Chapter 1
The Tuskegee Syphilis Study: *Miss Evers’ Boys* (1997)

Every basic lecture in healthcare ethics, health disparities, bioethics, public health or research ethics must include some mention of the Tuskegee Syphilis Study—a study funded by the U.S. Public Health Service that ran from 1932 until 1972\(^1\), when it was finally investigated, although the study did not formally close until March 1973 (Reverby 2009). The study followed over 400\(^2\) African American males with syphilis but withheld the standard of care treatment, including penicillin when it became available in the late 1940s. This infamous unethical research protocol exploiting African American males with syphilis was, in many ways, like the disease it studied. It had an acute phase, a latency stage, and then a final stage where it entered the entire “body politic” of civil rights, racial disparities and healthcare delivery.

The first formal apology for the Tuskegee Syphilis Study (hereafter referred to as the Tuskegee study) by a sitting U.S. President did not occur until May 16, 1997—when President Bill Clinton apologized on behalf of the United States to the study subjects and their families. It was the film, *Miss Evers’ Boys*, that ultimately coincided with the apology suggested by the 1996 Tuskegee Study Committee (see under Healthcare Ethics Issues). This 1997 film is based on the 1992 Pulitzer Prize-nominated play of the same name by physician and playwright, David Feldshuh. Feldshuh stated that the play was “suggested” by the first definitive scholarly book about the study, *Bad Blood* (Jones 1981). The film was released February 22, 1997,

\(^1\)In virtually every writing on the Tuskegee study, its length is cited as 40 years, from 1932–1972. That is not exactly accurate. The study was “outed” in the press July 25, 1972, investigated by a federal government panel (chartered August 1972) and recommended to be shut down in October 1972, with its final report issued in April 1973. Congressional hearings were held in February and March of 1973 (a.k.a. the “Kennedy hearings”), and it was not until these hearings concluded that the study was formally closed down, and the men administered full treatment. In this chapter, I will continue to refer to the oft-quoted “1932–72” time frame as the 40-year period the study ran unimpeded without oversight.

\(^2\)See under History of Medicine section for the trial enrollment details, as well as Reverby 2009, Appendix C for a full list of the subjects’ names.
during the 21st Black History Month; Black History month was officially declared in 1976 by President Ford; it began as “Negro History Week” in 1926 (Zorthian 2016).

The film juxtaposes the Congressional hearings held in 1973 (presented in the film as “1972”) with a 40-year timeline of the study itself. The film’s central character is based on the actual public health nurse involved over the duration of the study—Eunice Rivers (in her later years, Eunice Rivers Laurie)—whose surname is changed to “Evers” in the film; the film is from her point of view. The film also disguises the names of other medical providers involved in the study through the years by creating composite fictional characters. Most importantly, the film presents a “composite protocol” based on the public record that included many conflicting reports, accounts and oral histories from multiple perspectives of those involved. Historians point out that there was no official or formal written protocol to review in the final analysis (Jones 1981, 1993; Washington 2007; Reverby 2009), but there were several papers published on the study’s findings, while Nurse Rivers’ involvement was mentioned in a 1953 paper (See Jones 1993, pp. 281–282 for a complete list of published papers on the Tuskegee study).

This chapter will discuss the origins of the film Miss Evers’ Boys within its own time frame (1980s and 1990s), and then unpack the Tuskegee study protocol within the social location of its 40-year time span, exploring the roles of key study investigators, its African American collaborators and the study’s whistleblowers. The chapter will next discuss this study within a history of medicine context that considers: (1) African American medical care and disturbing, yet prevailing misconceptions about African American physiology; (2) the treatment of syphilis and clinical equipoise (Freedman 1987) over optimal therapies; and (3) the clinical rationale for observational protocols in general—many of which are still being done in multiple settings today, including “observation-only” trials of various cancers. An important misconception of this topic is to solely cite this study as a singular example of an “observational protocol” without treatment. In fact, as I’ll discuss in this chapter, it’s important to stress to students that variations of questionable observational protocols are ongoing in many different disease contexts.

Finally, this chapter will explore the multiple healthcare ethics issues entangled in the Tuskegee study, comprising violations of the “do no harm” concepts embedded in the Principle of Non-Maleficence, as well as other research ethics considerations; organizational ethics considerations; clinical ethics considerations; and public health ethics considerations. When planning a curriculum that includes the Tuskegee study, screening the film Miss Evers’ Boys helps to provide a context for how the U.S. Public Health Service (USPHS) prospective protocol called “The Tuskegee Study of Untreated Syphilis in [the] Male Negro”, an observational study on the natural history of syphilis, became a flashpoint for civil rights violations, medical harms and abuses in medicine, and a framework from which to examine deep racial and health disparities and the social production of illness. Educators should also spend some time on explaining the evolving vernacular surrounding reference to an African American.
At different points in history, the term “Negro”, “Black” and “African American” have been used, but there may be students who still find reference to the term “Negro” jarring. For clarity, the terms “Negro” or “Black” are used in this chapter only when citing other documents or organizations; otherwise, the term African American is used.

**Origins of Miss Evers’ Boys**

The play and later, film, *Miss Evers’ Boys* was inspired by the book, *Bad Blood* (Jones 1981), which was written by Southern historian and bioethicist James H. Jones, and was the first rigorous accounting of the Tuskegee study. The book’s title referred to the vernacular used to deceive study subjects to enroll in the study. Subjects were told that enrollment in the study was for treatment of “bad blood”—a general term that meant everything from high blood pressure to arthritis; few study subjects understood they had syphilis, or that their ailments were related to syphilis specifically. Jones’ book brought into focus that the Tuskegee study was a collaborative effort between white investigators and African American healthcare providers, who until that point, had been dismissed as either not responsible, not fully aware of the study, or “victims” when that was not the case. When Jones’ book came out in 1981, it soon became a public health ethics classic, and began to be included in various healthcare-related curricula—particularly in the areas of public health and bioethics. David Feldshuh, the playwright of “Miss Evers’ Boys” was a unique audience for Jones’ book. He had initially studied acting before going to medical school. Feldshuh read *Bad Blood* when he was doing his residency in Emergency Medicine, and worked on the play throughout the 1980s, at the dawning of the AIDS epidemic that gripped medicine at the time. The play “Miss Evers’ Boys” was published in 1989, winning The New American Play Award (Isenberg 1990) and began to debut in 1990 at various theaters (see further); it focuses on the experiences of the African American healthcare providers involved in the study as collaborators. Some scholars have criticized this work because it is a fictionalized and speculative account of the Tuskegee study with composite characters, and is not intended as a docudrama. The play and film have been described as an “interpretation” of the Tuskegee study. Yet the more time passes, the more “truth” there is to Feldshuh’s interpretation. I argue that the standard critique of his play, and the film, *Miss Evers’ Boys* is misplaced, and misses the merit, and point, of this work. The play (and film) was designed to address the public’s burning question of “what were they thinking?” in the absence of any definitively satisfying historically recorded answers by the African American healthcare providers who served as collaborators. In definitive scholarly works on the study (Jones 1981, 1993; Washington 2007; Reverby 2009), “what were they thinking?” is discussed speculatively, too. The clear answer to that question was absent from history because the African American champions of the study from the Tuskegee Institute (Drs. Moton and Dibble) were deceased when the study was halted in 1972. Nurse Rivers Laurie (1899–1986) was 73 years old in 1972, and had been interviewed by a government-appointed panel at that time (see further), but the panel
Chair, Broadus Butler, decided to destroy her interview tapes presumably because they were deemed problematic (Washington 2007; Reverby 2009). (See under Social Location.) In the Spring of 1977, Rivers was interviewed privately by James Jones for his book (Jones 1993), but the transcripts were never made public. Rivers gave her last interview on October 10, 1977 to A. Lillian Thompson for The Black Women Oral History Project (Hill 1991). The Thompson interview transcripts have been used and analyzed by multiple scholars, such as Susan Smith (Smith 1996), but the entire oral history project, including the Lillian Thompson interview of Rivers, is now online (Harvard Library 2018). At the time of these interviews, Nurse Rivers Laurie was 77, had tired after about an hour, but her interviews with both Jones and Thompson vindicates much of what is portrayed in the play and film (see further under Social Location). Rivers was also interviewed in 1977 by Dr. Dibble’s widow, Helen Dibble, who was a librarian, along with a Tuskegee University archivist, Daniel Williams (Reverby 2000).

Ultimately, since the July 25, 1972 Associated Press article broke the story (Heller 1972), scholars have spent almost 50 years trying to answer the “what were they thinking?” question to get to the “truth” of the Tuskegee study protocol. The play and later film, *Miss Evers’ Boys*, offers a reasonable and important answer from the perspective of the African American healthcare providers who participated in the Tuskegee study. Current viewers who are looking back from a twenty-first century lens must remember that Moton, Dibble and Rivers were professionals living in the Jim Crow South, in a pre-Civil Rights era, when lynching was a commonplace activity championed by law enforcement at the time (see further under the Social Location section).

**The Jones Book on the Tuskegee Syphilis Study (1977–1981)**

The only other major scholarship on the Tuskegee study prior to Jones’ book was a 1978 article by Allan Brandt, titled “Racism and Research: The Case of the Tuskegee Syphilis Experiment” (Brandt 1978). Brandt’s article was published just four years after the government reached a settlement with the harmed survivors and families of the study (see further).

James H. Jones was the first medical historian to write a book on the Tuskegee study, and his interest in the topic was serendipitous. While looking at PHS archives in the late 1960s for a planned book he wanted to write about Alfred Kinsey’s sex research, he came across some correspondence from the 1930s about the Tuskegee study, not really sure what he was reading, but made a mental note that it was interesting (Reverby 2009). Then, in 1972, when he heard about the study in the mainstream press while driving to Boston to start a postdoctoral position at Harvard university—a research position that was supposed to focus on his Kinsey book—he decided to write about the Tuskegee study instead (Reverby 2009). It’s understandable that his interest and knowledge about Kinsey, whose research focused on the sexual habits of Americans, would make for an easy transition to writing about a syphilis
study. After his Harvard position ended, Jones accepted a full-time position at the National Endowment for the Humanities; while there, he contacted attorney Fred Gray, who was amidst a class action suit on behalf of the study survivors, and they struck a “grand bargain”. Jones had something Gray wanted, and Gray had something Jones wanted. Jones would give Gray copies of the 1930s PHS correspondence he had, while Gray would give him access to all the Centers for Disease Control (CDC) original files on the Tuskegee study he had obtained. Unbeknownst to Jones, Brandt also had the same PHS documents from the 1930s tracking the origins of the study, and used them for his 1978 article in the *Hastings Center Report*, including the materials from the congressional hearings just a few years prior (Brandt 1978). Brandt referenced the participation of African American professionals only in a footnote. Brandt’s paper argued that the congressional hearings focused on informed consent, which was not the main transgression of the Tuskegee study. Brandt argued that the study’s premise was grounded in racism. Jones’ book picked up where Brandt left off, and would become the definitive work on the Tuskegee study until Susan Reverby’s *Examining Tuskegee* (Reverby 2009).

Jones discovered that sorting through fact from fiction was difficult; there was a lot of “fiction” investigators added to the facts, and in some ways, the facts of the study are clearer in the fictional representation of the study in *Miss Evers’ Boys*. When Jones first begins to research the Tuskegee study, it is still a fresh wound, but since he is successful in discovering and locating the critical PHS and CDC documents that uncovered how this observational study began, morphed, and ultimately continued for 40 years, the book became the definitive account.

Jones is researching the book in the late 1970s, during a time frame when the United States was in a reactionary mode from the traumas it endured in the 1960s, and still in recovery from Vietnam and Watergate. In fact, the Congressional hearings into the Tuskegee study overlapped with the Watergate investigation. The class-action lawsuit that had been filed by attorney Fred Gray (see further), on behalf of the Tuskegee study subjects, was still being negotiated when Jones began his research, but because of the PHS files Jones made available, Gray successfully negotiated a settlement in 1974 (see further).

Jones’ groundbreaking book, *Bad Blood: The Tuskegee Syphilis Experiment* is released in June 1981; it coincides with the June 5, 1981 article in *Morbidity and Mortality Weekly Report MMWR*, entitled “Pneumocystis pneumonia” (CDC 1981), the very first published medical article about HIV/AIDS. Meanwhile, the first review of *Bad Blood* appears in the *New York Times* on June 21, 1981, which opens with this text (Geiger 1981):

“Bad Blood” is the anatomy of a long nightmare—a particularly American episode in the treatment of black people. Some of the sentiments that inspired this horror, which ended a mere nine years ago, have an awful familiarity, and “Bad Blood” is as contemporary in its implications as yesterday’s Medicaid rollbacks, today’s food stamp cuts or tomorrow’s definitions of the truly needy. “Bad Blood” is more than mere history: As an authentic, exquisitely detailed case study of the consequences of race in American life, it should be read by everyone who worries about the racial meanings of governmental policy and social practice in the United States.
The New York Times review was written in the context of worrisome budget cuts announced by the new Reagan Administration, which would dramatically impact the CDC’s response to AIDS (see Chap. 2). As Jones’ book makes its way into a diverse and multidisciplinary readership, the AIDS epidemic really starts to bloom, and the African American community’s response and engagement with this new deadly sexually transmitted virus is met with suspicion and resistance. Thus, the “legacy of Tuskegee” as it became labelled in the next century (Katz 2008) has been identified as a major cause of early resistance to AIDS education and research in the African American community because its members did not trust that they were being told the truth about AIDS. In 1993, Jones released an expanded edition of his book, with a new chapter on AIDS. Jones states in the preface to his 1993 expanded edition of Bad Blood the following: (Jones 1993: x):

I have traced the Tuskegee Study’s legacy in the age of AIDS. Briefly, I have shown why many blacks believe that AIDS is a form of racial genocide employed by whites to exterminate blacks, and I have examined how the Tuskegee Study has been used by blacks to support their conspiracy theory…I hope this new edition of Bad Blood will find its way into the hands of new readers who want to learn more about this peculiarly American tragedy, for the AIDS epidemic has added both a new chapter and a new urgency to the story. Today, as before, the Tuskegee Study has much to teach us about racism in the United States and the social warrant of medicine in people’s lives.

When AIDS emerged in the African American community in the 1980s and 1990s based on the U.S. government’s delayed actions to screen risk groups or protect the public blood supply (see Chap. 2), it was eventually understood to be a blood borne virus (truly “bad blood”). There were indeed uncomfortable echoes of the syphilis epidemic. But the legacy of the Tuskegee study made containment through research and education about HIV especially challenging in the African American community (see further under Healthcare Ethics Issues). HIV/AIDS was one reason why Jones’ book on the Tuskegee study’s story resonated in the 1980s and Feldshuh’s play resonated in the early 1990s. In between these works on the Tuskegee study, a major bombshell book about AIDS would hit bookstores in 1987: And the Band Played On (see Chap. 2). In many ways, the story of AIDS was “déjà vu all over again.” I discuss this work thoroughly in Chap. 2.

The Feldshuh Play (1972–1992)

Dr. David Feldshuh was born in 1944, and is the older brother of actress Tovah Feldshuh. David Feldshuh came of age during the 1960s, and initially studied drama and acting before entering medical school. He did his initial actor training at the London Academy of Music and Dramatic Art; he then joined the Guthrie Theatre, located in Minneapolis, Minnesota as an actor, then as an Associate Director. He was at the Guthrie theater for seven years, and then completed two terminal degrees: a Ph.D. in theatre, and then an M.D., followed by a residency in emergency medicine,
which he still practices (Cornell University 2018). Feldshuh was 28 when three major news stories broke: June 17, 1972 was the first Washington Post story about Watergate, which would soon take the country by storm. The next month, on July 25, 1972, the Associated Press broke the first story about the Tuskegee study. Two months later, on September 5, 1972, 11 Israeli athletes at the 1972 Munich Olympics were attacked and later killed by a terrorist group known as Black September. It was the Munich story that most affected Feldshuh, who began to question whether medicine was a calling he should pursue at that time, in an effort to want to “do something more with his life”. In fact, it was not until he read Bad Blood when he was doing his Emergency Medicine residency, that he began to think about the Tuskegee study. When Feldshuh saw the wall to wall news coverage of the Munich Massacre, “it made me wonder ‘What am I doing here,’ and I realized there were questions I wasn’t really asking myself. I was relatively successful at a young age, so I knew the ‘dis-ease’ wasn’t related to a lack of achievement in my career. I had to look elsewhere; I had to look within myself” (Isenberg 1990). Feldshuh next studied consciousness-raising techniques, such as Zen, Gestalt therapy and bioenergetics, and completed his Ph.D. in theater arts in 1975 with a doctoral dissertation entitled “Seven Consciousness Expanding Techniques and Their Relevance to Creativity in Actor Training,” (Isenberg 1990). He next started medical school in 1976. Feldshuh was attracted to Emergency medicine because he was interested in something “more hands on and more concrete,” (Isenberg 1990). He continued to support himself with acting and directing while training as an ER doctor. In fact, he saw parallels in the two careers: “In both cases, you are called upon to make decisions, frequently rapid decisions. . . . If you’re not willing to make a decision and take responsibility for decisions, you shouldn’t be directing and you shouldn’t be doing emergency medicine. Neither are environments conducive to serene cogitation” (Isenberg 1990).

Feldshuh’s introduction to the Tuskegee study was in 1981, when he first read a review of Jones’ Bad Blood in a medical journal—it was likely the review that appeared in the December 4, 1981 issue of the Journal of the American Medical Association, or JAMA (Meyer 1981). “After he read it, he couldn’t stop—he read medical reports and Congressional testimony and, as the years went by, did personal interviews as well” (Isenberg 1990). He began working on the play at that time, and completed a rough draft of “Miss Evers’ Boys” by 1984, when he accepted an offer at Cornell University to become its Artistic Director for its Center for Theatre Arts. He continued to work on the play throughout the 1980s during his summers. “Miss Evers’ Boys” went through 27 drafts, and a number of workshops and readings until it more formally debuted on the stage. It premiered November 17, 1989, at Center Stage, in Baltimore, and then began touring extensively in 1990. At the Baltimore premiere, during a scene depicting a lumbar puncture, one of the audience members fainted, and Feldshuh attended to the audience member as a physician. He stated: “It was an interesting kind of nexus of my life as a playwriting physician…I’m there as a playwright, looking at the play to see if it works. And I find myself practicing medicine. Does this mean it works? Or that it works too well?” (Isenberg 1990).

Regarding his motivation for writing “Miss Evers’ Boys”, Feldshuh stated this (Isenberg 1990):
I was drawn to this subject because I recognized feelings in myself that concerned me…I asked myself a simple question: ‘Would I have done what these physicians did had I been there?’ I don’t know, but I think I was fearful enough that I wanted to find out exactly how it was they let themselves do it. I wanted to explore the process through which they allowed themselves to participate in something that was clearly in retrospect wrong.

Feldshuh continued to revise and rework “Miss Evers’ Boys” throughout its touring, which took place at the beginning of the first Bush Administration, a period in which the Cold War was ending, the Berlin Wall was finally torn down, a new international order was reshaping; and the National Commission on AIDS met for the first time. The year 1989 was a good time to revisit “old wounds” and the right time for staging a play about the Tuskegee study. In essence, the play was a continual work-in-progress. The play was performed frequently to good reviews, and discussion of developing it into a film began as early as 1990 (Isenberg 1990), after it debuted at the major Los Angeles theatre, the Mark Taper Forum, July 8, 1990. With respect to interest in developing it as a film, the Mark Taper Forum producer stated to the Los Angeles Times: “There was some early interest around the time of the Baltimore production… We thought it was better to finish the journey of the play as a play. I’m sure that there will be some increased interest once the show is seen here (but) one tends to want to hold off” (Isenberg 1990). Reviews of the play as a fictionalized representation were positive. A July 20, 1990 review (Drake 1990) noted:

Playwright Feldshuh, a theater man and medical doctor, has fictionalized [the Tuskegee study] but not the circumstances. He has reduced the 400 [men] to an emblematic four and the doctors involved down to two: a white Dr. John Douglas (Charles Lanyer) and a black Dr. Eugene Brodus (Bennet Guillory). The nurse who cares for these men is Eunice Evers (Starletta DuPois), a character modeled after real-life nurse Eunice Rivers, a black woman who participated in the study, though herself somewhat ambiguously misled into believing in its moral propriety.

The New York Times review of the play made the context of the play’s debut during the height of AIDS clear: “In these days of AIDS, it’s valuable to illuminate [the view that humans are subjects], particularly as it’s applied to people whose lives, in an unspoken but implicit social contract, are deemed dispensable” (Winer 1989).

The Los Angeles production had cast Starletta DuPois as Rivers, who had studied nursing at the Harlem Hospital School of Nursing before going into acting and read Jones’ Bad Blood. Feldshuh took the opportunity with Dupois to expand the character and role of Rivers because of the actress’ passion and intense interest in the character (Isenberg 1990). Feldshuh stated at the time that he wanted to focus on the presumed moral distress of Rivers, or “doubts she might have had but was unable to express…Here is a woman who exists as a black in a white world, female in a male world, nurse in a doctor’s world. She loves her patients and has at the same time great allegiance to her profession. Now what is she going to do when the profession demands that she treat her patients from a distance and not up close? A doctor tells her, ‘You’ve got to step back and look from a distance,’ and she says ‘I can’t.’ (Isenberg 1990). Feldshuh describes his creation of Miss Evers as a character who “seems to be making the right decisions at each point but the overall journey
Origins of *Miss Evers’ Boys*

is clearly down the wrong road. She is trapped in a vortex of small decisions, and it ultimately not only pulls her down but finally pulls her apart. It separates her from herself” (Isenberg 1990). Regarding the treatment of syphilis by the Tuskegee study healthcare providers, Feldshuh notes that syphilis “was also called ‘the great imitator’ because of how diversely it presented itself. Syphilis could have no effects, a mild or a devastating effect. It was a complex, subtle disease and that made moral thinking about it also complex and subtle. You could point to somebody and say ‘It’s not so bad. We’re not treating him and he’s fine’” (Isenberg 1990).

The Feldshuh play was nominated and was a finalist for the Pulitzer Prize in 1992, and it inspired several scholarly and artistic projects about the Tuskegee study, including a 1993 documentary he co-produced entitled *Susceptible to Kindness* (Cornell University 1993), which included a Study Guide developed by an African American bioethicist and legal scholar, Larry Palmer. *Susceptible to Kindness* included original interviews with survivors, and filmed scenes from the August 22–31 1991 production of “Miss Evers’ Boys” performed at the Illusion Theater, at Cornell University’s Center for the Theatre Arts. This documentary won the International Health and Medical Film Festival award in 1994. Feldshuh also later received a distinguished service award from the National Center for Bioethics at Tuskegee University.

On the 20th anniversary of the closing of the Tuskegee study, Feldshuh’s play was well-known, and began to inspire mainstream news documentaries. In 1992, ABC’s *Primetime Live* news magazine did a segment about the Tuskegee study, interviewing one of the surviving physician investigators, Sidney Olansky (see further) as well as a surviving subject, Charles Pollard. Olansky came off as unapologetic (Reverby 2009), and makes a case for why “Miss Evers’ Boys” was best as a fictionalized account. Feldshuh’s play no doubt inspired PBS’ *NOVA* series to produce its own documentary on the Tuskegee study, which aired in 1993, titled *Deadly Deception*. The public’s renewed focus on the Tuskegee study in this time frame also helped to derail the 1995 Senate confirmation of African American physician, Henry W. Foster Jr., (Lewis 1995; Reverby 2009) to the position of Surgeon General because he worked at the Tuskegee Institute in the final years of the study; there was an accusation that he knew of the study’s existence and may have been complicit with it, or did not speak out.

