on ethics, and it was really interesting to know there were any to begin with.

"Control Of Syphilis In America." *The British Medical Journal*, vol. 2, no. 3961, 1936, pp. 1151–1151. *JSTOR*, JSTOR, [www.jstor.org/stable/25354897](http://www.jstor.org/stable/25354897).

This article gave me some insight into the syphilis problem around the world in the 1930s. I learned it was not a problem just within the United States, but also in Sweden, England, and Denmark. This article claims that the disease in the United States is being tackled, but not as successfully as in those other countries. This article stresses the importance of treatment and believes there should be a nationwide push to eradicate it. Blood tests and education were discussed as possible options to tackle the problem. This article was useful in my background and build up to understand the context of the study. It became clear that syphilis was seen as a major health problem at this time, which helped me to understand why the Tuskegee study began in the first place, and why the men were so willing to participate.

"Ethics Of Human Experimentation." *The British Medical Journal*, vol. 2, no. 5348, 1963, pp. 1–2. *JSTOR*, JSTOR, [www.jstor.org/stable/20381330](http://www.jstor.org/stable/20381330).

This article was written in the early 1960s, and gave me some excellent context as to the medical norms and issues involving informed consent and proper ethics. This article states that "The voluntary consent of the human subject is absolutely essential. This means that the person involved should have legal capacity to give consent; should be so situated as to be able to exercise free power of choice, without the intervention of any element of force, fraud, deceit, duress, overreaching, or other ulterior form of constraint or coercion." This information was really valuable to know because these thoughts and norms made it clear why there was such passionate outcry. Many of these ideas became incorporated in the Belmont Report which is a standard in medical ethics today. This was useful in my main event when talking about medical ethics and norms of the mid to late 1900s.

"Ethics Of Human Experimentation." *The British Medical Journal*, vol. 2, no. 5402, 1964, pp. 135–136. *JSTOR*, JSTOR, [www.jstor.org/stable/25399488](http://www.jstor.org/stable/25399488).

This was a source that was useful for determining what was going on in the medical community regarding ethics and norms involving human experimentation. This article poses the question of "what are the desirable limits within which the medical research worker should remain?" I learned about important milestones protecting human subjects including the 1953 Medical Research Council where they drew up a general statement to indicate its "attitude towards the considerations involved in carrying out investigations on patients." I also learned about the importance of the Nuremberg Trials to the advancements of ethics. This article was used in my main event when I was trying to find out what was going on during the experiment and how the views on the rights and protections of human subjects changed overtime.

Extent of Rural Health Service in the United States, 1928-1932." *Public Health Reports (1896-1970)*, vol. 47, no. 51, 1932, pp. 2299–2314. *JSTOR*, *JSTOR*, [www.jstor.org/stable/4580637](http://www.jstor.org/stable/4580637).

This article was about the counties in the United States that benefited from rural health service. Macon County was on the list in Alabama. There was also a graph that showed the amount of rural populations in each of the states and lists Rosenwald Foundation as helping with the rural health outreach. Alabama was ranked third in largest rural population. This was a helpful source to compare rural population to other areas within the United States, and to understand why some areas needed more care. This was used when understanding my background when the study started.

Fletcher, John. "Human Experimentation: Ethics in the Consent Situation." *Law and Contemporary Problems*, vol. 32, no. 4, 1967, pp. 620–649. *JSTOR*, *JSTOR*, [www.jstor.org/stable/1190856](http://www.jstor.org/stable/1190856).

This article was published five years before the Tuskegee Study was revealed and gave me some excellent information to the medical norms regarding the importance of informed consent and the protection of the human subject. This article claims that it "attempts to assess the potential in the existing legal and professional ethical environment for continuing legal and moral conflict over the validity of a subject's consent to experimentation." Knowing informed consent was such an important part of medical practice and protocol during this time helped me understand why there was such heavy outcry about the study when it was revealed. Additionally, knowing that ethics in medicine was already causing a conflict in the medical community gave me some context as well as to why this study produced so much outcry. This information was used in my main event when I was studying what was going on with ethics and norms during those 40 years of experimentation.

Hazen, H. H. "A Leading Cause of Death Among Negroes: Syphilis." *The Journal of Negro Education*, vol. 6, no. 3, 1937, pp. 310–321. *JSTOR*, *JSTOR*, [www.jstor.org/stable/2292280](http://www.jstor.org/stable/2292280).

This article was written after multiple surveys were done to figure out what was the leading cause of death among Blacks, and also how this came to be. I learned some background on the syphilis epidemic in the 1800s and 1900s, like the fact that the Blacks' economic underdevelopment can be traced back to the emancipation and the reconstruction period. There was little money and even less healthcare, so a disease like syphilis in Blacks would go untreated and would be spread much more than it would in whites with more access to healthcare. I also learned about the surveys conducted and the outcomes they came up with. There was insight into the differences of syphilis between Blacks and Whites. This was extremely useful in my build up when I talk about the belief about those differences.

Herman Beerman. "Research Needs in Syphilis." *Public Health Reports (1896-1970)*, vol. 78, no. 4, 1963, pp. 305–313. *JSTOR*, [JSTOR, www.jstor.org/stable/4591783](http://www.jstor.org/stable/4591783).

This was an article written in the early 1960s when the Syphilis study was still going on but had not been revealed as an unethical study yet. This article is very honest with its audience about what is known about syphilis this far, and what still needs to be found out. I learned about the Wasserman tests and how they were used to test people for syphilis, but often they were inaccurate, showing people were positive when they were negative and negative when they were positive. At this time, it was still believed syphilis affected different races differently, as the author lists race as one of the "factors influencing the course of syphilis." At the end of this article, the author mentions that some studies have been done to study the effects of syphilis, and mentions Tuskegee as one of those places. This article helped me in my main event when I talk about the 40 years the study was going on. This helped me get some context for what was known at the time, and what was still to be learned about the effects of syphilis.

HOLMES, S. J. "DIFFERENTIAL MORTALITY IN THE AMERICAN NEGRO." *Human Biology*, vol. 3, no. 1, 1931, pp. 71–106. *JSTOR*, [JSTOR, www.jstor.org/stable/41447615](http://www.jstor.org/stable/41447615).

This source was incredibly helpful in understanding the shared knowledge about how syphilis affected Blacks and Whites. There was information about how many Black deaths from syphilis there were versus White deaths, and what was generally believed to be the differences of how the disease affected the races. There were multiple perspectives in here about those beliefs which was interesting to know that not everyone agreed that it affected them differently. Some researchers were even quoted by saying, there is "no difference in the course of the disease in the two races," or in their response to treatment. This was really useful in my build up when I talk about the belief about the differences in races in how they react and are affected by syphilis.

Holmes, S. J. "The Principal Causes of Death Among Negroes: A General Comparative Statement." *The Journal of Negro Education*, vol. 6, no. 3, 1937, pp. 289–302. *JSTOR*, [JSTOR, www.jstor.org/stable/2292278](http://www.jstor.org/stable/2292278).

This journal gave some really good insight into what were the beliefs about Blacks in medicine and how some diseases affected the races differently. This article went through the primary causes of death among Blacks, which included cancer, tuberculosis, and syphilis among other ones. This was really helpful because it was written during the Syphilis Study and was useful in understanding why PHS wanted to investigate how syphilis affected Blacks differently than it did Whites. This information was used in my build up when I talk about the how syphilis was believed to affect Blacks and Whites differently.

"In This Issue." *The Milbank Memorial Fund Quarterly*, vol. 32, no. 3, 1954, pp. 245–246. *JSTOR*, [JSTOR, www.jstor.org/stable/3348279](http://www.jstor.org/stable/3348279).

This article was an announcement/introduction for what was included in this issue of *The Milbank Memorial Fund Quarterly*, June 1954 issue. In here there is an

announcement for an article on the long term effects of untreated syphilis in the Negro Male. Very matter-of-factly, this short paragraph states that men have been investigated by the United States PHS by a method of continuous follow-up cases over 20 years. It announces that unusual data has been uncovered about this disease. It even says the "lethal effects" of syphilis will be evaluated in the article entitled "'Untreated Syphilis in the Male Negro. A Prospective Study of the Effects on Life Expectancy.'" This article was really useful to know what people knew about this study before it was revealed and how they described it. Apparently they knew it was "lethal", but still nobody blew the whistle for another 20 years. This was used in my main event when I was learning about what went on over those 40 years of experimentation.

Katz, Ralph V, DMD,PhD., M.P.H., et al. "Awareness of the Tuskegee Syphilis Study and the US Presidential Apology and their Influence on Minority Participation in Biomedical Research." *American Journal of Public Health*, vol. 98, no. 6, 2008, pp. 1137-42. *ProQuest*, <http://ezproxy.hclib.org/login?url=https://search-proquest-com.ezproxy.hclib.org/docview/215093719?accountid=6743>.

This article spoke a lot to the legacy of the Tuskegee Syphilis Study and the presidential apology ten years earlier and what effect that had on the willingness for minorities to participate in studies today. This paper talked about a questionnaire done in several U.S. cities and it found that Blacks were four times as likely to have heard of the Tuskegee Syphilis Study and twice as likely to correctly name Clinton as the president who made the apology. This article concluded that the Tuskegee Study had a lasting impact on the Black community and their willingness to participate in biomedical studies sponsored by the United States Government. This information was useful in my legacy when I discuss the long term impacts of this study.

