



---

**The Young Epidemiology Scholars Program (YES) is supported by  
The Robert Wood Johnson Foundation and administered by the College Board.**

## **The Tuskegee Syphilis Study**

**Felicia McCrary**

Department of History  
The Galloway School  
Atlanta, Georgia

and

**Diane Marie M. St. George**

Faculty Chair, Masters Programs in Public Health  
Walden University  
Minneapolis, Minnesota

# Contents

Lesson Plan . . . . . 03

Introduction (Teacher’s Document) . . . . . 06

Teacher’s Guide to Documents . . . . . 07

Student’s Guide to Documents . . . . . 28

Student’s Version of Documents . . . . . 29

Student’s Instruction and Document Sheet . . . . . 38

Wrap-up (Teacher’s Document) . . . . . 41

Assessment Instruction Sheet (Student Document) . . . . . 44

Appendix . . . . . 45

# Lesson Plan

**TITLE:** The Tuskegee Syphilis Study

**SUBJECT AREAS:** History, African-American studies, social studies

**OBJECTIVES:** At the end of this unit, students will be able to:

- Describe the facts surrounding the Tuskegee Syphilis Study
- Explain why the Tuskegee Syphilis Study is considered an important milestone in the history of public health research
- Understand the need for ethical guidelines to govern epidemiologic research
- Recognize the key hypotheses that underlie contemporary research assessing the continuing impact of the Tuskegee Syphilis Study on epidemiologic research

**TIME FRAME:** Two class periods

**PREREQUISITE KNOWLEDGE:** None

**MATERIALS NEEDED:**

- Packet of government documents (provided as attachments to this unit)
- Web-available documents (URLs provided within the unit)

**PROCEDURE:** This unit introduces students to one of the most notorious studies in public health and biomedical research—the Tuskegee Syphilis Study (TSS). The Tuskegee Study is well known because of the ethical violations inherent in its design. Those breaches became the impetus for major changes in the way in which human subjects research is viewed and handled in the United States.

The unit contains various in-class learning activities aimed at teaching the facts about the TSS, correcting misconceptions that the students may already have, and reviewing the “legacy” of the study.

Students will conduct a document analysis using selected historical as well as contemporary documents related to the TSS. They will use the documents to develop an understanding of the TSS and to create a timeline of the major events in its history. In the assessment, students will then use the information they have learned to make decisions about how the legacy of the TSS should affect the way in which participants are recruited for epidemiologic research.

The unit contains the following sections:

- Introduction to the unit for the teacher.
- Teacher's guide to documents: A description of each of the documents and key themes that the students should abstract from each document; a guide to the documents by subject matter. Note that by varying the number and types of documents included in the analysis, the teacher can vary the length and difficulty of this unit.
- Student instruction and document sheet: This sheet should be given to the students to provide them with directions for completing the class activities.
- Wrap-up: This document helps the teacher debrief the class activity and prepare the students for the assessment activity
- Assessment instruction sheet: This sheet is designed for the student. It contains the instructions for the assessment.

**ASSESSMENT:** Included

**SOCIAL STUDIES STANDARDS:**

- Social studies programs should include experiences that provide for the study of culture and cultural diversity.
- Social studies programs should include experiences that provide for the study of the ways human beings view themselves in and over time.
- Social studies programs should include experiences that provide for the study of interactions among individuals, groups, and institutions.

**Bibliography**

Several documents are required for this unit, some are available on the Internet, and others are included as attachments to this module. Those are listed in the Teacher's Guide.

There are also several print and audio materials that may be useful to the classroom teacher as background material and that can potentially be included, in part or in their entirety, as additional documents for review by the students in the Document Analysis activity. Those include the following:

*The Deadly Deception: The Tuskegee Study* (1-hour video recording). NOVA/WGBH-TV Films for the Humanities and Sciences; 1993. This video has been reviewed: Byers B, Byers PY. The Deadly Deception. *Journal of Criminal Justice and Popular Culture*. 1994;2:93-95. Available at: <http://www.albany.edu/scj/jcipc/vol2is4/deadly.html>

Gamble V. Under the shadow of Tuskegee: African Americans and health care. *American Journal of Public Health*. 1997;87:1773-1778.

Gamble V. A legacy of distrust: African Americans and medical research. *American Journal of Preventive Medicine*. 1993;9(6 Suppl):35-38.

Jones JH. *Bad Blood: The Tuskegee Syphilis Experiment* (new and expanded edition). New York: Free Press; 1993.

*Miss Evers' Boys*. (2-hour video movie recording). 1997; Home Box Office Films.

Reverby SM (Ed). *Tuskegee's Truths: Rethinking the Tuskegee Syphilis Study*. Chapel Hill: University of North Carolina Press; 2000.

Shavers-Hornaday VL, Lynch CF, Burmeister LF, Torner JC. Why are African Americans under-represented in medical research studies? Impediments to participation. *Ethnicity & Health*. 1997;2:31.

Thomas SB, Quinn SC. The Tuskegee Syphilis Study, 1932–1972: Implications for HIV education and AIDS risk education programs in the Black community. *American Journal of Public Health*. 1991;81:1498–1504.

# Introduction (Teacher's Document)

Begin class by asking students if they have ever heard of any medical or health research studies. Have students briefly explain the studies of which they are aware. Students may have heard of some national studies or some smaller scale studies such as surveys in their own communities. They may also have heard of well-publicized ones like the experiments described in the Nuremberg trials or Tuskegee. Inform students that they will now investigate one of the most famous studies in the history of public health research.

Divide students into small groups of three-four students each.

Pass out the student instruction sheet and document set to groups. (*Note:* Depending on class size or amount of class time, teachers can divide documents among the groups or provide each group with a full document set).

Students then work in their groups to evaluate the documents and create a timeline and description of the Tuskegee Syphilis Study.

# Teacher's Guide to Documents

## Introduction

To provide options for the class and to accommodate classes of varying sizes and lengths, several documents are referenced below, some of which can, at the teacher's discretion, be omitted without jeopardizing the integrity of the activity. The documents have been grouped into categories for ease of decision making. Explanations are provided for each of the documents so that teachers may be able to make decisions about which documents to assign. The authors of this unit strongly suggest the use of Documents 9 and 31 because these documents are accompanied by detailed assignments.

- Syphilis: Biology and general information about the disease—**Documents 1, 2, 3, 4, 25, 34**
- The Tuskegee Syphilis Study Years: Study data, reports of researchers' decisions during the study, study outcomes—**Documents 9, 11, 12, 13, 14, 16, 22, 24, 29, 30, 31, 32, 33**
- Early news reports about the story of the Tuskegee Syphilis Study—**Documents 7, 8, 15, 28, 37, 39, 40, 41, 42, 43**
- Legacy of the Tuskegee Syphilis Study—**Documents 5, 6, 10, 17, 18, 19, 20, 21, 23, 26, 27, 35, 36, 38**

## Accessing the Documents

Some of the documents referenced in this section have been scanned and attached to this unit. The remainder are either Web-accessible in their entirety or have abstracts available on the Web. In cases where only abstracts or summaries are available on the Web, teachers may wish to assign students the task of getting copies of the actual documents from the local library, since access to the original, complete source documents would certainly be preferred. This may be most feasible and appropriate when the documents are newspaper articles, which are readily available at many local libraries.

In the case of scientific journals, the teacher may prefer not to ask students to obtain the complete documents because those articles will be relatively long, less available at local public libraries, and possibly too technical for high school students. However, article abstracts that have been catalogued in the MEDLINE database are available for free through the National Library of Medicine's PubMed Web site at <http://www.nlm.nih.gov/>. For a direct link, go to <http://www.ncbi.nlm.nih.gov/entrez/query.fcgi>

## *Document 1*

**Document Name:** Syphilis Information

**Citation:** Centers for Disease Control and Prevention, National Center for HIV, STD and TB Prevention Web site. March 11, 2004 (last review date). Available at <http://www.cdc.gov/nchstp/od/tuskegee/syphilis.htm>

This document is included to provide a basic understanding of what is currently known about syphilis. At a minimum, students should come to know that it is a sexually transmitted disease that is potentially fatal if left untreated. They should know that it is a bacterial infection and that the natural history includes three distinct stages. They should be aware of the present-day treatment and prognosis for those diagnosed with syphilis.

## *Document 2*

**Document Name:** Syphilis

**Citation:** Centers for Disease Control and Prevention, National Center for HIV, STD and TB Prevention, Division of Sexually Transmitted Diseases Web site. December 2003 (content reviewed date). Available at <http://www.cdc.gov/std/Syphilis/STDFact-Syphilis.htm>

This document is included to provide a basic understanding of what is currently known about syphilis. At a minimum, students should come to know that it is a sexually transmitted disease that is potentially fatal if left untreated. They should know that it is a bacterial infection and that the natural history includes three distinct stages. They should be aware of the present-day treatment and prognosis for those diagnosed with syphilis. Students should also have some understanding of the distribution of the disease in modern times. This document provides a more expanded description than is provided in Document 1. So, it may be helpful for students to start with Document 1 and then move to Document 2 for further detail.

## *Document 3*

**Document Name:** Syphilis

**Citation:** History of Epidemics and Plagues (October 2001), Subsection entitled "Syphilis". Available at <http://uhavax.hartford.edu/bugl/histepi.htm#syph>

This document is part of the reading material for a course on epidemics and AIDS by a University of Hartford professor. This reading provides some interesting background on syphilis, including a brief ancient history of the disease with some humor interjected! It also includes pictures of syphilitic patients, so the teacher may wish to warn students that the illustrations are not for the faint of heart.



## *Document 4*

**Document Name:** Syphilis in History

**Citation:** Copyright by the Trustees of Indiana University (July 9, 2002). Available at <http://poynter.indiana.edu/sas/lb/syphilis.html>

This document provides a short general overview of the disease, duplicating information available in many other documents. However, of importance in this document is the history of the treatment of syphilis. To arrive at an understanding of the nature of the controversies surrounding the TSS, students need to be aware of the potential treatments that were available and when they became available. This paper helps them to understand the toxicity and the effectiveness of the early drugs as well as the currently accepted treatment (penicillin).