**The Play’s Staging and Stages**

Feldshuh’s play has been praised for its organization and staging details, which makes it an easy play to produce. Aside from Miss Evers, four study subjects (one character to symbolize each of the 100 men in the study to represent the oft-quoted 400); one white U.S. Public Health Service physician as a composite character for several through the years, and one African American physician who oversees the healthcare delivery for the study subjects at the Tuskegee hospital, as the composite for Dr. Eugene Dibble, Medical Director of the teaching hospital at The Tuskegee Institute (see further). The play is set in the Possom Hollow Schoolhouse, juxtaposed
with “testimony areas” in which a 1972 Senate subcommittee investigation is taking place, with a composite character probably for Senator Ted Kennedy. (In reality, the Kennedy hearings, discussed further, occurred in 1973). Nurse Evers is pulled in and out of action to give her testimony to the audience. (Theatrically, some of this technique echoes the interesting staging of Arthur Miller’s “Death of a Salesman” in which Willie Loman is in and out of different realities and contexts.). Act One takes place in 1932, where we meet the four study subjects who enroll and are initially treated with mercury and arsenic until funding runs out, and the study rationale for observation without treatment is dramatized. Act Two, takes place in 1946, when penicillin is debated as a treatment but not offered. There is an Epilogue in which Miss Evers raises questions about what has occurred. One of the most central criticisms of “Miss Evers’ Boys” is the fact that it is has “factual errors” due to its fictionalized characters. Fred Gray, the attorney for the Tuskegee study subjects and families, for example, who spoke out against the film version (see below), did not like how the study subjects were portrayed. The surviving study subjects had all seen the play (they were filmed seeing it in the PBS documentary), and while pointing out differences in their experiences in private (Reverby 2009), they did not disapprove of the play and saw its merit. Gray did not like that the characters were part of a local dance/entertainment troupe in the play, when this was not reality. (Portrayal of African Americans as performers is frequently considered stereotyped representations.) Feldshuh stated that he created the dancer characters so that he could, as a playwright, visually show the effects of an “invisible” disease (syphilis); when one of the characters begins to have difficulty dancing in the play after a long latency period, it is a sign that tertiary stage syphilis has begun, and is affecting him.

Again, it is imperative that any teaching of Miss Evers’ Boys emphasize that it is a work of fiction based on a real study, but that its characters are fictionalized. This is not unlike the fictional representations of a study in the film, Awakenings, for example, in which “Dr. Sayers” is a fictionalized Oliver Sacks (See Clinical Ethics on Film, Chap. 10). It’s important to emphasize that there is a difference between reality and art. A critical factor in Feldshuh’s work is its historical timing. When Feldshuh was creating this work, it was still not distant enough to “name names”; artistic interpretations of the truth are sometimes the best way to tell the story when wounds are too fresh, and historical figures or their immediate descendants or family members are still alive. This was evident by some of the damning interviews with the still-living physicians in both the PBS and ABC documentaries. For example, at one of the play’s performances, a white woman confronted Feldshuh and stated: “How dare you portray white doctors like this?” (Reverby 2009). Several directors were confronted by angry African American patrons or actors demanding that the play should show how the government “gave syphilis” to the study subjects, when this was not the case at all (Reverby 2009). On the flip side, one of Tuskegee’s mayors in the 1990s “stated that staging the play in the city ‘helped to absolve a sense of shame’ and he made sure that survivors came to see the production” (Reverby 2009). Indeed, a fictionalized representation of the Tuskegee study was the most prudent pathway to show it throughout the 1990s.
The Color Purple Problem

There is an “elephant-in-the-room” issue with “Miss Evers’ Boys” as a play and then film (see further), which I call The Color Purple Problem. “Miss Evers’ Boys” was not created by an African American writer, and so its “truths through fiction” genre was not as readily accepted as other works of fiction inspired by socio-political truths, such as Alice Walker’s The Color Purple, which was published in 1982, and won the 1983 Pulitzer Prize for fiction for which Walker was the first African American woman to win. (Her book was indeed controversial for its portrayal of African American males.) But then her novel was made into a film by Steven Spielberg in 1985, which also launched the careers of major African American stars, Whoopi Goldberg, Oprah Winfrey, and Danny Glover. Spielberg’s film was nominated for 11 academy awards but won nothing due to an interesting controversy over race—his. There was a perception that a white Jewish man should not have been allowed to take ownership of any part of this story—that it belonged to the African American community. In many ways, the film, The Color Purple mirrored the critiques that befell the film, Miss Evers’ Boys (see further). There was a perception with this work, too, that remains: white Jewish, privileged males have no business telling stories about the African American experience and therefore, any putative “truths” about the African American experience should not be trusted or valued from this “whitewashed” messenger. Walker, in fact, was involved in the film adaption, and her friend, Quincy Jones, recommended she choose Spielberg as the director for her book’s film, but she regretted the choice, and hated Spielberg’s filmed adaptation of her book. Her screenplay was edited/rewritten by a white Danish male writer (Holt 1996), who she felt changed the story and its truths. She made her critique very public around a decade later—just as “Miss Evers’ Boys” was being made into a film (see further), too. According to Walker, “Steven’s version of ‘The Color Purple’ would not deserve the name. And so I created an alternative title for his film” (Holt 1996). Remarkably, Walker was so profoundly disturbed that Spielberg made his film, she wrote another book, The Same River Twice (1996), entirely about her difficult experience with the film’s making, as it brought so much focus to her novel and to her. The Same River Twice was published during principal production for Miss Evers’ Boys, and shines a light on the problematic relationship between Hollywood and the African American experience.

Miss Evers’ Boys: The HBO Film (1996–1997)

The play “Miss Evers’ Boys” was adapted into a film by HBO, which was the first pay television network to make quality films using the same production standards as feature films. By 1997, HBO had already aired several quality films, including And the Band Played On (1993).
The Home Box Office (HBO) network debuted the same year the Tuskegee study was exposed in the press: 1972. At the time, it was just in a very small market of Allentown, PA., and not many Americans knew of its existence. HBO started to expand through the 1970s into the Manhattan market; designed as a subscription cable channel, it was primarily known for showing feature films and sports events, and first adopted a 24/7 schedule by December 1981. It began to produce its own feature films in 1983, and by the 1990s had completely transformed “made for television” films into high quality films that were comparable to feature films.

The most important fact to get across about the film, Miss Evers’ Boys, is that it is not an original screenplay about the Tuskegee study, but adapted from Feldshuh’s play. Thus, it is the same fictionalized representation of the Tuskegee study as the play, never intended to be a docudrama or documentary about the study. Many academic scholars miss this, and then criticized the film for being “not accurate”. Harriet Washington, in her book, Medical Apartheid, merely refers to it briefly as “HBO’s irresponsible film” (Washington 2007). Thus, those new to the film must understand that it was adapted from a long-running, Pulitzer prize-nominated play intended to dramatize the “moral truths” about the Tuskegee study through mostly composite characters, and addressed questions about the study no scholar had actually yet uncovered: what were the African American healthcare providers thinking? We must also remember that “Miss Evers’ Boys” debuted on-stage as another government deception had started to become a public health scandal surrounding knowingly exposing the general public to HIV through the blood supply (see Chap. 2). When the HBO film was released to a new generation of audiences through film, it was often treated as an original work and its stage origins were often forgotten. For example, the New York Times review of the film mentioned it was based on the fictional play but then stated this (Marriott 1997):

Yet while “Miss Evers’ Boys” attempts to illuminate its story with the glare of authenticity, questions of factual fidelity always arise—as with Oliver Stone’s “Nixon,” or Ron Howard’s “Apollo 13”—when pages of history books are rewritten into pages of a director’s script. This is no less true for the cinematic retelling of the Tuskegee study, a sensitive subject that is still creating reverberations, including a willingness among some blacks to consider maladies like AIDS and crack addiction part of a genocidal conspiracy against them by whites.

The Producers

Miss Evers’ Boys was filmed in Georgia, and produced by HBO New York, in association with Anasazi Productions, a small production company launched by married actors, Ted Danson and Mary Steenburgen, who met on the film set of Pontiac Moon (1993), a box office failure, but clearly a “hit” for their personal lives. When they met professionally, Danson and Steenburgen had both recently ended long marriages, fell in love and married in 1995; they are still married. At the time, Danson was most known for his role on the long-running television sitcom, Cheers, and Steenburgen had a prolific film career, starring in high profile films such as Philadelphia (1993), discussed in Chap. 2. Steenbergen was also the narrator in The Long Walk Home (1990), in which Whoopi Goldberg plays an African American maid who is
actively boycotting public transit in the famous 1955 Montgomery Bus Boycott—a case initiated by Rosa Parks who was represented by attorney Fred Gray. Danson and Steenburgen each had interesting personal relationships prior to the making of *Miss Evers’ Boys* that are relevant. Danson, who had been very active politically surrounding social and environmental justice issues, had a highly public romance prior to Steenburgen with Whoopi Goldberg in 1992–1993. As a high profile mixed race couple, they each became flashpoints for the changing attitudes surrounding race in the United States, which had reached a boiling point in Los Angeles then due to the Rodney King beating, a precursor to the 1992 L.A. riots. However, in one terrible decision the power couple made, Danson appeared at a 1993 Friar’s Club Roast for Goldberg in “blackface” and ate a watermelon. Roger Ebert opined at the time: “[The audience] cringed in disbelief during the opening monologue by … Ted Danson who appeared in blackface and used the [N-word] more than a dozen times during a series of jokes that drew smaller and smaller laughs, until finally the audience was groaning.” (Conner 2019). Goldberg tried to defend it as a piece of social commentary through satire and performance art: “Let’s get these words all out in the open. It took a whole lot of courage to come out in blackface in front of 3000 people. I don’t care if you didn’t like it. I did.” (Conner 2019). Several African American artists and politicians were deeply offended and Danson and Goldberg ultimately issued a public apology (Levitt 1993), and then ended their relationship in November 1993. (Goldberg went on to solo-host the 1994 Academy Awards, being the first African American woman to do so).

Meanwhile, Steenburgen, born in Arkansas, Bill Clinton’s home state, had a close personal friendship with Hillary Clinton, who was then the First Lady of the United States. Steenburgen met the Clintons in Little Rock when her father, a retired railroad worker had gone to hear Bill Clinton speak when he was a local politician. Clinton mentioned her in his speech as an example of local talent. Steenburgen recalled in an interview: “[Bill] goes, ‘And there’s a young woman in our community and she’s become an actor and it just shows you the kind of talent that’s out in Little Rock and North Little Rock and out in Arkansas…And my dad said [when he went up to him Bill Clinton after the speech], ‘Well, I’m Maurice Steenburgen and if you’re gonna talk about my daughter that way, I think you oughta meet her…’And so my so-called Hollywood connection with Bill and Hillary Clinton came through my freight train conductor dad. And so we’ve been friends ever since.” Steenburgen had noted that Hillary helped to inspire her to become politically active. (Gebreyes 2016). In this time frame, Danson’s fresh wound with racial politics from his Goldberg relationship, and Steenburgen’s involvement with the President and First Lady—at a time surrounding the first Presidential Apology for the Tuskegee study, undoubtedly made the *Miss Evers’ Boys* film project meaningful for them personally and politically.

The President of Anasazi Productions, one of Danson’s previous drama teachers, Robert Bendetti, was billed as the Executive Producer of *Miss Evers’ Boys*, and had a very similar acting and drama career as Feldshuh himself. Bendetti also authored several books on acting and drama. The writer hired to adapt the Feldshuh play to a screenplay was Walter Bernstein, who had been blacklisted during the McCarthy era, and who had written the screenplay for *The Front* (1976) about the blacklist.
Bernstein created some departures from the play: mainly, the romance between Miss Evers’ and the character, Caleb is more of an emphasis, while a scene where the nurse accompanies the men to one of their local performances shows her dancing in a provocative manner, something Fred Gray and some Tuskegee study survivors found disrespectful and insulting to her memory when the film debuted (Reverby 2009).

Joseph Sargent (see further), a veteran of made for television films on other networks, was selected as director. The film was adapted with the understanding that Feldshuh’s play was a fictionalized representation, but still very sensitive, potentially explosive subject matter. HBO, which had already produced a “whistleblowing” film about a public health disaster—And the Band Played On (1993)—was a natural host for Miss Evers’ Boys. Benedetti recognized that this material was not particularly well-suited for commercial network television, and stated (King 1997):

Once in a while the networks will do as a special event something worthwhile, but generally if I get a piece of material like this as producer, I immediately think cable… I was very happy to say that [HBO] was insistent that we not reduce the moral ambivalence [of the play]….The lead characters are somewhat ambivalent….You don’t know whether what they have done is right or not. Usually for television, you like to have fairly simple moral issues. You like to have good guys and bad guys. This is a situation where there were no good guys and no bad guys. The real villain is institutionalized racism, rather than any particular person… [And] I think the movie is fundamentally accurate. There are certainly no misrepresentations in it (Marriott 1997).

Laurence Fishburne, who plays Caleb Humphries in the film, was also Executive Producer. Miss Evers’ Boys was the second HBO film Fishburne had done in which the word “Tuskegee” figured prominently, as he had starred in The Tuskegee Airmen (1995), based on the first African-American combat pilots’ unit in the United States Army Air Corps. In fact, these pilots had trained in Moton Field in Tuskegee Alabama—so named after the very Robert Moton who was the second president of the Tuskegee Institute, and been involved with the Tuskegee study in its early years. Fishburne, by 1997, brought enormous star power to the film. He had attended the High School of the Performing Arts, and was only 14 when cast in Francis Ford Coppola’s Vietnam tour-de-force, Apocalypse Now (1979); he spent both his 15th and 16th birthdays making that film. “[One interviewer] quoted Fishburne as saying that shooting Apocalypse was ‘the most formative event’ of his life. He had a chance to observe several luminaries of American film acting—Marlon Brando, Robert Duvall, Martin Sheen, and others—and to consult them for advice. Coppola taught Fishburne that acting ‘could be taken seriously, as art, with potential for educating, entertaining and touching people.’” (Encyclopedia.com 2018). In 1983, Fishburne played a part in the PBS drama For Us the Living, based on the story of civil rights figure, Medgar Evers. Fishburne stated that “this is a gig where I had to put myself up and pay my own transportation, but to be involved with Roscoe Lee Browne, Howard Rollins, Dick Anthony Williams, Irene Cara. Well, that was my ancestors saying to me, ‘OK, here’s some work we can do (Encyclopedia.com 2018)”.

He also had a minor role in The Color Purple, discussed earlier. As an adult, Fishburne’s major breakthrough came when he starred in a culturally ground-breaking
film, *Boyz n the Hood* (1991), which was about the toxic conditions for African Americans living in South Central Los Angeles. Fishburne played Cuba Gooding Jr.’s father, even though he was only six years his senior. Fishburne had a good understanding of the differences between film and stage; he had starred in a long-running August Wilson play, “Two Trains Running,” for which he won a 1992 Tony Award and several other awards. He also played Othello in a film version of the Shakespeare play. Fishburne was also cast as the abusive Ike Turner opposite Angela Bassett in *What’s Love Got to Do with It?* (1993). Fishburne said of *Miss Evers’ Boys*: “For a Black woman in the ’30s to be involved with this sort of government experiment and to be privy to the sort of information she knew, it would be risky for her to go out on limb and say, ‘This is wrong.’ She would have to be thinking to herself, ‘Who would believe me?… My character, Caleb, is sort of the conscience of the movie because his point of view is very clear from the beginning. He answers some of the questions Miss Evers should be answering, but can’t, or the ones that she doesn’t really want to answer” (Jet 1997).

The other producers on the project were Derek Kavanagh, who worked on *Dances with Wolves* (1990) and Kip Konwiser, who had worked on several Oliver Stone projects before *Miss Evers’ Boys*.

**Director and the Star**

Joseph Sargent had worked on a number of diverse projects. Of note, one month after the Tuskegee study was publicized and shut down in 1972, a prescient film was released that Sargent directed called, *The Man*, about the first African American president played by James Earl Jones. The premise of the film is that Jones (who plays Douglass Dilman), as the President pro tempore of the U.S. Senate, succeeds when the President and Speaker of the House are killed in a building collapse at a Summit in West Germany; but since the Vice President is suffering from a terminal condition and refuses to assume the office, Dilman is sworn in as President (Canby 1972). The new President Dilman faces many of the same things Barack Obama would confront 36 years later; in the film, he especially experiences opposition to a minority rights bill he champions. Sargent would also direct *Something the Lord Made* (2004), discussed in Chap. 9.

In interviews, Joseph Sargent said he was drawn to the project because (King 1997):

[I]t’s not just a piece about a racial decision by a white government bureaucracy. It also reveals the unwitting collaboration of several black doctors and nurses, and that’s what gives dimension to this piece. It gives it a lot more substance…Basically, everyone had good intentions. Miss Evers is making the best of a terrible situation, and the inner struggle that produces makes the thing so dramatic….

He later shared (Kagan 2004):

[Miss Evers’ Boys] tended to put me into an angry frame of mind when I took this on, and I had to get away from that. I didn’t want to be in a position of commenting, politically, on
the subject matter, because the subject matter takes care of it...Sometimes you are dealing with content that makes you so uncomfortable that you have to transcend your emotional feelings and get into a neutral position so you are able to stay objective, so you don’t tip the boat too far. And that was the case here.

Alfre Woodard, who played the starring role of Eunice Evers, had distinguished herself as a major stage and screen character actress by the mid-1990s. She did her training in drama and acting at Boston University and began her career in stage plays. In 1976 she moved to Los Angeles. She later said, “When I came to L.A. people told me there were no film roles for black actors...I’m not a fool. I know that. But I was always confident that I knew my craft.” (Dougherty 1987). Woodard first received accolades for her television roles. She won her first Emmy award in 1984 for an extraordinary performance that still resonates in the “Black Lives Matter” era: she played the mother of a young boy on *Hill Street Blues* who was accidentally shot and killed by police. She next won an Emmy for her role as a woman dying of leukemia on *L.A. Law*, and she was then cast as an obstetrician and gynecologist in 1986, in the medical drama, *St. Elsewhere*, where her love interest is played by Denzel Washington; she was nominated for more Emmy awards with those roles. When Woodard migrated to film in the 1990s, she rose to prominence in several notable performances such as Winnie Mandela in *Mandela* (1987), also an HBO production; *Grand Canyon* (1991)—one of the “toxic L.A.” genre films of the period; and *Passion Fish* (1992), a nursing ethics film where she plays a nurse in recovery from addiction caring for an alcoholic paraplegic played by Mary McDonnell (who was also in *Grand Canyon*). Woodard won an Independent Spirit Award for Best Supporting Actress award for *Passion Fish*. She later said this about the role of a nurse (Jet 1997): “Doctors come in and are basically technical with their patients, but the nurses often form relationships with them because they’re the ones who have to soothe fears. They are the ones mopping your brow when you’re feverish in the middle of the night. They are the ones helping you to bathe when your body breaks down and betrays you.” (Jet 1997).

Throughout the 1990s, Woodard’s range in roles was limitless and prolific—she played a judge; she starred in “chick flicks”; she starred in comedies; she starred in sci-fi roles. By the time she was cast as Miss Evers, she brought many dimensions to the role.

Woodard had a living memory of the Tuskegee study hearings, as she had been demonstrating against the Vietnam War at Boston University at the time (Mills 1997). She recalled: “I was sitting on the trolley tracks on Commonwealth Avenue in Boston and the president of the university unleashed busloads of cops on us and anybody else they could grab and hit. In the midst of all that, learning about the hearings, I said, ‘Of course!’ What happened in Tuskegee didn’t surprise me then, out of a fired-up youthful defiance. And it doesn’t surprise me now, out of my more informed historical perspective” (Mills 1997).

Woodard did not initially warm to the role of Miss Evers because of her distaste for playing the “mind-set of a person who could be duped this way and then, in turn, sort of carry the banner [of the study]. The reason I couldn’t not do it was, I was going to be playing this person opposite Laurence, and you can’t walk away from a
character who is so complex. The exercise is to stay out of the way and don’t bring your opinions into it and really find out what this person was thinking.” (King 1997).

With respect to her thoughts on the character and the real Nurse Rivers, she stated the following (Mills 1997; King 1997):

Miss Evers was smart. She was educated. How could she have gone along with it?” …I understand that she was between a rock and a hard place, and I understand that she was told that the study was good for humanity, but I draw the line at people’s lives. I’m a hard-liner that way. Yes, I blame her. I’d never care to spend even tea-time with her….I do remember the hearings…I do believe [Rivers] was a small cog in a big rolling machine…Miss Evers wasn’t the culprit. She wasn’t the instigator or the sustainer of the injustice. But she was part of it, and everyone has to have responsibility for their part in a derailment. Even if her intentions were good and even if she did a lot of good, she kept a lot more good from being done….When things get out of control, as the Public Health Service did with this, people have a way of putting on blinders. And that doesn’t surprise me. No, as a person of African descent, as an American with Native American bloodlines, that doesn’t surprise me.

Although in the play/film, Feldshuh demonstrates that Miss Evers has moral distress over her role, Woodard never believed that, and stated, that she did not think Nurse Rivers felt guilty at all (King):

I think that’s why she was able to do it all of those years….[To her] these field hands, who have never been given the time of day, even by black people around them, that were a class above them, these guys were getting vitamins and tonics and things that even black people with jobs didn’t get. They were getting this specialized attention. She’s a smart woman and she had to have a smart logical reason [to do what she did].

In fact, when transcripts of actual interviews with Rivers were finally published, that is exactly what she said (see further under Social Location).

**Reception and Criticism**

*Miss Evers’ Boys* “color purple problem” (see earlier) was more pronounced with the film than the play, but the film project was championed by all of the African American artists involved—particularly since Fishburne had been one of the Executive Producers. For example, Obba Babatunde, who played Willie Johnson, stated: “After reading the script and then hearing about the actual case, I chased this project…I wanted to be one of the people to help to tell the story and, in a sense, pay homage to the men who sacrificed their lives. I believe the time is long overdue for this part of history to be told,” (Jet 1997).

Notes Reverby (2009):

Before the federal apology in 1997, the play/film appears to have functioned both to put the Study into wider cultural circulation and to provide a form of healing…Feldshuh’s focus on the nurse pushes viewers into what Holocaust survivor/essayist Primo Levi calls the ‘grey zone.’ With a focus on those caught in the middle, ‘grey zones’ provide seemingly more dramatic tensions [and for the viewer] ‘to reflect on the larger question of moral culpability and engage in an exercise of historical empathy.’
Two months after the film aired on HBO, the attorney representing the men, Fred Gray, called a press conference to correct inaccuracies in the film—again, not fully appreciating that the film was based on the play, *a work of fiction*. Gray took particular offense to scenes depicting Miss Evers as more seductive and dancing with the men. However, Nurse Rivers in interviews had actually discussed that she had enjoyed banter with the men, and had occasionally joined in on risqué jokes with them, and when she drove them around. She said: “So when the want to talk and get in the ditch, they’d tell me, ‘Nurse Rivers, we’re all men today!…Oh we had a good time. We had a good time. Really and truly’” (Reverby 2009).