"Late Effects Of Syphilis." *The British Medical Journal*, vol. 2, no. 4893, 1954, pp. 923–923. *JSTOR*, JSTOR, [www.jstor.org/stable/20330558](http://www.jstor.org/stable/20330558).

This article was written in 1954, 22 years after the Tuskegee Study began, and 18 years before it ended. This gave me some insight into what was known about syphilis at this time, and what was still to be known. I learned that from 1941-1946, there was a rapid increase in syphilis cases. It reached its peak in 1946, and with the discovery of penicillin, there was a rapid decrease. I also learned the difference in the cure for early and late syphilis. Apparently, early syphilis was being cured relatively quickly, but late syphilis, with all its manifestations, was taking longer to detect and cure. At the end, this claim was made: "Though syphilis is not the scourge it was, a good knowledge of its protean manifestations, a general awareness of the disease, and an increase in blood testing will help to ensure that treatment is always given in a stage where it is most effective." This was useful for me to know this may have been a reason why the men were withheld treatment - because perhaps the PHS believed treatment would not have been effective in the men's late stage of syphilis. This information was used in my main event when I talk about the 40 year study and helped me understand what new discoveries about syphilis were going on during that time.

Marley, Faye. "Are Human Tests Ethical?" *Science News*, vol. 90, no. 8, 1966, pp. 115–115. *JSTOR*, [www.jstor.org/stable/3950653](http://www.jstor.org/stable/3950653).

This was an excellent article that came out in the mid 1960s asking the question whether human tests were ethical, in concern for the rights and protections of human subjects. This really gave me some good insight into what ethical issues were going on at the time of this article and the Tuskegee experiment. This article mentions that the ethical dilemma of human experimentation has gotten almost as much attention as the rights and wrongs of animal research. This author stresses the absolute importance of informed consent and giving the patient the right, for any reason, to opt out of the research or to not begin at all. This made it clear that ethics were being debated at this time and the rights of human subjects were being fought for. This information was really useful in my main event when I was understanding what the ethical issues were and beliefs about human subjects during the experimentation.

Olansky, Sidney, et al. "Environmental Factors in the Tuskegee Study of Untreated Syphilis: Untreated Syphilis in the Male Negro." *Public Health Reports (1896-1970)*, vol. 69, no. 7, 1954, pp. 691–698. *JSTOR*, [www.jstor.org/stable/4588864](http://www.jstor.org/stable/4588864).

This report was published in 1954 that went through the background of the study and the differences in morbidity between the syphilitic group and the control group. This report went through the history of why Macon County was chosen for this study, and what economic and health state the men in this county were in at the time. There were numerous tables that showed different aspects of the men's lives that could contribute to their lifespan, like the percent of men that were obese and the number of men engaged in farming, and unemployed. The conclusion of this paper was that in the more than 20 years the study was going on, very few of the men were receiving improved healthcare, or were improving in their economic status; most men were still farming and living in their rundown shacks. I found the tables in this report very fascinating as they presented the actual numbers and percentages of men who had syphilis in 1932 in Macon County. I used one table in my background.

Rivers, Eunice et al. "Twenty Years of Followup Experience in a Long-Range Medical Study." *Public Health Reports (1896-1970)*, vol. 68, no. 4, 1953, pp. 391–395. *JSTOR*, [www.jstor.org/stable/4588428](http://www.jstor.org/stable/4588428).

This was a report written by Nurse Eunice Rivers, who was the PHS liaison between them and the syphilitic men. This was a report written in 1953, nearly 20 years before the study was revealed to the public. Nurse Rivers goes through how the study began 22 years ago, and also names the goals of the study, which in her words were to "follow as many patients as possible to post-mortem examination, in order to determine the prevalence and severity of the syphilitic disease process." It was interesting to hear this in her words because there has been much debate about Ms. Rivers' role in this study, and why she was helping the PHS. During this article, it appears she does not feel at all bad about the goals and even was the one who helped get permission to study the

men's autopsies. Rivers goes through her role as the liaison and how the doctors and nurses gained the patients' trust. She talks a lot about the excited attitudes of the men and nothing about whether she believed this was an ethical or unethical study. This was very useful information to use in my main event when talking about Nurse Rivers' role in the study.

Schick, F. B. "The Nuremberg Trial and the International Law of the Future." *The American Journal of International Law*, vol. 41, no. 4, 1947, pp. 770–794. *JSTOR*, [www.jstor.org/stable/2193089](http://www.jstor.org/stable/2193089).

This article was written a few years after the Nuremberg Trials occurred. I learned a bit about what these trials were and what this new code meant for the future of medicine and the protection of human subjects. The violation of these treaties and international laws were called "illegal war". This was a dense article, packed with information and was used to get some context as to what was going on during those 40 years of experimentation. These rules were set in place over 10 years after the study began, and yet the study continued.

Shafer, J. K., et al. "Untreated Syphilis in the Male Negro: A Prospective Study of the Effect on Life Expectancy." *Public Health Reports (1896-1970)*, vol. 69, no. 7, 1954, pp. 684–690. *JSTOR*, [www.jstor.org/stable/4588863](http://www.jstor.org/stable/4588863).

This report came out in 1954 about the results thus far about untreated syphilis in the male Negro. This came out nearly 20 years before the study was revealed to the public. The perspective and voice of this article is very matter-of-fact. It gave me the impression that the authors didn't think this study was wrong, or perhaps they didn't know all the deceptive details of the study. The time this report was written was before African Americans were recognized as having equal rights as Whites, so maybe people had less of a problem with the study in 1954 than they did in 1972. This article went into the life expectancy of men at different ages with and without syphilis. There were tables and graphs here that supported their claims. This was very useful in understanding what was going on in public knowledge during those 40 years of observation. I found the tone of the writing fascinating as the tone 20 years later was quite different.

"Untreated Syphilis." *The British Medical Journal*, vol. 1, no. 4966, 1956, pp. 560–562. *JSTOR*, [www.jstor.org/stable/20334721](http://www.jstor.org/stable/20334721).

This article discusses the results of the Oslo Study, which was conducted over 20 years prior to the Tuskegee Study. I learned about how that study was conducted, as well as the thinking behind the decision to keep those men from treatment. I learned that it was believed that the men's own defense mechanisms alone could better combat the disease than the antisyphilitic treatment of the day. This was important to know some context to the Tuskegee Study and to learn about what was commonly believed about the human defense system. I also learned about how syphilis was believed to attack the body and the effects of leaving it untreated. This information was useful in my

background when I was finding what was going on at the time the syphilis demonstrations began. It was also helpful in my build up when I discuss Clark's attempt to further the Oslo study with his own study on Blacks.

Vonderlehr, R. A. "Cooperative Clinical Studies of the Treatment of Syphilis in the United States." *The Milbank Memorial Fund Quarterly*, vol. 13, no. 2, 1935, pp. 133–145. *JSTOR*, [www.jstor.org/stable/3347623](http://www.jstor.org/stable/3347623).

This article was written by Raymond Vonderlehr in 1935, only 3 years after the initiation of the Tuskegee Study. Reading this article, it became clear that Vonderlehr was extremely interested and committed to treating syphilis and was getting clinics across the United States to agree to participate in an investigation to study problems related to the treatment of syphilis. Through this article, I learned what was believed about how syphilis affected the human body, and how the findings of this investigation would hold immense value and the knowledge would be distributed among members of the medical community. This information was really useful to get some context to the study and some background into Vonderlehr's life and interest in syphilis. This information was used in my build up.

### Books

Reverby, Susan M. *Tuskegee's Truths: Rethinking the Tuskegee Syphilis Study*. Univ. of North Carolina Press, 2001.

This was an amazing source where I found the quotes and testimonies from the Kennedy Hearings. In here were the interviews with the survivors of the study as well as the whistleblowers. This is the first source I found where there were the actual testimonies, the actual voices from the hearings. This was super useful when writing my impact when I discuss the hearings. Reading these testimonies gave me a deeper understanding of what the men went through and what they were thinking during those 40 years the study was going on. I found it fascinating that many of the participants had absolutely no clue they were part of a study that was putting their lives at risk. Even when the study was revealed, many men gave no thought that *they* were part of *that* study. As far as they were concerned, they were just men getting treated from government doctors for their "bad blood". This source was extremely useful to hear the actual voices of the men involved.

### Magazine Articles

Brandt, Allan M. "Racism and Research: The Case of the Tuskegee Syphilis Study." *The Hastings Center Report*, vol. 8, no. 6, 1978, p. 21., doi:10.2307/3561468.

This is an article from the *Hastings Center Magazine*, written in the wake of the revelation of the study, just six years earlier. This article makes the claim that this study was done on the basis of racial bias. Brandt gives some background information on the beliefs about the different races in the early 20th century. He acknowledges the fact

that there was a lot of interest in how diseases affected different races; however, the Tuskegee Syphilis Study crossed the line, not by the fact that only Black men were part of the study, but when penicillin was denied to the men and many of them even died as a direct result of untreated syphilis. This article was extremely useful in my main event and impact when I talk about penicillin and the conflict this study created.

