The Syphilis Study in Macon County, Alabama:

Tragedy in Tuskegee

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Historical Paper

Paper Length: 2,496 words

In 1932, the United States Public Health Service began what would become a forty-year-long study of untreated syphilis on hundreds of black men in the area of Macon County, Alabama. From 1932 to 1972, the study was unknown outside of the medical community and the Public Health Service. It took an exposé published four decades after the study's start for it to be revealed to the public. Great controversy followed, and the after-effects of the study and its disclosure persist to this day. The study is a leading example of several ugly truths regarding medicine and race in the United States. The United States Public Health Service Syphilis Study in Macon County, Alabama was a tragic example of immoral bioethics combined with clear racial prejudice and abuse of power by government health officials that had no outstanding triumphs until its termination, and it resulted in both lasting medical mistrust among black people in the United States, as well as the formal establishment of informed consent in biomedical research.

Until the latter half of the twentieth century, the medical community in the United States was a largely self-governing body, while the United States, especially the South, perpetuated racist systems in its government and society. Medical research in the 1930s was autonomous and self-regulating with doctors in complete control of their work (Jones 95). Medical ethics guidelines existed before and after the inception of the study, but many, including the Code of Medical Ethics adopted by the American Medical Association in 1847, were not law, merely standards ("Code of Medical Ethics Overview"; Skloot 211). Simultaneously, racial segregation and institutional discrimination against black people permeated the Deep South (Reverby 30). As stated in an article published in 1935, "... there is not a southern state that will admit a Negro physician to membership in its state or county medical society" ("Present Status" 79).

Pseudoscientific ideas about black people such as different and lesser reaction to disease and prejudiced perceptions of sexual promiscuity continued to persist through the early twentieth century, having been formed during and in support of slavery (Jones 18, 26). The environment of the nation as a whole, and the South in particular, was conducive to the study's beginning.

Macon County, Alabama, was often described by the men conducting the syphilis study as the perfect place to conduct their experiment. In 1930 there were five times more black people than white people in Macon (United States Census Bureau 133). Many black people in Macon were sharecroppers, and most of the county's residents were poor with little formal education, a situation exacerbated by the Great Depression (Jones 61-63). In the early 1930s, it was found that between thirty-five and forty percent of people in Macon tested positive for syphilis (Thomas and Quinn 1499). In 1932, the syphilis study in Macon County, Alabama began after a syphilis treatment program in Macon had run out of funding a year prior (Reverby 40-41). Around four hundred men with syphilis were selected by a Public Health Service doctor starting in 1932, with the later addition of around two hundred men who were presumed to be uninfected controls (Jones 1; Reverby 1). None of the men were informed of the true nature of their participation in the study or of their disease (Jones 1, 86). The men did not give their informed consent, and from then on, they became unconsenting participants in the Public Health Service's syphilis study (Head). The immediate history and demographics of Macon County enabled the study's beginning and continuation.

Every single participant of the study was black, and racism played a role in its inception and process. Black participants were involved in the study to satisfy the Public Health Service's desire to observe the progression of untreated syphilis in a population of black people (Reverby

37). Describing doctors' views on black people regarding syphilis, James H. Jones wrote in his book *Bad Blood*, "No disease seemed more suited to blacks than syphilis, for physicians were certain that exaggerated libido and widespread sexual promiscuity had led to a high incidence of the disease among blacks" (28). In the words of one study leader, Dr. Taliaferro Clark, "The rather low intelligence of the negro population, depressed economic condition, and the very common promiscuous sex relations not only contribute to the spread of syphilis, but also to the prevailing indifference in regard to treatment'" (qtd in *The Deadly Deception*). Demonstrating his views on race, Dr. Raymond Vonderlehr, another study leader, would refer to the study as a on "the Negro male" to white colleagues but as a study in "human economy" to a black doctor (qtd in Jones 138). The actions and words of the study's leaders display prejudiced views held during the time and demonstrate that race and racial bias were deeply involved in the study.