Gray stated in his press conference: “Miss Rivers was always professional and courteous to them. She did not accompany them to nightclubs. They did not dance, play music and entertain people…The entire depiction of them as dancers is a great misrepresentation” (Gray 1998).

After the official Presidential Apology in May 1997 (see further), things got worse in 1999, when a panel discussion at a bioethics conference at the Tuskegee University featured David Feldshuh and Fred Gray. They got into a defensive exchange with Gray criticizing Feldshuh’s play/film, Feldshuh defending it as an artist, and Gray making clear that it had misrepresented the true experiences of the study subjects and what occurred.

For these reasons, when screening or assigning *Miss Evers’ Boys* as part of a healthcare ethics/public health ethics curriculum, it’s important that it be accompanied by other readings and/or lectures on the facts of the Tuskegee study, covering the content I suggest in the History of Medicine section.

**Synopsis**

*Miss Evers’ Boys* is based on The Tuskegee study, and tracks it from its origins of initially offering a treatment protocol to continuing the study as an observation-only trial of untreated late syphilis when funding for treatment dries up. The story is told from the point of view of Nurse Evers (Alfre Woodard), a fictionalized Eunice Rivers. In fact, pictures of Eunice Rivers and Woodard’s Evers are identical. There is a composite character for the white PHS doctors, “Dr. Douglas,” played by Craig Sheffer, who initially helps to conceive and champion the observation trial (probably a composite for O.C. Wenger, active from 1932–1950, Austin V. Deibert, active 1936–40; and Sidney Olansky, active in the 1950s). A scene with an older white physician authorizing/planning the study was likely a composite for the two Venereal Disease (VD) Division Chiefs at the PHS who thought up the observation trial (Taliaferro Clark, active 1932–33 and Raymond Vondehlehr, active 1932–1940s). In reality, there were a series of PHS physicians and VD Division Chiefs who championed and continued the study through the years, but they essentially functioned as “composites” in reality, too—always approving, and never halting, the protocol.

Dr. Douglas approaches the African American physician in charge of the medical facility at The Tuskegee Institute, “Dr. Eugene Brodus” to help the PHS carry out
the study, and Brodus agrees to collaborate. Brodus is played by Joe Morton, and is a fictional character for Dr. Eugene Dibble (see further). It’s possible Feldshuh named the character “Brodus” as a nod to Dr. Broadus Butler, one of the original Tuskegee airmen, the President of Dillard University (a historically black college/university), who later chaired the ad hoc advisory panel on the Tuskegee study in 1972.

The film cuts back and forth between the story of the study and a Congressional hearing in which an older Nurse Evers is providing her testimony. (In reality, she never testified, and thus, has her say in the film.) The Senate Chairman asking questions, played by E.G. Marshall is a composite character for Senator Ted Kennedy, who held such hearings in 1973 (see further). Among the composite study characters, Caleb Humphries (Laurence Fishburne) eventually—like many men in the study—gets treatment with penicillin when he joins the army, while Willie Johnson (Obba Babatunde)—like many in the study—suffers deteriorating health through the years until he dies because he never receives penicillin. The film also covers the issue of clinical equipoise over the use of penicillin treatment for late stage syphilis, particularly in scenes where Nurse Evers and Dr. Brodus argue about whether it would be beneficial or not.

Geography and Demography Are Destiny: The Social Location of the Tuskegee Study

To really understand the origins of the Tuskegee study and its socio-political context, it’s critical to understand the demographics of the population that was studied in Macon County, Alabama—in the rural deep South in Depression America, where living conditions for African Americans at the time were “appalling” (Jones 1993).

The political conditions of apartheid and segregation permitted and enabled a completely racist environment in which African Americans did not have civil rights or civil liberties under the “Jim Crow” laws—state and local laws that enforced segregation in all public facilities. Jim Crow laws were enacted in the late nineteenth century and essentially remained in place until the Civil Rights Act passed July 2, 1964, a few months before Rivers retired from the study (Jones 1993; Smith 1996; Reverby 2009), both Drs. Moton and Dibble had died, and the Archives of Internal Medicine had published a paper on the 30th year of data from the Tuskegee study (Rockwell et al. 1964). “Jim Crow” was a minstrel character created by the “father of American minstrelsy,” Thomas D. Rice (1808–1860), a pre-Civil War white traveling actor, singer and dancer who was popular circa the 1830s. He would do his “Jim Crow” character in black face, and in 1828 created a catchy song called “Jump Jim Crow” after this character. This character became the worst stereotype of an African American sharecropper that defined how whites thought about African Americans; by 1838, the term “Jim Crow” became a derogatory term for African Americans. (Padgett 2018). The segregationist laws that local and state governments
began to enact became known as the “Jim Crow” laws after this well-known character—shorthand for laws in former slave states of the South that sanctioned both apartheid and racial terrorism targeting the African American population (Ferris State University 2018). Jim Crow laws were challenged, but upheld by the U. S. courts under the farce “separate but equal” (actually written as “equal but separate”) in the 1896 Plessy v. Ferguson decision. Separate but equal meant that there were inferior facilities for African Americans (or none at all), whereby almost all social goods and economic advantages—such as education, employment, housing, bank lending, voting, hiring practices, and the bare necessities for health and wellbeing (healthcare access; healthy food; or clean running water) were frequently absent, inferior, or blocked (as in voting—in which literacy tests or poll taxes kept African Americans from voting). Moreover, there were various unspoken laws that African Americans were to abide. For example, African Americans who did not “know their place” could be lynched and killed. Lynchings were not even fully acknowledged as a risk of daily African American life—especially in Alabama—until 2018, with the opening of the National Memorial for Peace and Justice in Montgomery, Alabama. The New York Times described the new museum as being “dedicated to the victims of American white supremacy. [The museum] demands a reckoning with one of the nation’s least recognized atrocities: the lynching of thousands of black people in a decades-long campaign of racist terror” (Robertson 2018).

Lying in complete juxtaposition to these terrible living conditions of the rural population, was the noted geographical location of the study hospital: the center of African American academic, intellectual and medical training—the Tuskegee Institute, founded by Booker T. Washington on July 4, 1881, as one of the first historically black colleges and universities (HBCU) and centers of higher education and learning in the South. Dr. Robert Russa Moton (1867–1940) became the next President of Tuskegee University in 1915, and was in that role until 1935, when he resigned due to his declining health. Moton was 29 years old when the Plessy v. Ferguson decision upheld segregation as the law of the land, which also led to the establishment of land grants for black colleges and universities in states where there were also land grants for white colleges and universities that restricted African Americans from attending. Moton died 14 years before the Brown v. Board of Education decision in 1954 (see further), which declared racial segregation of children in public schools was unconstitutional, and the legal doctrine of “separate but equal” as unconstitutional; he died 24 years before the Civil Rights Act was passed, ending the Jim Crow era, and 25 years before the Voting Rights Act was passed in 1965, when African Americans could finally vote in the South without being harassed or lynched. During Moton’s lifetime in the Plessy era, any study that could potentially improve anything for African Americans living under their present conditions was viewed as a “good thing”.

The Tuskegee Syphilis Study: Miss Evers’ Boys (1997)
Living Conditions in Macon County, Alabama

The 1930 Census documented that 82% of the population in Macon County, Alabama—27,000 residents—was African American. The percentage was the same in 1970 (Jones 1993) when half the residents were living below the poverty line, and a third did not have indoor plumbing. In 1930, conditions were even worse. Notes Jones (1993):

The typical dwelling was a tumble-down shack with a dirt floor, no screens, little furniture, a few rags for bedding, and a [toilet] only when underbrush was not nearby. Drinking water came from an uncovered, shallow well, often totally unprotected from direct surface drainage… the people who lived in this rural slum ate a pellagrous diet [leading to niacin deficiencies]… Salt pork, hominy grits, cornbread, and molasses formed the standard fare… while red meat, fresh vegetables and fruit, or milk seldom appeared on their tables. As a result, chronic malnutrition and a host of diet-related illnesses were serious health problems.

Clearly the health problems in this region were of particular concern. “In the early twentieth century, many rural African Americans lived in unhealthy surroundings and faced a range of health problems including malaria, typhoid fever, hookworm disease, pellagra, and venereal disease, along with malnutrition and high infant and maternal mortality rates” (Smith 1996).

Notes from Uva M. Hester, a Tuskegee Institute graduate in nursing, and the first black public health nurse in this region stated that “she was appalled by the flies, the dirt and the small rooms in the cabins she visited” (Smith 1996). Her diary noted the following from a June 1920 visit to a patient (Smith 1996):

I visited a young woman who had been bedridden with tuberculosis for more than a year. There are two openings on her chest and one in the side from which pus constantly streams. In addition, there is a bedsore on the lower part of the back as large as one’s hand. There were no sheets on her bed… The sores had only a patch of cloth plastered over them. No effort was made to protect the patient from the flies that swarmed around her.

The schools in Macon County were inferior (they did not improve after Brown v. Board of Education) and most residents were illiterate despite the proximity to the Tuskegee Institute. There was virtually no access at all to medical care, except for the Veteran’s Association hospital, which had a segregated unit of African American healthcare professionals. In 1906, the Tuskegee Institute successfully obtained funding to create The Movable School project to service the community. This comprised of traveling public health nurses and educators to teach rural residents about basic hygiene, and to also try to teach residents how to farm, so they could transition from tenants to landowners. This was a “racial uplift” project that reflected the worldview of Booker T. Washington, and ultimately became the worldview and philosophical context of most African American educators and professionals at the Tuskegee Institute founded by Washington; such professionals were known as “race men/race women” (Smith 1996; Reverby 2009). Nurse Rivers joined The Movable School project in Tuskegee in 1923, a year after she had graduated from the Tuskegee Institute School of Nursing, and traveled to rural families teaching public health
hygiene such as teeth brushing; safe birthing procedures; social hygiene; household hygiene; first aid care, etc. (Smith 1996; Reverby 2009). The Movable School project lasted until 1944, through the formative years of the Tuskegee study.

The John A. Andrew Memorial Hospital was founded on the campus of the Tuskegee Institute, and it primarily serviced the staff and students of the Tuskegee Institute. There were 16 private physicians (one who was African American) in Macon County during the 1930s who would treat African American patients for a fee; that essentially made seeing a doctor inaccessible for this population, while the sole African American physician was overwhelmed.

Remarkably, a commissioned sociological study published as a book in 1934, entitled *Shadow of the Plantation* by Charles Johnson, an African American professor of sociology and later, President of Fisk University, tracked living conditions during this time frame in Macon County. This book was based on qualitative interviews with roughly 600 families in Macon County in 1932, and was sponsored by the Rosenwald Fund (see under History of Medicine). Johnson was previously noted for his 1931 book, *The Negro in American Civilization* (Johnson 1931). As one scholar notes: *Shadow of the Plantation* “took on a racial myth, the conception of the easy-going plantation life and the happy Negro, and replaced the myth with the objective truth: Macon County was a twentieth century form of feudalism based on cotton cultivation” (Encyclopedia.com 2019). Ultimately, qualitative analysis of Johnson’s interviews at this time paints a picture of underdeveloped infrastructure, a population living in impoverished conditions with a myriad of chronic health problems; deaths from several preventable diseases for that time frame; and very poor medical literacy. Johnson conducted several interviews surrounding health and community interactions with doctors involved in treating syphilis through a Rosenwald funded study (see under History of Medicine). He observed that none of the interviewees adequately understood or were informed about what they suffered from, and what the treatments they were given were designed to do. Johnson also served as an Advisor to the Hoover and Roosevelt administrations regarding rural issues, and his grandson, Jeh Johnson, would go on to serve as Director of Homeland Security in the Obama Administration.

*The Generation Gaps: The View Between Plessy and Brown*

*Miss Evers’ Boys* squarely confronts the role that the African American healthcare providers played as either enablers, victims or champions of the Tuskegee study, creating ethically problematic assessments of their historical legacies. Hence, what must be stressed when teaching this film is that there were three distinct generations within the African American experience relevant to the Tuskegee study.

For example, there is an enormous chasm in the ethical, legal and social experiences that defined the world views of sociologist Charles Johnson, author of *Shadow of the Plantation* (Johnson 1934), who was born in the “Plessy Generation” (born
1893 and died 1956) and his grandson, Jeh Johnson, who was born in the “post-Brown Generation” in 1957—three years after the landmark Supreme court decision Brown v. Board of Education that overturned the “separate but equal” legal doctrine (see further). Essentially, the adult worlds of Charles and Jeh Johnson—grandfather and grandson—were as starkly different as being born into slavery or freedom and there was a critical generation in-between: “The Moses Generation”. The Moses Generation would become the leaders and participants of the Civil Rights movement, who would eventually define the pre- and post-Civil Rights era. The Moses Generation roughly comprised African Americans born between 1925 and 1945, who were between 20 and 40 years-old when major Civil Rights legislation was passed. For example, Malcolm X was born in 1925; Martin Luther King Jr. was born in 1929, and Jesse Jackson, a close “disciple” of King’s, was born in 1945. Those who were too young to participate in the Civil Rights movement, like Jeh Johnson and Barack Obama, were the direct beneficiaries of those struggles.

This means there are different African American generational lenses from which to judge the Tuskegee study, and the answer to how morally complicit Moton, Dibble or Rivers were in “aiding and abetting” what is now viewed as an unethical, racist protocol depends on this generational lens.

Moton, as mentioned above, was born two years after the Civil War ended, was 29 years old when Plessy v. Ferguson was decided, and died a year before the attack on Pearl Harbor. Eugene Dibble, involved in the Tuskegee study for most of its duration, was three years-old when Plessy v. Ferguson was decided, and died at age 75 on June 1, 1968—two months after Martin Luther King was assassinated, and less than a week before Robert F. Kennedy would be assassinated. That year marked one of the most demoralizing and disturbing years in twentieth century American history.

Eunice Rivers was born in 1899, three years after Plessy v. Ferguson was decided, when there was not even a theoretical constitutional right to vote because she was female. Although Rivers was 22 when the 19th Amendment was passed in 1921, it was meaningless for African American women in the South (Staples 2018).

Rivers was 33 years-old when the Tuskegee study began; she didn’t marry until 1952—when she was 53—and she retired at age 66 in 1965, when the Voting Rights Act was passed. Rivers spent most of her life living under the apartheid conditions of the Jim Crow South, but also in a pre-women’s rights era. By 1972, when the Tuskegee study was made public by the press, she was 73 years-old. Most African Americans under 65 at that time were horrified and offended by what they saw as an overt racist protocol, but perhaps not that surprised given their lived experiences. But those born in the Plessy Generation, which included Dibble and Rivers, saw things quite differently. As for the impact of the 1954 Brown decision, it would be well into the 1970s before anything changed in the deep South because there was no firm deadline for desegregation provided in the Brown decision (see further). Even the American Medical Association (AMA) would not desegregate until 1968 (see further). I discuss the professional roles of Dibble and Rivers in the Tuskegee study in the History of Medicine section further on.
Eunice Rivers—dubbed “You Nice” in Miss Evers’ Boys—was born a “Negro woman” in the Plessy era and essentially reached about the highest status possible within the racial and gender boundaries that existed for her. Rivers was encouraged by her parents to get an education to avoid working in the fields. Because of the Plessy decision, states had to comply with “separate but equal” by ensuring there were some places African Americans could go for post-secondary training because there needed to be African American professionals to take care of “their own”. Since African Americans were barred from white establishments, they could not be taught by white teachers; they could not go to white hospitals; they could not be treated by white nurses, and so forth. Thus, the Plessy system encouraged all black post-secondary institutions, and the “Black College/University” system began, which truly offered excellent post-secondary and graduate educations. Eunice Rivers thrived in that system, and graduated with her nursing degree at age 22 in 1921, just in time for the 19th Amendment that gave mostly white women the right to vote. Working in a respected profession, with a lot of autonomy and a living wage, Eunice Rivers, who remained single until her 50s and childfree (potentially recognizing how trapped women became when they had children), was living a much more productive, and financially independent life than most women were at that time, regardless of race.

Eunice Rivers was a product of the African American professional worldview known as “racial uplift” and “racial betterment”. As a proponent of this philosophy, she was known as a “race woman” (Reverby 2009; Smith 1996). This was a philosophy of “progress for the race” informed by a segregated existence, which emphasized community improvement through education, research and training. This was the “long game”—perseverance with the goal of creating a strong professional middleclass that would be able to self-govern within the confines of “separate but equal”. Terms like “credit to his/her race” were used frequently as a “compliment” in this time frame. For example, actress Hattie McDaniel, also born in the Plessy Generation in 1895, and essentially a contemporary of Rivers, was the first African American to win an Academy Award for Best Supporting Actress for her role as “Mammie” in Gone With the Wind (1939). In her acceptance speech on February 29, 1940 she stated: “I sincerely hope I shall always be a credit to my race and to the motion picture industry.” (Academy Awards 2019). We all cringe now when we see this speech, but it is an important reminder of the historical context of the Plessy era. Even in 1972, when the Tuskegee study was made public, white audiences did not view the portrayal of African Americans in Gone With the Wind (1939) as racist, and even accepted it as a reasonable portrayal of the Civil War. The next African American woman to win an Oscar after McDaniel would be Whoopi Goldberg in 1991 for Ghost (1990), just around the time she began dating Ted Danson, who produced Miss Evers’ Boys.

Rivers’ career was much more focused and successful than most women could hope for at that time. At 22, she had a job in The Moveable School Project, in which she helped hundreds of families as a public health nurse and educator, including
educating midwives and registering births and deaths for the state. She saw terrible conditions, and saw her role as truly contributing to the “racial uplift/racial betterment” movement. Cutbacks at the start of the Depression led to her being laid off, and she picked up a night supervisor position at the Tuskegee Institute hospital. She did that job for about 10 months, considered leaving to work in New York, when she was tapped to be the part-time “scientific assistant” for the 1932 Tuskegee study (Reverby 2009). (I discuss that role more under History of Medicine.) Undoubtedly, Rivers considered this role to be very worthwhile given the medical viewpoints surrounding race, medicine and syphilis at the time (see Under History of Medicine). She also stated in interviews that she was noted to be politically skilled at handling (presumably sexist and racist) “white doctors” and that O.C. Wenger could “yell all he wants. I don’t even hear him…He’ll be the one dying of high blood pressure, not me” (Reverby 2009).

When Rivers agreed to take the part-time position, it initially paid $1000 annually, plus $600 a year for gas money and transportation expenses (Jones 1993), which in 1932 was equivalent to $22,000. By 1933, the transportation stipend was reduced to $200. That was for a part-time role. She continued to work for the health department’s maternity service; worked as school nurse; and taught in the Tuskegee Institute’s School of Nursing. All of her jobs likely added up to at least the equivalent of an annual salary of $35,000 in today’s numbers. These were extraordinary earnings for a single African American woman in this time frame, when during the Depression, more than 24% of the country suffered from unemployment, with African Americans shouldering an even larger percentage of the burden. According to statistics published by the Department of Labor (Olenin and Corcoran 1942) the average white male factory worker in 1932 earned $17.86 per week at a full-time job for $857.00 annually, which was considered a living wage intended to support an entire family. In 1932, you could buy a decent house for about $500 in most areas (the very nicest homes in the country were around $4000). In Alabama specifically, “personal annual income fell from an already low $311.00 in 1929 to a $194.00 in 1935” (Downs 2015). In 1932, Nurse Rivers was very successful, exceeding the income of even most white males.

Rivers was interviewed only once by the ad hoc advisory panel in 1973 but she never gave Congressional testimony (Reverby 2009; Jones 1993; Washington 2007), which is why Feldshuh provided her with a fictionalized forum in which to “testify” to the audience. Remarks Reverby (2009): “Her only defense of her role publicly available is in three oral history interviews done in the late 1970s, and in her deposition from the class action law suit filed by Fred Gray…The real Nurse Rivers did not leave us a lot to understand if she was conflicted” (Reverby 2009). Yet I would venture to dispute this claim when teaching about Rivers. All one needs to do is look at the historical context and lived experiences in the Plessy era to understand Rivers and her peers.
African Americans in Medicine and the Tuskegee Institute 1932–1972

There was a thriving African American medical community in 1932, however it was indeed segregated, and physicians were barred from becoming members of the AMA until it desegregated in 1968. As a result of segregation, African Americans formed their own medical association known as the National Medical Association (NMA), which was instrumental in helping to get civil rights legislation enacted, and in helping to desegregate healthcare for African Americans. The NMA continues to focus on improving health disparities. Here is how the NMA describes its origins and early agenda (NMA 2018).

Under the backdrop of racial exclusivity, membership in America’s professional organizations, including the American Medical Association (AMA), was restricted to whites only. The AMA determined medical policy for the country and played an influential role in broadening the expertise of physicians. When a group of black doctors sought membership into the AMA, they were repeatedly denied admission. Subsequently, the NMA was created for black doctors and health professionals who found it necessary to establish their own medical societies and hospitals….

The discriminatory policies of the nation at the time the NMA was founded manifested countless examples of the inadequacies of a segregated health care system. A priority item on the first NMA agenda was how to eliminate disparities in health and attain professional medical care for all people.

Racism in medicine created and perpetuated poor health outcomes for black and other minority populations. In the South, hospital accommodations were frequently substandard. If blacks were admitted to general hospitals at all, they were relegated to all-black wards. In some instances, white nurses were prohibited from caring for black patients. Conditions in the North were also inequitable. It is reported that as late as 1912, only 19 of New York City’s 29 hospitals would admit black patients, and only three gave black physicians the right to tend to their patients or perform operations.

With respect to medical training for African Americans, some physicians had trained at white institutions in the North, which accepted the occasional African American applicant, but most trained at a number of black colleges and universities that grew as a result of segregation, reinforced by the Plessy decision. This is discussed more in Chap. 8.

The Tuskegee Institute and its medical training were thus anchored and established in the post-Plessy context. The Tuskegee Institute started with a nursing school and expanded to medical school training in 1902. Eugene Dibble co-authored a history of the Tuskegee Institute’s medical school training in 1961, and pointed out that the expansion of the medical school was also intended to “provide hospital facilities in which qualified Negro physicians had full privileges to treat their patients” (Dibble et al. 1961). Dibble’s article also noted:

John A. Kenney who completed his residency at Howard University, became resident physician and superintendent of the Tuskegee Hospital and Nursing school in 1902. In 1921, Dr. Kenney organized and conducted the first postgraduate course in medicine and surgery for
Negroes in the South. Dr. Eugene H. Dibble, Jr. was Dr. Kenney’s first assistant and aided in making the course a success.

Ultimately, the Tuskegee Institute and John. A. Andrew Memorial hospital developed into a robust academic medical center and teaching hospital for African American students.

Dibble received his medical degree in 1919 from Howard University Medical School, and interned at the hospital affiliated with Howard University—Freedmen’s Hospital in Washington, D.C. He then completed his surgical residency at the John A. Andrew Memorial Hospital in Tuskegee, Alabama in 1923, where he served as medical director from 1925–36. Dibble next did a stint at the Veterans Administration (VA) hospital in Tuskegee as its medical director and manager (1936–46), and then went back to serving as medical director at the John A. Andrew Memorial Hospital from 1946–1965. Dibble was essentially a continuous presence throughout most of the Tuskegee study years; he was forced to retire due to a cancer diagnosis and died three years later. Dibble also served as a member of the Board of Trustees at Meharry Medical College in Nashville, Tennessee, and was on the Editorial Board of the *Journal of the National Medical Association*—the same journal that published his 1961 article about his academic home institution (*JNMA* 1962; Reverby 2009). In that paper (Dibble et al. 1961), he even made a brief proud reference to the Tuskegee study:

Included in the long list of cooperative projects between the John A. Andrew Hospital and State and Federal health agencies is the U.S. Public Health Service study of syphilis in the Negro male in Macon County which began in the fall of 1932. The hospital cooperated in this plan to give each of 600 patients a complete physical examination, including chest x-rays.