Brown, Warren. "The Tuskegee Study Part I: A Shocking New Report on Black Syphilis Victims." *Jet*, 9 Nov. 1972, Vol. 43, No. 7, pp. 12–16.

This is a magazine article from an influential African American magazine. This is the first article in a series of three that came out in the next magazines. In this article, Warren Brown reports on the basic facts of the study, like what it was, how many men were involved, and who this affected. It was valuable to hear the perspective of the African American community on an experiment that was clearly racist and unjustifiable. There were many quotes in here from participants, Fred Grey and wives of the participants. These were perspectives I had not heard before. This was useful in my main event and impact when talking about when the study was revealed.

Brown, Warren. "The Tuskegee Study Part II: It Began As a Good Thing." *Jet*, 16 Nov. 1972, Vol. 43, No. 8 pp. 20–26.

This is the second article in the three part series and this issue highlights more of the study's origins. I learned more in depth about how it began with the Rosenwald Fund setting up a study to detect and treat syphilis. It began a good thing! Then the PHS took that good study that had ended as a result of the depression and turned it into an experiment that left men untreated with the objective of studying the men's autopsies. They were given fake/ineffective drugs to keep participation, but also to keep them untreated. This article gave me a lot of good insight for my background section.

Brown, Warren. "The Tuskegee Study Part III: Just a Drop in the Bucket of Oppression." *Jet*, 23 Nov. 1972, Vol. 43, No. 9, pp. 26–31.

This is the third article in the three part series about the Tuskegee study. In this issue, I learned that much of the Tuskegee community had little or no reaction to the study's revelation. It seemed like the community was used to being taken advantage of, and this was yet another way their community was used for the benefit of White science. One quote I found particularly interesting was a Tuskegee official who said this study was just another drop in the bucket of oppression. Many people are lucky if they live past 40. And, considering the study itself had gone on 40 years, it must have seemed even impressive that some of the men lived that long. This was a perspective I had not heard before and I was definitely not expecting. This article was useful for my main event when I talk about the study's revelation.

Ebony Magazine. "Condemned to Die." *Ebony*, Nov. 1972, pp. 177–190.

This magazine is an influential Black magazine that reported about the Tuskegee Syphilis study shortly after it was revealed in 1972. This was an amazing source to get

multiple perspectives from the Black community. It became clear after reading this that not all the people of Tuskegee were angry about the study. Many of them just accepted it as another way the government fooled the Black community, and moved on relatively quickly. There were so many quotes from the people of Tuskegee, Nurse Rivers, many players in the PHS, and the general public. I got many quotes from reading this article that were useful in the second half of my main event.

### Speeches

Clinton, Bill. "REMARKS BY THE PRESIDENT IN APOLOGY FOR STUDY DONE IN TUSKEGEE."

Presidential Apology May 16, 1997. Presidential Apology May 16, 1997, 17 Apr. 2017, Washington D.C, The East Room 2:26 P.M. EDT.

This is Bill Clinton's speech in 1997 as he apologized to the few remaining survivors of the Tuskegee Syphilis Study for what the United States Government did to the men and their families. There were many quotes in here that are filled with power and grief. Clinton acknowledges that most Americans would prefer not to remember that period of 40 years when our country compromised the health of hundreds of Black men in Alabama. Clinton also promises that an event like this need never happen again. We all need to take responsibility to ensure that a "Tuskegee" never occurs again. This speech was used in my legacy when I talk about preventing another Tuskegee, and shows pictures of Bill Clinton and his apology.

### Reports

Department of Health, Education, and Welfare. *Belmont Report*. Office of the Secretary, p. all, *Belmont Report*.

This is the Belmont Report, one of the legacies of the Tuskegee Syphilis Study. In here were all the new, explicit rules on medical procedure and experimentation on human subjects. This goes through the basic ethical principles, which include the respect for persons, beneficence, and justice. There was also a section about how to apply all these principles when conducting research. These three things included informed consent, full knowledge of information, full comprehension, and voluntariness. These things were clearly not all present during the Tuskegee Study and I could see why they were explicitly placed in this report outlining medical ethics. It was really helpful to see exactly what is in this report and exactly what rules researchers have to follow today. This was used in my legacy when I talk about the Belmont Report and how it is the standard today for medical ethics.

Mr. Ronald H . Brown Dr. Vernal Cave Mr. Barney H . Weeks Dr. Jean L . Harris,  
Co-Chairman Dr. Jeanne C . Sinkford, Co-Chairman and Mr. Fred Speaker, Panel  
Member. *FINAL REPORT TUSKEGEE SYPHILIS STUDY AD HOC ADVISORY PANEL*. pp.  
1-9, *FINAL REPORT TUSKEGEE SYPHILIS STUDY AD HOC ADVISORY PANEL*.

This is the final report by the Ad Hoc Advisory Panel, appointed by the Department of Health, Education, and Welfare, to investigate "whether the study was justified, whether it should be continued, and if existing H.E.W. regulations properly protected the rights of patients." The report goes into each of these questions. This committee found that in the context of 1932, when there was no clear cure for syphilis anyway, the study was not unethical or unjustified. However, when a cure became widely available in the 1940s, the committee agreed that is when it became an unethical study. The PHS should have administered penicillin no later than 1953. The panel also found no evidence of informed consent or a clear protocol. This report came in very useful in my impact when I talk about the panel being appointed and the outcomes of their investigation.

### Photographs

Center for Disease Control. *A Tuskegee Study Subject Undergoes a Spinal Tap to Obtain Spinal Fluid for Neurosyphilis Testing*. Tuskegee, Alabama.

This photograph was taken of nurses standing around a patient and victim of the Tuskegee Syphilis Experiment. The patient is receiving a spinal tap. This was useful because I never knew what a spinal tap looked like. I used this photograph in my build up when I talk about the experiment being under the guise of treatment. The men thought they were getting treatment for their disease, when really they were receiving spinal taps and ineffective drugs in the name of science and curiosity.

Corbis. *A Pharmacist in 1945 Posts a Sign Informing His Customers of the Availability of Penicillin*.

This photograph shows a man in a pharmacy putting up a sign announcing that penicillin is in stock. The sign reads "this store can now service the public through the medical profession with penicillin." This picture shows how much penicillin was a wonder drug at the time and how people believed they were doing a service to the public by carrying it and selling it. This was used in my main event when I talk about the discovery of penicillin in the 1940s and how it was denied to the men.

Grinnell.edu. *African and American Men Receiving "Special Free Treatment" from Physicians and Nurses*. Tuskegee, Alabama, 1932.

This is a photograph of hundreds of Black men in Tuskegee, Alabama lining up to get tested for syphilis from "Government Doctors and Nurses". This is what the men believed was "Special Free Treatment". This photograph helped me to see what the testing looked like, and just how much interest the PHS garnered with their clever wording like "special" and "free". This was used as a visual in my build up when I talk about the hundreds of men lining up to get tested.

*Herman Shaw*. Michigan State University.

This is a photograph of Tuskegee Survivor Herman Shaw. He was one of the men who was present at the presidential apology in 1997 and was interviewed about his accounts of the study. He was also one of the men who sought compensation with Pollard. This photograph was useful in my impact and legacy when I talk about the survivors and how they sought compensation and eventually received an apology from the President.

National Archives and Records Administration Southeast Region Records of the Center for Disease Control and Prevention. *Tuskegee Institute Nurse Eunice Rivers Helped Doctors Find Subjects in Macon and Surrounding Counties for the Tuskegee Syphilis Study*.

This photograph shows Nurse Eunice Rivers out in the field with a participant of the Tuskegee Syphilis Study. She seems to know him personally, and he appears to have a close relationship to her. This picture was used in my main event when I talk about Nurse Rivers and her role in the study. This photograph was useful when I was discovering what Nurse Rivers' relationship to the men was and how she helped in the deceptive aspect of the study.

Tenschert. [*Taliaferro Clark*]. National Library of Medicine, Washington, D.C. , 1 Mar. 1932.

This is a photograph of Dr. Taliaferro Clark wearing his USPHS uniform and cap. Clark was the one who decided to take the Rosenwald study to treat syphilis, and make it into the PHS study that observed *untreated* syphilis. This photograph was used in my build up when I talk about Clark taking the study in a new direction.

### **Cartoons**

Auth, Tony. "NOW Can We Give Him Penicillin?" 1972

<https://Courses.cit.cornell.edu/cb2061/esg55/Mistrust.html>.

This is a cartoon from 1972 that depicts a White doctor and a White nurse hovering over a patient in a hospital bed. The doctor is clearly trying to cover up the patient and the nurse is looking unaffected as she holds a syringe. There is a note on the foot of the bed that reads: "IGNORE THIS SYPHILIS PATIENT. (Experiment in progress)". The caption reads "NOW can we give him penicillin?" This cartoon really helped capture the feeling of the public at the time of the revelation. I used this in my main event when I talk about the revelation and the outcry it produced.

# Secondary Sources

## Interviews

Reverby, Susan. "Interview with Susan Reverby." 12 Apr. 2018.

I interviewed author and historian Susan Reverby earlier this April. Reverby had done some research about the participants' personal lives and experiences and went beyond the common thoughts and judgments about them. She shared with me a bit about each of their interests such as horse trading and Greek philosophy. I asked her about the role race played in the experiment and whether we use today's standards or 1932 standards when judging the ethicality of the experiment. I inquired about why Macon County was used and what was generally believed about how syphilis affects Blacks and Whites differently. Ms. Reverby also suggested more sources to me including some of the books she has written and some of the sources she has used in her writing. I used this information in my earlier sections of my project when talking about race in medicine.