Alongside their racial biases, doctors actively harmed participants by attempting to bar them from effective treatment. A statistical report from a syphilis study prior to the study in Tuskegee and repeated in a paper on the Tuskegee study states, "It was found that the life expectancy... is shortened from that in the general population... by 30 per cent in the Negro males" (Shafer et al. 265 [Millbank Fund]). While the men were given a small amount of treatment in the 1930s, the authors of a paper on the study stated, "The amount of specific antisyphilitic treatment given has been insufficient to modify significantly the course of disease" (Shafer et al. 688 [Public Health Reports]). The men were also deceptively administered placebo pills and aspirin to treat various ailments they reported to doctors (Reverby 51). Penicillin was never considered as a treatment option by the Public Health Service even once it was shown to treat syphilis (Reverby 46, 63-64). Autopsies were performed on 160 of the 276 men who died

over the course of the study until 1969, and syphilis was considered the primary cause of death for seven of those men and was diagnosed at autopsy in eighty-three of them ("Report on Tuskegee Syphilis Study"). By the end of the study, it was reported in the *Philadelphia Tribune* that 154 men had died of heart failure with doctors unsure of a direct link to syphilis (Fox 5). Other sources place the number dead due to syphilis higher than the 1969 report. According to a British political magazine, New Statesman, "... more than 100 of the men died, directly or indirectly, from their untreated infection" (Brooks 14). In addition to being denied treatment by the Public Health Service, participants were blocked from any other syphilis treatment options (Reverby 64). One participant went to a Birmingham clinic seeking treatment but was returned to Macon by the nurse employed by the Public Health Service who monitored the participants (Jones 111, 163). Peter Buxton, the study's whistleblower who worked as an investigator at the Public Health Service in the 1960s, recalled a story in which a physician was punished for treating a man in the study who was rushed to medical attention after exhibiting insanity due to syphilis (*The Deadly Deception*). Though evidence that untreated syphilis shortened life expectancy existed at the time of the study, the victims of the study were given no effective treatment, many losing their lives due to lack of treatment.

Another tragedy of the study was the deception, misinformation, and outright lies told throughout. The final report on the study's termination noted that, "There is ample evidence to us that the consent to participation was not obtained from the... subjects, but they were exploited, manipulated, and deceived" (Katz, Jay 14). One particularly harmful lie told to the participants regarded the collection of lumbar puncture samples. Lumbar punctures are used to diagnose neural syphilis, syphilis affecting the nervous system, and involve inserting a needle into the

fluid surrounding the spinal cord ("Lumbar Puncture"). The victims of the study were told that the lumbar punctures they were receiving were a form of treatment, and it was not explicitly stated that the procedure was only a diagnostic measure (Reverby 45). One man, Charles Pollard, recalled his experience with the lumbar puncture, saying that afterwards he was bedridden for "a week or two" (*The Deadly Deception*). In a description of an unnamed victim's experience during the study, a Public Health official reported, "He was not told what the disease might do to him" (Eagle). Several cases of deceit occurred during the study, which were tragic in their harm, disregard, and disrespect of the autonomy of the men studied.

The study utilized faulty scientific methods, an issue that negates scientific accomplishments argued to have been gained. The report on the decision to end the study in 1973 cites the study's numerous scientific faults, including, "lack of validity and reliability assurances; lack of calibration of investigator responses... questionable data base validity..." (Backus et al. 8). The study was rife with scientific errors causing unreliable data. Reevaluations in 1938 and 1939 found that many of the participants in the "infected" group had received some form of treatment considered negligible at the time (Norins 3; Shafer et al. 688 [Public Health Reports]). According to a draft of a report on the study, 179 of the men before 1949 had received up to fifteen doses of neoarsphenamine, a common treatment before penicillin ("Draft Report"). The goal of the study as an investigation in untreated syphilis was not met due to both ineffective treatment administered at the beginning of the study and participants receiving treatment later by other means. Additionally, the panel of doctors reevaluating the study in 1973 concluded that it was unjustified when it began because of unsound science (Cobb 347-348). With this argument,

they refuted the claim that substantial scientific good was brought about by the study (Cobb 347-348). The study came to an end with its process as a scientific study refuted.

Aside from a lack of scientific benefits, any possible positive intentions of the study were greatly overshadowed by concurrent human rights violations committed throughout its duration. Though the study ran for four decades, its initial objective was to observe the effects of late-stage syphilis in a group of black men over the course of around six months (Reverby 242). One goal of the study was to prove syphilis affected black individuals the same as whites to gain funding for treatment programs for black people (Jones 94). However, when President Franklin Roosevelt brought a syphilis treatment program to Macon in 1937, regardless of the study, the study's victims were intentionally excluded from this treatment due to their status as subjects (*The Deadly Deception*). Furthermore, the study broke numerous ethics codes. The Nuremberg Code and the World Medical Association's Declaration of Helsinki, two ethical codes published while the study was active, outlined guidelines of ethical biomedical research (Reverby 189). As the study continued into the 1970s, the codes did not influence its progress. The study broke several parts of the Nuremberg Code, written in 1947 to prevent experiments like those performed by Nazi doctors during the Holocaust from happening again, including the first rule, "The voluntary consent of the human subject is absolutely essential" ("Nuremberg Code"). In its deception and harm of people, the study contravened a section of the Declaration of Helsinki, established 1964, "While the primary purpose of medical research is to generate new knowledge, this goal can never take precedence over the rights and interests of individual research subjects" ("The World Medical Association Declaration of Helsinki"). The study was founded on a disregard of human rights.