Dibble’s specific role in the Tuskegee study is discussed further (see under History of Medicine), but it was he who convinced the President/Principal of the Tuskegee Institute, Robert Moton, one of the most respected African American university presidents, to participate in the USPHS syphilis study (Jones 1993; Reverby 2009). Moton’s role in the study was limited, and essentially amounted to approving the study and providing university resources for it. Moton retired three years after the Tuskegee study began (in 1935), but there was no reason to believe that Moton would not have felt the same way as Dibble about the research project and have a similar world view regarding racial uplift projects in a segregated society based on his own words and writings. Moton was a keynote speaker at the opening of the Lincoln Memorial on May 30, 1922, invited to “speak for his race” and also agreed to having his speech edited/censored by the organizers. Of course, given the Plessy era, he was also not allowed to sit with the other white speakers in the audience (NPS 2019; National Museum of American History 2019). On that notable day, long planned by the Lincoln Memorial Commission (chaired by former President Taft), and the American Commission of Fine Arts (whose Chair had perished on the Titanic), Abraham Lincoln’s 78 year-old son, Robert Todd Lincoln, was in the audience when Moton spoke. His speech was also broadcast on the radio (Furman 2012). As one historian observes (Fairclough 1997):
Robert Russa Moton, viewed the Lincoln Memorial as a moral symbol of the African-American fight against discrimination. He intended to deliver a passionate plea for racial justice. The speech Moton actually read out, however, contained no language of militant protest: at the insistence of the Lincoln Memorial Commission, he substituted soothing bromides reminiscent of Booker T. Washington’s Atlanta Exposition address of 1895… The affair also throws an interesting light on Moton, himself, now a largely forgotten figure, but then, by virtue of his position as president of Tuskegee Institute—Booker T. Washington’s successor—a man widely regarded by whites as the preeminent spokesman for Black America.

Moton’s uncensored speech, included the following in his closing remarks (Fairclough 1997):

[S]o long as any group does not enjoy every right and every privilege that belongs to every American citizen without regard to race, creed or color, that task for which the immortal Lincoln gave the last full measure of devotion-that task is still unfinished…More than sixty years ago [Lincoln] said in prophetic warning: ‘This nation cannot endure half slave and half free: it will become all one thing or all the other. With equal truth it can be said today: no more can the nation endure half privileged and half repressed; half educated and half uneducated; half protected and half unprotected; half prosperous and half in poverty; half in health and half in sickness; half content and half in discontent; yes, half free and half in bondage…This memorial which we erect in token of our veneration is but a hollow mockery, a symbol of hypocrisy, unless we together can make real in our national life, in every state and in every section, the things for which he died…. A government which can venture abroad to put an end to injustice and mob-violence in another country can surely find a way to put an end to these same evils within our own borders….honor. Twelve million black men and women in this country are proud of their American citizenship, but they are determined that it shall mean for them no less than any other group, the largest enjoyment of opportunity and the fullest blessings of freedom. Let us strive on to finish the work which he so nobly began, to make America the symbol for equal justice and equal opportunity for all.

And here is what Moton actually said that day (Fairclough 1997):

Here we are engaged, consciously or unconsciously, in the great problem of determining how different races cannot only live together in peace but cooperate in working out a higher and better civilization than has yet been achieved. At the extremes the white and black races face each other. Here in America these two races are charged…with the responsibility of showing to the world how individuals, as well as races, may differ most widely in color and inheritance, and at the same time make themselves helpful and even indispensable to each other’s progress and prosperity. This is especially true in the South where the black man is found in greatest numbers. And there today are found black men and white men who are working together in the spirit of Abraham Lincoln to establish in fact, what his death established in principle…. In the name of Lincoln, twelve million black Americans pledge to the nation their continued loyalty and their unreserved cooperation in every effort to realize in deeds…

Moton’s May 30, 1922 remarks about race, though cryptic and filled with subtext, essentially paraphrases the “racial uplift” philosophy that was espoused by his predecessor, Booker T. Washington, and demonstrates how he resolved to work within the Plessy system with his white peers. But it also informs how he likely saw the proposed USPHS syphilis study that Dibble brought forward for his approval a decade later. Undoubtedly, Moton, Dibble, Rivers and their peers at the Tuskegee Institute,
regarded the USPHS syphilis study as a way of “showing to the world how individuals, as well as races, may differ most widely in color and inheritance, and at the same time make themselves helpful and even indispensable to each other’s progress and prosperity” (Moton 1922; Fairclough 1997). Moton also wrote in 1929 (Moton 1929):

Here met the three elements—the North, the South, and the Negro—the three elements that must be taken into account in any genuinely satisfactory adjustment of race relations... Up to this time the Negro had usually been the problem and not regarded as an element worthy of serious consideration, so far as any first-hand contribution was concerned that he could make toward the solution of any large social question...and a cooperation vitally necessary in the promotion of any successful work for the permanent betterment of the Negro race in our country....

No greater or more serious responsibility was ever placed upon the Negro than is left us here at Tuskegee. The importance of the work and the gravity of the duty that has been assigned the principal, the officers, and the teachers in forwarding this work cannot be overestimated. But along with the responsibility and difficulties we have a rare opportunity, one almost to be envied—an opportunity to help in the solution of a great problem, the human problem of race, not merely changing the mode of life and the ideals of a race but of almost equal importance, changing the ideas of other races regarding that race.

Ultimately, Moton’s many works (Moton 1913; Moton 1916; Moton 1920; Moton 1922; Moton 1929) reveal his perspective as a proponent of the racial uplift philosophy.

Dibble as a “Race Man”

As discussed in earlier sections, Dibble’s world view regarding race, like Moton’s and Rivers’, was situated in “racial uplift/racial betterment” framework in a segregated society he thought would never change. Dibble was motivated to participate in research endeavors that would provide scientific stature to his institution, his peers and mentees. In his correspondence surrounding the Tuskegee study, he echoed Moton above and saw it as an “opportunity” to bring focus and attention to African American health needs in a time when the population was completely ignored (Reverby 2009; Jones 1993). In some ways, the African American medical community at that time mirrored the professionalization goals of their Jewish peers; Jewish physicians, too, needed to establish exclusively Jewish hospitals so they could train their own doctors, as there were severe quota restrictions in traditional academic medical centers discussed more in Chap. 9.

Dibble’s aim to bring his institution into national focus with important research was best exemplified by the Tuskegee Institute’s HeLa cell research in the 1950s. In 1951, an African American patient, Henrietta Lacks, was treated at Johns Hopkins University hospital for ovarian cancer, and died. Her tumor cells were propagated in a laboratory by George Gey, and became the first immortal cell line, known as HeLa cells. The Tuskegee Institute would become well-known the following year for its research with that cell line. In 1952–3, “a staff of six black scientists and technicians
built a factory at Tuskegee unlike any seen before.” HeLa cells were “squirted” into one test tube after another, and “the Tuskegee team mixed thousands of liters of [George Gey’s] culture medium each week, using slats minerals, and serum they collected from the many students, soldiers, and cotton farmers who responded to ads in the local paper seeking blood in exchange for money” (Skloot 2010). The science journalist, Rebecca Skloot, author of The Immortal Life of Henrietta Lacks, noted this:

Eventually the Tuskegee staff grew to thirty-five scientists and technicians, who produced twenty thousand tubes of HeLa—about 6 trillion cells—every week. It was the first-ever cell production factory and it started with a single vial of HeLa that Gey had sent [to a researcher] in their first shipping experiment, not long after Henrietta’s death. With those cells, scientists helped prove the Salk vaccine effective. Soon the New York Times would run pictures of black women hunched over microscopes examining cells, black hands holding vials of HeLa and this headline: ‘Unit at Tuskegee helps Polio fight. Corps of Negro Scientists has key role in evaluating of Dr. Salk’s vaccine.’ Black scientists and technicians, many of them women, used cells from a black woman to help save the lives of millions of Americans, most of them white. And they did so on the same campus—and at the very same time—that state officials were conducting the infamous Tuskegee syphilis studies. (Skloot 2010: 96–97).

In 1964, while the Tuskegee study was in its last stages, an egregious trial at a Jewish hospital in Brooklyn would be “outed” that involved injecting live HeLa cancer cells into unsuspecting elderly patients (Beecher 1966; AHRP 2014). It’s important to note that the Tuskegee study had plenty of company in research ethics infamy (see further under Healthcare Ethics Issues), partially due to a vacuum of research ethics awareness, training, and appreciation of vulnerable populations.

The Impact of Brown v. Board of Education

“Inferior school facilities for children and widespread illiteracy went hand in hand with poverty in Macon County, despite the presence of the Tuskegee Institute. Year in and year out Alabama ranked at or near the bottom nationally in the amount of money spent per pupil on education, and Macon County was not a leader in black education within the state” (Jones 1993). In 1932, 23 out of 1000 whites were illiterate in Macon County; in the African American population 227 out of 1000 were illiterate (Jones 1993). See Chap. 9 for more on this.

As a result of the Brown decision, states were required to dismantle dual systems of higher education, and white institutions were ordered to accept African American students and desegregate. However, in the South, desegregation was very slow due to specific wording in the Brown decision that was seen as a loophole for delaying desegregation: “with all deliberate speed” (Harvey et al. 2004; Brown v. Board of Education 1954). The effect of the Brown decision on higher education and black colleges and universities such as the Tuskegee Institute was a slow erosion of resources that one can see in Dibble’s 1961 paper on the goals for his medical institute, which had conducted a needs assessment published in the aftermath of Brown, which he called the “Tuskegee Institute Study” (having nothing to do with the syphilis study). He
wrote (bolded emphasis mine) the following as a request for funding which clearly demonstrates Dibble’s desire to be recognized as a leading academic medical center (Dibble 1961):

As part of the comprehensive Tuskegee Institute Study, a committee representing the medical and administrative staff of John A. Andrew Hospital has compiled, studied and analyzed data involving the hospital’s operation over the past 15 years. Some of the country’s leading hospital and medical consultants and other qualified individuals in the health field who are familiar with John A. Andrew’s program agree with this committee’s report that more adequate physical facilities and equipment are needed to provide up-to-date methods of treatment and for continued high quality medical care...

[Our goals for the future are]: To engage in research; to provide post-graduate training for physicians…to train nurses; to train doctors… [to serve our] medically indigent pregnant women and new mothers in the hospital…[and to] provide facilities, and personnel dedicated to the treatment of many medically indigent people in this area…To study, in cooperation with County, State, and Federal health agencies and other health organizations, the incidence of disease and high morbidity and mortality rates in this area…To organize clinics in rural areas to demonstrate what can be done in cooperation with existing public health agencies…

Years after the Brown decision, black colleges/universities were still segregated but suffered budget cuts, lack of adequate libraries, research equipment, and so forth (Coaxum 2018; Brownstein 2014). The Tuskegee Institute was no exception, and Dibble’s 1961 article makes clear that he was concerned about his shrinking resources. Ultimately, the Tuskegee Institute would become a shell of its former self by the 1970s and closed in 1987 as the last black hospital in Alabama, reopening in January 1999 as part of the Apology “package” as the National Center for Bioethics in Research and Healthcare in January 1999.

The Tuskegee Institute in the Civil Rights Era

What would be marked historically as the “civil rights era” began with the Brown decision, and its social impact in Alabama was enormous, as that state would become a focal point of non-violent protests led by the Moses Generation. For example, on December 1, 1955, 42 year-old Rosa Parks, born in 1913 (when Dibble was 20), became the modern “Plessy” by refusing to sit at the back of the bus, just as Plessy had refused to sit in a different train compartment. The Montgomery Bus Boycott (1955) followed, as the Moses Generation began to lead its people to the Promised Land. Moton’s speech at the Lincoln Memorial occurred seven years before Martin Luther King Jr. was born, who would, of course, go on to deliver his “I Have a Dream” speech 41 years later at the very same memorial, culminating into the Civil Rights Act in 1964, followed by the Voting Rights Act of 1965, as well as landmark healthcare reform legislation (see further). By then, Rivers had retired; Dibble was struggling with cancer and not only retired, but was at the end of his life. It seems plausible that neither of them had particular faith that “The Times they are A-Changin’” because they had never known anything except a segregated
world. It’s likely they both felt “nothing was really changing” when they witnessed the Martin Luther King assassination. But it would be another document that would ultimately have much more impact on Dibble’s and Rivers’ professional legacies, and the fate of the Tuskegee Institute, published the same year as the Civil Rights Act; that document would be the World Medical Association’s Declaration of Helsinki (1964) (see under Healthcare Ethics Issues). After Dibble’s and Rivers’ retirements, their roles would continue with others in their places. The Tuskegee Institute, a decade after the Brown decision, was now an HBCU by this period in history, but had not really left the Plessy era in terms of its mission. What would make the Tuskegee Institute into a truly historic—if not, anachronistic—institute was actually the dawn of a new era in medicine that came of age with Civil Rights: the post-Holocaust era and birth of modern medical ethics.

The Tuskegee Study Meets the Post-Holocaust Era

In the immediate aftermath of the Holocaust and the Nuremberg trials in the late 1940s, medical professionals were probably much more interested in penicillin than the Nuremberg Code (see under History of Medicine). Real post-Holocaust analysis and scholarship did not really emerge until the early 1960s, but Anne Frank: Diary of a Young Girl diary had been first published in the United States in 1952, with a Foreword by Eleanor Roosevelt (Anne Frank.org 2018). During the Civil Rights era, American Jews were particularly active and devoted to the cause of civil rights because it so deeply resonated with them. Many coming of age in the 1960s had either been the children of Holocaust survivors, or had relatives who perished. They viewed what was happening in the Jim Crow South as a comparable example to what had recently occurred in Nazi Germany.

Standing in remarkable juxtaposition to the Civil Rights Act of 1964 and The Declaration of Helsinki (1964), reaffirming the need for informed consent, was an unassuming journal article published in December of that same year, entitled “The Tuskegee Study of Untreated Syphilis” reviewing a 30-year study of “Negro males” who were followed, but not treated for syphilis (Rockwell et al. 1964). The paper was rather bland, and was written in a manner that was typical for medical journals. To Jewish medical professionals it started to raise alarm bells. One physician, Irwin Schatz, born the year the Tuskegee study began in 1932, was just four years out of medical school at the time (Roberts and Irwin 2015), and was prompted to write to the journal authors in early 1965 in disbelief that the study had been done. Schatz never received a reply, but archives show that co-author Anne Yobs indeed read, and disregarded, his letter (Reverby 2009). Another Jewish healthcare professional, Peter Buxton, who came across the study around 1966 when he was working for the CDC, would begin to review all of the documents about the long-running Tuskegee study and ultimately would become the main whistleblower who would bring it to its end (Jones 1993; Reverby 2009). I discuss the “whistleblowing phase” of the Tuskegee study further on.
The History of Medicine Context

When teaching *Miss Evers’ Boys*, it’s important, of course, to cover the history of the Tuskegee Syphilis Study, which actually comprised two studies over the course of its 40-year run. The first study was in fact, a treatment protocol sponsored by the Rosenwald Fund; it was the second study that was the infamous observational protocol, which became known by its 30th Anniversary by its journal article title: “The Tuskegee Study of Untreated Syphilis” which begins like this (Rockwell et al. 1964):

> The year 1963 marks the 30th year of the long-term evaluation of the effect of untreated syphilis in the male Negro conducted by the Venereal Disease Branch, Communicable Disease Center, United States Public Health Service. This paper summarizes the information obtained in this study—well known as the “Tuskegee Study”—from earlier publications, reviews the status of the original study group, and reports the clinical and laboratory findings on those remaining participants who were examined in the 1963 evaluation.

However, none of the Tuskegee study’s history will make any sense to your students without the accompanying context of the history of African American healthcare, and what actually counted as “medical knowledge” published in prestigious medical journals in a prevailing false narrative about medicine and race throughout the nineteenth and early twentieth centuries. The Tuskegee study cannot be understood, either, without explaining the history of treating syphilis, which includes clinical equipoise over the use of penicillin in later stages of syphilis. Finally, to put this into a more current perspective, it’s important to discuss current trends surrounding observational protocols in other diseases, such as prostate cancer, cervical cancer and thyroid cancer, in which patients have been/are being observed, but not treated with the standard of care.

History of African American Healthcare

First, access to healthcare in the general American population has always been a problem for the poor or underclass, for whom seeing a doctor was considered to be a luxury. There really was no such thing as regular primary care for most Americans until the early twentieth century, and most did not see a doctor if they didn’t have an acute problem. In the antebellum period, slave owners would have doctors come and treat their slaves as a matter of “household maintenance” since they were considered property. Sick slaves were not good for business. “Apart from humanitarian considerations, the economic value of slaves made their health a matter of solicitous concern” (Jones 1993).

After the Civil War, when the African American medical community began to grow, so did awareness of health disparities in urban areas. But Macon County, Alabama serves as a microcosm for what healthcare access really looked like for the
poor, rural, African American population; the health of its people was surveyed and documented in 1934 (see earlier), and the results were alarming.

In the Plessy era, the majority of African Americans typically had no access to white physicians or other healthcare providers either due to segregation or cost. Most “went from cradle to grave deprived of proper medical care. ‘I ain’t had a Dr. but once in my life and that was ‘bout 15 years ago’ an elderly black resident confessed in 1932” (Jones 1993). Cost prevented them from seeing private practice white physicians who would take care of any patient regardless of race so long as they got paid. People with incomes less than a dollar day had absolutely no way to pay for healthcare. There was also consensus that chronic poor health in the African American population affected white Americans, too, as their economy depended upon a healthy “servant class” or cheap labor class. This is why there was essentially a white medical-establishment consensus that black medical schools and black nursing schools within the black college/university system were critical.

As discussed earlier, the conditions in Macon County, Alabama were what we might call “third world” today, and healthcare access was essentially a pipe dream, as even basic living essentials were scarce. This is why the Tuskegee Institute’s Movable School project (see earlier) included public health/hygiene house calls, as well as maternity care, as most babies were born at home. By the later nineteenth century, there was a burgeoning African American medical community, which is why the National Medical Association was established in the first place. These medical professionals, from the start, indeed serviced their communities and the patients they could, but there were limited human resources for the need. Many physicians also sought to improve access to healthcare through community/public health research projects.

African American veterans’ care was a particular issue. At the Tuskegee Institute, one major development was for Robert Russa Moton to make a major push to have an all-black VA Hospital on its premises, to serve returning World War I African American veterans he had personally visited in Europe at the request of President Woodrow Wilson. Of note, African American soldiers were believed to have higher incidences of syphilis than white soldiers, but there were never any studies that actually determined incidence. However, they were still allowed to serve when white soldiers with syphilis were not (Reverby 2009). Moton even describes his fight for a black VA hospital in his 1921 autobiography.

Thus, when the Tuskegee study began in 1932, although access to healthcare for the majority of rural African Americans living in Macon County was minimal (with the exception of the traveling public health nurses in the Movable School project), there was at least recognition by the white medical establishment that this community was in poor health, and health disparities were a real problem.

Medical Misconceptions About Race

Layered onto the healthcare access problem were absurd and false theories about physiological, psychological, and medical differences between black and white races.
These were not sensationalized articles the masses read from non-credible sources; these were published as medical facts in high quality peer-reviewed medical journals, and the false theories about race were read, and accepted, by physicians of all colors and religions. In fact, many of these theories helped to support a flourishing eugenics movement. It’s critical to note that Eugene Dibble was not immune to many of the then-accepted scientific facts about race—one reason he was motivated to participate in the Tuskegee study.

For example, there was a pervasive view that African Americans were intellectually, mentally and physiologically inferior (Jones 1993); did not feel pain the same way as whites (Washington 2007); had uncontrollable, violent or larger sexual appetites (Jones 1993); and did not experience diseases (e.g. malaria) the same as in white patients, and so may not require the same treatments (Jones 1993; Washington 2007; Reverby 2009). At the same time, prominent physicians also considered them more prone to disease and “contamination” as the “weakest members of society” who were “self-destructive” (Jones 1993); many viewed syphilis as a result of immoral sexual indulgence (Jones 1993). Social realities helped to falsely validate some of these beliefs, which is why the leaders of the Tuskegee Institute at the time strongly believed that the education of African Americans was tied to the health of African Americans—one of the key missions of the Institute’s racial uplift framework. Indeed, illiteracy and low education gave the appearance of lower intellect, which translated for the white medical profession into fixed beliefs about African American patients’ inability to consent to, or comply with, treatment, justifying deception in “the patient’s best interests”.

A revealing book that illustrated the psychological effects of institutionalized white supremacy was authored by the Tuskegee Institute’s president, Robert Russa Moton in 1929. It exposed an obsequious tone that tells us a lot about Moton’s modus operandi: working cooperatively within the white establishment. The book was called: *What the Negro Thinks* (1929). Its Foreword, which is cringe-worthy today, starts:

> This volume aims to place on record some facts concerning a phase of the Negro problem of which, up to this time little has been known outside of the race; that is, what the Negro, himself, thinks of the experiences to which he is subjected because of his race and colour. The subject has lately excited a growing interest, especially among those who would approach the problem of the Negro’s presence in America with sympathy and understanding…

Of note, Moton’s 1921 autobiography, *Finding a Way Out*, actually discussed how well he and his family members were treated by their white masters, and that the abuse of slaves was really more at the hands of the white overseers. Clearly, Moton, who was born in 1867, was of an entirely different era. His agreement to cooperate with the Tuskegee study is not at all a mystery, given his writings and worldview.

The second myth of not feeling pain was reinforced by African Americans not “seeking help” for many acute and chronic health problems, which translated for the medical profession as thinking about African Americans as more robust research subjects. The third myth about hypersexuality was reinforced by the legal system perpetuating false rape charges (see below), which translated into beliefs that African
Americans were “syphilis soaked” (Jones 1993) and a threat to white civilization. But the wildest racial misconception of all—which “underwrote” the Tuskegee syphilis study was that the white race was actually superior, scientifically justifying that using African Americans in experiments was more ethical than using actual “human subjects” (meaning, white human subjects). These sentiments of using an underclass that was seen as “subhuman” justified the medical experiments on Jews during the Holocaust, too.

**Interracial Sex and Rape**

Within the white medical establishment, there was recognition that interracial couples existed, even if they were closeted, which certainly meant they could infect one another with diseases. When such relationships were “outed” in the South between a white woman and African American male, a common theme was for the African American male to be either lynched or put on trial for rape, and then convicted with little evidence. Or, they would be falsely accused when the perpetrator was white. In fact, a major trial in the news in 1931 Alabama, involved nine young African American males, known as the “Scottsboro Boys”, who were arrested on false charges for raping two white women (Reverby 2009). These consequences helped to deter interracial intercourse. In fact, this was such a common American experience and narrative that when Harper Lee based her Pulitzer prize winning novel, *To Kill a Mockingbird* (1960) on her own childhood observations, it resonated deeply in the civil rights era with many whites who had moral distress over these mockery’s of the legal system. Lee’s novel is set in 1936 Alabama, and it is her father’s moral integrity for justice that served as a role model for many white lawyers litigating civil rights cases who read the book growing up.

