

**THE TUSKEGEE SYPHILIS STUDY:
ACCESS AND CONTROL OVER CONTROVERSIAL RECORDS**

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No doubt throughout all past time there actually occurred a series of events which, whether we know what it was or not, constitutes history in some ultimate sense...The event itself once occurred, but as an actual event it has disappeared; so that in dealing with it the only objective reality we can observe or test is some material trace which the event has left—usually a written document. With these traces of vanished events, these documents, we must be content since they are all we have; from them we infer what the event was, we affirm that it is a fact that the event was so and so.¹

As the nation's archives, the National Archives and Records Administration (NARA) preserves and provides access to records that document how our government conducts business on behalf of the American people—past and present. For the American citizen, NARA provides a form of accountability through the records within its custody which affect the nation's collective memory. A plethora of these records, however, contain evidence of the federal government's misconduct in episodes in American history which affected public trust. The Tuskegee Syphilis Study records are a prime example of records within the custody of NARA that continue to have a lasting affect on public trust in the federal government. Even though NARA disclosed administrative records that document the government's role in the study, the Tuskegee Syphilis Study records continue to challenge the institution on a variety of archival issues such as access, privacy, collective memory, and accountability. Through historical case study methodology, this study examines the National Archives and Records Administration's administrative role in maintaining and providing access to the Tuskegee Syphilis Study records, especially the

¹ Carl Becker, "Everyman His Own Historian," *American Historical Review* 37 (January 1932): 221.

restricted information. The effect of the changing social context on NARA's recordkeeping practices of the Tuskegee Syphilis Study records is also explored.

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ACRONYMS USED IN THE TEXT

SF	Standard Form
FBI	Federal Bureau of Investigation
FRC	Federal Records Center
RG	Record Group
CDC	Centers for Disease Control and Prevention
NARA	National Archives and Records Administration and National Archives
NARS	National Archives Records Service
U.S.C	United States Code
C.F.R	Code of Federal Regulations
FOIA	Freedom of Information Act <u>5 U.S.C. § 552 (2002).</u>
	Exemption 6 <u>5 U.S.C. § 552(b)(6) (2000)</u>
HEW	Department of Health Education and Welfare

1.0 OVERVIEW OF AN ARCHIVAL PROBLEM

1.1 INTRODUCTION

The significance of archival records cannot be overstated. Archival records serve as instruments of accountability and building blocks of collective memory. John McDonald notes the connection between records and accountability, stating “without records, there can be no demonstration of accountability. Without evidence of accountability, society cannot trust in its public institutions.”¹ Thus, the records within the custody of the National Archives and Records Administration² are the bedrock for holding the federal government accountable to its citizens. Such records “provide evidence of actions, decisions, and intentions, both legal and illegal, proper and improper,” which is “...an inherent part of the accountability function and recordkeeping systems.”³ When records reveal illegal and improper governmental actions, archivists must not hesitate to expose the improprieties. As Kent Haworth states, “The essence of archives are the records in our care...the purpose of the archivist is to hold in trust for society the

¹John McDonald, "Accountability in Government in an Electronic Age," (paper presented at the International Records Management Trust Electronic Records Seminar, Kuala Lumpur, Malaysia , 25 June 1998). This paper is no longer available through the International Records Management Trust website, but can be accessed through the Internet Archive's Wayback Machine at <http://web.archive.org/web/20010726105930/www.irmt.org/education/malpaper2.html>.

² The National Archives and Records Administration and its acronym NARA will be used interchangeably.

³ Richard J. Cox and David A. Wallace, eds., *Archives and the Public Good: Accountability and Records in Modern Society* (Westport, CT: Quorum Books, 2002), 4, 11.

evidence of the truth, the evidence of justice and injustice in the society our archives document.”⁴

The “Tuskegee Study of Untreated Syphilis in the Negro Male (1932-1972)”⁵ continues to have a major impact on society socially and medically. More importantly, the records themselves are critical to revealing government misconduct that gave rise to this notorious episode of American history. In their edited volume, archivists Richard Cox and David Wallace assert, “We need to remember that records are critical to societal awareness and the memory of pivotal events, and that their use may be part of controversies forcing archivists to take stands on access to records.”⁶ Such is the case with the Tuskegee Syphilis Study records, where access to restricted records is a controversial issue.

In 1932, in Tuskegee, Alabama, the United States Public Health Service (PHS) began a study to observe the natural course of syphilis in 399 African-American men until they died in order to determine whether or not there were any racial differences between whites and blacks in the natural progression of the disease.⁷ As a control, a comparable group of 200 African-American men without syphilis were observed. The infected men were never told that they had

⁴ Kent Haworth, “The Principles Speak for Themselves: Articulating a Language of Purpose for Archives,” in *The Archival Imagination: Essays in Honour of Hugh A. Taylor*, ed. Barbara L. Craig (Ottawa: Association of Canadian Archivists, 1992), 94.

⁵ This is the official title of the study. However, over the years there have been a number of titles for this study such as: Tuskegee Study of Untreated Syphilis in the Negro Male, Tuskegee Syphilis Study, Syphilis Study at Tuskegee, Tuskegee Study, Tuskegee Syphilis Experiment and Tuskegee Syphilis Project. For this research study it will be referred to as the Tuskegee Syphilis Study.

⁶ Cox and Wallace, 11.

⁷ A similar study had taken place earlier in Oslo, Norway where white males and females were monitored. Such a study had not been done in the United States, particularly with African Americans. The United States PHS physicians saw this as an opportunity to track the natural progression of syphilis in the African-American male in Tuskegee, Alabama.

syphilis; they were merely told that they had “bad blood.” With the cooperation of state and local physicians, the researchers prevented these men from receiving any kind of treatment or discovering what “bad blood” meant. As a result of this concerted effort, the study continued for forty years. Often called the longest non-therapeutic experiment on human beings in medical history within the medical field, the study was exposed to the world on July 25, 1972. This controversial and unethical study officially ended in November 1972.

Public disclosure of the study has engendered a much closer scrutiny of many aspects of governmental and research practices. This study was instrumental in creating safeguards for those who would participate in future research experiments. The Tuskegee survivors and their families have received compensation from the federal government as well as free medical care for life. More importantly, they received a long awaited official apology from President William J. Clinton on May 16, 1997.

The records generated from the study revealed how meticulous the United States Public Health physicians were in carrying out this forty year study in which they deliberately withheld treatment. In addition, the records showed that from the inception of the study the participants believed they were in a treatment program. As a result of such recordkeeping, those same documents proved to be crucial in a lawsuit brought against the government.

Today the original records are in the custody of the National Archives and Records Administration. The records include a total of eighty-seven boxes. Almost half of these boxes pertain to individual patients. NARA had initially restricted the medical records until 2030 in order to protect the personal privacy interests of the participants. It seems obvious that protection of the Tuskegee participants medical records is non-negotiable, given the humiliation these men and their families have already endured. It is not that simple, however. Access to all of the

Tuskegee Syphilis Study records is a hotly contested issue among NARA, researchers, and the African-American community because of the conflict between the public's right to know what happened and the protection of the personal privacy interests of the participants.

Scholars interested in medical records for historical research purposes, face many obstacles which include confronting access and confidentiality issues relating to their research agendas. For archives, medical records raise special issues. Providing access to sensitive material has been and continues to be a balancing act. Thus, the challenge for repositories which have holdings containing medical information lies in protecting individual privacy interests while providing access to the intellectual content of the material.

NARA is bound by federal statutory laws that prohibit the release of sensitive or personal information. The public's right to be informed, to know, and to have access to important information is in direct conflict with the right to personal privacy. For archivists working at the National Archives, administering access to records that contain personal information is a challenge, given the nuances of the federal statutes they must follow, specifically the Privacy Act and the Freedom of Information Act (FOIA).⁸ As Heather MacNeil points out, for government archivists "personal information collected and maintained by government agencies eventually ends up in their custody, leaving them with the unenviable task of reconciling legitimate but conflicting interests—the individual's right to privacy and society's need for knowledge."⁹ The Tuskegee Syphilis Study is an opportunity to examine the way in which NARA balances these two competing interests.

⁸ Freedom of Information Act and its acronym FOIA will be used interchangeably.

⁹ Heather MacNeil, *Without Consent: The Ethics of Disclosing Personal Information in Public Archives* (Metuchen, NJ: The Scarecrow Press, Inc., 1992), 5.

1.2 PURPOSE OF STUDY AND RESEARCH QUESTIONS

The records that document the Tuskegee Syphilis Study contain sensitive information about the participants and their family members. The Centers for Disease Control and Prevention (CDC) restricted the medical records under Exemption (b)(6) of the Freedom of Information Act which protects personal information within medical files. Upon transfer, NARA agreed to continue the restrictions to access enforced by CDC. While NARA's mission is to provide ready access to government records within its legal custody, it must balance the disclosure of information against the invasion of personal privacy. NARA was encouraged by the researcher to re-examine its restrictions on the Tuskegee Syphilis Study medical records in order to determine whether or not the situation had changed, warranting full or partial disclosure since their transfer to NARA in 1991.

Both NARA and CDC determined that since the participants were deceased and there was limited third-party information within the files, the medical records should be opened. Since privacy rights diminish upon death, NARA decided that the balancing test favored full disclosure. Thus, during the course of this case study, the medical records were opened in 2004.

NARA's decision, however, does not affect the thesis of this case study that even though NARA reviews its access policy on a case by case situation, its management of the Tuskegee Syphilis Study records was inconsistent with providing access to restricted information. This inconsistency affected the public's increasing demand for access. Although NARA thought it was providing access to the Tuskegee Syphilis Study records, it was not under its own regulations and federal statutes. It took a Freedom of Information Act request for NARA to initiate a review of its access policy toward the Tuskegee Syphilis Study records.

In order to accession the Tuskegee Syphilis Study records, NARA agreed to the CDC's arbitrary restrictions placed on the medical records which were not based on any federal statute or regulation, which had been placed on the medical records by CDC. In formal practice, NARA does not approve the transfer of records from agencies that contain unreasonable restrictions that are not covered under statute or regulation. As a result, upon the transfer of historical records to NARA, agencies must have legal justification for their restrictions. However, NARA did not comply with formal policy and accepted the Tuskegee Syphilis Study records based on the CDC's restrictions. NARA's actual practices of receiving historical documents from government agencies without legally based reasons generated the following research questions:

1. What is NARA's official policy toward administering access to controversial records that contain restricted information?
2. In light of those policies and practices, how are the Tuskegee Syphilis Study records treated?
3. Does NARA's access policy toward restricted information and the agreement with the Centers for Disease Control (CDC) undermine the spirit of the Freedom of Information Act with respect to the Tuskegee Syphilis Study records? If so, what are the consequences in this particular case?
4. What do the recordkeeping practices of the Tuskegee Syphilis Study records, reveal about NARA's effectiveness in protecting personal information in those records?
5. How have the restrictions on the Tuskegee Syphilis Study records affected the collective memory of the study?

1.3 DESCRIPTION OF THE CASE STUDY

The Tuskegee Syphilis Study records document the longest non-therapeutic medical study in American history. The records illuminate government misconduct and allow an additional opportunity for the public to hold the federal government accountable for this misconduct. These records exemplify the National Archives and Records Administration's access policy and its attempts to reconcile the right to know with the right to personal privacy. The National Archives entered into an agreement with the Centers for Disease Control (CDC)¹⁰ intended to insulate the participants from the public by forbidding disclosure of their identities. Such information, however, has nonetheless found its way into the public domain. In addition, a researcher can challenge the release of all or part of the restricted information based on FOIA. Richard Cox and David Wallace state that "records frequently provide the scaffolding for the stories relayed and sometimes they even play central roles, yet they are rarely explicitly surfaced as objects receiving concentrated attention."¹¹ As a result of the public's increasing requests for access, the Tuskegee Syphilis Study records are now receiving that attention in this study.

1.4 LIMITATIONS OF THE CASE STUDY

This case study is limited to an examination of the recordkeeping policies of the Centers for Disease Control (CDC) and the National Archives and Records Administration (NARA) for maintaining the Tuskegee Syphilis Study records and is not the history of the study itself. The study itself was officially terminated in November 1972, and in 1976, the Centers for Disease

¹⁰ The Center for Disease Control and its acronym CDC will be used interchangeably.

¹¹ Cox and Wallace, 2.

Control officially scheduled the Tuskegee Syphilis Study records for permanent retention. In 1991, the records were transferred to the National Archives Southeast Regional Center in Atlanta, Georgia.¹² Although the National Archives became responsible for the maintenance of those records, an agreement between it and the Centers for Disease Control prohibited all general and research access to the medical records in their entirety.

The case study is limited to primary documents concerning the Tuskegee Syphilis Study which include the records themselves, court documents, appraisal and accession records. It also considers secondary archival literature regarding access; privacy and collective memory; and issues relating to access to medical records. The case study focuses on the Freedom of Information Act which outlines how access requests are typically handled by NARA. It also examines NARA's Code of Federal Regulations regarding access to and transfer of records. In addition, this study includes interviews with archivists, records managers, attorneys, historians, health professionals, and Freedom of Information Act specialists. NARA's restrictions on the Tuskegee Syphilis Study records had been central to the overall management of those records. The data collected for this case study examines this management.

The case study does not limit the scope of personal privacy to the individual participants but broadens it to consider third party interests i.e. family members. The public's right to know what happened included the identification of the participants. Prior to disclosing the records in 2004, NARA had not released any personal information about the participants, including their names. However, the names are in court documents which are available to the public. Fred Gray, a civil rights attorney who filed a lawsuit against the government on behalf of the participants, has written a book about the case. In his book, Gray names the 625 men who were a part of the

¹² The NARA Southeastern Region has moved to Morrow, Georgia in 2005.

study.¹³ Some of those same men and family members have openly given interviews and participated in events associated with the public outcry. This case study examines how NARA interprets personal privacy when using the balancing test between the public's right to know and personal privacy. This study considers two ways of interpreting personal privacy: individual and third party. Will NARA consider both the participant's personal privacy interest and that of their families or only that of the participants themselves? How NARA interpreted personal privacy affected its decision to disclose the medical records.

This case study does not include a discussion of the Health Insurance Portability and Accountability Act (HIPPA). Established in 1996, the purpose of HIPPA is to protect the health insurance of workers who leave or change jobs by transferring medical information electronically. There are national standards created to protect the privacy and confidentiality of patient information: health status, health care, or payment.¹⁴

Even though HIPPA is a statutory law, the Freedom of Information Act governs access to government records. NARA investigated the researcher's request for access to the medical records under FOIA. It analyzed whether or not to disclose the medical records based on the contract between the Centers For Disease Control and Prevention and NARA which referenced FOIA, and on the balancing test when considering Exemption 6 under FOIA. Exemption 6 is one of nine reasons that NARA can deny access to its records that contain personal information. The Tuskegee Syphilis Study records are considered historical records. Whether or not HIPPA is retroactive to historical medical records is a question for future research.

¹³ Fred D. Gray, *The Tuskegee Syphilis Study: The Real Story and Beyond* (Montgomery, AL: Black Belt Press, 1998), x.

¹⁴ Carl E. Schneider, "HIPPA-crazy," *Hastings Center Report* (January-February 2006): 10-11.

2.0 LITERATURE REVIEW

The Tuskegee Syphilis Study records challenge the archival community on a variety of archival issues such as access, privacy, collective memory, and their connection to accountability. Although there is considerable literature on each topic, there is little written about how these areas are interrelated, especially on the subject of recordkeeping practices. As a result, this literature review will focus on the accountability nexus between access, privacy, and collective memory. The literature review begins with separate discussions access, privacy, and collective memory as they relate to archives and records.

2.1 ACCESS

Initially the primary purposes of medical records were to facilitate diagnosis, treatment, and patient care. During the twentieth century, however, medical records have served an increasing number of secondary uses. Medical records document patient symptoms, costs, treatment and other administrative and legal matters. The medical records constitute a vital body of data and information for both medical and historical research. As the result of increased interest in social history, researchers have used medical records to attempt to understand the lives of ordinary people. Researchers have examined documents such as birth records and marriage records to

study people and this has led to an increased interest in the use of medical information.¹ However, for archivists, developing access policies for such records has and continues to be a challenge.

In “The Origins of Restrictions on Access to Personal Papers at the Library of Congress and the National Archives,” Raymond Geselbracht discusses two different access policies for donated papers that developed from the historical manuscripts tradition and the public archives tradition. He contends that the National Archives’ access policy for personal papers is inappropriate for collections that lack significant public policy interest, such as the papers of artists or novelists. He recommends that the Manuscript Division’s policy be expanded to include collections that have high public policy interest. Geselbracht maintains that such collections should not be closed for long periods of time and suggests establishing guidelines to identify documents requiring restriction, while opening the remainder of the collection.²

Written in the mid-1980s, Geselbracht’s article provides a benchmark for archivists who have the responsibility of writing or revising their repositories access policies. Geselbracht points out that archivists must understand the history behind access issues in order to create policies that reflect their times. If not, then “they will lose the opportunity to shape the conditions under which they must live and work.”³ Many of the questions that Geselbracht raises regarding access policies are pertinent today, especially when dealing with sensitive material. For example, should

¹ Joel D. Howell, “Preserving Patient Records to Support Health Care Delivery, Teaching, and Research,” in Nancy McCall and Lisa A. Mix, eds., *Designing Archival Programs to Advance Knowledge in the Health Fields* (Baltimore: The Johns Hopkins Press, 1995), 33-51.

² Raymond H. Geselbracht, “The Origins of Restrictions on Access to Personal Papers at the Library of Congress and the National Archives,” *American Archivist* 49 (Spring 1986): 161-162.

³ *Ibid*,162.

entire collections or series be restricted, or should the restriction decision be made on the item level? Even though Geselbracht contends that agreements must be made among donors and archivists so that the archival profession may formulate a position on the issue of access policies, this has yet to happen. Through the morass of ever-changing and often contradictory contexts of public access to information and personal privacy, archivists are not setting the agenda for establishing a publicly agreed upon and widely disseminated set of criteria for access to personal information in medical records.

One of the major impediments to the use of research resources in the health fields has been the reluctance of archival and manuscript repositories to deal with the issues of confidentiality that affect access to these materials. Many repositories have refused to collect documentation that includes patient and human-subject materials. As a result, a key segment of documentation is being lost and overlooked. In addition, repositories are confronted with an array of legal and regulatory requirements regarding access and use. Policy makers have to weigh the necessity of restricted controls for access against archival programs' obligations to facilitate the activity of research. For example, governmental archives have to deal with providing access to and use of sensitive information within their custody and at the same time preventing unwarranted disclosure of personal identities. Often the government has refused to grant access to medical records and thus is accused of duplicity. Diane Nixon, however, points out that "sometimes minimized is the government's responsibility to preserve the privacy of innocent parties mentioned in its records, its right to withhold information it has received in confidentiality or intends to use in litigation, and its need to protect its sources and ongoing

procedures.”⁴ There are a number of cases where researchers, news media, and ordinary citizens have demanded access to sensitive records in the custody of the government.

Allen Hornblum’s *Acres of Skin: Human Experiments at Holmesburg Prison: A True Story of Abuse and Exploitation in the Name of Medical Science* reveals that prisoners were used as guinea pigs in experimental research. Hornblum alleges a scandal ranking with the Tuskegee study. The story centers on Holmesburg Prison near Philadelphia where dermatological experiments occurred with the support of federal and local officials. In order to expose the inhumane experimentation taking place at the prison, Hornblum interviewed former inmates who were test subjects. However, the inmates lack of knowledge as to what chemicals and substances they were exposed to or the purposes of the experiments meant that a thorough historical investigation was warranted. Although he interviewed hundreds of prisoners, doctors, and others who had come in contact with the Holmesburg experiments, it was obvious to Hornblum that acquiring objective documentation of the prison research would be essential if the story was ever to be revealed.⁵

Hornblum decided to orchestrate a thorough search of government documentation on the Holmesburg medical research program. The Freedom of Information Act (FOIA) proved key in obtaining these important and highly informative documents. Through FOIA requests, Hornblum acquired thousands of pages of material that revealed the little known but questionable experiments on prisoners.

⁴ Diane S. Nixon, “Providing Access to Controversial Public Records: The Case of the Robert F. Kennedy Assassination Investigation Files,” *The Public Historian*, 11 (Summer 1989): 29.

⁵ Allen Hornblum, *Acres of Skin: Human Experiments at Holmesburg Prison: A True Story of Abuse and Exploitation in the Name of Medical Science* (New York: Routledge, 1998), xiii-xxi.

The full investigation of the wide-ranging nature of the studies undertaken at the prison necessitated more FOIA requests from other governmental departments.⁶ The documents that Hornblum obtained from these departments provided a nuanced and complete understanding of what took place at Holmesburg Prison. The Holmesburg prison experiments highlight the need for a change in the culture of clinical investigations.

Jonathan D. Moreno's *Undue Risk: Secret State Experiments on Humans* uncovers other observational studies conducted during the 1950s which caused hundreds of deaths. Unlike the Tuskegee scandal, these experiments were the outgrowth of cold war military needs. Moreno exposes the military's role in exploiting its own men. For example, Marshall Islanders were continually exposed to an unnaturally radioactive environment, including the food they ate, in the decades following the South Pacific atomic tests. The Atomic Energy Commission (AEC) carefully followed the islanders' physiological reactions through its doctors, who also provided the islanders with routine medical care. But like the Tuskegee Study, the doctors did not explain to their patients that they were research subjects or that their injuries were radiation-related. Similarly, Air Force physicians studied the thyroids of Alaskan natives who were exposed to nuclear fallout in the 1950s and 1960s. According to Moreno, they too were not informed of the reasons for the U.S. Military's interest in providing medical care.⁷

In order to tell the story of human experimentation, Moreno relied on primary materials. Moreno examined previous government investigations, newspapers clippings, interviews with

⁶ Hornblum made FOIA requests to the Department of Defense concerning the U.S. Army's chemical warfare studies, the Central Intelligence Agency's role in similar studies, the Nuclear Regulatory Commission's files on radioactive isotope use, and the Food and Drug Administration's files on the DMSO investigation.

⁷ Jonathan D. Moreno, *Undue Risk: Secret State Experiments on Humans* (New York: W.H. Freeman and Company, 2000), 220-221.

experts, and earlier studies of biological and chemical warfare research. Through his research, Moreno concluded that government secrecy is “corrosive to democracy, constituting a true threat to our way of life.”⁸

Eileen Welsome’s *The Plutonium Files: America’s Secret Medical Experiments in the Cold War* uncovers the darker side of human experimentation in America during the Cold War. While Moreno mentions this episode in American military history as part of a long stream of human experimentation, Welsome delves into the military’s involvement in injecting American citizens with plutonium during the mid-1940s. Welsome reported that between April of 1945 and July 1947, eighteen people (men, women, and children) scattered in hospital wards across the country were injected with plutonium. When Welsome interviewed the families of the victims, she discovered that none of the doctors ever told them that the real purpose of their study was to measure the plutonium circulating in the family members’ bodies.⁹

The public disclosure of the experiments prompted President Clinton to appoint an advisory committee on Human Radiation Experiments. The committee’s job was to examine archives, including classified documents to reconstruct events and policies. At the request of Hazel O’Leary, then Secretary of Energy, Clinton ordered the declassification of those documents in order to get at the truth of the experiments. The advisory committee was also charged not only with resolving questions of medical ethics but with determining who was harmed and recommending just compensation. What is important to note about Welsome’s discovery is that it started out as an investigative report and ended up influencing the president to declassify tens

⁸ Ibid, 16.

⁹ Eileen Welsome, *The Plutonium Files: America’s Secret Medical Experiments in the Cold War* (New York: Delacorte Press, 1999), 6.

of thousands of documents that underscored the culpability of the government in using its citizens as guinea pigs in the name of national defense.

In “Some Problems in Placing Modern Medical Records in Public Archives,” Irene Kearsy discusses the practical problems of depositing modern hospital medical records in a public archival facility. The objective of the archives is to make records available for public access seventy-five years after the date of last contact of the patient with the hospital or sooner under certain specified circumstances.¹⁰ Even though Kearsy is examining this issue from the Canadian perspective, many aspects of her study are relevant for other countries, including the United States. Kearsy states that there are a limited number of instances when it is generally accepted ethical practice to release medical information: with the patient’s consent, when the law requires it, or when duty to society overrides the duty to the patient.¹¹

Kearsy argues that placing medical records in a public archives breaches confidentiality. By examining the exceptions, she assesses whether this breach can be justified. Kearsy has problems with obtaining expressed or implied consent from patients for permanently maintaining their medical record. She contends that ethical issues arise as to when it is proper to make such a request. For example, patients might suspect a sinister reason that their records are wanted for permanent retention when they know others have not been so informed. Kearsy insists that a selection process must be in place that identifies a record for permanent retention.¹² To ask all patients for informed consent would only create more problems.

¹⁰ Irene Kearsy, “Some Problems in Placing Modern Medical Records in Public Archives” *American Archivist* 17 (November 1989): 183-196.

¹¹ *Ibid*, 185.

¹² *Ibid*, 186-187.

Kearsey is troubled by the release of medical records that are in the public's best interest. She asserts that the public's best interest would apply if enough patients benefited significantly from the availability of the record as well. If this were the justification for permanency, then every record should be retained, which is clearly beyond the capabilities of hospitals. Kearsey, however, admits that release of medical records where duty to society overrides duty to the patient has some relevancy. For example, death certificates are already available for public scrutiny and thus duty to the patient might have completely disappeared by the end of the closure period.¹³

Kearsey asserts that the only grounds on which confidentiality of medical records can be breached is when the law requires it. Since there is a legal requirement, there is justification for breaching confidentiality by placing patient records in a public archive. For Kearsey, placing hospital patient records in a public archives is permissible when assessed against current requirements for the confidentiality of records. During the closure period, an ethics committee of the original record owner assesses each research project and researcher and specifies conditions under which work can be done. For example, any request for records will be referred back to the original hospital for permission to grant access. Eric Ketelaar suggests that in the case of restricted access the archivist can, after consultation with the creating agency, lift a restriction at the request of an applicant if using the records outweighs the interests served by the restrictions.¹⁴

A review of the archival literature related to access illustrates an emphasis in three general areas: public demand to restricted collections, implications of disclosing sensitive

¹³ Ibid, 187.

¹⁴ Eric Ketelaar, "The Right to Know, the Right to Forget? Personal Information in Public Archives," *Archives and Manuscripts* 23 (May 1995): 8-17.

material, and equal access to open collections. Moreover, much of this literature focuses on broader issues of access. For example, in “The Ethics of Access,” Elena Danielson’s fundamental objective is to point out the continuing debate about personal privacy versus public interest and the archivist’s difficult role in applying guidelines and codes to appease those involved i.e. heirs, donors, collectors, researchers, and home institutions. Danielson contends that archivists have a tougher job of administering unpublished papers than librarians who handle printed material.¹⁵

Danielson points out that archivist’s play a key role in mediating these conflicting interests in order to avoid the ultimate threat: “the destruction of embarrassing but historically important documentation.”¹⁶ Archivists must have succinct standards for access policies in order to make decisions. Danielson provides examples of collections that emphasize the difficulties archivists face in implementing the concept of equal access to restricted or sensitive records and her study has far reaching ramifications for archivists who deal with medical records. Her study underscores the point that with the public’s demands for greater openness, archivists cannot be asked to protect the reputations of public figures indefinitely.

Most restrictions proposed by donors of personal papers fall within the scope of privacy considerations. These stipulations are intended to prevent the embarrassing disclosure of private facts concerning donors or other individuals whose names appear in donated materials. In appraising collections of personal papers, archivists must be prepared to discuss the implications of sensitive materials with potential donors. In instances when donors do not apply restrictions to collections of personal papers that contain patient records, the repository accepting the collection

¹⁵ Elena Danielson, “The Ethics of Access,” *American Archivist* 52 (Winter 1989): 55.

¹⁶ *Ibid*, 59.

must assume responsibility for protecting the privacy of the patient and assign the appropriate restrictions where necessary. The privacy of patient and human-subject information, however, is widely protected by laws, institutional regulations, and the ethics of the health professions. Repositories at institutions in the health fields are bound to uphold their institutional policies regarding access to patient and human-subject information and must regulate access in compliance with these policies.

In “State Archives and Issues of Personal Privacy: Policies and Practices,” Alice Robbin contends that archivists struggle with these competing values because policies and practices for responding to requests for restricted records are not well developed. Her survey of fifty state archives revealed that archivists are neither well informed about confidentiality and access statutes nor politically active.¹⁷ Lacking formal policies and clear definition of privacy limits, archivists are unable to determine when an invasion of personal privacy might be warranted by the public disclosure of personal information held in their archives. Hence, archivists are unable to manage access to sensitive information such as medical records consistently. Archivists who are responsible for the management of patient records in their holdings should obtain copies of their own state laws governing medical records as well as follow the regular discussion in the medical literature on the topics of confidentiality and the disclosure of patient information. By understanding state laws covering medical records and following relevant professional literature, archivists can be well informed when they are confronted with a particularly complex issue regarding access to medical records in their holdings, archivists can be well informed.

¹⁷ Alice Robbin, “State Archives and Issues of Personal Privacy: Policies and Practices,” *American Archivist* 49 (Spring 1986): 163.

The objective of the volume *Designing Archival Programs to Advance Knowledge in the Health Fields* is to demonstrate the ways in which medical archives programs can be transformed to meet new demands for services. The editors, Nancy McCall and Lisa Mix, developed the volume as a catalyst and a guide in accomplishing a new alignment for archives in medical centers. The volume covers all aspects of medical archives management. Specifically, Deborah McClellan, Nancy McCall, and Ann Slakey have a discussion on “Promoting and Facilitating Wider Use of Holdings.”¹⁸ According to these authors, a major goal of this volume is to promote greater awareness and use of archival resources in the health fields. McClellan, McCall, and Slakey present a model for use of archival holdings from the health field that fosters open intellectual inquiry within the bounds of legal and ethical requirements.¹⁹

These authors emphasize that archivists in charge of holdings that contain patient and human-subject records face a daunting situation. Legal and ethical codes require that they protect the privacy of the individuals who are represented in these records. But precedents exist in the health fields for research involving the collection of clinical data and information. Archivists in the health fields are therefore in a position to protect the disclosure of private information while promoting open inquiry for intellectual studies. The authors insist that even though information about available holdings should be freely obtainable by all users and policies and procedures regarding access should be clearly set forth, an archivist must respect the restrictions that limit access to specific holdings. Thus, instituting a procedurally fair process for reviewing applications for access to restricted materials that weighs the legitimacy of each request is

¹⁸ Deborah McClellan, Nancy McCall, and Anne Slakey, “Promoting and Facilitating Wider Use of Holdings,” in Nancy McCall and Lisa A. Mix, eds., *Designing Archival Programs to Advance Knowledge in the Health Fields* (Baltimore: The Johns Hopkins University Press, 1995), 125-146.

¹⁹ *Ibid*, 126-27.

probably not discriminatory.²⁰ For example, if personal identifiers are protected, then researchers may be given access to the intellectual content of records. The thrust of the decision then focuses on the merit of the proposed research. As a result, in reviewing applications for access, archivists are considering the following issues: protection of personal identifiers, purpose of the research, quality of the research plan, and credentials of the researcher.²¹

When preparing guidelines for access to the holdings of individual repositories, archivists must first articulate a set of ethical principles that pertain to the access issues associated with their own holdings. More importantly, because of the legal, regulatory, and ethical restrictions at archival repositories in the health fields, the administration of policies and procedures for access is particularly complex. As a result, McClellan, McCall, and Slakey assert that archivists “must, therefore, combine a broad based knowledge of the fields that are represented in the holdings...and a strong commitment to archival ethics.”²²

In many cases, access to archival materials has been restricted for physical rather than intellectual reasons. Because archival holdings are essentially irreplaceable, the risks posed by physical handling should also be addressed when specifying conditions for access. For preservation reasons, a repository may have to limit the handling of documents and artifacts that are in a poor state of conservation. Because archives bear a responsibility to protect users and staff, conditions on access should afford protection from exposure to hazards that may be in the holdings. Mold or insect infested documents may require special treatment in order to make them safe for research use.

²⁰ Ibid, 140.

²¹ Ibid, 137.

²² McClellan, McCall, and Slakey, 145.

Whenever archival materials have to be withheld from direct examination because of fragility or hazardous conditions, the archivist should make every effort to provide researchers with pertinent descriptions of the materials. In some instances, however, this does not happen. Also, the handling of records in hard copy with personal identifiers is more complex because there is usually no feasible way of removing identifiers without defacing original materials or engaging in a labor-intensive process of photocopying documents and deleting identifiers on photocopied documents. Developing coding mechanisms to identify the individuals in order to prevent disclosure of their names and at the same time permit wider use of the research data and information is warranted. Deleting the names and other personal identifying information of the patients can influence the results of a research project. For Elizabeth Yakel ensuring the confidentiality of patients impacted her data analysis. She further states that for future studies, “better provisions for handling confidential data are necessary.”²³

Although patient records are potentially useful for research, there is no well established standard in the United States for the length of time that patient records should be retained. The American Hospital Association had advised hospitals to store each record for ten years after the most recent date of patient care. They also note that the retention period for patient records depends on the purposes for which the record is being kept. The legal retention requirement established by state law varies from three years retention to permanent retention.²⁴

The retention of records has become more expensive, and the decision as to whether it is possible to save all records is often fundamentally financial. Records managers and archivists at

²³ Elizabeth Yakel, “Recordkeeping in Radiology: The Relationship Between Activities and Records in Radiological Processes” (Ph.D. diss., University of Michigan, 1997), 205.

²⁴ American Hospital Association (AHA), *Preservation of Medical Records in Health Care Institutions* (Chicago: American Hospital Association, 1990).

some point will be forced to make decisions about what to discard. Those who elect to discard some subset of hospital records while attempting to maintain a useful research resource should be aware of the consequences of that decision. First, if some types of research such as X-ray films are to be eliminated, researchers wishing to use older images will probably discover that they have been destroyed. Second, if one wishes to preserve records to document specific events, and if one cannot predict in advance exactly which records document those events, one is forced to save all of the records. Third, if the aim is to preserve the possibility of research on low frequency events, large samples will be needed. The act of selecting a sample of records to keep necessarily eliminates some research possibilities. If the sampling is done appropriately, however, it can allow researchers to document broad characteristics of a population.²⁵

Once the specific type of information to retain is determined, archivists must focus on the proper storage medium particularly for medical records in paper formats. Microfilming has long been an appropriate method of preservation. The activity of the records is the key factor in determining the retention and microfilming schedule. The level of complexity involved in finding a desired record and the number of people who need access to the information are some of the considerations related to the choice of a microfilming system.

Although archival repositories have employed microfilming as a primary measure for preservation, academic health centers have largely resisted this widespread use. Problems experienced in the access and use of microfilmed records have led to the unpopularity of the process in the health fields. Clinicians and scientists assert that accessing and retrieving documentation from microfilm systems is often time consuming and difficult because of inadequacies in indexing and technical processing. The greatest concern for personnel in the

²⁵ Howell, 42-43.

health fields is that the integrity of content is frequently diminished in the microfilm process. Health professionals are demanding that the integrity of content be maintained whenever the microfilm process is employed.²⁶

Content, format, and medium of documentation determine the researchers' primary mode of access to information. To ensure appropriate controls over access and use, policies and procedures regarding user services must make provisions for the range of content and the representation of formats and media. While the format of documentation largely determines the means of intellectual access, the medium primarily controls the means of physical access. For example, if an archive has extensive holdings in microfilm and in computer media, special technical accommodations will have to be made to facilitate access to these media. Microfilm readers and computer terminals are necessary equipment for the repository's reading room.

Gaining access to personal or sensitive information collected and maintained by government agencies can also be a difficult task. The Freedom of Information Act (FOIA) was established to assist the public in gaining access to information about government activities. The archival literature has focused on the impact of FOIA on archives and specifically government agencies. In *Archives and Manuscripts: Law*, Gary M. Peterson and Trudy Huskamp Peterson point out that "each agency must administer the act independently, relying for advice on the Department of Justice. Consequently, the implementation of the act has revolved around the Department of Justice and its interpretation of the act."²⁷

In her assessment of the amended federal Freedom of Information Act, Trudy Peterson examined the impact of the revised legislation on records creation, records disposition, and

²⁶ Ibid, 48-49.

²⁷ Gary M. Peterson and Trudy Huskamp Peterson, *Archives and Manuscripts: Law* (Chicago: Society of American Archivists, 1985), 45.

records availability. The 1974 amendments required that “any reasonably segregable portion of a record” be released, set tight time limits for responses, amended two exemption categories, and established penalties for non-compliance. According to Peterson, most archivists supported the new amendment. Following a five year examination of the impact of the new FOIA amendments on government agencies, Peterson suggests that in order for confidential information not to be released, agencies must “define more clearly for their employees the type of information that is covered by an exemption, and ... be consistent in the application of that definition...through good guidelines, handbooks, and repeated training sessions.”²⁸ Peterson also asserts that public trust is key. According to her, the public sector must trust that government agencies will use the appropriate exemption, delete or redact identifying information in records released, and that the courts will apply the right exemption in cases before them. The most serious impact of the amendments for the archivist is records disposition. Peterson, however, points out that in many cases FOIA has been used as an argument to prevent destruction. Overall, she contends that FOIA remains a challenge for archivists. Although the issue seems to be striking a balance between releasing some information that the agencies would like to withhold and withholding some information that requesters would like released, “it is up to archivists to state the concept of records so clearly that everyone—agencies, researchers, lawyers, and even judges—will understand it.”²⁹

Several articles examine how NARA and government agencies have complied with FOIA and the public’s right to know—a public right of access to government information. When Congress passed the Freedom of Information Act in 1966, the statute was weak and had little

²⁸ Trudy Huskamp Peterson, “After Five Years: An Assessment of the Amended U.S. Freedom of Information Act,” *American Archivist* 43 (Spring 1980): 164.

²⁹ *Ibid*, 168.

impact. During the Watergate scandal in 1974, however, Congress passed major amendments to the bill, giving it more power. Important features of the Act are the nine exemption categories. Peterson points out that of the nine categories, two are mandatory: Exemption 1 on national security classified information and Exemption 3 about information specifically exempted by other statutes. The other seven exemptions are discretionary. “This means that an agency can decide whether or not to release information that is covered by one of the seven discretionary exemptions.”³⁰ Thus, FOIA allows agencies to make determinations on some sensitive information. In addition, record availability is implicit, which means that the federal government has to justify withholding documents.

In “Researchers, Archivists, and the Access Challenge of the FBI Records in the National Archives,” James Gregory Bradsher contends that researchers face challenges of knowing what to ask for and discerning what they received in response to their FOIA requests.³¹ As for archivists, Bradsher observes that the challenge is in deciding what information should be withheld, specifically as it relates to issues of privacy and confidentiality. Bradsher points out that in deciding what information must be withheld from researchers, NARA archivists must rely on two sets of access restrictions: first, NARA access regulations, which provide general restrictions that are based on the FOIA and specific restrictions that agencies impose in conformance with the FOIA, and second, restrictions imposed under the FOIA. He contends that this task will be difficult because archivists have to balance the right of personal privacy with the public’s right to know.

³⁰ Trudy Peterson, “Archives, Access, and the Freedom of Information Act,” *Law Library Journal* 71 (Fall 1979): 660.

³¹ James Bradsher, “Researchers, Archivists, and the Access Challenge of the FBI Records in the National Archives,” *Midwestern Archivist* 11:2 (1986): 104.

Gary and Trudy Peterson have noted in their manual that “It is the tension between the two ideas—to provide access to research materials and to protect confidentiality—that creates the frustration archivists feel when confronted with access problems.”³² Furthermore, the Petersons state that “every archivist wishes there was a nice little checklist that could be followed to determine whether a particular record or set of records must be restricted. The plain fact is that there isn’t. Restricting records is making judgments. It is a matter of knowing the applicable law and its interpretation...understanding when the access problem involves a law and when it involves an ethical or practical issue.”³³ James Bradsher proposes that reference archivists be knowledgeable about laws, institutional regulations, and “the contents of their records.”³⁴ He suggests that this will reduce the frustration archivists incur in making records available to researchers.

In “Need to Know: An Attitude on Public Access,” William H. Harader discusses the concept of “need to know.”³⁵ Harader maintains that our need to know or right to access to government information is a mechanism for political accountability in our democratic society. Although FOIA is the tool used to regulate the regulators, Harader points out that there has been opposition to the true spirit of the Act. For example, many FOIA requests went to courts where judicial remedy was inadequate. Due to a lack of management support, FOIA responses were delayed by government agencies. Progress in governmental attitudes toward the need to know has come gradually and according to Harader, such change has occurred through training, experience, and stronger amendments to the FOIA.

³² Gary Peterson and Trudy H. Peterson, 39.

³³ Ibid, 60.

³⁴ Bradsher, 104.

³⁵ William Harader, “Need to Know: An Attitude on Public Access,” *Government Publications Review* 10 (September/October 1983): 441-448.

In “Archival Adventure Along the Freedom of Information Trail: What Archival Records Reveal About the FBI and the Universities in the McCarthy Period,” Sigmund Diamond asserts that “archivists, as custodians of the records of our times, have an ethical obligation to support the freest possible public access to public records.”³⁶ If archivists do not support open access, then scholars will continue to experience unduly restrictive access conditions. Diamond lamented the difficulties he encountered researching the article referenced here. The number of written requests and correspondence between Diamond and the FBI reached 1,700 letters. According to Diamond, the progress of the research was painfully slow. Diamond found that efforts to use the Freedom of Information Act created problems that were time-consuming and costly but at the same time yielded some discoveries. For the archivist, Diamond insists that “It should be enlightening, even inspiring, for archivists to know that their responsibility extends far beyond the custody and maintenance of records. It is no exaggeration to say that they are charged with the custody of the republic itself.”³⁷

2.1.1 Summary

A review of the literature on access to records encapsulates three key points relevant to this study: archivists have difficulties providing access to personal information, specifically medical information in government and private institutions; protecting personal privacy remains a challenge as does developing policies that can both provide access and protect privacy; and, since the establishment of the Freedom of Information Act, the public has taken advantage of

³⁶ Sigmund Diamond, “Archival Adventures along the Freedom of Information Trail: What Archival Records Reveal about the FBI and the Universities in the McCarthy Period,” *Midwestern Archivist* 12:1 (1987): 41.

³⁷ *Ibid.*

submitting requests to the government about its activities. Today the public wants to know everything without regard for personal privacy interest.

Medical information has become the center of this debate. Access to information is the mainstay of the archival profession. The upsurge of requests seeking to know everything has archivists questioning their own access policies. How does such information contribute to the disclosure of governmental activity? How will private and governmental archivists solve the problem of determining when public interests outweigh personal privacy? In “Trusting Archivists: The Role of Archival Ethics Codes in Establishing Public Faith,” Glenn Dingwall discusses archivists’ dilemma in making ethical decisions. He touches upon how the two questions raised above are interrelated by pointing out that:

The records we care for have the potential to do great good. The [records] also have the potential to lead to tremendous harm if used improperly...We try to draw a line between right and wrong acts, differentiating between those that contribute to the public good and those that detract from it...Sometimes the lines shift, sometimes you lose sight of where the line is, and sometimes forces beyond our control push us across that line.³⁸

2.2 PRIVACY

A review of the archival literature on privacy reveals that it has been a challenge for archivists to strike a balance between privacy and freedom of information since the establishment of the Privacy Act of 1974. Personal and sensitive information in their custody poses a unique dilemma. This section discusses some of the interpretations and the practical implications for archivists whose holdings contain personal and sensitive information by providing an overview

³⁸ Glenn Dingwall, “Trusting Archivists: The Role of Archival Ethics Codes in Establishing Public Faith,” *American Archivist* 67 (Spring/Summer 2004): 11-30.

of the challenges relating to privacy and the legal nuances under which archivists work. One of the major principles of the archival profession is the responsibility to encourage free and equal access to the public records and historical documents. The profession has attempted to balance such a principle through legal and ethical guidelines that lay out specifically what information should be restricted. For example, information considered to be an unwarranted invasion of an individual's privacy constitutes an archivist or donor imposing certain restrictions.