In 1972, Jean Heller of the Associated Press published the story of the "Tuskegee Study" in the New York Times, a triumphant revelation of such a tragic event. Then Public Health Service investigator Peter Buxton had told the story of the syphilis study in Tuskegee to a friend of Heller's working at the Associated Press (Jones 191, 204). Heller's article was the first time the public was made aware of the study, and national condemnation followed (Jones 1, 206). The conclusion of the 1973 ad hoc committee reevaluating the study was its immediate termination (Cobb 347-348). Fred Gray, a notable civil rights lawyer, represented surviving members of the study in a lawsuit that resulted in a meager settlement (Gray 750). The community around Macon and the descendants of its victims continue to remember the study and its effects (Associated Press). Annual ceremonies in Macon County honor the lives of the men (Associated Press). Lillie Tyson Head, daughter of unconsenting participant Freddie Lee Tyson and representative of the Voices for Our Fathers Legacy Foundation formed by and for descendants of the study's victims, stated, "After the Study's main purpose was made known the news was sickening to everyone and still very troubling today. It is also felt that the Study boldly demonstrated how poor African American families were under valued and considered unworthy of respect, dignity and equality in all aspects of their lives" (Head). The impact the study had on the lives of those affected by it was immediate following Heller's article.

Since its disclosure, various studies have been performed on how the study in Tuskegee influences the way that black people in the United States interact with the medical community. According to a 2016 study, "...the disclosure of the study in 1972 is correlated with increases in medical mistrust and mortality and decreases in both outpatient and inpatient physician interactions for older black men" (Alsan and Wanamaker). Another study examining an effect of

the study in Tuskegee found that, "the data show a statistically significant difference across the three racial/ethnic groups... with Blacks being 1.8 times as likely as Whites to have a higher fear of participation in biomedical research" (Katz, Ralph V.). An article in the *Philadelphia Tribune*, a black American newspaper, reiterates this apprehension, "There is a hesitancy of some African Americans to donate blood or organs for transplant or even to have children vaccinated because of the legacy of the Tuskegee experiment" (Jackson 7A). The study in Tuskegee has had negative effects on black Americans' conceptions of the medical community.

A triumphant outcome of the study was the establishment and reexamination of informed consent laws and standards of biomedical research. Following the congressional hearing regarding the study, the National Research Act was signed in 1974, establishing the *National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research*, whose work was summarized in the Belmont Report in 1976 (Kennedy). Before the late 1960s, notable court cases on medical informed consent focused almost exclusively on informed consent in the area of surgery (Murray 104-109). The Belmont Report established three principles for biomedical research, one of these being informed consent: "The Report advises that the process of informed consent include complete disclosure of all known risks and anticipated benefits of the research" (Bertholf 123). This establishment of guidelines on informed consent in biomedical research in the United States are an ultimately triumphant result of the study, though it is impossible to weigh it against the study's inherent tragedies.

On May 16th, 1997, President Bill Clinton issued a formal apology to the unconsenting subjects of the "syphilis study at Tuskegee" at the White House. Present at the address were five men who had been an unknowing part of the study for a large portion of their lives. In 2004, the

last living victim of the study, Ernest Hendon, died at age ninety-six. Acknowledgement of, reconciliation for, and education on the racism and broken bioethics inseparable from the study in Tuskegee are vital today as much as ever. It is paramount to learn from the tragedy of the past. The United States Public Health Service Syphilis Study in Macon County, Alabama continues to stand as an infamous instance of flawed medical ethics, oppressive and racist systems, and abuse of power, and it is a critical event with lasting consequences regarding the attitudes of black people toward medicine in the United States along with the enactment of informed consent in bioethics.