## *Document 5*

**Document Name:** Knowledge of the Tuskegee Study and Its Impact on the Willingness to Participate in Medical Research Studies.

**Citation:** Shavers VL, Lynch CF, Burmeister LF. *Journal of the National Medical Association*. 2000;92:563–572. Abstract available from PubMed.

This study was a survey conducted among African Americans and whites in Detroit. The findings were that the TSS was well known by African Americans and much less so among the white population. Moreover, the impact of knowledge of the TSS on trust in researchers was greater among African Americans than among whites. These data will provide students with insight into the continuing impact of the TSS on contemporary attempts to recruit African Americans into epidemiologic research.

## *Document 6*

**Document Name:** The Presidential Apology

**Citation:** Historical Collections Department at The Claude Moore Health Sciences Library, University of Virginia Health System. June 23, 2004 (last modified date). Available at: [http://www.healthsystem.virginia.edu/internet/library/historical/medical\\_history/bad\\_blood/apology.cfm](http://www.healthsystem.virginia.edu/internet/library/historical/medical_history/bad_blood/apology.cfm)

This document is a brief news-style account of the 1997 ceremony in which President Clinton apologized for the TSS on behalf of the people of the United States. It includes the names of the men who at that time were still survivors and shows pictures of two in attendance, Mr. Shaw and Mr. Pollard. Other pictures from the ceremony included one of members of the Tuskegee Syphilis Study Legacy Committee, which had advocated for the presidential apology.

## *Document 7*

**Document Name:** Syphilis Study Ends Sessions Held in Secret

**Citation:** *The Washington Post, Times Herald* (1959–1973). February 15, 1973, page A7. Abstract available at: [www.washingtonpost.com](http://www.washingtonpost.com) (click on Archives in left frame).

This news article reports that the Department of Health, Education, and Welfare–appointed committee, which had heretofore been making inquiries into the TSS, were going to make their deliberations public.

## *Document 8*

**Document Name:** Open Quiz Urged in Syphilis Study

**Citation:** *The Washington Post, Times Herald* (1959–1973). February 3, 1973, page. A3. Abstract available at: [www.washingtonpost.com](http://www.washingtonpost.com) (click on Archives in left frame).

This newspaper article reports that a Connecticut senator had called for the deliberations of the Department of Health, Education, and Welfare–appointed committee making inquiries into the TSS to be made public.

## *Document 9*

**Document Name:** Table Depicting Number of Participants in the Tuskegee Syphilis Study Showing Number of Patients with Syphilis and Number of Controlled Nonsyphilitic patients (NARA name). Data presented by Dr. B. C. Brown: Classification of Cases in Tuskegee Study (actual table header).

**Citation:** Department of Health, Education and Welfare document stored in the U.S. National Archives and Records Administration (NARA) Southeast Region facility, Georgia. ARC identifier 281642. Document dated 2/4/69. Available from the NARA Web site at <http://arcweb.archives.gov> by entering the report identifier number in the search box.

This table shows the disease classification and outcomes for subjects in the TSS. When providing this document to the students, the teacher should include the following questions and activities to increase the learning potential of this document review:

- Have the students draw a flow chart to display the data shown in the table. The flow chart should be as detailed as possible and should start with the number 611 on the top, with dates and subject status shown at the nodes.
- Doing that flow chart may help students realize that they do not have all the information they need to create a complete flow chart. So, students should ask themselves the follow question: In what ways could Dr. Brown have improved upon his presentation of the data in this table?

- The table title may be misleading to some readers. The term “cases” is customarily used to refer to persons with a given disease, e.g., a case of measles, a case of heart disease. Dr. Brown is using the term to describe all study subjects—both men with syphilis (whom Dr. Brown is calling syphilitics) as well as men without syphilis (called controls in the table).
- It would have been helpful to have dates associated with all data points. For instance, there was no date of initial examination, so the reader is left to assume that it was at some point prior to 1938, since line 2 tells us that cases were added in 1938–1939. We also would have benefited from knowing the date used for “known dead.” One would logically ask, known dead *by when*? Again, we must assume that these numbers reflect the number of men known dead at or just before the time of the 1968 examination. Students who read Document 16 will note that the report states that there were 425 syphilitic men at the initial examination in 1932–1933, so the reports are conflicting.
- We are not told what happens to the men who were not “known dead,” but not examined in 1968. We may assume that they were presumed dead, known to be alive but not examined for some reason, or some combination thereof. Students should be helped to understand that lack of complete data in epidemiologic studies can make it difficult to answer research questions. They should note that an estimate of the proportion of men dying in the study is based on an accurate count of the number of men who died and the number who are still alive, therefore, incomplete data would compromise our ability to make those estimates.
- We are not told whether the men who died, died of syphilis. Since the study was about syphilis, deaths attributed to syphilis should be distinguished from deaths from other causes.
- Third, students should learn about a measure of disease frequency called the mortality rate by answering the following questions:
  - What proportion of men who were diagnosed with syphilis by final classification died? 0.623 or 62.3%. This proportion is similar in some ways to what is known in epidemiology as a mortality rate. A true mortality rate includes the number of persons who died during a given period of time in the numerator (as is done for the proportion that was calculated here). In the denominator of a mortality rate, we would put a measure of “person-time.” Person-time is the total length of time each person in the population was “at risk” of death during the given time period (same time period as covered by the numerator). So, in a one-year time period, a man who moves out of the population in the middle of the year would contribute only 0.5 person-years or 6 person-months to the denominator.

Note, however, that students were not looking at true mortality rates, because the denominator did not include a measure of person-time. In this exercise, the proportion is used as a surrogate “mortality rate.” Students should note that they may encounter this type of mortality rate in other places.

- What proportion of men who were not diagnosed with syphilis by final classification died? 0.533 or 53.3%. In other words, what was the “mortality rate” among the nonsyphilitics?
- If we assume that all deaths were from syphilis, the ratio of the mortality rate in the syphilitic men to the mortality rate in the nonsyphilitic men can be considered an estimate of the strength of the relationship between syphilis and death. What is that ratio? 1.2—this number can be interpreted as follows:
- Mortality rates were 1.2 times (or 20%) greater in men with syphilis than in men without syphilis.

This document helps us understand the outcomes of the TSS. We learn the facts about the number of men involved in the study and the number surviving through to the late 1960s (presumably). Students may realize that the number of men involved in the study, as reported in secondary accounts, varies widely. This document, which was created by someone involved in the TSS, can be considered to provide a more accurate count than those provided in secondary sources. However, students will also note that these numbers differ somewhat from counts in other primary sources.

## *Document 10*

**Document Name:** Remarks by the President in Apology for Study Done in Tuskegee

**Citation:** The White House Office of the Press Secretary. Text of President Clinton’s Apology for Study Done in Tuskegee. May 1, 1997, 2:26 pm EDT, The East Room, The White House. Available at: <http://clinton4.nara.gov/textonly/New/Remarks/Fri/19970516-898.html>

This document is the transcript of President Clinton’s speech at the White House, in which he made a public apology for the TSS. In attendance were some of the survivors of the TSS. The President apologized for the study’s violation of the rights of the subjects. He also announced several initiatives aimed at achieving reparations, including a grant to establish what would later become known as the Tuskegee University National Center for Bioethics in Research and Health Care and a postgraduate fellowship training program for students of bioethics.

## *Document 11*

**Document Name:** Image of a U.S. Public Health Service Poster

**Citation:** The Duties of the Health Department in Syphilis Control (image of a poster), 1945. National Library of Medicine *Images from the History of the Public Health Service collection*. Available at: [http://www.nlm.nih.gov/exhibition/phs\\_history/68.html](http://www.nlm.nih.gov/exhibition/phs_history/68.html)

This poster will suggest to students that the U.S. Public Health Service was engaged in discordant activities. While the U.S. Public Health Service was actively engaged in public education campaigns designed to encourage diagnosis and treatment of syphilis, it was also funding the TSS, in which treatment was being actively withheld from syphilitic men.

## *Document 12*

**Document Name:** Merck Advertisement for Penicillin

**Citation:** Canadian Broadcasting Corporation IDEAS Web site. Image of a print advertisement from late 1940s. Available at: <http://www.cbc.ca/ideas/features/Aids/pictures/mercbig.gif>

This advertisement points to the marketing of penicillin as a therapy for syphilis.

## *Document 13*

**Document Name:** Obituary—Ernest Hendon

**Citation:** January 31, 2004, edition of *The Economist*, page 84. Available at: [http://www.economist.com/people/displayStory.cfm?story\\_id=2383949](http://www.economist.com/people/displayStory.cfm?story_id=2383949)

This one-page magazine obituary gives news of the death of the last survivor of the TSS, Mr. Ernest Hendon, at age 96. Mr. Hendon died on January 16, 2004. The article includes a picture of Mr. Hendon, ostensibly at the Alabama House of Representatives in 2002. The article also includes some general information about the study, some of which came from Mr. Hendon's personal account.

## *Document 14*

**Document Name:** Letter from Dr. David Sencer to an unknown TSS subject, dated April 13, 1973.

**Citation:** Letter available from the NARA archives. (Attached to the unit.) It is government property and may be reproduced as long as the NARA wording is included in the copies.

This is a copy of the letter hand-delivered to the TSS subjects after the study was stopped. The letter from the then Director of the Center for Disease Control tells the recipient that the study has been terminated and that they will be eligible for free medical examinations and treatment. For subject privacy, the name was covered in the archived document.

## *Document 15*

**Document Name:** U.S. Testers Let Many Die of Syphilis: Syphilis Killed Many Untreated in U.S. Test

**Citation:** Heller J. *The Washington Post*. July 26, 1972, page A1. Abstract available at: [www.washingtonpost.com](http://www.washingtonpost.com) (click on Archives in left frame).

This article was written by the reporter Jean Heller and was picked up by many newspapers. This was the news article that first broke the story of the TSS. This would be the first of many news articles that appeared in the early 1970s and that continue through today, the most recent being the death of the last survivor (Document 13).