Although not explicitly granted in the U.S. Constitution, this founding document implies that everyone has a conditional right to privacy. In their landmark article "The Right to Privacy," Samuel D. Warren and Louis D. Brandeis cogently expressed the individual's "right to be let alone."³⁹ Their article expanded the concept of the right to privacy as a distinct right and has since been cited in many court decisions confronting the issue. Warren and Brandeis also clarified the point that "...the principle which protects personal writings and all other personal productions...against publication in any form, is in reality not the principle of private property, but that of an inviolate personality."⁴⁰

As a result of governments maintaining large amounts of information about private citizens, the right to privacy is a major concern. Much of this personal information gathering coincides with the development of new technology that could maintain, access, and link information in data banks. In "Problems of Confidentiality in the Administration of Personal Case Records," Virginia Stewart points out that "...computerization of records presents a new dimension to the questions of personal privacy versus social utility. Whether the data is recorded on typed pages in files or by magnetic impressions on tape, the problems of privacy are

³⁹ Samuel D. Warren and Lewis D. Brandeis, "The Right to Privacy," *Harvard Law Review* 4 (December 1890): 193.

⁴⁰ *Ibid*, 205.

conceptually the same. Someone must delineate policy on access to and acceptable use of data which exists in record systems.”⁴¹ In her examination of the impact of new record practices on personal case records in the custody of health and welfare organizations, Stewart describes how personal case record information is being disseminated among third parties “with justifiable claims for access to records formerly regarded as the exclusive property of the creating institution or professional.”⁴²

Furthermore, the type of research in case records has changed and expanded to include the social historian. During the late 1960s, there was a general shift among historians from focusing on traditional, political, diplomatic, socioeconomic, and military subjects to examining the history of the masses, especially women, racial and ethnic groups. This change is known as the new social history. Social historians put old records (such as census figures, legal documentation, medical records, and personnel information) to new uses. Hence, a greater concern emerged among government agencies and the public with respect to the protection of individual privacy. Stewart cautioned that efficient records management of personal information can be antithetical to scholarship. In these cases, she insists that the archivist “must overcome a certain reluctance to deal with confidentiality issues posed by personal case records in order to preserve them for future uses. At the same time, the archivist must recognize that in assuming custody over case records he becomes responsible for administering materials in which two social values—public’s right to know and the individual’s personal privacy—come into potential conflict.”⁴³

⁴¹ Virginia R. Stewart, “Problems of Confidentiality in the Administration of Personal Case Records,” *American Archivist* 37 (July 1974): 397-398.

⁴² *Ibid*, 388.

⁴³ *Ibid*, 389.

In “Historians, Archivists, and the Privacy Issue,” Walter Rundell, Jr. and Bruce F. Adams discuss the growing conflict among government officials, archivists, and historians about obtaining access to information. They point out that “serious questions have been raised about whether a democratic society can function properly without easy access to information generated by its government.”⁴⁴ Before Congress made several amendments to the Freedom of Information Act, Rundell and Adams described how government officials made access to their agency records very difficult, especially for historians. Rundell and Adams asserted that government agencies were using the FOIA as a shield. “In this sense, the agency is maintaining its own privacy against unwarranted intrusion.”⁴⁵ Furthermore, government officials at the time harbored a proprietary feeling about their agencies, which was promoted ahead of the public’s right to know about government activity.

According to Rundell and Adams, such government operations “belie any effort or intention of complying with the Freedom of Information Act and can only create in citizens distrust and cynicism for their government.”⁴⁶ However, both insist that archivists must demand and provide access to the records of the American experience. They assert that as archivists, “We will have to remind our government and ourselves that we do serve a function in this society, that the study of history...does help us understand and deal with the complex forces of our political, social, and economic life,” and that “We should appreciate the antagonistic forces in the clash of

⁴⁴ Walter Rundell, Jr. and Bruce F. Adams, “Historians, Archivists, and the Privacy Issue,” *Georgia Archives* 3 (Winter 1975): 5.

⁴⁵ *Ibid.*, 6.

⁴⁶ *Ibid.*

secrecy, privacy, and the historian's need to know," and if not, then government will continue to "use privacy to cloak dishonesty and other activities inimical to the public good."⁴⁷

In the early 1980s, the issue of individual privacy was a major concern for archivists and historians. In "The Public's Right to Know and the Individual's Right to Be Private," Ruth Simmons points out that governmental documents are a major source of documentation of non-elite groups. Simmons believes that researchers should have access to part of the record provided that all personal identifiers are protected. Simmons insists, however, that, "Archivists must not lose the opportunity to help resolve the question of whether there is a point in time when the right to know overcomes the need to protect confidentiality."⁴⁸

In "Privacy and Confidentiality: The Responsibilities of Historians," David H. Flaherty acknowledges that historians, especially social historians who are focusing on the lives of ordinary people, are confronted with "sensitive issues in the use of personal information, especially those pertaining to the protection of the privacy and confidentiality of individuals."⁴⁹ Flaherty states that historians are exempt from establishing or following any rules or guidelines governing the use of information and personal data. But now that way of thinking has become an issue for other academic professions, Flaherty insists that the historical profession should reexamine its position on its code of ethics, pertaining to accessing and using confidential materials. He contends, "Historians should at least attempt to standardize and make explicit in general terms the conditions which govern their use of sensitive personal information and data for any type of historical research." If not, "...the historical profession, among others, runs major

⁴⁷ Ibid, 14.

⁴⁸ Ruth Simmons, "The Public's Right to Know and the Individual's Right to be Private," *Provenance* 1 (Spring 1983): 3.

⁴⁹ David H. Flaherty, "Privacy and Confidentiality: The Responsibilities of Historians," *Reviews in American History* 8 (September 1980): 419.

risks to its integrity and reputation from the occurrence of even one significant well publicized breach of confidentiality, whether using information on individuals in the hands of government or in private depositories.”⁵⁰ Flaherty suggests that historians establish detailed and explicit ethical codes to protect the confidentiality of personal data and that professional organizations form appropriate rules and regulations for information use. Even though establishing ethical guidelines on information use is not a simple task, Flaherty insists that it is necessary if “holders of data and the general public are to be persuaded that the research community is trustworthy.”⁵¹

In “The Archivist’s Balancing Act: Helping Researchers While Protecting Individual Privacy,” Judith Schwarz affirms that as an archivist, “Weighing issues of privacy while trying to meet the access and informational needs of researchers is one of the most difficult balancing acts that archivists perform in carrying out their professional duties.”⁵² Schwarz emphasizes that by constructing policies that protect privacy, archivists can encourage donors to save and donate revealing materials. As a collector herself, Schwarz states that she too encountered what historians face on a regular basis—denied access to materials. From her experience, Schwarz believes that “classification and written but flexible policies on access give archivists ways to balance conflicting concerns.”⁵³ As the coordinator of the Lesbian Herstory Archives, Schwarz is sensitive to the information contained in her archives. More importantly, she understands “the impulse to suppress material or at least to restrict its use for a time...to protect both the reputations of individuals and families and the welfare of the institutions.”⁵⁴ Schwarz points out,

⁵⁰ Ibid, 421.

⁵¹ Ibid, 427.

⁵² Judith Schwarz, “The Archivist’s Balancing Act: Helping Researchers While Protecting Individual Privacy,” *Journal of American History* 79 (June 1992): 179.

⁵³ Ibid, 181.

⁵⁴ Ibid, 185.

however, that the archivist must continue to “figure in these stories as balancers of competing concerns and interests.”⁵⁵ As Kent Haworth succinctly explains, “While the purpose of the historian may be the search for truth, the purpose of the archivist is to hold in trust for society the evidence of the truth, the evidence of justice and injustice in the society our archives document.”⁵⁶

In the 1990s, the archival literature continued to discuss access issues relating to case files (legal, medical, social work) held in public archives as well as confidential information collected by the government. In “Private Lives: Confidentiality in Manuscript Collections,” Sara Hodson discusses ethical and legal concerns archivists face when acquiring an individual’s papers. Hodson points out that a collection that contains personal information could represent an invasion of privacy if released. In order to prevent this, Hodson contends that “restrictions may be placed on all or part of a collection.”⁵⁷ She suggests either a specified time (ten, twenty, or fifty years) or until the individual’s death. Hodson asserts that such restrictions are reasonable and set clear guidelines. These restrictions protect the privacy of the donor or that of a friend or family member while providing unambiguous access guidelines for the archivist. More importantly, Hodson insists that as archivists or curators, “it is in our hands to safeguard the privacy of those who cannot do so themselves. Yet...imposed restrictions must be used with great caution.”⁵⁸ Hodson also recommends that an institution store restricted materials in a separate location. In addition, a list of restricted material should be distributed to the staff in order to ensure that restricted items will not be provided to researchers by mistake. Hodson

⁵⁵ Ibid.

⁵⁶ Haworth, 94.

⁵⁷ Sara Hodson, “Private Lives: Confidentiality in Manuscript Collections,” *Rare Books and Manuscripts Librarianship* 6 (Fall 1991): 109.

⁵⁸ Ibid, 110.

notes, however, that despite the efforts of archival institutions to restrict this material, the information does make it into the public domain. She believes that despite the risks of exposure, there is hope that archivists can manage modern research collections ethically and legally without restricting freedom of access into perpetuity.

Unlike Hodson, Mark Greene contends that archivists are not as hopeful about their ability to provide unrestricted access to collections. Greene asserts that instead of discussing the theoretical and practical issues associated with disclosing private information in manuscript collections, archivists are imposing restrictions beyond the wishes of donors. Furthermore, he argues that the discussion on access to private papers has become confusing.⁵⁹ Although a trend towards openness emerged in the early 1990s (less restrictions or qualifications on access), publicized incidents involving J.D. Salinger, James Joyce, and Thurgood Marshall have placed archivists in an awkward position in dealing with freedom of access and fair use issues.⁶⁰ In trying to answer what would cause an individual injury and embarrassment, Mary Jo Pugh concludes in her 1992 Society of American Archivist (SAA) manual, *Providing Reference Services for Archives and Manuscripts*, that:

Privacy protects not only good reputation, but also any personal information that individuals want to keep from being known. Some people do not care if their age is known; others feel considerable interest in keeping such information to themselves, perhaps with good reason because they have witnessed or experienced age

⁵⁹ Mark Greene, "Moderation in Everything, Access in Nothing?: Opinions about Access Restrictions on Private Papers," *Archival Issues* 18:1 (1993): 31-41.

⁶⁰ J. D. Salinger sought to preserve his privacy by copyrighting his private letters held by Harvard, Princeton, and the University of Texas. James Joyce's grandson publicly admitted that he had destroyed family letters and other materials in order to protect his family's privacy. In the case of Thurgood Marshall's papers, the Library of Congress decided to release Justice Marshall's papers while he was alive. The Library of Congress stated that Marshall wanted his papers released. The Supreme Court Justices wanted the papers restricted despite Marshall's wishes. They cited third party interests.

discrimination. The concept of confidentiality refers first to private communications. Confidential communication between two people is restricted to them alone, and unauthorized inquiry into the content of the communication is forbidden. Communications resulting from friendship, may not be protected by law, but archivists may need to recognize and protect the confidentiality implied in them.⁶¹

Greene insists by this definition, every document not created by the donor of a collection is a potential confidentiality problem, “if not a lawsuit waiting to happen.”⁶² He asserts that archivists should not be burdened with making such difficult decisions. Instead, Greene wants to place more responsibility on the donor, allowing the individual donor to make decisions granting access to the restricted portions of the collection. Furthermore, Greene states that donors are “almost always in the best position to judge the sensitivity of their papers.”⁶³ According to Greene, in order for a policy of donor-controlled access to have any chance of working properly, the archival institution would have to explain to donors what donating their papers means in terms of public access. Although he agrees with Hodson that separating restricted materials from the rest of the collection is a good idea, Greene contends that the archival profession should “formulate concrete and realistic guidelines (or a broad and useful body of case studies) for determining what kind of information would represent an invasion of privacy if opened to researchers while the creators were still living.”⁶⁴

The archival discussion thus far suggests that if such guidelines are not re-formulated or re-thought, then individuals and their families will face the dilemma of whether to donate

⁶¹ Mary Jo Pugh, *Providing Reference Services for Archives and Manuscripts*, Archival Fundamentals Series (Chicago: The Society of American Archivist, 1992), 56-57.

⁶² Greene, 34.

⁶³ *Ibid*, 37.

⁶⁴ *Ibid*.

personal papers. In *Private Matters: In Defense of the Personal Life*, Janna Malamud Smith faced such a dilemma in trying to determine the disposition of her famous father's papers. In this cogent discussion of the history of privacy, Smith questions the trend toward the disclosure of intimate, private details of individuals' lives with the assistance of the media, computerization and electronic surveillance. She defines privacy as "...enjoying the freedom of being unobserved." Smith insists that our right to privacy is threatened when we do not have "control over when, how, to whom, and where you disclose personal material."⁶⁵ Furthermore, Smith asserts that as a society we have become spectators, which fuels the need to know more intimate details about individuals, especially famous ones. For Smith, the biography has become that tool by which society views public individuals. She states that "we read biographies, we search for a friend, a mentor, a kindred spirit, and ultimately for ourselves."⁶⁶ However, for Smith "biographies welcome us to the table without demanding that we earn our place."⁶⁷

Smith's experience with biographers taught her a valuable lesson about privacy, which inspired her book. When explaining why she turned down biographers, Smith stated that "among many reasons for wishing to fend off his biographers was a wish to protect him from my own desire to write and thus invade his privacy. I was also hiding from myself as a potential violator."⁶⁸ Smith also believes that as a society we need to be cautious when protecting our individual privacy. And, if we are more careful, then "we will have to examine the sale or exposure of all kinds of personal information more carefully than we have of late...[and] write

⁶⁵ Janna Malamud Smith, *Private Matters: In Defense of the Personal Life* (New York: Addison-Wesley Publishing Company, Inc., 1997), 241.

⁶⁶ *Ibid*, 163.

⁶⁷ *Ibid*, 164.

⁶⁸ *Ibid*, 243.

laws and reinforce them.”⁶⁹ But Smith points out that until we see our individual privacy connected to that of others, we run the risk of destroying it. She asserts that “If we continually, gratuitously, reveal other people’s privacies, we harm them and ourselves, we undermine the richness of the personal life, and we fuel a social atmosphere of mutual exploration.”⁷⁰ Overall, Smith’s discussion of privacy underscores how important it is for archivists to be sensitive to the nature of privacy when granting access to collections that contain personal information as well as the psyche of their donors.

The administration of personal information in government archives and the complex access issues associated with it has generated much discussion within the archival literature. In *Without Consent: The Ethics of Disclosing Personal Information in Public Archives*, Heather MacNeil discusses the challenges government archivists confront when they take into custody records containing personal information. MacNeil points out that archivists must be sensitive to the individuals who are the subject of records that contain personal information. She states, “Archival professional ethics demand that, in administering access to records containing personal information, archivists demonstrate a sensitivity to the sensibilities of the individuals represented in the records and, more specifically, that they actively work toward ensuring the protection of the individual’s right to privacy,”⁷¹ which is “integral to the notion of proper archival management of records.”⁷²

MacNeil has suggested ways in which government archivists can reconcile research and privacy interests while closing the gap between theory and practice. She insists that proper

⁶⁹ Ibid, 240.

⁷⁰ Ibid.

⁷¹ Ibid, 181.

⁷² Ibid, 3.

archival management of such records requires a strong and systematic policy that is consistent in administering access to restricted records. Before such records are transferred, confidentiality issues need to be worked out, including exceptions to the non-disclosure rule. Institutional guidelines should “specify the conditions under which access to records normally restricted to protect personal privacy will be allowed to accommodate research and statistical purposes.”⁷³ Furthermore, MacNeil insists that it is extremely important that archivists realize that they are acting in the best interest of the individual who is unaware that records concerning him or her are being used for research purposes. MacNeil concurs with Roland Baumann in his assessment of state archival policies for administering access to confidential records that if such a coherent policy and clearly defined procedures for administering access to records containing personal information were in place, then this would “reduce...the undue amount of discretion archivists themselves are sometimes inclined to exercise in their dealing with researchers seeking access to restricted records.”⁷⁴ More importantly, archivists would be actively contributing to improving “the archival status quo in matters relating to privacy”⁷⁵ and not “paralyzed with apprehension or indecision.”⁷⁶

The archivist’s arduous task of understanding the concept of privacy is now discussed fully in the edited volume *Privacy and Confidentiality Perspectives: Archivists and Archival Records*. Editors Menzi L. Behrnd-Klodt and Peter J. Wosh have gathered a variety of views and case studies about how archivists have dealt with privacy. Previously written articles by Elena

⁷³ MacNeil, 183.

⁷⁴ Roland M. Baumann, “The Administration of Access to Confidential Records in State Archives: Common Practices and the Need for a Model Law,” *American Archivist* 49 (Fall 1986): 367.

⁷⁵ MacNeil, 182.

⁷⁶ Hodson, 117.

Danielson and Sara Hodson are included. Behrnd-Klodt and Wosh have assembled this volume to support their idea that “archivists do think about privacy in their own special way.”⁷⁷

The Behrnd-Klodt and Wosh volume contains a section on administrative perspectives. In this section, archivists Sarah Rowe-Sims, Sandra Boyd, and H.T. Holmes discuss the controversy of providing access to the Mississippi State Sovereignty Commission Records. The Mississippi State Sovereignty commission was formed after the 1954 *Brown v. Board of Education*. Its objective was to protect Mississippi from the interference of the federal government and to promote states rights. Promoting states rights included investigative, public relations, or advisory activities.

The state archivists were in charge of determining what records would be disclosed to the public. The archivists confronted people who wanted the records concealed and those who wanted full disclosure. After battling this issue in state courts from 1977-1994, a compromise was reached which allowed the records to be open to the public while respecting the personal privacy of those mentioned in the records. This case represents the influence of the public’s right to know about how the Commission conducted itself. Like the Tuskegee Syphilis Study records, the Commission records caused a stir that pitted the public against the individual. However, balancing the two interests “...affirms the archival role in enabling people to see for themselves just what the state government did and allows Mississippi citizens to hold the government accountable.”⁷⁸

⁷⁷ Menzi L. Behrnd-Klodt and Peter J. Wosh, *Privacy and Confidentiality Perspectives: Archivists and Archival Records* (Chicago: The Society of American Archivists, 2005), 8.

⁷⁸ *Ibid*, 174.

The book entitled *The Mississippi State Sovereignty Commission: Civil Rights and States' Rights* chronicles the history of the Commission from 1953-1973.⁷⁹ Because of the release of the official records of the Commission, Yashuhiro Katagiri provides in great detail about why it was created, its activities, and its impact on the history of Mississippi, especially during the civil rights movement. It should be noted that while researching the agency at Mississippi Department of Archives and History in Jackson, Sarah Rowe-Sims, Sandra Boyd, and H.T. Holmes assisted Katagiri with his research. As a result of the court case and the ensuing compromise of allowing access to the Mississippi State Sovereignty Commission records, Katagiri was able to educate and increase the knowledge of the public about the agency.

2.2.1 Summary

The review of the literature on privacy has progressed from the issue of individual privacy to developing practical management guidelines to keep donors contributing their papers. Discussion has focused on setting a time limit for disclosure of such information, allowing the donor to participate actively in the decision-making regarding restrictions and the archivist's autonomy in dealing with such matters. As Greene states, however, there need to be "realistic guidelines." There are not enough case studies to generate a new discussion about protecting personal information, defining the characteristics of personal information and who is affected by the its disclosure. This dissertation initiates a discussion of how archivists define personal information,

⁷⁹ Yashuhiro Katagiri, *The Mississippi State Sovereignty Commission: Civil Rights And State's Rights*(Jackson: University of Mississippi Press, 2001).

how governmental archivists use this information and how disclosure affects individuals or third parties (i.e. families) referenced in sensitive records.

This study suggests that personal information is data an individual would not usually disclose to the public (i.e., sex life, medical condition, financial situations) because of the potential effect on his/her life. As a result, personal information is defined by the privacy interests (disclosure or nondisclosure to the public) of the individual. Keep in mind that the disclosure of personal information differs for each individual. In the ideal case, the donor determines what is private. In information created or collected by the government, individuals are protected by the Privacy Act and the Freedom of Information Act. However, the discretion of the federal agency can determine whether or not public knowledge outweighs personal privacy.

2.3 COLLECTIVE MEMORY

In light of the profusion of literature on collective memory in several disciplines, this section of the literature review will focus on the connection among collective memory, history, and myth all of which are linkages to the past. Although each one can provide access to the past in its own way, they are “neither fixed nor firmly bounded; they overlap and shift their focus.”⁸⁰ Thus, this literature review will underscore how the creation and structure of collective memory is influenced by other linkages to the past—history, myth, and archives. Maurice Halbwachs, the French sociologist, influenced the collective framework in which the study of memory would take place over the years. In *On Collective Memory*, Halbwachs argues that collective memory is

⁸⁰ David Lowenthal. *Possessed By the Past: The Heritage Crusade and the Spoils of History* (New York: Free Press, 1996), 3.

a socially constructed notion which may include family, religion, class, and the delimitation of time and space. In addition, Halbwachs contends that present situations affect how the past is remembered or “reconstructed.” He states that “our conceptions of the past are affected by the mental images we employ to solve present problems, so that collective memory is essentially a reconstruction of the past in the light of the present.”⁸¹ Moreover, Halbwachs believes that despite the fact that recollections of past are based on distortions, memory does serve a collective function. He asserts, “As soon as each person and each historical fact has permeated this memory, it is transposed into a teaching, a notion, or a symbol and takes on a meaning.”⁸²

Although Halbwachs’ analysis of memory did not focus on the connection between collective memory and history, historians have taken up Halbwachs’ framework and applied it to their analyses of the creation of group and national pasts. In “Memory and American History,” David Thelen is interested in how people construct and narrate memories in the “social dimensions of memory.” He writes that “the study of memory exist in different forms along a spectrum of experience, from the personal, individual, and private to the collective, cultural, and public.”⁸³ Furthermore, postulating a dichotomy between memory and history negates the political dimensions of both collective memory and history. Thelen asserts that “the struggle for possession and interpretation of memory is rooted among the conflict and interplay of social, political, and cultural interests and values in the present.”⁸⁴

In *Phantoms of Remembrance*, Patrick J. Geary states, “All memory, whether ‘individual,’ ‘collective,’ or ‘historical,’ is memory for something, and this political purpose

⁸¹ Maurice Halbwachs, *On Collective Memory*, ed. and trans., with an introduction by Lewis A. Coser (Chicago: The University of Chicago Press, 1992), 34.

⁸² Ibid, 188.

⁸³ David Thelen, “Memory and American History,” *Journal of American History* 75 (March 1989): 1120.

⁸⁴ Ibid, 1127.

cannot be ignored.”⁸⁵ In *Tense Past: Cultural Essays in Trauma and Memory*, Paul Antze and Michael Lambek agree and state that “memory has found a prominent place in politics as a source of authority and as a means of attack.”⁸⁶ Thus, if historical memory is essentially political, so too is collective memory.

Jacques Le Goff believes that there is a relationship between memory and history. He insists that although each is distinct, history and memory are interdependent on one another. For example, Le Goff states that “the discipline of history...seek[s] to be objective and to remain based on the belief in historical truth. It is true that history involves a rearrangement of the past which is subject to the social, ideological, and political structures in which historians live and work.”⁸⁷ Le Goff further states that “memory is the raw material of history. Whether mental, oral, or written, it is the living source from which historians draw.”⁸⁸ He points out that memory and history are subject to manipulation by time and societies but insists that history and memory can help each other connect the present and past. He states, “Memory, on which history draws and which it nourishes in return, seeks to save the past in order to serve the present and the future. Let us act in such a way that collective memory may serve the liberation and not the enslavement of human beings.”⁸⁹ Even though Le Goff views collective memory as mythic,

⁸⁵ Patrick J. Geary, *Phantoms of Remembrance: Memory and Oblivion at the End of the First Millennium* (Princeton, New Jersey: Princeton University Press, 1994), 12.

⁸⁶ Paul Antze and Michael Lambek, eds., *Tense Past: Cultural Essays in Trauma and Memory* (New York: Routledge, 1996), vii.

⁸⁷ Jacques Le Goff, *History and Memory*, trans. Steven Rendall and Elizabeth Clamon (New York: Columbia University Press, 1992), xi.

⁸⁸ *Ibid.*

⁸⁹ *Ibid.*, 99.

deformed, and anachronistic, he believes history is present to “illuminate memory and help it rectify its errors.”⁹⁰

Peter Burke suggests that social memory is transmitted through oral traditions, histories, memoirs and other written records; images, pictorial or photographic, still or moving; actions; and space. Burke reminds us that oral traditions are passed down but can be altered over time, thus affecting the collective memory of a particular group. Written records are not “innocent acts of memory but rather attempts to persuade, to shape the memory of others.”⁹¹ Images have been constructed in order to “assist the retention, and transmission of memories.”⁹² Actions are re-enactments of the past, including commemoration and “...attempts to impose interpretations of the past.” They are in every sense collective representations.⁹³ Space places “images that one wishes to remember in particular locations such as memory palaces or memory theatres.”⁹⁴ Peter Burke also suggests that the remembered past can turn into myth. He insists that he uses myth to illuminate a story that has “...symbolic meaning.”⁹⁵ He does not use myth in a negative way. Burke contends that for social or collective memory, the past and myth are useful in defining individual and group identity.

In *The Myths We Live By* Raphael Samuel and Paul Thompson point out that “...this persistent blindness to myth undeniably robs us of much of our power to understand and interpret

⁹⁰ Ibid, 111.

⁹¹ Peter Burke, “History as Social Memory,” in Thomas Butler, ed., *Memory: History, Culture, and the Mind* (New York: Basil Blackwell Ltd., 1989), 101.

⁹² Ibid.

⁹³ Ibid.

⁹⁴ Ibid.

⁹⁵ Ibid, 103-104.

the past.”⁹⁶ Samuel and Thompson contend that oral historians can observe the distortions, omissions and reinterpretations through which myths in individual and collective memory take shape. They insist that life stories “should be seen, not as blurred experience, as disorderly masses of fragments, but as shaped accounts in which some incidents were dramatized, others contextualized, yet others passed over in silence, through a process of narrative shaping in which both conscious and unconscious, myth and reality, played significant parts.”⁹⁷ Furthermore, “to identify the element of myth in oral sources is certainly not to say that we are working with memories of a false past.”⁹⁸ The authors assert, however, that if the subjective and the unconscious come into play with memories, it does not mean that the scholar must choose one and abandon the other. Thus, it is the facts (or lack thereof), the omissions and the shaping of these stories of the past that make it a myth, a way of structuring memory and exploring life experiences.

Samuel and Thompson also claim that “...the most powerful myths are those which influence what people think and do: which are internalized, in their ways of thinking, and which they pass on consciously or subconsciously to their children and kin, their neighbors, workmates, and colleagues as part of the personal stories which are the currency of such relationships.”⁹⁹ In particular, they contend that such myths are extremely important to minorities or marginalized groups in a society. They state that “...for minorities, for the less powerful, and most of all for the excluded, collective memory and myth are often still more salient: constantly resorted to both in reinforcing a sense of self and also as a source of strategies for survival. Survival of defeat or

⁹⁶ Raphael Samuel and Paul Thompson, eds., *The Myths We Live By* (New York: Routledge, 1990), 4-5.

⁹⁷ *Ibid*, 5.

⁹⁸ *Ibid*, 6.

⁹⁹ *Ibid*, 14-15.

humiliation is a common thread, not only in the myths of minorities, but more widely in other persecution myths or common horror stories”¹⁰⁰ Thus, Samuel and Thompson point out “To call such stories myths is not to deny their roots in real incidents and real social conflicts. It is rather to indicate that, however, we evaluate their literal meaning, the very fact that they recur so widely is real symbolic evidence of a collective sense of injustice and both anger and pride in having personally come through such hardships.”¹⁰¹ Furthermore, Samuel and Thompson urge historians to understand that the mythical elements in memory (written or oral) need to be seen both as evidence of the past and as a continuing historical force in the present. Colin Grant would agree that despite the truth, “...myths stay with us...They are the visual, intellectual, and spiritual atmosphere in which we live.”¹⁰²

William G. Doty provides a comprehensive overview of the approaches to studying myths and rituals today. Doty points out that disciplines such as religion, anthropology, political science, and sociology take a positive approach to myths. Myths are “seen as really existing, important social entities that express and mold culture”¹⁰³ and “forming a constitutive part of a society’s worldview.”¹⁰⁴ Like Samuel and Thompson, Doty contends that myths serve a function. Doty, however, believes that myths are multilayered and multifunctional—evolving to meet the demands of social, intellectual, and political life.

Doty has included a list of questions to address the significance, meaning, and value of mythic texts. The five parts of the questions are: social context; psychological aspects; structural

¹⁰⁰ Ibid, 19.

¹⁰¹ Ibid.

¹⁰² Colin Grant, *Myths We Live By* (Ottawa: University of Ottawa Press, 1998), 16.

¹⁰³ William G. Doty, *Mythography: The Study of Myths and Rituals*, 2nd ed. (Tuscaloosa: The University of Alabama Press, 2000), 12-13.

¹⁰⁴ Ibid.

aspects; literary, textual, and performative aspects; and other interpretive matters. The social context questions focus on how the myth functions within the society and the psychological questions center on what part of the psyche the myth addresses in the individual or the group. The structural questions concentrate on the dynamics itself while the literary, textual, and performative questions target the characteristics of the myth. The other questions refer to other functions of a myth in society; whether or not it is constructive or destructive. These questions can also apply to contemporary oral myths.

2.4 CONCLUSION

Although access, privacy, and collective memory were discussed separately, in unison they underscore throughout the study the archival challenges confronted by the National Archives in maintaining and providing access to the Tuskegee Syphilis Study records. The access literature points out what researchers confront when attempting to achieve access to sensitive material such as medical records, especially those in the custody of the government. In addition, researchers also deal with personal privacy issues. When it comes to access to sensitive material, the archivist has to decide who can see what.

Issues of access and privacy can in turn affect the collective memory of a particular event. For this study, collective memory will be defined as “the perceptions and uses of the past by the public—including both government and citizens.”¹⁰⁵ More importantly, the interrelation of the literature will highlight the public’s right to all records that explain the circumstances surrounding the Tuskegee Syphilis Study and NARA’s attempt at balancing privacy and

¹⁰⁵ Richard J. Cox, “The Concept of Public Memory and Its Impact on Archival Public Programming,” *Archivaria* 36 (Autumn 1993): 122.

freedom of information. Francis Blouin concludes that what archivists do affects how people view the past.¹⁰⁶ Thus, if people still have unresolved questions or myths about the Tuskegee Syphilis Study, access to the records should answer those questions and challenge the legitimacy of those myths. According to Blouin, “When extant documentation challenged a belief, then the authority of the documentation often settled the question.”¹⁰⁷

¹⁰⁶ Francis X. Blouin, Jr., “Archivists, Mediation, and Construction of Social Memory,” *Archival Issues* 24:2 (1999), 102.

¹⁰⁷ *Ibid.*, 104.

3.0 A QUALITATIVE STUDY: A METHODOLOGICAL APPROACH TO UNDERSTANDING NARA’S ADMINISTRATIVE TREATMENT OF THE TUSKEGEE SYPHILIS STUDY RECORDS

To receive approval from University of Pittsburgh’s Institutional Review Board (IRB), the research protocol for this study had to be sound in its methodology, objectives and specific aims. This qualitative study implemented the historical case study method to examine and analyze the National Archives and Records Administration’s (hereafter cited as NARA) access policy toward the Tuskegee Syphilis Study records within the context of three archival issues: access, privacy, and collective memory. Historical data as well as secondary sources were utilized to detail the history of the Tuskegee Syphilis Study records and to provide a description of NARA’s recordkeeping practices.

3.1 HISTORICAL RESEARCH

Stephen Isaac and William B. Michael note that the purpose of historical inquiry is “to reconstruct the past systematically and objectively by collecting, evaluating, verifying, and synthesizing evidence to establish facts and reach defensible conclusions, often in relation to a

particular hypothesis.”¹ Historical research seeks to interpret past events. The subject under investigation is interpreted through an explicit hypothesis, which includes an examination, evaluation, and explanation of the event. Primary sources and interviews provide an interpretive narrative, the conclusions of which will either support or invalidate the initial hypothesis.

Historical research can contribute to the body of knowledge about a particular phenomenon, and it can also enhance our understanding of when, how, and why past events occurred and the significance of these events. Charles Busha and Stephen Harter state that in order to carry out an effective historical research project the following procedures must be followed:

- a. Recognition of a historical problem or the identification of a need for certain historical knowledge.
- b. The gathering of as much pertinent information about the problem or topic as possible.
- c. If appropriate, forming a hypothesis that tentatively explains relationships between historical factors (variables).
- d. Rigorous collection and organization of evidence and the verification of the authenticity and veracity of the information and its sources.
- e. Selection, organization, and analysis of the most pertinent collected evidence, and the drawing of conclusions.
- f. Recording of conclusions in a meaningful narrative.²

¹ Stephen Isaac and William B. Michael, *Handbook in Research and Evaluation*, 2nd ed. (San Diego, CA: Edits Publishers, 1981), 44.

² Charles H. Busha and Stephen P. Harter, *Research Methods in Librarianship: Techniques and Interpretation* (New York: Academic Press, 1980), 91.

To determine the authenticity and veracity of the data collected, the researcher must subject them to additional evaluations. In historical research, data are evaluated using external and internal criticism. External criticism of records is concerned with the authenticity of each document used (i.e., whether the document is what it purports to be). Internal criticism judges the value of a document's contents and is concerned with the question of whether the information contained in the document is factual or false. Busha and Harter assert that using the historical research method successfully "will depend greatly upon the ability of the researcher to adequately conceptualize the purpose and problem of the research, to vigorously evaluate and categorize the collected evidence, and to analyze data intelligently in view of research objectives."³

3.2 CASE STUDY

The case study research method allows for the concentrated examination of a particular phenomenon and results in the development of a comprehensive understanding of a specific context. Raya Fidel contends that in case studies, "analysis of the data is performed throughout the duration of the study. New data are constantly analyzed and results of previous analysis direct future investigations."⁴ In addition, the case study method offers the researcher flexibility

³ Ibid, 115.

⁴ Raya Fidel, "The Case Study Method: A Case Study," in Jack D. Glazier and Ronald R. Powell eds. *Qualitative Research in Information Management* (Englewood, CO: Libraries Unlimited, 1992), 38.

in dealing with unexpected findings and safeguards against assumptions that may turn out to be incorrect. The case study approach is most appropriate for “how” and “why” questions.

Researchers often strive to expand their case-specific findings into more generalized theoretical statements applicable to related phenomena happening outside the specific case being examined. Fidel cautions researchers against extracting too much from a single case or even from multiple cases because “one cannot satisfactorily determine which regularities are general and which are unique.”⁵ Thus, a researcher must be aware of this potential pitfall and abstain from drawing too many connections from the particular to the general.

The case study approach utilizes a wide array of data-gathering methods which include interviews, documents, archival records, physical artifacts, participant-observation and direct observation. Busha and Harter point out that researchers interested in a single phenomenon “attempt to gather extensive data about it so that relationships among variables associated with the observed phenomenon can be identified.”⁶ Case studies offer “thorough and detailed examinations and analysis of a research problem so that findings can be applied directly to the object of inquiry.”⁷ Therefore, the case study approach is appropriate for studying the relationship between NARA’s access policy toward the Tuskegee Syphilis Study records and on restricted information.

The case study method complements the historical research method when used to analyze a single problem. The historical method supports the case study by allowing the subject of the case study to be evaluated over time, while the case study aids historical analysis by closely

⁵ Ibid, 39.

⁶ Busha and Harter, 151.

⁷ Ibid, 152.

focusing attention upon a specific phenomenon. Combining the two methods allows the researcher to draw upon the strengths of each.

3.3 HISTORICAL CASE STUDY

Through historical case study methodology, this qualitative study examines the National Archives and Records Administration's administrative role in maintaining and providing access to the Tuskegee Syphilis Study records, especially the restricted medical records. The combination of historical and case study methods enables the researcher to describe and analyze in detail a historical case while examining a particular phenomenon in-depth. The context and events surrounding the accession of the Tuskegee Syphilis Study records by NARA are detailed and analyzed through the historical study of primary and secondary sources, while the effects of the administration of the records by NARA is described as a case study through interviews and primary sources. Both methodologies provide a discourse for the five research questions:

1. What is NARA's official policy toward administering access to controversial records that contain restricted information?
2. In light of those policies and practices, how are the Tuskegee Syphilis Study records treated?
3. Does NARA's access policy toward restricted information and the agreement with the Centers for Disease Control (CDC) undermine the spirit of the Freedom of Information Act with respect to the Tuskegee Syphilis records? If so, what are the consequences in this particular case?

4. What do the recordkeeping practices of the Tuskegee Syphilis Study records, reveal about NARA's effectiveness in protecting personal information in those records?
5. How have the restrictions on the Tuskegee Syphilis Study records affected the collective memory of the study?

A triangulation of data and methodologies resulted in a narrative that highlights the ongoing access challenges NARA faces with these records, thereby increasing the validity of the study.

3.4 DATA

3.4.1 Interviews

The interviews were designed to supplement the documentation collected to address the research questions. The interviews underscore the impact of federal legislation and agency regulations on records, access rights, individual and third party rights, and government archivists' commitment to preservation and promotion of information.

Nine interviews were conducted with individuals who have consulted the records for research, legal, administrative and work related purposes. Each interviewee provided a unique perspective towards dealing with the records. The interviewees consisted of a retired Public Health Service officer, civil rights attorney, federal government attorney, federal records manager, manager of CDC benefits program, historian, FOIA officer, federal government archivist, and former surgeon general. The professional background of each interviewee and their connection with the records are as follows:

Peter Buxtun is the retired Public Health Service employee who exposed the Tuskegee Syphilis Study in 1972. In addition to being the whistleblower, he discussed documents that he found while uncovering the circumstances of the study in the late 1960s and early 1970s.

Civil rights attorney **Fred Gray** represented some of the Tuskegee Syphilis Study participants in a civil suit against the government. In addition, he recalled the type of records he received in order to bring the civil suit.

As records manager for the Center for Disease Control and Prevention, **Jimmy Harrison** was responsible for arranging the Tuskegee Syphilis Study records to be accessioned by the NARA.

Bill Jenkins, Ph.D., is the former manager of the Tuskegee Health Benefits Program at the National Center for HIV, STD, and TB Prevention of the Center for Disease Control and is familiar with the issues surrounding the Tuskegee Syphilis Study. In addition, he maintained contact with those participants who were living and their family members.

James Jones, who wrote the definitive book on the Tuskegee Syphilis Study, entitled *Bad Blood*, also provided Fred Gray with the records to bring his lawsuit against the government on behalf of the participants.

Ramona Oliver the FOIA Officer, Office of the General Counsel, National Archives and Records Administration (Archives II, College Park, Maryland), investigated my FOIA request regarding access to the medical records. I also wanted her to explain to me the process of investigating my FOIA request and others. In addition, we discussed NARA's access restriction policy and how it relates to the Tuskegee Syphilis Study records.

Charles Reeves, former Director of Archival Operations, National Archives Southeast Region was in direct contact with the Tuskegee Syphilis Study records and is familiar with NARA access regulations.

Sarah Rutgers, Assistant Attorney of the Office of the General Counsel (Archives II, College Park, Maryland) investigated my FOIA request. She and Ramona Oliver worked together on this request. In addition, she explained the role of the Office of General Counsel in assisting NARA with FOIA requests involving personal privacy.

Dr. David Satcher, M.D., is the former Surgeon General of the United States (1998-2002) and was director of the CDC and Administrator of the Agency for Toxic Substances and Disease Registry from 1993 to 1998. Dr. Satcher played a key role in influencing President Clinton to make an apology to the participants in 1997 and encouraging access to the Tuskegee Syphilis Study records. He is currently director of the National Center for Primary Care at Morehouse School of Medicine located in Atlanta, Georgia. He made an effort to make sure that records related to the Tuskegee Syphilis Study found at the National Center for Infectious Diseases were transferred to NARA.

Of the nine interviewees, four were African American, two were women, and seven were males. The issue of race affecting the release of the records was raised. For this study race is a peripheral issue that does not affect the outcome of this study. However, it does warrant a brief discussion.

The remaining six interviews did not take place because the people were adamant about maintaining their privacy.

Interviews ranged from forty-five minutes to two hours, with an average interview time of an hour and twenty minutes. All interviews were tape recorded. The researcher transcribed all

tape recorded interviews. The tapes remain with the researcher and will not be made available to the public. Interested parties must make a special request to the researcher in order to get access to the transcripts.

Interviews took place over a three month period in-person (interviewee's home or office) and via email. The researcher traveled to several sites, including Atlanta, Georgia; San Francisco, California; Washington, D.C.; and College Park, Maryland.

NARA officials were personally contacted by the researcher to get permission to interview staff who were familiar with the records. She contacted the records manager at the Center for Disease Control via email to request an interview. The remaining interviewees were contacted via email and telephone.

The identities and job titles of the individuals were important to this research study because they provided context for the case study and for the analysis of NARA's access policy for the Tuskegee Syphilis Study records. The researcher sought permission to identify individual interviewees. The interviewee and researcher discussed the consent form which had to be signed by the interviewee in order for the interview to take place (see [APPENDIX N](#)). The form stated that with their permission, their identities would be included in the research study and that direct quotes might be used in the final analysis. Interviewees were also advised that they had a right to remain anonymous.

Individual interviews were one of the primary sources used to address the questions for this study. They were used to “fill in meanings of [open gaps],”⁸ which the written records could not explain. Catherine Marshall and Gretchen Rossman assert that “qualitative research is

⁸ Carol A.B. Warren, “Qualitative Interviewing,” in Jaber Gubrium and James Holsten, eds., *Handbook of Interview Research: Context and Method* (Thousand Oaks, CA: Sage Publications, 2002), 85.

appropriate when the issue or interaction being explored are ambiguous or unclear.”⁹ As a qualitative technique of collecting data, interviewing these individuals provided a means of filling in gaps that were unclear. The questions for the interviews were mostly open-ended. However, obtaining similar information from all interviewees, as well as allowing them to elaborate on certain questions, was crucial as well. According to Herbert Rubin and Irene Rubin, “...[the] qualitative interview uses three kinds of questions:

1. Main questions with which to begin and guide the conversation.
2. Probe questions to complete and clarify the answer or to request examples and evidence.
3. Follow-up questions that pursue the implications of answers to the main questions.¹⁰

This study used a combination of all three. In addition, these interviews provided an opportunity for participants to express their issues and interpretations regarding these records. Carol Warren points out the “...qualitative interview tends to be more constructionist than positivist.”¹¹ The combination of the primary sources and the individual interviews increased the validity and reliability of this study.

The interviews were semi-structured and consisted of specific questions as well as open-ended questions that allowed for flexible responses. The semi-structured questions were applicable to the interviewee and the basis of each experience with the records. The five core questions that represented the types of questions asked of the interviewees were as follows:

⁹ Catherine Marshall and Gretchen Rossman, *Designing Qualitative Research*, 3rd ed. (Thousand Oaks, CA: Sage Publications, 1995), 45.

¹⁰ Herbert Rubin and Irene Rubin, *Qualitative Interviewing: The Art of Hearing Data* (Thousand Oaks, CA: Sage Publications, 1995), 145-146.

¹¹ *Ibid*, 183.

1. Does the public have the correct information about the study? If not, what is the correct information?
2. Does the public's right to know about what happened in this study outweigh the participants and their family personal privacy? Please explain.
3. Should the public have access to all the records, including the medical records? Please explain.
4. Why have the myths continued about the study? How does this affect the memory of the study, particularly in the African American community?
5. How important are these records?
6. When did you first hear about the study?
7. How should NARA provide access to the restricted records, especially the medical records?
8. Please describe your experience with the records.
9. Do you think that NARA has deliberately denied access to the medical records?
10. Do you know of anyone who has filed a FOIA request seeking access to the medical records?

In analyzing the interviews, the researcher concluded that the core and general questions focused on NARA's experience with the Tuskegee Syphilis Study records than its general access policy (see [APPENDIX O](#)). As a result, the study shifted its focus toward examining NARA's management of the Tuskegee Syphilis Study records. The questions covered the importance of the records and the public's right to know versus personal privacy. The historian, James Jones states the Tuskegee Syphilis Study records "has a large claim to the public's attention...People

still care about this...it hasn't gone away."¹² The NARA FOIA official and the attorney representing Office of the General Counsel discussed the balancing test. The balancing test determines whether the public's right to know about government activity outweighs revealing personal information about an individual. In the case of the Tuskegee Syphilis Study medical records, NARA released the records because all of the participants were deceased and there was limited third-party data within the files (see [APPENDIX K](#)).