Annotated Bibliography

Primary Sources

Backus, Robert C. et al. "Report on Charge I." Final Report of the Tuskegee Syphilis Study Ad Hoc Advisory Panel. *The Climate Change and Public Health Law Site*, Louisiana State University, 24 April 1973. biotech.law.lsu.edu/cphl/history/reports/tuskegee/report1.pdf.

The Climate Change and Public Health Law Site contains firsthand documents in the areas of climate change law, public health law, and various other categories. As a part of the "Final Report of the Tuskegee Syphilis Study Ad Hoc Advisory Panel," this source describes the panel's decision on the first charge regarding whether the study was justified when it began. I used this source to demonstrate how the study was faulty science, thus showing that it was not triumphant in that aspect.

Cobb, W. M. "The Tuskegee Syphilis Study." *Journal of the National Medical Association* vol. 65, no. 4, 1973, pp. 345–348. *National Center for Biotechnology Information, U.S. National Library of Medicine, National Institute of Health, PubMed*, www.ncbi.nlm.nih.gov/pmc/articles/PMC2609060/.

This article was published in the *Journal of the National Medical Association*, an organization of black physicians. It addresses the study in Tuskegee and the decision to end it, giving a report of the decision made and briefly describing the study itself. The article includes an official statement on the termination of the study by a member of the 1973 ad hoc panel. I used this article to help describe the final decision to end the syphilis study in Tuskegee and on what grounds such a decision was officially concluded, specifically describing the 1973 ad hoc committee's decision. I also used this to support the argument that the study held no substantial scientific value.

"Draft Report." United States, Department of Health, Education, and Welfare, Public Health Service, Health Services and Mental Health Administration, Center for Disease Control, Venereal Disease Branch 1970-1973, 1949. National Archives Catalog, catalog.archives.gov/id/281640.

The *National Archives Catalog* where I accessed this source is a government-run public database of historical government documents in various formats. This source was originally created in 1949 and is a draft of a report on the findings of the study. The digitized copy of the document has sections that are unclear with handwritten redactions. I used the draft report to support the point that the men were given some form of treatment early in the study and that this contributed to the study being faulty science, and this source provided specific numerical support for my argument.

Eagle, Jay. "Interview Notes." United States, Department of Health, Education, and Welfare, Public Health Service, Health Services and Mental Health Administration, Center for Disease Control, Venereal Disease Branch 1970-1973, 11 Jan 1972. National Archives

Catalog, catalog.archives.gov/OpaAPI/media/650715/content/arcmedia/fhh/6003 001 a.gif.

This source is a document describing an interview with an unnamed participant of the study. The interview was conducted after the study's existence was released to the press. I used this source to demonstrate how the study's victims were not informed of the details of their disease during the study.

Fox, Jeanne. "Tribune Analyzes Ala. VD Study." *Philadelphia Tribune*, 5 Aug 1972, p. 5. ProQuest Historical Newspapers, search.proquest.com/hnpphiladelphiatribune/docview/532623059/A02C5A206BB1479B PQ.

ProQuest is one of the foremost database resources, and provides full-text, subscription-based databases in many subjects. The *Philadelphia Tribune*, a voice of the black community in Philadelphia, is the oldest continuously published black newspaper in the United States. This article was published soon after the Jean Heller article, and describes the study, as well as asks questions regarding the race of the study participants and its continuance after the discovery of penicillin. I used this article to show that the study in Tuskegee was harmful by providing another account of how many men remained alive in 1972.

Gray, Fred. "Lecture: Bus Ride to Justice: A Conversation with Fred Gray (with Introduction by Jonathan L. Entin)." *Case Western Reserve Law Review* vol. 64, no. 3, 2014, 732-753. scholarlycommons.law.case.edu/cgi/viewcontent.cgi?article=1136&context=caselrev.

This source is a lecture in interview format conducted in 2014 by Jonathan L. Entin with Fred Gray regarding Gray's career. Fred Gray is a notable civil rights lawyer who was active most prominently during the civil rights movement in the United States, defending several famous civil rights leaders. In the interview, Gray describes many parts of his career, including his role in the Tuskegee study lawsuit. I used this source to provide the historical significance of the study, briefly describing Fred Gray's lawsuit as part of the study's outcome.

Head, Lillie. "Re: Phone Call." Received by Emmie Chacker, 17 January 2019.