## *Document 16*

**Document Name:** Report on Tuskegee Syphilis Study, 1969 (NARA name). Tuskegee Study (actual document title).

**Citation:** Department of Health, Education, and Welfare document stored in the U.S. National Archives and Records Administration (NARA) Southeast Region facility, Georgia. ARC identifier 281643. Available from the NARA Web site at <http://arcweb.archives.gov> by entering the report identifier number in the search box.

This is identified as a report of a medical society meeting in Tuskegee that was prepared for someone whose name is illegible. Students should use the information in this document to fill in some additional information on the flow chart they created in Document 9. They may notice the discrepancy in numbers shown for the initial dates. In Document 9, the table suggests that at initial classification, there were 200 nonsyphilitic and 411 syphilitic men, and in 1938–1939, an additional 14 syphilitic men were included in the study. Document 16 states that they began with 200 nonsyphilitic and 425 syphilitic men in 1932–1933. The teacher may suggest that the flow chart should include the original 200 and 411 and then have the 14 added later as indicated in Document 9.

## *Document 17*

**Document Name:** Statewide Tuskegee Alliance for clinical trials. A community coalition to enhance minority participation in medical research.

**Citation:** Fouad MN, Partridge E, Wynn T, Green BL, Kohler C, Nagy S. *Cancer*. 2001;91(1 Suppl):237–241. Abstract available from PubMed.

This journal article reports on a community-university research partnership that developed between minority community members and University of Alabama at Birmingham researchers. Results from focus groups and individual interviews showed that there were barriers to participation, but TSS did not affect their willingness to participate. Through their readings, students will come to realize that these results tell a different story about the legacy of the TSS than some other research studies that concluded that the TSS did indeed impact upon willingness to participate. Another important message in this article/abstract is that it provided two suggestions for ways to improve research participation: providing information about the purpose and benefits of the study and endorsement by a cleric or physician. This information will be useful to them as they work on the assessment activity.

## *Document 18*

**Document Name:** African Americans' Views on Research and the Tuskegee Syphilis Study

**Citation:** Freimuth VS, Quinn SC, Thomas SB, Cole G, Zook E, Duncan T. *Social Science and Medicine*. 2001;52:797–808. Abstract available from PubMed.

This is another article about research participation among the African-American population. A key finding of this study was that distrust of public health researchers was a factor in lack of willingness to participate in research.

## *Document 19*

**Document Name:** Health Emergency 2001: The Spread of Drug-Related AIDS and Hepatitis C Among African Americans and Latinos

**Citation:** Day D. Copyright 2000 Page 3. Available at:  
<http://www.lindesmith.org/docUploads/HE2001.pdf>

This is a lengthy document that touches on many topics, so students should be advised to limit their review to just the page noted above. This reading is included to demonstrate another part of the legacy of the TSS. Laypersons, as well as professionals, have drawn parallels between TSS and several other public health concerns. It is not surprising to hear comments such as, "See what I mean, *health issue X* is just like Tuskegee all over again." In this paper, Dr. Day, an activist and researcher, is arguing that laws should be changed to allow needle exchange programs to exist for the purpose of reducing the impact of AIDS and hepatitis C among intravenous drug users. Dr. Day suggests that since there is a disproportionate burden of these diseases among persons of color, failure to allow needle exchange is doing a disservice to those populations hardest hit by the drug epidemic. On page 3, she argues that both TSS and needle exchange are examples of refusal to provide access to a proven medical treatment.

## *Document 20*

**Document Name:** Regulation Urged in Human Testing: Panel Calls for Controls in Federally Aided Research

**Citation:** Hicks N. *New York Times*. March 21, 1973, page 30. Abstract available at:  
<http://www.nytimes.com/ref/membercenter/nytarchive.html>

One year after the end of the TSS, there was a call for protections of the rights of human subjects in research. Students will see this as one of the steps toward the development of the stringent Institutional Review Board approval process currently required of not only all federally funded research but also all non-federally funded research in institutions that receive federal research funds.

## *Document 21*

**Document Name:** Past Imperfect: Ghosts of Tuskegee

**Citation:** Cobb WJ. Publication date: February 17, 2004. Available at:  
<http://africana.com/columns/cobb/ht20040217ghosts.asp>



This is an example of a narrative news-style report that starts with reporting the death of the oldest survivor of the TSS and then goes on to provide an abbreviated background about the study. The reporter suggests that TSS is a form of “medical racism.”

## *Document 22*

**Document Name:** Untreated Syphilis in Negro Male

**Citation:** Document header: From CDC files; 1 Basic. Untreated Syphilis in Negro Male. Dr. Wenger; Hot Springs Seminar. Document dated 9/18/50. Reproduced from records in the U.S. National Archives and Records Administration (NARA) Southeast Region facility, Georgia. Available as attachment to the unit. As a government document, this is in the public domain, but the “Reproduced at NARA” stamp in the footer must be included in copies made.

This document was found among the archives from the TSS at the NARA. It appears to be the transcript of a speech given by a Dr. Wenger at a seminar. The end of the document is dated 9/18/50 with initials KHJ/mrb. The speechmaker provided his rationale for conducting the study and reported the preliminary results of the study thus far. Students will note several important points from this document.

1. The speechmaker reports that results had shown that untreated syphilis is associated with increased morbidity (illness) and mortality (death) (page 2, fifth paragraph).
2. The rationale for selection of Macon County for the study included the fact that the population was expected to be stable and thus it would be easier to follow up the men throughout the course of the study (page 2, last paragraph, which continues to page 3).
3. The argument is being made that since the researchers denied the subjects access to treatment, the researchers are obliged to follow up as many of the subjects as possible in order that their morbidity and mortality not be in vain (page 3, first full paragraph).
4. It appears that a previous speaker (or speakers) at the meeting may have argued that the study should be made public and that an effort to actively identify and presumably treat cases of syphilis should be undertaken (page 3, second full paragraph).
5. The speechmaker appears to be calling for the TSS to remain a “quiet undertaking” and to actively continue to seek out and observe the health status or document the deaths of those men who had been unaccounted for in the study (pages 3 to 4). The speechmaker does not make mention of the need for treatment of the remaining men.

## *Document 23*

**Document Name:** Tuskegee Re-examined

**Citation:** Shweder RA. Internet article dated January 8, 2004. Available at: <http://www.spiked-online.com/articles/0000000CA34A.htm>



This article provides the counterargument to many of the other contemporary writings that assert that the TSS was a horrible tragedy. Students will learn a different perspective from this author, who incidentally also shares one of the myths about Tuskegee—that the subjects were deliberately infected with syphilis. The author raises the following key issues: (1) Treatment was administered to some men, so the study could not have been that awful. (2) There are those who contend that the available treatments in the pre-penicillin era were so toxic that subjects were not willing to take them anyway. (3) The research was done in the context of trying to help improve the health status of African Americans. (4) The study was not done in a secretive manner. (5) Racism could not have been a motive, since African-American professionals were involved with the study. (6) The study did no harm to the subjects. (7) When penicillin became available, many of the men would have already been in late-stage syphilis and any organ damage that had already occurred was irreversible, even with antibiotic treatment. (8) Critics of TSS are guilty of “presentism,” i.e., judging historical events using contemporary contexts. (9) If subjects had been fully informed they may have agreed to participate, so the fact that informed consent was not sought is not so heinous.

## *Document 24*

**Document Name:** Letter from Dr. Olansky to Dr. Cutler with Enclosure Entitled “Outline of Problems to Be Considered in Tuskegee Study”

**Citation:** Letter dated November 6, 1951. Reproduced from records in the U.S. National Archives and Records Administration (NARA) Southeast Region facility, Georgia. Available as attachment to the unit. As a government document, this is in the public domain, but the “Reproduced at NARA” stamp in the footer must be included in copies made.

In this letter with its 2.5-page enclosure, Dr. Olansky shares with Dr. Cutler two key concerns. Issue A seems to be part of an ongoing discussion about whether the men had been accurately diagnosed upon entry into the study. Olansky suggests that there was *false positivity*. False positivity means that a man who did not have syphilis (i.e., who was truly negative) was classified as positive for syphilis by the diagnostic test. Malaria is cited as one reason for false positivity.

The second paragraph alludes to a phenomenon known in epidemiology as confounding. Confounding exists when some factor other than the main factor of interest to the study can be responsible for differences observed between groups. For example, in a study of the effects of tanning beds on skin cancer among 18 to 25-year-old women, one should also consider the potential confounding effect of sun exposure. If those who sun-bathe are also predominantly the same ones who use tanning beds, and if regular sun-bathing is linked to skin cancer, then sun-bathing is a confounder in the study of tanning-bed use and skin cancer.

Using Olansky’s terms, if the “universe” or population of tanning-bed users differs from the universe of non-tanning-bed users with respect to their sun-bathing habits, then it is difficult to compare them. Furthermore, if we still try to compare them and find differences in skin cancer

rates between the tanning-bed users and the non-tanning-bed users, it could be the differences in sun-bathing habits, not the differences in tanning-bed usage, that are causing the differences in skin cancer rates.

Incidentally, in epidemiologic research, the effect of confounding can be overcome by measuring the prevalence of the confounder in the two populations, e.g., asking the group of young adult women in the study about their sun-bathing use, in addition to their tanning-bed use.

In Issue A, Olansky suggests that because the differences in rates of morbidity (illness) between the syphilitic and nonsyphilitic men are so large, they *must* be related to differences in the social and economic backgrounds of the men. This would be equivalent to saying that if there are large differences in skin cancer rates between tanning-bed users and non-tanning-bed users, they *must* be related to sun-bathing differences between the groups.

The teacher may wish to help the students determine whether this argument makes sense to them. What types of differences may Olansky have been considering? Is it likely that there could have been such large differences in the population of sharecroppers in Macon County? Was Olansky trying to minimize the stark differences in morbidity between the groups? If so, was this because an admission of stark differences attributable to syphilis infection would have argued that the study should be stopped and the syphilitic men treated?

Olansky's Issue B is that the study should be continued and as many data should be gathered from the subjects as possible, because (1) there has been considerable investment of resources in the first two decades of the study already, (2) they are obligated to the male subjects to honor them in that way, and (3) they should gather additional information about the natural history of syphilis if they can.