Wilhelmi, Kari. "Interview with Kari Wilhelmi." 24 Apr. 2018.

Kari Wilhelmi is currently a healthcare practitioner who works with patients. She was a very useful source with insight into the legacy of Tuskegee and how it affects healthcare today. I asked her questions regarding what areas of medicine are shaped by the Tuskegee Study and what new protocol is in place to better protect human subjects. Wilhelmi stated that the foremost principle of medicine is "do no harm", and the aftermath of Tuskegee really was the final push for that principle. I learned from Wilhelmi that a new issue in medicine is the right of privacy. She mentioned mandatory institutional review boards (IRB) that were put in place due to the 1974 National Research Act. Finally I learned about different ethical documents that are used today in medicine. This interview was very helpful to learn that medical professionals today are very aware of the Tuskegee Study and have to practice medicine so that they hold responsibility to not repeat the mistakes made at Tuskegee.

## Journals

Agich, George J. "Guest Editorial: Ethics and Innovation in Medicine." *Journal of Medical Ethics*, vol. 27, no. 5, 2001, pp. 295–296. *JSTOR*, JSTOR, [www.jstor.org/stable/27718750](http://www.jstor.org/stable/27718750).

This article gave me insight into the movement to protect human subjects. I learned about all the new protocol coming out to ensure the safety of the subject and the accountability of the researcher. This article references the Belmont Report and talks about how it was created and is used to protect the subject. I learned about the importance of informed consent and the idea of innovation. What do/can researchers do when there is no known cure for a disease and they need to experiment? Where does this fit in and what are researchers allowed to do in this situation? This article was

really helpful to know some ethical questions going on today in medicine as we search for a cure for various diseases. I learned that old rules and ethical norms still have a say in what is allowed.

Bowman, James E., et al. "Tuskegee as a Metaphor." *Science*, vol. 285, no. 5424, 1999, pp. 47–50. *JSTOR*, JSTOR, [www.jstor.org/stable/2898246](http://www.jstor.org/stable/2898246).

This is an article in response to another article I read titled "Uses and Abuses of Tuskegee" written by Amy M. Fairchild. One response focuses sharply on the fact that the Tuskegee Experiment was only possible because of the collaboration of the Black nurses, doctors and hospitals in the Tuskegee Community. This is how the participants gained trust in the experiment and its goals. The author of this article is an African American man and makes the point that, "We African Americans must learn from history, but we will only do so if our abuses to ourselves are not hidden. Too often, we have seen the enemy - and it is also us." This article also raises the question of how far we should go when we compare the Tuskegee Study to other unethical studies in history. This article was really helpful for my main event when I talk about the trust between the participants and the "Government Doctors", and the importance of the partnership with the Tuskegee hospital.

Caplan, Arthur L. "When Evil Intrudes." *The Hastings Center Report*, vol. 22, no. 6, 1992, pp. 29–32. *JSTOR*, JSTOR, [www.jstor.org/stable/3562946](http://www.jstor.org/stable/3562946).

This article focuses on Buxtun's role in revealing the study. I learned what led to his decision to blow the whistle, and how in his earlier efforts, he had been ignored, so he took it to the press. I learned that the result of this revelation was a series of congressional hearings and ultimately a review of national guidelines on the ethics of experimentation. I learned about the importance of the public outcry, which led to the appointment of the Ad Hoc Panel to review the ethics of the study. This article was used in my main event and impact. It was important to learn about Buxtun's background and efforts to reveal the study, as well as the outcry that led to changes in protocol of medical research on human subjects.

Cassell, Eric J. "The Principles of the Belmont Report Revisited: How Have Respect for Persons, Beneficence, and Justice Been Applied to Clinical Medicine?" *The Hastings Center Report*, vol. 30, no. 4, 2000, pp. 12–21. *JSTOR*, JSTOR, [www.jstor.org/stable/3527640](http://www.jstor.org/stable/3527640).

This article was really useful in understanding the evolution and changes of the relationship between patient and doctor over time. It became clear that during the early and mid 1900s, there was little concern for the justice of the patient, and full concern on treating patients and maintaining optimism. However as time went on, certain principles became the norms and eventually the rules of medicine. I learned these rules are called: beneficence, respect for persons, and justice. This article broke down these principles and applied them to situations and the Belmont Report. This was very useful to understand how doctors and patients were viewed overtime, because the study went on for 40 years, and a lot changed during that time. I used this

information in my main event and impact and legacy sections when understanding the public views of medicine in the late 1900s and today.

Claudio, Luz. "Environmental Justice. The Tuskegee Legacy Project." *Environmental Health Perspectives*, vol. 115, no. 3, 2007, pp. A130–A130. *JSTOR*, JSTOR, [www.jstor.org/stable/4133149](http://www.jstor.org/stable/4133149).

This article talks about the Tuskegee Legacy Project, which was created to assess how the Tuskegee Experiment affected African Americans' attitudes towards health research. This article talks about the questionnaire they created to assess this question and see if the assumptions were true - that the infamous experiment caused African Americans to be more likely to distrust medical research and refuse participation than Whites. Their findings were that Blacks overall had more fear of participating in research, but it didn't necessarily affect their willingness to participate. This information was useful when I was trying to figure out what my legacy should be.

CRENNER, CHRISTOPHER. "The Tuskegee Syphilis Study and the Scientific Concept of Racial Nervous Resistance." *Journal of the History of Medicine and Allied Sciences*, vol. 67, no. 2, 2012, pp. 244–280. *JSTOR*, JSTOR, [www.jstor.org/stable/24632043](http://www.jstor.org/stable/24632043).

This was a very thorough article exploring racial nervous resistance. I learned a lot about the context of the study and what medical developments were going on at the time, and what were the general beliefs about syphilis. This article talked about the partnership of the PHS with the hospitals in Tuskegee, which was an essential part of gaining the men's trust to participate in the study. This article introduces the main characters in the PHS like Clark and Vonderlehr and explores their motives and thoughts on race. One idea brought up was that initially Clark wanted to conduct this study to gain a general understanding of syphilis, and not have it be a race-related study. This article was really useful for my build up when I talk about Clark reviving the study and his thoughts and motives for doing so.

Edgar, Harold. "Outside the Community." *The Hastings Center Report*, vol. 22, no. 6, 1992, pp. 32–35. *JSTOR*, JSTOR, [www.jstor.org/stable/3562947](http://www.jstor.org/stable/3562947).

This article started by giving me insight into the challenges of Fred. D. Grey's lawsuit in defense of the Tuskegee participants. I learned Grey had to overcome hurdles such as the question of the relevance of the Nuremberg Trials, and the question of whether our government's conduct violated the fundamental principles of liberty and justice embodied in the American concept of due process. This was useful for my impact because I had little background knowledge about Grey's case. I also learned about how the study was conducted on the basis of deception - participants were unaware of their disease and believed they were being treated for whatever they were told they had. Thirdly, I learned about the believed racial differences. This study was done to compare untreated syphilis in Blacks to untreated syphilis in Whites (studied in Oslo, Norway.) This information was useful in my build up when understanding how the study was run

and how the PHS maintained the trust and interest of participants for so long. I also got insight into the goals of the study.

Fairchild, Amy L., and Ronald Bayer. "Uses and Abuses of Tuskegee." *Science*, vol. 284, no. 5416, 1999, pp. 919–921. *JSTOR*, JSTOR, [www.jstor.org/stable/2899191](http://www.jstor.org/stable/2899191).

This was a really helpful article that went through a quick summary of the study and the main events that took place during it. This was a really clear article that went over the three abuses that took place during the study. The first abuse was the deception aspect- the fact that those who would otherwise seek care were not given the right to choose whether to be research subjects. Secondly, it exploited social vulnerability to recruit and retain subjects. Third, researchers made an effort to withhold treatment from participants even though an accepted treatment was available. This site was helpful to learn about the main abuses that took place and to see what were the main areas in medicine that called for more protection and protocol to better protect human subjects.

Grodin, Michael A. "The Nuremberg Code and Medical Research." *The Hastings Center Report*, vol. 20, no. 3, 1990, pp. 4–4. *JSTOR*, JSTOR, [www.jstor.org/stable/3563152](http://www.jstor.org/stable/3563152).

This was a short article talking briefly about the Nuremberg code and how it applies to ethics in the medical field. I learned a lot of background about the Nazi experiments on concentration camp prisoners during the Second World War and how that initially sparked a debate about medical ethics. The Nuremberg code emphasized that informed consent is essential to medical research. I learned about the major players involved in the Nuremberg code and how they brought new thoughts and ideas to the ethics debate. This information was really useful in my build up and main event when I talk about the lack of ethics and protocol and how the study went on for 40 years essentially without interruption. This code didn't even put a halt to this experiment.

Higby, Gregory J. . "Tuskegee Syphilis Study Revisited." *Pharmacy in History*, vol. 41, no. 4, 1999, pp. 169–170. *JSTOR*, JSTOR, [www.jstor.org/stable/41112664](http://www.jstor.org/stable/41112664).