All of the interviewees discussed the issue of personal privacy. Access to the medical records sparked a discussion that challenged each interviewee personally and professionally. The CDC records manager, Jimmy Harrison states that "...I battle with the fact that we need to be as open as possible...I don't think there is ever one clear answer to these issues [privacy and access]...how we respond to that defines us in terms of what our values and opinions are and in some cases there maybe mistakes."¹³ Bill Jenkins, former manager of the Tuskegee Health Benefits Program of the CDC wanted the medical records destroyed. According to Jenkins, no new knowledge could be gained from making these records available to the public. After spending many years with the participants and their families, Jenkins felt that opening the medical records would do more harm than good.

The objective of the interviews was to gather information from subjects intimately familiar with the Tuskegee Syphilis Study records. The researcher originally planned to interview fifteen individuals, but was only able to interview nine. She was unable to interview participants in the study and family members of the participants, whom she found were unwilling to speak about their experiences with the study. The nine individuals who were interviewed,

¹² James Jones, interview by author, December 13, 2003.

¹³ Jimmy Harrison, interview by author, September 21, 2001.

however, still provided invaluable and varying degrees of perspectives on how NARA should administer access to the Tuskegee Syphilis Study records, especially the medical records.

3.4.2 Government Records

In order to elicit answers for the questions, the researcher examined records that were accessible. The Tuskegee Syphilis Study Administrative Records 1930-1980 (Record Group 442, Box nos. 1-20 and 20a.) were examined.¹⁴ The Administrative records provided the history of the study. The voluminous documents revealed that the Public Health Physicians knew from the inception of the study that the participants were unaware of the objectives of the study. The files consisted of records created during the course of the study that related to: individual patients; publications based on findings of the study; correspondence between medical personnel; administrative records; and photographs of various medical tests or procedures. In addition, the documents reveal how meticulous these physicians were in carrying out the initial steps of the study. However, as the researcher examined the files, a document in the files stated that documents had been removed to protect personal privacy. Removal of certain documents suggested that the records had been sanitized to a degree. What had been removed? The researcher was told by a NARA archivist that the documents removed contained names and addresses and other sensitive information about the participants. For the researcher, this proved to be a limitation of examining those records. In addition, the challenge was gaining access to those documents without revealing sensitive information.

NARA archivists at the Southeastern Regional Center provided the researcher with the index of the Tuskegee Syphilis Study Records. The index outlines what is restricted. The only

¹⁴ Records are available at the NARA Southeastern Regional Center at Morrow, Georgia.

drawback was that it does not identify why certain records were restricted. It is a list that identifies what is restricted or unrestricted, the box number, and title of the folder (see [APPENDIX M](#)). The index along with the sanitizing of the administrative records made it difficult to understand why the Tuskegee Syphilis Study records were managed in this manner.

More importantly, after discovering that NARA had the medical records but denied access helped to frame the questions for this dissertation. The medical records pertain to the participants in the study. Those records are separate from the administrative records and are restricted for privacy reasons. The medical files (forty-seven boxes) and files from the administrative records were removed and placed in the stacks separate from the unrestricted administrative records (1 through 3 and 21 through 35 and 32a of the administrative records are restricted).

NARA archivists provided the researcher copies of the accession records. The accession records documented the transfer of the Tuskegee Syphilis Study Records from the Center for Disease Control to the National Archives and Records Administration's Southeast Regional Center. The records were accessioned in 1990, 1991, 1992, 1993, 1994, and 1999. According to the initial accession record, NARA agreed to the transfer of the records under the condition that the medical records be restricted until 2030. This document was crucial in filing a FIOA request with NARA. The CDC records manager who participated in this transfer admitted that 2030 was an arbitrary year chosen in order to please the former CDC manager of the Tuskegee Syphilis Study Health Benefits program who had the records within his possession. The program was established to provide medical benefits to the surviving participants and their wives and children. Although the records were not being utilized for this program, this CDC manager felt he had to guard against anything or anyone destroying them.

However, to withhold access entirely was in direct violation of NARA's Freedom of Information Act regulations on restrictions and use of records codified under 36 C.F.R § 1256 (revised 6/30/2004). The regulations were examined to understand NARA's formal access policy for government records. The researcher concluded that NARA was inconsistent in applying their access policy to the Tuskegee Syphilis Study records. The archivists at the Southeastern Regional Center were relying on the agreement which prohibited access.

Denying full access also compromised the spirit of the Freedom of Information Act (FOIA), as amended. This federal statute assists citizens in obtaining information about government activity. There is a presumption of disclosure with FOIA. Within the statute information can be made available to the public in part or in full. Since 1966, the statute has evolved from the public being obligated to provide reasons for access to federal agencies being required to justify nondisclosure. This statute holds the government accountable for its actions through public access to information. The concept of government accountability is crucial to the analysis of this case study.

With the data already gathered, the researcher filed a FOIA request to obtain access to the medical records. The researcher's request initiated a second review by NARA to see whether, after the passage of time, releasing the records was in the best interest of the public. As privacy rights diminish upon the death of the individual, the balancing test favored the public. As a result, the medical records were made available for research. The records revealed participant's medical history, including the type of test done by the government physicians.

The researcher also obtained the Center for Disease Control Appraisal Report on Disposition of Records (Nov. 3, 1977). The report states that the "Tuskegee syphilis study files (item 101) are proposed for permanent retention because these records provide information

linking health problems with racial and social conditions.” The former CDC manager of the Tuskegee Syphilis Study Health Benefits Program was unaware of this document. He assumed that if NARA received the records, it would destroy them. The Center for Disease Control Records Disposition Authority (NCI-90-78-1, item 101) (January 27, 1978), enumerates the types of materials that were kept for permanent retention: medical records, pictures and charts, follow-ups with doctors, obligation documents, and x-rays of participants in the study. NARA received permission from the CDC to destroy the x-rays. Both documents stipulate that the records were kept for permanent retention.

3.4.3 Legal Documents

The case of *Pollard v. United States*¹⁵ was a class action suit filed on behalf of the participants against the federal government. The suit was filed July 23, 1973 in the United States District Court for the Middle District of Alabama. Civil Rights attorney, Fred Gray sought three million in damages for each participant. The suit stated that the participant’s constitutional rights were violated. The court documents stated Gray charged that the men had suffered:

physically and mentally disability, affliction, distress, pain, discomfort, and suffering; death; loss of earnings; racial discrimination; false and misleading information about their state of health; improper treatment or lack of treatment; use as subjects in human experimentation without informed consent; the maintenance of Plaintiff-subjects as carriers of a communicable disease that can cause harm to others, including birth defects in children born of mothers to whom the disease has been communicated and the shortening of their lives.¹⁶

¹⁵ *Pollard v. United States*, 384 F. Supp.304 (M.D. Ala. 1974).

¹⁶ Jones, 217.

The matter was settled out of court in the amount of ten million dollars. The primary resources documenting these and other issues included docket sheets; plaintiffs' filings; defendant's filings; judicial orders and rulings; and depositions by several participants and family members representing deceased participants. The researcher learned NARA possessed those same documents. However, the public could not get access to them. Attorney Fred Gray mentioned in his interview that the researcher could gain access by contacting the court in which the lawsuit was filed: the Middle District of Alabama. Those documents were not sanitized. There were testimonies by participants that the researcher was able to use as direct quotes. In addition, the names of the participants and their family members were publicly documented. The researcher was well aware that the information in the court documents was limited. Even though the men stated they had syphilis, the medical record was more explicit about their medical history. Using the court documents and the medical records provided the researcher information that spoke to the participant's experience in the study.

3.4.4 Secondary Sources

Secondary sources were used to augment the primary sources in analyzing the NARA's access policy toward the Tuskegee Syphilis Study records. In addition, they provided the context for the case study which details the journey of the records in chapter four. Also, the secondary sources were valuable in highlighting the discussion around government access, privacy (individual and third party), and collective memory.

3.5 CONCLUSION

In order to examine and analyze the NARA's access policy toward the Tuskegee Syphilis Study records, the historical case study method was used. The historical research approach allowed the researcher to reconstruct the journey of the Tuskegee Syphilis Study records, while the case study allowed for an examination of NARA's access policy toward the records. In addition, the case study approach offered the researcher flexibility to deal with unexpected findings such as refocusing the case study on NARA's access policy toward Tuskegee Syphilis Study records, instead of NARA's general access policy. Hence, the case study shifted as the research progressed.

4.0 THE TUSKEGEE SYPHILIS STUDY RECORDS: CASE STUDY

4.1 INTRODUCTION

The Tuskegee Syphilis Study records have played a significant role in exposing and terminating the study, and holding the United States accountable for its deliberate misconduct. Chapter four provides a brief overview of the history of the study and discusses the discovery of the records and analyzes their affect on the *Pollard v. U.S.* civil suit. The chapter then examines how the records were managed by the CDC, their transfer to the NARA, and analyzes their treatment while in the custody of NARA. Overall, this chapter explores the myriad of access challenges surrounding these records, including personal privacy issues and public access.

4.2 HISTORY OF THE TUSKEGEE SYPHILIS STUDY

In 1928, the Director of Medical Services for the Julius Rosenwald Fund, a Chicago-based philanthropy, approached representatives of the United Public Health Service (PHS) to discuss ways to improve the health of African Americans in the South. At the time, the PHS had just completed a study of the prevalence of syphilis among more than 2,000 African American employees of the Delta Pine and Land Company of Mississippi. Twenty-five percent of the sample had tested positive for syphilis, and the PHS and the Rosenwald Fund worked together in

treating these individuals. This arrangement led to the expansion of the treatment program in five counties in the South. Macon County, Alabama, was one of the sites that reported between thirty-five and forty percent of all age groups testing positive for this disease.¹ Those infected were treated with a certain amount of arsenic and mercury. Before the treatment phase of the project could really be implemented, the Great Depression set in and the Rosenwald Fund withdrew its financial support. The PHS could not afford to continue the treatment program itself.²

Instead of terminating the treatment program, Taliaferro Clark, head of the PHS, decided to continue the study. Clark reasoned that the treatment project could be used to study the effects of untreated syphilis on living subjects. Although much is known about the natural history of syphilis, Clark wanted to know more about the effects of the disease on African Americans. At that time, there was no empirical knowledge about whether syphilis affected African Americans differently from Caucasians. Clark realized that there was a “ready-made situation...for carrying on the proposed study,”³ of untreated syphilis in African-Americans males in Tuskegee, Alabama. The PHS enlisted the support of the Tuskegee Institute⁴ where the John A. Andrew Memorial Hospital was established. Since the Tuskegee Institute had a history of service to the local African American community, its participation guaranteed the execution of the experiment. In return, Tuskegee Institute received money to train nurses and employ nurses at the John A. Andrew Memorial Hospital. The Public Health Service solicited the assistance of churches and community leaders and others to encourage African-American men to participate.

¹ James Jones, *Bad Blood: The Tuskegee Syphilis Study Experiment* (New York: Free Press, 1981), 85.

² *Ibid.*, 87-88.

³ *Ibid.*, 94.

⁴ The school has been renamed Tuskegee University.

For many of the African-American men who participated in the experiment, the examination by government physicians was probably the first medical attention they had received. For participating in the study, these men received a free examination, food, transportation to the hospital, and a fifty dollar burial stipend paid to the family. In order to receive the stipend, deceased participants and their family members agreed to allow the physicians permission to perform postmortem examination of these men.

The Tuskegee Syphilis Study was divided into two groups. Three hundred and ninety-nine men were selected who had syphilis and two hundred men were chosen to be a part of a control group (see [APPENDIX A](#) for the names of the participants).⁵ Those who were infected with syphilis were never told that they had the disease. The men referred to what they had as “bad blood,” a term the physicians used as well to describe the participants’ condition. With the cooperation of state and local physicians, the researchers prevented these men from receiving any kind of medical treatment.⁶

During World War II, many of the study participants wanted to sign up for the draft. However, draft boards were ordering enlistees to undergo treatment for syphilis. The PHS physicians convinced the draft board to exclude the study participants from consideration for the draft. More importantly, in 1945, when penicillin was being administered for syphilis, the participants were denied the medicine. In 1952, the PHS solicited local health departments to track participants who had left Macon County in order to prevent these men from receiving any kind of treatment for syphilis. As a result of these efforts, the study was able to continue for forty years.

⁵ Initially, 600 African-American men were chosen for the study. However, over the course of forty years, some men left the study (17%) and were replaced. At the end of the study, 625 were apart of the study.

⁶ Ibid., 162.

On July 25, 1972, a front-page headline in the *Washington Star* read, “Syphilis Victims in U.S. Study Went Untreated for 40 Years.”⁷ The article revealed the explicit details of the study. The *Washington Star* article highlighted how the experiment shifted from offering treatment to actively denying it. Public outcry came from everywhere. The federal Assistant Secretary for Health and Scientific Affairs appointed an *ad hoc* advisory panel to review the study.

The nine member panel included people from the fields of medicine, law, religion, labor, education, health administration, and public affairs. The panel found that the study participants had willingly agreed to be examined. The panel also concluded that there was no evidence that researchers had informed the infected men of the study or its real purpose. In fact, the participants had been misled, and were not given all the information necessary in order to provide informed consent. With regard to informed consent, the panel stated that a human subject should not be “subjected to avoidable risk of death or physical harm unless he freely and intelligently consents.”⁸ According to the panel, these men were not given the opportunity to choose. The advisory panel found that the Tuskegee Syphilis Study was unjustified and concluded that no formal protocol ever existed for this experiment. Department of Health Education and Welfare (HEW) concluded that the “study” was unethical and should be terminated. The study officially ended in November 1972.

In that same year, the federal government decided to provide life time medical benefits to the survivors of the study. The CDC took on the task of locating these men to inform them of the proposed benefits. In 1975, the government extended those same benefits to wives and children

⁷ The story also appeared in the *New York Times* the following day. Jean Heller, “Syphilis Victims in the U.S. Study Went Untreated for 40 years,” *New York Times*, July 26, 1972, 1,8.

⁸ “Selections from the Final Report of the Ad Hoc Tuskegee Syphilis Study Panel, Department of Health, Education, and Welfare, 1973.” In Susan Reverby, ed., *Tuskegee’s Truths: Rethinking the Tuskegee Syphilis Study* (Chapel Hill: University of North Carolina Press, 2000), 166.

of the participants who had contracted syphilis. According to James Jones, author of *Bad Blood*, the government's failure to offer some type of compensations as part of its health plan made a class-action civil suit inevitable.

4.3 DISCOVERY OF THE TUSKEGEE SYPHILIS STUDY RECORDS

Before writing his book in 1981, James Jones, a graduate student at the time of the exposure of the study, had done some research at the National Archives. Under Record Group 90 (hereafter cited as RG) of the United States Public Health Service records, Jones had come across four letter boxes that referred to the Tuskegee Syphilis Study. In 1969, he had no idea that the study was continuing. In Susan M. Reverby's edited volume, *Tuskegee's Truths: Rethinking the Tuskegee Syphilis Study*, Jones states, "I had seen other examples in my archival research of non-therapeutic medical research studies and I had no way of knowing that the Tuskegee Study was still active. I was, after all, in an archives."⁹ Jones assumption about the study was not unreasonable given the perceived role of archives in society, specifically governmental archives. Many historians have the notion that archives consist of records of the past that do not have value, unless they give them life through the form of a narrative. Jones discovered as a researcher, that his notions of an archive inhibited his ability to realize that he himself had unearthed a horrible experiment that was going at the time he was conducting research at the National Archives.

⁹ Susan M. Reverby, ed., *Tuskegee's Truth: Rethinking the Tuskegee Syphilis Study* (Chapel Hill: University of North Carolina Press, 2000), xi.

While a post doctoral candidate in the History of Medicine and Medical Ethics Program at Harvard University, Jones began investigating the study. According to Jones, the United States Department of Justice at the time had asked the National Archives “to produce the records but also to sequester the records and to let no one see them but attorneys from the Justice Department.”¹⁰

In 1972, Jones knew where to look to begin his research. As a result, he called on his good friend, Albert H. Leisinger Jr., a high ranking official at NARA.¹¹ According to Jones, Leisinger had an abiding belief that the public had a right to know and “that the role of the National Archives was to facilitate inquiry and to be forth coming.”¹² When Jones contacted Leisinger, his friend claimed that the records could not be found and that archivists had been looking for them for almost two weeks. Once the records were found, however, the Department of Justice formally requested that the records be turned over and sequestered.¹³

Leisinger informed Jones that the records were not in the Washington D.C institution, but in the Federal Records Center located in Suitland, Maryland. With the assistance of staff members, Leisinger allowed Jones access to the records in the Federal Records Center. Jones conducted his own search, despite the fact that the Justice Department wanted the records

¹⁰ James Jones, interview by author, December 13, 2003.

¹¹ Albert H. Leisinger was a member and fellow of the Society of American Archivists (SAA). In 1941, Leisinger starting working for the National Archives. In 1961, Leisinger became head of the Exhibits and Publications Division, which is now called Educational Programs Division. He was special assistant to the archivist of the United States for academic relations, deputy to the assistant archivist and director of the Scientific and Technological Division. In addition, he was an expert on archival micrographics. In 1981, he retired from the National Archives. On March 3, 1991, Leisinger died of a heart attack. (Richard Pearson, obituary, *Washington Post*, March 9, 1991, B4).

¹² James Jones, interview by author, December 13, 2003.

¹³ James Jones, interview by author, December 13, 2003.

sequestered once found. According to Jones, his friend allowed him access to the records because he did not trust the Justice Department. Leisinger believed that if the records were found and turned over to the Justice Department, there would be a cover-up.¹⁴

Jones stated that once he had found the records of the Tuskegee Syphilis Study, Leisinger directed him to copy all of the study records with the official stamp of the NARA. Leisinger wanted all documents officially stamped so that they could be admissible in a court of law. More importantly, if the original records were destroyed, Jones would have certified records. Jones complained at first about the difficult task of finding any records concerning the study and remembers that materials were misplaced in boxes or boxes were out of place. Jones went through an estimated four hundred boxes with the assistance of an index of RG 90. According to Jones, he discovered at least a thousand documents on the study.¹⁵ After finding those boxes, Jones admits that among those records were patient records. He states “I remember having a very strong ethical dilemma about whether I would look at actual patient record[s] and decided I wouldn’t. I just closed those.”¹⁶ After Jones copied the documents, he acknowledged that he did not know what happened to the original records.¹⁷

¹⁴ Ibid.

¹⁵ The papers that dealt with the early years of the Tuskegee Syphilis Study were found in the United States Public Health Service Division of Venereal Disease, Record Group 90 (1918-1936) in the Federal Records Center, Suitland, Maryland.

¹⁶ James Jones, interview by author, December 13, 2003.

¹⁷ During the civil rights movement, Fred Gray represented Rosa Parks when she was arrested for not giving up her seat on a bus in Montgomery, Alabama.

4.4 POLLARD V. U.S. CIVIL SUIT

In 1973, Charles Pollard, one of the surviving participants, contacted Fred Gray,¹⁸ a civil rights attorney in Tuskegee, Alabama concerning the “study.” Pollard and others believed that the federal government owed the participants compensation, lifetime medical benefits, and free burial services. Gray knew that it would be an uphill battle to win compensation and relief for these men. On July 24, 1973, Gray filed a class-action civil suit in the U.S. District Court for the Middle District of Alabama on behalf of the participants. The CDC was among the defendants named in the suit. The filing of this class action lawsuit placed a renewed focus on the Tuskegee Syphilis Study records.

Fred Gray alleged that the federal government was stonewalling in providing key documents for the suit. The complaint enumerated seven allegations against the federal government in which he had to prove. As a result, Gray solicited the assistance of Attorneys, Michael I. Sovern, then dean of Columbia University Law School and Harold Edgar. Gray sought damages for the surviving participants and the heirs of those study participants who had died.

For Gray, one of the major obstacles in preparing the case against the federal government was obtaining discovery. By way of background, discovery is the stage of litigation during which both parties exchange factual information that is relevant to each other’s claims and defenses. In order to obtain the information he needed from the federal government, Gray sought depositions,

interrogatories, requests for admissions, and requests for production of documents.¹⁹ According to Gray, when he filed a motion to produce the records of the study during its early stages, he was told that “no records were available so far as the government knew.”²⁰ If Gray could not obtain those records within a particular time, his case would be dismissed.

In 1975, James Jones, a Program Officer for the National Endowment for Humanities, followed Gray’s efforts in the media. When Jones read that Gray’s case would be dismissed due to lack of evidence, he contacted Gray by phone. Jones stated that “I am Jim Jones...I have in my possession several boxes of material on the origins of the experiment.”²¹ The next day Gray flew to Washington, D.C. to meet with Jones and discuss what he had in his possession. The lawyers representing the government, including the United States Department of Justice, asserted that they did not know where the records were or how they could find them. Gray stated that he knew there had to be records because “there were some 11 or 12 printed reports of the study that were general public information. It [articles] referred to a lot of details about the study. So the question was where are those primary records that these articles were written from.”²² Gray

¹⁹ Reverby, ed. “The Lawsuit,” in *Tuskegee’s Truths: Rethinking the Tuskegee Syphilis Study*, 473-488. Gray states that interrogatories are written questions which must be answered in writing under oath. These questions were given to U.S. Public Health officials involved with the study.

²⁰ *Ibid*, 481.

²¹ James Jones, interview by author, December 13, 2003.

²² Attorney Fred Gray is referring to the thirteen articles that were written by the PHS physicians. They include: R.A. Vonderlehr et al., “Untreated Syphilis in the Male Negro: A Comparative Study of Treated and Untreated Cases” *Venereal Disease Information* 17 (1936): 260-265; J.R. Heller et al., “Untreated Syphilis in the Male Negro: II. Mortality During 12 Years of Observation” *Venereal Disease Information* 27 (1946): 34-38; A.V. Deibert et al., “Untreated Syphilis in the Male Negro: III. Evidence of Cardiovascular Abnormalities and Other Forms of Morbidity” *Journal of Venereal Disease Information* 27 (1946): 301-314; Pasquale J. Pesare et al., “Untreated Syphilis in the Male Negro: Observation of Abnormalities Over Sixteen Years” *American Journal of Syphilis, Gonorrhoea, and Venereal Diseases* 34 (1950): 201-213; Eunice Rivers et al., “Twenty Years of Follow-up Experience in a Long-Term Range Medical Study” *Public Health Reports* 68 (1953): 391-395; J.K. Shafer et al.,

claimed that the information that Jones had in his possession helped with the case. Although the government attorneys had claimed that they did not know where the records were, both Jones and Gray knew the records existed because Jones had copies of records prior to 1936. Jones states, “I don’t see how they could have said that with a straight face because the fact that I had them was proof that they existed and if I had them somebody else had them.”²³

Jones committed to spending his vacation time and weekends to help Gray with the case in exchange for access to all documents that he received from the government. Thereafter, Gray argued to the court that if Jones had discovered a thousand documents on the origins of the case, than more had to exist somewhere. Based upon Gray’s arguments, the court issued an order allowing Gray and his assistants, including Jones, to conduct an investigation at the CDC where the records generated from the study after 1937 had been placed. As stated earlier, when the CDC added the Venereal Disease Division in the 1950s, the Tuskegee Syphilis Study became apart of the Division. While working with the CDC’s records managers, Jones and an assistant

“Untreated Syphilis in the Male Negro: A Prospective Study of the Effect on Life Expectancy” *Milbank Memorial Fund Quarterly* 32 (1954): 262-274; Sidney Olansky et al., “Environmental Factors in the Tuskegee Study of Untreated Syphilis” *Public Health Reports* 69 (1954): 691-698.; Jesse J. Peters et al., “Untreated Syphilis in the Male Negro: Pathologic Findings in Syphilitic and Nonsyphilitic Patients” *Journal of Chronic Diseases* 1 (1955): 127-148; Stanley H. Schuman et al., “Untreated Syphilis in the Male Negro: Background and Current Status of Patients in the Tuskegee Study” *Journal of Chronic Diseases* 2 (1955): 543-558; Sidney Olansky et al., “Untreated Syphilis in the Male Negro: Twenty Two Years of Clinical Observation of Untreated Syphilitic and Presumably Nonsyphilitic Groups” *Journal of Chronic Diseases* 4 (1956): 177-185; Sidney Olansky et al., “Untreated Syphilis in the Male Negro: Twenty Two Years of Serologic Observation in a Selected Syphilis Study Group” *A.M.A. Archives of Dermatology* 73 (1956): 516-522; Donald Rockwell et al., “The Tuskegee Study of Untreated Syphilis: The 30th Year of Observation” *Archives of Internal Medicine* 114 (1961): 792-798; Joseph G. Caldwell et al., “Aortic Regurgitation in the Tuskegee Study of Untreated Syphilis” *Journal of Chronic Diseases* 26 (1973): 187-194.

²³ James Jones, interview by author, December 3, 2003.

discovered “filing drawers of stuff on Tuskegee.”²⁴ According to Jones, the records were in reasonably good order. However, to get a sense if the records had been tampered with, Jones and an assistant went through the records carefully to determine how complete the records were. As a historian, Jones stated that:

We read all the stuff and made sure from examining the documents that there weren't obvious lapses or holes in it where people had pulled stuff because if you sit down with files and you've done this as a historian you get a sense pretty quickly of how the story is going to play out and how the evidence will be consistent based upon other stuff that you've read and if there are big kind of glaring omissions or gaps you are to be forgiven for suspecting that someone had tampered with the evidence or someone has pulled stuff out of those files.²⁵

Jones explained to Gray that he was very satisfied that the CDC did not withhold any significant material. The files consisted of: records created during the course of the study that related to individual patients; publications based on findings of the study; correspondence between medical personnel; administrative records; photographs of various medical tests or procedures; and minutes. More important, the documents revealed how meticulous these physicians were in carrying out the initial steps of the study during the early years.

The records revealed how the government physicians secured the cooperation of the study participants and the local community. They gave a list of participants in the study to local physicians, both syphilitics and control. The physicians argued that cooperation was needed in the study, which included not treating anyone for syphilis because it would spoil the data. The doctors sent annual letters to participants informing them the federal doctors were returning to treat their “Bad Blood.” Initially, those deprived included syphilitics and controls that developed

²⁴ James Jones, interview by author, December 3, 2003.

²⁵ James Jones, interview by author, December 3, 2003.

syphilis in the intervening years and had received no treatment for their condition. Those doctors knew that syphilis could be acquired or congenital. Because of the concealment about the severity of the disease from the participants by the government physicians, the participant's wives and children were not only exposed but went untreated for syphilis.

Overall, in December 1974, the discovery of the records uncovered facts, which probably motivated the government to settle out of court in the amount of \$10 million dollars. The records revealed that:

1. The study was financed by the federal government;
2. The study started out as a short term survey (6 months);
3. There were no rules or regulations governing the study;
4. The participants thought they were in a treatment program;
5. The government physicians never told the study participants that they had syphilis.²⁶

In addition to the out of court settlement, the government promised to continue free medical and burial services to all surviving participants and their family members. The federal government established the Tuskegee Health Benefits Program in order to provide such services. Gray asserted that "Jim Jones is the person who really helped us break the case and get it over."²⁷

²⁶ Fred Gray, interview by author, June 16, 2003.

²⁷ Fred Gray, interview by author, June 16, 2003.

4.5 RECORDKEEPING HISTORY OF THE OF THE TUSKEGEE SYPHILIS STUDY RECORDS WHILE IN THE CUSTODY OF THE CENTERS FOR DISEASE CONTROL AND PREVENTION

In order to explain the recordkeeping of the Tuskegee Syphilis Study records while in the custody of the CDC, the creation of and the connection between the center under the United States Public Health Service with the Tuskegee Syphilis Study must be told. The Communicable Disease Center (now known as the Centers for Disease Control and Prevention) was established in Atlanta, Georgia in 1946. Under the Malaria Control agency, the CDC assisted in eradicating malaria in the southeastern states during World War II. The federal government renamed it the Communicable Disease Center and added programs to fight against infectious diseases. In 1967, the federal government changed the name to the National Communicable Disease Center. In 1970, the name was changed to the Center for Disease Control to underscore the significance of its work while upgrading it to an agency. In 1980, a “s” was added to better describe the agencies expansion and structure (each major unit was redesigned as a center and subdivided into divisions, which were subdivided into branches).²⁸

In the 1950s, the CDC added the Venereal Disease Division. In 1957, the Tuskegee Syphilis Study was transferred from the Public Health Service to the CDC. Initially the records of the study from 1918 to 1936 were a part of the PHS records. When the transfer occurred, the records generated from 1936 to 1972 were a part of the CDC records. As a result, the CDC records, including the Tuskegee Syphilis Study records, were a part of the U.S. Public Health Service RG 90. The RG number is significant because it plays a crucial part in deciding under

²⁸ Elizabeth W. Etheridge, *Sentinel for Health: A History of the Centers for Disease Control* (Berkeley: University of California, 1992), xvii-xviii.

which RG number the Tuskegee Syphilis Study records will reside when the CDC separates from the PHS.

On May 5, 1975, the Centers for Disease Control officially became RG 442 at the request of the Records Officer of the United States Department of Health, Education and Welfare (HEW) to accommodate both the large number of records and organizational structure of HEW. HEW suggested that RG 90, records of the Public Health Service, should be a closed RG as of the dates that the organizational units were abolished. It was also recommended that all permanent records created during its operating years should be assigned to this RG when they were accessioned by the National Archives.²⁹ However, the Records Officer of HEW at the time and a National Archives Records Services (NARS)³⁰ official requested that record 442 be cancelled. They reasoned that RG 442 was unnecessary at the time and concluded that PHS was still an operating agency.³¹ They suggested that perhaps the title could be changed to reflect the current situation and cover a number of diverse health related records. As a result, RG 442 was cancelled on December 23, 1975.

NARS officials concluded that if the CDC started to create huge quantities of records in the near future, consideration of a separate RG should be discussed again. On October 30, 1984, the Regional Archivist and Chief of Appraisal and Disposition Section sent a memorandum requesting a separate RG for the Centers for Disease Control. They insisted that the CDC records be withdrawn from RG 90. Both officials of NARA stated, “We believe that structuring a separate record group for CDC records...will be both useful to NARA in that the records can be

²⁹ Memorandum, Jane Smith, Director of Civil Archives Division, April 28, 1975.

³⁰ Between 1949 and 1985, the National Archives and Records Administration (NARA) was formally known as the National Archives Records Service (NARS).

³¹ Memorandum, Meyer H. Fishbein, Director Records Appraisal Staff, June 27, 1975.

examined and administered by [an] archivist who will have physical access to the records and administrative responsibility, and will demonstrate to CDC officials that their concerns about access to their records are being dealt with and responded to.”³² In November 1985, the CDC records received its own RG number and were withdrawn from the PHS. In addition, on April 7, 1993, the RG 442 title would change to the current name of the agency, Centers for Disease Control and Prevention. The Tuskegee Syphilis Study records were accessioned into NARA’s Southeast Regional Center in Atlanta, Georgia beginning in 1990 under RG 442.

The nonexistence of a separate RG for the CDC records between December 1975 and November 1985 explains why the CDC records schedule was drawn up in 1977 under RG 90. In 1977, the CDC’s records were appraised and a records schedule was developed. The records were approved by the Records Disposition Division (NCD) of the Office of the Federal Records Centers (NC). A November 3, 1977 memorandum from Peter Laugesen, an archivist in the Records Disposition Division who appraised the CDC records and drafted the records schedule (see [APPENDIX B](#)), is revealing. In his memorandum to Thomas W. Wadlow, Director of the Records Disposition Division (NCD), Laugesen cited two cases of records which were “diseased-control efforts of special significance” that the CDC recommended be permanently retained. One was the polio studies, the records of that were to be retained “because the polio program received national attention and resulted in the virtual elimination of the disease.” The other study was the Tuskegee Syphilis Study (item 101) “because these records provide information linking health problems with racial and social conditions.”³³

³² Memorandum, Gayle P. Peters and Thomas W. Steinichen to Office of the National Archives (NN), October 30, 1984.

³³ Memo, Peter Laugesen to Thomas W. Wadlow, November 3, 1977.

There are a number of memoranda from other NARS units that comment on Laugesen's draft schedule and the November 3, 1977 memorandum. The units involved that reviewed Laugesen's draft for the CDC are as follow: Civil Archives Division of the National Archives (NNF); Civil Archives Division (NNF); Records Disposition Division (NCD); and Audiovisual Archives Division (NNV). The Appraisal Report on Disposition of Records, Job Number NC1-90-78-1 was signed on January 27, 1978 with all of the required approval and concurrence signatures (see [APPENDIX C](#)). Furthermore, the records schedule was drafted and approved by the CDC and other high ranking officials in 1976-1977 and authorized disposition of the Tuskegee Syphilis Study files, which included medical records, pictures and charts, follow-up surveillance, obligation documents, and x-rays of participants in the study were to be retained. The records were to be transferred to the Federal Records Center four years after the records closed and then offered to the National Archives sixteen years later.³⁴

The Freedom of Information Act (FOIA) governs public access to federal records and files. Although disclosure is encouraged as a matter of policy under FOIA, there are exemptions to the statute's disclosure requirements. With respect to requests for access to the Tuskegee Syphilis Study records, CDC officials often cited Exemption 6 of the FOIA, which is often referred to as the personal privacy exemption, to bar access to the study records (See 5 U.S.C. § 552(b)(6)). Researchers were told that they could not view any medical files due to Exemption 6, which permits federal agencies to withhold "personnel, medical, and similar files whose disclosure would constitute a clearly unwarranted invasion of personal privacy (See 5 U.S.C. § 552(b)(6))." Usually information for study records requests would end there, especially

³⁴ RG 64, Records of the National Archives and Records Administration [Series title:] External Disposal Jobs, FY 1978-1979, [Case No.] NC1-90-78-1, Public Health Service-Center for Disease Control.

considering that researchers were not familiar with the legal nuances of FOIA and the Privacy Act.³⁵ Instead, CDC officials sent a list of articles about the study, a timeline of the study, a brief history of the study and the aftermath, and information about syphilis to researchers. For the researcher, their FOIA request would usually end at this point. However, the researcher of this study decided to seek further information about why the records were restricted.

In 1990, the Tuskegee Health Benefits Program whose primary responsibility was to pay all medical costs for the remaining survivors and family members was inundated with FOIA requests to see the Tuskegee Syphilis Study records. According to Jimmy Harrison, Records Officer for the Centers for Disease Control and Prevention, the benefits program was operated by a small group of people and did not have the resources to answer such requests. More importantly, as Arzell Lester, Director of the Tuskegee Health Benefits Program acknowledged, responding to FOIA requests was outside their responsibility. As a result, Jimmy Harrison took a look at the CDC's records control schedule and found that the Tuskegee Syphilis Study records were scheduled for permanent retention by the CDC. He also realized from examining the records control schedule, it was time for the records to be transferred to the Southeast Regional Center. Jimmy Harrison stated that, "I was really kind of excited about the opportunity to look at and review and hopefully make efforts to make these records permanent and save them."³⁶

Jimmy Harrison went over to the Health Benefits Office to review the records. Harrison admitted that the employees working in Health Benefits Office did not trust him to review the records and were reluctant to turn over custody of the records to anyone, including NARA, despite the records control schedule. Harrison's observation of the situation suggested how little

³⁵ For information on these federal statutes see the Freedom of Information Act (FOIA), 5 U.S.C. § 552, as amended and the Privacy Act of 1974, 5 U.S.C. §552a, as amended.

³⁶ Jimmy Harrison, interview by author, September 21, 2001.

the employees knew about NARA. Harrison asserted that the employees “didn’t understand the procedures about working with permanent records of the National Archives. They had not heard about what it means to store records in perpetuity. The laws of regulations which require permanent records to go to the National Archives did not filter down to the rank and file.”³⁷

Harrison convinced Arzell Lester, Director of the Tuskegee Health Benefits Program, to let him [Harrison] examine the records. Harrison stated “...I went into Ike Lester (Arzell) and we sat down...It was a matter of talking and talking and doing a lot of talking and just letting him know that what we were trying to do is not destroy the records or close access to them but to make them as open as possible and also allow people to know that these would be saved forever and preserved.”³⁸

Harrison was allowed to examine the records briefly. He found three types of records: 1) administrative records that went from the inception of the study to the 1990s; 2) the epidemiological records that included the medical files of the participants; and 3) the physical records (i.e., specimens). Harrison remembered that there were files containing the most sensitive information. PHS physicians actually visited participants’ homes and asked these men very intimate personal questions about their sexual activity. According to Harrison, the record system was less than ideal. Folders were found in staff offices, including the directors’ personal file cabinets. In addition, boxes were stored in the director’s office and a back room. Harrison stated, “They were really a mess. They were really not very well kept.”³⁹ Overall, the vast majority were at least in folders.

³⁷Jimmy Harrison, interview by author, September 21, 2001.

³⁸ Jimmy Harrison, interview by author, September 21, 2001.

³⁹ Jimmy Harrison, interview by author, September 21, 2001.

Harrison and his assistant returned to try and bring some order to records before transferring them to the Southeast Regional Center in Atlanta, Georgia. They had a difficult task ahead of them trying to determine why certain records were organized a particular way. Harrison stated:

I wouldn't call them disarray. Disarray is probably too strong. I would call them maybe some of them were out of order. Maybe some of the folders were kind of fading and rotting. The records themselves looked in pretty good condition. I would call it more of that. I think you would actually have to go through and do a detailed study. We were not able to do that. We needed to get the records out as quickly as possible. So we wanted to make sure that they were in the box and we did not disrupt anything or try to do an investigation or reorganize them. We didn't want to do that.⁴⁰

Harrison and his assistant basically did folder listings. In addition, they came up with their own dissection of the records (see [APPENDIX D](#)). This was sent with the transfer of the records to NARA. According to Harrison, it took him and his assistant three weeks to box the records in order to have them transferred.

Further discussions with Harrison revealed how he felt about applying archival principles to these records. Harrison commented that there was loose material but most were in folders. He stated that “We tried not to organize them of course the old archival thing of *respect des fonds*. We were very fearful of doing anything much more than putting them in file folders, keeping the original arrangement with our key (see [APPENDIX D](#)).”⁴¹ The *respect de fonds* is the archival principle of provenance which means keeping the records together. It is not unusual that the archival principles of original order and provenance were not applied to the Tuskegee Syphilis

⁴⁰ Jimmy Harrison, interview by author, September 21, 2001.

⁴¹ Jimmy Harrison, interview by author, September 21, 2001.

Study records at the CDC. As Harrison stated, he divided the records based on what he found and if there was some sort of order he and his assistant just did folder listings.

4.6 TRANSFER OF THE TUSKEGEE SYPHILIS STUDY RECORDS TO THE NARA

After much discussion, Harrison finally convinced the Director of the Tuskegee Health Benefits Program to allow the records to be transferred to NARA. Harrison did not approach the director legally demanding the records. “There are all kinds of laws but in terms of following all these rules and regulations, sometimes people do what they want anyway.”⁴²

Considering that the records had been boxed and were for transfer, issues regarding confidentiality and privacy emerged. Harrison stated that the Director of the Tuskegee Health Benefits Program would not transfer the records until an agreement was made between the CDC and NARA. The CDC, including the Director of the Tuskegee Health Benefits program, did not want anyone to have access to the medical information of the participants. NARA would try to make the other groups of records as open as possible with an initial review. The agreement between the two agencies, which was attached to the accession record, stated that:

The National Archives and Records Administration will be responsible for preserving and maintaining the records in accordance with the approved CDC Records Control Schedule, item 101 (records will be preserved in perpetuity for future historical research)

Because of the sensitive nature of the information contained in these medical records of Tuskegee Study Health Benefit Recipients, and the potential negative effects on the subject

⁴²Jimmy Harrison, interview by author, September 21, 2001.

individuals and their families, *disclosure is not permitted to the general public, including researchers, per 5 U.S.C. § 552 (b)(6), until the year 2030* (see [APPENDIX E](#)).

According to the agreement, the National Archives became the responsible party that maintained the records in accordance with the requirements of the Freedom of Information Act and the Privacy Act.⁴³ Harrison pointed out that “...our legal office looked at this issue and I indicated to them that I needed something to convince Arzell Lester [Director of the Tuskegee Benefits Program] and his employees that these records were not going to be blatantly open. That’s what they were fearful of because they work with these people and they didn’t want their medical records open and so the legal office came up with that [2030].”⁴⁴

The National Archives obtained custody of the Tuskegee Syphilis Study records by making numerous assurances to and entering the aforementioned agreement with the CDC. Even though NARA is federally mandated to take custody of records from governmental agencies, exercising this authority continues to be a challenge. There have been a number of reported cases where governmental agencies have failed to turn over records to the National Archives, especially records with sensitive information. MacNeil points out that the transfer of records to a governmental archive is a challenge when “...even in jurisdictions [mandated by legislation] archivists are often refused access to records containing sensitive personal information which are either maintained by the record-creating agency in perpetuity or destroyed before archivists have had an opportunity to determine whether they have archival value.”⁴⁵ So if the Tuskegee Health Benefits Program had not been inundated with FOIA requests, NARA may not have received the

⁴³ National Archives and Records Administration, Transfer, Approval, and Receipt of Records to National Archives of the United State, RG 442. Tuskegee Syphilis Study Administrative Records. Accession Nos. 4NN-442-90-01.1992.

⁴⁴ Jimmy Harrison, interview by author, September 21, 2001.

⁴⁵ MacNeil, 193.

records when scheduled which would have further undermined public accountability of the Tuskegee Syphilis Study.

On July 29, 1992, NARA officially had custody of the Tuskegee Syphilis Study records.⁴⁶ The files consisted of records created during the course of the study that related to: 1) individual patients; 2) publications based on findings of the study; 3) correspondence between medical personnel; 4) administrative files; 5) photographs of various medical tests or procedures; and 6) minutes. Between 1991 and 1999 more records have been found at the CDC and transferred to NARA (see [APPENDIX F](#)). These records include affidavits relating to: 1) the federal court case; 2) agendas and committee hearings; and 3) materials relating to public scrutiny to which the study and the agency were subjected once the study was exposed. Currently, there are forty boxes of the administrative files. Of the forty boxes, boxes one through twenty and twenty (a) are open to the public. The remaining boxes, an additional one through three, and twenty-one through thirty-five and thirty-two (a), which contain information about individual patients and the court case, are also restricted until the year 2030 in order to protect the personal privacy interests of the participants and their families. In addition, there are forty-seven boxes of medical files, which according to the agreement are restricted until 2030. Thus, there are a total of eighty-seven boxes pertaining to the Tuskegee Syphilis Study.

Harrison recalled that there were a number of transfers from 1990 to 1999. There were several transfers because files were found throughout those years. Harrison stated that this happened due to less than ideal filing practices. Harrison conceded that folders were discovered everywhere. Dr. Bill Jenkins, the retired manager of the Tuskegee Health Benefits Program

⁴⁶ The Tuskegee Syphilis Study records were transferred to NARA's Southeast Regional Center. In 1992, the center was located in Atlanta, Georgia.

stated that, “As people found records...they would give them to me and I would hand them over to Jimmy.”⁴⁷ In addition, Harrison found the records in the Tuskegee Health Benefits Program at the National Center for Infectious Diseases, now called the National Center for HIV, AIDS and Tuberculosis Prevention (NCHSTP). However, the methods for locating records varied. However, it does beg the question of what led to the poor condition of the records from 1973 to 1990, particularly since the records were officially closed?

4.7 THE RECORDKEEPING HISTORY OF THE TUSKEGEE SYPHILIS STUDY RECORDS WHILE IN THE CUSTODY OF THE NATIONAL ARCHIVES AND RECORDS ADMINISTRATION (NARA)

Upon receiving the Tuskegee Syphilis Study records, providing public access proved to be an issue for NARA. How would NARA handle requests for these records, especially sensitive information? In a memorandum dated May 30, 1990 Mary Ronan, a FOIA officer for NARA, expressed concern, particularly given that there was no case law yet regarding the privacy interests of third parties who have had relationships with deceased individuals. However, Ronan developed a solution (see [APPENDIX G](#)). Ronan stated, “I suggest we approach these records [Tuskegee Syphilis Study records] in a different way. First, remove names and personal identifiers from the files to protect the family members. Second, close the files until NARA receives a FOIA request” and “only then should we take on the project of sanitizing.”⁴⁸ Trudy Peterson, assistant Archivist at the time of the transfer, agreed with Ronan (see [APPENDIX H](#)).

⁴⁷ Dr. Bill Jenkins, interview by author, September 23, 2001.