Actually, it was much more common for white males to either gangrape, or individually rape an African American female with no consequences, upholding a long tradition of white slave owners abusing their slaves. But syphilis experts of that time were less concerned with legal justice and more concerned with implications for public health. If a white abuser became infected, he could presumably infect his white wife, and even unborn child through congenital syphilis, although the latter was not well understood at the time (Jones 1993). There was an unsubstantiated medical theory that syphilis in the white population was a potentially more serious disease than syphilis in the African American population (Jones 1993; Reverby 2009).

Within African American culture sexual abuse was also a big problem, and the painful tale of Alice Walker’s rural 1930s Georgia character, Celie, in *The Color Purple* (1982) “outed” the secret lives and suffering of African American females within their own family units.

All of this context is necessary to truly understand the origins of the Tuskegee syphilis study. Reverby (2009) states that “historians and members of the public… who cannot comprehend the context of racism and violence that shaped what happened,” are analyzing this trial in a vacuum.
The History of Medicine Context

The Pathogenesis and Treatment for Syphilis

Syphilis first appeared in Naples, rumored to have been brought back to Europe by Columbus’ team of men, leading to the “syphilization of Europe” (Reverby 2009). No one understood the disease’s stages until the early twentieth century (Reverby 2009), and in 1906, Paul von Wassermann developed “a complement fixation serum antibody test for syphilis” (Ambrose 2016), known as the Wassermann reaction test. This new diagnostic test could detect antibodies to syphilis based on a reaction when blood or spinal fluid was introduced to another chemical; the more severe the reaction, the more progressive the disease. However, the Wassermann reaction test produced false positives and negatives and there was long debate over its specificity. It was the gold standard however well into the 1970s.

There was no good treatment for syphilis in 1932, and no cure. Treatment was based on mercurial, arsenical and bismuth-based therapies (referred to as the “heavy metal” treatment), but it was not a cure, had many side-effects, and not considered very effective in later stages. Fever therapies were also used for neurosyphilis, which involved infecting the patient with malaria or a bacteria to induce a fever (Ambrose 2016; Reverby 2009).

One of the least understood aspects of the Tuskegee study surrounds who was being followed and denied treatment for syphilis. There are four stages of syphilis: primary, secondary, a latency period, and a tertiary stage (a.k.a. late-stage syphilis). The Tuskegee study followed, and did not seek to treat, men who had entered their latency phase, or who had late-stage syphilis; the study was never designed to enroll men with primary or secondary syphilis. The study did not enroll any women, or treat any women at-risk even though some physicians at that time saw more women with syphilis than men (Jones 1993). Finally, the Tuskegee study did not infect anyone with syphilis, which was a rumor historians have spent decades trying to dispel (Reverby 2009). That said, by not treating syphilis in the men they followed, opportunities for new infections occurred in women, which lent weight to that rumor.

The primary stage of syphilis lasts from 10–60 days, starting from the time of infection. During this “first incubation period” the chancre appears at the point of contact, such as the genitals. This is the primary lesion of syphilis. The chancre heals without the need for treatment and will leave a scar but no other symptoms. The second phase begins at this point, with a rash that looks like the measles or chicken pox. The bones and joints can become painful and there may be complications with the circulatory system. There may be fever, indigestion, patchy hair loss, headaches, and a range of diffuse complaints. Sometimes there are moist open sores with spirochetes that are infectious. After these symptoms, prior to tertiary syphilis, there is a latency period that can last from several weeks up to 30 years; it was men in this phase who were being followed in the Tuskegee study, although the sloppy science and methods did not always follow men in later stages, and some had much earlier stages. In the latency phase, syphilis symptoms mostly disappear outwardly, but the spirochetes begin to do a lot of internal damage to the central nervous system (CNS). Many people with syphilis can live almost full lives and “coexist” with the disease,
but more often, the signs of tertiary syphilis contribute to shortened life span. Tertiary syphilis affects the functioning of bones, liver, cardiovascular system, and the brain with neurosyphilis.

Due to the complexity of syphilis, a separate medical specialty of “syphilology” had developed by the early twentieth century, which essentially disappeared by the time penicillin became the standard of care. In addition to the heavy metals therapy available, there were also a number of ineffective home remedies and patented medicine designed to purify “bad blood” (Reverby 2009) often exploiting the poor. In the African American community, the term syphilis was never used to describe the disease; the term “bad blood” was used instead. But that term was a non-specific way to describe a number of health problems (Jones 1993; Reverby 2009).

From a public health standpoint, in the 1920s, there was interest in reducing contagion of syphilis, which had long been ignored because it was considered a disease associated with “immoral behaviors”—not unlike the AIDS discourse in the 1980s (see Chap. 2). A 1941 textbook noted that the heavy metals therapy regimen was the standard of care, and could remove contagion after “at least 20 injections each of an arsphenaminine and a heavy metal” (Reverby 2009). That was the standard regimen suggested for patients who were untreated and had syphilis for more than five years. But “more than anything else, syphilologists wanted to understand the disease’s natural history to determine how much treatment was really needed” (Reverby 2009).

**Legitimate Questions About 1932-Era Treatment**

When the Tuskegee syphilis study began, it was before the penicillin era, and treatment for syphilis involved only the heavy metal treatment. “In the 1930s, one treatment schedule for [syphilis] included three intramuscular injections sequentially over a six-week period of arsphenamine, a bismuth salt, and a mercury compound.” (Ambrose 2016).

In 1908 Paul Ehrlich was awarded the Nobel Prize for his discovery of an organic arsenical therapy for syphilis, which was later developed into the drug arsphenamine, known as Salvarsan, or the “magic bullet” (Frith 2012) and in 1912, neoarsphenamine, or Neo-salvarsan Arsenic had many toxic side-effects, was hard to administer, and required a lot of intramuscular injections over long periods of time. By 1921, bismuth was found to be effective, too, and made arsenic more effective when they were combined. Ultimately, “Arsenic, mainly arsphenamine, neoarsphenamine, acetarsone and mapharside, in combination with bismuth or mercury, then became the mainstay of treatment for syphilis until the advent of penicillin in 1943” (Frith 2012). In 1986, one author noted “the heavy-metal cure often caused thousands of deaths each year” (Frith 2012).

Ultimately, the delivery system for the heavy metals therapy generally involved salves and intramuscular injections, which is what is shown in Miss Evers’ Boys. Because the heavy metals treatment was thought to be more beneficial in the early phases, and could have lethal side-effects, there were legitimate medical and clinical ethics questions about whether the current standard of care was beneficial beyond
The latency period. But race interfered with the science, and polluted any legitimate study design. The 1932 study sought to address two medical research questions about syphilis, which the Tuskegee Institute’s leadership also thought was worthy, and beneficial to their community: (a) Does the pathogenesis of syphilis manifest as the same disease in African American males as in Caucasian males? (b) Is treatment necessary once it reaches the latency phase, given that the side-effects of the 1932 heavy metals therapy can be worse than the disease?

Clearly, the first question was based on racist medicine frameworks. But this was a question the African American medical community wanted answered, too, because if the answer was “the disease is equally bad or worse” then health disparities in syphilis treatment could be improved. The second question was legitimate until the penicillin era emerged (see further).

It’s imperative to impress upon students that the scientific rationale for a study of late-phase syphilis was based on genuine clinical equipoise over treatment beyond latency, as there were no good treatments at that time. This rationale became harder to defend in the penicillin era (see further). “Describing the dangers of the 1930s treatment regimes, [Nurse Rivers] claimed they were ‘really worse than the disease if it was not early syphilis…If syphilis was not active the treatment was worse than the disease’ ” (Reverby 2009).

Notes Jones (1993):

[As one CDC officer put it, the drugs offered ‘more potential harm for the patient than potential benefit’ ” …PHS officials argued that these facts suggested that the experiment had not been conceived in a moral vacuum for if the state of the medical art in the early 1930s had nothing better than dangerous and less than totally effective treatment to offer, then it followed that, in balance, little harm was done by leaving the men untreated…Apologists for the Tuskegee Study contended that it was at best problematic whether the syphilitic subjects could have been helped by the treatment that was available when the study began.

Notes Reverby:

By the time the study began in 1932, concern over treatment, debates over racial and gender differences, and the problematic accuracy of the [diagnostic] blood tests filled medical journals and texts. It was becoming clear that not everyone died from the [syphilis] or even became seriously sickened by it. From a public health perspective, as Surgeon General Thomas Parran argued in 1938: ‘with one or two doses of arsphenamine, we can render the patient promptly non-infectious [but] not cured.’ …Discrediting the efficacy of mercury and salvarsan helped blunt the issue of withholding treatment during the early years, but public health officials had a great deal more difficulty explaining why penicillin was denied in the 1940s.

The first Tuskegee study subjects were enrolled when Herbert Hoover was President, while the country slid into the worst economic Depression in its history. The study design is historically located in Hoover’s America—pre-Nuremberg Code: there was no informed consent; there was deception; there was coercion; there was bias. But ethical abuses notwithstanding, later data analysis revealed highly flawed methodology that became an insult to scientific integrity because the data became so badly polluted (see further).
The Oslo Study

The Oslo study, discussed in the film, had been the only study on the effects of untreated syphilis in the literature prior to the Tuskegee study. In this retrospective study, by Bruusgaard (1929), the investigators “had reviewed the medical records of nearly 2000 untreated syphilitic patients who had been examined at an Oslo clinic between 1891 and 1910. A follow up had been published in 1929 and that was the state of published medical experimentation on the subject before the Tuskegee Study began” (Jones 1993). This study was referenced in the 1973 Ad Hoc Panel Report like this:

The Oslo study was a classic retrospective study involving the analysis of 473 patients at three to forty years after infection. For the first time, as a result of the Oslo study, clinical data were available to suggest the probability of spontaneous cure, continued latency, or serious or fatal outcome. Of the 473 patients included in the Oslo study, 309 were living and examined and 164 were deceased. Among the 473 patients, 27.7% were clinically free from symptoms and Wassermann negative.

In 1955, Gjestland, then chief of staff at the same Oslo clinic, revisited this data and published the findings (Gjestand 1955); he also advised the PHS study investigators in 1952 (see further).

Rivers was aware of the Oslo study, too, and relayed in interviews that she thought of the Tuskegee study as a comparative study in the African American male, having made the assumption that there could be racial differences (Reverby 2009).

Ultimately, the Oslo study became the “touchstone” for the Tuskegee study design, but there was an enormous difference: the Oslo study was retrospective, having assessed untreated patients in a time frame where there was no good treatment. The Tuskegee study design that became notorious (see further) was a prospective study that actively harmed its subjects. Ethically, Oslo and Tuskegee were very far apart.

The First Tuskegee Treatment Study: The Rosenwald Fund Demonstration Project (1929–1932)

The entire saga of the Tuskegee syphilis study essentially started, and ended, because of Jewish humanitarian efforts. It was Jewish philanthropist, Julius Rosenwald who got the whole ball rolling. Julius Rosenwald was born in 1862 during the Lincoln Administration. As a major player in the garment industry and other investments, he eventually became co-owner of the huge Sears, Roebuck and Company, touted as the “Amazon” of its day. Rosenwald’s biographers describe him as having been passionate about human rights causes, and he became a philanthropist who also established the current donor model of “matching funds”. Through discussions with his friend, Paul Sachs, co-founder of Goldman Sachs, and his own rabbi, Rosenwald was bitten by the philanthropy bug, felt that the plight of African Americans was close to his heart, and this became the focus of most of his philanthropy for the
rest of his life. Rosenwald read Booker T. Washington’s 1901 autobiography, *Up From Slavery* (1901), reached out to the author, and began a very close friendship with Washington. Ultimately, Rosenwald endowed the Tuskegee Institute and also match-funded a number of projects devoted to the education of African Americans. Rosenwald was asked to serve on the Board of Directors of the Tuskegee Institute in 1912, and remained a board member until he died. One biographer notes (Zinsmeister 2018):

In 1912, Rosenwald...announced he would be celebrating his 50th birthday by giving away close to $700,000 (about $16 million in current dollars)...“Give While You Live,” was his slogan. One of Rosenwald’s birthday gifts was $25,000 to Washington’s Tuskegee Institute. Soon Rosenwald and Washington were ramping up their program, [leading to] schools all across the South over more than 20 years.

In 1917, after Booker Washington’s death, Rosenwald started the Rosenwald Fund, for “the well-being of mankind”, which became the chief sponsor of several southern African American school projects (called Rosenwald Schools) prior to the *Brown* decision (see earlier and Chap. 9). The fund also offered $1000 “Fellowship Grants” from 1928–48 to various African American artists and intellectuals for their personal growth; recipients ranged from Marion Anderson to social scientists Kenneth and Mamie Clark, of the “Clark Doll Study” fame, which was ultimately used to argue the *Brown* decision, and was a “Who’s Who of black America in the 1930s and 1940s” (Schulman 2009).

Finally, the Rosenwald Fund expanded into “medical economics” (Jones 1993)—later termed community medicine, and named Michael Davis as its medical director. The Fund was eager to sponsor public health initiatives benefiting the African American community and was reviewing proposals. In 1929, the same year as the stock market crash, the Rosenwald Fund partnered with the PHS to help sponsor the first “major serological survey and treatment program for syphilis” (Reverby 2009). The Rosenwald Fund provided matching funds to the PHS to help find and treat syphilis in the African American population of six rural states/counties whose populations typically could not be served even by free clinics (Jones 1993), which were already overextended. The study “for demonstrations of the control of venereal disease in the rural South, in cooperation with the United States Public Health Service and with the state and local authorities” (Jones 1993) was approved in November 1929 by the Rosenwald Fund Board. Drs. Thomas Parran, director of the Division of VD and Taliaferro Clark, Advisor to the PHS (appointed by Hugh S. Cumming, the Surgeon General of the USPHS) selected the treatment sites; one of them was Macon County, Alabama, where there were eight African Americans for every white American. The PHS would use staff from the Tuskegee Institute, as the Rosenwald Fund required them to use African American healthcare professionals. Nurse Rivers was one of the nurses that had assisted in this project as well (Jones 1993). The goal of the treatment study was to find out the extent of syphilis incidence and to prove that containment with treatment was possible. The treatment study began in Macon County around February 1930, and continued until around September 1931. Oliver C. Wenger, who handled a similar project in Mississippi, and a venereal disease expert, was put in charge of the study.
The syphilis case-finding and treatment project was a high-quality research initiative even by today’s standards, with the exception of problems with informed consent, which was not yet a standard. The Rosenwald Fund sent outside observers and evaluators (African American physicians, Drs. Frost and H.L. Harris Jr.) to review onsite conditions, provide oversight and report back various concerns and problems; it also commissioned a follow-up qualitative study of the patients treated, which was the Johnson study discussed earlier. As for an outside syphilologist, Dr. Thomas Parran, and E.L. Keys, former president of the American Social Hygiene Association, acted as reviewers and had only praise for the study.

There were lots of technical and methodological problems with sampling and enrollment (going house to house vs. blood sample drives in one setting); adequate amount of therapies; melting mercury; as well as medical and clinical ethics issues: drug side-effects; poor conditions in overcrowded shack-schoolhouses, and very poor consent protocols with the poor and illiterate population, including coercion through power relations, as noted by Dr. Frost (Jones 1993), as well as participants “who were entirely ignorant of the character of the disease for which they were being treated” because they were confused by the term “bad blood” (Jones 1993). Later, Johnson would note that not one of the 612 interviews he conducted understood the connection between sex and syphilis, and also stated that “bad blood” was a non-specific term that typically referred to a whole host of ailments (Jones 1993).

In the final analysis, the Rosenwald Fund treatment study could best be described as a “successful failure” in that it indeed found a very high incidence of syphilis using a “Wasserman test dragnet” approach (Reverby 2009) where they essentially tested all at-risk African Americans in the county; they also treated them. To the PHS, the findings seemed to assure continuation of the treatment project.

The Rosenwald Fund saw things differently. The issue according to their outside reviewers was that they found so many problems with barriers to consent and compliance due to poverty, illiteracy, co-morbidities, treatment contraindications—including starvation from malnutrition—that resource allocation became confounding and morally distressing. What they found, and could realistically address with their available Fund was essentially “too big to fund” and not feasible, regardless of the Wall Street crash. After a careful review and analysis, the Rosenwald Fund suggested to the PHS that primary care—and not solely syphilis—was a much bigger problem, and the best way to deal with the syphilis problem, given the extraordinary amount of chronic disease and malnutrition they found, was to consider funding overall healthcare and nutrition, not just case-finding and treating syphilis. The PHS was open to transitioning to a more comprehensive healthcare program. But they also felt the study’s goals were achieved: they were able to effectively demonstrate that they could establish the prevalence of syphilis and treat contagion.

Pulling Funding

The year the Rosenwald Fund treatment project began was the same year as the Wall Street crash in October 1929. The Crash was not just a one-time event; between
October 1929 and July 1932, there were small fits and starts of the stock market rebounding. By 1931, roughly 2300 banks had failed, $1.7 billion in deposits were lost, over 100 businesses were closing per day. Julius Rosenwald died January 6, 1932 before things got even worse: on July 8 1932, the stock market closed at $41.22—it’s lowest level that century, and stocks lost 89 percent of their value across the board (Kenton 2018). That period marked the beginning of the worst financial crisis in U.S. history and the official start of the Great Depression. As today, study funding was volatile, but it is inaccurate to say that the Rosenwald Fund pulled funding from the syphilis treatment study entirely due to the crash, but it was certainly a factor. The Rosenwald Fund mainly pulled funding because of their analysis of the data and needs assessment of the region: continuing to focus solely on treating syphilis wasn’t a good use of their resources, given the extent of the health inequities they found; addressing primary care and basic nutrition was what their data told them was the best use of resources. The other factor in pulling their funding was that the Rosenwald Fund required matching state funds from Alabama, which was indeed reeling from the Depression and was not prepared to match funding at that time for a major free healthcare initiative. What the treatment study also revealed would become the foundation for the observational protocol. Johnson noted in his qualitative interviews after the treatment study: “The tradition of dependence and obedience to the orders of authority, whether these were mandatory or not, helps to explain the questionless response to the invitation to examination and treatment” (Jones 1993).

Thus, the now infamous observational protocol designed to follow African American men with latent and/or late stage syphilis was an afterthought that arose from the data analysis phase of the well-intentioned Rosenwald Fund treatment study.

**The Second Tuskegee Observational Study Protocol (1932–1972): What We Mean When We Say “Tuskegee Study”**

After funding for the Rosenwald treatment study ended, the PHS investigators found the data too rich to simply “drop” and so they began to think about what they could study given their limited funding. Talliaferro Clark felt that the incidence of syphilis uncovered in Macon County was an ideal setting in which to study the “natural history” of late stage syphilis in African Americans. Since there was a dearth of published studies about syphilis (with the exception of the Oslo study), Clark wanted to build on the treatment study data and design an observational protocol to track morbidity and mortality in late stage syphilis “to assess the extent of medical deterioration” (Gray 1998). Since there was no funding to continue the treatment study anyway, the PHS could still follow the infected men, and examine them clinically to see what really happened to them when the disease was left untreated. When Clark reviewed the data from 1930–31, and considered the extent of syphilis prevalence in the Macon County region, he felt the region was an excellent site for an African American version of the Oslo study since leading syphilologists believed that “Syphilis in
the negro is in many respects almost a different disease from syphilis in the white.” But instead of a retrospective study, it would be an improved prospective study. To make it easier to stage, he would select only men because their genital sores in early syphilis would be far easier to see and stage than women. The study Clark had in mind would be for about a year. At that point, Clark named 35 year-old Raymond Vondehler, a PHS Officer, to direct the new prospective observational study of late stage syphilis, and asked Wenger to continue to be involved.

Clark next met with all the stakeholders: the Alabama Board of Health, the private practitioners in the region, and the Tuskegee Institute. The Alabama Board of Health’s director, J.N. Baker, made it clear that Clark’s study design would be approved by the State on condition that every person diagnosed with syphilis would be treated; as it would only be a short trial of 6–8 months, no one could get the current recommended standard of care, but they agreed to minimal treatment of eight doses of neoarsphenamine and some additional mercury pills unless it was contraindicated. As these doses were regarded by syphilologists to be wholly insufficient, or even useless to treat late stage syphilis, the men they followed were considered, for their purposes, to have “untreated syphilis” (Jones 1993; Gray 1998; Reverby 2009).

Clark approached Dibble with his plan, and Dibble briefed Moton by letter about the “worldwide significance” of the Clark PHS study and how the opportunity could benefit Tuskegee Institute nurses and interns (Reverby 2009), while the Tuskegee Institute would “get credit for this piece of research work …the results of this study will be sought after the world over. Personally, I think we ought to do it” (Jones 1993). Both Moton and Dibble agreed it was definitely worthwhile, and offered the Tuskegee Institute and John A. Andrew Memorial Hospital resources for this “new deal”—the observational study. The plan was for Dibble to have some of his interns in the field help deliver the minimal treatment protocol agreed upon with the State Health Board. Dibble and Moton fully understood the practical purpose of Clark’s PHS study—that it could identify how much treatment was really necessary, since most of their community had no access to it at all. (This same design would later be invoked in the 1990s in African AIDS protocols, discussed in Chap. 2.)

The initial Clark PHS study was just one version away from what would become the notorious “Tuskegee Study of Untreated Syphilis in the Male Negro” (or “Negro Male” in some documents) that lasted 40 years.

Dibble and Moton undoubtedly viewed Clark’s study design within a “global health ethics” framework—justifying a project that could potentially benefit the most people in the long-term where there are no resources at all. Even Wenger had noted that there were greater health resources in China and the Phillipines “where better medical services are rendered to the heathens than we find right here in [Macon County]” (Jones 1993:76). There were no defined ethics guidelines for human subject research in 1932 (see under Healthcare Ethics Issues), so informed consent was not on anyone’s mind. The country was still plunged into economic chaos, as “Hoovervilles” (Shanty towns for millions of white Americans who were homeless) were becoming the norm as the unemployment rate rose to over 25% for white Americans. The thinking went: Without the Clark study, the men would have died with late stage syphilis anyway with no treatment at all; what harm was there in assessing them,
with the benefit of giving them some minimal treatment, a hot meal on exam days and medical attention to other smaller ailments?

In 1933, just as President Franklin Roosevelt had begun his first term, and more socialist “New Deal” programs would begin, Clark wrote in a PHS annual report that: “the ideal method of therapy is seldom possible of attainment, and the vast majority of infected people receive treatment that is generally regarded as inadequate or no treatment at all. It is highly desirable, therefore to ascertain, if possible, the relative benefits accrued from adequate and inadequate treatment” (Reverby 2009).

But with the goal of observation and some undertreatment, Jones (1993) noted that: “The Tuskegee Study had nothing to do with treatment. No new drugs were tested; neither was any effort made to establish the efficacy of old forms of treatment. It was a nontherapeutic experiment, aimed at compiling data on the effects of the spontaneous evolution of syphilis on black males.”