This article takes another angle on the Syphilis Study and how we as a society judge the ethics of it. This article talks about how the study was terribly flawed, but asks us to consider the time period it was happening. Penicillin was a relatively new drug and the effects of it on syphilis were unknown. So judging the act of withholding it from participants has to be viewed not through our current lens, but through the lens of the 1940s and 1950s. This article was useful in understanding my main event when I talk about penicillin and how it was withheld. I also learned to consider this withholding from a new perspective and learn the context of the time before I judge the act.

Isenberg, Barbara. "Blowing the Whistle on the Experiment." *Los Angeles Times (pre-1997 Fulltext)*, Jul 15, 1990, pp. 84. *ProQuest*.

This article was written in 1990 - 18 years after the revelation, and seven years before the United States Government formally apologized for the 40 year experiment. This

article goes into detail about some of the criticisms of the study. One man believes that it was not only wrong, but also flawed: PHS failed to develop a clear protocol and an explicit set of goals. I learned also about how Peter Buxtun became involved in the study, what obstacles he faced with getting people's attention about the study, and how he eventually blew the whistle on it, which led to its termination shortly after. This article ends with a hope and plea for the future: That we as a society can understand this study so we make sure it never happens again. This source was really useful in my main event when I talk about Peter Buxtun blowing the whistle. It also helped in my build up when I talk about the lack of protocol the study contained.

Jones, James H. "The Tuskegee Legacy AIDS and the Black Community." *The Hastings Center Report*, vol. 22, no. 6, 1992, pp. 38–40. *JSTOR*, JSTOR, [www.jstor.org/stable/3562949](http://www.jstor.org/stable/3562949). This article gave me insight into a specific legacy of the Tuskegee Study that was seen in the 1990s. Because of the distrust caused by the Tuskegee Study on the African American community, when the AIDS outbreak occurred, many Blacks maintained that distrust in government medical treatment and refused to get tested. I learned that a lot of this suspicion stemmed from the fact that White Americans viewed AIDS victims similar to the way they viewed Black syphilis victims. This article touched on a legacy I had never considered before and this information was used in my legacy when understanding what resulted from the study and how the African American community views medicine today.

Karigan, Maria. "Ethics in Clinical Research: The Nursing Perspective." *The American Journal of Nursing*, vol. 101, no. 9, 2001, pp. 26–31. *JSTOR*, JSTOR, [www.jstor.org/stable/3522432](http://www.jstor.org/stable/3522432). This source talked about medical ethics from a nursing perspective. In the middle of this article, there was a section labeled "Historical Perspective" that went through several studies in history where ethics were not applied through a current lens. These studies included the Tuskegee Syphilis Study, denying and deceiving 600 Black men from Tuskegee Alabama, and the Nazi experiments, which experimented on concentration camp prisoners during the World War Two. These Nazi experiments led to the Nuremberg code which developed a set of medical ethics. Additionally, I learned about the three ethical dilemmas that presented themselves during the Tuskegee Syphilis Study: Informed consent, research protocols, and disclosure, all of which were not present in the Tuskegee Study. Finally, the article goes on to talk about how to apply these ethics in nursing. This clear article was useful in my impact and legacy when I talk about the ethics conflict.

Katz, Jay. "The Regulation of Human Experimentation in the United States: A Personal Odyssey." *IRB: Ethics & Human Research*, vol. 9, no. 1, 1987, pp. 1–6. *JSTOR*, JSTOR, [www.jstor.org/stable/3563644](http://www.jstor.org/stable/3563644). This article gave information into the Ad Hoc Panel and their findings on the Tuskegee Study. I learned that although the Panel agreed unanimously that the study was unethical and unjustified, the direct evidence was weak because no original study

protocol was found. I learned that nowhere in the Panel's final report did it state the participants were lied to, which calls into question the thoroughness of their investigation. This article was interesting and gave me some details that helped me understand my impact section when talking about the Panel.

Katz, R.v., et al. "The Legacy of the Tuskegee Syphilis Study: Its Impact on Willingness to Participate in Biomedical Studies." *Annals of Epidemiology*, vol. 17, no. 9, 2007, p. 744., doi:10.1016/j.annepidem.2007.07.066.

This journal gave insight into a legacy of the Tuskegee Study, which is the belief that Blacks are less willing to participate in biomedical research studies. This journal reported on a study they conducted to see if this was true. They found that while Blacks had higher levels of general awareness of the Tuskegee Syphilis Study, there was no association between either awareness or detailed knowledge of the Tuskegee Syphilis Study and willingness to participate in biomedical research, either for Blacks or Whites observed in their survey. This was an interesting conclusion because I have heard many times that Blacks are less willing to participate. This was helpful for figuring out my legacy.

King, Patricia A. "The Dangers of Difference." *The Hastings Center Report*, vol. 22, no. 6, 1992, pp. 35–38. *JSTOR*, JSTOR, [www.jstor.org/stable/3562948](http://www.jstor.org/stable/3562948).

This article emphasized the curiosity of different races. This author states that the "The racism that played a central role in the Tuskegee tragedy continues to infect even our current well-intentioned efforts to reverse the decline in health status of African Americans." Additionally, "These perceived differences have often reinforced and justified differential treatment of blacks and whites, and have done so to the detriment of blacks." It states that racial differences were used as a justification for the Tuskegee Experiment, just showing how dangerous interest in differences can be. At the end of this article, King offers a way out of this dilemma which starts with accepting that races are biologically the same, and overturning beliefs about differences is necessary to avoiding another "Tuskegee". This information was useful in my build up when I talk about the believed beliefs about Blacks and Whites in response to infectious diseases.

King, William D. . "Examining African Americans' Mistrust of the Health Care System: Expanding the Research Question. Commentary on 'Race and Trust in the Health Care System.'" *Public Health Reports (1974-)*, vol. 118, no. 4, 2003, pp. 366–367. *JSTOR*, JSTOR, [www.jstor.org/stable/4598865](http://www.jstor.org/stable/4598865).

This article talks about the roots of African American mistrust in the American healthcare system and goes into the reasons for that. It argues that "patient awareness of invidious past events such as the experimentation on slaves and the Tuskegee syphilis experiment have contributed to minority patients having less access to and knowledge of specific medical treatments than their white counterparts, lower levels of trust, and greater unwillingness to participate in clinical trials." This information was

really useful when I was writing my legacy and trying to figure out what the legacy of this study is. I also learned how important it is to regain this trust going forward.

Lederer, Susan. "Experimentation on Human Beings." *OAH Magazine of History*, vol. 19, no. 5, 2005, pp. 20–22. *JSTOR*, JSTOR, [www.jstor.org/stable/25161974](http://www.jstor.org/stable/25161974).

This article focuses on how human experimentation has shaped American science and medicine, and how at the discovery of every new drug, somebody has to be the first to try it. The main question focused on in this article is this: In order to promote medical research and the search for cures for debilitating and often fatal diseases, what limitations, if any, should be placed on researchers? I learned a bit about experiments on orphans in New York City as well as how human experimentation was an issue in the Tuskegee Syphilis Study. There is a photograph here that shows a Tuskegee woman reading a flyer announcing "special free treatment for bad blood". This was a really helpful visual to see the recruitment process for this infamous study. This information was useful to get to know the context and history of human experimentation and its ethical implications.

LOMBARDO, PAUL A., and GREGORY M. DORR. "Eugenics, Medical Education, and the Public Health Service: Another Perspective on the Tuskegee Syphilis Experiment." *Bulletin of the History of Medicine*, vol. 80, no. 2, 2006, pp. 291–316. *JSTOR*, JSTOR, [www.jstor.org/stable/44448396](http://www.jstor.org/stable/44448396).

This article takes another angle when analyzing the reason for the long duration of the Study. It accepts the previously accepted reasons such as racism, bureaucratic inertia, and the personal motivation, but adds another perspective based on the history of the three main PHS officers' background. This article argues that Drs. Clark, Vonderlehr and Cummings graduated from a medical school in Virginia, which was the center of eugenics teaching. It is argued that Tuskegee simply was the perfect platform for testing out the eugenics hypothesis that racial groups were differently susceptible to infectious diseases. This helped me view another perspective as to why these men were chosen for this experiment and why it lasted so long without treatment. This was used in my background and build up when I talk about the targeting of the men.

Marshall, Ernest. "Does the Moral Philosophy of the Belmont Report Rest on a Mistake?" *IRB: Ethics & Human Research*, vol. 8, no. 6, 1986, pp. 5–6. *JSTOR*, JSTOR, [www.jstor.org/stable/3564238](http://www.jstor.org/stable/3564238).

This article went into depth about the principles stated in the Belmont Report, and how those effectively or ineffectively apply to medical research today. First, I learned that the report does not have the weight of law, but it is the basic ethical principle and does add a lot of ethical weight. This article points out some holes and flaws that maybe aren't as ethical as they are intended to be. I learned about the word "research", and what that means to the subject and the researcher, and how "beneficence" means something different to both of them. I learned about the different ethical principles, like Kantian and Utilitarian, and how each apply to the Belmont Report in regards to

human experimentation. The author argues that the uses of these different principles in the Belmont Report has led to confusion. This article was useful in my legacy when I was talking about the Belmont Report and helped me understand some strengths and weaknesses in the writing of it.