⁴⁸ Memorandum, Mary Ronan, FOIA Officer to Trudy Peterson, Assistant National Archivist of NARA, May 30, 1990.

NARA's treatment of the Tuskegee Syphilis Study records was consistent with the CDC. Charles Reeves, Director of Archival Operations stated that files were placed in acid free folders and acid free boxes. But as stated in this chapter, some of them were and continued to be unarranged. Many of the folders did not have titles on them. As a result, such folders would say "unfolded records with no title on them." Reeves stated that just like Harrison, archivists at NARA left the records in the arrangement that they were in.

The records would not receive any more attention until Dr. Henry Foster, an African-American obstetrician-gynecologist from Tennessee, was nominated for Surgeon General by former President Bill Clinton in 1995. Foster's willingness to perform abortions was among the reasons the Senate did not want to approve Foster's nomination. However, the most disturbing allegation raised about Foster's career was that he was a local physician that took part in the Tuskegee Syphilis Study. Even though Foster served as chief of obstetrics and gynecology at Tuskegee Institute's John A. Andrew Memorial Hospital from 1965-1973 and president of the Macon County Medical Society in 1970, he denied any connection to the study. He claimed that he heard about the study when it was revealed to the public at large.

In 1995, as a general practice, when the Southeast Regional Center received a reference request, the staff would then work on processing more records. It was not until the Foster case, however, that the staff worked overtime to process even more records for access. Charles Reeves remembered that there was a lot of interest from the media, congressional offices, and the White House on whether or not Dr. Foster took part in the Tuskegee Syphilis Study. Reeves stated that Southeast Regional Center received a phone call from staffers of the Senate Committee. The Senate staffers informed the Southeast Regional Center that they were coming to Atlanta to look at the records. Reeves also mentioned that reporters were interested in the allegations about Dr.

Foster's conduct with respect to the study. Although the White House did not send anyone, Reeves claimed that it too wanted to know whether there was anything with Foster's name on it. Reeves insisted that they did not find anything that would indicate Foster's involvement with the study and reported this to the White House.

NARA invested a great deal of resources, which it did not have, to examine numerous documents. Reeves stated that two or three of them stayed until midnight examining records for the White House request. Reeves commented that "...we spent more time with those [records] at that time than any time probably before or since."⁴⁹ Reeves recalled that the only records that they went through were administrative files. If someone requested information, Reeves stated that they could go through and sanitize information in the administrative files. However, some folders have been pulled because they were completely restricted. Reeves commented that "its just too much."⁵⁰ What he was referring to was what Ramona Oliver spoke of in her interview concerning resources. She stated that:

We don't hold records wholesale. We apply the FOIA exemptions. We release segregable portions. The problem with these other files [other restricted documents] is that there is a plethora of information that would require withholding. And because of resources in Atlanta and elsewhere there is some files that we don't take any action on until we have a FOIA request in hand for that requiring us to take some sort of action and so theoretically all the records could be open eventually but because we don't have the time to systematically review all the files you have to make request at any information about deceased individuals more likely than not will be released at certain caveats to that rule.⁵¹

⁴⁹ Charles Reeves, interview by author, September 20, 2001.

⁵⁰ Charles Reeves, interview by author, September 20, 2001.

⁵¹ Ramona Oliver, interview by author, December 22, 2003.

NARA treated the medical records like the administrative files. These records were not arranged in alphabetical or numerical order. Considering that the records were restricted, no one bothered to rearrange the records in any order. Instead a red dot was placed on each box containing these records, which indicated they were restricted. When I requested a file, Charles Reeves had to check with the NARA's Office of the General Counsel in order to get permission to grant my request. Afterwards, he selected a file, which had to be redacted of all personal identifiers. It took Reeves almost an hour to complete this task. Reeves commented that he was glad that he had done so because if someone else requested a medical file, he would have one already sanitized.

For NARA, protecting the Tuskegee participant's medical records appears to be a non-negotiable goal, given the humiliation that the participants and their families have endured. However, protecting the personal privacy interests of the participants and their families is an issue for NARA. NARA restricting access to medical records continues to perpetuate suspicion. Furthermore, it undercuts the public's right to know what happened.

Since 2002, the researcher had tried to gain access to the medical files after realizing that such records could be accessed upon an initial review of a FOIA request. After examining NARA's regulations, the researcher learned that NARA could redact any personal identifiers such as names and addresses while granting access to sensitive information such as medical files. Upon consulting with the Office of the General Counsel in Washington, D.C., Charles Reeves, the Director of Archival Operations at the Southeast Regional Center decided to allow me to make copies of two medical files after they were redacted. When I had called to find out if the files had been redacted, a staff member told me that I could not see such files because they were restricted under Exemption 6. Such a lack of knowledge brings up Jimmy Harrison's point about

staff being uninformed about policies, procedures, or plain simple in-house decisions. Once I informed them that I had permission from the Director of Archival Operations, I was granted access to those specific files. NARA has an archival description of the Tuskegee Syphilis Study records on-line. It gives a brief history as well as a general outline of the records within its custody (see [APPENDIX I](#)). Researchers only have access to the administrative files. The dates that are given, 1929 to 1970, refer to the study. However, records have been transferred that include documents after 1970 (1990, 1991, 1992, 1993, 1994, and 1999) which have been found over the years at the CDC.

Documents within the administrative files have remained restricted. Charles Reeves states that when the records were transferred to NARA he and his staff went through as many files as they could to redact such information. However, many of the documents had too many personal identifiers, and “you would have more holes than you would information.”⁵² According to Reeves, officials made judgment calls as to what information to redact. He also remembers that despite the agreement between the two agencies, he had redacted some medical files, which I had come across when examining the administrative records. Reeves commented that “as far as I know you are probably the first person who has looked at those medical records.”⁵³ He asserted that if he had examined the agreement between the two agencies, I would not have had access to the medical files. I found this to be odd, since Reeves had consulted with the Office of the General Counsel in Washington, D.C. and subsequently provided redacted medical files to me. There were discussions back and forth between Reeves and the Office of the General Counsel about how to resolve my request.

⁵² Charles Reeves, interview by author, September 20, 2001.

⁵³ Charles Reeves, interview by author, September 20, 2001.

In Reeve's opinion, the Tuskegee Syphilis Study records are treated differently because of the agreement between the CDC and NARA. He felt that NARA is not only protecting the privacy of the participants but especially their families, which on the surface is not unusual. When trying to balance personal privacy and the public's inquiry, NARA does have the discretion to determine on a case by case basis what documents will be released and what personal information should be redacted. Even though privacy ends at death, NARA does make exceptions. Reeves believed that the Tuskegee Syphilis Study records required guidance on access. However, withholding the medical records in their entirety undermines the spirit of FOIA. After further discussion, Reeves did point out that the agreement between the CDC and NARA could be challenged.

After my interview with the Director of Archival Operations at the Southeast Regional Center, I emailed NARA's Office of General Counsel in Washington, D.C. in July 2003. I also submitted a written FOIA request to review the agreement between the CDC and NARA regarding access to the medical records. My request inquired: How did the CDC and NARA agree on 2030?; Why is NARA still protecting the names of the participants if they are already in the public domain?; Why are the medical files restricted even though most of the participants are dead (only two remained living)?; Do the participants' rights diminish upon death or does it have to do with third party rights?; and are there any documents that speak directly to the Tuskegee Syphilis Study records that I could receive (see [APPENDIX J](#))? I also wanted to understand NARA's policy regarding balancing personal privacy and the public's right to know, especially in this specific case.

I had the opportunity to interview Ramona Oliver, FOIA and Privacy Act Officer of General Counsel Office and Sarah Rudgers, Assistant General Counsel, who were responsible

for answering my request. Oliver and Rudgers described how they went about gathering answers to my questions. Both of them called the Southeast Regional Center to determine what their practices and policies were regarding the medical records. The NARA staff at the Southeast Regional Center forwarded to Oliver and Rudgers a copy of the transfer documentation which included the CDC's recommendation that the medical records be restricted until 2030. Afterwards, Sarah Rudgers contacted the CDC to find out why 2030 was recommended. Rudgers explained that although the Tuskegee Syphilis Study records were now under the custody of NARA, the institution did "try to take into account the originating agencies policies and concerns before we make a determination."⁵⁴ Oliver and Rudgers learned from Records Officers such as Jimmy Harrison and attorneys, that the CDC was concerned about the privacy of both the living participants and family members. As a result, Oliver contacted the Director of Archival Operations and requested a representative sample (approximately 30 percent) of medical records to examine. Oliver's job was to gauge the privacy interests of the affected parties. She commented that if the medical records contained intimate details about the participants or their family members, than such information was too sensitive to release to the public.

Oliver and Rudgers found that the sample of medical files reviewed did not affect the family members of the participants directly. The files contained examinations over the course of the study and medical procedures. According to Oliver, family members were listed as points of contact if PHS physicians could not find a subject. Oliver asserted, "Keeping that in mind, we felt that third party privacy was a minimal issue."⁵⁵ Rudgers used this position with the CDC officials. Both Oliver and Rudgers believed that the CDC officials did not know what was

⁵⁴ Sarah Rudgers, interview by author, December 22, 2003.

⁵⁵ Ramona Oliver, interview by author, December 22, 2003.

actually contained in the medical records. After some discussion with the CDC, Oliver and Rudgers persuaded them to reconsider their recommendation, especially after they learned that two participants were living. NARA agreed to keep the medical records of those living restricted. Furthermore, the CDC was less concerned about those who were dead. Thus, as long as NARA could assure the CDC officials that there were no third party concerns and protected the medical records of the living participant, than the public could have access to the remaining medical records.

In February 2004, I received a response from the National Archives and Records Administration's General Counsel (see [APPENDIX K](#)). The letter stated that the CDC recommended that the medical records be closed until 2030 because at the time several participants and their immediate family members were still living. Although NARA claims that it never categorically withheld the medical records, public access after the transfer of those records was nonexistent. There are no records to indicate whether or not NARA made these records available to the public, or even redacted them. However, Oliver stated that "...ever since 1990, there has always been the possibility of these records being released if it was possible to redact personal identifiers in such a way that you have meaningful record without identifying the subject. So we have been dealing with this issue since transfer."⁵⁶ As Charles Reeves stated as far as he knew I was the first to see the records. Overall, the Office of General Counsel pointed out "Given the special sensitivities and the subject matter of the Tuskegee Syphilis Study, NARA decided not to release the names in order to protect both the living and survivors who might hold a privacy interest in the medical records."⁵⁷ In the interview, Oliver stated that:

⁵⁶ Ramona Oliver, interview by author, December 22, 2003.

⁵⁷ Ramona Oliver interview by author, February 11, 2004.

I think we do for medical records in some instances where we are talking about third party privacy we have a sound legal basis to invoke Exemption 6. And there is case law that supports even protecting deceased persons records because it may cause some problems or some anxiety or some depression or sadness for surviving family members. So I think we could continue to withhold the records.⁵⁸

Moreover, Rudgers admitted that although NARA's policy is to try to be as open as possible, it did not want to hinder the research efforts of the CDC. Overall, NARA treaded lightly in negotiating with the CDC in releasing the medical records.

4.8 CONCLUSION

Overall, Rudgers and Oliver agreed with the arguments that I made in the email. Rudgers enumerated the factors that contributed to disclosing the records. For example, most if not all of the names of the participants have been published. In May 1997, President Clinton made a public apology to these men. Some survivors and their families attended the ceremony in Washington, D.C. while others watched from Tuskegee, Alabama. Oliver realized that the medical information was not that sensitive or descriptive. "The records didn't talk about anything graphic with regards to sores...any other thing that would be indicative of having a STD⁵⁹...it wasn't really the type of intimate detail that would cause angst to the third party."⁶⁰ Rudgers pointed out that the Office of General Counsel had to factor in all those major points before making a final decision. Hence, the medical records had few intimate details about the participants, limited information about third parties, and much information already out there in the public domain

⁵⁸ Ramona Oliver, interview by author, December 22, 2003.

⁵⁹ STD is the acronym for Sexually Transmitted Disease

⁶⁰ Ramona Oliver, interview by author, December 22, 2003.

such as the names of the participants. Rudgers uttered, “It seemed like we weren’t protecting much by keeping these closed.”⁶¹

My FOIA request for access to the Tuskegee Syphilis Study medical records had challenged NARA to review its own access policy of these records, opening the records in their entirety and creating the opportunity for the public to review these long awaited medical records in 2004 instead of 2030. Even though the records are open, Rudgers admits “The only hard part I think was making sure that we protected everybody’s interest, both the outside public’s access interest as well as the CDC’s concerns about its records and how we [NARA] manage them.”⁶²

⁶¹ Sarah Rudgers, interview by author, December 22, 2003.

⁶² Sarah Rudgers, interview by author, December 22, 2003.

5.0 MANAGING AND PROVIDING ACCESS TO THE TUSKEGEE SYPHILIS STUDY RECORDS

5.1 INTRODUCTION

NARA's decision to open the records in 2004 instead of 2030 has an impact on this study because this decision reveals the process by which NARA reconciles personal privacy and public access with the Tuskegee Syphilis Study records. In order to understand NARA's decision and to put chapter four into context, chapter five integrates and triangulates the data described in chapter three. The data collected analyzes the National Archives and Records Administration's administrative role in maintaining and providing access to the Tuskegee Syphilis Study records. The data collected for this study and the questions from chapter one underscore that even though NARA reviews its access policy on a case by case situation, particularly when privacy interests are involved, its handling of the Tuskegee Syphilis Study records appears to be inconsistent with FOIA and NARA regulations and policies. The maintenance of these records, makes NARA vulnerable to many questions:

1. What is NARA's official policy toward administering access to controversial records that contain restricted information?
2. In light of these policies and practices, how are the Tuskegee Syphilis Study Records treated?

3. Does NARA's access policy toward restricted information and its agreement with the Centers for Disease Control (CDC) undermine the spirit of the Freedom of Information Act (FOIA)? If so, what are the consequences in this particular case?
4. What do the recordkeeping practices of the Tuskegee Syphilis Study records, reveal about the effectiveness of NARA's access policy to protect personal information in those records?
5. How have the restrictions on the Tuskegee Syphilis Study records affected the collective memory of the study?

These records document one of the most heinous governmental experiments in medical history. From the records, the public could examine when, how, and why governmental physicians deliberately denied valuable medical treatment. NARA archivists deemed medical records to be “unique” because of the nature of the experiment and personal privacy issues associated with the participants and their families.¹ As such, the only records that were available to the public were the administrative records. These questions raise issues about the sanitized version that is offered to explain what happened to the participants. In addition, the issue of protecting these men and their families by not releasing any restricted information conjures up government secrecy. Thus, the data and questions point out that the public can get at the truth behind governmental conduct and still honor the participants' privacy by redacting personal

¹ Charles Reeves, Director of Archival Operations at the National Archives and Administration in the Southeast Region, commented that, “I guess this may be in the only instance in the National Archives that we agreed to protect the privacy of the dead. Basically to protect their heirs, who I am sure would not want made public that their father or mother had syphilis.”

information. However, the inconsistent management of the records by NARA in the past undermined the ability to strike this compromise.

5.2 QUESTION ONE: WHAT IS NARA’S POLICY TOWARD ADMINISTERING ACCESS TO RECORDS THAT CONTAIN RESTRICTED INFORMATION THAT ARE IN ITS CUSTODY?

According to its mission statement, the National Archives and Records Administration “ensures, for the citizen and the public servant, for the President and for the Congress and the Courts, ready access to essential evidence.”² Even though NARA attempts to make as much information available to the public about governmental activity, information can be restricted by law. The Freedom of Information Act is the federal law that governs access to records under NARA’s control. Although FOIA is a public disclosure statute, it has nine exemptions to its disclosure requirements:

1. National Security
2. Internal Personnel Rules and Practices of an Agency
3. Information Exempt Under Other Laws
4. Confidential Business Information
5. Internal Government Communications
6. Personal Privacy
7. Law Enforcement

² National Archives and Records Administration’s Mission Statement at <http://www.archives.gov/about/info/mission>.

8. Financial Institutions

9. Geological Information³

Under NARA's regulations "access to archival records containing information access to which would invade the privacy of an individual is restricted."⁴ To this end, NARA will balance the privacy interests implicated by the requested records against the public interest that would be advanced by the disclosure of the records. If NARA determines that the public interest far outweighs personal privacy and sheds light on government activity, then NARA will release the information.

To determine such decisions, NARA receives legal advice from the Office of the General Counsel (OGC). The OGC has several responsibilities which include:

- Legal advice;
- Legal research and analysis;
- Administrative and federal court litigation in support of NARA's programs; and, activities, which would include the federal Statute FOIA; and,
- Formulating, recommending policy and providing advice to the NARA FOIA Privacy Act Officer.⁵

In compliance with 5 U.S.C. 552(b)(6), NARA will withhold records in personnel and medical and similar files containing information about a living individual that reveals details of a personal nature that, if released, would cause a clearly unwarranted invasion of personal

³ *A Citizens's Guide on Using the Freedom of Information Act and the Privacy Act of 1974 to Request Government Records, Second Report*. Washington, D.C. U.S. Government Printing Office, 2005.

⁴ See National Archives and Records Administration's 36 CFR 1256.56, amended 6/30/04.

⁵ See Office of General Counsel at www.archives.gov/about/organizations/summary/general-counsel.html. The Office of the General Counsel advised the NARA FOIA officer in determining whether or not the Tuskegee Syphilis Study medical records should be released to the public.

privacy.⁶ Under NARA policy, the types of information identified as private may include information that the individual has not made public or events that took place less than seventy-five years ago. In addition, agencies that transfer their records to NARA can impose restrictions to decrease the public's opportunity for access. However, such restrictions must comply with the FOIA.

For researchers, understanding access policies can be a challenge, especially requesting restricted information that requires the use of the balancing test which is an analytical framework under the FOIA to apply the personal privacy exemptions. Government agencies use the balancing test to evaluate the personal privacy interests of those affected by the requested information and the public interest in disclosure in that information. The public interest is defined as information that educates the public about government conduct. The two exemptions that require the balancing test are Exemption 6 and Exemption 7(C). The Supreme Court developed the framework for the test in a series of court cases which government agencies use when public interests and personal privacy interests conflict in FOIA requests under these two exemptions.⁷

NARA can make restricted information available by sanitizing or redacting personal information in compliance with the FOIA. NARA may grant access to researchers who request information for biomedical research, if they have justified their use of the information. The Archivist of the United States may feel enough time has passed that such information would not affect the individual. Ramona Oliver stated, "FOIA also gives agencies the discretion to make

⁶ Ibid.

⁷ Some of the court cases include *Department of the Air Force v. Rose*, 425 U.S. 352 (1976); *Department of Justice v. Reporters Committee for Freedom of the Press*, 489 U.S. 749 (1989); *Department of State v. Washington Post*, 456 U.S. 595 (1982); *FBI v. Alabama*, 456 U.S. 615 (1982); *National Archives and Records Administration v. Favish*, 123 S. Ct. 1570 (2004).

certain types of records available.”⁸ This mechanism enables the public to hold its government accountable for its actions.

Litigation stemming from NARA’s appraisal of the investigative case files of the Federal Bureau of Investigation (FBI) raised issues about the access policy governing these records. In investigating the history of the Federal Bureau of Investigation and its abuses, Theoharis supports the necessity of researching individual case files, which are considered sensitive information. Theoharis insists that “As historians of the American past and as citizens required to make an informed judgment about the role of the FBI in a democratic society, we need to know how extensively the FBI violated privacy rights in the recent past and how, in the process, the Bureau broke the law. And this knowledge can only come from uncensored research into FBI records.”⁹ He also calls attention to the significance of the incomplete record. For example, Theoharis learned of the FBI’s omission of break-in victims from research into the FBI files released under the FOIA. In this study and others, Theoharis has focused on how incomplete records should be interpreted. Would the withholding of records rebut, modify, or confirm the conclusions of the recipient researcher?¹⁰

Theoharis questions the role of the National Archives in ensuring the preservation of the FBI records was questioned. One observer, Theoharis, wonders about the role of the National Archives in ensuring the preservation of the FBI records. He points out that the National Archives personnel had not reviewed FBI records in order to ensure the preservation of FBI historic records until a court order forced it to do so in 1980. According to Theoharis, the

⁸ Ramona Oliver, interview by author, December 22, 2003.

⁹ Athan Theoharis, “FBI Files, the National Archives, and the Issue of Access,” *Government Publications Review* 9: 1 (1982): 29.

¹⁰ Athan Theoharis, ed., *A Culture of Secrecy: The Government Versus the People’s Right to Know* (Lawrence, KS: University Press of Kansas, 1998).

National Archives looked the other way and approved FBI record destruction without insisting upon its legal authority of direct access to the documents. In effect, this discretion permitted FBI officials to destroy files which, if preserved, would have documented the scope and nature of FBI abusive practices. Theoharis has asserted that role of the National Archives constituted “a dereliction of its record retention responsibilities.”¹¹

NARA employee James Bradsher lays out myriad access challenges for the agency and researchers. After the 1980 lawsuit, the National Archives had to make available the case files of the FBI. This effort took a lot of manpower to appraise the records. A large percentage of the records were kept. However, access to the records proved to be a challenge. Both researchers and archivists would have a difficult time determining how to access this information because of the filing system kept by the FBI. According to Bradsher, who participated in this project, “the first challenges to researchers will be knowing what to ask for”¹² Bradsher believed that researchers could not figure out what they needed without the index.

Privacy presented another major issue for the National Archives. Bradsher states that individuals could request that part or all of their information be destroyed before the records even transferred to NARA. In this case, personal privacy outweighed the public’s right to know. For the researcher, this proved to be a battle that he/she could not win, but personal information was not needed to understand the FBI’s investigative activities.

The FBI files tested the statutes and regulations that guided NARA when deciding what information to withhold from the public. NARA can restrict information based on the nine exemptions of the FOIA and restrictions imposed by the agency. In this case, the FBI did not

¹¹ Ibid, 32.

¹² James G. Bradsher, “Researchers, Archivists, and the Access Challenge of the FBI Records in the National Archives,” *Midwestern Archivist* 11: 2 (1986): 97.

impose any specific restrictions on the files. However, Bradsher points out that the files would pose a challenge because of their age and whether or not they could be protected from disclosure under any of the FOIA exemptions, particularly Exemption 6 and Exemption 7(C), the ones dealing with personal privacy. If Exemption 6 or 7 (C) applied, then the archivist would have to decide what information should be released based on the balancing test and whether or not personal privacy outweighs the public's right to know.

Defining what information should be released was another challenge. Bradsher discusses how Exemption 7 protects the confidentiality of those who have participated in law enforcement investigations. The information that was considered intimate and personal in nature was not disclosed to the public. The researcher has the right to the information in a file requested. However, the archivist must decide if the information will be in the public's best interest or will harm the individual. As a result, the archivist must make a decision to release all or part of a record. Bradsher contends that the information may be released with personal information redacted under the appropriate exemption. More importantly, the release of the information must be in the public's interest not in the interests of "not individuals seeking information for their own benefit, particularly if it is to satisfy their curiosity."¹³

Disclosing part of a file does not mean that the public cannot continue to hold the government accountable for its actions. However, agencies placing extreme restrictions on their records can prevent NARA from releasing certain records. Such frustrations make it difficult for NARA to live up to its access policy. Bradsher states, "With patience and knowledge, the access challenge of the FBI's records should be met in a manner which makes substantial quantities of

¹³ Ibid,102.

information available while at the same time protecting the privacy of individuals and the legitimate security and law enforcement concerns of the government.”¹⁴

Another source of insight to a study of the handling of the Tuskegee Syphilis Study records is a recent Supreme Court case dealing with the privacy rights of third parties under the FOIA. In National Archives Administration v. Favish, 124 S. Ct. 1570 (2004), the Supreme Court examined whether disclosing certain law enforcement investigative records, particularly photographs, under the FOIA would violate the surviving family members of a White House Official who allegedly committed suicide. The case involved the Deputy White House Counsel, Vincent W. Foster, Jr. On July 20, 1993, Foster was found dead in Marcy Park outside Washington, D.C. Several federal investigations determined that he had committed suicide. Official reports on his death were released in June 1994 and October 1997. After the official investigations were concluded, the records, including photographs, were turned over to NARA. Allan Favish, an attorney from California, challenged the official conclusions. Favish filed a FOIA request for specific photos of the death scene. After his FOIA request was denied, Favish sued the Office of Independent Counsel in order to gain access to certain photographs of the death scene, including photographs of Foster’s body.

Favish mounted his legal challenge under Exemption 7(C), which protects the personal information within law enforcement records against the disclosure which “could reasonably be expected to constitute an unwarranted invasion of personal privacy.”¹⁵ Ultimately, Favish, who

¹⁴ Ibid,104.

¹⁵ 5 U.S.C. § 552 7(C).

is an attorney, tried to gain access to the Vince Foster investigative record on behalf of a client through the federal courts in the District of Columbia. The United States Court for Appeals for the District of Columbia Circuit determined that the photographs should be withheld under Exemption 7(C). However, Favish, on his own behalf, filed again in California where the United States Court of Appeals for Ninth Circuit Court granted him access to four of the ten photographs. Favish argued that the public had a right to know if there was any wrongdoing on the part of the government in their investigation. Upon ruling in Favish's favor, the Ninth Circuit Court did recognize that Foster's family had a right to privacy.

The Department of Justice appealed the Ninth Circuit Court decision to the Supreme Court. The Court ruled that Favish did not have any pertinent evidence to show that there was actual wrongdoing on the part of the government. In this instance, the Court's decision placed the future burden of proof on requesters. The requester will have to show "a meaningful evidentiary showing" that would require an agency to invoke the balancing test between personal privacy and public interest. The court declared that Exemption 7(C) "requires us to protect, in the proper degree, the personal privacy of citizens against the uncontrolled release of information compiled through the power of the state."¹⁶

Foster's family also did not want the photographs disclosed to the public. Favish, however, argued that Exemption 7(C) only recognized the personal privacy of the individual, in this case Vincent Foster, and that family members had no right of privacy over the pictures. The Supreme Court felt that Favish's definition of personal privacy as an individual's right to control information about oneself was too narrow. It ruled that Foster's family had a right to invoke their own personal privacy protection. In writing for the majority, Justice Anthony Kennedy stated

¹⁶ NARA v. Favish, 124 S. Ct. at 1580 (2004)

that “Foster’s relatives...invoke their own right and interest to personal privacy...They [Foster family] seek to be shielded by the exemption to secure their own refuge from a sensation-seeking culture for their own peace of mind and tranquility, not for the sake of the deceased.”¹⁷

What the court termed “survivor privacy” was predicated on three factors:

- Broad definition of personal privacy to protect surviving family members; not “some limited or cramped notion of that idea”
- Acknowledging a family’s control over the body and death images of the deceased
- Under 7(C), two Attorneys General extended privacy protection to families.¹⁸

Using the balancing test demonstrates a pattern that NARA engages in when personal privacy is an issue. The FBI and Foster cases had different outcomes. NARA has the discretion to disclose information which is protected under FOIA. However, NARA’s discretionary decisions can conflict with FOIA when personal privacy is an issue. The Tuskegee Syphilis Study records tested NARA’s decision-making.

5.3 QUESTION TWO: IN LIGHT OF THESE POLICIES AND PRACTICES, HOW WERE THE TUSKEGEE SYPHILIS STUDY RECORDS TREATED?

NARA’s access policy and guidelines were not followed with respect to the recordkeeping of the Tuskegee Syphilis Study records. Although the records were deemed to have significant value and therefore retained for permanency by the CDC, the employees of the CDC were unwilling to

¹⁷ Ibid, at 1577.

¹⁸ *NARA v. Favish*, 124 S. Ct. (2004).

transfer the records to NARA in 1990. The employees of the Tuskegee Benefits Program were unaware of the retention schedule for the Tuskegee Syphilis Study records. The constant requests for documents forced the director of the program to seek assistance from the records manager. Once Jimmy Harrison, the records manager, discovered that it was time for the records to be transferred to NARA, the director, Arzell Lester, was hesitant to release the records.

Lester was unaware of the role of the National Archives in preserving governmental records and the retention schedule covering the records of the Tuskegee Syphilis Study. Harrison made several visits to convince the director that NARA would not destroy the records. Unfortunately, agencies withholding records that should be transferred to NARA is not unusual. On behalf of NARA, a study was conducted to ascertain governmental employees' views and perceptions about records creation, maintenance, use, and disposition. The study found that recordkeeping and current records management issues receive low priority from agency personnel due to lack of staff, budget, training and accountability. The study highlighted that, overall, NARA's influence was needed in federal agencies. This was definitely the case with the management of the Tuskegee Syphilis Study records.

As the research progressed, it became apparent that the transfer of the records from the CDC to NARA did not occur in accordance with standard procedures. As stated earlier in the chapter, agencies can make specific restrictions on their records that are being transferred to NARA. If an agency requests restrictions for their records after they are transferred, the agency has to identify the proper statute for nondisclosure and convince NARA of the need for the restrictions. However, in this particular case with the Tuskegee Syphilis Study records, the records manager Jimmy Harrison, the director of the Tuskegee Benefits Program, Arzell Lester, and NARA personnel entered into an agreement that restricted the medical records until 2030

based on Exemption 6. The transfer has far reaching implications reaching farther than an archaic agreement made to protect the participants and their family members. NARA's decision to withhold the medical records in their entirety highlights how NARA trampled the public's right to know what occurred even when there was a mechanism in place to protect the privacy interest at issue.

5.3.1 May 30, 1990 Memorandum

The 1990 memorandum that was written to deal with the sensitivity of the medical records was not disseminated to the Southeast Regional Center. As far as the staff knew, Exemption 6 was the reason that certain records, including the medical records, were restricted. There was no questioning this reason at NARA or the CDC. As stated earlier in this study, both agencies were using Exemption 6 as a shield. When asked how the staff learned about new policies and procedures or changes within NARA, Reeves stated, "We have training usually when the directors meet which is about once a year. That is part of our training and there is the National Archives web-site and memos and all kinds of regulations that are sent to us that we are supposed to study."¹⁹

Even though Reeves receives information about new policies and procedures, he too was unaware of the memorandum. At the time of the transfer, the memorandum was shared between Mary Ronan, FOIA officer, and Trudy Peterson, Deputy Archivist of NARA. Reeves relied more on the contract as a guide and the OGC and the NARA FOIA officer to assist him with this matter. Reeves stated, "I have contacted them a number of times about these records. Basically under what condition to grant access. What I could let them see and what I couldn't let them

¹⁹ Charles Reeves, interview by author, March 12, 2003.

see.”²⁰ In describing the contributions of the railroads to the development of managerial methods and formal internal communications, JoAnne Yates points out the significance of downward communication as a managerial tool. “Regular flows of upward, downward, and lateral communication as well as detailed record-keeping procedures played a critical role in the new systems.”²¹ In the case of NARA, there was a breakdown within the internal communication system between the NARA in Washington, D.C. and the Southeast Regional Center in Atlanta, Georgia.

The 1990 memorandum was sent to me along with NARA’s decision stating that the records were going to be released. Since the memorandum existed, both Oliver and Rutgers offered the explanation that NARA did not categorically deny access to the records. Oliver pointed out, however, that Reeves and his staff had only the contract to go by and Reeves “didn’t think that he was empowered to do anything other...without somebody at a higher level making a different decision for him.”²² It would seem that if Reeves had known about the memorandum, there would have been less consultation with the NARA FOIA officer and the OGC. Thus, Oliver, Rutgers, and Reeves have conflicting outcomes of providing access to the medical records.

5.3.2 Are the Records Unique?

The staff at NARA also emphasized how the uniqueness of the Tuskegee Syphilis Study records has affected public access. Reeves stated “these records are somewhat different from normal

²⁰ Ibid.

²¹ JoAnne Yates, *Control through Communication: The Rise of System in American Management* (Baltimore: John Hopkins University Press, 1989), 2.

²² Ramona Oliver, interview by author, December 12, 2003.

records. We have an agreement with the CDC that they [the records] remain closed until 2030. So we have not allowed anybody to look at anything that reveals names, knowingly at least.”²³ Like Reeves, Oliver and Rutgers cited the agreement as well. The Tuskegee Syphilis Study is unique because of the political and social controversy, the racial element, and the government’s misconduct. However, the underlying rationale is that the records themselves are not unique in the way described by NARA. There was a written memorandum that stipulated how the records should be handled like any other records that are transferred to NARA.

Again, NARA’s letter presents what actually happened with the transfer. For NARA, the CDC’s “recommendation” for restriction was based on Exemption 6 of the FOIA. However, NARA did not investigate the CDC’s claim for non-disclosure. There are two distinct duties that NARA must carry out with respect to government records. First, NARA has the authority to allow records to be transferred to it. Second, NARA must do an independent FOIA analysis to determine if restrictions placed on transferred records are tied to specific statutory or legal authorities that allow for the records to be restricted from public access, such as exemptions contained in FOIA, the Presidential Records Act, or the current Executive Order on classified national security information. When the records arrived at NARA, the FOIA officer, Mary Ronan, analyzed how NARA could protect the personal privacy of the men and their families while providing public access. It would seem that Ronan had judged the situation carefully. In her 1990 memorandum, Ronan stated that upon a request for restricted information any identifiable personal information would be redacted. Instead of following the memorandum, NARA recognized the agreement and categorically denied access. However, describing the

²³ Charles Reeves, interview by author, September 20, 2001.

records as “unique” does not preclude public access. FOIA determines the analytical framework of access, not uniqueness.

In *Pollard v. United States*, a number of participants were named, including family members. The case not only contained a list of names, it revealed the participants’ medical status. Plaintiffs’ attorney, Fred Gray, commented, “If a person wanted the names, they could get them...all they have to do was go to the records of the court file and the settlement agreement which set out the names of everybody whether they were a control subject or syphilitic...living or dead.”²⁴ In this document, there was a paragraph the participants had to sign that indicated their lack of knowledge of the study. The paragraph read:

I am one of approximately four hundred (400) syphilitic participants in what has become known as the Tuskegee Syphilis Study. I understand that the study was conducted by the United States Department of Public Health. The department kept detailed records of the activities and involvement of each participant in the study. At the time of my involvement, I was unaware of the fact that a study of untreated syphilis was being conducted, and that I was a participant in the experiment.²⁵

Other participants substituted the word “syphilitic” with “control” for the same statement.

The names and groups the participants belonged to are as follows:

Charles W. Pollard-S
Fred Simmons-S
Jessye Maddox-S
Sam Donar-S
Archie Foster-S
Lee Foster-S
Percy Gaines-S

²⁴ Fred Gray, interview by author, June 16, 2003.

²⁵ *Pollard v. United States*

Ben Eddie Foster-S
Charlie Griggs-C
Ernest Hendon-C
Fonzie Mahone-C
John Wesley Smith-C
Otis Pace-S (contracted syphilis after study commenced)
Jim Black-S (contracted syphilis after study commenced)²⁶

For the public, access to the names of the participants seemed vital to understanding what happened during the study. However, it must be noted that even though the names are in the public domain, it is not relevant to increasing the public knowledge of what happened. Furthermore, information contained in medical files may be different and/or more invasive than information provided in legal or court files. Personal privacy means the ability to control information about oneself, i.e. name, addresses, social security numbers, etc. It may also include intimate and embarrassing details. So does this information shed light on what happened during the study? Demanding the names and any personal identifiers of the participants and their families redirects the focus to them and not to the government's misconduct. Reeves commented that, "A number of the participants in the study have been on national television and all kinds of things. We aren't able to keep up with everybody...who's been on t.v...who has come forward and who has not. All we can do is keep them all restricted."²⁷ Although the participants have publicly expressed their outrage about the study, the underlying outcome is that their names do not add to the public knowledge about what happened during the Tuskegee Syphilis Study.

²⁶ Ibid.

²⁷ Charles Reeves, interview by author, September 20, 2001.

Including the names with the medical files, however, does expose more information about the participant, causing emotional harm to them and their family.

The records document the longest non-therapeutic study in medical research. The records describe in great detail how the governmental physicians carried out the study. Those interviewed for this study gave different reasons why the records have significant value. James Jones stated that:

I think the records are powerfully important...A one of kind study... It's also one that has a large claim to the public's attention. People still care about this. It hadn't gone away. Those records are going to be important for future generations who will have other questions to ask and who want to make their own assessment of what happened.²⁸

The information provided in those records enable the government to be held accountable for its actions even today. Richard Mulgan defines accountability as “the obligation to be called to account...a method of keeping the public informed and the powerful in check.”²⁹ Accessing the records of government activities is a method of accountability. FOIA is a democratic measure used to guarantee equal access and to ensure that the government is keeping adequate records of its activities. In this case, the PHS physicians kept meticulous records documenting their activities. Such records guaranteed that the government would answer for its actions to the men and to the public. For Harrison, the records showed “the government had more than hands. They had hands, feet, arms, every appendage they seemed to use quite actively in this.”³⁰ As a result, the government paid the ultimate price, public distrust.

²⁸ James Jones, interview by author, December 3, 2003.

²⁹ Richard Mulgan, *Holding Power to Account: Accountability in Modern Democracies* (New York: Palgrave, 2003), 1.

³⁰ Jimmy Harrison, interview by author, September 21, 2001.

The Tuskegee Syphilis Study medical records are not without their own controversy. These records contain personal sensitive information about the health of these men. What can the public learn from the medical records that will shed anymore light on government misconduct? The administrative records that detail the study over a forty year period are available to the public. To play devil's advocate, the files record the demographic information, types of examinations, and whether or not a participant was syphilitic or of the control group. So why should the public have access to these records?

The participants' medical files provide historical content, specifically corroborating the government physicians' omission of treatment. The records also corroborate that the doctors did not deliberately infect the participants with syphilis. It is possible to glean from these files the social constructions of patient doctor relationships. Guenter B. Risse and John Harley Warner comment on patient records as "surviving artifacts of the interaction between physicians and their patients in which individual personality, cultural assumptions, social status, bureaucratic expediency, and the reality of power relationships are expressed."³¹ The medical records provided the basic demographic information: name, sex, age, marital status, occupation, race, and place of residence. Moreover, these records allow the researcher to trace the medical history of the men over a forty year period. However, does the privacy interest of the participants far outweigh the public's interest in disclosing the records?

The interviewees for this study shared their opinions about disclosing the records, including the medical records. Dr. Bill Jenkins, manager of the Tuskegee Health Benefits Program, who has since retired from his position, succeeded Arzel Lester in 1995. Jenkins held

³¹ Guenter B. Risse and John Harley Warner, "Reconstructing Clinical Activities: Patient Records in Medical History," *The Journal of the Society for the Social History of Medicine* 5:1 (1992): 189.

the position for over five years. During that time, Jenkins has developed a personal, even protective, connection with the men and their families. He has his own thoughts about what the public should have access to and why. Jenkins states that “the public should examine the administrative records... and...the ethics and politics of the study and not the individual physical health of these men.”³² For Jenkins:

The issue about the Tuskegee Study in my mind is not whether Mr. Jones was positive for syphilis or whether Mr. Sams was positive for syphilis. The issue is what were the decisions around recruiting these men, informing these men, encouraging these men to continue in this study. Issues around when it became a question of ethics, maintaining correspondence, getting permission from the community. Those are the issues that are important which are in the correspondence, not in the medical records. The medical records only hide the real issues.³³

Dr. Jenkins commented that he would never give permission to anyone to look at the medical records. Jenkins would even support destroying the medical records. Thus, for Jenkins there is nothing to be gained from the medical records.

Peter Buxtun, a former PHS official and whistleblower of the Tuskegee Syphilis Study, thinks that all records should be released. Buxtun does have some reasons as to why the records are closed until 2030. And, although he would prefer the records to be open, he states that:

They want all the doctors dead. They want all the participants and their wives dead. And a lot of their children directly born of those marriages to be either old enough that they are not going to hire a lawyer...makes it simpler for everyone. I do believe in getting as much data out that can be gotten out but hopefully not hurting people.³⁴

³² Dr. Bill Jenkins, interview by author, September 23, 2001.

³³ Dr. Bill Jenkins, interview by author, September 23, 2001.

³⁴ Peter Buxtun, interview by author, December 13, 2003.

James Jones is one of those researchers who believed that, “The public’s right to know or need to know trumps other rights.”³⁵ Jones also thinks that if the government wants to restrict something for a long time, then it is hiding something. He states:

...the government wants to sequester material for X amount of time. Its to keep the public from knowing...I think the reason they do that is that they don’t want the truth told. They think that there are things in that record that will make individuals look bad, that will create opportunities for knowledge is power and that they have it and you don’t. They’ve got more power than you’ve got. I am always on the side of disclosure.³⁶

With regards to records in general, Jones asserted, “They are the primary material that let us conduct an important part of our research in trying to understand the past.”³⁷ He feels the same about the Tuskegee Syphilis Study records. “It has a large claim to the public’s attention. People still care about this. It hasn’t gone away. Those records are going to be important for future generations who will have other questions to ask and who want to make their own assessment of what happened...Those records always have to be there so whatever person wants to make an assessment will have those records to use.”³⁸

Jimmy Harrison, records officer for the CDC, organized the records to be transferred to NARA. Harrison’s response to access to the records is that the public is “welcome to look through any administrative records...When we transferred these records to the National Archives in ‘91, ‘94, and ‘95 we transferred legal custody of them in accordance with Federal Law, so we no longer own the records. They belong to the Nation.”³⁹ However, Harrison does feel that the

³⁵ James Jones, interview by author, December 13, 2003.

³⁶ James Jones, interview by author, December 13, 2003.

³⁷ James Jones, interview by author, December 13, 2003.

³⁸ James Jones, interview by author, September 13, 2003.

³⁹ Jimmy Harrison, interview by author, September 21, 2001.

medical records should be restricted until 2030. He stated, “We recommended a closure based upon the privacy issue so in a way maybe it’s not fair to the Archives. We shifted that responsibility to the National Archives but of course we still have a responsibility. We still feel connected to the records even though legal custody has been transferred.”⁴⁰

Dr. David Satcher, former Surgeon General, believes the records are important for medical research. For Satcher, the Tuskegee Syphilis Study represents “one of the pivotal studies in the history of medical ethics from the standpoint of justice and beneficence...in the development of guidelines for medical research.”⁴¹ He, however, also had reservations about releasing medical records. He stated, “Ethics require I think that you protect the privacy of a patient record. I still feel that way about any patient records.”⁴²

Charles Reeves, director of Archival Operations at the National Archives Southeast Regional Center, discussed his views about public access. “We should be able to release the records that tell what happened.”⁴³ However, he commented on the fact that the Southeast Region to a certain extent has advertised that they have them. So in a sense he claims that “we are certainly not trying to conceal the fact that we have them and when we’ve done presentations to groups, we usually mention that these are among the records that we have.” And, he jovially pointed out that “the Center can brag on them a bit as important records in our holdings.”⁴⁴ Fred Gray stated, “I think the facts and circumstances surrounding the study and how it was conducted should be a matter of public inquiry and a matter of public discourse.”⁴⁵ Gray insisted that he did

⁴⁰ Jimmy Harrison, interview by author, September 21, 2001.

⁴¹ Dr. David Satcher, interview by author, August 11, 2003.

⁴² Dr. David Satcher, interview by author, August 11, 2003.

⁴³ Charles Reeves, interview by author, September 20, 2001.

⁴⁴ Charles Reeves, interview by author, September 20, 2001.

⁴⁵ Fred Gray, interview by author, June 16, 2003.

not support releasing medical files unless for medical purposes. Gray had in his possession medical files on each individual participant as well as other documents relating to the Tuskegee Syphilis Study in his law firm in Tuskegee. When asked if he would donate his documents, Gray commented that he would get around to doing something about his collection of documents. Unfortunately, attorney Gray was too late. On February 11, 2004 at 4 a.m., Gray's law office in Tuskegee burned down in what was considered one of the worst fires in the area since 1850. Gray lost everything in his office. (see below).



What is left of Attorney Fred Gray's law firm in Tuskegee (Montgomery Advertiser, Tuskegee, Alabama)

While watching the flames, Gray commented, “We talked just last week about moving those documents to another location so that the records of the civil rights movement would be preserved forever...Now they’re all gone.”⁴⁶

5.3.3 NARA’s Decision to Release the Records in 2004

In response to the researcher’s request, NARA stated that the records would be released in their entirety in 2004 instead of 2030. NARA asserted that under its FOIA policy and regulations, it had been releasing such redacted records over the years upon request. The agency referred to the May 30, 1990 memorandum (see [APPENDIX G](#)). “NARA never categorically withheld the medical records (see [APPENDIX K](#)).” However, the Director of Archival Operations at the Southeast Region Center commented that as far as he knew, the researcher was the only one to examine a medical record. There is no documentation to substantiate NARA’s assertion that access had been granted. From NARA’s response letter, it would seem that there is consistency in granting access to the medical records. However, responses from NARA staff and historians say otherwise.