**Methods: 1932–1933**

The plan was to do another Wassermann testing sweep to enroll men similarly as they did in the Rosenwald study by inviting them for testing and examination. This time, they would enroll only males in the latent or tertiary phase, and follow them by doing clinical exams to take a good look at what was going on. The minimal heavy metal treatment they agreed to provide would be furnished to anyone found with early stage syphilis to prevent contagion. Again, the men with latent or tertiary syphilis also received the minimal metals treatment, and was less than half the dosage recommended by the PHS to cure syphilis; it was thus considered so inadequate and ineffective, the study investigators still defined it as “untreated syphilis.” The exams would comprise continued Wassermann blood tests, urine tests, cardiac exams (fluoroscopy and x-rays), lumbar punctures to test spinal fluid for neurosyphilis, and if they died, an autopsy.

The goal was to study the “natural history” of late stage syphilis in African Americans to (1) help settle debates over racial differences in syphilis pathogenesis; (2) determine whether treatment in later stages was really necessary, given the side-effects of the heavy metal treatments in general. The social significance to the Tuskegee Institute was that if there were significant morbidity, the data could convince the government that funding public health and syphilis disparities in the African American population was an important health priority.

Regarding the consent procedures, as in the first study, the men would be told that they were being checked by “government doctors” for “bad blood,” and would receive “treatment” for their ailments (in addition to the minimal heavy metal doses, they would receive aspirin, tonics and vitamin pills). The men would also be served a hot meal on exam days. But there would be no “informed” consent as it was not yet a standard: there was no disclosure they were being followed for syphilis specifically, and no disclosure for the enrolled men that their syphilis was not being adequately treated. There was ongoing deception as to the purpose of the study, deceptive practices surrounding lumbar puncture described as “spinal shots” and
“special free treatment” and its potential risks. (See Reverby 2009, pg. 45 for the actual study letter.)

As one of the men later said when questioned in the 1970s about his 40 years of participation, “I ain’t never understood what this study was about” (Jones 1993).

In terms of study personnel roles: Vondelehr, Wenger, and some of Dibble’s interns at the Tuskegee Institute would work in the field; Dibble would be in charge of the team at the Tuskegee Institute, and John A. Andrew Memorial Hospital would serve as the local teaching hospital site for the cardiology tests, lumbar punctures, acute medical needs, and any autopsies to be performed, which meant that when the men were close to death, they were brought to Dibble’s hospital so they could die there to improve the autopsy results (Jones 1993). Nurse Rivers, suggested by Dibble, would be hired at this point as the study nurse (“Scientific Assistant”) at $1600 per annum ($1000 per annum, and $600 for transport expenses) to serve as a liaison who would interact with the men, ensure they made it to their exams, and offer any primary nursing consultation or care.

By the end of the recruitment phase, they enrolled 399 men in the disease group, did their exams, and Vonderlehr performed the spinal taps on 296 of them—often incompetently (Jones 1993; Gray 1998; Reverby 2009), which caused many side-effects; the men would stay in the hospital overnight after the spinal taps. As the team started to write everything up in 1933, Vonderlehr suggested to Clark that they should consider extending the study between 5 and 10 years as the data was so rich. Before Clark could decide, he retired and Vonderlehr was named as his replacement as director of the Division of Venereal Diseases. And so, the Clark design now turned into the Vonderlehr design—which ultimately lasted for 40 years. In the 1933 Vonderlehr design of the PHS study, they added 201 men without syphilis as controls, who were not informed that they were actually a “control” in a study (Jones 1993), for a total of 600 men. They stopped doing the spinal taps to improve retention (the men were actively refusing them), and so simply stopped diagnosing neurosyphilis. They also decided that all the men in the syphilis group should have autopsies at death, as that yielded the best data. Wenger noted in a letter to Vonderlehr: “As I see it, we have no further interest in these patients until they die” (Reverby 2009). They would still provide small amounts of “treatment” in the form of aspirins, tonics, and oral mercury compounds “if asked” (Reverby 2009). Vonderlehr reached out again to the Tuskegee Institute—Moton and Dibble. The Institute would continue as the teaching hospital site for the exams, and Dr. Jesse Jerome Peters, an African American pathologist, would handle the autopsies at the VA hospital onsite at the Tuskegee Institute (Jones 1993). Dibble would handle treatment of any study subjects (using the minimal treatment), while local African American doctors were to refer any study subject who wanted syphilis treatment back to Dibble should they encounter one of the enrolled men. At this point, Dibble was named as one of the Tuskegee study’s official government consulting doctors ($1/annum); and they would rehire Rivers as the study nurse for $1200.00 per annum ($1000 per year, and $200 for expenses). The PHS would next appoint John R. Heller to the study site to direct the field work. By 1934, the PHS secured $50 per family for burial costs as an incentive
to agree to autopsy; the funder was the Milbank Memorial Fund (the Rosenwald Fund was approached first).

Vonderlehr had now shaped the study design into what is meant by the “cultural shorthand of Tuskegee Study or Tuskegee Experiment…it was never really an experiment in the sense of a drug, biologic or device being tested. It was supposed to be prospective study of what the doctors called the ‘natural history’ of late latent syphilis…Its name varies in published articles” (Reverby 2009). As for the issue of withholding adequate treatment from the enrolled men, Jones notes (1993):

Apologists for the Tuskegee study contended that it was at best problematic whether the syphilitic subjects could have been helped by the treatment that was available when the study began...The [heavy metal treatments] were highly toxic and often produced serious and occasionally fatal reactions in patients… was painful and usually required more than a year to complete. As one CDC officer put it, the drugs offered ‘more potential harm for the patient than potential benefit’…PHS officials argued that these facts suggested that the experiment had been conceived in a moral vacuum. For if the state of the medical art in the early 1930s had nothing better than dangerous and less than totally effective treatment to offer, then it followed that, in the balance, little harm was done by leaving the men untreated…

Yet undertreatment totally corrupted the data from the very beginning. Gray (1998) notes:

Nearly all these patients were given some treatment with arsenicals or mercury, and often with both in the course of the initial 1932–33 [Clark design]. The amount was believed too small to have effect on the disease, but it ruined the study as one of “untreated syphilis”. The doctors botched the sample doing the short-term study, secured it by going through the motions of treatment, before a long-term study was even contemplated. Rather than call it quits, the doctors falsified the sample selection procedure in their initial papers by arbitrarily defining the little treatment as no treatment at all. Although it baffled later doctors how so many patients had gotten some, albeit obviously inadequate, treatment, no one had read the files.

The Shift to Lifetime Follow-Up

The standard one-slide summary of the observational study on almost every “Introduction to Research Ethics” course typically reads: “From 1932–1972, the U.S. PHS followed ~400 black males with syphilis but didn’t treat them and didn’t tell them they were not being treated.” But the devil is in the details: They enrolled 600 men, when you count the controls—several of whom wound up with syphilis, too, and were then moved into the syphilitic arm; most men in the syphilitic arm received some heavy metals treatment or protoiodide pills (dispensed by Heller), but the medication dispensed highly varied among the men, and was often left up to practitioner discretion (Jones 1993). This created a quagmire of confusing data for anyone trying to analyze a study of “untreated” syphilis.

As the study ticked on into subsequent calendar years, it began to dawn on everyone that the “pot of gold” was really the data obtained from the autopsies so they could best validate their clinical findings, and ascertain to what extent syphilis was really a factor in the death. Since many African American men died in Macon County
from a range of untreated chronic diseases, it was difficult to figure out whether they were actually dying from syphilis, or to what extent it was a contributing factor. The team thus shifted its goals by 1936 to *lifetime follow up*. Jones (1993) uncovered that:

The PHS was not able to locate a formal protocol for the experiment. Later it was learned that one never existed; procedures, it seemed, had simply evolved…but the basic procedures called for periodic blood testing and routine autopsies to supplement the information that was obtained through clinical examinations.

In addition to the burial stipend, another incentive for the men to stay enrolled was lifetime *access to Nurse Rivers*, who formed deep relationships with the men followed, drove them into town for their periodic exams, responded to their questions, and also provided them and their families with basic public health hygiene and nursing regarding primary care, reminiscent of her Movable School days. Nurse Rivers had other incentives to getting to know the men’s families: she was the one who consented the family for autopsy after each man died. A year before the shift to lifetime follow-up was made, Moton retired.

In 1938, Austin V. Diebert, a Johns-Hopkins trained PHS syphilologist, joined the study to work in the field. Diebert reviewed the data so far, and had major problems with its corruption due to “some treatment” in a supposed study of *no treatment*. He re-tweaked the protocol again to ensure that fresh men were recruited into the syphilitic arm who were to receive no treatment for syphilis at all; he also noted that undertreatment of several of the men may explain why they weren’t seeing as severe complications in the men as they would predict (Jones 1993). This finding, alone, should have been cause to end the study. No new men were added to the study after 1939 (Reverby 2009).

Moton died in 1940, and was honored when an air field nearby was named after him: Moton Field. Things pretty much ticked along through the rest of the Depression era until the bombing of Pearl Harbor in December 1941, when the United States entered World War II. At this point, needing as many troops as possible, Moton Field became the site for training the first African American fighter pilots to be sent overseas. They were called the “Tuskegee Airmen,” and the initiative was known as the “Tuskegee Experiment” because the prevalence of sickle cell disease in African Americans had been associated with barring them from flying or becoming pilots. Since the Tuskegee Airmen completed many successful bombing missions in Europe, the so-called “Tuskegee Experiment” was associated with *this* event 30 years before Moton’s legacy would be linked to the notorious “Tuskegee Syphilis Study”. More germane to this time frame, however, was another “experimental” miracle drug introduced into the military to combat syphilis: penicillin. *The Henderson Act* was passed in 1943, “requiring tests and treatments for venereal diseases to be publicly funded” which eventually included penicillin (McVean 2019).
The Penicillin Era and Beyond

Penicillin did not become a standard of care for syphilis treatment until 1946. By 1947, the Henderson Act led the USPHS to open Rapid Treatment Centers in which syphilis was being treated with penicillin (McVean 2019). When penicillin was first dispensed to U.S. soldiers during the war, it was still experimental, and bioethicists have raised many questions about that study design, too. Around that time, a completely secret and egregious penicillin experiment was also going on in Guatemala in which the USPHS was actually infecting men with syphilis using prostitutes they enlisted and then treating them with penicillin to test doses and efficacy (Reverby 2013). This study’s fallout is discussed more under Healthcare Ethics Issues (further).

Providing inadequate heavy metal treatment was not considered medically or ethically problematic in the pre-penicillin era considering its risks and questionable efficacy beyond latency. But the withholding of penicillin started to become an ethical issue, despite clinical equipoise. To deal with the risk of “curing” their enrolled men, a “do not treat list” of study subjects was circulated to the local physicians as well as a “do not enlist/do not treat” list to the army recruiters in the area (Jones 1993; Reverby 2009). A local physician in Macon County recalled that at that point in the study’s history, the men “were being advised they shouldn’t take treatment [with penicillin] or they would be dropped from the study” which meant that they would lose the benefits being promised (Jones 1993).

When interviewed by historian James H. Jones in 1977, Rivers relayed: “I never told somebody not to take any medication.” When asked how she was able to keep the men from getting penicillin, she said “I don’t know that we did…I was never really told not to let them get penicillin, and we just had to trust that to those private physicians” (Reverby 2009). In another interview in the 1970s, Rivers stated: “I never told anybody that you couldn’t get treatment. I told them “So who’s your doctor? If you want to go to the doctor go and get your treatment…that [the white doctors] had to…have an excuse so they put it on me that I wouldn’t let the patients get treatment.” (Reverby 2009:179, note 85)

Jones (1993) surmised:

Discrediting the efficacy of mercury and slavarsan helped blunt the issue of withholding treatment during the early years, but public health officials had a great deal more difficulty explaining why penicillin was denied in the 1940s. PHS spokespersons noted later that withholding penicillin was “the most critical moral issue…one cannot see any reason that they could not have been treated at that time…” [and] “I don’t know why the decision was made in 1946 not to stop the program…” (Jones 1993).

When penicillin became widely available in the later 1940s, it was known to cure early stage syphilis, but no one knew if it was effective on latent or tertiary syphilis; there were theories that it would do more harm than good because of reactions to the drug. It took about a decade to understand that penicillin could cure syphilis at the latency stage if organ damage had not yet occurred (Reverby 2009), but since the men in the study were beyond that, the investigators were convinced “the men could not be helped at this point” (Reverby 2009). Jones (1993) refers to “therapeutic nihilism”
in that there was a belief that “penicillin was a new and largely untested drug in the 1940s [and that] the denial of penicillin was a defensible medical decision.”

It is historically inaccurate to state that penicillin was a “standard of care” in latent or tertiary syphilis until at least the mid-1950s. On the contrary, there was clinical equipoise over that question (see under Healthcare Ethics Issues). Penicillin only became a standard of care for late stage syphilis by the later 1950s, and there was still debate as late as 1964 (Reverby 2009). It took years of its use for its benefits in latent or late stage syphilis to be clear; part of the clarity was due to incidental use of penicillin. Many men in the Tuskegee study had indeed been given penicillin incidentally for other problems if they saw local physicians, and so the data again was becoming polluted. Vonderlehr remarked in 1952 to one of the field doctors at the time: “Hope that the availability of the antibiotics has not interfered too much with this project” (Reverby 2009).

During the penicillin era, investigator bias surrounding the Tuskegee study caused the team to “double down” on the original aims of the study. Thus, rationalizing the ongoing study dominated the paper trail from that point on.

Sidney Olansky, John C. Cutler and Stanley Schuman, became the observational study’s new leaders in the 1950s (Reverby 2009). In a memo by Olansky to Cutler in 1951, he wrote: “We have an investment of almost 20 years of Division interest, funds and personnel; a responsibility to the survivors both for their care and really to prove that their willingness to serve, even at risk of shortening of life, as experimental subjects. And finally, a responsibility to add what further we can to the natural history of syphilis” (Reverby 2009:69).

Hiding in Plain Sight: Data Sharing and the Road to Moral Outrage

As Miss Evers states, the study “wasn’t no secret; everybody knew what was going on”. Indeed, the study investigators were pretty good about data sharing over the years. The first paper on the second study was published in 1936 by Vonderlehr, Clark, Wenger and Heller to report on their findings, followed by 11 more papers over 40 years (See Jones 1993). Notes Reverby (2009):

> The PHS was not hiding the Study, and medical journals published the articles and reports. Unless a physician picking up the articles thought deeply, it would have been easy to see the men as ‘volunteers’, and indeed in one report they were referred to as ‘people [who] responded willingly.’ Reading between the lines would have been necessary since the reports did not make clear that the aspirins, tonics, and spinal punctures were being described to the men as ‘treatment’. The language and titles of the articles—‘untreated syphilis in the Male Negro’—easily distanced the medical reader.

> From a data integrity standpoint, the Tuskegee study was almost as egregious as the ethical abuses; none of the published papers really reflected what the investigators were doing, and the papers began to raise questions from peers. Any rigorous reading of the articles revealed badly compromised data, particularly when articles referred to “some treatment”. It was very sketchy to decipher who got treated and who did not, how much treatment each man in the study received, and how it affected clinical
findings. With such murky data, the ethical questions were more pronounced because it made it harder to justify why the men had been enrolled in this research to begin with, and why the study was continuing. As to the clinical findings, it was considered “messy science” (Reverby 2009) because it was not clear what the team was ever really observing when documenting complications of syphilis; every problem in someone with syphilis seemed to be attributed to syphilis when this was not the case (Reverby 2009).

In 1948, the new director of the Division of VD, Theodore J. Bauer, was alerted to problems with the study by Albert P. Iskrant, chief of the Office of Statistics in his division. Iskrant questioned the methods, data contamination, and whether the investigators had followed Alabama law for testing and treatment. Iskrant concluded that the data could be salvaged if it were analyzed as a study of “inadequately treated” syphilis (Jones 1993).

In 1951, Olansky and Shuman undertook a major internal review of the data to determine how to improve the data analysis, and even if the study should continue. They arranged for an outside reviewer to take a look at the scientific merits. Norwegian syphilologist, Trygve Gjestland, who had also re-examined the Oslo data, came to Atlanta in 1952 to meet Olansky and Cutler. Gjestland thought the entire observational study was a “scientific mess because of unclear categories and uncertain criterion for much of the diagnoses” (Reverby 2009). However, Gjestland suggested how to improve the data instead of suggesting the study end. Additionally, by 1952, the investigators thought the study data could also be used to study aging in their aging men; Peters was also furnished with better equipment to improve autopsies, which he continued until the early 1960s (Jones 1993).

The first documented ethical concern by peers surfaced in 1955. Count D. Gibson, an Associate Professor at the Medical College of Virginia heard Olansky give a lecture about the observation study, presumably reviewed the literature, and wrote to Olansky:

I am gravely concerned about the ethics of the entire program…The ethical problem in this study was never mentioned…There was no implication that the syphilitic subjects of this study were aware that treatment was being deliberately withheld…It seems to me that the continued observation of an ignorant individual suffering with a chronic disease for which therapeutic measures are available cannot be justified on the basis of any accepted moral standard: pagan (Hippocratic Oath), religious (Mainmonides, Golden Rule), or professional (AMA Code of Ethics)…Please accept this letter in a spirit of friendliness and an intense desire to see medical research progress in its present remarkable rate without any blemish on its record of service to humanity. (Reverby 2009: 71).

Reverby documents Olansky’s response, as follows:

He acknowledged Gibson’s worries that the Study was ‘callous and unmindful of the welfare of the individual.’ But he explained: ‘I’m sure it is because all of the details of the study are not available to you.’ He confessed that when he had started with the study in 1950 ‘all of the things that bothered you bothered me at the time…Yet after seeing these people, knowing them and studying them and the record I honestly feel that we have done them no real harm and probably have helped them in many ways… No females were selected so that the question of congenital [syphilis] could be eliminated.’ Olansky repeated what would
become the mantra: that the men had no chance to get treatment elsewhere when the Study started, that they ‘knew that they had syphilis and what the study was about, [and that] only those with latent syphilis were chosen. They got far better medical care as a result of their being in the study than any of their neighbors’ and a nurse ‘takes care of all their needs.’ “ (Reverby 2009: 71)

Olansky also inadvertently revealed to Gibson that the data was truly compromised. He wrote that “some of the patients did receive penicillin, but we are continuing to follow them…” Gibson was “deeply disturbed” by Olansky’s response (Reverby 2009).

On the 30th anniversary of the study in 1964, when the Archives of Internal Medicine published the paper on untreated syphilis by Rockwell et al., it prompted a letter to the editor by a young Canadian physician, Irwin Schatz. According to the New York Times (Roberts and Irwin 2015):

Dr. Schatz sent his letter, comprising three sentences, to the study’s senior author, Dr. Donald H. Rockwell. He wrote: “I am utterly astounded by the fact that physicians allow patients with potentially fatal disease to remain untreated when effective therapy is available. I assume you feel that the information which is extracted from observation of this untreated group is worth their sacrifice. If this is the case, then I suggest the United States Public Health Service and those physicians associated with it in this study need to re-evaluate their moral judgments in this regard.”

The letter was passed to a co-author, Dr. Anne R. Yobs of the Centers for Disease Control, who wrote in a memo to her bosses: “This is the first letter of this type we have received. I do not plan to answer this letter.”

Years later, Schatz learned that William B. Beam, editor of the Archives of Internal Medicine in 1972, noted then that he regretted that the journal had published the 1964 report, and said the journal had “obligations to apply moral and ethical standards” (Reverby 2009).

In 1965, Rivers and Dibble retired, but Rivers continued to see the men until her replacement could be found (see further). No medical historian has identified any replacement role for Dibble per se, but autopsies continued to be performed by Dr. Peters until the study was closed. A prominent polio expert at the Tuskegee Institute, Dr. John Hume, appears to have served as “Acting Medical Director” sometime after Dibble had left until 1971 (Jet 1971), when Dr. Cornelius L. Hopper became the new Medical Director of the John A. Andrew Memorial Hospital and Tuskegee Institute’s Vice President of Health Affairs. Hume was then named chief of staff and director of the orthopedic services at John A. Andrew Memorial Hospital (AAOS 2018). There are no specific documents that describe what Drs. Hume or Hopper knew about the study.

The Whistleblowing Phase

In 1966, a year after the Civil Rights Act was passed, and the same year that a major whistleblowing paper in the New England Journal of Medicine had been published
by Henry Beecher (see further below), Peter Buxton, a 27 year-old Jewish PHS social worker (hired in 1965) and based in San Francisco, started to look at internal documents and records about the ongoing Tuskegee study. Buxton was born in Prague, and brought to the United States as a baby when his parents fled the Holocaust. Buxton heard “watercooler” chatter about the study while lunching with some of his co-workers and found it hard to believe it was going on. As part of his job, he was expected to do short papers on venereal disease, and so he decided to focus on the Tuskegee study, and review what was available on it. He was so concerned about the moral issues with the trial, he sent a registered letter to the director of the Division of Venereal Disease, William J. Brown, with his own ethical analysis of the study in the context of the Nuremberg Trials. Brown did not respond immediately to the letter but asked a CDC colleague based there to meet with Buxton and explain the study to him. Buxton was not placated. At a conference a few months later, Buxton was summoned to a PHS meeting with Brown and Cutler to review the goals of the study in light of his concerns. The meeting did not go well; Cutler “dug in” about the value of the study and dismissed Buxton’s concerns. Buxton resigned in 1967 and went to law school, as the turbulent late 1960s raged on. In 1968, after the assassination of Martin Luther King, when racial tension exploded in riots across the country, Buxton wrote a second letter to Brown. In June 1968, Dibble died. During late 1968, Brown showed the letter to David Sencer, the director of the CDC, and it prompted the PHS to have a major interdisciplinary medical team meeting, inviting Olansky who had left. The meeting took place on February 6, 1969 (no African Americans were present); its purpose was to review the study to date, and decide whether to end or continue the study. One attendee agreed that the study should end and there was a moral obligation to treat the men, but he was outnumbered, and the rest decided to continue the study but re-seek stakeholder approval. They discussed hiring Rivers replacement, and they also discussed the potential that the study could be viewed as “racist” by some, but dismissed it as an impediment.

Stakeholder approval meant they needed to seek support for continuing the study from local African American physicians who now made up the majority membership of the Macon County Medical Society, as well as the medical professionals and new leadership at the John A. Andrew Hospital. John Caldwell, now in charge of the Tuskegee study briefed all the stakeholders on the study, and the local African American physicians agreed to continue to support it. In 1970, the PHS renewed its partnership with the John A. Andrew Memorial Hospital at the Tuskegee Institute for handling the x-rays, and hired Elizabeth Kennebrew to replace Rivers. During this period, Brown wrote back to Buxton to let him know there was overwhelming consensus to continue the study and that its design was sound.

Meanwhile, Buxton, continued to have considerable moral distress over the knowledge that the study was ongoing. In July 1972, one month after the Watergate news was breaking, he was introduced at a social event to an Associated Press reporter (Edith Lederer) and told her all about the study, and provided documentation. Lederer took the story to her editors, who assigned it to Jean Heller. The story broke July 25, 1972. A new era had begun in the Tuskegee Syphilis Study (See Heller 1972, for the link to the original Associated Press article).
Fred Gray, an accomplished civil rights attorney who lived not far from Macon County, Alabama, first read about the Tuskegee study in the newspaper like everyone else (Gray 1998). Gray had represented Rosa Parks in 1955, and was involved in several major civil rights cases. He was approached a few days later by Charles Pollard, who also read Heller’s story, didn’t realize he was part of an experiment until then, and told Gray he was one of the men in the study and wanted to sue. Thus Pollard et al. v. United States et al. was filed3 which led in 1975 to a multi-million-dollar settlement for the surviving men and their families; the estates and heirs of the deceased men. That settlement still provides reimbursement to heirs.