Paul, Charlotte, and Barbara Brookes. "The Rationalization of Unethical Research: Revisionist Accounts of the Tuskegee Syphilis Study and the New Zealand "Unfortunate Experiment"." *American Journal of Public Health*, vol. 105, no. 10, 2015, pp. E12-E19. *ProQuest*.

This article went into depth about the *defense* of the Tuskegee study and evaluating those claims. The claims were then compared to the defense claims of the New Zealand study of women with untreated carcinoma. The claims were split into three categories and then broken down further and compared. The categories included scientific claims, political claims, and moral arguments. The author argues that these claims were made on incomplete evidence and an exaggeration of uncertain science. These two studies are claimed to have ethical implications for today's research. This information was really useful for my main event when I talk about the conflict in the public and medical community about the study. I have a lot of information about the outcry against the study, but it was useful to see the perspective of the defense.

Paul, Charlotte. MB PhD. "Defenses of the Tuskegee Syphilis Study: Assessment of Empirical Claims." 17 July 2015, pp. 1–17.

This journal article was an analysis in the claims defending and condemning the Tuskegee Syphilis study. This was very useful in my impact when I talk about the public outcry and the conflict in the medical community about medical ethics. This paper goes through many quotes from Tuskegee staff, and editorials from the public and assess where their perspective comes from and why they may have believed what they do about the study. Some people defended it for the sheer reason that, when the study began, standards were very different than they were when it was revealed in 1972. Then there would be a quote from somebody who condemned it agreeing that standards were different, but they *changed* as time went on, but the study ignored the changing norms and continued their deceptive practices. It was really good to see both perspectives of the debate and understand, before judging, where these claims came from and understand the time this study took place in.

Post, Stephen G. "THE LEGACY OF RACIAL HYGIENE: Hearing the Voice of the Victims." *Soundings: An Interdisciplinary Journal*, vol. 74, no. 3/4, 1991, pp. 541–558. *JSTOR*, [www.jstor.org/stable/41178554](http://www.jstor.org/stable/41178554).

This article compared the Tuskegee study to the Nazi studies during World War Two and talked about eugenics. When referencing the Tuskegee study, the author mentions all the ethical milestones that the study ignored. The Nuremberg Trials did not stop the study, neither did the discovery of penicillin, neither did the Civil Rights Movement. This article was useful to know what other studies in history were condemned as being

unethical and gave way for new protocols in medicine. This information was used in my main event when understanding what was going on during the experimentation years.

REVERBY, SUSAN M. "Inclusion and Exclusion: The Politics of History, Difference, and Medical Research." *Journal of the History of Medicine and Allied Sciences*, vol. 63, no. 1, 2008, pp. 103–113. *JSTOR*, JSTOR, [www.jstor.org/stable/24632418](http://www.jstor.org/stable/24632418).

This article explored how society's beliefs on race and racism shape the medical field and how we conduct medical research. Reverby explains how African Americans have been negatively shaped by their experiences in medicine in the past and how it is important as a society to recognize, understand and remember these events to better shape medicine for the future. She analyzes other books and papers that explore race and medicine and racism and goes through their claims to find where they are valid, or lacking validity. This article was useful for understanding the role race playing in the study and was used to better understand my build up and legacy of the study.

Reverby, Susan M. "More Than Fact and Fiction: Cultural Memory and the Tuskegee Syphilis Study." *The Hastings Center Report*, vol. 31, no. 5, 2001, pp. 22–28., doi:10.2307/3527701.

This source was useful in investigating some aspects of the study I had not considered before. This article brought up important misconceptions about the study, such as the belief that the men were actually *infected* with the disease. Reverby goes in depth as to why this is false. Additionally, I knew that the men were denied treatment, but this article goes into detail as to where some men may have received treatment anyway, making this "untreated" syphilis study able to yield some very inaccurate results. This article was useful when I was gaining an understanding of the topic and helped to stamp out my misconceptions. It was also useful to know some of this extra information like the treatment.

Robert S. Levine, Jamila C. Williams, Barbara A. Kilbourne, and Paul D. Juarez. "Tuskegee Syphilis Study in the United States."

This article spoke a lot more to what the United States did to change their practices after the Tuskegee Syphilis Study as to not repeat their mistakes. This article is split into paragraphs, going into detail about all the changes in medical protocol including the 1974 National Research Act, the mandatory informed consent, Ethics Advisory Boards, and a National Bioethics Advisory Commission, among other changes. These were all made in an effort to promote the highest ethical standards in research. This also went into what was going on with laws and segregation prior to the infamous study, which may have played a part in allowing a study like this to happen. Things like the segregated medical care in Alabama allowed for many Blacks to live without access to it. This is an angle I had never considered before and was extremely useful when writing my background to understand what was the state of medical care for these men at the time.

Rothman, David J. "Were Tuskegee & Willowbrook 'Studies in Nature'?" *The Hastings Center Report*, vol. 12, no. 2, 1982, pp. 5–7. *JSTOR*, [www.jstor.org/stable/3561798](http://www.jstor.org/stable/3561798).

This article goes deep into the question of what qualifies as a "study in nature", where the researcher is a passive observer of the course of some natural process, such as a disease, which he or she is powerless to change. Additionally, the question is posed as to what research designs ought to be considered ethically permissible when subjects live under conditions of overwhelming social deprivation? Rothman compared Tuskegee to Willowbrook, where institutionalized children were injected with hepatitis. This article tackles that often asked question of how these experiments went on so long without receiving attention. One of the conclusions made was that "experiments that build upon social deprivation are likely to manipulate the consent of the subjects. In Tuskegee the blacks were informed that they had "bad blood," not syphilis, and so were kept ignorant of the potential risks of contagion." This article was really useful for me to know what other experiments happened without informed consent and what made these experiments unique in the outcry they produced. This information was used in my background and build up when I talk about the guise of treatment and the deception of the study.

Sharma, Alankaar. "Diseased Race, Racialized Disease: The Story of the Negro Project of American Social Hygiene Association Against the Backdrop of the Tuskegee Syphilis Experiment." *Journal of African American Studies*, vol. 14, no. 2, 2010, pp. 247–262. *JSTOR*, [www.jstor.org/stable/41819249](http://www.jstor.org/stable/41819249).

This journal article compares the Tuskegee Syphilis Study to that of the Negro Project and explored why one study failed while the other prevailed. I learned that the Negro Project was another study aimed at studying the prevalence of venereal diseases in Blacks, but gained little attention in the press and public. It was interesting to read as this article went through the context of the time and analyzed some claims that defended the study with claims that condemned it. There was a quick overview of the Tuskegee Study, where it states that the main goal of the study was to see whether syphilis affected races differently. Then it went into whether the researchers began the studies simply because they believed Blacks were a "diseased race". This article went into depth on many claims and it was interesting to hear this perspective and comparison. I used this information in my background and build up when I talk about when and why the study started, and the race beliefs coupled with diseases.

Smith, Charlie. "Victims of a Diseased Society; Tuskegee Syphilis Experiment; America." *The Times*, Aug 08, 1992. *ProQuest*.

This article touched on the context of the study. You can look at this study through two lenses - the 1932 lens or the 1972 lens. For 1932 standards, the White PHS doctors were liberals, working with the Black community, initially, to find a cure for syphilis. 40 years later, they are labeled as racist and accused of genocide. It is also argued that this study could have never taken place if it wasn't for the cooperation of the Black institutions in the Tuskegee community. This article went into details of the study that

were more personal. Some of the quotes that were here gave insight into the personality of the speakers, and there was a lot of information about Nurse Rivers' uneasiness about the study. I learned that whatever justification the study retained at the beginning was gone in the 1950s because the Nuremberg Trials had been held and penicillin had been proven to cure syphilis very quickly with little side effects. This article helped me in many aspects of my project including finding defense claims and understanding exactly when this study held no more ethical justification.

Vollmann, Jochen, and Rolf Winau. "Informed Consent In Human Experimentation Before The Nuremberg Code." *BMJ: British Medical Journal*, vol. 313, no. 7070, 1996, pp. 1445–1447. *JSTOR*, JSTOR, [www.jstor.org/stable/29733726](http://www.jstor.org/stable/29733726).

This article gave a history on informed consent before the Nuremberg Trials. I learned about the 19th century's excitement with experiments involving human subjects. The result of injury to some patients was the beginning of the conflict about medical ethics. I learned about specific cases where certain ethics were debated, and certain laws going into effect due to controversy over the protection of human subjects. This was useful for my background and build up for understanding what ethics were in place at the time, and what was acceptable research to conduct.

Wasserman, J., et al. "Raising the Ivory Tower: The Production of Knowledge and Distrust of Medicine among African Americans." *Journal of Medical Ethics*, vol. 33, no. 3, 2007, pp. 177–180. *JSTOR*, JSTOR, [www.jstor.org/stable/27719823](http://www.jstor.org/stable/27719823).

This article calls attention to the structural contexts of events like the Tuskegee Syphilis Study and the "contributions and responsibilities of popular media and academic disciplines in the production of (often mythic) knowledge." The argument this paper makes is that ignoring context of events has enormous impacts on healthcare, especially for African Americans, and endangers ethics. I learned also the background to the economic depression for Blacks in Alabama during the late 1800s and early 1900s. This really helped to give me some background and understanding about the health system for Blacks and why this area was chosen for this study.