NARA’s decision to open the records in their entirety was based on the Exemption 6 balancing test. NARA concluded that the medical records should be disclosed to the public because they provided even more documentation on government misconduct. In addition, most of the men were deceased, except two.⁴⁷ However, in weighing the personal privacy interests and public interests, NARA chose to release the records with the participants’ names. Its interpretation of Exemption 6 appeared to be too narrow. The information in the medical records

⁴⁷ All of the participants are now deceased.

deserved to be accessed. But that information could have been released without the patients' names. At first the researcher felt the names were significant. However, the 1990 memorandum stated that the records presented a major privacy issue for NARA. The FOIA Officer worried that researchers could trace participants and their families in this specific community and know which participants had syphilis. The 1990 memorandum suggested that all personal identifiers be redacted in order to protect the privacy of the living. The memorandum also stated, "Pragmatically, I suggest [we] keep the records closed until get a FOIA [request]; only then should we take on the project of sanitizing."⁴⁸

Arguably, releasing the names along with the medical records adds nothing to understanding the government's involvement in the study. The decision from NARA attempts to explain how it takes into account third parties. It states that:

Even information that is not particularly sensitive in and of itself may be withheld to protect the privacy interests of surviving family members if disclosure would cause a disruption of their peace of minds. Given the special sensitivities and the subject matter of the Tuskegee Study, NARA decided not to release the names in order to protect both the living individuals and survivors who might hold a privacy interest in the medical records.⁴⁹

The rationale for protecting third parties from information that is not particularly sensitive in and of itself has been inconsistently applied to the Tuskegee Study. In reviewing a sample of the medical files, NARA determined that there were no personal, intimate details that affected them directly. However, releasing the names along with the medical file would seem to cause "a disruption of their peace of minds." As the 1990 memorandum commented, Tuskegee is

⁴⁸ National Archives memorandum, May 30, 1991.

⁴⁹ Ramona Oliver, NARA FOIA Officer, Office of General Counsel to author, February 11, 2004.

a small area and it is easy to identify victims' families, wives and children. The statutory language of Exemption 6 does not specifically state who is being protected. To whom do the records specifically pertain to? It does not exclude third party interests. Invasion of personal privacy can include third parties. If a third party is considered, then including the names with the records would negatively impact the family. Sarah Rudgers commented that the sample did not reveal descriptive check-ups of the participants and was not descriptive in terms of a third party. As result, "Third party was a minimal issue."⁵⁰

In this particular case, NARA should have considered the family members personal privacy. Indirectly, they were mentioned in the medical records. But directly releasing the records with the participants' name hurts them as well. The personal privacy interest of the family members should have been factored directly into NARA's decision. In *NARA v. Favish*, the Supreme Court ruled that the Foster family needed to be shielded by Exemption 7(C) to "secure their own refuge from a sensation-seeking culture for their own peace of mind and tranquility, not for the sake of the deceased." It would seem that the two cases are similar. With *NARA v. Favish*, the requester wanted access to photographs. In this particular case, the researcher wanted access to medical records. But unlike the court case, NARA did determine that the medical records should be disclosed to the public. However, in an attempt to apply the balancing test under Exemption 6, NARA could have used this case and concluded that it was applicable to these records. If so, then the personal privacy interests that would have been considered directly are not those of the deceased individual but the living, i.e., the Tuskegee study participants' surviving family members. Then the final outcome could have been disclosure, but with redactions. A compromise could have been reached. The privacy interests of

⁵⁰ Sarah Rudgers interview by author, December 22, 2003.

the surviving family members could be protected and at the same time, the public would know the extent of the government's misconduct that happened during this medical study.

5.4 QUESTION THREE: DOES NARA'S ACCESS POLICY TOWARD RESTRICTED INFORMATION AND THE AGREEMENT WITH THE CENTERS FOR DISEASE CONTROL (CDC) UNDERMINE THE SPIRIT OF THE FREEDOM OF INFORMATION ACT WITH RESPECT TO THE TUSKEGEE SYPHILIS STUDY RECORDS? IF SO, WHAT ARE THE CONSEQUENCES IN THIS PARTICULAR CASE?

The written "agreement" or contract between NARA and CDC is inconsistent with the spirit of FOIA and the values that the statute espouses, such as promoting public discourse on matters of public interest. Federal agencies must follow the federal statutes passed by Congress. There has been conflict between federal statutes and agency regulations. As discussed herein, the contract between NARA and the CDC compromised the FOIA statute.

As FOIA is a disclosure statute, NARA must uphold this principle. Agencies can place their own restrictions on access, but they must comply with FOIA. If records have been accessioned by NARA, then NARA rather than the originating agency has the authority to decide what information is released to the public. Although OGC attorney, Sarah Rudgers, explained that NARA did not want to hinder the CDC's efforts in performing their work, she did point out that the agreement in question was merely a suggestion between the two agencies. Rudgers stated, "The Archivist can at his discretion impose specific restrictions on records. And we clearly state that if the Archivist of the United States and the head of the agency that is

transferring records agree on this approach, then that is what will happen.”⁵¹ However, she conceded, “I guess by the CDC and NARA signing the schedule with the attachment we in essence agreed.”⁵² The CDC placed unreasonable restrictions on access that were not in alignment with FOIA. As a result, over the years, the staff of the Southeast Regional Center’s response to the public for access was consistent with the “suggestive” agreement.

The researcher was confronted with this agreement when she requested to see the medical files. As stated earlier, the Director of Archival Operations stated that if he had read the agreement again, he would not have allowed access. However, Rudgers insisted that NARA archivists do have discretion in providing access to the medical records. But Oliver pointed out that NARA had been adhering to the agreement up until now. Thus, no one had gone back to review the agreement until there was a FOIA request. Rudgers and Oliver believed that the agreement was outdated. The response was that the agreement was signed. Rudgers commented that the agreement was just a suggestion. Oliver stated that the Director of Archival Operations contacted them because, “Charlie didn’t think that he was in empowered to do anything other than that without somebody at a higher level making a different decision for him.”⁵³

Since there had been requests over the years, no one at NARA reviewed or reassessed the agreement. Oliver stated that when the records were transferred in 1990, NARA had been thinking of ways to release these records if personal information could be redacted. She claimed it was not a new issue. However, since the records had been transferred, it was learned that no one has ever had access to the medical records until now. Oliver pointed out that “...perhaps the

⁵¹ Sarah Rudgers, interview by author, December 22, 2003.

⁵² Sarah Rudgers, interview by author, December 22, 2003.

⁵³ Ramona Oliver, interview by author, December 22, 2003.

way it was phrased or perhaps you [the researcher] asked the right series of questions that made Charlie want to take a second look at this [agreement].”⁵⁴

NARA’s letter stated that “upon a review of the files, NARA concluded that, other than names, there was no other mention, and certainly no intimate details about third parties.”⁵⁵ But earlier in the letter, it stated that these records were not released in order to protect both living participants and their family members “who might hold a privacy interest in the medical records.”⁵⁶ However, as discussed previously, NARA was able to protect third party interests while releasing pertinent information by redacting personal information from the medical files.

Although there was this agreement between the CDC and NARA, the 1990 memorandum clearly advises that NARA should not do anything until they received a FOIA request. And when that happened, then the personal information could be sanitized or redacted. Even though NARA has stated that it has been providing the public with redacted medical records, the interviews and agreement between the two agencies contradict this assertion. Requests by the Southeast Regional Center on how to handle requests for medical records, demonstrates that the 1990 memorandum has not been put into practice. The use of the agreement and Exemption 6 has curtailed the public from gaining access to the Tuskegee Syphilis Study medical records. The Exemption 6 balancing test was skipped. Among NARA officials there has been an inadvertent yet detrimental disconnect preventing the public from accessing the records over the years.

The NARA decision disclosing the medical records does not effectively deal with the agreement. It does not disavow the agreement, especially considering that NARA regulations state that records of a sensitive matter can be released if redacted. The agreement has far

⁵⁴ Ramona Oliver, interview by author, December 22, 2003.

⁵⁵ Ramona Oliver, letter to author, February 11, 2004.

⁵⁶ Ibid.

reaching ramifications. NARA's abuse of its discretion of FOIA is highlighted in this contract. In their investigation of my FOIA request, NARA simplified its entering into an improper agreement with the CDC. Because the Director of the Tuskegee Health Benefits Program hesitated to transfer the records to NARA, NARA abused its discretion of FOIA to acquire the records using Exemption 6 as a shield and closing them until 2030. Rudgers characterized the agreement as archaic. But the contract violated the spirit of FOIA. In its investigation, NARA found a memorandum that described how requests should be handled. However, the archivists deferred to the agreement denying full access to the medical records. In the final analysis, NARA's decision revealed that it was not being self-critical about how it managed the records.

Upon my FOIA request, NARA conducted a FOIA analysis of the medical records. Rudgers and Oliver requested 30% of the medical records to determine if the records should be released. Both found that the records, although descriptive, did not impact family members directly. "So keeping that in mind, we felt that third party privacy was a minimal issue."⁵⁷

Exemption 6 and NARA regulations issued under FOIA do not allow NARA to decide categorically to withhold medical records without weighing the public interests in disclosure against the personal privacy interests at stake. NARA FOIA regulations on restricting the use of records are contained in the 36 C.F.R. §1256.56 (2004). NARA interprets information that would invade the privacy of an individual as follows:

Records containing information about a living individual which reveal details of a highly personal nature that the individual could reasonably assert a claim to withhold from the public to avoid a clearly unwarranted invasion of privacy, including but not limited to information about the physical or mental health or the medical or psychiatric care or treatment of the individual, and that contain

⁵⁷ Ramona Oliver, interview by author, December 22, 2003.

personal information not known to have been previously made public, and relate to events less than 75 years old.⁵⁸

This particular regulation, on its face, deals with first party privacy interests rather than third party privacy interests. As mentioned earlier, the Tuskegee Syphilis Study records present third party privacy interests, which were apparently minimized by NARA in its decision letter determining to release the medical records in their entirety.

Furthermore, agencies place restrictions on their records when transferring them to NARA. In the case of the Tuskegee Syphilis Study medical records, NARA agreed to restrict access until 2030. This agreement, however, did not comply with the Freedom of Information Act.

5.5 QUESTION FOUR: WHAT DO THE RECORD KEEPING PRACTICES OF THE TUSKEGEE SYPHILIS STUDY RECORDS REVEAL ABOUT THE EFFECTIVENESS OF NARA'S ACCESS POLICY TO PROTECT THE PERSONAL PRIVACY WITH THOSE RECORDS.

NARA's handling of the Tuskegee Syphilis Study records may be characterized as bureaucratic ineptitude. On the other hand, the handling of these records may have been plagued by massive miscommunication. Decisions made by upper level management cannot be implemented if they are not communicated to operational staff within an organization. According to the FOIA, NARA may release records that contain personal information with redactions. NARA may take into consideration the recommendations of the respective agency that submitted their records.

⁵⁸ See National Archives and Records Administration' 36 CFR § 1256.56 (2004).

However, NARA's decision to release information from that agency's records should not be based solely on the agency's recommendation but in conjunction with an independent FOIA analysis of the records by NARA. With respect to the Tuskegee Syphilis Study records, NARA may have given too much deference to the CDC by entering into an agreement to withhold categorically the medical records, in complete violation of the spirit of FOIA.

Nondisclosure challenges NARA's policy of open access with regard to government records. The information and evidence provided in agency records holds the government accountable for its actions. Even more importantly, NARA needs to held accountable for its procedures for open access. Elena Danielson asserts, "Procedures can be designed that reconcile privacy rights and the right to information about one's life and one's national history."⁵⁹ Overall, the release of requested information serves a democratic purpose. The U.S. statutes and NARA's guidelines can "...build confidence in the democratic process."⁶⁰

NARA must provide citizens with access to evidence that sheds light on government activity, but it must do so without compromising personal privacy. Under Exemption 6, the agency bears the burden of justifying nondisclosure. In balancing personal privacy and public access, NARA must determine if disclosure of the information would constitute a clearly unwarranted invasion of personal privacy, thereby causing undue stress and embarrassment or whether the disclosure of the information would advance public knowledge of governmental activity. Exemption 6 pertains to records containing information on government personnel, medical files and similar files containing personal information.

⁵⁹ Elena Danielson, "Privacy Rights and the Rights of Political Victims: Implications of the German Experience," *American Archivist* 67 (Fall/Winter 2004): 193.

⁶⁰ *Ibid.*

The extenuating circumstances that would cause NARA to disclose these types of records if the information has been disclosed by the individual, if the person is deceased, or if the records refer to the employment status and duties of government employees. Ramona Oliver stated NARA released the Tuskegee Syphilis Study medical records because “The medical information was not extremely sensitive or descriptive. They were check-ups...They didn’t talk about anything graphic with regards to sores...any other thing that would be indicative of having STD.”⁶¹ Sarah Rudgers added that the participants’ names had been published and that the public knew who they were. In addition, there had been a public apology from President Clinton. Some of the men were at that ceremony. “We have to factor all of that into our decisions about what we are releasing.”⁶²

Rudgers describes how NARA decides if disclosure is necessary. Under Exemption 6, NARA can release all “reasonably segregable” nonexempt portions of requested records. However, redaction may not be possible if the request is limited to private information that could identify an individual. But what is significant about NARA’s decision-making process is that NARA is not bound by its decisions regarding disclosure or nondisclosure of records. Each request is different and NARA factors in all the information when deciding if information should be released.

NARA has released the Tuskegee Syphilis Study medical files in their entirety based on the investigation they conducted as a result of my FOIA request. However, in the near future they could reverse that decision based on new facts. This is true for all their records. This is always a judgment call for NARA. There is no hard and fast way of thinking about requests. The

⁶¹ Ramona Oliver, interview by author, December 22, 2003.

⁶² Sarah Rudgers, interview by author, December 22, 2003.

outcome may be different for each case; one fact can change the analysis of a request; death, time frame, public interests, etc. Why should Y records be bound by the decision made about X records? This is why the Tuskegee Syphilis Study records are not unique. However, in this particular situation, NARA made a disturbing call by not redacting the participants' names.

5.6 QUESTION FIVE: HOW HAVE THE RESTRICTIONS ON THE TUSKEGEE SYPHILIS STUDY RECORDS AFFECTED THE COLLECTIVE MEMORY OF THE STUDY?

For African Americans, the collective past is always present. More important, remembering historical events or experiences, tends to blur “the boundaries of the personal and the public, the individual and the collective.”⁶³ The boundaries tend to blur even more when memories recall acts of violence, brutality, and exploitation, such as lynching, race riots, and being used as guinea pigs. This ‘study’ integrates all such atrocities and permeates throughout the construction of social, historical, and cultural memory. Through images, narratives and records, the Tuskegee Syphilis Study has not gone quietly into the night, but become a “case of remembering to remember.”⁶⁴ Barbie Zelizer states that “...the authority of collective memories increases as time passes, taking on new complications, nuances, and interests. Collective memories allow for the fabrication, rearrangement, elaboration, and omission of details about the past, often pushing aside accuracy and authenticity so as to accommodate broader issues of identity formation,

⁶³ Roy Rosenzweig and David Thelen, *The Presence of the Past: Popular Uses of History in American Life* (New York: Columbia University Press, 1998), 149.

⁶⁴ Barbie Zelizer, *Remembering to Forget: Holocaust Memory through the Camera's Eye* (Chicago: The University of Chicago Press, 1998), 171.

power, authority, and political affiliation. Memories in this view become not only the simple act of recall but social, cultural, and political action at its broadest level...”⁶⁵

Limited access to records, particularly the medical records of the Tuskegee Syphilis Study, has continued to perpetuate misconceptions about the study, entangling fact with fiction. In addition, the public continues to distrust the government. The African American community has long been suspicious of the medical establishment.⁶⁶ As a result, it has been difficult to get blacks to participate in clinical trials of any kind. Over the years there has been the creation of myths about the study. In a positive sense, such myths have kept the Tuskegee Syphilis Study alive among the public. According to Colin Grant, “...the study of myth becomes even more significant when myth is understood in more positive terms.”⁶⁷ However, such inaccuracy can override the truth, particularly when recalling a shared experience through time and space. Although more records have been released by NARA, including the medical records, the remembrance of previous exploitation has convinced the public and the African American community that the PHS physicians infected the participants with syphilis. As James Jones points out:

...Tuskegee is the medical part of that story. It has become a metaphor for malpractice, neglect, for people being deceived, for people being injured by people who were supposed to help them. And when African Americans think today about Tuskegee they see

⁶⁵ Ibid, 3.

⁶⁶ In the antebellum South, African Americans were used as human guinea pigs for medical experimentation. In his 1968 article, J. T. Fisher stated that “an abundance of materials in the Southern Medical Journals reveals that slaves had a fairly significant role in medical education and in experimental and radical medical and surgical practice of the antebellum South.” See J.T. Fisher, “Physicians and Slavery in the Antebellum Southern Medical Journal,” *Journal of the History of Medicine and Allied Sciences* 23 (January 1968): 45. See also Todd L. Savitts “The Use of Blacks for Medical Experimentation and Demonstration in the Old South,” *The Journal of Southern History* 47 (August 1982): 331-348.

⁶⁷ Colin Grant, *Myths We Live By* (Ottawa: University of Ottawa Press, 1998), 1.

it not in isolation. They see it as part of a record, a few hundred years of contact and that...collective memory begins with capture, slavery...broken promises of reconstruction...Jim Crow and from Jim Crow it doesn't get better it gets worse. The segregated society. There are no lengths to the degradations and constantly defining of a lower position of society.⁶⁸

Although the records available at NARA say otherwise, the majority of the public insist that the government deliberately infected these men. David Thelen states that “from actors’ conflicts and negotiations over memory are born traditions, legends, myths, rituals, and more formalized cultural expressions of collective memory.”⁶⁹ The Tuskegee Syphilis Study has emerged as justification by the public to expect dishonesty and nondisclosure from investigators concerning research risks. “Even if you give them informed consent, like the Tuskegee thing—those men were told they would be treated but they weren’t.”⁷⁰ Thus, the well publicized existence of the Tuskegee Syphilis Study records is a double-edged sword for the government.

There have been a number of surveys conducted that have enlisted African Americans to discuss reasons for not participating in clinical trials. The Tuskegee Syphilis Study was one of the main reasons. Few could give accurate historical facts about the study. Those recruited believed that the participants in the study were injected with the disease. Even though there were 400 African-American men who had syphilis and 200 who were part of the control group, those recruited for the survey believed that approximately twenty to forty men were in the study. Furthermore, some thought that the government infected the entire Macon County area.

⁶⁸ James Jones, interview by author, December 13, 2003.

⁶⁹ Thelen, 1127.

⁷⁰ Giselle Corbie-Smith, Stephen B. Thomas, Mark V. Williams, and Sandra Moody Ayers, “Attitudes and Beliefs of African Americans Toward Participation in Medical Research” *Journal of General Internal Medicine* 14: 9(1999): 541.

However, when given the actual facts about the study, challenging their misinformation, the recruiters did not believe it. They insisted that the documentation could possibly be false.⁷¹ One recruiter stated, “I’m not saying you are lying or anything, but just like you are telling me one side, there could be a lot of different sides. You may have been misled as to the facts.”⁷²

Despite the fictitious information about the study, such misperceptions are what keep the memory alive today. Halbwachs defines collective memory as “... a current of continuous thought whose continuity is not all artificial, for it retains from the past only what still lives or is capable of living in the consciousness of the groups keeping the memory alive.”⁷³ The Tuskegee Syphilis Study continues to exist in the memory of those who had participated in the study, participant’s family members, the public at large, specifically in the African American community.

5.6.1 Memories of Tuskegee Syphilis Study Participants and Their Families

In *Bad Blood*, Jones states that “archival materials acquire a new meaning in the light of conversations with the participants in the study.”⁷⁴ On the value of oral history, Ronald J. Grele has pointed out that such sources “are but one form of documentation. In some cases they are not the best form; in others they are the only form. When used with care and modesty, they increase our understanding of our past and reveal hidden levels of discourse.”⁷⁵

⁷¹ Ibid.

⁷² Ibid.

⁷³ Maurice Halbwachs, 80.

⁷⁴ Jones, xiii.

⁷⁵ Ronald J. Grele, “On Using Oral History Collections: An Introduction,” *Journal of American History* 74 (September 1987): 577.

By discussing their experiences, the participants in their own way documented the Tuskegee Syphilis Study and broke the silence that had surrounded the participants and their families. When describing the spinal tap procedures done to him, Charles Pollard stated “they give me one of them back shots, and it put me down, put me down on the ground on my hands and knees for weeks. They stuck them needles in me for forty years so you couldn’t feel good. They never did tell me what was wrong with me.”⁷⁶

In Carol Kaesuk Yoon’s 1997 *New York Times* article “Families Emerge As Silent Victims of Tuskegee Syphilis Experiments,” Albert Julkes, Jr., the son of a participant, noted “You get treated like lepers. People think it’s the scourge of the earth to have it in your family.” Lillie Head, the daughter of a participant, lamented, “it was something to be ashamed of, so it wasn’t talked about.” Herman Shaw, a survivor of the study, offered one of the few memories of a wife’s reaction to learning the truth about the study. “She was somewhat shocked, may I say, because it was a disease. It wasn’t anything that we’d heard about and nobody seemed to know about.”⁷⁷

The lingering shame and distrust of the government for what they did to the participants and their family members and their community in the past is documented through the voices of the victims in the present. George Key, born in 1907 remembers the government officials using the term guinea pig. He recalls that “...some kind of funny name they called us...guinea pigs...That’s what they called us.”⁷⁸ After realizing what had happened to her father, Mrs. Rosetta Deborah Wilson daughter of Reverend Seagram Charles Chappell, was suspicious of

⁷⁶ Dan Hulbert, “Tuskegee Horror Remains Real,” *Atlantic Constitution*, January 14, 1990, M1.

⁷⁷ Ibid.

⁷⁸ “Voices of the Tuskegee Syphilis Study,” Centers for Disease Control and Prevention (CDC) and Tuskegee Human and Civil Rights Multi-Cultural Center (THRMC), December 2000-February 2001.

tests, especially if it involved her family. She did not even want her children to be any part of any testing. She commented:

I told my children when I found out what was happening about them going to get the blood tests and all that...Don't get a blood test unless you're sure getting one from the doctor. And don't let anyone tell you to come and get tested and get paid for your blood...which someone told my twins in high school and I told them not to participate in it. I don't know what was going to happen, but I was afraid the same thing was going to happen to my daughters that happened to my father. So I told them not to participate in it.⁷⁹

Publicly retelling these experiences has placed the Tuskegee Syphilis Study experiment upon the public stage. More important, memorializing the participants of the clinical tragedy cemented their experience within public memory.

In 1998, a museum in Tuskegee, Alabama was established to memorialize the participants of the Tuskegee Syphilis Study. The Tuskegee Human and Civil Rights Center's objective is to draw public attention and pay tribute to the participants of the study. Attorney Fred Gray commented that what these men wanted "was a permanent memorial in Tuskegee that would not only acknowledge their contribution but the contribution that others had made in the field of Civil and Human Rights."⁸⁰ Mrs. Rosetta Deborah Wilson praised the center "...because there's a lot I don't know and I need to know."⁸¹ Albert Julkes envisions the center "...blossoming in years to come because there's so much involved...Everyone should come to

⁷⁹ Ibid.

⁸⁰ Fred Gray, interview by author, June 16, 2003.

⁸¹ Voices of the Tuskegee Syphilis Study.

that center and see exhibits not only that exist right now but those that will become a part of that Multicultural Center.”⁸²

African American museums have held a dual responsibility to convey the African American story, while at the same time telling a broader American story. In addition, the African American museum has become a public forum for addressing something that is uncomfortable about our collective past. The Tuskegee Syphilis Study constitutes one of many examples of horrible treatment in African American history. The institution of slavery and the Civil Rights Movement, though a shared heritage, were not experienced in the same way by whites as by African Americans. In a broader sense African Americans who heard about the study felt a connection based on past experiences. For them, the memory of the Tuskegee Syphilis Study blurred the “I and... we.”⁸³ Yet these subjects allow us to stimulate reconciliation and healing as well as self-knowledge for African Americans and others who are moved by the common experience.

Currently in the museum are taped interviews with subjects remembering their experiences and photographs. When commenting on how significant photographs are in documenting historical events, James O’Toole states that:

A written record describing an event might be valuable enough, but how more informative was a photograph that showed what the participants themselves actually did and saw. If writing could freeze time by describing what had happened, a photograph could freeze time even better by showing what recognizable individuals looked like and how they behaved”⁸⁴

⁸² Ibid.

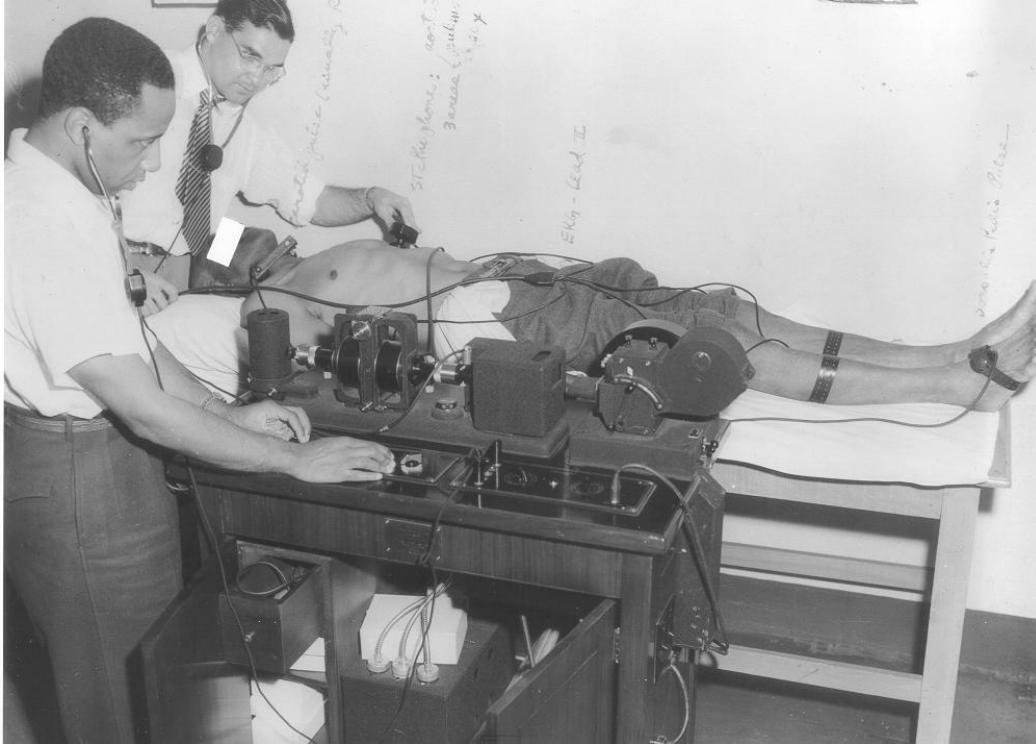
⁸³ Roy Rosenzweig and David Thelen, 150.

⁸⁴ James M. O’Toole, *Understanding Archives and Manuscripts* (Chicago: Society of American Archivists, 1990), 18.

The photographs gave faces to the physicians involved, disturbing examinations of the participants and their interaction with them. These pictures underscore how these doctors portrayed themselves as assisting these men while using them as ‘guinea pigs.’ Thus, photographic records, narratives and written documentation together breathe new life into the memory of this study. (See the following pages).



Left: Dr. David Albritton, Nurse Eunice Rivers and Dr. Walter Edmondson (National Archives, Atlanta, Ga)



Left: William Bouie, unidentified subject, and Dr. David Albritton (National Archives, Atlanta, Ga)



Unidentified subject, onlookers and Dr. Walter Edmondson taking a blood test (NARA, Atlanta, Ga.)



Blood test and unidentified subject (National Archives, Atlanta, Ga)



Left: unidentified subject, Dr. David Albritton, and Dr. Edmondson (NARA, Atlanta,GA)



Left: unidentified subjects, Nurse Rivers, Dr. David Albritton, Dr. Walter Edmondson (National Archives, Atlanta, Ga)

The Tuskegee Syphilis Study has come to symbolize the medical misconduct and blatant disregard for human rights that took place in the name of science. The participants in the study underscore the point that the burden of medical experimentation has historically been conducted on those unable to protect themselves. By failing to obtain informed consent and offering incentives for participation, the Public Health Service doctors were performing unethical experiments on human subjects. The Tuskegee Syphilis Study was an immoral experiment from the outset. Moreover, similar comparisons can be made with inhumane medical experiments on humans living under the Nazi Regime during World War II as well as to other U.S. government experiments that tested drugs and chemical and biological weapons on unwitting U.S. citizens. Arthur Caplan, director of the medical ethics program at the University of Pennsylvania in Philadelphia, described the Tuskegee Syphilis Study as “America’s Nuremberg.” Caplan, author of *When Medicine Went Bad: Bioethics and the Holocaust*, commented that, “Tuskegee was really the experiment that set American medicine on its ear. I think Americans had this belief that they couldn’t or wouldn’t do the kind of evil things that the Germans did. Tuskegee was a gigantic wake-up call.”⁸⁵ The outcry over the Tuskegee Syphilis Study led to experimental reforms, including the requirement of informed consent, the creation of institutional review boards, data and safety monitoring boards, and continuing ethics education for researchers.

On May 16, 1997, President Bill Clinton did what the PHS officials refused to do twenty-five years earlier when the experiments came to light. He offered a formal White House apology to the participants and the survivors. Even though there was an official apology and measures were put into place to prevent people from being treated again like laboratory rats, the underlying

⁸⁵ Howard Wolinsky, “Steps Still Being Taken to Undo Damage of ‘America’s Nuremberg,’” *Annals of Internal Medicine* (August 15, 1997): 18. February 25, 2004. <org/journal/annals/15aug97/currnazi.htm>.

fact is that the Tuskegee Syphilis Study was not an isolated incident. Rather, it was apart of a larger disturbing trend of unethical secret experimentation on humans throughout the twentieth century. Americans have not only been left to suffer silently from syphilis, but have also been injected with Plutonium 239, blistered with mustard gas, and sprayed with bacteria. Like the Tuskegee Syphilis Study, the victims of these experiments were usually the most vulnerable members of society: poor African Americans, hospital patients, and children.⁸⁶ Striking a balance between protecting vulnerable classes of subjects and seeing that minorities are adequately represented in and reap the benefits of clinical trials has become a challenge for medical investigators. The exposure of the Tuskegee Syphilis Study prompted the National Research Act of 1974 which mandated that institutional review boards approve federally funded proposed research involving human subjects. As a result, the Tuskegee Syphilis Study records are relevant to the notion of accountability, ensuring that the contemporary biomedical community justifies its experiments through formal protocol process as well as a formal human subject review process.

The Tuskegee Syphilis Study did not just happen to the 625 men and their families living in Macon County, Georgia. The African American community connected with the experience because of the racial identity of the victims. Their community's sense of a collective past is used as a means to force the U.S. government to be accountable for its actions. Through the vehicles of interviews, a commemorative museum, and public policies, the African American community is able to remember the participants of the study, their ordeal, and the government's role. Paul

⁸⁶ In March 1997, the Department of Energy paid \$6.5 million to the families of seventeen individuals who were injected with plutonium and uranium in secret government Cold War era experiments. In November 1996, Energy Secretary Hazel O'Leary paid \$4.8 million to the families of another twelve victims of government radioactivity experiments. For a historical overview of children and research see Leonard H. Glantz's article "Research with Children," *American Journal of Law and Medicine* 24, 2-3 (1998): 213-244.

Antze and Michael Lambek contend that “memories are never simply records of the past, but are interpretive reconstructions that bear the imprint of local narrative conventions, cultural assumptions, discursive formations and practices, and social contexts of recall and commemoration.”⁸⁷ The remembrance of the Tuskegee Syphilis Study is a prime example of an American tragedy that continues to be an issue in both private and public memories.

Since the administrative records were open to the public, I wanted to see what type of information the public requested from the CDC and NARA. I requested redacted letters written to the CDC and NARA after 1990.⁸⁸ I chose 1990 because I wanted to know if requesters realized that the records had been transferred. NARA informed me in writing that such letters had been destroyed. The CDC, however, sent letters.

A requester wanted “any or all materials relevant to the infamous Tuskegee Syphilis Experiment.” The FOI Officer of the CDC usually responded:

We are providing a copy of the final report which may be helpful to you. Also, there are numerous reports in the medical literature, available in most libraries, which were produced during and after the Tuskegee Study.⁸⁹

There was one letter that struck me. In March 1997, this individual submitted a hand written FOIA request to the CDC. She wanted information on her husband who she believed was part of the study. She needed to know for sure in order to produce evidence to prove she was a relative. Fred Gray had mentioned that over 10,000 people have received funds from the lawsuit.


⁸⁷ Paul Antze and Michael Lambek, eds., *Tense Past: Cultural Essays in Trauma and Memory* (New York: Routledge, 1996), vii.

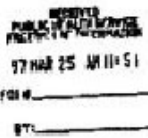
⁸⁸ Even though citizens who file FOIA requests have limited privacy (i.e. names are not redacted), I chose to request redacted letters. I felt the names were not significant for this study only the specific information requested by the requester.

⁸⁹ Thomas Mathews, CDC FOI Officer to author, September 12, 2004.

There have been many FOIA requests to the CDC and NARA for this reason. If she did not receive such information "I wood go to Jail" (see below). The requester did receive a response to her inquiry from the CDC (see the following page).

CDC
97-335
9/25/44
02





Dear Sir

I am requesting copy of your record from 1932 to 1974 when Black was not treated for syphilis. My husband was among them, he was drafted in service. Please can I get copy of these records they will prove I was not wrong. I was told if I ask for the records or go back to I wood go to jail please will you help me.

Freedom of Information Act Request. Please can you waive the fee.



97-334

DEPARTMENT OF HEALTH & HUMAN SERVICES

Public Health Service

Centers for Disease Control
and Prevention (CDC)
Atlanta GA 30333
April 16, 1997

Dear

This letter is in response to your Freedom of Information Act (FOIA) request, which my office received on March 28.

Enclosed is a report that may be of interest to you.

Our records on the Tuskegee Study consist of medical records of living study participants; files on all Tuskegee Health Benefits Program (THBP) beneficiaries; copies of paid THBP medical bills processed for payment; and information on individuals interviewed and processed for eligibility for medical benefits. A search of these records failed to reveal any documents pertaining to

While we believe that an adequate search of appropriate files was conducted for the records you requested, you have the right to appeal this determination that no records exist which would be responsive to your request. Should you wish to do so, you must send your appeal within 30 days of the date of this letter to the Assistant Secretary for Public Affairs, Department of Health and Human Services, Room 13C-24, 5600 Fishers Lane, Rockville, Maryland 20857. Please mark both the letter and envelope "FOIA Appeal."

The National Archives also has CDC-generated records on the Tuskegee Study. You may wish to contact that agency at the following address: National Archives, Southeast Region, 1557 St. Joseph Avenue, East Point, Georgia 30344. The phone number is 404-763-7477.

Since our agency located no records responsive to your request, we did not have to ask you for proof of death for or for a notarized statement regarding your status as a relative of but the National Archives may request such documentation.

The Tuskegee Syphilis Study is a prime example of the complex interaction between history and collective memory. Memories of the Tuskegee Syphilis Study have survived since its exposure in the early 1970s. There have been plays, movies, documentaries and a number of articles written about the study. But how do memory and history coexist? Memories do serve a purpose in keeping the most horrible acts alive in one's mind. However, such memories can only take us so far. Documents play a significant role in cementing those memories, even correcting them. Catherine Clinton believes "the power of memory must draw us out of the novel and into the archives."⁹⁰ If this is done, then the story of the Tuskegee Syphilis Study will survive.

⁹⁰ Catherine Clinton, "With a Whip in His Hand: Rape, Memory and African-American Women," in Genevieve Fabre and Robert O'Meally, eds. *History and Memory in African-American Culture* (New York: Oxford University Press, 1994), 215.

6.0 CONCLUSIONS AND RESEARCH IMPLICATIONS

6.1 CONCLUSIONS

This study began with an examination and analysis of the National Archives and Records Administration's official policy on access to controversial records, including those of the Tuskegee Syphilis Study records as the case study. As the study progressed, however, the examination shifted to NARA's access policy regarding the Tuskegee Syphilis Study records in particular. This dissertation argued that even though NARA reviews its access policy on a case by case situation, its management of the Tuskegee Syphilis Study records was inconsistent with providing access to restricted information (i.e., medical records). During this study, NARA was prompted by a FOIA request from the researcher to examine its agreement with the Centers for Disease Control and Prevention on restricting access to the medical records of the Tuskegee Syphilis Study. NARA examined this agreement using the balancing test to determine if the personal privacy of the participants and their families outweighed the public's right to further information about the Tuskegee Syphilis Study. NARA decided to release the medical records in 2004 instead of 2030 because the public's right to know outweighed the personal privacy of the participants and their families. The release of the medical records altered this dissertation argument. However, NARA's decision highlighted the process by which NARA used the balancing test to determine if disclosing the medical records shed more light on the government's involvement during this study.

NARA's access policy toward the Tuskegee Syphilis Study records was inconsistent with NARA's regulations and federal statutes (i.e., Freedom of Information Act). NARA has discretion in deciding whether information from sensitive records should be disclosed, and if so, whether that information should be released in part or in its entirety. Such discretion is based on nine Exemptions of FOIA. In 1990, when the Tuskegee Syphilis Study records were transferred, NARA applied Exemption 6 of FOIA to restrict the medical records in full until 2030 in order to receive the records from the CDC. As a result, the agreement between the CDC and NARA was in violation of the spirit of FOIA.

Upon investigating my FOIA request, NARA discovered a 1990 memorandum that stipulated how to handle the records. The memorandum stated that upon a request for access to the Tuskegee Syphilis Study records, personal identifiers would be redacted so that the information could be released. My interviews with NARA staff revealed that they did not know that the memorandum existed. It is important to note that the memorandum remained within the NARA office in Washington, D.C. NARA insists that access to the medical records was granted to researchers requesting them. It asserted that the agreement between it and CDC categorically denying access was archaic and needed to be reevaluated. NARA released the records because it found that enough time had passed since the study, that at the time of its review of my FOIA request all but two of the 625 men were deceased, that the records contained limited information about third parties (i.e., family members), and that many participants had discussed their experiences in public forums. NARA released the records in their entirety, including the names of the participants.

It is important to consider NARA's decision to provide the names along with the medical records. In providing the names along with the medical files, NARA failed to give adequate

consideration to the privacy rights of individuals, specifically third parties with privacy interests in the records. Privacy entails the ability to control information. This concept of privacy is linked to protecting the individual which would include third party interests. The public has the right to have access to the medical records; however, the names of the participants do not advance any knowledge about the study. The public may know that a participant had syphilis. However, if the name is included with the medical file, the public also learns information that does not shed light on government activity. Thus, the personal privacy of the participants and their families is affected, causing undue stress, especially for the families. So the medical records are now open, but at what cost?

In addition, the study revealed that NARA deflected the criticism from itself in how it provided access to the Tuskegee Syphilis Study records. Its assertion that the public had access to the medical records runs counter to the interviews conducted for this study. NARA staff at the Southeast Regional Center stated that they were unaware of the memorandum and were in constant contact with the Office of General Counsel upon requests for access to the medical records. Thus, it can be inferred that prior to my FOIA request, NARA categorically denied access to the Tuskegee Syphilis Study records.

Nondisclosure of restricted records that contain sensitive information, specifically the medical records, has affected the collective memory of the Tuskegee Syphilis Study. The restrictions have perpetuated myths and misinformation about the study. Some of the misinformation in the public sphere is as follows:

1. The participants were deliberately infected with syphilis by the United States Public Health Service physicians.
2. The entire Tuskegee community was infected.

3. The Tuskegee Airmen were infected.
4. Less than 600 men participated in the study.
5. No participants were ever treated for syphilis.

Even though the administrative records and the medical records counter these myths and misinformation, the public continues to believe otherwise, especially within the African American community.

6.1.1 The Importance of This Case Study

This case study demonstrates that there is a need for more studies that include government archivists and the challenges they face when confronting the issue of protecting personal privacy while providing access to the public, because most of the literature on privacy focuses on manuscript collections. The literature includes the issue of third parties, but again from the perspective of manuscript collections. The combination of privacy, access, and collective memory provides a unique way of including government archivists in this emerging discussion. Examining governmental procedures for providing specific information about governmental activity or personal information affects all three. How does the government reconcile the people's right to know and personal privacy? How does the government define the personal privacy of individuals and third parties? There is a need for this discussion because answers to such questions affect how government archivists define access, personal privacy, and historical "truths."

6.2 RESEARCH IMPLICATIONS

There are other areas related to privacy needing further study. NARA's overall official policy towards providing access to controversial records in general remains a topic for future research. This dissertation briefly discussed the policy. Such a case study would include understanding how well informed NARA staff are about regulations and federal statutes. More importantly, it is essential to examine how NARA conducts FOIA analysis when records are transferred to NARA. Does NARA defer to federal agencies' restrictions on their records or investigate whether or not those restrictions are appropriate?

In a much larger framework, this study has broader, social implications. The Tuskegee Syphilis Study records underscore the relationships among privacy, collective memory and access. [Figure 6.1](#) suggests a model of these relationships, using the records of the Tuskegee Syphilis Study as an example:

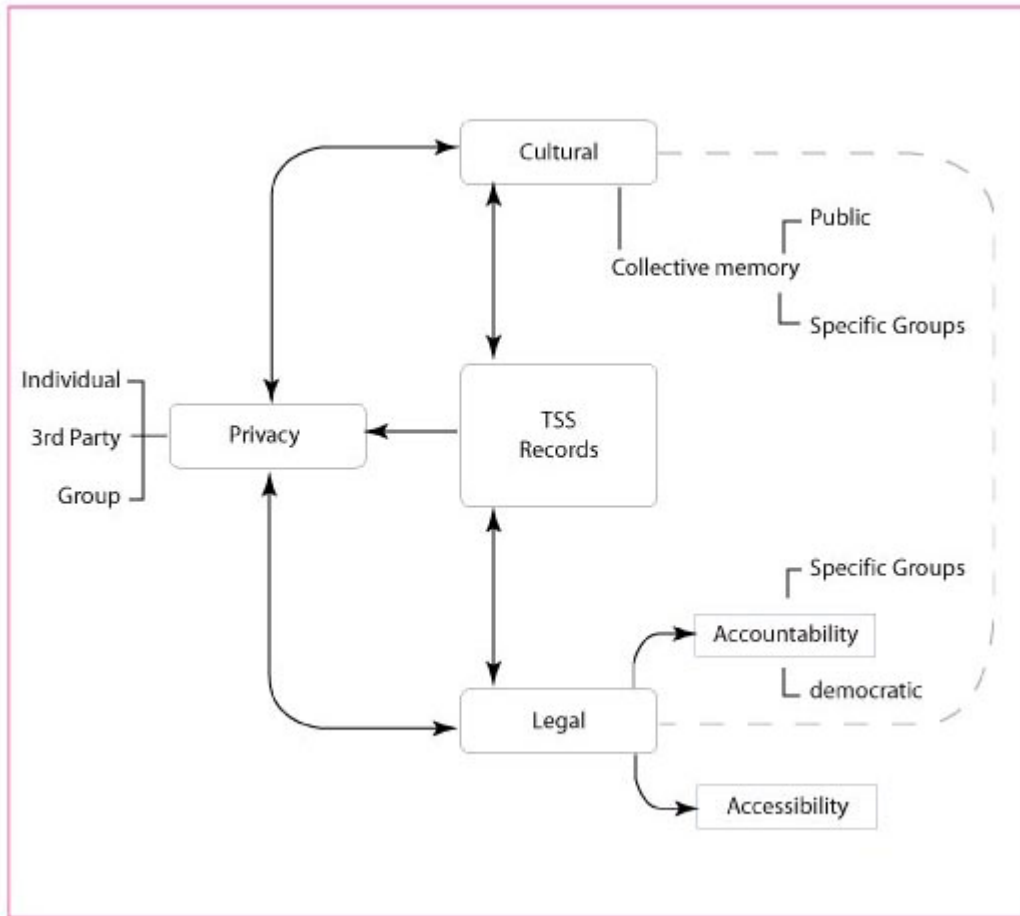


Figure 6-1: These overlapping relationships underscore how records can be interpreted

As [Figure 6.1](#) demonstrates, personal privacy has many layers involving individuals, third parties, and the general public. In providing access to public records, government archivists strive to balance the privacy rights protected by freedom of information and privacy legislation against the public's right to monitor the government's conduct documented in the records, which relies on open access. In reality, archivists can find it difficult to ensure a proper balance. But when attempting to balance personal privacy and the public's right to know, providing access to

records that contain sensitive information can be achieved by redacting such information. NARA's 2004 decision to provide access to the medical records of the Tuskegee Syphilis Study in their entirety sacrifices personal privacy to uphold government accountability.