Fallout from the Heller article led the Assistant Secretary for Health and Scientific Affairs to appoint a panel to review the study; The Tuskegee Syphilis Study Ad Hoc Advisory Panel was chartered August 28, 1972, and was charged to investigate the study, and make recommendations on a defined set of questions4, including whether the study should end. The multidisciplinary subcommittee was chaired by Brodus Butler, and was a diverse committee. Astonishingly, the Ad Hoc Panel indeed interviewed Rivers, but the Chair decided to destroy her interview tapes (Washington 2007), clearly concerned that they may be problematic for Rivers. Ultimately, the Ad Hoc Panel wound up becoming bitterly divided, but did make the recommendation for the study to end immediately when they submitted their first report on October 27, 19725, The final report was dated April 28, 1973.6 But this protocol thereafter would become forever “studied” by medical historians and ethics scholars as one of the most notorious chapters in medical research history and health disparities.

In February and March 1973, the Senate Subcommittee on Health of the Committee of Labor and Public Welfare, led by Senator Ted Kennedy, held hearings on medical research, and discovered the Tuskegee study was not yet closed. Rivers never testified, but Buxton was among several witnesses who testified. The study finally closed after the Kennedy hearings insisted the men get treated. Hopper was involved in negotiating with the federal government over how best to treat the patients, but there is no evidence he participated in the study.

Coming full circle to the film, as many began to read about the study in subsequent decades, the decision to silence Rivers in 1972 motivated Feldshuh to allow her to speak her truth:

Evers: We proved there was no difference between how whites and blacks respond to syphilis.

Senator: If they were white would they have been treated as anyone?

3Pollard v. United States, 384 F. Supp. 304 (M.D. Ala. 1974) may be viewed here: https://law.justia.com/cases/federal/district-courts/FSupp/384/304/1370708/.
4See Footnote 1.
5See Footnote 1.
6The committee report can be viewed as this link: http://www.research.usf.edu/dric/hrpp/foundations-course/docs/finalreport-tuskegeestudyadvisorypanel.pdf.
Evers: You wouldn’t have dared. You wouldn’t have voted for it for forty years, if they were white. Somebody would have said something about this before now. Everybody knew what was going on. It wasn’t no secret. But because they were black nobody cared.

Consequently, a new phase of the Tuskegee study would begin: the postmortem Bioethics Phase (see under Healthcare Ethics Issues further), which blossomed in the 1990s as a direct result of Jones’ and Feldshuh’s works. The Bioethics Phase comprised the commissioning of a new committee to recommend “moral reparations” that culminated into a Presidential Apology, a national endowment and revitalization of the Tuskegee Institute to become a University and major Center for Bioethics, as well as more revelations about unethical syphilis studies conducted by the U.S. government on vulnerable populations.

**Other Observation and Non-treatment Studies**

When teaching from the history of medicine context of the Tuskegee study, it’s important to note that troubling non-therapeutic, or “under-therapeutic” observational protocols abound with problematic consent in both the United States and other countries. In the AIDS era, “protocol 076” was essentially a Tuskegee study, prompting the Editor of the *New England Journal of Medicine* to resign (see Chap. 2). In India, cervical cancer screenings were denied to 138,624 women to see if the unscreened women developed cervical cancer more frequently; 254 died (Suba 2015). In 1994, observing prostate cancer and withholding treatment had become a standard in men over 65 (Wilt et al. 2017), but the data shows that significant numbers of men died prematurely, consequent to no treatment (Frandsen et al. 2017). Debates are currently raging over observation-only of early breast cancers—ductal carcinoma in situ (O’Connor 2015; Lagnado 2015; Drossman et al. 2015; Bath 2016; Rosenthal 2015); and observation-only of biopsied confirmed thyroid cancer without informed consent, echoing the Tuskegee study (Rosenthal et al. 2017). In essence, once race is removed from the story, the Tuskegee study protocol is ongoing in many different disease contexts and remains a problematic theme in medicine, where observation is motivated by the desire to save money with less treatment. As for current treatment protocols for syphilis, we have come full circle, too. Although antibiotics have long been the treatment since the penicillin era began, due to some emerging antibiotic-resistant strains in underserved populations, some practitioners suggest re-exploring the metals treatments again (Ambrose 2016).

**Healthcare Ethics Issues**

When examining the plethora of healthcare ethics issues entangled with the Tuskegee study, and the film *Miss Evers’ Boys*, there are four areas to consider for discussion.
First, there are research ethics considerations, which surround the study design within the prevailing research ethics standards or guidelines, as well as the “reparations” phase of the Tuskegee study, which involved compensation to the harmed subjects and their families. Second, there are clinical ethics considerations: did the healthcare providers involved deliver the standard of care, and did they knowingly violate the prevailing clinical and professional ethical standards of care? Third, there are distributive justice considerations that surround health disparities in this specific population vs. health disparities overall; public health considerations surrounding the study’s impact on syphilis. Finally, there is the “Bioethics Phase” of this study surrounding “preventative ethics” guidelines; moral corrections, and accountability. The staging of the play, “Miss Evers’ Boys” as well as the making of the film, is considered by some to be part of this final phase—letting the public see what occurred as part of an accounting of the harms.

Research Ethics Considerations

In the field of bioethics, invoking the noun “Tuskegee” is code for “egregious study design”. As discussed in the History of Medicine section above, the initial Rosenwald treatment study is not what we mean when we say “Tuskegee.” What we really mean is the observational study that resulted from the “Vonderlehr design”.

Although even the Rosenwald treatment study had problems with informed consent, it was debatable at that stage whether consent standards were any better in other populations at the time. What made the Rosenwald treatment study ethical were its specific aims, which indeed met the beneficence standard for both the individuals treated and the population at large. When the Rosenwald study ended, the “Clark design” of the study fails the informed consent test, but had some ethically defensible aims in that it indeed provided the standard of care immediately to men in the earlier phases of syphilis, with the goal of treating all study subjects within a six-month period. It’s clear that if the Clark design ended as planned, nobody would have ever heard of the Tuskegee study at all.

What makes the Tuskegee study infamous was its morphing into the “Vondelehr design”: deliberate misinformed consent and deceit; withholding the pre-penicillin standard of care; and finally, withholding penicillin in the penicillin era, which could have cured the subjects.

Research Ethics Guidelines 1932–1972

To ethically locate the research ethics issues initially, it’s important to first consider the research ethics guidelines in 1932. When the Tuskegee study began in 1932, the obvious problems with informed consent were not unique, and public health studies were judged by the quality of the generalizable data that led to improved public health. Between 1932 and 1947, there were no codified “research ethics” guidelines
at all, and “research ethics” was not a consideration. However, as discussed earlier, the Tuskegee study’s data by even these standards was a bad study because its sloppy design and methods polluted the data.

After the Nazi medical experiments were revealed in 1945, and the subsequent Nuremberg Trials took place, The Nuremberg Code was created by the American military. It was the first codified Research Ethics guideline and formally published by the U.S. government in 1949 (NIH 2020). It is clear to medical historians that by 1947 the Tuskegee study was in violation of The Nuremberg Code because there was no informed consent. But so were dozens of other American studies going on at that time, many of which involved vulnerable populations such as children. In the 1950s, for example, the polio vaccine was tested on children without consent (Wellner 2005). American practitioners did not seem to recognize that The Nuremberg Code was applicable in the United States, and many assumed it was intended to define Nazi medical experiments specifically; undoubtedly, the word “Nuremberg” confused U.S. practitioners, and they did not seem to understand its purpose.

In 1964, the World Medical Association announced The Declaration of Helsinki in the July 18 issue of the British Medical Journal. This set of guidelines largely echoed the Nuremberg Code, but helped to define distinctions between therapeutic and nontherapeutic clinical research. By the new 1964 standards, the Tuskegee study fell into the category of nontherapeutic clinical research without informed consent, now in violation of the Declaration of Helsinki. It’s possible that the Declaration of Helsinki may have been influenced by an infamous 1962 study truly resembling Nazi medical experiments. In this case, Chester Southam from Memorial Sloan Kettering, partnered with the Jewish Chronic Disease Hospital to inject live HeLa cells into some of its elderly patients without informed consent. Three Jewish doctors refused to participate in the study, but many took part. This experiment was exposed in 1964 when the front-page headline of the New York World-Telegram on Jan. 20, 1964 read: “Charge Hospital Shot Live Cancer Cells Into Patients.” (Hornblum 2013).

There were no other codified U.S. guidelines at this time, but by 1966, a whistle-blowing article in the New England Journal of Medicine by Henry Beecher was published that “outed” 22 clinical trials in violation of the Nuremberg Code, which included the Brooklyn Jewish Chronic Disease Hospital.

Informed Consent Versus Beneficence

In the post-war years, once the study continued past the Nuremberg Code (1947), lack of informed consent started to become viewed as a serious ethical issue as awareness of Nazi medical experiments became more widely known. Even by 1932 standards, informed consent problems were noted. According to Jones (1993):

Dr. J.W. Williams, who was serving his internship at Andrews Hospital at the Tuskegee Institute in 1932 and assisted in the experiment’s clinical work, stated that neither the interns nor the subjects knew what the study involved. ‘The people who came in were not told what was being done…we told them we wanted to test them. They were not told, so far as I know, what they were being treated for, or what they were not bring treated for…and the subjects’
thought they were being treated for rheumatism or bad stomachs... We didn't tell them we were looking for syphilis. I don't think they would have known what that was'.

Charles Pollard, one of the subjects, clearly recalled the day in 1932:

when some men came by and told him that he would receive a free physical examination if he appeared the next day at a nearby one room school. 'So I went on over and they told me I had bad blood...and that [is] what they've been telling me ever since. They come around from time to time and check me over and they say Charlie, you've got bad blood... All I knew was that they just kept saying I had the bad blood—they never mentioned syphilis to me, not even once. (Jones 1993)

But in 1932, informed consent was not the standard, especially when it came to patients with literacy issues. Even in more educated patient populations, few doctors provided "informed consent"; in fact, "therapeutic misconception" was much more the standard. Clearly, the Nuremberg Code's first requirement was violated in that the voluntary consent of the subject was not obtained, and coercive incentives to participate were used, which included deception. However, pre-Nuremberg, by 1930s standards, what did "coercion" really mean?

Jones observes (1993):

The press quickly established that the subjects were mostly poor and illiterate, and that the PHS had offered them incentives to participate. The men received free physical examinations, free rides to and from the clinics, hot meals on examination days, free treatment for minor ailments, and a guarantee that [fifty dollars for] burial stipends would be paid to their survivors.

Post-Nuremberg, the incentives continued: in 1957, in honor of the 25th year of the Study, each man also received a special certificate signed by Surgeon General Leroy E Burney for "completing 25 years of active participation in the Tuskegee medical research study" and a dollar for every year of 'service'…. Rivers stated the men were "thrilled with their cash awards" (Reverby 2009). Rivers acknowledged the consent issues in interviews, but she also considered the Tuskegee study as "beneficent" because the men got more attention than they would have otherwise. She was fully aware of the deception, but given the research standards of the time, did not think anything of it. She states (Smith 1996):

I got with this syphilitic program that was sort of a hoodwink thing, I suppose....Honestly, those people got all kinds of examinations and medical care that they never would have gotten. I've taken them over to the hospital and they'd have a GI series on them, the heart, the lung, just everything. It was just impossible for just an ordinary [black] person to get that kind of examination... they'd get all kinds of extra things, cardiograms and... some of the things that I had never heard of. This is the thing that really hurt me about the unfair publicity. Those people had been given better care than some of us who could afford it... They didn't get treatment for syphilis, but they got so much else".

In terms of meeting the standard of "beneficence", it's a stickier question in the pre-penicillin era because of clinical equipoise over the metals therapy, but the concept of "clinical equipoise" would not be articulated until 1987, which refers to clinical disagreement among the community of experts over which therapy is better or more effective (Freedman 1987). Freedman argued in 1987 that when there is
clinical equipoise, a randomized controlled trial can ultimately disturb equipoise so long as there is enough statistical power to settle the question. It can be argued that the observation trial was the presumed rationale to attempt to disturb equipoise, but the fact that the men got variable amounts of (under)treatment ruled out any potential for disturbing equipoise. What about the argument that there was “some benefit” to the subjects that transpired in the pre-penicillin years given the health disparities in the region, as most would have had “no treatment” otherwise. Under-treatment where “usual care” is nothing has been used as an ethical justification to enroll subjects in many clinical studies. But once penicillin became a standard of care, there is no “beneficence” argument that could justify continuing the study.

It’s possible that some of the men may still have consented to the Tuskegee study had they been told the true nature of the study, and its potential benefits and risks. For example, had they been told that they will receive less treatment than the standard of care, but more treatment than not seeing a doctor at all given the regional health disparities, informed consent would have become the “honest broker” as to whether the study was advantageous to them in some way.

Rivers stated: “Now a lot of those patients that were in the Study did get some treatment. There were very few who did not get any treatment” (Reverby 2009). Historians have tried to analyze Rivers’ views on beneficence-based grounds:

[Rivers] knew that the ‘iron tonics, aspirin tablets and vitamin pills’ that she gave out were not treatments for syphilis. But she described these drugs, as well as the physical exams, as being part of the treatment. She knew the aspirins helped with the pains of arthritis and the iron tonics gave the men ‘pep’ in the spring. She said: ‘This was part of our medication that they got and sometimes they really took it and enjoyed it very much. And these vitamins did them a lot of good. They just loved those and enjoyed that very much very much.’ … Nurse Rivers seemed more troubled when she talked in her interviews about what penicillin had meant for the treatment of syphilis after the 1940s…She communicated in a ‘just following orders’ nursing voice…But, as with any of the doctors, she also emphasized the dangers of the Herxheimer reactions and her memory of someone dying from anaphylactic shock from a penicillin allergy (Reverby 2009).

By 1950, the PHS investigators clearly started to question whether the study was, in fact, “beneficent”. They mused that maybe the medical activities performed to date on this population weren’t so benign after all. The inadequate heavy metal treatments provided through the years may have caused morbidity and sped up some of the men’s deaths (had treatment been adequate with a cure intended, the risks could be justified); many invasive diagnostic tests, including lumbar punctures, had significant risks (had the tests’ purpose been to determine treatment, those risks could have been justified), and finally, the issue of medical neglect overall through the years took a toll on the population. Thus, O.C. Wenger concluded in a 1950 paper he delivered at a venereal disease conference: “[T]hese patients received no treatment on our recommendation. We know now, where we could only surmise before that we have contributed to their ailments and shortened their lives. I think the least we can say is that we have a high moral obligation to those that have died to make this the best possible study” (Gray 1998; Reverby 2009). In essence, stopping the study seemed “unethical” at a certain point to the study investigators.
The wording of The Nuremberg Code, however, specifically references that the code applied to an “experiment” (NIH 2020). It is not clear whether the PHS investigators viewed the Tuskegee study as an “experiment” per se, and the term “study” had different connotations. Since they were “following” a disease, but not testing any new drug or therapy, and even providing some nominal amounts of treatment, the Tuskegee study did not fit neatly into traditional categories of “experiment”. By 1964, when the first version of the Declaration of Helsinki was unveiled, the Tuskegee study could more clearly be defined as “non-therapeutic research” and it is clear that it violated most of the guidelines set forth in that document (WMA 2020), including all of Sections II and III. But by this period, the Tuskegee study published its findings on its 30th anniversary, and it is not clear—even now—how any investigator in this time frame would have applied “new” guidelines to old studies, in a pre-institutional/ethics review board (IRB) era. Were these new guidelines to be retroactive to 30 year-old studies? This question, even now, remains unclear.

John R. Heller, who was the decision-maker regarding penicillin from 1943–48 said in 1972 there was “nothing in the experiment that was unethical or unscientific” (Jones 1993). A CDC spokesperson defended the Tuskegee study that same year: “We are trying to apply 1972 medical treatment standards to those of 1932…At this point in time, with our current knowledge of treatment and the disease and the revolutionary change in approach to human experimentation, I don’t believe the program would be undertaken” (Jones 1993). It’s important to note that Heller called it an “experiment” while the CDC spokesman referred to the Tuskegee study as a “program”. There is complete inconsistency in how the investigators viewed the Tuskegee study overall, and thus, it is difficult to assess what they understood to be applicable to either The Nuremberg Code or The Declaration of Helsinki.

Where there is consistency is in the contemporaneous peer assessment of when the Tuskegee study became definitively “unethical”. Because there was clinical equipoise over the use of penicillin in latent or tertiary syphilis until about the mid-1950s (see earlier), the withholding of penicillin beyond that time frame is when the PHS was seen as truly crossing a bright moral line for medical practitioners reviewing the study, which is what led to someone finally blowing the whistle.

**Clinical and Professional Ethics Issues**

One of the core themes in *Miss Evers’ Boys* surrounds the moral actions of the African American healthcare providers in enabling the Tuskegee study and collaborating with the PHS investigators. In evaluating the clinical and professional ethics issues surrounding the Tuskegee study, it’s important to try to uncover what the healthcare providers involved believed was the prevailing clinical and professional ethical standards of care at the time, and whether they were in violation with those standards. The central problem in evaluating this question is germane to clinical trials in general: when patients are research subjects, what standard of patient care should apply? (For a prolonged discussion, see Clinical Ethics on Film, Chap. 1.) Even today,
these questions are difficult to nail down, but in the years the Tuskegee study ran, particularly in the Plessy era, the complexity of holding African American healthcare providers to the same patient care standards applicable today are not realistic. At the same time, dismissing the African American healthcare providers involved as having no moral agency is not responsible, either. In 1974, Fred Gray had taken a deposition from Nurse Rivers. He decided that she, along with all other Tuskegee Institute personnel, were merely “victims” of a racist protocol, with absolutely no power or control to stop the study, and had no choice but to go along (Gray 1998). Gray’s perspective reduced the Tuskegee Institute professionals to non-autonomous, childlike beings, who had no moral agency whatsoever; it is a position that can be understood in the context of the 1970s, but became an increasingly problematic lens from which to view Dibble, Rivers and Moton in future years, given their training and positions (see earlier sections). The real answer is that these healthcare professionals agreed with the study aims at the time from a global health ethics perspective, in much the same way that we look upon studies in developing countries today where the standard of care is nothing. To these providers, the Tuskegee study was a “racial uplift” project (see earlier) they thought would address an important question for science regarding how much treatment was necessary in late stage syphilis in a population that had no access to medical care. They also thought the Tuskegee study was providing some benefit to the men, who were otherwise a completely medically neglected population. What they could not control were the wider health disparities issues that existed, which is a wider macro-ethics problem for which we cannot hold them responsible. Because most important of all, they saw the study as a vehicle for drawing more resources to the cause of African American healthcare—to potentially reduce health disparities. As for their professional ethics duties and the issue of deception—they were modeling the paternalistic attitudes that prevailed throughout American medicine in that time frame. Medical paternalism was equally applied to white patients, too.

In 1957, Rivers received the Oveta Culp Hobby Award for her “selfless devotion and skillful human relations…had sustained the interest and cooperation of the subjects of a venereal disease control program in Macon County Alabama” (Reverby 2009). She continued to take pride in her role right up until the Associated Press article outed the trial in 1972. Unfortunately, we don’t know what Dibble would have said about this study if he were still living in the 1970s, but I have provided reasonable speculative analysis in earlier parts of this chapter.

Rivers was blindsided by the criticism over her participation in the Tuskegee study. According to Jones (1993): “Once her identity became known, Nurse Rivers excited considerable interest, but she steadfastly refused to talk with reporters. Details of her role in the experiment came to light [through] an article about the Tuskegee Study that appeared in Public Health Reports in 1953.” In that article, she was noted to be the liaison between the researchers and subjects and to live in Tuskegee. She apparently stated in 1973 to a Jet magazine reporter (Smith 1996): “I don’t have any regrets. You can’t regret doing what you did when you knew you were doing right. I know from my personal feelings how I felt. I feel I did good in working with the people. I know I didn’t mislead anyone”.

Healthcare Ethics Issues 63
It’s possible that Rivers, over time, reconsidered her role. Reverby (2009) notes that James Jones was “sure [Rivers] had no moral uncertainty during the Study years, [but] he recalled that she told him to shut off the audiotape he was using [when interviewing her]. She then turned to him and said: ‘We should have told those men they had syphilis. And God knows we should have treated them.’ ”

Smith (1996) observes:

Black professionals faced a dilemma imposed by American racism in how to provide adequate health services to the poor within a segregated system. Furthermore, the gendered nature of public health work meant that the nurse, invariably a woman, was at the center of public provisions, both good and bad. As her actions show most starkly, black professionals demonstrated both resistance to and complicity with the government and the white medical establishment as they attempted to advance black rights and improve black health. Rivers and other black professionals counted on the benefits of public health work to outweigh the costs to the poor…but there were dire consequences when they were wrong.

In my view, the “moral complicity” argument is not applicable when given the lived context of these African American healthcare providers, living in the Plessy era in the Jim Crow South. Remember: these African Americans did not see any substantive changes to segregation and their civil liberties for most of their natural lives. The following scene from Miss Evers’ Boys perhaps best captures the issue they faced with respect to withholding treatment.

Evers: I’m a nurse. I’m not a scientist.

Brodus: There is no difference. Not here. Not now. Not for us…You serve the race your way. I serve it in mine…I can’t rock the boat while I’m trying to keep people from drowning. There are trade-offs you can’t even imagine. Don’t you see that?

Distributive Justice and Health Disparities

The original sin in the Tuskegee study are the conditions that created a vulnerable population and health disparities to begin with: mainly racism and apartheid as federal and social policy. The concept of social and racial justice in the Plessy era was not on speaking terms with American law at that time, while the Brown decision (see earlier) was specific to education. Healthcare access would remain largely inaccessible for impoverished Americans until the passage of Medicaid. The concept of “vulnerable population” was not properly articulated until 1978, when it first appeared in The Belmont Report (HHS 2020) which was largely informed by the Tuskegee study, but was also responding to the studies revealed in the Beecher paper in 1966. The 1973 Kennedy hearings surrounding protections for medical research subjects were indeed prompted by the Tuskegee study as well as other egregious studies such as Willowbrook and the Jewish Chronic Disease Hospital. These hearings led to the National Research Act (1974) and the formation in 1975 of the National Commission for the Protection of Human Subjects; its first report, Research With Children (National Commission 1977), addressed the Willowbrook experiments, followed by The Belmont Report in 1978 (HHS 2020), which addressed the Tuskegee study, and
which specifically articulates the meaning of “vulnerable population” and distributive justice considerations as a requirement in research, codifying that such populations cannot be exploited in research, and that the burdens and benefits of research must be evenly distributed across populations.

**The Bioethics Phase**

The bioethics legacy of the Tuskegee study was to craft future preventative ethics guidelines that more clearly defined universal ethical principles in clinical research, codified in The Belmont Report: Respect for Persons, Beneficence, and Justice. All three were reverse-engineered principles designed to prevent another Tuskegee study from recurring. The Principle of Respect for Persons articulated that even those who cannot consent must be protected in research; the Principle of Beneficence makes clear that research must ensure that there is a greater balance of benefits than harms and that researchers must maximize benefits and minimize harms; and finally, the Principle of Justice dealt with preventing exploitation of vulnerable populations.