## *Document 25*

**Document Name:** Ehrlich Finds Cure for Syphilis

**Citation:** A Science Odyssey: People and Discoveries. Available at:  
<http://www.pbs.org/wgbh/aso/databank/entries/dm09sy.html>

This tells a brief story of the discovery of Salvarsan, an arsenic-based drug, for the treatment of syphilis.

## *Document 26*

**Document Name:** Racial Differences in Factors That Influence the Willingness to Participate in Medical Research Studies

**Citation:** Shavers VL, Lynch CF, Burmeister LF. *Annals of Epidemiology*. 2002;12:248–256.  
Abstract available from PubMed.

This article reports some additional results of the research study conducted in 1998–1999 in Detroit which was the basis for the article numbered Document 5. In that study, whites were more willing than African Americans to participate in research. The differences were, in part, due to the higher distrust of research by African Americans. The conclusions of this paper suggest some ways to overcome these barriers in attempting to recruit African Americans to research studies.

## *Document 27*

**Document Name:** Blacks in U.S. Syphilis Program Settle Their Suit Out of Court.

**Citation:** *New York Times*. December 17, 1974, page 20. Abstract available at: <http://www.nytimes.com/ref/membercenter/nytarchive.html>

This article reports that the outcome of the lawsuit filed on behalf of the TSS subjects was an out-of-court settlement that amounted to \$37,500 per survivor.

## *Document 28*

**Document Name:** HEW Will Study Syphilis Project: A Panel Set Up to Report on Tuskegee Experiment

**Citation:** *New York Times*. August 25, 1972, page 40. Abstract available at: <http://www.nytimes.com/ref/membercenter/nytarchive.html>

This newspaper article tells that a small panel had been convened by the Department of Health, Education, and Welfare (the predecessor to the Department of Health and Human Services) to review the TSS. This happened approximately one month after the story about the TSS was reported in the press.

## *Document 29*

**Document Name:** Tuskegee Research Report; three tables of data

**Citation:** Tables of data from the study. Reproduced from records in the U.S. National Archives and Records Administration (NARA) Southeast Region facility, Georgia. Available as attachment to the unit. As a government document, this is in the public domain, but the “Reproduced at NARA” stamp in the footer must be included in copies made.

These tables show data from the clinical examinations performed in 1932, 1938, and 1948. Identifying information about study subjects has been blacked out to protect privacy. The document is not dated, but based on the titles of Tables 2 and 3, we know that the data were analyzed sometime after December 12, 1951. Table 1 shows the subjects entered into the study. Tables 2 and 3 show the outcomes for the subjects on December 12, 1951. Table 2 includes those living at that date by age at entry, and Table 3 shows those known dead by December 12, 1951, again by age at entry. Therefore, the column totals in Tables 2 and 3 should sum to the corresponding column totals in Table 1.

## Document 30

**Document Name:** Memo from Eleanor N. Walker to Dr. John C. Cutler

**Citation:** Memo dated December 4, 1952. Reproduced from records in the U.S. National Archives and Records Administration (NARA) Southeast Region facility, Georgia. Available as attachment to the unit. As a government document, this is in the public domain, but the “Reproduced at NARA” stamp in the footer must be included in copies made.

This is a brief memo from another stakeholder in the TSS who echoes some of the same sentiments seen in some other documents. She appears to be supportive of the continuation of the study and sees the need to put more effort into trying to find those subjects with whom the study team had lost contact.

## Document 31

**Document Name:** Differential Mortality Rates Among Tuskegee Syphilis Study Participants

**Citation:** Document apparently dated April 26, 1974. Reproduced from records in the U.S. National Archives and Records Administration (NARA) Southeast Region facility, Georgia. Available as attachment to the unit. As a government document, this is in the public domain, but the “Reproduced at NARA” stamp in the footer must be included in copies made.

Unlike most of the documents that students can analyze and understand independently, this one is more complex. Many interesting epidemiologic concepts can be demonstrated. Therefore, this is another document for which students should be given general questions to help guide them through the analysis. Examples of possible questions and teacher's key are given below.

- Some of the other documents are newspaper articles, Internet articles, memos, etc. This document is a proposal. What is being proposed?  
**Answer: This is a proposal for a short study to evaluate TSS mortality data to compare differences in mortality rates between the syphilitic and nonsyphilitic groups.**
- What are the reasons for the study to which the author refers in paragraph 1?  
**Answer: The author presents the following rationale for the study: (1) The mortality data should be analyzed, since the last “rigorous” analysis was in 1955 (page 1, paragraph 1); (2) preliminary analyses of the most recent data (through 1971) appeared to show that the mortality rates among syphilitics differed from those of nonsyphilitic men; and (3) given that a lawsuit had been filed by attorney Fred Gray against the government, on behalf of the survivors, the data analysis may be helpful in mounting a defense.**
- The flow chart on page 5 has information labeled as death rates for syphilitic and nonsyphilitic men (see columns of data at the left and right of the flow chart boxes). However, lines 6 to 8 of the Background section of page 1 note that the purpose of the

study is to compare death rates. At first glance, this author appears to be proposing to ask a question to which he or she already has the answer, since the rates are laid out on page 5. However, the difference is in the types of mortality rates that will be used in the proposed study. A mortality (death) rate is the proportion of persons in a population who die during a specified period of time. Look at the flow chart and write out the formula for the death (mortality) rate that is being used there. As an example, show the calculation that was done to determine the death rate listed as 21.2% (fourth rate on left-hand column), and in words, write out what that death rate means.

**Answer: As was noted in Document 9, the term “rate” here is not a true rate; i.e., the denominator does not contain person–time. It is a proportion used as a surrogate for a rate. Students will be able to look at the numbers and determine that the death rate = # dead/# at risk, where # at risk means the number of men in the group. For instance, the death rate of 21.2% is the death rate among nonsyphilitic men who died between 1945 and 1948 under the assumption that all men whose status is unknown are actually still alive. The numerator is the number of nonsyphilitic men who died between 1945 and 1948, and the denominator is the number of non-syphilitic men in the population (in other words, those who are “at risk” of death). Therefore, the rate = 40 dead/189 at risk = 0.212, which can be multiplied by 100 to convert to a percentage = 21.2%.**

- The difference between the formula you derived and the formula that is being proposed for the study is basically in the denominator. The flow chart uses a “down and dirty” method of calculating a mortality rate, and the proposed study uses a more complicated, yet more precise method. The proposed method essentially uses the same numerator (number of deaths) and divides that by a measure known as person-time in the denominator. Person-time helps you to account for the fact that during any given time period, the number of men in the population at risk differs. It really does not stay the same over time, and especially in the situation where men from the original study group fall out of contact with the researchers and their status is unknown. So, while they are in the study the subjects should be counted, but when they drop out, they should be removed from the count. Therefore, in any given 5-year time period, person-time or person-months can be used to calculate the number of months that a man was in the study. If a man moved out of Macon County on June 1, 1955, and could not be traced by the researchers, he was present for only five months in the 1955–1959 time period, so he is one person who contributes five months to the denominator. Then if his neighbor, another subject in the study, moved out two months later, he would have been in the study for seven months and would add another seven months to the denominator. Together they contributed  $5 + 7 = 12$  months of person-time, or 12 person-months. However, there is another reason why the proposed study would be superior to the information available from the flow chart, and that is that the proposed study would incorporate additional information about the subjects. The person who created the flow chart appears to have used only very basic information such as

syphilitic versus nonsyphilitic and alive versus dead versus lost to follow-up. What pieces of information were being considered for the proposed study?

**Answer:** Page 2 shows that in addition to the original flow chart information, they would also have age or year of onset of syphilis, treatment received, cause of death, identification number, date of entry into study, date of death or last observed, age at entry into study, birth date, autopsy, treatment status.

- Why might cause of death be an important variable to consider for the proposed study?

**Answer:** Cause of death is important information because it will allow for the distinction between syphilis-related mortality and other mortality. When attempting to determine whether treating men for syphilis would have affected their mortality, one must be able to distinguish between death due to syphilis and death due to other causes, since deaths due to syphilis are more specifically relevant to that question.

- On page 1, lines 4 to 6, the author claims that “the mortality of control participants was higher than that of syphilitics in 1948 and 1951–1954.” From the flow chart sheet, identify the information that was used to make that claim, and then determine whether you agree with that statement.

**Answer:** The student should note that the data in the flow chart show death rates on both the left- and the right-hand columns. The rates are based on different assumptions about men “lost to follow-up”—meaning those men for whom status is not known because they either died without the knowledge of the researchers or dropped out of the study and are no longer able to be observed or examined. The rate calculated on the left is predicated upon the assumption that all men who were lost to follow-up were actually alive, and the rate on the right assumes they had all died. Of course, in reality, it is likely that neither of those scenarios is true; it is more likely that some are alive and some are not. However, those two calculations allow us to create upper and lower bounds within which the actual rate would lie.

With this in mind, the students would realize that in order to determine whether the author's claim is true, they would need to look at rates for 1948 and for 1951–1954 for both syphilitics and nonsyphilitics and compare them. However, this is not that straightforward for three reasons:

1. We do not have rates; we actually have ranges of rates (as mentioned above).
2. In 1951–1954, there were four rates calculated for syphilitic men. This was because, for some reason, they did not have an accurate count of the number of syphilitics who were known to have died. The author does not tell us why, but the number dead is listed as 159 to 176. So, they calculated a death rate using both numbers.



3. The author appears to have made a mistake in reading the chart! As students may observe from the handwritten notes, someone, presumably the author, drew arrows pointing to two rates—56.6% and 51.4%—and jotted down what looks like the words “control mortality higher,” although the document is old and partly illegible, so it is difficult to read.