As long as the public had access to only the administrative records of the Tuskegee Syphilis Study, the public perceived that it was not able to hold the government accountable for its actions in this shameful episode in United States history. As a result, the collective memory of the Tuskegee Syphilis Study reflects the public's efforts to provide for itself plausible rationales and interpretations of what happened during the study, especially in the African American community. This has perpetuated myths and misconceptions surrounding the study. The documentary truth of the event as embodied in the administrative as well as the medical records counters this myth-making.

Also, there is a need for a comparative study of the access policies of national archives. Such a study might focus on national archival institutions in Canada, the United Kingdom, Australia, and the United States. I have chosen these national archives because historically they have had the greatest impact on access to public records. This research would examine internal decision-making at the four governmental archives with respect to their administration of access to records. This would include investigating records in the custody of these institutions that had posed an access challenge to the archives. The myriad of access challenges would include considering the personal privacy of individuals and third parties, confidentiality, and the public's right to know. There are a number of topics that could be explored:

1. How knowledgeable are governmental archivists about regulations, laws, and procedures governing access to records and about the contents of their holdings?

2. How much discretion do national archives have in disclosure or nondisclosure of restricted records?
3. How does each balance the right to privacy and the public's right to know?
4. What is the access policy toward administering access to records that contain sensitive information?

Such a comparative study will allow national archives too learn from one another by highlighting similarities and differences in policies for administering access to records with sensitive information. In addition, this type of would enable historians, researchers, and the public at large to become more knowledgeable about requesting records that contain sensitive information. These kinds of dialog could lead to more government records being opened to the public sooner rather than later.

APPENDIX A

LISTING OF STUDY PARTICIPANTS, 1932-1972

Adair, Green ¹	Austin, George	Black, Ishman
Adams, Courtney	Austin, Hyth	Black, Jim
Adams, James	Austin, Nelson	Black, Tommie Lee
Adams, Louis	Austin, Wiley	Black, Wiley
Albert, Prince	Baker, George	Blackburn, Will
Alexander, Ben	Banks, Early	Blackman, Prismus
Alexander, Joe	Banks, Jack	Bledsoe, Pustell
Alexander, Marion	Barrow, David	Borum, Muncie
Allen, Jefferson	Barrow, Seth	Boyd, Grant
Allen, Sam	Battle, Enoch	Boyd, Jimmie
Allen, Selden	Battle, Lee	Boyd, Richard
Anderson, George T.	Beasley, Nathaniel	Boyd, Tobe
Anderson, George	Beasley, Robert	Brooks, Ealy (Eli)
Anthony, Will	Berry, John	Brown, Bailey, Jr.
Askew, Sebon	Berry, Leornie	Brown, Doll
Austin, Alfred	Bessick, Edward	Brown, John C.
Austin, Dean	Bessick, Ernest	Brown, Logan

¹ Names of Participants are found in Fred D. Gray's *The Tuskegee Syphilis Study: An Insider's Account of the Shocking Medical Experiment Conducted by Government Doctors Against African American Men*. Montgomery, Alabama: Black Belt Press, 1998.

Brown, K. L.	Carmichael, Gus	Collins, Willie
Brown, Riley	Carr, Jim	Collis, Dan
Brown, Vance	Caston, Eugene	Collis, Sylvester
Bryant, J. R.	Caupbell, Charlie	Comer, Ben
Bryant, Willie	Chambless, William	Cooper, Amos
Bryant, Winfield	Chambliss, Henry	Cooper, Frank
Buchanan, Ben	Chambliss, Jerry	Cooper, Gentry
Buchanan, Charlie	Chambliss, Pollard	Cox, Fletcher
Buchanan, Columbus	Chappel, Seaborn	Cox, Jeff
Buchanan, Gene	Chappel, Hilliard	Cox, Redonia
Buchanan, John	Charleston, Rufus	Cox, Tom
Buchanan, Sol	Chatman, Georgie	Crawford, George
Buchanan, Wash	Cheeks, John	Crawford, Jimmie Lee
Buford, James (Clemmie)	Chisholm, Ben	Crawford, John
Burton, William	Chisholm, Ed	Crawford, Wash
Buscom (Bascomb), Bishop	Clabon, James	Crawley, James
Butler, Eli	Clark, Joshua	Crayton, Ernest
Byrd, Sam	Clark, Moses	Crayton, Lonzo
Caldwell, William	Clements, Ludie	Daniel, Albert
Calhoun, Forney	Cole, Allen	Daniel, Clark
Campbell, Alfred	Coleman, Samuel	Daniel, John Wesley
Campbell, Charlie	Collier, Isaac	Daniel, Mac
Campbell, Ishmael	Collins, Algie	Darkey, Floyd
Campbell, Jack	Collins, Jim	Davis, Anthony
Campbell, Judge	Collins, John	Davis, Bonnie
Campbell, Will	Collins, Julius	Davis, Elbert
Carlisle, Robert	Collins, Relice	Davis, Henry

Davis, Martin	Evans, Lemuel	Gamble, Elijah
Davis, Meriman	Felton, Cleve	Garner, Alfred
Day, Frank	Felton, Tom	Gaston, Will
Demps, Benjamin	Fitzpatrick, Green	Gauchett, Nick
Dennis, Nat	Fitzpatrick, Ned	Germany, Albert
Dixon, Frank	Fitzpatrick, Tom	Germany, Fred
Doggett, Zettie	Fitzpatrick, Willie	Gholston, Ben
Donar, Kelley	Foote, Bill	Giles, Fred
Donar, Mose	Foote, Joe	Gilmer, Quince
Donar, Sam	Ford, Abbie	Gilmer, Doc
Doner, Wilbert	Ford, Arthur	Glenn, Sam
Doner, Wiley	Ford, Percy	Goode, John
Dorsey, Aleck	Fort, Calvin	Goodson, G. C.
Dorsey, Jim	Fort, E. Gary	Gordon, Virgil
Dorsey, Will	Fort, Jasper	Gray, Desibe
Dowdell, Crawford	Fort, Sandy	Greathouse, Clabon
Downer, Willie	Fort, Nathan	Greathouse, Clifton
Dozier, Bill	Foster, Archie	Greathouse, John E.
Driscoll, Harvey	Foster, Ben Eddie	Green, Mose
Dubose, N. D.	Foster, Bonnie	Green, Walter
Echols, D. C.	Foster, David	Green, Will
Echols, John	Foster, Lee	Greer, George
Echols, Presley	Foster, Reuben	Griffin, Colonel
Echols, Wade	Foster, William	Griffin, Dave
Echols, Wiley	Foster, Pomp	Griffin, Samuel
Echols, Willie	Foy, Jim	Griggs, Charlie
Ellington, John A.	Foy, Louis	Grimes, Emmett
Ellington, Samuel	Franklin, Ulysses	Grimes, James
Epps, Henry	Gaines, Percy	Grove, Frank
Evans, Ben	Galgher, Ben	Hagins, G. B.
Evans, Henry Mark	Gamble, Bob	Hall, Cary

Hagood, Andrew	Henderson, Hilliard	Jackson, Tommy J
Hamilton, Columbus	Henderson, James	James, Clifton
Haney, Sherman	Henderson, Wilbur (Dick)	James, George
Hann, Freeman	Hendon, Ernest	James, Jessie
Hardy, Albert	Hendon, Louie	James, John C.
Harper, Clifton	Henry, Johnnie	James, Wilbert
Harris, Adolphus	Hicks, Phil	Jenkins, Howard
Harris, Alonzo	Hicks, William	Jenkins, West
Harper, Robert	Hill, Phillip	Jenkins, William, Jr.
Harris, Elisha	Hoffman, Clayborn	Jenkins, Willie
Harris, George	Holliday, Joseph	Jernigen, Will
Harris, Jak	Holmes, Zan	Johnson, Charles
Harris, Jake	Howard, Carter	Johnson, Faegin
Harris, James	Howard, Tony	Johnson, G. C.
Harris, Louis	Hudson, John	Johnson, Jimmie
Harris, Theodore	Huffman, Benny Lee	Johnson, Johnnie J.
Harris, Will	Huffman, Marcus	Johnson, Price
Harris, Will	Hughly, Arthur	Johnson, Simon
Harris, William	Hurt, Will	Johnson, Spencer
Harrison, Edward	Hutchinson, Zack	Johnson, Sylvester
Harrison, Willie, Sr.	Iszell, Minor	Johnson, Thomas
Hart, Frank	Jackson, David	Johnson, Thomas J. C.
Hart, John	Jackson, Fleming	Jonakings (Jernigan), Jim
Hart, L. Z.	Jackson, Isiah	Jones, Chancy
Harvey, Charlie	Jackson, James	Jones, Clifford
Harvey, Walter	Jackson, Jim	Jones, Dan Jeff
Hatten, Ludie	Jackson, Martin	Jones, Hayes
Hatten, Sandy	Jackson, Randall	Jones, Henry
Hatton, Square	Jackson, Roosevelt	Jones, Major
Hawkins, Henry	Jackson, Stephanie	Jones, Roosevelt
Henderson, Absolomi	Jackson, Tom	Jones, Shepherd L.

Jones, Willie	Long, Will	Moore, Felix
Jones, Willie Moffett	Love, Milton	Moore, Marshall
Jorden, James	Loveless, Ed	Morgan, Lenza
Julkes, Albert	Loyd, Ernest	Morris, Hobbie
Julkes, Ephrom	Macon, V. M.	Moore, Willie Bill
Julkes, Warren	Maddox, Jesse	Moss, Frank
Kelly, Ad Kelly	Mahone, Dave L.	Moss, Frederick
Kelly, John K.	Mahone, Fonzie	Moss, Grant
Kelly, Mitchell	Manley, Charlie Y.	Moss, John J.
Kennebrew, Usher	Martin, Governor	Moss, Otis
Key, Charlie B.	Martin, Lewis	Motley, Peter
Key, George	Martin, Roosevelt	Mott, Julius
Key, Henry	Martin, Wesley	Murphy, Dock
Key, Jesse	Mason, Frazier	Murray, Albert
Key, Ned	Mays, Clabon	Mutry, Jim
Key, Nathan	McGrady, Thomas	Myrick, I. S.
Kindell, R. T.	McKee, Essex	Neal, Rubin
Kitt, Edmond	McMullen, Wash	Neal, Rufus
Laine, Nathaniel	McNeill, Willie	Norwood, Ed
Lane, John Edward	Menefee, Joe	Nunley, Willie
Lane, Johnnie W.	Menefee, John	O'Neal, Thaddaus
Lane, Wylie	Miles, William	Ogletree, York
Laster, James	Mims, Richard	Pace, Eddie
Laury, Andrew	Mindingall, Samuel	Pace, Elmore
Levett, William	Mitchell, Gary	Pace, Evans
Lewis, Peter M.	Moore, Frank	Pace, George
Lewis, Sherman	Mitchell, John	Pace, Henry
Ligon, Riley	Moore, Aaron	Pace, Lonzie
Lockett, George	Moore, Abner	Pace, Nelse
Lockwood, W. P.	Moore, Alonzo	Pace, Otis
Long, Sim	Moore, Ezekial	Pace, Steve

Padgett, Whitelaw	Pugh, Arthur	Samuel, George
Parker, Eli	Randolph, Joe	Samuel, Odell
Patrick, Will	Randolph, Johnnie	Samuel, Tom George
Patterson, Cleveland	Randolph, Major	Sanford, E.
Paulk, Frank	Randolph, Robert	Sanford, Fletcher
Payne, Ludie	Ray, George	Scott, Lester
Pearsall, Pender	Ray, William	Scott, O. T.
Pearson, Ed	Reed, Andrew	Scott, William
Pendleton, John	Reed, Douglas	Seatts, John
Philips, Tom	Reed, Fletcher	Shaw, Charlie
Phillips, Charlie	Reynolds, Charles	Shaw, Herman
Phillips, Ed	Reynolds, Gus	Shelton, John
Phillips, John W.	Rhone, C. H.	Shelton, Purvis
Phillips, Ned	Ries, Clinton	Shumpert, Paul
Phillips, Prince	Roberson, Lige	Simmons, Fred
Philpot, Roland	Robbins, Tom	Simmons, John
Pinkard, Charles Lee	Robert, Bob Lee	Simpson, Bennie
Pinkard, Charlie	Robinson, Albert	Simpson, Jimmie
Plezes, Walter	Robinson, Butler	Sinclair, Anderson, Jr.
Polk, Albert	Rockamore, Ben	Sinclair, Oscar
Pollard, Charlie	Rogers, Henry	Sistrunk, Henry
Pollard, Elbert	Rowell, Charlie	Slaughter, John
Pollard, Lucius	Rowell, Edmond	Smith, Cain
Pollard, Osburn	Rowell, Theodore	Smith, Dudley
Pollard, Vertis	Ruff, R. L.	Smith, Eugene
Pollard, Will	Rush, Lieutenant	Smith, Hilliard
Pollard, Woody	Rush, Wash	Smith, Jimmie
Porch, Bertha	Russell, Clarence	Smith, Joe
Potts, Jethro	Russell, Jeff	Smith, John Wesley
Pruitt, Taylor	Russell, Willie McK.	Smith, Lieutenant
Pugh, Armistead	Samuel, Bill	Smith, Low

Smith, Richard	Thomas, Oran	Watson, John L.
Smith, Robert Harvey	Thomas, Pat	Watt, Willie
Smith, Thomas K.	Thompson, Pete	Weathers, Alonza
Sparks, Ed	Thompson, Willie	Weatherspoon, Sam
Speed, Olin	Tinsley, Edison	Webb, William
Spivey, Jim	Todd, Walter	Welch, Dan
Stewart, Mack	Tolbert, George Washington	West, Anthony
Story, Millard	Tolbert, Jim	Wheat, Tobe
Swanson, Mark	Tolbert, Ocie	Wheeler, Jake
Swanson, Please	Tramble, Willie	White, Archie
Swanson, Tom	Trammell, Percy	White, Leonard
Swanson, Tump	Tredwell, Alf	White, Sonny
Swanson, Will B.	Turk, Will	Whitlow, Ed
Swanson, Willie	Turner, Joe	Whitlow, Motelle
Swift, Lawrence	Turner, West	Williams, Albert
Swift, Son	Turpin, Jim	Williams, Andrew
Talbert, Oscar	Tyner, Stephen	Williams, Bill
Swint, Andrew	Tyson, Freddie, Sr.	Williams, Bill Henry
Talley, Louis	Upshaw, Milton	Williams, Bill Jesse
Tarver, Eugene	Veal, Coleman	Williams, Coleman
Tarver, Oscar	Veal, Jim	Williams, Eugene
Tate, Edward	Wade, Mitchell	Williams, George
Tate, Robert Lee	Waggoner, John	Williams, Henry
Tatum, Mayso	Walker, Andrew	Williams, James
Tatum, Sylvester	Walker, Johnnie W.	Williams, Lewis
Taylor, Richard	Walls, Joe Nathan	Williams, Mathew
Taylor, Van	Ware, Alex	Williams, Meshack
Taylor, Warren	Warren, Atlee	Williams, Morris
Temple, George	Warren, Ed	Williams, Reuben
Theney, Bob	Warren, Sonnie	Williams, Steve J.
Thomas, Jessie	Watson, John H.	Williams, Tom

Willis, J. W.
Willis, Wilbur
Wilson, Govenor
Wilson, Houston
Wilson, Logan
Wilson, Ray
Wilson, Wilbur
Wimbush, James
Wood, Charlie, Jr.
Wood, Charlie, Sr.
Wood, Grant

Wood, Louis
Woodall, R. D.
Woodall, Nelson
Woolfolk, Jesse
Wood, Louis
Wood, Grant
Woodall, R. D.
Woodall, Nelson
Woolfolk, Jesse
Wright, Clarence
Wright, Ernest

Wright, Jim
Wright, Ludie
Wright, Rev. T. W.
Wright, Will
Wyatt, Tom
Yancey, Booker
Yarbough, Mark
York, Harrison
Young, Jack

APPENDIX B

RECORDS RETENTION SCHEDULE (CDC)

November 3, 1977

NCl-90-78-1 (CDC)

Director
Records Disposition Division

Disposition schedule NCl-90-78-1 is the comprehensive records schedule of the Center for Disease Control, PHS-DHEW. Our comments on this schedule are listed below by item.

7. Disposal recommended. Congressional correspondence was approved for disposal in the HRA schedule, and recommended for disposal in the FDA and HSA schedules. In the schedule for the Office of the Assistant Secretary for Health (OASH), the records were appraised as permanent.

9. As written, this item provides for permanent retention of all delegations of authority. The same records are better described and more appropriately scheduled in the HSA schedule. We recommend that the HSA description replace the CDC item with appropriate changes in wording.

22. Recommend that description be reworded as follows: " Formal documents which affect the authority, organization, and functions of CDC. These records establish, or substantively change the organization, functions and/or relationships of CDC components. Included are copies of proposed and approved statements of organizational functions and missions, staffing plans, organizational charts, and codes."

25. Records pertain only to public advisory committees established ^{to} explore scientific-medical matters. Committee members are medical professionals, not CDC staff. No records of CDC administrative operations committees are included under this item. Volume of records is very small.

39. Disposition instructions must provide for sample selection by program and records personnel before retirement of records to the FARC. Recommend items "a" and "b" as follows.

a. PERMANENT. Case files for health projects of widespread public or Congressional interest, and cases which document major regional or international disease-control efforts, precedential CDC decisions, controversial policies or programs, significant disease-control techniques. Using the above criteria, CDC program and records personnel will select, before transfer to the FARC, a sample not to exceed 5% for offer to NARS when 15 years have elapsed since project completion.

b. All case files not covered by "a". Transfer to FARC 2 years after completion of project. Destroy 12 years after project completion.

53. Records document CDC responsibility for determining if astronauts and spaceships returning from lunar missions present contamination problems. Records are arranged alphabetically by subject and include minutes of meetings, correspondence, and other subject-file type records. This is a dead file.

58. Although some documentation on this subject should be preserved for archival purposes, we need not retain all case files.

If we decide that a sample is appropriate, we might consider the following.

a. PERMANENT. Cases of widespread public or Congressional interest and cases involving repeated violations of the Act of 1967. Offer to NARS when 20 years old. (A sample percentage can be specified, if desired)

b. All cases not covered in "a" above. Disposable.

64. The manuscripts and final reports which are recommended for permanent retention are the end-products of all CDC research projects. The size and scope of final reports varies according to the nature and length of the project.

Clearly, permanent retention of documentation concerning the results of CDC's primary mission, the control and prevention of disease, is appropriate. We cannot retain, however, voluminous project files for general research in each disease-control effort. The value of these files is limited because many of the documents are intelligible only to medical professionals. End-product documentation essentially summarizes the history of a disease-control project and documents the significant accomplishments resulting in disease control. In some cases, CDC has recommended retention of additional studies on disease-control efforts of special significance. Polio studies are listed as permanent under item 73 because the polio program received national attention and resulted in the virtual elimination of the disease. The Tuskegee Syphilis Study Files (item 101) are proposed for permanent retention because these records provide information

linking health problems with racial and social conditions.

114. Traditionally NARS has appraised training instructional materials as permanent records. Do we want to accession, however, case files of training materials which accumulate annually by three cubic feet? Undoubtedly, these records contain extraneous materials. We can rewrite this description to provide for a. permanent retention of manuals/directives, course outlines, and other end-products which relate directly to scientific and research programs and b. disposal of all other course materials. NNF comment requested.

We recommend approval of this disposition schedule with the changes outlined in this memorandum.

Peter N. Laugesen
Records Disposition Division

NOTE: Copy of audiovisual sections of schedule sent to NNV.

APPENDIX C

DISPOSITION OF RECORDS (NARA)

**REQUEST FOR AUTHORITY
TO DISPOSE OF RECORDS**

(See Instructions on Reverse)

TO: GENERAL SERVICES ADMINISTRATION
NATIONAL ARCHIVES AND RECORDS SERVICE, WASHINGTON, DC 20408

1. FROM (AGENCY OR ESTABLISHMENT)
Department of Health, Education and Welfare

2. MAJOR SUBDIVISION
Public Health Service

3. MINOR/SUBDIVISION
Center for Disease Control

4. NAME OF PERSON WITH WHOM TO CONFER
Sara S. Owens *P-404* 5. TEL. EXT.
283-7723

6. CERTIFICATE OF AGENCY REPRESENTATIVE:

LEAVE BLANK

DATE RECEIVED **OCT 1977** JOB NO.
NC1 90 78 1

NOTIFICATION TO AGENCY

In accordance with the provisions of 44 U.S.C. 3303a the disposal request, including amendments, is approved except for items that may be stamped "disposal not approved" or "with-drawn" in column 10.

1-27-78 *[Signature]*
(Date) Archivist of the United States

I hereby certify that I am authorized to act for this agency in matters pertaining to the disposal of the agency's records; that the records proposed for disposal in this Request of 60 page(s) are not now needed for the business of this agency or will not be needed after the retention periods specified.

11/25/77 Date *[Signature]* for Russell O. Hess (Signature of Agency Representative) Dept. Records Mgt. Officer (Title)

7. ITEM NO.	8. DESCRIPTION OF ITEM (With Inclusive Dates or Retention Periods)	9. SAMPLE OR JOB NO.	10. ACTION TAKEN
	<p>The Center for Disease Control provides leadership and direction to programs and activities designed to improve the health of the people of the United States by preventing or controlling diseases, improving laboratory performance, and assuring safe and healthful working conditions for all working people.</p> <p>To these ends, the Center for Disease Control:</p> <p>(1) Maintains active surveillance of diseases through epidemiologic and laboratory investigations and the collection, analysis, and distribution of data related to preventable diseases and conditions; (2) undertakes measures designed to prevent the importation or spread of communicable diseases from foreign countries into the United States or its territories; (3) provides assistance in the control and prevention of diseases, including</p>		

Copies sent to WNF, NNV, NNB - 1/30/78 (PL)
Copies to WNR 3/15/78

11/6/78. All changes of - 132 items proved by J. Hall of CDC (PL)

STANDARD FORM 115
U.S. GOVERNMENT PRINTING OFFICE
Approved by GPO
(E)WFR (41 CFR) 101-11.4

REQUEST FOR AUTHORITY TO DISPOSE OF RECORDS—Continuation Sheet

7. ITEM NO.	8. DESCRIPTION OF ITEM (WITH INCLUSIVE DATES OR RETENTION PERIODS)	9. SAMPLE OR JOB NO.	10. ACTION TAKEN
	<p>environmentally induced human health problems; and provides epidemic aid to States and communities upon the request of appropriate health authorities;</p> <p>(4) maintains surveillance of the immunization status of the population; (5) develops through investigations, studies, and research, new or improved standards and methods for the diagnosis, treatment, prevention, or control of communicable and vector-borne diseases and other preventable conditions; and upgrades the performance of health workers engaged in prevention and control activities; (6) conducts a national program for improving the performance of clinical laboratories; (7) administers a nationwide program of professional and public information and education in the field of smoking and health; (8) administers a national program to develop and establish recommended occupational safety and health standards to assure safe and healthful working conditions for every working person; (9) provides consultation to, and participates with, other nations and international agencies in the eradication or control of communicable diseases and other preventable conditions.</p>		

Four copies, including original, to be submitted to the National Archives and Records Service

5010-108-01-1

REQUEST FOR AUTHORITY TO DISPOSE OF RECORDS—Continuation Sheet

7. ITEM NO.	8. DESCRIPTION OF ITEM (WITH INCLUSIVE DATES OR RETENTION PERIODS)	9. SAMPLE OR JOB NO.	10. ACTION TAKEN
99.	<p><u>Veneral Disease Patient Files (Early Syphilis Study)</u></p> <p>Medical examinations, patient histories, laboratory test results, medical disposition of the patient, and surveillance reports.</p> <p><u>Authorized Disposition:</u></p> <p>Transfer to the FRC when 2 years old and destroy when 20 years old.</p>		
100.	<p><u>Veneral Disease Research Files</u></p> <p>Research findings, reports, correspondence, special studies, pilot projects, surveys, treatment evaluation, investigations, experiments, screening tests, plans, and project precedent materials pertinent to sexually transmitted diseases.</p> <p><u>Authorized Disposition:</u></p> <p>Transfer to FRC 5 years after completion of project and destroy when 20 years old unless needed for further reference.</p>		
101.	<p><u>Veneral Disease Research (Tuskegee Syphilis Study Files)</u></p> <p>Medical records, pictures and charts, follow-up surveillance, obligation documents, and x-rays of participants in study.</p> <p><u>Authorized Disposition:</u></p> <p>Permanent. Transfer to the FRC 4 years after file is closed and offer to National Archives 16 years thereafter.</p> <p>Current accumulation: 20.0 cubic feet Annual accumulation: None Filing arrangement: Subject-numeric, then alphabetically by patient.</p>		

Four copies, including original, to be submitted to the National Archives and Records Administration.

APPENDIX D

OVERVIEW OF RECORDS BY CDC

TUSKEGEE STUDY RECORDS

- I. 625 Medical Records (including the 36 living participants)
 - A. Medical History
 - B. Examination - initial
 - 1. Serology
 - 2. EKG
 - 3. Radiology
 - C. Examination - follow-up
 - 1. Serology
 - 2. EKG
 - 3. Radiology
 - 4. Autopsy
- II. Card file on each participants (2 Sets)
 - A. Address
 - B. Principle diagnosis
 - C. Date of follow-up examination
 - D. Status
 - 1. living
 - 2. deceased
 - 3. unable to locate
- III. Research documents
 - A. Planning minutes
 - B. Protocols
 - C. Findings (Results from examinations and autopsy reports)
 - D. Correspondence (Memos and letter between colleagues)
 - E. Publications reprints
- IV. Specimens
 - A. Slides - Microscope
 - B. Tissue (Fluid suspension & Waxed incapsulated)

V. Photographs

- A. Ophthalmic study file with notes
- B. Documentary snap-shots and negatives

VI. Miscellaneous

- A. 25 yrs participants award certificates
- B. Inverted photostat copies of medical records
- C. Study critiques
 - 1. 1969 Committee Review
 - 2. Peter Buxton - Correspondence

APPENDIX E

REQUEST TO TRANSFER TO NARA

MMF

REQUEST TO TRANSFER, APPROVAL, AND RECEIPT OF RECORDS TO NATIONAL ARCHIVES OF THE UNITED STATES (See Instructions on reverse)		LEAVE BLANK		RG 442
		UNIT	DATE RECEIVED	UNIT
		JOB NUMBER		JOB NUMBER
		4NN 442-92-252		4NN 442-92-01
1. TYPE OF ACTION	2. TO	3. UNIT THAT CREATED THE RECORDS		
<input type="checkbox"/> A. OFFER OF UNSCHEDULED RECORDS	<input type="checkbox"/> A. RECORDS DISPOSITION DIVISION MAILING ADDRESS: GENERAL SERVICES ADMINISTRATION (NCD) WASHINGTON, DC 20408	A. AGENCY OR ESTABLISHMENT PUBLIC HEALTH SERVICE		
<input checked="" type="checkbox"/> B. TRANSFER OF SCHEDULED RECORDS	<input type="checkbox"/> B. NATIONAL ARCHIVES MAILING ADDRESS: GENERAL SERVICES ADMINISTRATION (NNA) WASHINGTON, DC 20408	B. MAJOR SUBDIVISION CENTERS FOR DISEASE CONTROL		
	<input checked="" type="checkbox"/> C. REGIONAL ARCHIVES FEDERAL ARCHIVES AND RECORD CENTER 1557 St. Joseph Avenue East Point, GA 30344	C. MINOR SUBDIVISION		
		D. NAME OF UNIT		
		E. NAME OF PERSON WITH WHOM TO CONFER ABOUT THE CONTENT OF THE RECORDS Jimmy A. Harrison		F. TELEPHONE (include area code) (404) 639-0441
4. CURRENT LOCATION OF RECORDS	<input checked="" type="checkbox"/> A. AGENCY SPACE (Give location) 1600 Clifton Rd., NE, Atlanta, GA 30333	C. REQUESTED TRANSFER DATE 7/1/92		
	<input type="checkbox"/> B. FEDERAL RECORDS CENTER (Identify center and FRC accession no. and enter location)			
5. RECORDS DATA				
A. DESCRIPTION OF RECORDS (Give overall title of records, individual documents, dates, and other pertinent information. Attachments) Continue on separate sheet of paper, if necessary.				
DATE: 8/3/92 6710/14044 #: 4NS-92-73				
<input type="checkbox"/> SF 135 ATTACHED				
<input checked="" type="checkbox"/> SEPARATE SHEET(S) ATTACHED (See attached box lists for description of records) Circa 1929-1970				
B. EST. VOLUME cu. ft. cu. mtr.	C. ARE RECORDS SUBJECT TO PRIVACY ACT? (If yes, cite agency system number and F.R. volume and page number for most recent notice and attach a copy)		D. SPECIFIC RESTRICTIONS TO BE IMPOSED (Include justification and cite statute or FOI exemption that authorizes such restrictions)	
10	YES. 09-20-0096 ; FR Vol 51, No. 226 pp. 42460-61 ;		RESTRICTED per 5 USC 552, FOIA exemption (b) (6)	
E. RECORDS CONTROL SCHEDULE/ITEM NO. OR APPRAISAL JOB NO.		F. AGENCY REMARKS:		
CDC RCS B-321, Item 101		Concurrence of additional agency officials attached.		
6. STATEMENT OF AGENCY REPRESENTATIVE				
The records described above and on the attached pages are hereby offered for deposit with the National Archives of the United States in accordance with 44 U.S.C. 2103. It is agreed that these records will be administered in accordance with the provisions of 44 U.S.C. Chapter 21, 41 C.F.R. 101-11.411, 41 C.F.R. 105-61, and such other rules or regulations as may be prescribed by the Administrator of General Services or the Archivist of the United States. Unless specified and justified above, there are no restrictions on the use of these records other than the general and specific record group restrictions on the use of records in the National Archives of the United States that have been published in 41 C.F.R. 105-61.53 or in the Guide to the National Archives of the United States. The Archivist of the United States may destroy, donate, or otherwise dispose of any containers, duplicate records, unused forms, blank stationery, nonarchival printed or processed material, or other nonrecord material in any manner authorized by law or regulation without further consent of this agency. I certify that any restrictions specified by this agency on the use of these records are in conformance with the requirements of 5 U.S.C. 552 and that I am authorized by the head of this agency to act for the agency on matters pertaining to the disposition of agency records.				
A. SIGNATURE OF AGENCY REPRESENTATIVE	B. TITLE	C. MAILING ADDRESS	D. DATE	
<i>Jimmy A. Harrison</i>	CDC Records Officer	1600 Clifton Rd., NE Mailstop: E11 Atlanta, GA 30333	7/1/92	
7. ACTION TAKEN BY NATIONAL ARCHIVES AND RECORDS SERVICE, GENERAL SERVICES ADMINISTRATION				
A. ACTION	B. NARS CONCURRENCES			C. FOR NARS USE ONLY
<input checked="" type="checkbox"/> APPROVED	INITIALS	UNIT	DATE	
<input type="checkbox"/> DISAPPROVED				
D. NARS REMARKS REGARDING DISPOSITION/SHIPPING				
E. SIGNATURE OF NARS AUTHORIZED REPRESENTATIVE		F. TITLE	G. DATE	
<i>Hayle P. Peltan</i>		Director National Archives - SE Region	7/29/92	
B. RECORDS RECEIVED NARS DEPOSITORY	A. DATE	B. SIGNATURE	C. TITLE	
	7/29/92	<i>Hayle P. Peltan</i>	Director N.A. - Southeast Region	

Mr. Gayle Peters
Director
Atlanta Branch
National Archives
1557 St. Joseph Avenue
East Point, Georgia 30344

Dear Mr. Peters:

Enclosed is Standard Form 258 transferring to the National Archives and Records Administration approximately 33 cubic feet of scheduled records relating to the Tuskegee Syphilis Study. We are transferring these records to the Archives in accordance with item 101 of the Centers for Disease Control Records Control Schedule B-321 (a copy of the item from the schedule is enclosed). The records consist of seven large boxes of X-ray film and 19 boxes of patient records and miscellaneous files. Included in the transfer of records is accession 090-75A-2219 which is located in the Atlanta Federal Records Center (a copy of the SF-135 for these records is enclosed).

Our Privacy Act Official has recommended that the personal medical files in these records be closed to researchers until the year 2030 because several study participants and their immediate family members are still living. The appropriate Privacy Act system number is cited on the SF-258 and a copy of the system notice from the Federal Register is enclosed. For your information we have also enclosed a copy of a report by the CDC Safety Officer concerning the composition of the X-ray film in the records. As you will note, it is important that these records be stored in an archivally stable environment as quickly as possible.

We can arrange for the immediate shipment of these records to your facility when you are ready to receive them. If you have any questions regarding this matter, please contact Jimmy Harrison of my staff (telephone number 842-6704). Thank you for your cooperation and assistance.

Sincerely yours,

David K. Rowe
Records Officer
Centers for Disease Control

Enclosures

cc:
Laura Leathers, OPA
Arzell Lester, CPS
Joseph E. Salter, MASO
Gwen Strickland-Cid, OD

CDC:MASO:DKRowe:jah:04/27/90:FTS 236-6706
Spelling Verifier used by:Traci Rhew:04/27/90
Doc 0005H

List of Box Contents - Tuskegee Records

- Box 1 of 10 Tuskegee Study - Examination Reports and Research Data
- Box 2 of 10 Tuskegee Study - Examination Results and Data
- Box 3 of 10 Tuskegee Study - Review Documents
Photographs and Photo negatives
- Box 4 of 10 Minuets - Advisory Panel
Memo and Letters - Tuskegee Study Researches
Follow-up - Wives and Children of Study Participants
- Box 5 of 10 Court Actions - Tuskegee Study
- Box 6 of 10 Tuskegee Study Examination ledgers
Medical History Photostats
- Box 7 of 10 Tuskegee Syphilis Study Ad Hoc Advisory Panel's files and
background information.

Followup records for medical benefit eligibility

Copies of historical memo, letters related to Tuskegee Study
- Box 8 of 10 Tuskegee Study - Ad Hoc Advisory Panel's Files
- Box 9 of 10 Tuskegee Study - Periodic Examination and Review Folders 1929 - 1966
- Box 10 of 10 Tuskegee Study - Research Data

Over⁶size ledger of demographic data

Attachment to SF-258

The following represents approval of the attached SF-258, Request to Transfer, Approval and Receipt of Records to National Archives of the United States which will initiate the legal transfer of some 33 cubic feet of records relating to the Tuskegee Syphilis Study to the National Archives and Records Administration's Regional Archives located at 1557 St. Joseph Avenue, East Point, GA 30344.

- o The National Archives and Records Administration will be responsible for preserving and maintaining the records in accordance with the approved CDC Records Control Schedule, item 101 (the records will be preserved in perpetuity for future historical research),
- o Because of the sensitive nature of the information contained in these medical records of Tuskegee Study Health Benefit Recipients, and the potential negative effects on the subject individuals and their families, disclosure is not permitted to the general public, including researchers, per 5 USC 552 (b) (6), until the year 2030.
- o The National Archives will become the responsible party regarding maintaining the records in accordance with the requirements of the Freedom of Information Act and the Privacy Act

CONCURRENCES

Clyde Hester / date April 24, 1990 / CDC Program Official
James W. Baker / date 4/24/90 / CDC FOIA Official
Joseph E. Saltin / date April 24, 1990 / CDC Privacy Act Official
Quindley A. Shull / date 4/24/90 / CDC Legal Advisor

INSTRUCTIONS

This form may be initiated by either the transferring agency or a Federal records center.

INITIATED BY AGENCY:

Agency completes items 1 through 6 (see specific instructions below). Item 6 must be signed and dated. Send original and 4 copies to the appropriate address in item 2 sixty days before planned date of transfer.

INITIATED BY FEDERAL RECORDS CENTER:

Federal records center completes items 1, 2, 3A-F, if known, 4B, 5A and B, D and E and sends original and 3 copies to transferring agency records officer.

Agency completes/corrects items 3, 5A, 5C-F, and 6. Item 6 must be signed and dated. Agency sends original and 3 copies to the address indicated in item 2 sixty days before planned date of transfer.

ITEM 1, TYPE OF ACTION:

If 1B is checked, a reference to the records control schedule number or NARS appraisal job number must be included in 5E. (Item 1B may be checked for unscheduled records if an appropriate appraisal job is cited to reflect an accretion according to prior evaluation of the series).

ITEM 2, TO:

When 1B is checked, requests are sent to the National Archives (NNB) unless the records control schedule or appraisal job specifies a regional archives or Presidential library.

When 2C is checked, include in that block address (number and street, city, State, and zip code) of the regional archives branch being offered the records.

ITEM 3, UNIT THAT CREATED THE RECORDS:

Fully identify the agency, subdivision, and unit that created or originated the records (not the agency records office). If this is not possible, or a successor unit or agency is transferring the records, then explain under Agency Remarks, item 5F.

ITEM 4, CURRENT LOCATION OF RECORDS:

Identify the agency location or the particular records center in which the records are located and provide FRC accession number. The stack location in the center may also be provided.

ITEM 5, RECORDS DATA:

5A. Describe the records. If the records are in a Federal records center, attach SF 135. Arrangement statement must be provided and enough description to substantiate responses in items 5B (with volume for each item) 5C and 5D.

5B. Estimated volume may be indicated in either cubic feet or cubic meters.

5C. Privacy Act notices must be cited for records subject to the Privacy Act (5 U.S.C. 552a) and should be attached.

5D. Specific restrictions must be fully justified and may not violate the Freedom of Information Act (5 U.S.C. 552).

5E. If the records have previously been scheduled in a records control schedule, the schedule and item number must be cited, and the schedule itself may be attached. If the records are not scheduled but a part of the series has been appraised as permanent in the past and transferred to a NARS depository, then cite the appraisal job number as authority and treat as a scheduled offer.

ITEM 6, STATEMENT OF AGENCY REPRESENTATIVE:

Signature and title of agency records officer is placed here and normally is not the name or office given in item 3.

ITEM 7, ACTION TAKEN BY NARS:

NARS will indicate approval and provide shipping or delivery instructions, or disapproval and recommend appropriate disposition of the records. NARS will indicate quantity of offer approved, disapproved and for which action is deferred.

If NARS approves the transfer, the Office of the National Archives sends SF 258 to the agency (or to the Federal records center if the records are in a center) with a transfer date and shipping or delivery

If NARS disapproves the transfer, the Records Disposition Division returns SF 258 to the agency with suggestions for disposition of the records.

ITEM 8, RECORDS RECEIVED:

After receipt of records by a NARS depository NARS will sign and return one copy of SF 258 to the agency.

STANDARD FORM 258 BACK (REV. 10-78)

APPENDIX F

REQUEST TO TRANSFER ADDITIONAL RECORDS

AGREEMENT TO TRANSFER RECORDS TO THE NATIONAL ARCHIVES OF THE UNITED STATES		1. INTERIM CONTROL NO. (NARA Use Only)
TERMS OF AGREEMENT		
<p>The records described below and on the attached _____ pages are deposited in the National Archives of the United States in accordance with 44 U.S.C. 2107. The transferring agency certifies that any restrictions on the use of these records are in conformance with the requirements of 5 U.S.C. 552.</p> <p>In accordance with 44 U.S.C. 2108, custody of these records becomes the responsibility of the Archivist of the United States at the time of transfer of the records. It is agreed that these records will be administered in accordance with the provisions of 44 U.S.C. Chapter 21, 36 CFR XII, 36 CFR Part 1256 and such other rules and regulations as may be prescribed by the Archivist of the United States (the Archivist). Unless specified and justified below, no restrictions of the use of these records will be imposed other than the general and specific restrictions on the use of records in the National Archives of the United States that have been published in 36 CFR Part 1256 or in the <i>Guide to the National Archives of the United States</i>. The Archivist may destroy, donate, or otherwise dispose of any containers, duplicate copies, unused forms, blank stationery, nonarchival printed or processed material, or other nonrecord material in any manner authorized by law or regulation. Without further consent, the Archivist may destroy deteriorating or damaged documents after they have been copied in a form that retains all of the information in the original document. The Archivist will use the General Records Schedule and any applicable records disposition schedule (SF 115) of the transferring agency to dispose of nonarchival materials contained in this deposit.</p>		
2A. AGENCY APPROVAL	2A. NARA APPROVAL	
Signature <u>Jimmy A. Harrison</u> Date <u>4/12/99</u>	Signature _____ Date _____	
2B. NAME, TITLE, MAILING ADDRESS	2B. NAME, TITLE, MAILING ADDRESS	
<u>Jimmy A. Harrison, CDC Records</u> <u>1600 Clifton Rd. NE, OFFICE</u> <u>Atlanta, GA 30333</u>		

RECORDS INFORMATION

4A. RECORDS SERIES TITLE <u>Tuskegee Court and Trial Case Records, Final Report, and Participants Information</u>	
4B. DATE SPAN OF SERIES <u>1978-1979</u> (Attach any additional description.)	
5A. AGENCY OR ESTABLISHMENT <u>Department of Health and Human Services</u>	9. PHYSICAL FORMS
5B. AGENCY MAJOR SUBDIVISION <u>Centers for Disease Control and Prevention</u>	<input checked="" type="checkbox"/> Paper Documents <input type="checkbox"/> Posters
5C. AGENCY MINOR SUBDIVISION <u>NCHSTP</u>	<input type="checkbox"/> Paper Publications <input type="checkbox"/> Maps and Charts
5D. UNIT THAT CREATED RECORDS <u>Tuskegee Program</u>	<input type="checkbox"/> Microfilm / Microfiche <input type="checkbox"/> Arch / Eng Drawings
5E. AGENCY PERSON WITH WHOM TO CONFER ABOUT THE RECORDS Name: <u>Bill Jenkins</u> Telephone Number: <u>(404) 639-8367</u>	<input type="checkbox"/> Electronic Records <input type="checkbox"/> Motion / Sound / Video
6. DISPOSITION AUTHORITY: <u>CDC RCS B-321, Item 2-70</u>	<input type="checkbox"/> Photographs <input type="checkbox"/> Other (specify): _____
7. IS SECURITY CLASSIFIED INFORMATION PRESENT? <input checked="" type="checkbox"/> NO <input type="checkbox"/> YES LEVEL: <input type="checkbox"/> Confidential <input checked="" type="checkbox"/> Secret <input type="checkbox"/> Top Secret SPECIAL MARKINGS: <input type="checkbox"/> R0/FRD <input type="checkbox"/> SCI <input type="checkbox"/> NATO <input type="checkbox"/> Other _____ INFORMATION STATUS: <input type="checkbox"/> Segregated <input type="checkbox"/> Declassified	10. VOLUME: _____ CONTAINERS: Cu. Mtr. _____ (Cu. Ft. <u>6</u>) Number <u>6</u> Type <u>ERC</u>
8. CURRENT LOCATION OF RECORDS <input checked="" type="checkbox"/> Agency (Complete 8A only) <input type="checkbox"/> Federal Records Center (Complete 8B only)	11. DATE RECORDS ELIGIBLE FOR TRANSFER TO THE ARCHIVES <u>1999 (early transfer)</u>
8A. ADDRESS <u>CDC</u> <u>Executive Park Bldg. 22</u> <u>Atlanta, GA</u>	12. ARE RECORDS FULLY AVAILABLE FOR PUBLIC USE? <input type="checkbox"/> YES <input checked="" type="checkbox"/> NO (If no, attach limits on use and justification.)
8B. PRO ACCESSION NUMBER <u>N/A</u>	13. ARE RECORDS SUBJECT TO THE PRIVACY ACT? (If yes, cite Agency System Number and Federal Register volume and page number of most recent notice and attach a copy of this notice.) <u>69-26-0096-10151</u>
	14. ATTACHMENTS <input type="checkbox"/> Agency Manual Excerpt <input type="checkbox"/> Listing of Records Transferred <input type="checkbox"/> Additional Description <input type="checkbox"/> NA Form 14067 or Equivalent <input type="checkbox"/> Privacy Act Notice <input type="checkbox"/> Microform Inspection Report <input checked="" type="checkbox"/> Other (specify): <u>Box List</u> <input type="checkbox"/> SF(1) 135

NARA PROVIDES

15. SHIPPING INSTRUCTIONS TO AGENCIES / REMARKS REGARDING DISPOSITION		RG
16. RECORDS ACCEPTED INTO THE NATIONAL ARCHIVES OF THE UNITED STATES Signature _____ Date _____		17. NATIONAL ARCHIVES ACCESSION NO.