When Jones published the first definitive medical history of the Tuskegee study, it was just after The Belmont Report was published, and also informed by the first definitive scholarly text on medical ethics: Principles of Biomedical Ethics (Beauchamp and Childress 1979). But there were few bioethics courses available, and the field, per se, did not yet exist. As one bioethicist would later note, however, “Tuskegee gave birth to modern bioethics and James H. Jones was the midwife” (Reverby 2009). Coming full circle to the beginning of this chapter, one could say, too, that James H. Jones was the midwife to the film, *Miss Evers’ Boys*.

As bioethicists began to populate academic medical centers, and the teaching of the Tuskegee study led to further analysis, there was a renewed sense of morally unfinished business. One piece of unfinished business, partly informed by this notorious study, was the articulation of a fourth bioethics principle.

**The Principle of Non-Maleficence and the Duty to Warn**

The Principle of Non-Maleficence spelled out the specific duty not to “intentionally” harm patients or their beneficiaries by performing known harmful therapies with no benefit, as well as knowingly withholding beneficial therapies.

In 1976, an obscure health law case would become relevant to public health ethics in particular. *Tarasoff v. Regents of the University of California* established the “duty to warn” third parties in imminent danger. (See Chap. 2.) By the 1980s, the “duty to warn” began to be a standard applied to the public health context, which meant that the duty to warn identifiable third parties that they may have contracted a serious sexually transmitted disease, including syphilis, was another factor to consider in the laundry list of harms done to the Tuskegee study enrollees. Family members who were known to be at-risk during the study years, and contracted syphilis, or who
gave birth to children with congenital syphilis, were also considered harmed by the Tuskegee study.

The 1973 class action lawsuit filed by Fred Gray\(^7\) was essentially based on the violation of the Principle of Non-Maleficence. Compensation packages were not just to the men, but to the families connected to this study who were not informed or warned they were at risk for syphilis, as well as those born with congenital syphilis because their fathers were never treated.

**The Tuskegee Committee**

A major outgrowth of the bioethics phase was to reconvene a bioethics committee to re-examine the Tuskegee study with more historical distance. Thus, the Tuskegee Syphilis Study Committee was formed in 1996, and issued its report, which included a recommendation for a formal Presidential Apology.\(^8\) The report stated (Tuskegee Syphilis Study Committee 1996):

> Because the Tuskegee study is a starting point for all modern moral reflection on research ethics, a meeting of the NBEAC at Tuskegee in conjunction with a Presidential apology would be an ideal new beginning.

The apology finally came to fruition May 16, 1997,\(^9\) also following Fred Gray’s reaction to the HBO airing of *Miss Evers’ Boys* in February of that year.

President Clinton’s formal apology was an important enhancement to the film’s release—still the only feature film made about the Tuskegee study as of this writing. With the film’s release, and the apology, a new generation of scholarship and journalism surrounding the Tuskegee study began to flourish, which informed deeper insights into health disparities in the African American population, as well as trust issues that scholars now coin the “legacy of Tuskegee” (Reverby 2009). Harriet Washington in her book, *Medical Apartheid* (2007), pointed out that the Tuskegee study was fully representative of the treatment of African American patients received, but was not at all unique. Then an unexpected event occurred. Historian Susan Reverby, while doing research for her book, *Examining Tuskegee* (2009), discovered a *second* unethical syphilis study conducted by the U.S. government that had been kept secret, known as The Guatemalan Syphilis Study (1946–8). Here, the U.S. government enrolled human subjects in Guatemala without informed consent, deliberately infected them with syphilis, and then treated them with penicillin (Reverby 2012). The purpose of the Guatemalan study was to optimize penicillin dosages for the treatment of syphilis—the drug treatment withheld from the Tuskegee study subjects at the time. This time, a second “Clinton Apology” was needed. Hillary

---

\(^7\)See Footnote 3.

\(^8\)The entire report can be viewed here: [http://exhibits.hsl.virginia.edu/badblood/report/](http://exhibits.hsl.virginia.edu/badblood/report/).

\(^9\)The Apology transcripts can be reviewed at this link: [https://www.cdc.gov/tuskegee/clintonp.htm](https://www.cdc.gov/tuskegee/clintonp.htm).
Clinton in the role of Secretary of State, serving the first African American U.S. President, Barack Obama, issued the formal apology about the second egregious syphilis study conducted by the U.S. government that harmed Guatemalans and their families and American medical research integrity in general (Hensley 2010).

Conclusions

Ultimately, the infamous Tuskegee Syphilis Study dramatized in Miss Evers’ Boys spans multiple generations, lasted more than the average life span of any of its enrolled human subjects, was rooted in twentieth century systemic racism, but continues to harm patients and their families well into this century because of lasting disparities and mistrust of the medical community, and the American government institutions that are supposed to provide protections. Echoes of this study can be seen in the twenty-first century from the wake of Hurricane Katrina (2005), to the poisoning of African American citizens in Flint Michigan (2013), to the burden of the COVID-19 deaths in 2020 (see Afterword). When teaching Miss Evers’ Boys today—as an enhancement to any number of courses—the first question we must address is whether we have made any progress at all in racism and health disparities. We need to be transparent about the fact that the United States is still a racist country—just “less racist” than it was when the Tuskegee study was running. Within this context, no one should be shocked that this study not only ticked along for 40 years, but that Congress continued to vote for it year after year—as Miss Evers reminds us in the film. The Tuskegee study’s protocol, as Nurse Evers correctly states, “wasn’t no secret; everybody knew what was going on…we gave the best care that was in our power to give to those men.”

Theatrical Poster

Miss Evers’ Boys (1997)

Director: Joseph Sargent
Producer: Robert Benedetti, Laurence Fishburne, Derek Kavanagh, Kip Konwiser, Kern Konwiser, Peter Stelzer
Screenplay: Walter Bernstein
Based on: “Miss Evers’ Boys” (1992 stage play) by David Feldshuh
Starring: Alfre Woodard, Laurence Fishburne, Craig Sheffer, Joe Morton, Obba Babatunde, and Ossie Davis
Music: Charles Bernstein
Cinematography: Donald M. Morgan
Editor: Michael Brown
Production Company: HBO NYC Productions and Anasazi Productions
Distributor: HBO
Release Date: February 22, 1997
Run time: 118 min
References

Academy Awards. (2019). *Speech for 1939 actress in a supporting role.* http://aaspeechesdb.oscars.org/link/012-2/.

Alliance for Human Research Protection. (2014). 1962: Dr. Chester Southam injected live cancer cells into 22 elderly patients. http://ahrp.org/1962-dr-chester-southam-injected-live-cancer-cells-into-22-elderly-patients-at-jewish-chronic-disease-hospital-in-brooklyn/.

Ambrose, C. T. (2016). Pre-antibiotic therapy of syphilis. *NESSA Journal of Infectious Diseases and Immunology, 1*(1), 1–20. https://uknowledge.uky.edu/microbio_facpub/83.

American Academy of Orthopedic Surgeons (AAOS). (2018). John F. Hume. http://legacyofheroes.aaos.org/AboutHeroes/stories/hume.cfm.

Anne Frank.org. (2018). www.annefrank.org.

Bath, C. (2016). Is observation without surgery a viable strategy? *The ASCO Post*, November 10, 2016. http://www.ascopost.com/issues/november-10-2016/is-observation-without-surgery-a-viable-strategy-for-managing-ductal-carcinoma-in-situ/.

Beauchamp, T. L., & Childress, J. F. (1979). *Principles of biomedical ethics*. New York: Oxford University Press.

Beecher, H. K. (1966). Ethics and clinical research. *New England Journal of Medicine, 274*(24), 1354–1360.

Brandt, A. M. (1978). Racism and research: The case of the Tuskegee Syphilis study. *The Hastings Center Report, 8*, 21–29.

Brownstein, R. (2014). How Brown v. Board of education changed—and didn’t change American education. *The Atlantic*, April 25, 2014. https://www.theatlantic.com/education/archive/2014/04/two-milestones-in-education/361222/.

Bruusgaard, E. (1929). The fate of syphilitics who are not given specific treatment. *Archiv fur Dermatologie and Syphilis, 157*, 309.

Canby, V. (1972, July 20). Irving wallace’s ‘the man’: Political movie stars James Earl Jones. *New York Times*.

Centers for Disease Control (CDC). (1981). *Pneumocystis pneumonia, 30*(21), 1–3. https://www.cdc.gov/mmwr/preview/mmwrhtml/june_5.htm.

Coaxum, J. (2018). Historically black colleges and universities. *State University Webpage*. http://education.stateuniversity.com/pages/2046/Historically-Black-Colleges-Universities.html.

Conner, E. (2019). https://www.ranker.com/list/whoopi-goldberg-and-ted-danson-dated/eric-conner.

Cornell University. (1993). Documentary. *Susceptible to Kindness*.

Cornell University. (2018). David Feldshuh faculty page: http://pma.cornell.edu/david-m-feldshuh.

Dibble, E., Rabb, L., & Ballard, R. (1961). John A. Andrew Memorial Hospital. *Journal of the National Medical Association, 53*, 104–118. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2641895/pdf/jnma00690-0004.pdf.

Dougherty, M. (1987). Playing South African Activist Winnie Mandela, Alfre Woodard Captures the soul of a nation. *People*, September 28, 1987. https://people.com/archive/playing-south-african-activist-winnie-mandela-alfre-woodard-captures-the-soul-of-a-nation-vol-28-no-13/.

Downs, M. L. (2015). *Great depression in Alabama*. April 21, 2015. http://www.encyclopediaofalabama.org/article/h-3608.

Drake, S. (1990). Stage review: Subject propels Miss Evers’ Boys. *Los Angeles Times*, July 20, 1990. http://articles.latimes.com/1990-07-20/entertainment/ca-18_1_miss-evers-boys.

Drossman, S. R., Port, E. R., & Sonnenblick, E. (2015). Why the annual mammogram matters. *New York Times*, October 29, 2015. http://www.nytimes.com/2015/10/29/opinion/why-the-annual-mammogram-matters.html?_r=1.

Encyclopedia.com. (2018). Laurence Fishburne, 1961. Contemporary black biography. *Encyclopedia.com*. July 17, 2018. http://www.encyclopedia.com/education/news-wires-white-papers-and-books/fishburne-laurence-1961.
Encyclopedia.com (2019). Charles Spurgeon Johnson (1893–1956). Encyclopedia of world biography. Encyclopedia.com. July 12, 2019. https://www.encyclopedia.com/people/history/historians-miscellaneous-biographies/charles-s-johnson.

Fairclough, A. (1997). Civil rights and the Lincoln Memorial: The censored speeches of Robert R. Moton (1922) and John Lewis (1963). The Journal of Negro History, 82(4), 408–416. https://www.jstor.org/stable/2717435?seq=1#page_scan_tab_contents.

Ferris State University. (2018). Jim Crow Museum or Racist Memorabilia. https://www.ferris.edu/HTMLS/news/jimcrow/who/index.htm.

Frandsen, J., Orton, A., Shrieve, D., & Tward, J. (2017). Risk of death from prostate cancer with and without definitive local therapy when gleason pattern 5 is present: A surveillance, epidemiology, and end results analysis. Cureus, 9(7), e1453. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5590810/.

Freedman, B. (1987). Equipoise and the ethics of clinical research. New England Journal of Medicine, 1987(317), 141–145.

Frith, J. (2012). Syphilis—Its early history and treatment until penicillin and the debate on its origins. Journal of Military and Veterans’ Health, 20, 4. https://jmvh.org/article/syphilis-its-early-history-and-treatment-until-penicillin-and-the-debate-on-its-origins/.

Furman, M. (2012). 90th Anniversary of the dedication of the Lincoln memorial. Ranger Journal, 30 May, 2012. https://www.nps.gov/nama/blogs/90th-anniversary-of-the-dedication-of-the-lincoln-memorial.htm.

Gebreyes, R. (2016). Actress Mary Steenburgen’s friendship with the Clintons goes way back. Huffington Post, Oct. 27, 2016. https://www.huffingtonpost.com/entry/mary-steenburgen-hillary-clinton_us_581110a8e4b064e1b4b04957.

Geiger, J. H. (1981). An experiment with lives. Book Review. New York Times, June 21, 1981. https://archive.nytimes.com/www.nytimes.com/books/98/12/06/specials/jones-blood.html?mcubz=1.

Gjestland, T. (1955). The Oslo study of untreated syphilis; an epidemiologic investigation of the natural course of the syphilitic infection based upon a re-study of the Boeck-Bruusgaard material. Acta Derm Venereol Suppl (Stockh), 35(Suppl 34), 3–368; Annex I-LVI. https://www.ncbi.nlm.nih.gov/pubmed/13301322.

Gray, F. D. (1998). The Tuskegee Syphilis study. Montgomery, AL: New South Books.

Harvard Library (2018). Rivers interview by BWOHP. https://sds.lib.harvard.edu/sds/audio/443302359.

Harvey, W. B., Harvey, A. M., & King, M. (2004). The impact of Brown v. Board of Education on post-secondary participation of African Americans. https://www.jstor.org/stable/4129615?seq=1#page_scan_tab_contents.

Health and Human Services (HHS). (2020). The Belmont Report. https://www.hhs.gov/ohrp/regulations-and-policy/belmont-report/index.html.

Heller, J. (1972). Syphilis victims in U.S. study went untreated for 40 years. New York Times, July 26, 1972. https://www.nytimes.com/1972/07/26/archives/syphilis-victims-in-us-study-went-untreated-for-40-years-syphilis.html.

Hensley, S. (2010). U.S. apologizes for syphilis studies in Guatemala. NPR, October 1, 2010. https://www.npr.org/sections/health-shots/2010/10/01/130266301/u-s-apologizes-for-medical-research-that-infected-guatemalans-with-syphilis.

Hill, R. E. (Ed.). (1991). The black women oral history project: From the Arthur and Elizabeth Schlesinger library on the history of women in America, Radcliffe College. In R. E. Hill (Ed.), Westport, CT: Meckler.

Holt, P. (1996). Alice Walker on the making of the film ‘The Color Purple’. San Francisco Chronicle. January 7, 1996. https://www.sfgate.com/books/article/Alice-Walker-on-the-Making-of-the-Film-The-Color-3000001.php.

Horblum, A. M. (2013). NYC’s forgotten cancer scandal. New York Post, December 28, 2013. https://nypost.com/2013/12/28/nycs-forgotten-cancer-scandal/.

Jet (1971). People: Dr. John Hume. Jet, Mar 25, 1971.
Jet (1997). Laurence Fishburne and Alfre Woodard star in HBO movie about Tuskegee experiment on syphilis. Jet, February 24, 1997.

Journal of the National Medical Association (JNMA). (1962). Dr. Eugene Heriot Dibble, Jr., Distinguished Service Medalist for 1962. Journal of the National Medical Association, 54, 711–712.

Isenberg, B. (1990). Recreating a night of good intentions: Dr. David Feldshuh’s ‘Miss Evers’ Boys’ examines a dark hour in medicine: the Tuskegee syphilis study. Los Angeles Times, July 15, 1990. http://articles.latimes.com/1990-07-15/entertainment/ca-372_1_miss-evers-boys.

Johnson, C. (1931). The Negro in American civilization. London: Constable and Company Ltd.

Johnson, C. (1934). In the shadow of the plantation. Chicago: University of Chicago Press.

Jones, J. (1981, 1993). (First edition, 1981; Revised edition, 1993). Bad blood. New York: Free Press.

Kagan, J. (2004). Visual History with Joseph Sargent. Interviewed by Jeremy Kagan, Directors Guild of America. Retrieved from https://www.dga.org/Craft/VisualHistory/Interviews/Joseph-Sargent.aspx.

Katz, R. V. (2008). The legacy of Tuskegee. Journal Healthcare Poor Underserved, 19(4), 1168–1180. (https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2702151/).

Kenton, W. (1929). Stock market crash of 1929. Investopedia, Apr 17, 2018. https://www.investopedia.com/terms/s/stock-market-crash-1929.asp.

King, S. (1997). A government study gone bad. Los Angeles Times. Retrieved from http://articles.latimes.com/1997-02-16/news/tv-29113_1_miss-evers.

Lagnado, L. (2015). Debate over early stage cancer. Wall Street Journal, October 19, 2015. http://www.wsj.com/articles/debate-over-early-stage-cancer-to-treat-or-not-to-treat-1445276596.

Legal Defense Fund. (2019). Landmark: Brown v. Board of Education. http://www.naacpldf.org/case/brown-v-board-education.

Levitt, S. (1993). Changing partners. People, November 22, 1993.

Lewis, N. A. (1995). Ex-colleague says Clinton nominee knew of Tuskegee study in 1969. New York Times, February 28, 1995. https://www.nytimes.com/1995/02/28/us/ex-colleague-says-clinton-nominee-knew-of-syphilis-study-in-1969.html.

Marriott, M. (1997). First, do no harm: A nurse and the deceived subjects of the Tuskegee Study. New York Times, February 16, 1997. https://www.nytimes.com/1997/02/16/tv/first-do-no-harm-a-nurse-and-the-deceived-subjects-of-the-tuskegee-study.html.

McVean, A. (2019). 40 years of human experimentation in America: The Tuskegee Syphilis Study. McGill Office for Science and Society, January 25, 2019. https://www.mcgill.ca/oss/article/history/40-years-human experimentation-america-tuskegee-study.

Meyer, H. S. (1981). Bad blood: The Tuskegee syphilis experiment. JAMA, 246(22), 2633–2634. https://jamanetwork.com/journals/jama/article-abstract/365193.

Mills, B. (1997). It takes a special kind of villain to sacrifice herself for … Chicago Tribune, February 16, 1997. http://articles.chicagotribune.com/1997-02-16/entertainment/9702160182_1_tuskegee-syphilis-study-miss-evers-boys-untreated-syphilis.

Moton, R. R. (1913). Some elements necessary to race development. Press of the Hampton Normal and Agricultural Institute. https://docsouth.unc.edu/fpn/moton/moton.html.

Moton, R. R. (1920). The Negro’s debt to Lincoln. Unknown binding. https://www.amazon.com/Negros-Lincoln-Robert-Russa-Moton/dp/B000882EZS/ref=sr_1_12?ie=UTF8&qid=1533950894&sr=1-12&refinements=p_27%3ARobert+Russa+Moton.

Moton, R. R. (1922). The Negro’s debt to Lincoln. Unknown binding. https://www.amazon.com/Negros-Lincoln-Robert-Russa-Moton/dp/B000882EZZ/ref=sr_1_12?ie=UTF8&qid=1533950894&sr=1-12&refinements=p_27%3ARobert+Russa+Moton.

Moton, R. R. (1929). What the Negro thinks. Doubleday, Doran and Company.
References

National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research. (1977). Report and recommendations: Research involving children. (O77-0004). Federal Register: U.S. Government.

National Institutes of Health. (2020). The Nuremberg Code. https://history.nih.gov/research/downloads/nuremberg.pdf.

National Medical Association (NMA). (2018). https://www.nmanet.org/page/History.

National Park Service. (2019). Lincoln memorial webpage. https://www.nps.gov/linc/learn/historyculture/lincoln-memorial-important-individuals.htm.

O’Connor, S. (2015). Why doctors are rethinking breast cancer treatment. Time, October 1, 2015. http://time.com/4057310/breast-cancer-overtreatment/.

Oelen, A. & Corcoran, T. F. (1942). Hours and earnings in the United States 1932–40. U.S. Department of Labor, Bulletin No 697. https://fraser.stlouisfed.org/files/docs/publications/bls/he_bls_1942.pdf.

Padgett, M. (2018). Black face minstrel shows. http://black-face.com/minstrel-shows.htm.

Reverby, S. M. (2000). Dibble interview: [Helen Dibble, Daniel Williams, “An Interview with Nurse Rivers,” Tuskegee’s Truths, ed. Reverby, p. 327.]

Reverby, S. M. (2009). Examining Tuskegee. University of North Carolina Press.

Reverby, S. M. (2012). Ethical failures and history lessons: the U.S. Public Health Service Research Studies in Tuskegee and Guatemala. https://publichealthreviews.biomedcentral.com/track/pdf/10.1007/BF03391665.

Roberts, S., & Irwin, S. (2015). 83, Rare critic of Tuskegee study is dead. New York Times, April 18, 2015. https://www.nytimes.com/2015/04/19/health/irwin-schatz-83-rare-critic-of-tuskegee-study-is-dead.html?_r=1.

Robertson, C. (2018). A lynching memorial is opening. New York Times, April 25, 2018. https://www.nytimes.com/2018/04/25/us/lynching-memorial-alabama.html.

Rockwell, D., et al. (1964). The Tuskegee study of untreated syphilis: The 30th year of observation. Archives of Internal Medicine, 114, 792–798.

Rosenthal, M. S. (2015). Boo: Scary new guidelines for breast cancer. Endocrine Ethics Blog, October 30, 2015. http://endocrineethicsblog.org/2015/10/.

Rosenthal, M. S., Ain, K. B., Angelos, P. A. et al. (2017). Problematic clinical trials in thyroid cancer. Published online at: https://doi.org/10.2217/ije-2017-0008.

Schulman, D. (2009). A force for change: African American art and the Julius Rosenwald Fund. Evanston: Northwestern University Press.

Skloot, R. (2010). The immortal life of Henrietta Lacks. New York: Crown Publishing.

Smith, S. L. (1996). Neither victim nor villain: Nurse Eunice Rivers, the Tuskegee syphilis experiment, and public health work. Journal of Women’s History, 8, 95–113. https://muse.jhu.edu/article/363745/pdf.

Smithsonian National Museum of History. (2019). Lincoln Memorial webpage. https://americanhistory.si.edu/changing-america-emancipation-proclamation-1863-and-march-washington-1963/1963-lincoln-memorial.

Staples, B. (2018). How the Suffrage movement betrayed black women. New York Times, June 28, 2018. https://www.nytimes.com/2018/07/28/opinion/sunday/suffrage-movement-racism-black-women.html?action=click&module=RelatedLinks&pgtype=Article.

Suba, E. J. (2015). India cervical cancer testing is Tuskegee 2.0. Alabama.com, June 17, 2015. https://www.alf.com/opinion/2015/06/india_cervical_cancer_testing.html.

Tuskegee Syphilis Study Committee Report. (1996). http://exhibits.hsl.virginia.edu/badblood/report/.

Washington, H. (2007). Medical apartheid. New York: Doubleday.

Wellner K. L. (2005). Polio and historical inquiry. OAH Magazine of History, 19 (5), Medicine and History (Sep., 2005), 54–58.

Wilt, T. J. et al. (2017). Follow up of prostatectomy versus observation for early prostate cancer. New England Journal of Medicine 377, 132–142. https://www.nejm.org/doi/full/10.1056/NEJMoa1615869.
Winer, L. (1989). Patients sacrificed in the name of research. *New York Times*, December 21, 1989. https://www.nytimes.com/1989/12/21/theater/review-theater-patients-sacrificed-in-the-name-of-research.html.

World Medical Association (WMA). (2020). *Declaration of Helsinki*. https://www.wma.net/policies-post/wma-declaration-of-helsinki-ethical-principles-for-medical-research-involving-human-subjects/.

Zinsmeister, K. (2018). Philanthropy round table website, 2018. https://www.philanthropyroundtable.org/almanac/people/hall-of-fame/detail/julius-rosenwald.

Zorthian, J. (2016). This is how February became Black History Month. *Time*, January 29, 2016. http://time.com/4197928/history-black-history-month/.