This email is a part of an email correspondence I had with Lillie Head. Her father, Freddie Lee Tyson, was an unknowing participant in the syphilis study in Tuskegee, and she is a part of the *Voices for Our Fathers Legacy Foundation*, a foundation of and for descendants of men involved in the study. The foundation seeks to remember the study and honor its victims and their descendants. I cited Head's expertise in stating the men involved in the study did not give consent and therefore were not properly consenting participants. I also used a section from a longer statement made by her in her email to me in order to demonstrate the local and personal legacy of the study.

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

www.nytimes.com/1972/07/26/archives/syphilis-victims-in-us-study-went-untreated-for-40-years-syphilis.html.

Jean Heller was an investigative journalist working for the research bureau at the Associated Press when she published the article that revealed the study. She was provided with proof of the study in Tuskegee by Public Health Service worker Peter Buxton after he had divulged the story to Edith Lederer, his friend who worked in the Associated Press at the time. This article describes the Tuskegee study, and it was the first article to break the existence of the study to the public. All subsequent public response and further press surrounding the study followed Heller's article. I did not notice any clear biases in Heller's words. I used this source to describe the article itself and provide the detail of the study being called a "moral and ethical nightmare" by a politician to elaborate on the study's immediate effects.

Katz, Jay. "Reservations About the Panel Report on Charge I." "Final Report of the Tuskegee Syphilis Study Ad Hoc Advisory Panel," pp. 14-15. *The Climate Change and Public Health Law Site*, Louisiana State University, biotech.law.lsu.edu/cphl/history/reports/tuskegee/katz1.pdf.

This source is the digital copy of a paper regarding the 1973 ad hoc committee selected to review the syphilis study in Tuskegee. The Climate Change and Public Health Law Site contains firsthand documents in the areas of climate change law, public health law, and various other categories. A part of the "Final Report of the Tuskegee Syphilis Study Ad Hoc Advisory Panel," this source is Dr. Jay Katz's additional notes on the decision made by the ad hoc committee regarding if the study was justified at its beginning in 1932. Dr. Jay Katz was a white physician and law professor with a history of involvement in cases involving the ethics of human experimentation. This source provided me with a quote explaining that informed consent was not gained by the participants of the study, and I used it to support the argument that the victims of the study were tragically deceived during the study.

Norins, Dr. Leslie C. "Ad Hoc committee meeting to examine data from the Tuskegee Syphilis Study and offer advice on continuance of this Study." *United States, Department of Health, Education, and Welfare, Public Health Service, Health Services and Mental Health Administration, Center for Disease Control, Venereal Disease Branch 1970-1973,* 1969. *National Archives Catalog*, catalog.archives.gov/id/281641.

The National Archives Catalog is an online database of government documents and is maintained by the United States Government. This source is a transcript of the proceedings of the ad hoc meeting that convened in 1969 to discuss the continuity and possible termination of the Tuskegee study. I assume that the meeting was transcribed exactly, however, there are a few sections described in less detail than others. I used this source to argue that the study was not triumphant due to faulty science.

"Present Status of the Negro Physician and the Negro Patient." *Journal of the National Medical Association*, vol. 27, no. 2, 1935, pp. 79-80. *National Center for Biotechnology Information*, U.S. National Library of Medicine, PubMed, www.ncbi.nlm.nih.gov/pmc/articles/PMC2623558/?page=2.

This source is an article published in the *Journal of the National Medical Association* that describes the treatment of black doctors in the United States during the time of publication, the 1930s. The National Medical Association is an association of black doctors. I used this source to describe the way the profession was segregated and white physicians were intolerant towards black physicians. It also gave background on the larger context of the beginning of the study.

"Report on Tuskegee Syphilis Study." *United States, Department of Health, Education, and Welfare, Public Health Service, Health Services and Mental Health Administration, Center for Disease Control, Venereal Disease Branch 1970-1973*, 1969 *National Archives Catalog*, catalog.archives.gov/id/281640.

This source is a brief report on findings of the syphilis study in Tuskegee. I used this source to describe the number of men who passed before 1969 and by what cause, including how many deaths were considered to be caused by syphilis and how many cases involved syphilis being diagnosed at autopsy. In context, I used the death statistics to indicate that suffering and unjust loss of human life was indeed caused by the study.

Shafer, J.K., et al. "Untreated Syphilis in the Male Negro: A Prospective Study of the Effect on Life Expectancy." *The Millbank Fund* vol. 32, no. 3, 1954, pp. 262-274. www.milbank.org/wp-content/uploads/mq/volume-32/issue-03/32-3-Untreated-Syphilis-in-the-Male-Negro.pdf.