BOX LISTING

Box 1, Tuskegee court records (alphabets A-D), civil action # 4126N
Box 2, Tuskegee court records (alphabets F-M), civil action # 4126N
Box 3, Tuskegee court records (alphabets N-S), civil action # 4126N
Box 4, Tuskegee court records (alphabets T-Z), civil action # 4126N
Box 5, Tuskegee trial case records 1973-1976, Tuskegee trial interim reports 1976-1979, Order of disbursement records 1976-1979, Listing of attorney Grey's clients, Final Report Manuscript regarding the Tuskegee Syphilis Study.
Box 6, Health Benefit Program Participants information.

safeguards may be built into the program by the system analyst as warranted by the sensitivity of the data. CDC employees who maintain records are instructed to check with the system manager prior to making disclosures of data. When individually identified data are being used in a room, admittance is restricted to specifically authorized personnel.

4. IMPLEMENTATION GUIDELINES: The safeguards outlined above are developed in accordance with Chapter 45-13, "Safeguarding Records Contained in Systems of Records," of the HHS General Administration Manual, supplementary Chapter PHS.hf: 45-13; Part 6, "Automated Information System Security," of the HHS Information Resources Management Manual; the National Bureau of Standards Federal Information Processing Standards (FIPS Pub. 41 and FIPS Pub. 31). FRC safeguards are in compliance with GSA Federal Property Management Regulations, Subchapter B—Archives and Records.

RETENTION AND DISPOSAL:

Records are maintained in agency for five years. Disposal methods include erasing computer tapes, burning or shredding paper materials or transferring records to the Federal Records Center when no longer needed for evaluation and analysis. Records destroyed by paper recycling process when 20 years old, unless needed for further study.

SYSTEM MANAGER(S) AND ADDRESS:

Director, Division of Tuberculosis Control, Center for Prevention Services, Freeway Office Park, Rm. 111, Centers for Disease Control, 1600 Clifton Road, Atlanta, GA 30333.

NOTIFICATION PROCEDURE:

An individual may learn if a record exists about himself or herself by contacting the system manager at the address above. Requesters in person must provide driver's license or other positive identification. Individuals who do not appear in person must either (1) submit a notarized request to verify their identity or (2) certify that they are the individuals they claim to be and that they understand that the knowing and willful request for or acquisition of a record pertaining to an individual under false pretenses is a criminal offense under the Privacy Act subject to a \$5,000 fine.

An individual who requests notification of or access to medical records shall, at the time the request is made, designate in writing a responsible representative who is willing to review

the record and inform the subject individual of its contents at the representative's discretion.

A parent or guardian who requests notification of, or access to, a child's medical record shall designate a family physician or other health professional (other than a family member) to whom the record, if any, will be sent. The parent or guardian must verify relationship to the child by means of a birth certificate or court order, as well as verify that he or she is who he or she claims to be.

The following information must be provided when requesting notification: (1) Full name; (2) the approximate date and place of the study, if known; and (3) nature of the questionnaire or study in which the requester participated.

RECORD ACCESS PROCEDURES:

Same as notification procedures. Requesters should also reasonably specify the record contents being sought. An accounting of disclosures that have been made of the record, if any, may be requested.

CONTESTING RECORD PROCEDURES:

Contact the system manager at the address specified under System Manager above, reasonably identify the record and specify the information being contested, the corrective action sought, and the reasons for requesting the correction, along with supporting information to show how the record is inaccurate, incomplete, untimely, or irrelevant.

RECORD SOURCE CATEGORIES:

Individuals and hospitals.

SYSTEMS EXEMPTED FROM CERTAIN PROVISIONS OF THE ACT:

None.

09-20-0096

SYSTEM NAME:

Records of Tuskegee Study Health Benefit Recipients. HHS/CDC/CPS.

SECURITY CLASSIFICATION:

None.

SYSTEM LOCATION:

Center for Prevention Services, Freeway Office Park, Rm. 306, Centers for Disease Control, 1600 Clifton Road, Atlanta, GA 30333 and Federal Records Center, 1557 St. Joseph Avenue, East Point, GA 30344.

CATEGORIES OF INDIVIDUALS COVERED BY THE SYSTEM:

Adult participants in the study and their family members.

CATEGORIES OF RECORDS IN THE SYSTEM:

Medical records.

AUTHORITY FOR MAINTENANCE OF THE SYSTEM:

Public Health Service Act, Section 301, "Research and Investigation" (42 U.S.C. 241).

PURPOSE(S):

To determine eligibility and provide medical benefits for participants and qualified family members.

ROUTINE USES OF RECORDS MAINTAINED IN THE SYSTEM, INCLUDING CATEGORIES OF USERS AND THE PURPOSES OF SUCH USES:

A record may be disclosed for a research purpose, when the Department(A) has determined that the use or disclosure does not violate legal or policy limitations under which the record was provided, collected, or obtained;(B) has determined that the research purpose (1) cannot be reasonably accomplished unless the record is provided in individually identifiable form, and (2) warrants the risk to the privacy of the individual that additional exposure of the record might bring;(C) has required the recipient to (1) establish reasonable administrative, technical, and physical safeguards to prevent unauthorized use or disclosure of the record, (2) reasonably identify the information that identifies the individual at the earliest time at which removal or destruction can be accomplished consistent with the purpose of the research project, unless the recipient has presented adequate justification for a research or health nature for retaining such information, and (3) make no further use or disclosure of the record except (a) in emergency circumstances affecting the health or safety of any individual, (b) for use in another research project, under these same conditions, and with written authorization of the Department, (c) for disclosure to a properly identified person for the purpose of an audit related to the research project, if information that would enable research subjects to be identified is removed or destroyed at the earliest opportunity consistent with the purpose of the audit, or (d) when required by law;(D) has secured a written statement attesting to the recipient's understanding of, and willingness to abide by these provisions.

Records may be disclosed to health departments and other public health or cooperating medical authorities in connection with program activities and related collaborative efforts to deal more effectively with diseases and conditions of public health significance.

Disclosure may be made to a congressional office from the record of an individual in response to a verified

Privacy Act

inquiry from the congressional office made at the written request of that individual.

In the event of litigation where the defendant is (a) the Department, any component of the Department, or any employee of the Department in his or her official capacity; (b) the United States where the Department determines that the claim, if successful, is likely to directly affect the operations of the Department or any of its components; or (c) any Department employee in his or her individual capacity where the Justice Department has agreed to represent such employee, for example, in defending a claim against the Public Health Service based upon an individual's mental or physical condition and alleged to have arisen because of activities of the Public Health Service in connection with such individual, disclosure may be made to the Department of Justice to enable that Department to present an effective defense, provided that such disclosure is compatible with the purpose for which the records were collected.

POLICIES AND PRACTICES FOR STORING, RETRIEVING, ACCESSING, MAINTAINING, AND DISPOSING OF RECORDS IN THE SYSTEM:

STORAGE:

File folders.

RETRIEVABILITY:

Records are retrieved alphabetically by name.

SAFEGUARDS:

1. **AUTHORIZED USERS:** Access is granted to only a limited number of physicians, scientists, statisticians, and designated support staff of the Centers for Disease Control (CDC), as authorized by the system manager to accomplish the stated purposes for which the data in this system have been collected.

2. **PHYSICAL SAFEGUARDS:** Locked cabinets in locked rooms, electronic anti-intrusion devices in operation at the Federal Records Center, 24-hour guard service in buildings, personnel screening of visitors.

3. **PROCEDURAL SAFEGUARDS:** Users of individually identified data protect information from public scrutiny, and only specifically authorized personnel may be admitted to the record storage area. CDC employees who maintain records are instructed to check with the system manager prior to making disclosures of data.

4. **IMPLEMENTATION GUIDELINES:** DHHS Chapter 45-13 and supplementary Chapter PHS.M: 45-13 of the General Administration Manual. FRC safeguards are in compliance with GSA Federal

Property Management Regulations, Subchapter B—Archives and Records.

RETENTION AND DISPOSAL:

Records are maintained in agency for five years. Disposal methods include erasing computer tapes, burning or shredding paper materials or transferring records to the Federal Records Center when no longer needed for evaluation and analysis. Records are to be maintained permanently.

SYSTEM MANAGER(S) AND ADDRESS:

Director, Center for Prevention Services, Freeway Office Park, Rm. 310, Centers for Disease Control, 1600 Clifton Road, Atlanta, GA 30333.

NOTIFICATION PROCEDURE:

An individual may learn if a record exists about himself or herself by contacting the system manager at the address above. Requesters in person must provide driver's license or other positive identification. Individuals who do not appear in person must either (1) submit a notarized request to verify their identity or (2) certify that they are the individuals they claim to be and that they understand that the knowing and willful request for or acquisition of a record pertaining to an individual under false pretenses is a criminal offense under the Privacy Act subject to a \$5,000 fine.

An individual who requests notification of or access to medical records shall, at the time the request is made, designate in writing a responsible representative who is willing to review the record and inform the subject individual of its contents at the representative's discretion.

A parent or guardian who requests notification of, or access to, a child's medical record shall designate a family physician or other health professional (other than a family member) to whom the record, if any, will be sent. The parent or guardian must verify relationship to the child by means of a birth certificate or court order, as well as verify that he or she is who he or she claims to be.

The following information must be provided when requesting notification: (1) Full name; (2) the approximate date and place of the study, if known; (3) nature of the questionnaire or study in which the requester participated.

RECORD ACCESS PROCEDURES:

Same as notification procedures. Requesters should also reasonably specify the record contents being sought. An accounting of disclosures that have been made of the record, if any, may be requested.

CONTESTING RECORD PROCEDURES:

Contact the official at the address specified under System Manager above, reasonably identify the record and specify the information being contested, the corrective action sought, and the reasons for requesting the correction, along with supporting information to show how the record is inaccurate, incomplete, untimely, or irrelevant.

RECORD SOURCE CATEGORIES:

Participants and family members of participants entitled to medical care; Social Security Administration for Medicare information; and State welfare departments for information on Medicaid.

SYSTEMS EXEMPTED FROM CERTAIN PROVISIONS OF THE ACT:

None.

00-20-0102

SYSTEM NAME:

Alien Mental Waiver Program. HHS/CDC/CPE.

SECURITY CLASSIFICATION:

None.

SYSTEM LOCATION:

Vice Medical Activity, Division of Quarantine, Center for Prevention Services, Freeway Office Park, Rm. 206, Centers for Disease Control, 1600 Clifton Road, Atlanta, GA 30333 and Federal Records Center, 1557 St. Joseph Avenue, East Point, GA 30344.

CATEGORIES OF INDIVIDUALS COVERED BY THE SYSTEM:

Immigrant aliens with waivers of excludability who are mentally retarded or who have had one or more attacks of insanity.

CATEGORIES OF RECORDS IN THE SYSTEM:

Medical history files.

AUTHORITY FOR MAINTENANCE OF THE SYSTEM:

Public Health Service Act, Section 325, "Examination of Aliens" (42 U.S.C. 252); Immigration and Nationality Act, Section 212(g), "Application for Waiver of Grounds of Excludability" (8 U.S.C. 1182(g)).

PURPOSE(S):

To comply with the requirements of Section 212(g) of the Immigration and Nationality Act, the Centers for Disease Control (CDC) must receive and maintain medical records on aliens who apply for waivers of excludability due to mental retardation or a previous attack of insanity. CDC is furnished with a copy of the alien's medical examination

Tuskegee Records
5 USC 552 (FOIA Exemption)

552. Public information; agency rules, opinions, orders, records, and proceedings

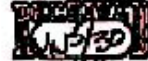
(a) Each agency shall make available to the public information as follows:

(b) **This section does not apply to matters that are -**

(6) **personnel and medical files and similar files the disclosure of which would constitute a clearly unwarranted invasion of personal privacy;**

APPENDIX G

NARA MEMORANDUM OF TRANSFER



May 30, 1990

Mery Rosen

Fuskegee Syphilis Study Records

MN, NYE, MCh, 4NN, NZL

JRM has received some of the records of the Fuskegee Study. CDC transferred the medical records of those men it knows to be dead and retained the files of those who are still living. The study lasted from the 1930s until the early '70s. The records present an overwhelming privacy problem. CDC believes that no member of the public, other than Jim Jones, the author of Had Blood, has seen these files. (Jones saw them at CDC under what CDC believes were false pretenses. He claimed he was an attorney for the men in the study.)

While there is some case law on the issue of residual privacy rights for the dead (Marzen v. HHS, Price v. DOJ, Leaar v. DOJ) the DC circuit has only just heard arguments on the FOIA case involving the release of the tape documenting the last recordings of the Challenger astronauts' existence. They have published no decision yet & per a DOJ attorney present during the arguments, the bench seems to be strongly divided on the question of privacy for the dead.

I suggest we approach these records in a different way. Each male in the study, in all probability, passed syphilis on to every sexual partner and child he had. Thus while these men are dead, I think that by leaving their names or personal identifiers in the records, we will allow a researcher to identify living individuals (wives & children, named or otherwise) who may have had syphilis.

The records are those of a static population in a rural county. I think anyone with a working knowledge of the community could trace the link from father to child or from husband to wife. Thus, I suggest we remove (as NS material) all names & personal identifiers from these files in order to protect the privacy of living individuals.

Pragmatically, I suggest we keep the records closed until we get a FOIA; only then should we take on the project of sanitizing. We may also need to dust off the regulation on biomedical researchers doing quantitative research. I don't think anyone has used it before but these records might produce such a request.

APPENDIX H

ASST. ARCHIVIST RESPONSE TO MEMO

National Archives



Washington, DC 20408

Date : MAY 31 1990
Reply to :
Attn of : NN
Subject : Tuskegee Syphilis Study Records
To : NNR

I agree with the position Mary Ronan proposes regarding the
Tuskegee Syphilis Study Records.

Trudy Huskamp Peterson
TRUDY HUSKAMP PETERSON
Assistant Archivist
for the National Archives

Attachment

APPENDIX I

INDEX OF RECORDS

NAIL Full Results

Much of this series is restricted! Please consult with staff

How to Order

Change Full Results Format	Brief Results	Refine Search
Exit NAIL		

Control Number NRCA-442-TSS001

Location Southeast Region-Atlanta, stack B: 69/26/1/2 through 69/26/6/6 containers #1-38
Includes Box 20a

Media Textual records
Photographs

Descr. Level Series

Record Group 442

Series TSS001

Title Tuskegee Syphilis Study Administrative Records

Dates 1929-1972

Former RG Number 90

Creating Org. Public Health Service. Centers For Disease Control. Venereal Disease Branch.

Record Type/Genre Affidavits; Agendas; Committee Hearings; Correspondence; Minutes; Photographs

Scope & Content This record series includes two types. First, records created during the course of the study from its beginning until its end. Second, records created during the Congressional hearing and the federal litigation, and as a result of the intense public scrutiny to which the study and the Agency were subjected when the existence of the study became public.

The files consist of records related to individual patients; publications based on findings of the study; copies of other studies and publications, apparently used for reference by physicians and scientists in the study; correspondence between medical personnel; correspondence with various foundations which provided funds for the study; administrative records created during the study; photographs of various medical tests or procedures; and photographs showing the conditions in the area around Tuskegee.

The records also include the charter, lists of members, minutes, agenda, etc. of the Department of Health, Education and Welfare Ad Hoc Advisory Study Committee, and transcripts of hearings before a Senate Health Subcommittee on the Tuskegee Syphilis Experiment. There are also records relating to the Federal Court Case, Civil Action 4126-N, Charlie Pollard vs. The United States of America, filed in the United States District Court in the Middle District of Alabama, Northern Division. These files include copies of pleadings in the case, correspondence between the plaintiff's attorney and CDC, and affidavits of study participants and others to establish their participation in the study.

APPENDIX J

FOIA REQUEST TO NARA

Date: Tue, 29 Jul 2003 08:49:41 -0400 (EDT)
From: Tywana Whorley <twhorley@mail.sis.pitt.edu>
To: garym.stern@nara.gov
Subject: Tuskegee Syphilis Study records

Mr. Sterns,

My name is Tywana Whorley and I am a doctoral student at the University of Pittsburgh. I'm in the School of Information Sciences where I am concentrating on archives and records management. I'm currently working on my dissertation which is examining the National Archives administrative role in maintaining and providing access to the Tuskegee Syphilis Study records.

I have examined the records at the Southeast regional center and spoke with archivists. However, I have several unanswered questions concerning the records, especially regarding the restricted information.

This past week, I had the opportunity to speak with Mr. Tom Blanton, director of the National Security Archive. He suggested that I contact you in hopes that you could assist me.

I was able to obtain the accession record for the transfer of the records from the Centers for Disease Control. Attached to the accession was a written agreement between the two agencies which partly stated that "Because of the sensitive nature of the information contained in these medical records of Tuskegee Study Health Benefit Recipients, and the potential negative effects on the subject individuals and their families, disclosure is not permitted to the general public, including researchers, per 5 U.S.C 552 (b) (6), until the 2030."

I have several questions regarding this agreement. The first is how did the CDC and NARA agree on 2030. There was not a document in the accession record to explain this reasoning between the two parties. Also, most of these men are dead. In fact, there are only two participants living out of 625. I thought that NARA usually releases the records of individuals who are deceased. there could be an explanation here, but the archivists at the Southeast Region in East Point, Georgia could not give me a clear one. In addition, the names of the participants are in the public domain. The attorney who represented them in their lawsuit against the government has written a book where he names all 625 men. My question is why is NARA still protecting the names of the participants if they are already in the public domain?

I have examined NARA's regulations regarding access to records, especially records with sensitive information in them. And that NARA will release records of such nature with redactions. I have received such records. But I am still puzzled as to why the information I requested, which were the medical files are still restricted eventhough most of the participants are dead. Why is NARA making exceptions with the Tuskegee Syphiis Study Records? Perhaps these are legal reasons. I would like to understand. Do the participants rights diminish upon death or does it have to do with third party rights.

I hope I have not overwhelmed you with my questions. I am trying to understand how NARA manages these records, especially the restricted information. Also are there any documents that speak directly to the Tuskegee Syphilis Study records that I could received. I have a copy of the accession record and appraisal report.

I would greatly appreciate any help you can give me in this matter.

Sincerely,

Tywanna Whorley
Doctoral Student
School of Information Sciences
Department of Library and Information Science
University of Pittsburgh
twhorley@mail.sis.pitt.edu

APPENDIX K

NARA'S RESPONSE TO FOIA REQUEST



National Archives and Records Administration

8601 Adelphi Road
College Park, Maryland 20740-6001

February 11, 2004

Tywenna Whorley
34 Kennedy Way, Apt. 2
Pittsburgh, PA 15219

Dear Ms. Whorley:

This is in response to your July 29, 2003 email asking a number of questions about the role of the National Archives and Records Administration (NARA) in maintaining and providing access to the medical records related to the Tuskegee Syphilis Study (1932 – 1972). You asked how NARA and the Centers for Disease Control (CDC) came to agree on the year 2030 for the release of the medical files. You also asked about NARA's decision to keep the files closed, despite the fact that most of the subjects are deceased and that the names of the subjects are already in the public domain. This letter answers the questions posed in your email.

The transfer documentation (SF 258) that accompanied the records of the Tuskegee Syphilis Study included a memorandum from the CDC "recommending" that the personal medical files in these records be closed to researchers until the year 2030 because several study participants and their immediate family members were still living. NARA never categorically withheld the medical records; however, we did endeavor to protect the privacy interests of the individuals referenced in the records. The SF 258 indicated that those files would be restricted in accordance with 5 U.S.C. § 552(b)(6), which permits the government to withhold all information about individuals in "personnel and medical files and similar files" when the disclosure of such information "would constitute a clearly unwarranted invasion of personal privacy." Consistent with established Freedom of Information Act (FOIA) policy and NARA's internal guidance concerning these records, NARA made redacted versions of the medical records available upon request. NARA released the vast majority of the medical information, but redacted all names and personal identifiers to protect the privacy of living individuals. For your reference, we are including a copy of the NARA guidance concerning the medical files, signed on May 31, 1990.

You mentioned in your email that the names of the participants are already in the public domain. That is true. However, when the records were transferred, many of the intimate details contained in the medical files on each of the participants were not yet in the public domain. Moreover, the CDC relies greatly on the willingness of human subjects to participate in medical research, and maintaining the confidentiality of the resulting records is a crucial piece of that process. Accordingly, under the (b)(6) balancing test, NARA decided to redact the names of the participants while releasing all the pertinent medical information.

In your email you also mentioned that most of these participants had passed away and therefore the privacy right has ceased. Although there is a general rule under FOIA that death extinguishes privacy rights, particularly sensitive information may be withheld when necessary to protect the privacy interests of surviving family members. Even information that is not particularly sensitive in and of itself may be withheld to protect the privacy interests of surviving family members if

NARA's web site is <http://www.archives.gov>

disclosure would cause "a disruption of their peace of minds," see Cowles Publ'g Co. v. United States, No. 90-349, slip op. at 6-7 (E.D. Wash. Dec. 20, 1990). Given the special sensitivities and the subject matter of the Tuskegee Study, NARA decided not to release the names in order to protect both living individuals and survivors who might hold a privacy interest in the medical records.

Upon receipt of your initial request, NARA contacted the CDC and requested further explanation about the recommendation that the medical files be closed until 2030. We also reviewed a sample of the medical files in question to determine what, if any, information about third parties was contained therein, and what type of personal, intimate details were included about the participants.

At the time of our calls, the CDC confirmed that only one Tuskegee participant was still living. (Note that since that conversation that person has passed away.) The CDC confirmed that its original concerns stemmed from the fact that these were medical files containing intimate details about the individuals that should not be revealed while the individuals were alive. The CDC was also concerned that third parties, namely the family members of these individuals, would be negatively impacted by the release of this information.

Upon a review of the files, NARA concluded that, other than names, there was no other mention, and certainly no intimate details, about third parties. That conclusion, combined with the fact that all the participants are now deceased, led to our recommendation to open the medical files of the Tuskegee Study participants in their entirety. You will be pleased to know that after careful consideration of all the factors involved, we are opening the Tuskegee Syphilis Study medical files in their entirety. The CDC concurs with this determination. Please note that other files pertaining to the Tuskegee Study are also subject to the provisions of FOIA and may need to be screened before they are released.

Accordingly, I have notified our Southeast Regional Archives that the medical files for the Tuskegee Study participants may now be opened in their entirety.

If you have any questions feel free to contact me at 301-837-2024 or Sarah Rudgers (301-837-2926).

Sincerely,


RAMONA BRANCH OLIVER
NARA FOIA Officer
Office of General Counsel

Enclosures

cc: Charles Reeves
Gary M. Stern
Sarah Rudgers

APPENDIX L

REDACTED MEDICAL RECORD

SYPHILIS RESEARCH STUDY
(Macon County)

Last examined 1968
U.S. DEPARTMENT OF
HEALTH, EDUCATION, AND WELFARE
PUBLIC HEALTH SERVICE
BUREAU OF DISEASE PREVENTION
AND ENVIRONMENTAL CONTROL
NATIONAL COMMUNICABLE DISEASE CENTER
ATLANTA, GEORGIA 30333

FORM APPROVED
BUDGET BUREAU NO. 68-R0191

No blood

PERSONAL HISTORY

PATIENT NO.	023-S
DATE	November 1970
AGE	64
BIRTHDATE	2/22/1906

NAME _____

ADDRESS _____
Rt. 1, _____, Roba, Alabama

NEAREST RELATIVES

NAME	ADDRESS

MARITAL HISTORY	<input type="checkbox"/> SINGLE	<input type="checkbox"/> DIVORCED	NO. OF CHILDREN LIVING _____ DEAD _____ MIS-CARRIAGES _____ STILLBIRTHS _____	NO. OF DELIVERIES HOSPITAL _____ M.D. (Not in Hospital) _____ MIDWIFE _____	OTHER (Specify) _____
	<input type="checkbox"/> MARRIED	<input type="checkbox"/> SEPARATED			
	<input type="checkbox"/> WIDOWED				

WIFE EXAMINED (STS)	TREATMENT
<input type="checkbox"/> YES <input type="checkbox"/> NO	
CHILDREN EXAMINED (STS)	
<input type="checkbox"/> YES <input type="checkbox"/> NO	

OCCUPATION	OWN FARM _____ SHARECROPPER _____ RENT _____	
WORKING NOW	CHURCH	REGULAR ATTENDANCE
<input type="checkbox"/> YES <input type="checkbox"/> NO DAYS/WK. _____ HRS./DAY _____		<input type="checkbox"/> YES <input type="checkbox"/> NO
EDUCATION	GRADE LEVEL	READ
		<input type="checkbox"/> YES <input type="checkbox"/> NO
MEMBER OF LODGE		P.T.A.
		<input type="checkbox"/> YES <input type="checkbox"/> NO

PUBLIC HEALTH EDUCATION	WIFE ATTEND MATERNITY CLINIC
	<input type="checkbox"/> YES <input type="checkbox"/> NO
	CHILDREN HAVE IMMUNIZATION
	<input type="checkbox"/> YES <input type="checkbox"/> NO
	VITAMINS

VISITS TO HOME BY VISITING NURSE (If yes, describe)

YES NO

REMARKS
No blood taken.

CHIEF COMPLAINT _____

WEIGHT LOSS _____

HEADACHES _____

PARALYSIS _____ STROKES _____ PARESTHESIAS _____

NEUROMUSCLAR _____

EYES:

LOSS OF VISION _____ INFLAMMATION _____ DIPLOPIA _____

EAR, NOSE AND THROAT:

DEAFNESS _____ TINNITUS _____ HOARSENESS _____

GASTRO INTESTINAL _____

RESPIRATORY _____

CARDIAC:

CHILDHOOD GROWING PAINS _____

RHEUMATIC FEVER OR ARTHRITIS _____

DIPHTHERIA _____

DYSPNEA:

EXERTION _____ NO. FLIGHTS OF STAIRS _____ DURATION _____

ORTHOPNEA _____ NO. PILLOWS _____ DURATION _____

NOCTURNAL PAROXYSMAL _____ FREQUENCY _____ DURATION _____

CHEST PAINS:

LOCATION _____ DURATION _____

CHARACTER _____

RELATION TO MEALS _____ EXERTION _____ DRUGS _____

PALPITATION _____

EDEMA _____

CARDIAC DRUGS OR TREATMENT _____ DURATION _____

SKIN ERUPTIONS _____

GENITO-URINARY:

GONORRHEA _____ DATE _____

PENILE SORE _____ DATE _____

BUBO _____ ASSOCIATED SKIN ERUPTION _____ DATE _____

ANTIBIOTIC EVALUATION PHYSICAL EXAMINATION

Height _____ Weight _____ General health Fair

SKIN: PRIMARY LESION: Location _____ Number _____ Date of onset _____
Bubo: Present , Absent . Size: Small , Medium , Giant

ERUPTION: Type: Indurated , Erosive , Ulcerated , Darkfield _____
Date of onset _____
Type: Macular , Maculopapular , Small papular , Rupial , Roseola ,
Large papular , Papulosquamous , Annular , Follicular , Other
dermatoses _____
Distribution: Trunk , Arms , Soles , Face , Breasts , Palms , Toes ,
Scalp .

ALOPECIA: Symptomatic , Essential
Location: Scalp , Eyebrows , Lashes , Pudendal , Other .

LEUCODERMA COLLI: _____

CONDYLOMA LATA: Location _____ ACUMINATE CONDYLOMAS: Location _____

MUCOUS MEMBRANES: Normal , Involved
Location: Mouth , Tongue , Lip , Nasal , Vulvar , Conjunctival
Type of lesion: Mucous patches , Papuloerosive , Ulcerative .

EYES: Normal , Abnormal OD OS
Cornea _____ OK OK
Sclera _____ pterygium _____
Visual acuity _____ OK non
Media _____ clear clear
Fundi _____ OK OK

NOSE: Normal , Abnormal
Deformities _____
Other abnormalities _____

TEETH: Normal , Abnormal
Deformities _____ Caries
Other abnormalities _____

CARDIOVASCULAR: Pulse rate 100 Character reg Blood pressure: Right Left
HEART: P. M. I. _____ R. M. D. _____
Right border _____ Left border OK
Auscultation _____ OK

LUNGS: Percussion _____
Auscultation clear

ABDOMEN: _____

RECTAL: _____ WNL

GENTALIA: _____ WNL

(Surname of patient) (Given name) (Examining physician) 023-S

(Serial number)

PHYSICAL EXAMINATION
(4)

EXTREMITIES:

LYMPH NODES:

Normal , Abnormal
Enlarged , Tender , Consistency _____ Location _____

NEUROLOGIC:

	RIGHT	LEFT
EYES:		
Pupillary reflexes:		
Light	1+	1+
Accommodation	1+	1+
Ptosis	/	/
Other ocular palsies	/	/
Gross visual fields	OK	OK
FACIAL PALSIES:		
(Central or peripheral)	OK to 1+	OK to 1+
HEARING	OK	OK
TONGUE		
REFLEXES:		
Deep:		
Upper extremities	2+	2+
Lower extremities	2+	2+
Superficial:		
Abdominal	↓	↓
Cremasteric	↓	↓
Pathological:		
Babinski, Hoffman, etc.	↓	↓
SENSORY DISTURBANCES	↓ grossly WNL	
VIBRATORY DISTURBANCES		
TREMORS		
MOTOR POWER		
SPEECH		
GAIT		

OTHER FINDINGS:

VENEREAL DISEASE:

DIAGNOSIS:

1. _____
2. _____
3. _____

TREATMENT SCHEDULE:

LABORATORY REPORTS

URINALYSIS:

SPECIFIC GRAVITY _____ ALBUMEN _____

REACTION _____ SUGAR _____

MICROSCOPIC _____

SEROLOGY:

1. VDRL No Blood Drawn

2. KAHN _____

3. KOLMER _____

CEREBROSPINAL FLUID:

1. CELLS _____ TOTAL/PER CUBIC MM

_____ WITH ACID

_____ % MONONUCLEARS } ON SMEAR

_____ % POLYMORPHS }

2. TOTAL PROTEIN (TRICHLORACETIC ACID) _____

3. COLLOIDAL GOLD _____

4. VDRL _____

5. KOLMER _____

TREPOONEMA IMMOBILIZING TEST:

1. HILL _____

2. MAGNUSON _____

PATIENT DECEASED

DATE OF DEATH	CAUSE OF DEATH
---------------	----------------

SOURCE OF INFORMATION	POST-MORTEM EXAM <input type="checkbox"/> YES <input type="checkbox"/> NO	INCLUDING BRAIN <input type="checkbox"/> YES <input type="checkbox"/> NO
-----------------------	--	---

CERTIFICATE OF DEATH (If yes, state where filed. If no or unknown, give place of death)

YES NO UNKNOWN

Name _____ Date of Death **8-23-73**
 Place of Death { County **Macon** City or Town **Tuskegee**
 Beat No. **1** Name of Hospital **Macon County**
 Residence of Deceased **Rt. 2, Union Springs, Ala.**
 IF LESS THAN ONE YEAR OLD { Full Name of Father _____
 Maiden Name of Mother _____
 Birth Place of this Infant _____
 Attendant at Birth _____ Date Reported _____
 Sex **M** Race **W** Age **67** Yrs. **67** Mos. _____ Days _____ Hrs. _____ Min. _____
 Cause of Death { Primary **Myocardial infarction**
 Contributory **Barton's F. H., Tuskegee, Ala.**
 Funeral Date Received **9-13-73** Attendant **Robert H. Story, M. D.**
 Informant _____ Address **Union Springs, Ala.**
 ALABAMA DEPARTMENT OF PUBLIC HEALTH DEATH SUMMARY CARD - CVS 2

THIS IS A LEGAL RECORD AND WILL BE PERMANENTLY FILED
SEE OTHER SIDE
FILL IN WITH A TYPEWRITER OR WRITE PLAINLY WITH DARK INK. DO NOT USE GREEN NOR RED INK. LEGAL COPIES CANNOT BE MADE IF ENTRIES ARE DIM
ALL ITEMS MUST BE COMPLETE AND ACCURATE
IF NO DOCTOR WAS IN ATTENDANCE MEDICAL CERTIFICATION SHOULD BE COMPLETED BY THE LOCAL HEALTH OFFICER, OR CORONER
 1973-72
 REVISED 7-72

MEDICAL CERTIFICATE OF DEATH M
STATE OF ALABAMA

1. PLACE OF DEATH a. COUNTY Macon		b. CITY, TOWN, OR LOCATION Tuskegee		2. USUAL RESIDENCE (Where deceased lived, if institution: Residence before admission) a. STATE Alabama b. COUNTY Bullouck	
3. NAME OF DECEASED (Type or print) First _____ Middle _____ Last _____		4. DATE OF DEATH Month 8 Day 23 Year 73		5. SEX Male 6. COLOR OR RACE Black	
7. MARRIED <input checked="" type="checkbox"/> NEVER MARRIED <input type="checkbox"/> WIDOWED <input type="checkbox"/> DIVORCED <input type="checkbox"/>		8. DATE OF BIRTH 2-22-06		9. AGE (In years last birthday) 67	
10a. USUAL OCCUPATION (Give kind of work done during most of working life) Retired Farmer		10b. KIND OF BUSINESS OR INDUSTRY INDUSTRY		11. BIRTHPLACE (State or foreign country) Alabama	
12. CITIZEN OF WHAT COUNTRY? U.S.A.		13. FATHER'S NAME (See) UNKNOWN		14. MOTHER'S MAIDEN NAME (See) UNKNOWN	
15. WAS DECEASED EVER IN U. S. ARMED FORCES? (Yes, no, or unknown) (If yes, give war or dates of service) No		16. SOCIAL SECURITY NO. 22-61-8416		17. INFORMANT'S NAME Everlean Banks	
18. CAUSE OF DEATH (Enter only one cause per line for (a), (b), and (c).) PART I. DEATH WAS CAUSED BY: IMMEDIATE CAUSE (a) Myocardial infarction Conditions, if any, which gave rise to above cause (a), stating the underlying cause last. DUE TO (b) arteriosclerotic heart disease DUE TO (c) _____ PART II. OTHER SIGNIFICANT CONDITIONS CONTRIBUTING TO DEATH BUT NOT RELATED TO THE TERMINAL DISEASE CONDITION GIVEN IN PART I (a) Coronary atherosclerosis		19. WAS AUTOPSY PERFORMED? NO		INTERVAL BETWEEN ONSET AND DEATH 2 days	
20a. (Probably) ACCIDENT SUICIDE HOMICIDE <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>		20b. DESCRIBE HOW INJURY OCCURRED. (Enter nature of injury in Part I or Part II of item 18.)			
20c. TIME OF HOUR Month, Day, Year a. m. _____ p. m. _____		20d. INJURY OCCURRED WHILE AT WORK <input type="checkbox"/> NOT WHILE AT WORK <input type="checkbox"/>			
20e. PLACE OF INJURY (e. g., in or about home, farm, factory, street, office)		20f. CITY, TOWN, OR LOCATION COUNTY STATE			
21. I attended the deceased from June 1972 to Aug 23, 73 and last saw her alive on 8-22-73 Death occurred at 5:00 P.M. on the date stated above; and to the best of my knowledge, from the causes stated.					
22. SIGNATURE (Degree or title) Robert H. Story, M.D.		22b. ADDRESS Tuskegee Clinic, Tuskegee		22c. DATE SIGNED 8/27/73	
23. BURIAL/CREMATION/REMOVAL (Specify) Burial		23b. DATE 8/26/73		23c. NAME OF CEMETERY OR CREMATORY Anteck Baptist Church, Ala. (Macon)	
24. FUNERAL DIRECTOR Barton's Funeral Home, Tuskegee, Ala.		25. DATE RECD. BY LOCAL REG. 8/27/73		26. REGISTRAR'S SIGNATURE Deloris Ham	



DEPARTMENT OF HEALTH, EDUCATION, AND WELFARE
PUBLIC HEALTH SERVICE
HEALTH SERVICES AND MENTAL HEALTH ADMINISTRATION

April 13, 1973

CENTER FOR DISEASE CONTROL
ATLANTA, GEORGIA 30333
TELEPHONE: (404) 632-3311

~~████████████████████~~
Union Springs, Alabama

Dear Mr. ~~██████████~~

For many years now, you and a number of other men were part of a study begun in Macon County, Alabama in 1932 to learn more about untreated syphilis. Some of the participants in the study had syphilis, others did not. It was expected that the difference in the health of men with syphilis as compared to that of men without syphilis would further explain the effects of this disease.

A careful review of this study has just been completed by a committee of experts in the fields of medicine, law, education, and religion. As a result of that review, it has been recommended that you and all other participants in the study obtain a thorough medical examination and any needed treatment, and be offered continuing medical care. This includes care for any health problems you may have now or experience in the future. We can arrange for a well-qualified doctor or a hospital to provide this examination and care. If you prefer to see your own doctor or another doctor of your own choosing, this too can be arranged. Whichever you prefer, we will pay for the costs involved.

The Public Health Worker who brings you this letter can make the necessary arrangements for you if you want these services. He can arrange and pay for your travel to the doctor or hospital. Furthermore, if you choose to have these services but later decide that you no longer want them, you can withdraw. Likewise, if after consideration you should choose not to receive these services now, they can be provided later. In any event we will respect your decision and also your personal privacy in this matter.

You may feel it would be helpful to discuss this matter with others prior to making a decision; therefore, the Public Health Worker will return at your convenience in a day or two to learn of your decision and to assist you.

Sincerely yours,

David J. Sencer, M.D.
Assistant Surgeon General
Director

Name: [REDACTED]
Married

ID No: 74-M-19-1

Entrance into Study 1932 - Age 24

Initial Exam:

Patient has a history of having had a chancre on the glans penis in 1931 with unilateral lymphadenitis. Patient also had a generalized rash 1-2 weeks after the sore disappeared.

Patient has been totally deaf since 1928.

Patient has had poor vision of his right eye since 1919.

Physical examination revealed total deafness and right eye blindness. Patient also noted to have a staggering gait which dates back to the time of his becoming deaf.

Post influenza attack.

Radiographic examination is normal.

1938

No change in history.

Physical examination reveals a soft, low systolic murmur at the apex of the heart and a low, blowing murmur at the base of the heart.

Patient received anti-syphilitic treatment.

Radiographic examination reveals slight dilatation of the aorta.

1948

Patient gives a 3-year history of bronchial asthma with shortness of breath.

Physical examination is unchanged.

Radiographic examination reveals a slightly enlarged heart with a slightly dilated ascending aorta.

1952

A recent history of chest pain associated with shortness of breath.

Physical examination is unchanged.

Radiographic examination reveals a narrow aorta.

Page 2 - [REDACTED]

1958

A recent history of pains in the stomach with weight loss.

Physical examination is unchanged.

Radiographic examination reveals chronic bronchitis with no evidence of syphilitic heart disease. The configuration of the aorta suggests arteriosclerosis.

1963

History, physical examination and radiographic examination are unchanged.

1965

Unchanged

1966

Unchanged

1968

History of chest pain is suggestive of coronary artery disease. Patient relates some treatment for syphilis in 1931.

Physical examination reveals benign prostatic hypertrophy.

1970

Unchanged

Died August 20, 1973 -- cause unknown -- Age 65

Opinion-- There is no evidence in our records that syphilis contributed to his demise.

MEMORANDUM

Date: 8-27-73

To: L.A. Rabb Administrator

Re: [REDACTED] pt. #023

From: E. Kenneth W. R.N.

Please have check drawn on the Midbank
fund for the amount of one hundred (\$100.00) dollars,
made payable to Mrs. [REDACTED], wife of the
deceased for patient's participation in a research
study project

A-28

ROENTGENOLOGICAL REPORT

6-3-33

THORAX: Symmetrical, bones negative.
CARDIA: Within normal limits. Trachea is
in midline.

LUNG FIELDS: The pulmonary shadows are slightly
increased in the perihilus regions of the inner
and middle zones. The apices, peripheral zones
and costo-phrenic sinuses are clear. The
diaphragm is smooth. The hilus glands are
enlarged. The aorta is not broadened.
IMPRESSIONS: No pulmonary pathology.


J.J. Peters, M.D.

September 6, 1973

Mr. John Raugh
Vice President for Administration
Milbank Memorial Fund
40 Wall Street
New York, New York 10005

Dear Mr. Raugh:

We have been advised of the death of Mr. ~~XXXXXXXXXX~~ ^{one of the patients}
in the Tuskegee Syphilis Study.

It is requested that \$100.00 be transmitted by the Fund to the Treasurer
of the Tuskegee Institute incident to the next death.

Sincerely yours,

Ralph H. Hensler, M.D.
Chief, Venereal Disease Branch
Bureau of State Services

cc:
BSS

BSS(VD)GDH:comb:isf

September 6, 1973

Mr. H. K. Logan
Business Manager
Tuskegee Institute
Tuskegee, Alabama 36088

Dear Mr. Logan:

Information has been received of the death of Mr. ~~XXXXXXXXXX~~, one of
the Tuskegee Syphilis Study patients in Macon County.

We have requested the Milbank Memorial Fund to forward you a check for
\$100.00 to cover payment to the family.

Sincerely yours,

Ralph H. Henderson, M.D.
Chief, Venereal Disease Branch
Bureau of State Services

cc:
BSS

BSS(VD)GDHolcomb:isf

TF 9.13 (GDC)

7-58

NAME

Original Diagnosis

TUSKEGEE STUDY

7/1: 8/1/58 M.H.

Number 083-5

Old

New

1958 Diagnosis late latent

Findings Normal ECG - Normal Urine, clear specimen appearance of eye

DATE	BLOOD SPECIMENS					SPINAL FLUID			VDRL					
	Kahn Stand.	Kolmer Quant.	VDRL Slide	KRP	TPI	FTA	Kolmer Quant.	VDRL Test	Total Protein	USR-II	RPCF	TPCF	tpcf-50	Other
1950														
1951														
1/4/1952	N		N											
10/12/1953	N	N	N		Pos.									
1954														
1/1/1955	N	N	N		Pos.									
1956														
1957														
1/9/1958	N	N	N	N	Pos	Pos				WR 2.5	N	Pos	Pos	
1959														
8/2/1960			N		N	N								
1961														
1962														
8/1/1963			WR	N	N	N								

08/1/63

WR-0

R

WR-AB

R

TF 9.13 (GDC)
7-58

TUSKEGEE STUDY

NAME 

Number 023-1 Old New

Original Diagnosis _____ 1958 Diagnosis _____

Findings _____

DATE	BLOOD SPECIMENS					SPINAL FLUID			VDRL				Other	
	Kahn Stand.	VDRL Slide	KRP	TPI	FTA-RS	Kolmer Quant.	VDRL Test	Total Protein	USR-II	RPCF	TPCF	tpcf-50		
1948														
1950		AK												
1951														
1952														
1953														
1954														
1955														
1956														
1957														
1958														
1959														
1960														
1961														
1962														
1963														

OCT 29 1965

PHYSICAL EXAMINATION

Height Weight General health *Bright - Severe asthma - deaf 25 years*

SKIN: PRIMARY LESION: Location Number Date of onset
 Bubo: Present , Absent . Size: Small , Medium , Giant .
 Type: Indurated , Erosive , Ulcerated , Darkfield
 ERUPTION: Date of onset
 Type: Macular , Maculopapular , Small papular , Rupial , Roseola ,
 Large papular , Papulosquamous , Annular , Follicular , Other
 dermatoses
 Distribution: Trunk , Arms , Soles , Face , Breasts , Palms , Toes ,
 Scalp .
 ALOPECIA: Symptomatic , Essential .
 Location: Scalp , Eyebrows , Lashes , Pudendal , Other .
 LEUCODERMA COLLI:
 CONDYLOMA LATA: Location ACUMINATE CONDYLOMAS: Location

MUCOUS MEMBRANES: Normal , Involved .
 Location: Mouth , Tongue , Lip , Nasal , Vulvar , Conjunctival .
 Type of lesion: Mucous patches , Papuloerosive , Ulcerative .