## Books

Byrd, W. Michael., and Linda A. Clayton. *An American Health Dilemma: Race, Medicine, and HealthCare in the United States, 1900-2000*. Routledge, 2002.

This book went really in depth about how race played a role in American medicine from 1900-2000. Many times, the Tuskegee Study was mentioned. It went into depth about how this study came to be, and how African Americans were viewed in medicine at the time the study began and was going on. There was a really good graph in here that showed the number of non-white deaths from syphilis from the years 1910-1965 compared to the deaths of whites. The line of the non-whites is significantly higher than that of whites. This book was really helpful when describing why the study initially began in the 1930s, and how it became the infamous study we know today.

Jones, James H. *Bad Blood: the Tuskegee Syphilis Experiment*. Free Press, 1993.

This was an excellent source that went into serious depth and detail on the syphilis experiment. I learned about the evolution of the experiment all the way at the start with Julius Rosenwald's study that was meant to help economic growth in the south. From here, I learned that the Great Depression forced Rosenwald to pull his support and the PHS wasn't going to continue without Rosenwald's money. The study was meant to be over. But this is when Taliaferro Clark had a new idea that evolved into the Tuskegee Study we know today. I also learned about the Ad Hoc Panel and the importance of the Kennedy hearings, as well as the story of Peter Buxtun, who ultimately led to the termination of the study. This book was helpful in every single section and understanding of my project.

Library.armstrong.edu. *Human Subjects: The Tuskegee Syphilis Study*. Library.armstrong.edu.

This book went in depth into the ethical issues caused by the study. Specifically, the issues they named were deception and informed consent. Researchers never even told the men they had syphilis, instead they just said they had "bad blood". Never giving the men an option to get real treatment, they were just under the impression they had something wrong and the government doctors were fixing it. I also learned about the racism linked to this study. It raised the question of whether this could have happened to a group of White men. I also learned about the beliefs about how syphilis affects different races. This was really helpful in my impact and legacy when I talk about medical ethics, as well as in my build up when I talk about the beliefs about the different races.

Pollock, Anne. *Medicating Race: Heart Disease and Durable Preoccupations with Difference*. Duke University Press, 2012.

This book goes into the origin of the beliefs that diseases affect Blacks and Whites differently. I learned about some of the people who studied the differences and then led the public to believe that a difference actually existed. With this belief and a group of poor Black men in Tuskegee Alabama, it can be seen why a group of physicians used Macon County to test if this theory was actually true. In this book there are quotes from early 1920s researchers stating that syphilis is especially common among African Americans. This gave me some framework when writing my background as to why this study could happen and what was going on at the time that led to researchers wanting to study syphilis in African Americans.

Reverby, Susan M. *Examining Tuskegee The Infamous Syphilis Study and Its Legacy*. The University of North Carolina Press, 2013.

This book had a ton of good information and quotes from the Kennedy hearings. I learned that Kennedy held these hearings because for eight months after the study was revealed, almost nothing was done to compensate the men. So, Senator Ted Kennedy held these hearings to gain testimonies from many perspectives involved in the study

including the Center for Disease Control (CDC), Department for Health, Education and Welfare (HEW), Peter Buxton and many survivors. It was important to know that Kennedy heard testimonies from many perspectives. Additionally, I learned about the Ad Hoc Panel and a bit about the significance of the Oslo Study. This source was useful throughout my project but primarily used in my impact to talk about the panel and the hearings.

### Encyclopedia Articles

"Tuskegee syphilis study." *Britannica School*, Encyclopædia Britannica, 8 Jan. 2016. [school-eb-com.proxy.elm4you.org/levels/high/article/Tuskegee-syphilis-study/2212](http://school-eb-com.proxy.elm4you.org/levels/high/article/Tuskegee-syphilis-study/2212). Accessed 18 Mar. 2018.

This article gave a really good summary of the experiment. Here I learned what the officials were hoping to gain from the experiment: They wanted to know whether the natural course of syphilis in the Black man was significantly different than in Whites. They were looking for whether the disease caused more neurological or cardiovascular damage. This information was super useful in my build up when I explain why PHS decided to continue the study. I also learned that when no useful data resulted from this 6-12 month study, the decision was made to follow the men until death so PHS could study their autopsies. This information was useful in my main event when I talk about "bringing them to autopsy".

### Dissertations

Fourtner, Ann W., et al. "Bad Blood: A Case Study of the Tuskegee Syphilis Project." *Journal of College Science Teaching*, vol. 23, no. 5, 1994, pp. 277–285. JSTOR, JSTOR, [www.jstor.org/stable/42984608](http://www.jstor.org/stable/42984608).

This dissertation focused on the written documents that were a major part of the Tuskegee Syphilis Study. I learned about the importance of archival records, as they serve as the building blocks to collective memory, and without them, there is no evidence of an event that occurred. There is no accountability. The argument was made that "Without evidence of accountability, society cannot trust in its public institutions." Specifically, in the Tuskegee Study, these documents serve as evidence of "government misconduct that gave rise to this notorious episode of American history." In this study, access to these documents has caused a lot of controversy over the use of these records. The result of the meticulous record keeping during this study has served as evidence that the men believed they were in a treatment program, and that these same documents helped Fred D. Grey bring a lawsuit against the PHS years later. It was interesting to hear this take on the study as I had never considered the importance of these meticulously kept records.

### Maps

Courtesy of University of Alabama Cartographic Research Laboratory. "Macon County Map." *Encyclopedia of Alabama*.

This is a map of Alabama with all the counties outlined. Macon County, Alabama, where the Syphilis Study took place is filled in. This picture was used in my background and was helpful in understanding exactly where the study took place.

### Websites

Associated Press. "Descendants of Men in 'Tuskegee Syphilis Study' Still Struggle with Stigma." *AL.com*, AL.com, 10 May 2017, [www.al.com/news/index.ssf/2017/05/descendants\\_of\\_men\\_in\\_tuskegee.html](http://www.al.com/news/index.ssf/2017/05/descendants_of_men_in_tuskegee.html).

This article looked at a part of the study I had not considered before. This article talked about the \$9 million dollar settlement that the men and their descendents were granted. A question was proposed by this article: What should be done with unclaimed settlement money that still sits in court-controlled accounts? Then there were many perspectives of descendents and other people in rural Alabama. I learned about Fred D. Grey's lawsuit and what some of the wives and family members were going through at the same time. I learned that many of the remaining participants died in the early 2000s, and many of their descendents are still struggling with the stigma. This was useful in my impact when understanding the out of court settlement.

Dartmouth.edu. "Protection from Harm: The Tuskegee Syphilis Study." *Tuskegee Syphilis Study*, Dartmouth, [www.dartmouth.edu/~thabif/newfiles/tuskee.html](http://www.dartmouth.edu/~thabif/newfiles/tuskee.html).

This website gave me really good insight into the background of the experiment that I had not received elsewhere. I learned about the other counties that were initially studied in Alabama and learned the prevalence of syphilis among each of those counties. I also learned about the importance of the partnership of the PHS and the Tuskegee Institute. This meant the execution of PHS's plan would go smoothly in partnership with a trusted hospital, and the hospital received money, training and employment. This was a good deal for both sides. This was really useful in my background when writing about the beginning of the study.

DUJS. "Tuskegee Syphilis Study." *Tuskegee Syphilis Study*, Dartmouth Undergraduate Journal of Science, 13 Nov. 2008, [dujs.dartmouth.edu/2008/11/a-wake-up-call-for-bioethics-examining-the-tuskegee-syphilis-study/#.Wq8ZQejwZPZ](http://dujs.dartmouth.edu/2008/11/a-wake-up-call-for-bioethics-examining-the-tuskegee-syphilis-study/#.Wq8ZQejwZPZ).

This was a very good analysis of the study starting with the goals of Dr. Taliaferro Clark, to the lack of treatment. I learned a bit about Nurse Rivers' role in the study and read that she truly believed the Tuskegee men were part of a privileged group of participants receiving care from government doctors. This article went on to talk about the aftermath of the study, which included the recommendation of newer protections and the later apology from President Clinton. I also learned that a legacy was patient empowerment, and how the debate on bioethics is still going on today. This was super

useful when I was writing my build up when I talk about Nurse Rivers, as well as my legacy when I talk about the reforms that resulted from this study.

Genealogy Roadshow Editor. "The Sad Truth Behind the Tuskegee Experiment." *PBS*, Public Broadcasting Service, 25 May 2016, [www.pbs.org/genealogy-roadshow/blogs/extras/the-sad-truth-behind-the-tuskegee-experiment/](http://www.pbs.org/genealogy-roadshow/blogs/extras/the-sad-truth-behind-the-tuskegee-experiment/).

This website gave a quick overview of the study and was useful to know the main points of the study as well as the main legacies. I learned that none of the patients were aware of their disease, and the fact that they were offered and promised treatment, but were never given it. I learned that the National Research Act was passed in 1974 and President Bill Clinton gave a formal apology in 1997. This was really useful for figuring out my legacy of my project.