This source is a paper that exists in PDF format on the website of the Millbank Fund, and I accessed it there. There is no material on the website further explaining this document. This document is a medical paper on the syphilis study in Tuskegee and describes statistical data on life expectancy from the study at the time of publication in 1954. The Millbank Fund itself was involved in the study, working with the Public Health Service, it provided burial funds for victims of the study who died during its duration. Using this paper to argue that the study harmed its participants, I quoted the paper and described data showing that, before the beginning of the study, untreated syphilis was shown to cause shorter life expectancy in black men.

Shafer, J.K. et al. "Untreated Syphilis in the Male Negro: A Prospective Study on the Effect on Life Expectancy." *Public Health Reports*, vol. 67, no. 7, 1954, pp. 684-690. *National Center for Biotechnology Information, U.S. National Library of Medicine, PubMed*, www.ncbi.nlm.nih.gov/pmc/articles/PMC2024307/.

This source is a paper on the statistical results of the syphilis study in Tuskegee regarding life expectancy. Though similar to the previous article by the same J. K. Shafer et al., this paper was originally published in the Public Health Reports and includes slightly different content. I used this source to argue that the men were harmed by the study by providing a quote explaining that the syphilis treatment given to some men at the beginning of the study was insufficient to treat the disease.

United States Census Bureau. "1930 Decennial Census." 1930, census.gov, www2.census.gov/library/publications/decennial/1930/population-volume-3/10612963v3 p1ch02.pdf.

This source is the census data from the 1930 decennial census in the states of Alabama, Arizona, and Arkansas. Being a government census report, I assume that this source is unbiased and as accurate as possible. A section of this census report provides the racial makeup statistics in Macon County. It is unclear how exactly racial categories were differentiated at the time, but the statistics provided demonstrate the racial disparity in Macon. I used this source to report exact census data from Macon on race in 1930, thus demonstrating the racial disparity in Macon in order to provide local context for the beginning of the study.

Secondary Sources

Alsan, Marcella, and Marianne Wanamaker. "Tuskegee and the Health of Black Men." *National Bureau of Economic Research*, National Bureau of Economic Research, June 2016, www.nber.org/papers/w22323.pdf.

This study was originally published in June 2016 and revised in June 2017. The National Bureau of Economic Research has stated that it is dedicated to unbiased research. This study examines the effects of the disclosure of the study in Tuskegee on the African American community and found a relevant figure demonstrating years of loss of life due to the ensuing mistrust of medical institutions. I used this source to provide an important example of a measurable outcome of the Tuskegee study and argue that the study caused medical mistrust among the black community. The words I took from this source were a part of the study's abstract and have no page number.

Associated Press. "Descendants of Men in 'Tuskegee Syphilis Study' Still Struggle with Stigma." *AL.com*, Advance Local Media, 10 May 2017, www.al.com/news/index.ssf/2017/05/descendants_of_men_in_tuskegee.html.

I accessed this source on AL.com, *Advance Local Media*'s local Alabama news site. Because this source is affiliated with the Associated Press, it meets its standards of journalism. This source is a news article by the Associated Press about the descendants of subjects of the study in Tuskegee and the study's effects on the people of Macon County. I used this source to describe a local outcome of the study, the annual memorial services for the victims of the study.

Bertholf, Roger L.. "Protecting Human Research Subjects." *Annals of Clinical & Laboratory Science*, vol. 31 no. 1, 2001, pp. 119-127. www.annclinlabsci.org/content/31/1/119.full.

This paper is a report about various medical ethics codes on the protection of human research subjects. *The Annals of Clinical & Laboratory Science*, where I accessed this source, is an academic journal published quarterly by the Association of Clinical Scientists. I used a part of this source that describes the Belmont Report, a report outlining guidelines of bioethics, in order to show an example of the way that the study in Tuskegee affected medical ethics standards in the United States.

Brooks, Michael. "Sir, there's an ethical dimension in my policy." *New Statesman*, 21 March 2011, pp. 14. *Business Collection, Gale Virtual Reference Library*, link.galegroup.com/apps/doc/A253538090/GPS?u=pl7321r&sid=GPS&xid=5b3bdf05.