	Syphilitics (range from lowest possible to highest possible death rate)	Nonsyphilitics (range from lowest possible to highest possible death rate)
1948	23.9%–38.2%	21.2%–56.6%
1951–1954	37.7%–51.4%	26.5%–36.0%

The author is making that claim on page 1 based on the comparison that 56.6% is greater than 38.2%, and that 51.4% is greater than 47.4%. However, for many reasons, that is a shaky claim, at best. Clearly the 51.4% is not the control group; it is actually the syphilitic group, assuming that there were 176 dead. Second, the claim ignores the left-hand death rates, which show a syphilitic mortality rate of 23.9%, which is greater than the control rate of 21.2% in 1948, and in 1951–1954, a syphilitic mortality rate of somewhere between 37.7% and 41.7%, which is greater than the control rate of 26.5%. Third, from the table above, it is clear that there is some degree of overlap in the range of possible rates for syphilitics and controls in 1948, so if one assumes that the “true death rate” lies within those ranges, it is difficult to tell which group is higher. For instance, suppose the true rate for syphilitics is 31.6% and the true rate for nonsyphilitics is 22.4%; then the syphilitics death rate would be higher. However, if the true rate for syphilitics was closer to the lower end at 25.1%, and the true rate for controls was at the higher end at 55.2%, then the controls would have a higher death rate. Fourth, there is no overlap in 1951–1954, so even if the syphilitic rate was at its lowest extreme (37.7%) and the nonsyphilitic rate was at its highest extreme (36.0%), one would still be able to assert that the syphilitics had greater mortality than the nonsyphilitics.

Students may not pick up all nuances, but it is a useful skill for them to look closely at the data and make their own decisions about what conclusions are supported by the data.

- The author of this proposal (see bottom of page 3) presents a valid argument: “If the mortality experience of the two groups is similar after 1950, then . . . it may be argued that withholding of penicillin in the early 1950’s had minimal or no effect on the mortality of syphilitics who survived until the advent of the penicillin (era).” What the author is arguing is that the rationale for administering penicillin to syphilitic men is to “allow” their mortality rate to be comparable to the general population (in this case, the men without syphilis). So, if the mortality rates of the

syphilitic men and the nonsyphilitic men were the same after 1950, failure to administer penicillin did not have an adverse effect on the mortality of the syphilitic men. This author appears to stop shy of stating this, but other authors extend the argument to state that since the penicillin could not have made that “difference,” the ethical concerns are moot. Is there evidence from the flow chart that the mortality rates had converged by the time penicillin was available?

**Answer:** On the basis of comparisons of the mortality rates between syphilitic and non-syphilitic men, students can observe that in using the extremes of the ranges (as discussed above), there appears to have been increased mortality among the syphilitic men throughout the course of the study. Some may suggest that because of reasons stated earlier, it is difficult to tell. In either case, it would be interesting to hear their opinions on the argument that ethics cannot be questioned if penicillin would not have made a difference. Some may argue that treatment should have been offered anyway.

## *Document 32*

**Document Name:** Ad Hoc Committee Meeting to Examine Data from the Tuskegee Syphilis Study and Offer Advice on Continuance of This Study (NARA name).

**Citation:** Document stored in the U.S. National Archives and Records Administration (NARA) Southeast Region facility, Georgia. ARC identifier 281641. Available from the NARA Web site at <http://arcweb.archives.gov> by entering the report identifier number in the search box.

This document presents the minutes of a meeting held on February 6, 1969. The group of scientists is debating the continuation of the TSS. This is a 15-page document, but in most cases, it is nontechnical and therefore easy reading. However, some technical language is included. Students can gloss over it, since it is not critical to understanding the take-home message. The key point is that some of those present appear to have been in favor of and others opposed to termination of the study.

## *Document 33*

**Document Name:** Twenty Years of Follow-up Experience in a Long Range Medical Study

**Citation:** Rivers E, Schuman SH, Simpson L, Olansky S. *Public Health Reports*. 1953;68:391–395. Available full-text at: <http://www.tuskegee.edu/Global/Story.asp?s=1207636>

This is an article whose lead author is Nurse Rivers. The role of Nurse Rivers in the recruitment and retention of men in the study is one of the interesting themes throughout the TSS. Some argue that as an African-American woman, she was critical in getting and keeping them involved. Others suggest that she was a “victim” of the same recruitment deception that was used to bring the men into the study. Students should read her words and make up their minds about how she fit in. They should also take a lesson about subject recruitment from this paper and keep it in mind when designing their recruitment plans for the assessment.



## *Document 34*

**Document Name:** Fleming Discovers Penicillin, 1928–1945

**Citation:** A Science Odyssey: People and Discoveries. Available at:  
<http://www.pbs.org/wgbh/aso/databank/entries/dm28pe.html>

This is a brief story of the circumstances surrounding the accidental discovery of penicillin by Alexander Fleming in 1928 and those leading up to the eventual acceptance of the benefits and mass production of the drug by the 1940s.

## *Document 35*

**Document Name:** Attitudes and Beliefs of African-Americans Toward Participation in Medical Research

**Citation:** Corbie-Smith G, Thomas SB, Williams MV, Moody-Ayers S. *Journal of General Internal Medicine*. 1999;14:537–546. Abstract available from PubMed.

This is a manuscript reporting the results of a study in which 33 African Americans participated in focus groups in which they shared their attitudes toward medical research. When asked about the TSS, participants were generally aware of the study but had misconceptions about the facts surrounding the study. Participants cited mistrust of health care providers as a factor in their unwillingness to participate in research studies.

## *Document 36*

**Document Name:** “Why Don’t They Come to Pike Street and Ask Us?”: Black American Women’s Health Concerns.

**Citation:** Freedman TG. *Social Science and Medicine*. 1998;47:941–947. Abstract available from PubMed.

In this small study in which African-American women were interviewed about research participation, the results conflicted with the hypothesis that the legacy of the TSS affected their willingness to take part in research studies.

## *Document 37*

**Document Name:** Ex-chief Defends Syphilis Project: Says Alabama Plan Was Not Unethical or Unscientific

**Citation:** *New York Times*. July 28, 1972, page 29. Abstract available at:  
<http://www.nytimes.com/ref/membercenter/nytarchive.html>

This abstract includes a quote from one of the TSS researchers who claims that the study was not unethical.

## *Document 38*

**Document Name:** Guidelines for the Conduct of Research Involving Human Subjects at the National Institutes of Health (Appendices 1 and 2 only)

**Citation:** National Institutes of Health Office of Human Subjects Research. Available at: <http://ohsr.od.nih.gov/guidelines/graybook.html>

Appendix 1 is entitled “Historical, Ethical and Legal foundations for the NIH’s Policies and Procedures” and Appendix 2 is “The Ethical Principles of the Belmont Report.” These documents are from the U.S. Public Health Service agency, the National Institutes of Health (NIH). Appendix 1 identifies the TSS as one of the historical research events that, because of concerns about violations of the rights of their human subjects, prompted the development of strict guidelines governing research. Appendix 2 is a brief outline and definition of the three ethical principles guiding current public health research: respect for persons, beneficence, and justice.

## *Document 39*

**Document Name:** Syphilis Study Is Hit on Notifying Patients

**Citation:** Heller J. *The Washington Post, Times Herald* (1959–1973). February 24, 1973, page A10. Abstract available at: [www.washingtonpost.com](http://www.washingtonpost.com) (click on Archives in left frame)

This newspaper article reports on testimony that the TSS subjects did not provide informed consent to participate in the study.

## *Document 40*

**Document Name:** Experiment Settlement Is Faulted

**Citation:** Cohn V. *The Washington Post*. December 18, 1974, page A6. Abstract available at: [www.washingtonpost.com](http://www.washingtonpost.com) (click on Archives in left frame)

This newspaper article reports on a reaction to the settlement provided to the TSS survivors after their lawsuit was settled. The survivors were each awarded \$37,500.

## *Document 41*

**Document Name:** Syphilis Experiment Termed Unjustified

**Citation:** *New York Times*. March 29, 1973, page 54. Abstract available at: <http://www.nytimes.com/ref/membercenter/nytarchive.html>

This is a news article stating that the Department of Health, Education, and Welfare panel investigating the TSS ruled that the TSS was “unjustified” but they wanted to acknowledge the historical context of the era in which the study was begun.

## *Document 42*

**Document Name:** US Syphilis Study Called “Ethically Unjustified”: Report of Tuskegee Panel to Congress Urges a Board to Guide Human Research

**Citation:** *New York Times*. June 13, 1973, page 21. Abstract available at: <http://www.nytimes.com/ref/membercenter/nytarchive.html>

This is another article reporting the deliberations and results of the DHEW panel that investigated the TSS. This one highlights the recommendation for human subjects review panels to monitor research. Students should note that these panels now exist at research and other types of institutions and are known as institutional review boards (IRBs) or human subjects review committees (HSR Committees).

## *Document 43*

**Document Name:** HEW to End Alabama Study of Syphilis

**Citation:** *The Washington Post, Times Herald* (1959–1973). October 28, 1972, page A2. Abstract available at: [www.washingtonpost.com](http://www.washingtonpost.com) (click on Archives in left frame)

This newspaper article reports the finding of the Department of Health, Education and Welfare panel that the TSS study should be terminated and all survivors treated as medically necessary.

# Student's Guide to Documents

## Introduction

To provide options for the class and to accommodate classes of varying sizes and lengths, several documents are referenced below, some of which can, at the teacher's discretion, be omitted without jeopardizing the integrity of the activity. The documents have been grouped into categories for ease of decision making. Explanations are provided for each of the documents so that teachers may be able to make decisions about which documents to assign. The authors of this unit strongly suggest the use of Documents 9 and 31 because these documents are accompanied by detailed assignments.

- Syphilis: Biology and general information about the disease—**Documents 1, 2, 3, 4, 25, 34**
- The Tuskegee Syphilis Study Years: Study data, reports of researchers' decisions during the study, study outcomes—**Documents 9, 11, 12, 13, 14, 16, 22, 24, 29, 30, 31, 32, 33**
- Early news reports about the story of the Tuskegee Syphilis Study—**Documents 7, 8, 15, 28, 37, 39, 40, 41, 42, 43**
- Legacy of the Tuskegee Syphilis Study—**Documents 5, 6, 10, 17, 18, 19, 20, 21, 23, 26, 27, 35, 36, 38**

## Accessing the Documents

Some of the documents referenced in this section have been scanned and attached to this unit. The remainder are either Web-accessible in their entirety or have abstracts available on the Web. In cases where only abstracts or summaries are available on the Web, teachers may wish to assign students the task of getting copies of the actual documents from the local library, since access to the original, complete source documents would certainly be preferred. This may be most feasible and appropriate when the documents are newspaper articles, which are readily available at many local libraries.