Heintzelman, Carol A. "The Tuskegee Syphilis Study and Its Implications for the 21st Century." *SocialWorker.com*, The New Social Worker, 28 Sept. 2015, [www.socialworker.com/feature-articles/ethics-articles/The\\_Tuskegee\\_Syphilis\\_Study\\_and\\_Its\\_Implications\\_for\\_the\\_21st\\_Century/](http://www.socialworker.com/feature-articles/ethics-articles/The_Tuskegee_Syphilis_Study_and_Its_Implications_for_the_21st_Century/).

This article focused a lot more on the legacy and helped answer the question, "why does this matter today?" Heintzelman brings up the ethical issues she saw in the experiment. Issues like informed consent (the fact that the participants had no idea that the study they were participating in could possibly kill them), and the fact that the participants were denied penicillin. After learning about this study, the nation had to rethink their practices regarding human experimentation. The Tuskegee Experiment still affects the African American population; they are much less likely to participate in medical programs and get vaccinated because of the continued distrust of our medical establishment. This was really useful when writing my legacy to see what some of the long term impacts of this study are.

KERR, DEREK, and MARIA RIVERO. "Whistleblower Peter Buxtun and the Tuskegee Syphilis Study." *Whistleblower Peter Buxtun and the Tuskegee Syphilis Study | GAP*, Government Accountability Project, 30 Apr. 2014, [www.whistleblower.org/blog/04302014-whistleblower-peter-buxtun-and-tuskegee-syphilis-study](http://www.whistleblower.org/blog/04302014-whistleblower-peter-buxtun-and-tuskegee-syphilis-study).

This article had some excellent information on the story of Peter Buxtun, the Tuskegee whistle-blower. I learned he actually worked for the PHS and that is how he caught wind of an ongoing experiment involving syphilitic men in Tuskegee, Alabama. He decided to investigate and eventually met with a reporter for the *Washington Star* who revealed the story to the public. Buxtun's whistleblowing led to new laws involving medical ethics involving human subjects. This information was used in my main event when I talk about Buxtun revealing the study to the press and public.

King, Timmia. "If Not for the Public Outcry: The Tuskegee Syphilis Project/ Study." *National*

*Archives and Records Administration*, National Archives and Records Administration, 9 May 2017,

[rediscovering-black-history.blogs.archives.gov/2017/05/09/if-not-for-the-public-outcry-the-tuskegee-syphilis-project-study/](https://rediscovering-black-history.blogs.archives.gov/2017/05/09/if-not-for-the-public-outcry-the-tuskegee-syphilis-project-study/).

This is an article highlighting the public's outcry role in the investigation and reforms after the Tuskegee Syphilis Experiment. I learned that when the study began, it was believed that syphilis affected Blacks and Whites differently, and to persuade participation, the PHS offered incentives, like free transportation to and from clinics, hot meals and free medical treatment. This article argues that it was the public outcry that inspired a congressional hearing to be held, which resulted in new laws and regulations being passed. I used this information when I was outlining my project and deciding what information would go in each section. I decided that the public outcry would be discussed in my impact, and the result of the congressional (Kennedy) hearings would be discussed in my legacy.

Landau, Elizabeth. "Studies Show 'Dark Chapter' of Medical Research." *CNN*, Cable News Network, 1 Oct. 2010,

[www.cnn.com/2010/HEALTH/10/01/guatemala.syphilis.tuskegee/index.html](http://www.cnn.com/2010/HEALTH/10/01/guatemala.syphilis.tuskegee/index.html).

This article shed light on another PHS funded experiment in 1946 which took place in Guatemala. In this experiment, the participants were infected with a disease to see whether penicillin could treat or prevent it. In both the Tuskegee and Guatemala experiments, the medical questions they were answering, although answered through unethical methods, were very relevant for the time. "The real unethical part," said Peter Brown, a medical anthropologist at Emory University, "had to do with denial of treatment and, most importantly, the denial of information about the study to the men involved." This was really helpful for an overview of the Tuskegee Study, and for understanding other studies the PHS conducted.

Michigan State University. "Faces of Tuskegee." *"The Syphilis Men"*, Michigan State University, [msu.edu/course/hm/546/tuskegee.htm#The+Oslo+Study](http://msu.edu/course/hm/546/tuskegee.htm#The+Oslo+Study).

This was my most helpful source when beginning this project. In short paragraphs, I learned about each of the major players in this study and how they were involved and what decisions they were responsible for making. I learned about Clark and Vonderlehr and Nurse Rivers, but I also learned about Macon County and why it was such a prime target for an experiment like this. I also learned about some officials at the Tuskegee hospital and why they partnered with the PHS for this experiment. I learned that Fred Grey, the Tuskegee attorney, argues that a prominent Black institution, very much dependent upon White philanthropy, could not afford in the 1930s to risk antagonizing the U.S. Government by refusing to participate in a PHS activity of this sort and should not be blamed for this experiment. This was useful in all sections of my study when I was deciding which major players to talk about.

National Center for HIV/AIDS, Viral Hepatitis, STD, and TB Prevention, Centers for Disease

Control and Prevention. "U.S. Public Health Service Syphilis Study at Tuskegee." *Centers for Disease Control and Prevention*, Centers for Disease Control and Prevention, 30 Aug. 2017, [www.cdc.gov/tuskegee/timeline.htm](http://www.cdc.gov/tuskegee/timeline.htm).

This source was really good for my preliminary research. There is a timeline of the Tuskegee Study starting in 1895 with Booker T. Washington's dream for Black development in the south and gaining support from Julius T. Rosenwald. After the Great Depression hit, this work led to Tuskegee Syphilis Study as we know it today. I learned about important dates associated with the study as well as important people, like Peter Buxtun who revealed the study to the public. This was really useful when I was making the outline of my project.

Records of the Tuskegee Syphilis Study, National Archives and Records

Administration--Southeast Region (Atlanta). "Science Museum. Brought to Life: Exploring the History of Medicine." *Tuskegee Syphilis Study*, Science Museum, [broughttolife.sciencemuseum.org.uk/broughttolife/techniques/tuskegee](http://broughttolife.sciencemuseum.org.uk/broughttolife/techniques/tuskegee).

This source gave a very quick overview of the Tuskegee Syphilis Study and was quite useful when I was gaining initial information. Here, I learned that the Tuskegee Study has become the "byword for racist unethical medical experimentation." I learned that the "treatment" that the men received were actually placebos and aspirin, not anything that was actually going to cure or help their disease. I also learned that the medical staff allowed nothing to get in the way of their work. Even when 250 of the men were drafted for military service in WWII, strings were pulled to ensure they remained part of the study instead. This showed the complete determination of the medical staff conducting the study - these men *could* have gotten treatment, but every possible way they could have done this was made unavailable. This was useful for my main event when understanding what went on during those 40 years the study was conducted.

Reverby, Susan M. "Frequently Asked Questions Examining Tuskegee." *Examining Tuskegee: About the Author Susan M. Reverby*, 30 June 2008, [www.examiningtuskegee.com/faq.html](http://www.examiningtuskegee.com/faq.html).

This was a really helpful source about questions and misconceptions many people have about the study. The biggest thing I learned was why only African Americans were chosen for the study: The Oslo study had yielded some results of untreated syphilis in Whites, and it was the belief at the time that the disease would affect Blacks differently. So, the PHS used the remnants of the Rosenwald study in Macon County, Alabama and set up a new study to compare to the Oslo Study. I also gained a very clear definition of syphilis and what it does to the body. The most surprising thing was that this study was not a secret. There were a ton of reports published about the study; however, the term "volunteer" was used, so nobody made a big deal about it. This was really helpful in clearing up some misconceptions about the study and gaining more information on the areas I was most confused about.

Sundararajan, Narayan, et al. "Kennedy Hearings." *"Bad Blood"*:

*The Tuskegee Syphilis Study*, 2014, [tuskegeestudy.weebly.com/kennedy-hearings.html](http://tuskegeestudy.weebly.com/kennedy-hearings.html). This site was really helpful for understanding the Kennedy Hearings. They took place after Buxtun reported the study to the press, and were held to hear testimonies from multiple perspectives, participants and whistleblowers. Many medical reforms came from these hearings including the 1974 National Research Act, and required informed consent, as well as the establishment of institutional review boards. This website was very organized as it had clear sections explaining what the study was, and what exactly were the legacies that came from it. This was used in my impact and legacy when I talk about the Kennedy Hearings and the result of it.

University of Missouri-Kansas City. "History of Research Ethics." *Research & Economic Development*, . University of Missouri-Kansas City, [ors.umkc.edu/research-compliance-\(iacuc-ibc-irb-rsc\)/institutional-review-board-\(irb\)/history-of-research-ethics](http://ors.umkc.edu/research-compliance-(iacuc-ibc-irb-rsc)/institutional-review-board-(irb)/history-of-research-ethics).

This article gave a brief history of medical ethics and states and explains different periods in history that called for reforms. I learned first about the Nuremberg Code, (1948) which stated "The voluntary consent of the human subject is absolutely essential," making it clear that participants in a study are fully aware of the risks. Although this was not a law, it was the first international document that advocated for informed consent. Then it got into the Tuskegee Syphilis Study and how this did not abide by the Nuremberg Code because the subjects were not even aware of their disease, let alone know the risks of the study they were a part of for 40 years. This was really helpful in understanding medical ethics in context, and knowing what was deemed reasonable and justified in the 1930s and '40s.