I accessed this source from the Business Collection of the Gale Virtual Reference Library which itself is accessible through *POWER Library*, Pennsylvania's Electronic Library. All *POWER Library* sources are stated by the electronic library to be highly reliable. Originally published in the *New Statesman*, a British political and cultural magazine, this short article describes an effort by scientists to discover the realities of bioethics in the present day and briefly touches on the study in Tuskegee. I used a quote from this source to provide an example of a source that places the number of men who passed during the study as higher than that told by Public Health Service reports in order to argue that harm was done to the men involved in the study.

"Code of Medical Ethics Overview." *The American Medical Association*, The American Medical Association.

www.ama-assn.org/about/publications-newsletters/code-medical-ethics-overview.

This source is a web page from the website of The American Medical Association that gives a brief overview of their Code of Medical Ethics. There is no author listed. I used this source to describe an example of a medical ethics code that was not law and existed before the beginning of the syphilis study in Tuskegee in order to provide larger context on the beginning of the study.

The Deadly Deception: Tuskegee Syphilis Experiment. Produced by Denise Dilanni, narration by Bill Mason, WBGH Boston for NOVA, 1993. YouTube. www.youtube.com/watch?v=AuyTzgY8eSc.

I accessed this documentary on YouTube. The documentary gives an overview of the experiment, the controversy and different opinions held by different people, and includes interviews from subjects of the study, doctors leading the study, and other important relevant figures, and seeks to provide the views of both the subjects and those fully against the study, as well as the perspective of a doctor who defends his involvement in the study. The documentary also gives a historical overview. I used this source to provide details supporting multiple arguments I made in my paper, including that racial bias was

involved in the study, that study victims were prevented from receiving treatment, and that the deception of the unknowing study participants by the Public Health Service doctors resulted in their suffering. Additionally, I utilized this source to argue the study was tragic and did not fulfil one of its proposed goals of eventual treatment.

Jackson, Bernice. "The Legacy of the Tuskegee Syphilis." *Philadelphia Tribune*, 2 May 1997, p. 7A. *ProQuest*, Historical Newspapers, search.proquest.com/hnpphiladelphiatribune/docview/533243277/77AEFAF05EDC4183 PQ.

ProQuest is one of the largest a database resources available. The *Philadelphia Tribune* is the longest continuously published black newspaper in the United States, and is a voice of the black community in Philadelphia. This briefly describes the study in Tuskegee before elaborating on the harmful outcomes that its disclosure. I used this article to support the fact that the study led to increased medical mistrust among black people.

Jones, James H. *Bad Blood: The Tuskegee Syphilis Experiment - New and Expanded Edition*. 1981. New York, The Free Press, 1993.

I accessed this book at the Charles L. Blockson Afro-American Collection. This book is about the Tuskegee study and follows the greater factors that led to it and continues by describing the course of this study, ending by relating the syphilis study in Tuskegee to reactions to the AIDS crisis. *Bad Blood* gives an informative, clinical review of study in Tuskegee and focuses on the events leading up to it. Jones is a now retired history professor, and his book was the first to provide an in-depth description of the study from before its inception to its outcomes. I contacted Jones regarding his expertise on the study in Tuskegee, though I did not include this correspondence in my paper due to i's having no clear place. While providing larger context on the study, I used this source to describe the way that the medical profession functioned at the time of the study along with describing the racist attitudes of the United States. I also used this source to provide local context for the study, to describe the racial attitude of health officials at the time, to provide an example of a subject's being denied treatment, and to recount a goal of the study in order to show that that goal was not met by the study.

Katz, Ralph V. et al. "The Tuskegee Legacy Project: willingness of minorities to participate in biomedical research" *Journal of Health Care For the Poor and Underserved* vol. 17, no. 4, 2006, pp. 698-715. *National Center for Biotechnology Information, U.S. National Library of Medicine, PubMed*, www.ncbi.nlm.nih.gov/pmc/articles/PMC1780164/.

The *Journal of Health Care for the Poor and Underserved*, the original source of the paper cited, is a peer reviewed journal. This paper is a report on a study that examined the effects of the Tuskegee study on black men's willingness to participate in medical studies. I used this source to provide an example of a study that found that the Tuskegee study had an effect on black men in regard to their attitude towards medical research.

Kennedy, Shawn. "The National Research Act - 1974." *IMARC*, IMARC Research, Inc., 29 May 2015, www.imarcresearch.com/blog/the-national-research-act-1974.