In the case of scientific journals, the teacher may prefer not to ask students to obtain the complete documents because those articles will be relatively long, less available at local public libraries, and possibly too technical for high school students. However, article abstracts that have been catalogued in the MEDLINE database are available for free through the National Library of Medicine's PubMed Web site at <http://www.nlm.nih.gov/>. For a direct link, go to <http://www.ncbi.nlm.nih.gov/entrez/query.fcgi>

# Student's Version of Documents

## *Document 1*

**Document Name:** Syphilis Information

**Citation:** Centers for Disease Control and Prevention, National Center for HIV, STD and TB Prevention Web site. March 11, 2004 (last review date). Available at <http://www.cdc.gov/nchstp/od/tuskegee/syphilis.htm>

## *Document 2*

**Document Name:** Syphilis

**Citation:** Centers for Disease Control and Prevention, National Center for HIV, STD and TB Prevention, Division of Sexually Transmitted Diseases Web site. December 2003 (content reviewed date). Available at <http://www.cdc.gov/std/Syphilis/STDFact-Syphilis.htm>

## *Document 3*

**Document Name:** Syphilis

**Citation:** History of Epidemics and Plagues (October 2001), Subsection entitled "Syphilis". Available at <http://uhavax.hartford.edu/bugl/histepi.htm#syph>

## *Document 4*

**Document Name:** Syphilis in History

**Citation:** Copyright by the Trustees of Indiana University (July 9, 2002). Available at <http://poynter.indiana.edu/sas/lb/syphilis.html>

## *Document 5*

**Document Name:** Knowledge of the Tuskegee Study and Its Impact on the Willingness to Participate in Medical Research Studies.

**Citation:** Shavers VL, Lynch CF, Burmeister LF. *Journal of the National Medical Association*. 2000;92:563–572. Abstract available from PubMed.

## *Document 6*

**Document Name:** The Presidential Apology

**Citation:** Historical Collections Department at The Claude Moore Health Sciences Library, University of Virginia Health System. June 23, 2004 (last modified date). Available at: [http://www.healthsystem.virginia.edu/internet/library/historical/medical\\_history/bad\\_blood/apology.cfm](http://www.healthsystem.virginia.edu/internet/library/historical/medical_history/bad_blood/apology.cfm)

## *Document 7*

**Document Name:** Syphilis Study Ends Sessions Held in Secret

**Citation:** *The Washington Post, Times Herald* (1959–1973). February 15, 1973, page A7. Abstract available at: [www.washingtonpost.com](http://www.washingtonpost.com) (click on Archives in left frame).

## *Document 8*

**Document Name:** Open Quiz Urged in Syphilis Study

**Citation:** *The Washington Post, Times Herald* (1959–1973). February 3, 1973, page. A3. Abstract available at: [www.washingtonpost.com](http://www.washingtonpost.com) (click on Archives in left frame).

## *Document 9*

**Document Name:** Table Depicting Number of Participants in the Tuskegee Syphilis Study Showing Number of Patients with Syphilis and Number of Controlled Nonsyphilitic patients (NARA name). Data presented by Dr. B. C. Brown: Classification of Cases in Tuskegee Study (actual table header).

**Citation:** Department of Health, Education and Welfare document stored in the U.S. National Archives and Records Administration (NARA) Southeast Region facility, Georgia. ARC identifier 281642. Document dated 2/4/69. Available from the NARA Web site at <http://arcweb.archives.gov> by entering the report identifier number in the search box.

## *Document 10*

**Document Name:** Remarks by the President in Apology for Study Done in Tuskegee

**Citation:** The White House Office of the Press Secretary. Text of President Clinton's Apology for Study Done in Tuskegee. May 1, 1997, 2:26 pm EDT, The East Room, The White House. Available at: <http://clinton4.nara.gov/textonly/New/Remarks/Fri/19970516-898.html>

## *Document 11*

**Document Name:** Image of a U.S. Public Health Service Poster

**Citation:** The Duties of the Health Department in Syphilis Control (image of a poster), 1945. National Library of Medicine *Images from the History of the Public Health Service collection*. Available at: [http://www.nlm.nih.gov/exhibition/phs\\_history/68.html](http://www.nlm.nih.gov/exhibition/phs_history/68.html)

## *Document 12*

**Document Name:** Merck Advertisement for Penicillin

**Citation:** Canadian Broadcasting Corporation IDEAS Web site. Image of a print advertisement from late 1940s. Available at: <http://www.cbc.ca/ideas/features/Aids/pictures/mercbig.gif>

## *Document 13*

**Document Name:** Obituary—Ernest Hendon

**Citation:** January 31, 2004, edition of *The Economist*, page 84. Available at: [http://www.economist.com/people/displayStory.cfm?story\\_id=2383949](http://www.economist.com/people/displayStory.cfm?story_id=2383949)

## *Document 14*

**Document Name:** Letter from Dr. David Sencer to an unknown TSS subject, dated April 13, 1973.

**Citation:** Letter available from the NARA archives. (Attached to the unit.) It is government property and may be reproduced as long as the NARA wording is included in the copies.

## *Document 15*

**Document Name:** U.S. Testers Let Many Die of Syphilis: Syphilis Killed Many Untreated in U.S. Test

**Citation:** Heller J. *The Washington Post*. July 26, 1972, page A1. Abstract available at: [www.washingtonpost.com](http://www.washingtonpost.com) (click on Archives in left frame).

This article was written by the reporter Jean Heller and was picked up by many newspapers. This was the news article that first broke the story of the TSS. This would be the first of many news articles that appeared in the early 1970s and that continue through today, the most recent being the death of the last survivor (Document 13).

## *Document 16*

**Document Name:** Report on Tuskegee Syphilis Study, 1969 (NARA name). Tuskegee Study (actual document title).

**Citation:** Department of Health, Education, and Welfare document stored in the U.S. National Archives and Records Administration (NARA) Southeast Region facility, Georgia. ARC identifier 281643. Available from the NARA Web site at <http://arcweb.archives.gov> by entering the report identifier number in the search box.

This is identified as a report of a medical society meeting in Tuskegee that was prepared for someone whose name is illegible.

## *Document 17*

**Document Name:** Statewide Tuskegee Alliance for clinical trials. A community coalition to enhance minority participation in medical research.

**Citation:** Fouad MN, Partridge E, Wynn T, Green BL, Kohler C, Nagy S. *Cancer*. 2001;91(1 Suppl): 237–241. Abstract available from PubMed.

## *Document 18*

**Document Name:** African Americans' Views on Research and the Tuskegee Syphilis Study

**Citation:** Freimuth VS, Quinn SC, Thomas SB, Cole G, Zook E, Duncan T. *Social Science and Medicine*. 2001;52:797–808. Abstract available from PubMed.

## *Document 19*

**Document Name:** Health Emergency 2001: The Spread of Drug-Related AIDS and Hepatitis C Among African Americans and Latinos

**Citation:** Day D. Copyright 2000 Page 3. Available at:  
<http://www.lindesmith.org/docUploads/HE2001.pdf>

This is a lengthy document that touches on many topics, so students should be advised to limit their review to just the page noted above.

## *Document 20*

**Document Name:** Regulation Urged in Human Testing: Panel Calls for Controls in Federally Aided Research

**Citation:** Hicks N. *New York Times*. March 21, 1973, page 30. Abstract available at:  
<http://www.nytimes.com/ref/membercenter/nytarchive.html>

## *Document 21*

**Document Name:** Past Imperfect: Ghosts of Tuskegee

**Citation:** Cobb WJ. Publication date: February 17, 2004. Available at:  
<http://africana.com/columns/cobb/ht20040217ghosts.asp>

## *Document 22*

**Document Name:** Untreated Syphilis in Negro Male

**Citation:** Document header: From CDC files; 1 Basic. Untreated Syphilis in Negro Male. Dr. Wenger; Hot Springs Seminar. Document dated 9/18/50. Reproduced from records in the U.S. National Archives and Records Administration (NARA) Southeast Region facility, Georgia. Available as attachment to the unit. As a government document, this is in the public domain, but the "Reproduced at NARA" stamp in the footer must be included in copies made.

This document was found among the archives from the TSS at the NARA. It appears to be the transcript of a speech given by a Dr. Wenger at a seminar.

## *Document 23*

**Document Name:** Tuskegee Re-examined

**Citation:** Shweder RA. Internet article dated January 8, 2004. Available at:  
<http://www.spiked-online.com/articles/0000000CA34A.htm>



## *Document 24*

**Document Name:** Letter from Dr. Olansky to Dr. Cutler with Enclosure Entitled “Outline of Problems to Be Considered in Tuskegee Study”

**Citation:** Letter dated November 6, 1951. Reproduced from records in the U.S. National Archives and Records Administration (NARA) Southeast Region facility, Georgia. Available as attachment to the unit. As a government document, this is in the public domain, but the “Reproduced at NARA” stamp in the footer must be included in copies made.

## *Document 25*

**Document Name:** Ehrlich Finds Cure for Syphilis

**Citation:** A Science Odyssey: People and Discoveries. Available at:  
<http://www.pbs.org/wgbh/aso/databank/entries/dm09sy.html>

This tells a brief story of the discovery of Salvarsan, an arsenic-based drug, for the treatment of syphilis.

## *Document 26*

**Document Name:** Racial Differences in Factors That Influence the Willingness to Participate in Medical Research Studies

**Citation:** Shavers VL, Lynch CF, Burmeister LF. *Annals of Epidemiology*. 2002;12:248–256. Abstract available from PubMed.

This article reports some additional results of the research study conducted in 1998–1999 in Detroit which was the basis for the article numbered Document 5.

## *Document 27*

**Document Name:** Blacks in U.S. Syphilis Program Settle Their Suit Out of Court.

**Citation:** *New York Times*. December 17, 1974, page 20. Abstract available at:  
<http://www.nytimes.com/ref/membercenter/nytarchive.html>

## *Document 28*

**Document Name:** HEW Will Study Syphilis Project: A Panel Set Up to Report on Tuskegee Experiment

**Citation:** *New York Times*. August 25, 1972, page 40. Abstract available at:  
<http://www.nytimes.com/ref/membercenter/nytarchive.html>

## Document 29

**Document Name:** Tuskegee Research Report; three tables of data

**Citation:** Tables of data from the study. Reproduced from records in the U.S. National Archives and Records Administration (NARA) Southeast Region facility, Georgia. Available as attachment to the unit. As a government document, this is in the public domain, but the “Reproduced at NARA” stamp in the footer must be included in copies made.

These tables show data from the clinical examinations performed in 1932, 1938, and 1948. Identifying information about study subjects has been blacked out to protect privacy.

## Document 30

**Document Name:** Memo from Eleanor N. Walker to Dr. John C. Cutler

**Citation:** Memo dated December 4, 1952. Reproduced from records in the U.S. National Archives and Records Administration (NARA) Southeast Region facility, Georgia. Available as attachment to the unit. As a government document, this is in the public domain, but the “Reproduced at NARA” stamp in the footer must be included in copies made.

This is a brief memo from another stakeholder in the TSS.

## Document 31

**Document Name:** Differential Mortality Rates Among Tuskegee Syphilis Study Participants

**Citation:** Document apparently dated April 26, 1974. Reproduced from records in the U.S. National Archives and Records Administration (NARA) Southeast Region facility, Georgia. Available as attachment to the unit. As a government document, this is in the public domain, but the “Reproduced at NARA” stamp in the footer must be included in copies made.

- Some of the other documents are newspaper articles, Internet articles, memos, etc. This document is a proposal. What is being proposed?
- What are the reasons for the study to which the author refers in paragraph 1?
- The flow chart on page 5 has information labeled as death rates for syphilitic and nonsyphilitic men (see columns of data at the left and right of the flow chart boxes). However, lines 6 to 8 of the Background section of page 1 note that the purpose of the study is to compare death rates. At first glance, this author appears to be proposing to ask a question to which he or she already has the answer, since the rates are laid out on page 5. However, the difference is in the types of mortality rates that will be used in the proposed study. A mortality (death) rate is the proportion of persons in a population who die during a specified period of time. Look at the flow chart and write out the formula for the death (mortality) rate that is being used there. As an example, show the calculation that was done to determine the death rate listed as 21.2% (fourth rate on left-hand column), and in words, write out what that death rate means.

- The difference between the formula you derived and the formula that is being proposed for the study is basically in the denominator. The flow chart uses a “down and dirty” method of calculating a mortality rate, and the proposed study uses a more complicated, yet more precise method. The proposed method essentially uses the same numerator (number of deaths) and divides that by a measure known as person-time in the denominator. Person-time helps you to account for the fact that during any given time period, the number of men in the population at risk differs. It really does not stay the same over time, and especially in the situation where men from the original study group fall out of contact with the researchers and their status is unknown. So, while they are in the study the subjects should be counted, but when they drop out, they should be removed from the count. Therefore, in any given 5-year time period, person-time or person-months can be used to calculate the number of months that a man was in the study. If a man moved out of Macon County on June 1, 1955, and could not be traced by the researchers, he was present for only five months in the 1955–1959 time period, so he is one person who contributes five months to the denominator. Then if his neighbor, another subject in the study, moved out two months later, he would have been in the study for seven months and would add another seven months to the denominator. Together they contributed  $5 + 7 = 12$  months of person-time, or 12 person-months. However, there is another reason why the proposed study would be superior to the information available from the flow chart, and that is that the proposed study would incorporate additional information about the subjects. The person who created the flow chart appears to have used only very basic information such as syphilitic versus nonsyphilitic and alive versus dead versus lost to follow-up. What pieces of information were being considered for the proposed study?
- Why might cause of death be an important variable to consider for the proposed study?
- On page 1, lines 4 to 6, the author claims that “the mortality of control participants was higher than that of syphilitics in 1948 and 1951–1954.” From the flow chart sheet, identify the information that was used to make that claim, and then determine whether you agree with that statement.
- The author of this proposal (see bottom of page 3) presents a valid argument: “If the mortality experience of the two groups is similar after 1950, then . . . it may be argued that withholding of penicillin in the early 1950’s had minimal or no effect on the mortality of syphilitics who survived until the advent of the penicillin (era).” What the author is arguing is that the rationale for administering penicillin to syphilitic men is to “allow” their mortality rate to be comparable to the general population (in this case, the men without syphilis). So, if the mortality rates of the syphilitic men and the nonsyphilitic men were the same after 1950, failure to administer penicillin did not have an adverse effect on the mortality of the syphilitic men. This author appears to stop shy of stating this, but other authors extend the argument to

state that since the penicillin could not have made that “difference,” the ethical concerns are moot. Is there evidence from the flow chart that the mortality rates had converged by the time penicillin was available?

### *Document 32*

**Document Name:** Ad Hoc Committee Meeting to Examine Data from the Tuskegee Syphilis Study and Offer Advice on Continuance of This Study (NARA name).

**Citation:** Document stored in the U.S. National Archives and Records Administration (NARA) Southeast Region facility, Georgia. ARC identifier 281641. Available from the NARA Web site at <http://arcweb.archives.gov> by entering the report identifier number in the search box.

### *Document 33*

**Document Name:** Twenty Years of Follow-up Experience in a Long Range Medical Study

**Citation:** Rivers E, Schuman SH, Simpson L, Olansky S. *Public Health Reports*. 1953;68:391–395. Available full-text at: <http://www.tuskegee.edu/Global/Story.asp?s=1207636>

This is an article whose lead author is Nurse Rivers.

### *Document 34*

**Document Name:** Fleming Discovers Penicillin, 1928–1945

**Citation:** A Science Odyssey: People and Discoveries. Available at: <http://www.pbs.org/wgbh/aso/databank/entries/dm28pe.html>

### *Document 35*

**Document Name:** Attitudes and Beliefs of African-Americans Toward Participation in Medical Research

**Citation:** Corbie-Smith G, Thomas SB, Williams MV, Moody-Ayers S. *Journal of General Internal Medicine*. 1999;14:537–546. Abstract available from PubMed.

### *Document 36*

**Document Name:** “Why Don’t They Come to Pike Street and Ask Us?”: Black American Women’s Health Concerns.

**Citation:** Freedman TG. *Social Science and Medicine*. 1998;47:941–947. Abstract available from PubMed.

### *Document 37*

**Document Name:** Ex-chief Defends Syphilis Project: Says Alabama Plan Was Not Unethical or Unscientific

**Citation:** *New York Times*. July 28, 1972, page 29. Abstract available at: <http://www.nytimes.com/ref/membercenter/nytarchive.html>

## *Document 38*

**Document Name:** Guidelines for the Conduct of Research Involving Human Subjects at the National Institutes of Health (Appendices 1 and 2 only)

**Citation:** National Institutes of Health Office of Human Subjects Research. Available at: <http://ohsr.od.nih.gov/guidelines/graybook.html>

Appendix 1 is entitled “Historical, Ethical and Legal foundations for the NIH’s Policies and Procedures” and Appendix 2 is “The Ethical Principles of the Belmont Report.” These documents are from the U.S. Public Health Service agency, the National Institutes of Health (NIH).

## *Document 39*

**Document Name:** Syphilis Study Is Hit on Notifying Patients

**Citation:** Heller J. *The Washington Post, Times Herald* (1959–1973). February 24, 1973, page A10. Abstract available at: [www.washingtonpost.com](http://www.washingtonpost.com) (click on Archives in left frame)

## *Document 40*

**Document Name:** Experiment Settlement Is Faulted

**Citation:** Cohn V. *The Washington Post*. December 18, 1974, page A6. Abstract available at: [www.washingtonpost.com](http://www.washingtonpost.com) (click on Archives in left frame)

## *Document 41*

**Document Name:** Syphilis Experiment Termed Unjustified

**Citation:** *New York Times*. March 29, 1973, page 54. Abstract available at: <http://www.nytimes.com/ref/membercenter/nytarchive.html>

## *Document 42*

**Document Name:** US Syphilis Study Called “Ethically Unjustified”: Report of Tuskegee Panel to Congress Urges a Board to Guide Human Research

**Citation:** *New York Times*. June 13, 1973, page 21. Abstract available at: <http://www.nytimes.com/ref/membercenter/nytarchive.html>

## *Document 43*

**Document Name:** HEW to End Alabama Study of Syphilis

**Citation:** *The Washington Post, Times Herald* (1959–1973). October 28, 1972, page A2. Abstract available at: [www.washingtonpost.com](http://www.washingtonpost.com) (click on Archives in left frame)

# Student Instruction and Document Sheet

## *Activity 1*

Your job today is to examine the attached documents and create a summary of the Tuskegee Syphilis Study in timeline form.

**Your timeline should include the following:**

- Background and purpose of the study
- Information that spans seven decades and includes several key events during and after the study
- Outcome of the study

Be prepared to share your timelines with the class.

## *Activity 2*

Now you will look more closely at selected documents (Documents 1, 2, 9, and 31). From those documents, prepare answers to the following questions:

**Using Documents 1 and 2:**

- Describe the disease syphilis.
- What is the present-day prognosis and outcome for those with syphilis?

**Using Document 9:**

- Draw a flow chart to display the data shown in the table. The flow chart should be as detailed as possible and should start with the number 611 on the top, with dates and subject status shown at the nodes.
- In what ways could Dr. Brown have improved on his presentation of the data in this table? Focus on the use of the word “cases,” cause of death, and the use of dates. Do the data in this table conflict with any other documents in the set?
- How can lack of complete data in epidemiologic studies make it difficult to answer research questions?
- What proportion of men who were diagnosed with syphilis by final classification died?

- What proportion of men who were not diagnosed with syphilis by final classification died? In other words, what was the “mortality rate” among the nonsyphilitics?
- If we assume that all deaths were from syphilis, the ratio of the mortality rate in the syphilitic men to the mortality rate in the nonsyphilitic men can be considered an estimate of the strength of the relationship between syphilis and death. What is that ratio?
- What does Document 9 help us to understand about the TSS?