This source is a post published on the blog of IMARC Research by Shawn Kennedy. Kennedy has written several blog posts regarding medical ethics codes and the study in Tuskegee, and all of his work is thoroughly and appropriately sourced with in-text links to reliable websites. IMARC Research is a company that provides outsourced research services to biotechnology and related industries, and the blog contains numerous articles regarding biotechnology and other relevant fields. I used this source to introduce the Belmont Report and the events leading up to it in order to explain one of the study's outcomes, this being the Belmont Report's emphasis on informed consent in research involving human subjects.

"Lumbar Puncture (Spinal Tap)." *Mayo Clinic*, Mayo Foundation for Medical Education and Research, 24 Apr. 2018,

www.mayoclinic.org/tests-procedures/lumbar-puncture/about/pac-20394631.

The Mayo Clinic is a non-profit medical center. This source is a brief informative article about what a spinal tap is, why it is done, risks, and other important basic information. I used this information to give brief background on what a lumbar puncture is in order to discuss the deception involved in administering lumbar punctures to the subjects.

Murray, Peter M.. "The History of Informed Consent." *Iowa Orthopedic Journal* vol. 10, 1990, pp. 104-109. *National Center for Biotechnology Information, U.S. National Library of Medicine, PubMed*, www.ncbi.nlm.nih.gov/pmc/articles/PMC2328798/?page=1.

This source gives brief profiles on informed consent law cases in the United States during the 20th century, also providing a summary of informed consent in early history. I used this source to provide context regarding that status of informed consent as a legal concept in the United States before the 1960s. This detail helped me to show how the Belmont Report was novel in its explicit emphasis on informed consent in research involving human subjects.

"Nuremberg Code." *United States Holocaust Memorial Museum*, United States Holocaust Memorial Museum,

www.ushmm.org/information/exhibitions/online-exhibitions/special-focus/doctors-trial/nuremberg-code.

This webpage briefly chronicles the Nuremberg Code and trials and lists the items of the Nuremberg Code with the purpose of informing readers about the Nuremberg Code. I used this source to provide the first item of the Nuremberg Code and to show that the study went against it, and I used this to demonstrate a human rights violation of the study.

Reverby, Susan M. Examining Tuskegee: the Infamous Syphilis Study and Its Legacy.

University of North Carolina Press. 2009.

I accessed this book at the Charles L. Blockson Afro-American Collection and the Free Library of Philadelphia. This book describes the study from its beginning to its aftermath into the twenty-first century. The author is a professor of history, and the book won multiple academic awards. In order to show that the study was racially motivated, I used this source to explain why black subjects were required by the study. I also used this source while arguing that the study caused harm, briefly discussing how treatments were given and not given during the study and explaining that withholding syphilis treatment was thought to decrease life expectancy. Using this source to depict the deception of the study, I explained the detail that lumbar punctures were not a diagnostic measure.

Skloot, Rebecca. The Immortal Life of Henrietta Lacks. New York, Crown Publishers, 2010.

This book describes the story of Henrietta Lacks and her immortal HeLa cells, her case being a notorious case of dubious bioethics alongside race and medicine. Skloot is a writer who works prominently with the topics of science and mathematics. The book is thoroughly cited, and Skloot has relevant academic degrees. While providing larger context on the beginning of the study, I used this book to describe the Code of Medical Ethics and how it and other medical ethics codes were not law at the time of the study.

Thomas, Stephen B. and Sandra Crouse Quinn. "The Tuskegee Syphilis Study, 1932 to 1972: Implications for HIV Education and AIDS Risk Education Programs in the Black Community." *American Journal of Public Health*, vol. 81, no. 11, 1991, pp. 1498-1505, ajph.aphapublications.org/doi/pdf/10.2105/AJPH.81.11.1498.

This article describes the syphilis study in Tuskegee and its effects on the black community sixty years later, focusing on HIV/AIDS in black Americans and the effects of conceptions surrounding the Tuskegee study. The article is written in plain language and does describe in detail any individual studies, focusing on informing the reader of the issue it is discussing. I used this source to provide background on syphilis rates in Macon County, Alabama, before the beginning of the study.

"The World Medical Association Declaration of Helsinki – Ethical Principles for Medical Research Involving Human Subjects." *The World Medical Association*, The World Medical Association, Inc.,

www.wma.net/policies-post/wma-declaration-of-helsinki-ethical-principles-for-medical-research-involving-human-subjects.

This webpage provides the entirety of the most recent version, as well as past versions beginning from the Declaration's first draft in 1964. I used this source to provide a clear example of the syphilis study in Tuskegee violating a part of a medical ethics codes that existed while the study was active. I used this in my argument to show that the study disregarded human rights.