### **Using Document 31:**

- Some of the other documents are newspaper articles, Internet articles, memos, etc. This document is a proposal. What is being proposed?
- What are the reasons for the study to which the author refers in paragraph 1?
- The flow chart on page 5 has information labeled as death rates for syphilitic and nonsyphilitic men (see columns of data at the left and right of the flow chart boxes). However, lines 6 to 8 of the Background section of page 1 note that the purpose of the study is to compare death rates. At first glance, this author appears to be proposing to ask a question to which he or she already has the answer, since the rates are laid out on page 5. However, the difference is in the types of mortality rates that will be used in the proposed study. A mortality (death) rate is the proportion of persons in a population who die during a specified period of time. Look at the flow chart and write out the formula for the death (mortality) rate that is being used there. As an example, show the calculation that was done to determine the death rate listed as 21.2% (fourth rate on left-hand column), and in words, write out what that death rate means.
- The difference between the formula you derived and the formula that is being proposed for the study is basically in the denominator. The flow chart uses a “down and dirty” method of calculating a death rate and the proposed study uses a more complicated, yet more precise method. The proposed method essentially uses the same numerator (number of deaths) and divides that by a measure known as person-time in the denominator. Person-time helps you to account for the fact that during any given time period, the number of men in the population at risk differs. It really does not stay the same over time, and especially in the situation where men from the original study group fall out of contact with the researchers and their status is unknown. So, while they are in the study the subjects should be counted, but when they drop out, they should be removed from the count. Therefore, in any given 5-year time period, person-time or person-months can be used to calculate the number of months that a man was in the study. If a man moved out of Macon County on June 1, 1955, and could not be traced by the researchers, he was present for only five months in the 1955–1959 time period, so he is one person who contributes five months to the denominator. Then if his neighbor, another subject in the study, moved out two months later, he would have been in the study for seven months and would add another seven months to the

denominator. Together they contributed  $5 + 7 = 12$  months of person-time or 12 person-months. However, there is another reason why the proposed study would be superior to the information available from the flow chart, and that is that the proposed study would incorporate additional information about the subjects. The person who created the flow chart appears to have used only very basic information such as syphilitic versus non-syphilitic and alive versus dead versus lost to follow-up. What pieces of information were being considered for the proposed study?

- Why might cause of death be an important variable to consider for the proposed study?
- On page 1, lines 4 to 6, the author claims that “the mortality of control participants was higher than that of syphilitics in 1948 and 1951–1954.” From the flow chart sheet, identify the information that was used to make that claim, and then determine whether you agree with that statement.
- The author of this proposal (see bottom of page 3) presents a valid argument as follows: If the mortality rates of the syphilitic men and the nonsyphilitic men started to converge after penicillin was developed, then penicillin administration itself would not have made a difference in the mortality rates of the syphilitic men. This author appears to stop shy of stating this, but other authors extend the argument to state that since the penicillin could not have made that “difference,” the ethical concerns are moot. Is there evidence from the flow chart that the mortality rates had converged by the time penicillin was available?



# Wrap-up (Teacher's Document)

## Debriefing of the Document Analysis

Even if students do not review every document, they should be able to create a timeline that spans seven decades and includes several key events, such as the start of the study, discovery of penicillin, meetings and discussions about continuation of the study, news reports about the study, Department of Health, Education, and Welfare committee to review the study, end of the study, lawsuit filed on behalf of the subjects, public responses to the TSS, research related to the impact of the TSS on African-American recruitment into public health research, presidential apology, and the death of the last survivor in 2004.

After the document analysis activity is complete, have students process what they have learned. Did they have any preconceptions about the TSS? If so, were these changed in any way by the class activity?

Have students display and debrief their timeline. If these issues do not emerge, teachers may wish to prompt with some of the following questions:

- Was the study unethical in 1932? Should it ever have been started? Did the subjects provide informed consent?
- Was it ethical at first, but then unethical after penicillin was discovered?
- Could this study have been done differently? Should it have been done differently?
- When, if ever, should it have been stopped?
- What do you think the subjects felt about their participation? Did they believe they were being treated unfairly? Does the answer to that question change over time (1930s, 1940s, 1950s, etc.)? Would they have thought to question the study doctors or Nurse Rivers? If they did, what could they have done about it? Was there some point in time when the subjects' feelings may have changed?
- What was the impact of using churches and schools to recruit subjects?
- What was Nurse Rivers's role in this project? What is your opinion of her and her role?
- How do students feel about using data from unethical research—i.e., should science “profit” from questionable research, or should the data be ignored? Students may recall that some of the documents raise the issue of honoring the subjects by continuing the study.

There will undoubtedly be disagreement among the students about these issues. However, it is

important to focus on a full account of the facts of the TSS, as separated from some of the myths they may have heard, e.g., that men were intentionally infected with the bacteria that cause syphilis. It is also important for them to grapple with the issue of whether it is unfair to “judge” the TSS researchers using contemporary values and beliefs. This is a difficult issue to address. Many would argue that human rights were at stake in the TSS, and those are timeless values. However, the following counterargument has been raised: In the early 1930s, it would not have been unusual for members of that segregated society to have thought that the TSS was a legitimate and ethical research project. There are those who would argue that the ethical dilemmas are unclear because the prepenicillin treatments for syphilis were highly toxic. Furthermore, there are those who might argue that the TSS subjects were in the late latent or tertiary stage at the time when penicillin became available and penicillin would not have reversed any organ damage that they might have had.

Students must come to terms with arguments on both sides. Students will wrestle with the issue of whether withholding information about the true purpose of the study should be excused, since the onset of the TSS predated federal requirements for informed consent. They will undoubtedly debate whether race and racism played a role in the selection of these men as subjects for the TSS. Some may decide that the study was appropriate when it started, but will believe that it should have been stopped and all men offered treatment when penicillin became available. They will, no doubt, struggle with the issue of the role of African-American professionals in the study. There will surely be these, as well as other concerns. However, it is important for them to recognize that they are not alone in their feelings about the history as well as the ongoing legacy of the TSS.

After hearing the opinions of the students about this historical event, ask them to consider whether this study could happen now. Why or why not? Prompt them to think of broad societal contexts. Has society changed? Would these changes make it easier or more difficult to conduct such a study? What might be different now? What might be the same now? Is there something that we should be doing now to undo the damage that has been done? Is it too late? Is it a moot point?

There are two important issues that have been said to be related to the legacy of the TSS. The first is that there are now extensive efforts that, by law, are required to protect the rights of human participants in research. The second issue is the postulated relationship between the knowledge of the TSS and distrust of biomedical and public health research and researchers by communities of color.

These two ideas should have emerged from the students’ document analyses. What is their opinion of the legacy of the TSS? Do any of them agree with Dr. Gamble, Tuskegee Legacy Committee, who suggests that African Americans can point to other examples of mistreatment and that TSS is but one example (Gamble, 1997)?

## Preparing for the Assessment

To help students move toward the assessment component, discuss with them the following:

What is epidemiology? It is one of the many fields of public health. Students may be familiar with public health because of the visibility of programs that are designed and administered by public health agencies, e.g., immunization programs, food safety, sanitation, 5-a-day nutrition education, cholesterol screening, etc. Epidemiology is the research arm of public health. Epidemiologists design, carry out, and analyze results from research studies that help us answer basic questions about the health status of populations, such as who is sick and who is well. In addition, epidemiologists also look more closely at the patterns of diseases in populations in order to answer the question, why are the sick persons getting sick and why are the well persons well? In this way, epidemiology helps us determine what the agents of disease might be. That is why epidemiologists are often called medical detectives. Police detectives collect evidence to help them identify the causes of crime, i.e., the guilty persons. Similarly, medical detectives—epidemiologists—collect evidence to help them identify the causes of disease.

The evidence to determine disease causation comes from research studies in which epidemiologists compare groups of well and ill persons to ascertain how they differ, or they may compare groups of persons who have certain agents or exposures and see who develops the disease and who doesn't. Therefore, without research and without persons willing to participate in research studies, epidemiologists wouldn't be able to help determine disease causation and hence could not help to keep people healthy.

To help students with the assessment exercise, the teacher may wish to remind them that in some of their readings there were ideas about the impact of the TSS on recruitment. In addition, the teacher may wish to share the following. In their review of the literature, Shavers-Hornaday and her colleagues (1997) have provided a list of strategies that were identified by various researchers as having been effective at increasing minority participation in their studies. These included

- an active commitment to the recruitment of African American subjects; efforts to enhance the credibility of the study in the general community through outreach programs and advertisements; the involvement of local churches and community organizations; publicity campaigns directed at African Americans; patient considerations such as convenient hours of operation, study-supplied transportation or reimbursement for transportation costs and the location of the study centers; the use of incentives; the use of African American role models; flexibility and the willingness to make necessary adjustments to the study design; the use of lay health workers; door to door canvassing.

Then teachers should ask students to return to their small groups from the previous class activity and work together on the assessments. Hand them the student assessment instruction sheet.

# Assessment Instruction Sheet (Student Document)

You are members of a firm that conducts research around the country. Part of your research requires recruiting willing subjects to participate in the studies for your firm. Your team recently targeted five Southern communities for subject recruitment. Interest in participation was relatively good in four of the communities, but when a preliminary recruiting meeting was held in Macon County, Alabama, no potential participants attended. Curious about the lack of response to the opportunity, you and your team members decide to talk to residents of the community. The general consensus among those questioned was “Not us! Not again!”. The local librarian, the last person with whom you spoke, refused to answer your questions, but instead referred your team to the documents about the Tuskegee Syphilis Study. Your team is responsible for recruiting participants from this community. The success of the study depends on it.

Using the documents provided and knowledge of the Tuskegee Syphilis Study, create a recruitment plan (one page minimum) to persuade members of the Tuskegee community to participate in your firm’s study. Members of each group may wish to consider the following elements in their plan: Where will they recruit? Whom will they involve in the recruitment process? What recruitment methods will they use (mass media, TV ads, school flyers, etc.)? How will they address any potential barriers or resistance? What if there are community questions about the research endeavor? How will that be handled? What, if anything, will they do to address the issue of the Tuskegee Syphilis Study? Your recruitment plan must successfully recognize the history of the Tuskegee Syphilis Study and incorporate current ethical practices in epidemiology. Your proposal should reference various documents for support, as necessary.