EYES: Normal , Abnormal . OD OS
 Cornea
 Sclera
 Visual acuity
 Media
 Fundi

NOSE: Normal , Abnormal .
 Deformities
 Other abnormalities

TEETH: Normal , Abnormal .
 Deformities
 Other abnormalities

CARDIOVASCULAR:
 Pulse rate *50* Character Blood pressure: Right Left
 HEART: P. M. I. *Normal* R. M. D. *140/100 140/100*
 Right border Left border
 Auscultation *NO*

LUNGS: Percussion
 Auscultation *As of asthma - normal today*

ABDOMEN:

RECTAL:

GENITALIA:

..... (Ward surgeon) 023
 (Surname of patient) (Given name) (Serial number)

PHYSICAL EXAMINATION (4)

EXTREMITIES:

LYMPH NODES:

Normal , Abnormal .

Enlarged , Tender , Consistency _____ Location _____

NEUROLOGIC:

EYES:

RIGHT

LEFT

Pupillary reflexes:

Light.....

Accommodation.....

Ptosis.....

Other ocular palsies.....

Gross visual fields.....

FACIAL PALSIES:

(Central or peripheral).....

HEARING.....

TONGUE.....

REFLEXES:

Deep:

Upper extremities.....

Lower extremities.....

Superficial:

Abdominal.....

Cremasteric.....

Pathological:

Babinski, Hoffman, etc.....

SENSORY DISTURBANCES.....

VIBRATORY DISTURBANCES.....

TREMORS.....

MOTOR POWER.....

SPEECH.....

GAIT.....

OTHER FINDINGS:

(Use Form 1946D if more space is required.)

VENEREAL DISEASE:

DIAGNOSIS:

1. _____

2. _____

3. _____

TREATMENT SCHEDULE: (Include daily dose of arsenoxide.)

150

Has treatment schedule been planned to avoid menstrual periods? Yes No

November 1966

DEPARTMENT OF HEALTH, EDUCATION, AND WELFARE
PUBLIC HEALTH SERVICE
COMMUNICABLE DISEASE CENTER
ATLANTA, GEORGIA 30333

FORM APPROVED
BUDGET BUREAU NO. 66-R671

ANTIBIOTIC EVALUATION PHYSICAL EXAMINATION

Height _____ Weight _____ General health _____

SKIN: PRIMARY LESION: Location _____ Number _____ Date of onset _____
Bubo: Present , Absent . Size: Small , Medium , Giant

Type: Indurated , Erosive , Ulcerated , Darkfield _____

ERUPTION: Date of onset _____

Type: Macular , Maculopapular , Small papular , Rupial , Roseola ,
Large papular , Papulosquamous , Annular , Follicular , Other
dermatoses _____

Distribution: Trunk , Arms , Soles , Face , Breasts , Palms , Toes ,
Scalp

ALOPECIA: Symptomatic , Essential

Location: Scalp , Eyebrows , Lashes , Pudendal , Other

LEUCODERMA COLLI: _____

CONDYLOMA LATA: Location _____ ACUMINATE CONDYLOMAS: Location _____

MUCOUS MEMBRANES: Normal , Involved

Location: Mouth , Tongue , Lip , Nasal , Vulvar , Conjunctival

Type of lesion: Mucous patches , Papuloerosive , Ulcerative

EYES: Normal , Abnormal OD OS

Cornea _____ arcus senilis

Sclera _____

Visual acuity _____

Media _____ not done

Fundi _____

NOSE: Normal , Abnormal

Deformities _____

Other abnormalities _____

TEETH: Normal , Abnormal

Deformities _____

Other abnormalities _____

CARDIOVASCULAR:

Pulse rate 84 Character Regular Blood pressure: 160/90 Right Left

HEART: P. M. I. _____ R. M. D. _____

Right border _____ Left border within M.C.L.

Auscultation _____ murmur

LUNGS: Percussion _____ clear

Auscultation _____

ABDOMEN: _____

RECTAL: _____

GENITALIA: _____

m & s

(Examining physician)

Campbell

(Surname of patient)

W422

(Given name)

075 A

(Serial number)

023

TF 9.70 (CDC)
3-65

PHYSICAL EXAMINATION
(9)

EXTREMITIES:

normal

LYMPH NODES:

Normal , Abnormal

Enlarged , Tender , Consistency _____ Location _____

NEUROLOGIC:

EYES:

RIGHT

LEFT

Pupillary reflexes:

Light..... *not done*

Accommodation.....

Ptosis.....

Other ocular palsies.....

Gross visual fields..... *↓*

FACIAL PALSIES:

(Central or peripheral)..... *S*

HEARING..... *v*

TONGUE..... *↓*

REFLEXES:

Deep:

Upper extremities..... *normal*

Lower extremities.....

Superficial:

Abdominal.....

Cremasteric.....

Pathological:

Babinski, Hoffman, etc..... *normal*

SENSORY DISTURBANCES.....

VIBRATORY DISTURBANCES.....

TREMORS.....

MOTOR POWER..... *Normal*

SPEECH.....

GAIT.....

OTHER FINDINGS:

VENEREAL DISEASE:

DIAGNOSIS:

1. _____

2. _____

3. _____

TREATMENT SCHEDULE:

Composites

P.E 1932 hx

- (1) x-ray
- (2) smears

Blood 1932 Wass., Kahn

(3)

UA 1932

CSF 1932

X-ray 1932

1938 PE hx

1948 hx PE R fluoresc

fluoresc x-ray

UA VDRL Kahn CSF TPI

UA CF E.T.

Kahn

1948 hx P.E.

1958 hx PE R x-ray

fluoresc x-ray

VDRL FJA USRI RPCF

UA CF EJ

Kahn Tp50 KRP TP

CSF Kahn Kalmer Coyle Wachs

TRCF

1963 hx PE x-ray up

1965 hx PE

Kahn Kahn VDRL KAP TPI EJA

1952

1953

1958

1958

1960

1963

1965

1966

Name: [REDACTED]
Married

ID No: 74-M-19-1

Entrance into Study 1932 - Age 24

Initial Exam:

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Patient has been totally deaf since 1928.

Patient has had poor vision of his right eye since 1919.

Physical examination revealed total deafness and right eye blindness. Patient also noted to have a staggering gait which dates back to the time of his becoming deaf.

Post influenza attack.

Radiographic examination is normal.

1938

No change in history.

Physical examination reveals a soft, low systolic murmur at the apex of the heart and a low, blowing murmur at the base of the heart.

Patient received anti-syphilitic treatment.

Radiographic examination reveals slight dilatation of the aorta.

1948

Patient gives a 3-year history of bronchial asthma with shortness of breath.

Physical examination is unchanged.

Radiographic examination reveals a slightly enlarged heart with a slightly dilated ascending aorta.

1952

A recent history of chest pain associated with shortness of breath.

Physical examination is unchanged.

Radiographic examination reveals a narrow aorta.

Page 2

1958

A recent history of pains in the stomach with weight loss.

Physical examination is unchanged.

Radiographic examination reveals chronic bronchitis with no evidence of syphilitic heart disease. The configuration of the aorta suggests arteriosclerosis.

1963

History, physical examination and radiographic examination are unchanged.

1965

Unchanged

1966

Unchanged

1968

History of chest pain is suggestive of coronary artery disease. Patient relates some treatment for syphilis in 1931.

Physical examination reveals benign prostatic hypertrophy.

1970

Unchanged

Died August 20, 1973 -- cause unknown -- Age 65

Opinion-- There is no evidence in our records that syphilis contributed to his demise.

APPENDIX M

**INDEX OF TUSKEGEE SYPHILIS STUDY RECORDS (RESTRICTED AND
UNRESTRICTED)**

AL B069126/112

RESTRICTED	BOX_NUMBER	FOLDER_NO	LBUD_TSS	TITLE	NO_FOLDERS	CRRSPNDING	ACC_NO
N	01	1-13	N	1937	1	N	92-01
N	01	1-19	N	1943	1	N	92-01
N	01	1-20	N	1945	1	Y	92-01
N	01	1-6	N	1958	1	N	92-01
N	01	1-22	N	1959	1	N	92-01
N	01	1-9	N	1960	1	N	92-01
N	01	1-21	N	1961	1	N	92-01
N	01	1-51	N	1938	1	Y	92-01
N	01	3-26	N	1962 (70-060-02)	1	N	92-01
N	01	5-10	N	1952	1	Y	94-02
N	01	1-44	N	365	1	Y	94-02
N	01	1-37	N	1951	1	Y	92-01
N	01	1-36	N	1956	1	N	92-01
N	01	1-64	N	1957	1	N	92-01
N	01	1-38	N	1937	1	Y	92-01
N	01	1-32	N	1952	1	Y	92-01
N	01	1-1	N	1953	1	Y	92-01
N	01	1-55	N	1958	1	Y	92-01
N	01	1-11	N	1962	1	Y	92-01
N	01	1-10	N	1972	1	Y	92-01
N	01	1-18	N	1973	1	Y	92-01
N	01	1-52	N	1940	1	Y	92-01
N	01	1-12	N	1941	1	Y	92-01
N	01	4-16	Y	1962	1	Y	92-01
N	01	7-24	Y	AD HOC ADVISORY PANEL - AGENDA	1	N	92-01
N	01	4-17	Y	AD HOC ADVISORY PANEL - AGENDA	1	N	92-01
N	01	8-1	Y	MEETING - 10/25/72; 11/2/72	1	N	92-01
				AD HOC ADVISORY PANEL - AGENDA	1	N	92-01
				BOOK - SECOND AND THIRD	1	N	92-01
				AD HOC ADVISORY PANEL - AGENDA	1	N	92-01
				MEETING - 10/25/72; 11/2/72	1	N	92-01
				AD HOC ADVISORY PANEL - AGENDA	1	N	92-01
				BOOK - FOURTH MEETING 11/30/72	1	N	92-01
				AD HOC ADVISORY PANEL - FOLDER	1	N	92-01
				1	1	N	92-01

RESTRICTED	BOX_NUMBER	FOLDER_NO	BLD_TSS	TITLE	NO_FOLDERS	CORRESPONDING	ACC_NO
N	01	4-13	Y	AD HOC ADVISORY PANEL - COMMITTEE MEETING 2/6/69	1	N	92-01
N	02	1-15	N	ADMINISTRATIVE MANAGEMENT - GENERAL	1	N	94-02
N	02	3-31	N	ADMINISTRATIVE MANAGEMENT - 1	1	N	94-02
N	02	3-32	N	POLICY AND PROCEDURE	1	N	94-02
N	02	3-32	N	ADMINISTRATIVE MANAGEMENT - 5	1	N	94-02
N	02	3-33	N	STAFFING	1	N	94-02
N	02		N	ADMINISTRATIVE MANAGEMENT - 7	1	N	94-02
N	02		N	RECORDS	1	Y	92-01
N	02		N	ALABAMA UNTREATED SYPHILIS - MISCELLANEOUS ROUGH DRAFTS	1	N	92-01
N	02		N	ALABAMA UNTREATED SYPHILIS - PROCEDURE	1	N	92-01
N	02	2-32	N	ALABAMA - MACON COUNTY - AUTOPSIES	1	Y	92-01
N	02	2-17	N	ALABAMA STUDY	1	N	92-01
N	02	2-19	N	ALABAMA STUDY - DATA	1	N	92-01
N	02	2-16	N	ALABAMA UNRX'D STUDY	1	Y	92-01
N	02	2-3	N	ALABAMA UNRX'D E - 1952	1	Y	92-01
N	02	8-37	N	ALABAMA STATE BOARD OF HEALTH - ANNUAL REPORTS - RESEARCH	1	N	92-01
N	02	1-4	N	ALABAMA UNRX'D E 1949	1	Y	92-01
N	02	6	Y	AD HOC COMMITTEE - 2/6/69	1	N	94-02
N	02	4-11	Y	AD HOC ADVISORY PANEL - FOLDER I	1	Y	92-01
N	02	4-12	Y	AD HOC ADVISORY PANEL - FOLDER II	1	N	92-01
N	02	7-22	Y	AD HOC ADVISORY PANEL - III	1	N	92-01
N	02	7-31	Y	ORIENTATION SESSION 9/14/72	1	N	92-01
N	03		N	AD HOC ADVISORY PANEL - FOLDER IV	1	N	92-01
N	03	3-35	N	ALABAMA UNTREATED SYPHILIS - TABLES AND TEXT, DEC '46	2	N	92-01
N	03	3-23	N	ASSOCIATIONS AND COMMITTEES, ETC - SELECT SPECIALIST GROUP	1	N	94-02
N	03	3-23	N	ASSOCIATIONS AND COMMITTEES, ETC - AD HOC COMMITTEE, 1969	1	N	94-02

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RESTRICTED	BOX_NUMBER	FOLDER_NO	LEAD_TSS	TITLE	NO_FOLDERS	CRSPNDING	ACC_NO
N	03	3-24	N	ASSOCIATIONS AND COMMITTEES, ETC - AD HOC COMMITTEE, 1973	1	N	94-02
N	03	3-36	N	ASSOCIATIONS AND COMMITTEES, ETC - MEDICAL CARE REVIEW COMMITTEE	1	N	94-02
N	03	3-37	N	AUTOPSIES - GENERAL	1	N	94-02
N	03	4-11	N	BRUCE, DICK - MAIL	1	N	94-02
N	03	9-34	N	AUTOPSIES - GENERAL	1	Y	92-01
N	03	2-30	N	ARTICLE WRITTEN FOR STATISTICAL REPORTER	1	N	92-01
N	03	1-56	N	BRUCE, RICHARD H.	1	N	92-01
N	03	7-5	N	ASSOCIATIONS, COMMITTEES, ETC - TUSKEGEE STUDY - AD HOC ADVISORY PANEL	2	N	92-01
N	03	2-35	Y	AUTOPSY STUDY	1	Y	92-01
N	03	8-3	Y	ARCHIVES	1	N	92-01
N	04	1-6	N	BUXTON, PETER (EMPLOYED BY CDC)	1	N	94-02
N	04	4-5	N	C TO S AND TOTAL TSS ROSTER AND DECEASED WITH DATES OF DEATH	1	Y	94-02
N	04	3-38	N	COMMUNICATIONS - GENERAL	1	N	94-02
N	04	3-39	N	COMMUNICATIONS - 7 TELEPHONE CALLS	1	N	94-02
N	04	3-40	N	CONTRACTS - 1 COOPERATIVE AGREEMENTS	1	N	94-02
N	04		N	CONTRACT FILE	1	Y	94-02
N	04		N	CONTROLLED CORRESPONDENCE - 1974-1975	1	Y	92-01
N	04		N	CONTROLLED CORRESPONDENCE - 1976	1	N	92-01
N	04	7-26	N	BUXTON - CORRESPONDENCE	1	Y	92-01
N	04	8-4	N	CDC 1-A BASIC	1	Y	92-01
N	04	8-29	N	CHARGES, ETC. - DUVAL	1	N	92-01
N	04	8-34	N	COMPUTER	1	N	92-01
N	04	9-54	Y	COMMITTEE MEETING, 1957	1	N	92-01
N	04		Y	CONTRACTS, VOUCHERS AND PURCHASE ORDERS FOR PAYMENT	1	N	94-02

RESTRICTED	BOX_NUMBER	FOLDER_NO	LBLD_TSS	TITLE	NO_FOLDERS	CRSPNDNG	ACC_NO
N	04	4-23	Y	CONSULTANTS - MR. BRUCE	1	Y	92-01
N	04	7-20	Y	CHRONOLOGY	1	N	92-01
N	05	1-3	N	CONTROLLED CORRESPONDENCE -	1	N	94-02
N	05	8-12	N	CONGRESSIONAL	1	N	92-01
N	05	7-2	Y	CORRESPONDENCE - DEATH/AUTOPSY	1	Y	92-01
N	05		Y	CORRESPONDENCE - 1974-1975	1	Y	92-01
N	05		Y	CORRESPONDENCE	6	Y	92-01
N	06		N	DISEASES AND CONDITIONS - 11-1	1	N	94-02
N	06		N	TUSKEGEE SYPHILIS STUDY, CY	1	N	94-02
N	06	5-2	N	1975-1976	1	N	94-02
N	06		N	DISEASES (VD) - 8 TUSKEGEE	1	N	94-02
N	06		N	STUDY	1	N	92-01
N	06	1-10	N	DR. CALDWELL'S PAPER -	1	N	92-01
N	06		N	CARDIOVASCULAR 1971	1	N	92-01
N	06	1-41	N	DEATH RATE BY AGE	1	N	92-01
N	06	2-18	N	DEFINITION OF TERMS - ALABAMA	1	N	92-01
N	06		N	STUDY	1	N	92-01
N	06	1-63	N	DR. ROCHAT	1	Y	92-01
N	06	8-25	N	CV'S CONSULTANTS	1	N	92-01
N	06	7-10	N	DR. JONES REQUEST FOR	1	N	92-01
N	06		N	PHOTOGRAPHS AND TSS MATERIAL	1	N	92-01
N	06	4-8	N	DR. SENCER'S LETTER	1	N	92-01
N	06	1-63	Y	DIFFERENTIAL MORTALITY	1	N	92-01
N	06	2-38	Y	EVALUATION - LIST OF PATIENTS	1	Y	92-01
N	06	8-2	Y	EXTRAS FROM M45 MAILING -	1	N	92-01
N	06		Y	WILBUR INDEX ON PARTICIPANTS	1	N	92-01
N	06		Y	[SIC] CLINICAL DATA FORMAT	1	N	92-01
N	06	8-44	Y	EXTRAS FROM M47 MAILING	1	N	92-01
N	06	8-47	Y	EXTRAS FROM M48 MAILING	1	N	92-01
N	06	8-48	Y	EXTRAS FROM M49 MAILING - KATZ	1	N	92-01
N	06		Y	REPORT III PD-13 BASIC	1	N	92-01
N	06	8-50	Y	EXTRAS FROM M50 MAILING	1	N	92-01
N	06	8-53	Y	EXTRAS FROM M51 MAILING	1	N	92-01
N	06	8-55	Y	EXTRAS FROM M52 MAILING	1	N	92-01
N	06	8-58	Y	EXTRAS FROM M55 MAILING	1	N	92-01
N	06	8-52	Y	EXTRAS FROM M58 MAILING	1	N	92-01
N	06	8-64	Y	EXTRAS FROM M59 MAILING	1	N	92-01
N	06	8-66	Y	EXTRAS FROM M60 MAILING	1	N	92-01

RESTRICTED	BOX_NUMBER	FOLDER_NO	LBDL_TSS	TITLE	NO_FOLDERS	CORRESPONDING	ACC_NO
N	06	8-10	Y	EXTRAS FROM M62 MAILING	1	N	92-01
N	06	8-28	Y	EXTRAS FROM M63 MAILING	1	N	92-01
N	06	8-32	Y	EXTRAS FROM M65 MAILING	1	N	92-01
N	06	8-19	Y	EXTRAS FROM M66 MAILING	1	N	92-01
N	06	8-17	Y	EXTRAS FROM M67 MAILING - KATZ	1	N	92-01
N	06	8-7	Y	DRAFT TWO - CHARGE III	1	N	92-01
N	06		Y	EXTRAS FROM M68 MAILING - GOLDWATER HISTORICAL PERSPECTIVE	1	N	92-01
N	06	8-22	Y	EXTRAS FROM M70 MAILING	1	N	92-01
N	06	8-14	Y	EXTRAS FROM M71 MAILING	1	N	92-01
N	07		N	FINAL DIAGNOSIS MASTER SHEET - 1952	1	N	92-01
N	07	5-26	N	FOLLOW UP	1	Y	94-02
N	07	5-16	N	FOLLOW UP OF CHILDREN - EXAM RESULTS	1	Y	94-02
N	07		N	FIFTH MEETING OF THE TSS AD HOC COMMITTEE	1	N	92-01
N	07	7-27	N	FORM FOR FAMILY TREE	1	N	92-01
N	07	7-17	N	FIS IDENTIFICATION CODES	1	N	92-01
N	07		Y	GENERAL - 1933	1	N	
N	07		Y	GENERAL - 1936	1	N	
N	07		Y	GENERAL - 1937	1	N	92-01
N	07		Y	GENERAL - 1938	1	N	
N	07		Y	GENERAL - 1939	1	Y	92-01
N	07		Y	GENERAL - 1940	1	Y	92-01
N	07	9-16	Y	GENERAL - 1941	1	Y	92-01
N	07	9-15	Y	GENERAL - 1946	1	Y	92-01
N	07	9-14	Y	GENERAL - 1947	1	Y	92-01
N	07	9-13	Y	GENERAL - 1948	1	N	92-01
N	07	9-12	Y	GENERAL - 1949	1	N	92-01
N	07	9-11	Y	GENERAL - 1950	1	N	92-01
N	07	9-10	Y	GENERAL - 1951	1	N	92-01
N	07	9-38	Y	GENERAL - 1952	1	Y	92-01
N	07	9-35	Y	GENERAL - 1953	1	Y	92-01
N	07	9-9	Y	GENERAL - 1954	1	Y	92-01
N	07	9-27	Y	GENERAL - 1955	1	Y	92-01
N	07	9-25	Y	GENERAL - 1956	1	N	92-01
N	07	9-23	Y	GENERAL - 1956	1	N	92-01

RESTRICTED	BOX_NUMBER	FOLDER_NO	LBLD_TSS	TITLE	NO_FOLDERS	CORRESPONDING	ACC_NO
N	07	9-22	Y	GENERAL - 1957	1	Y	92-01
N	07	9-21	Y	GENERAL - 1958	1	Y	92-01
N	07	9-20	Y	GENERAL - 1960	1	Y	92-01
N	07	2-7	Y	FINAL TABULATIONS - WORK SHEETS - 1932-1966 (1 LEGAL SIZED)	2	Y	92-01
N	07		Y	FOLLOW UP WIVES AND CHILDREN - 1972 FOLLOW UP CHARTS AND DATA	1	Y	92-01
N	08		N	GRANTS - MILBANK GRANT RENEWAL 1935-1949	1	Y	92-01
N	08	1-28	Y	GENERAL - 1963	1	Y	92-01
N	08	9-30	Y	GENERAL - 1964	1	Y	92-01
N	08	9-33	Y	GENERAL - 1965	1	Y	92-01
N	08	9-31	Y	GENERAL - 1966	1	Y	92-01
N	08		Y	GENERAL - 1967	1	N	92-01
N	08	9-29	Y	GENERAL - 1968	1	Y	92-01
N	08	9-32	Y	GENERAL - 1969	1	N	92-01
N	08	9-18	Y	GENERAL - 1970	1	Y	92-01
N	08		Y	GENERAL - 1971	1	Y	92-01
N	08	4-2	Y	GENERAL FOLDER I	1	N	92-01
N	08	4-3	Y	GENERAL FOLDER I:1	1	N	92-01
N	08	4-2A	Y	GENERAL FOLDER IV	1	Y	92-01
N	08	4-19	Y	GENERAL FOLDER I:	1	N	92-01
N	08	7-29	Y	GENERAL FOLDER V	1	Y	92-01
N	09		N	GRANTS - MILBANK GRANT RENEWAL 1949-1971	1	N	92-01
N	09		N	GRANTS - MILBANK MEMORIAL FUND - GENERAL CORRESPONDENCE	1	N	92-01
N	09	3-41	N	GRANTS - MILBANK MEMORIAL FUND - GENERAL 1972 - CURRENT	1	N	94-02
N	09		N	GRANTS - ROSENWALD FUND 1929-1940	1	N	92-01
N	09	4-9	N	HOME HEALTH AIDE ASSIGNMENT SHEETS - SUBSEQUENT BILLING	1	Y	94-02
N	09	3-30	N	FORMS INFORMATION - 2 BIBLIOGRAPHY	1	N	94-02
N	09	3-11	N	INFORMATION - 3 CDC PUBLICATIONS - GENERAL	1	N	94-02

RESTRICTED	BOX_NUMBER	FOLDER_NO	LBLD_TSS	TITLE	NO_FOLDERS	CRRSPNDING	ACC_NO
N	09	3-5	N	INFORMATION - 3-1 PUBLISHED TSS REPORTS	2	N	94-02
N	09		N	INFORMATION - 3-1 PUBLISHED TSS REPORTS	1	N	92-01
N	09	3-12	N	INFORMATION - 3-2 UNPUBLISHED TSS MANUSCRIPTS	2	N	94-02
N	09	3-7	N	INFORMATION - 10 REQUESTS FOR INFO AND PUBLICATIONS - GENERAL	1	N	94-02
N	09	3-34	N	INFORMATION - 10-1 WASHINGTON REPLIES TO REQUEST FOR INFO	2	N	94-02
N	09	7-8	N	HISTORY OF CDC	1	N	92-01
N	09	1-7	N	HISTORIES OF PATIENTS IN THE TUSKEGEE STUDY 1970	1	Y	92-01
N	09	4-22	Y	GUIDELINES FOR PUBLIC HEALTH ADVISORS	1	N	92-01
N	10	3-16	N	INFORMATION - 3-3 BACKGROUND PAPER ON TSS - RECORD COPY WITH REVISIONS	1	N	94-02
N	10	3-14	N	INFORMATION - 3-4 MISC. PUBS. RELATING DIRECTLY OR INDIRECTLY TO TSS	1	N	94-02
N	10	3-13	N	INFORMATION - 5 NEW NEWS RELEASES	1	N	94-02
N	10	3-8	N	INFORMATION - 6 THE DETROIT FREE PRESS	1	N	94-02
N	10	3-9	N	INFORMATION - 6-1 ASSOCIATED PRESS AND OTHER ACTIVITIES	1	N	94-02
N	10	3-27	N	INTERPRETATION OF X-RAYS - DR. MOORE - UNTREATED MALES IN ALABAMA	1	Y	94-02
N	10	4-2	N	JAMES, CAROLYN (PUBLIC HEALTH NURSE) TUSKEGEE TDY FY 1975-1976	1	N	94-02
N	10	3-47	N	LEGAL - 1 DIVISIONS, OPINIONS AND INTERPRETATIONS	1	N	94-02
N	10	5-7	N	LEGAL - AFFADAVIT - JOHN D. MILLAR, MD - TUSKEGEE SUIT	1	N	94-02

RESTRICTED	BOX_NUMBER	FOLDER_NO	LBLD_TSS	TITLE	NO_FOLDERS	CRRSPNDG	ACC_NO
N	10	5-6	N	LEGAL - AFFDAVIT - SIDNEY OLANSKY, MD - TUSKEGEE SUIT	1	N	94-02
N	10	5-8	N	LEGAL - AFFDAVIT - WILLIAM HATSON - TUSKEGEE SUIT	1	N	94-02
N	10	3-3	N	KENNEDY HEARINGS ON HUMAN EXPERIMENTATION - SENATE HEALTH SUBCOMMITTEE	1	Y	92-01
N	10	3-2	N	LEGAL TUSKEGEE AFFDAVITS	1	Y	92-01
N	10	4-15	N	INITIAL PLANNING 1950-1958	1	N	92-01
N	10	4-6	N	LEGAL STIPULATIONS AND PT LIST - GRAY'S LIST OF "LOST TO FOUND"	1	Y	92-01
N	10	3-29	N	INFORMATION - 3-2 UNPUBLISHED TSS MANUSCRIPTS (EXTRA COPY)	1	N	94-02
N	10	5-25	Y	INTERNAL REVIEW AND DRAFTS	1	N	94-02
N	10	7-33	Y	LAURIE, ANNIE RIVERS	1	N	92-01
N	11	1-4	N	LEGAL TUSKEGEE INVESTIGATION - AUGUST 1972 (AD HOC COMMITTEE INFO, ALSO)	1	N	94-02
N	11	5-12	N	LETTER FILE	1	Y	94-02
N	11	3-45	N	MAPS? (MISCELLANEOUS)	1	N	94-02
N	11		N	MEETINGS - MINUTES OF SECOND MEETING OF MEDICAL CONSULTANTS TO REVIEW MEDICAL CARE AND INFORMATION GIVEN (STUDY PHOTOGRAPHS)	1	N	94-02
N	11	3-5	N	MISC - 3RD GENERATION SYPHILLIS (1988-1989)	1	N	92-01
N	11	7-16	N	LETTERS TO PHA'S	1	Y	92-01
N	11	7-12	N	LETTERS TO GLORIA STONE, RN	1	Y	92-01
N	11	8-36	N	M&S ORIGINALS	1	N	92-01
N	11	8-9	N	MAILING LABELS	1	N	92-01
N	11		Y	LISTS	1	Y	92-01
N	11	5-15	Y	MEDICARE	1	Y	94-02
N	11	3-6	Y	MEETING TO REVIEW RESULTS OF EXAMINATION AND TREATMENT OF TSS PARTICIPANTS	1	N	92-01

RESTRICTED	BOX_NUMBER	FOLDER_NO	LBLD_TSS	TITLE	NO_FOLDERS	CRRSPNDING	ACC_NO
N	11	7-30	Y	MEETING	1	N	92-01
N	12	3-46	N	MISCELLANEOUS - SAMPLE COPIES OF CORRESPONDENCE, FORMS	1	N	94-02
N	12		N	MISCELLANEOUS	1	Y	92-01
N	12		N	MISCELLANEOUS INFORMATION	1	N	92-01
N	12	9-17	N	MONOGRAPH 1953 (SIC)	1	N	92-01
N	12		N	NATIONAL RESEARCH COUNCIL - US	1	N	92-01
N	12		N	PUBLIC HEALTH SERVICE - MEETING OF PENICILLIN INVESTIGATORS	1	N	92-01
N	12		N	NOTIFICATION OF PROPOSED TRAVEL	1	N	92-01
N	12	3-44	N	PERSONNEL - GENERAL 1938-1939	1	N	92-01
N	12	3-6	N	PERSONNEL - GENERAL	1	N	94-02
N	12		N	PERSONNEL - 1 ASSIGNMENTS - DETAILS	1	N	94-02
N	12	2-27	N	MONOGRAPH - 1955 TUSKEGEE STUDY	1	N	92-01
N	12	4-20	N	HMHR	1	N	92-01
N	12	7-32	N	MAT'L VD RESEARCH PROGRAM - OMB CLEARANCES	1	N	92-01
N	12	7-9	N	NEWS ITEMS ON TSS MOVIE	1	N	92-01
N	12	5-14	Y	MISCELLANEOUS	1	N	94-02
N	12		Y	MONTHLY AND ANNUAL REPORTS, 1973-1978	1	N	94-02
N	12	1-27	Y	NEWS ARTICLES	1	N	92-01
N	12	4-3	Y	OPINION	1	N	94-02
N	12	3-7	Y	PACKET OF INFORMATION TAKEN BY DR. SENCER TO WASHINGTON ON FIRST TRIP	1	N	92-01
N	13	1-5	N	PRIVILEGED COMMUNICATION	1	Y	94-02
N	13	3-42	N	PROGRAMS AND PROJECTS - 1973-1974	1	Y	94-02
N	13	3-43	N	PROGRAMS AND PROJECTS - AUTOPSY STUDY 1955	1	N	94-02
N	13		N	PROGRAMS AND PROJECTS - TSS - BLOOD PRESSURE BY AGE 1967	1	N	94-02

RESTRICTED	BOX_NUMBER	FOLDER_NO	LBLD_TSS	TITLE	NO_FOLDERS	CRRSPINDING	ACC_NO
N	13		N	PROGRAMS AND PROJECTS - TSS - 2	N		92-01
				MISC STUDIES ON PATIENTS EXAMINED FROM 1958-1968			
N	13		N	PROGRAMS AND PROJECTS - TSS - 1	N		92-01
				PROJECT CLEARANCE 1971			
N	13		N	PROGRAMS AND PROJECTS - TSS - 1	N		94-02
				PROJECT CLEARANCE 1966			
N	13		N	PROGRAMS AND PROJECTS - TSS - 1	N		92-01
				PERCENTAGE OF ADJUSTMENT BETWEEN TESTS			
N	13	1-26	N	PROGRAMS AND PROJECTS - VENEREAL DISEASE BRANCH - CASE - TUSKEGEE STUDY 1971-1972	1	N	92-01
				PROJECT 1939	1	N	92-01
N	13	1-5	N	PT #021-C	1	N	92-01
N	13		N	PT #009S	1	N	92-01
N	13	2-34	N	PROJECT #313, TUSKEGEE ALA, DECEASED PATIENTS	1	Y	92-01
N	13		N	PHS 0.19 REQUISITION FOR . . . OF SERVICES, SUPPORT . . . EQUIPMENT	1	N	92-01
N	13	8-39	N	PRESS COMMENTS	1	N	92-01
N	13	1-16	N	PT #048-S	1	N	92-01
N	13	3-4	Y	PROTOCOL FOR MEDICAL EVALUATION	1	N	92-01
N	14	1-24	N	PT #277-C	1	N	92-01
N	14		N	PURCHASE ORDERS	1	Y	92-01
N	14		N	RECEIVING REPORT	1	N	92-01
N	14		N	RECORDS - THE PRIVACY ACT	1	N	92-01
N	14		N	RECORDS - TRANSMITTAL AND RECEIPT	1	N	92-01
N	14		N	REPORTS - PRELIMINARY ANALYSIS OF TABLES IN THE LATE MANIFESTATION OF UNTREATED SYPHILIS	1	N	92-01
N	14	9-26	N	REPORTS - 1954 DRAFTS	1	N	92-01
N	14	9-2	N	REPORTS - PATHOLOGY IN THE UNTREATED SYPHILIS STUDY -	1	Y	92-01

RESTRICTED	BOX_NUMBER	FOLDER_NO	BLD_TSS	TITLE	NO_FOLDERS	CRRSPNDING	ACC_NO
N	14	8-7	N	STATISTICS AND COMMENTS REPORTS - AUTOPSED PATIENTS IN ALABAMA STUDY - BASIC INFORMATION	1	Y	92-01
N	14	3-25	N	REPORTS - 2 SPECIAL	1	N	94-02
N	14	8-43	N	READING FILE - M47	1	N	92-01
N	14	8-46	N	READING FILE - M48	1	N	92-01
N	14	8-45	N	READING FILE - M49	1	N	92-01
N	14	8-49	N	READING FILE - M50	1	N	92-01
N	14	8-51	N	READING FILE - M51	1	N	92-01
N	14	8-54	N	READING FILE - M52	1	N	92-01
N	14	8-56	N	READING FILE - M53	1	N	92-01
N	14	8-57	N	READING FILE - M54	1	N	92-01
N	14	8-59	N	READING FILE - M56	1	N	92-01
N	14	8-60	N	READING FILE - M57	1	N	92-01
N	14	8-61	N	READING FILE - M58	1	N	92-01
N	14	8-62	N	READING FILE - M59	1	N	92-01
N	14	8-63	N	READING FILE - M60	1	N	92-01
N	14	8-11	N	READING FILE - M62	1	N	92-01
N	14	8-27	N	READING FILE - M63	1	N	92-01
N	14	8-24	N	READING FILE - M64	1	N	92-01
N	14	8-23	N	READING FILE - M65	1	N	92-01
N	14	8-21	N	READING FILE - M66	1	N	92-01
N	14	8-18	N	READING FILE - M67	1	N	92-01
N	14	8-8	N	READING FILE - M68	1	N	92-01
N	14	8-5	N	READING FILE - M70	1	N	92-01
N	14	8-15	N	READING FILE - M71	1	N	92-01
N	14	8-16	N	READING FILE - M72	1	N	92-01
N	14	8-13	N	READING FILE - M73	1	N	92-01
N	14	8-40	N	READING FILE - M74	1	N	92-01
N	14	8-41	N	READING FILE - M75	1	N	92-01
N	14	8-26	N	REPORTS	1	N	92-01
N	14	1-8	N	PT #080-C	1	N	92-01
N	14	1-14	N	PT #194-S	1	N	92-01
N	14	9-19	Y	REPORTS - 1970 TRIPS	1	N	92-01
N	14	2-29	Y	RECORD OF DEATHS AND AUTOPSIES - SEPTEMBER 1965	1	Y	92-01
N	14	1-6	Y	RECORD OF DEATHS AND AUTOPSIES	1	Y	92-01

RESTRICTED	BOX_NUMBER	FOLDER_NO	BLD_TSS	TITLE	NO_FOLDERS	CROSSPINDING	ACC_NO
N	15		N	- JUNE 1957-DECEMBER 1963 REPORTS - TO SURGEON GENERAL OF VISIT TO SOUTHERN STATES TO OBSERVE GENITOINFECTIONS	1	N	92-01
N	15	9-1	N	DISEASE CONT REPORTS - TWENTY - TWO YEARS OF SEROLOGIC OBSERVATION IN A SELECTED GROUP	1	N	92-01
N	15	8-5	N	REPORTS - TWENTY YEARS OF CLINICAL OBSERVATION OF SYPHILITIC AND NONSYPHILITIC GROUPS	1	N	92-01
N	15		N	REQUESTS FOR TUSKEGEE INFORMATION	2	N	92-01
N	15		N	ROENTGENOLOGICAL RECORD - MISCELLANEOUS DOCUMENTS SAMPLE OF CONGRESSIONAL CORRESPONDENCE	1	Y	92-01
N	15	2-22	N	SERIOLOGY SHEETS (XEROX COPIES) REVIEW OF THERAPY RECOMMENDATIONS	1	N	92-01
N	15	1-67	N	ROSENWALD AREA REPORTS ON TUSKEGEE STUDY FOR	1	Y	92-01
N	15	7-23	N	MEETING HELP 2/6/69 RESOURCE DOCUMENTS	1	N	92-01
N	15	8-31 7-28	N	SAMPLE OF MATERIAL USED IN FOLLOW UP OF WIVES/WIDOWS OF FORMER TUSKEGEE STUDY PARTICIPANTS	1	N	92-01
N	15	7-1	N	SIXTH MEETING OF THE TUSKEGEE SYPHILIS STUDY AD HOC ADVISORY PANEL 3/1/73	1	N	92-01
N	15	2-21	N	RESULTS OF ROSENWALD DEMONSTRATION - SEROLOGICAL STUDY	1	Y	92-01
N	15	1-1	Y	RESULTS EXPECTED, RESULTS OBTAINED, SYPHILIS AS IT EXISTED IN 1932	1	Y	94-02

RESTRICTED	BOX_NUMBER	FOLDER_NO	LBLD_TSS	TITLE	NO_FOLDERS	CRSPNDING	ACC_NO
N	16	1-3	N	STATUS REPORTS OF PARTICIPANTS 1974	1	N	94-02
N	16	1-4	N	STATUS REPORTS OF PARTICIPANTS 1972	1	N	94-02
N	16		N	STUDY OF UNTREATED SYPHILIS IN GROUP OF UNSELECTED RURAL MALES OVER 25 YEARS OF AGE 1935 COMPILAT	1	N	92-01
N	16	3-22	N	SUPPLIES AND EQUIPMENT - GENERAL	1	N	94-02
N	16	1-25	N	SYPHILIS DIAGNOSED AT AUTOPSY BY AGE AT DEATH	1	N	92-01
N	16	9-36	N	THERAPY - REVIEW OF THERAPY RECOMMENDATIONS FOR LATE SYPHILIS - 1932-1972	1	N	92-01
N	16	1-18	N	THCP - FOLLOW UP RESULTS	1	Y	94-02
N	16	3-21	N	TRAINING - GENERAL	1	N	94-02
N	16	3-10	N	TUSKEGEE STUDY	1	Y	94-02
N	16	5-24	N	TUSKEGEE	1	Y	94-02
N	16		N	UNFOLDED MATERIAL (MISC CORRESPONDENCE)\	1	N	94-02
N	16	1-61	N	SSA FOLLOW UP DATA - ETHEL BURROWS	1	Y	92-01
N	16	1-43	N	SUMMARY STATUS OF TUSKEGEE PATIENTS - SEPT 1972	1	Y	92-01
N	16	1-42	N	TABLES AND CHARTS ON CARDIOVASCULAR FINDINGS	1	N	92-01
N	16	3-9	N	UNFOLDED DOCUMENT (MAP OF TUSKEGEE)	1	N	92-01
N	16	2-6	N	UNFOLDED RECORDS	1	N	92-01
N	16	2-36	N	UNFOLDED RECORDS	1	Y	92-01
N	16	3-1	N	UNFOLDED RECORDS (MILBANK MEMORIAL FUND PUBLICATIONS)	1	N	92-01
N	16	4-5	N	SPOUSES AND CHILDREN	1	Y	92-01
N	16	4-18	N	TERMINATION OF TSS	1	N	92-01
N	16	4-7	N	THCP CARD AND MEDICARE CARD	1	N	92-01
N	16		N	UNFOLDED (1970)	1	Y	92-01
N	16	2-8	N	UNFOLDED RECORDS (1 LEGAL	2	Y	92-01

RESTRICTED	BOX_NUMBER	FOLDER_NO	LBLD_TSS	TITLE	NO_FOLDERS	CRRESPONDING	ACC_NO
N	16	3-11	N	(SIZED)			
N	16	2-13	N	TABP CHILDREN FOLLOW UP HX	1	Y	92-01
N	16	7-11	N	UNFOLDED RECORDS	1	Y	92-01
N	16	9-24	Y	TELEPHONE LISTS OF ACCEPTING CALLS	1	Y	92-01
N	16	1-54	Y	TRIPS	1	Y	92-01
N	16	21	n	TUSKEGEE	1	Y	92-01
N	16	23	n	Serologic Results Related to Cardiovascular Findings 1970	1	n	92-01
N	16	24	n	Transcripts of Proceedings-Fourth Meeting Tuskegee Syphilis Study 1972	1	n	91-01
N	16	25	n	Request for Contract With Blue-Cross Blue-Shield of Alabama	1	n	92-01
N	16	26	n	Untreated Syphilis in the Negro Male 1951-52	2	n	92-01
N	16	27	n	Twenty-two Years of Serologic Observation	1	n	92-01
N	16	28	n	Socio-economic Background of Macon County Study	1	n	92-01
N	16	29	n	Follow up of Tuskegee Study-25th Year	1	n	92-01
N	16	30	n	Patient Information	1	n	29-01
N	16	31	n	Medical Terminology	1	n	92-01
N	16	32	n	Autopsy Information	1	n	92-01
N	16	33	n	Public Vouchers	1	n	92-01
N	16	22	Y	Milbank Memorial Fund Map of Tuskegee 1950	1	n	92-01
N	17	12	N	UNLABELLED FOLDER	1	Y	92-01
N	17	17	N	UNLABELLED FOLDER	1	Y	92-01
N	17	1-3	N	UNLABELLED FOLDER	1	Y	92-01
N	17	1-23	N	UNLABELLED FOLDER	1	Y	92-01
N	17	1-30	N	UNLABELLED FOLDER	1	N	92-01
N	17	2-5	N	UNFOLDED RECORDS (PUBLICATIONS)	1	N	92-01
N	17	2-30	N	UNLABELLED ENVELOPE	1	Y	92-01
N	17	1-59	N	UNLABELLED FOLDER	1	N	92-01

RESTRICTED	BOX_NUMBER	FOLDER_NO	LBLD_TSS	TITLE	NO_FOLDERS	CRRSPNDING	ACC_NO
N	17	1-60	N	UNLABELED FOLDER	1	N	92-01
N	17	1-62	N	UNLABELED FOLDER	1	Y	92-01
N	17	2	N	UNLABELED FOLDER	1	Y	92-01
N	17	2-12	N	UNLABELED FOLDER	1	Y	92-01
N	17	2-37	N	UNLABELED FOLDER (DRAFT OF	1	Y	92-01
N	17	3-10	N	UNLABELED FOLDER (DRAFT OF	1	N	92-01
N	17	4-4	N	CRITERIA FOR INITIAL PHASE)	1	Y	92-01
N	17	4-14	N	UNLABELED FOLDER	1	Y	92-01
N	17	4-10	N	UNLABELED FOLDER (MISC CORRES	3	N	92-01
N	17	2-2	N	AND PERSONAL HISTORIES)	1	Y	92-01
N	17	1	N	UNLABELED FOLDER	1	n	92-01
N	17	2	N	Correspondence of Dr. R. A.	1	n	92-01
N	17	3	N	Vonderlehrer	1	n	92-01
N	17	5	N	Medical Forms	1	n	92-01
N	17	6	N	Correspondence of Dr. M. O.	1	n	92-01
N	17	7	N	Bousfield	1	n	92-01
N	17	8	N	Report on Medical Activities	1	n	92-01
N	17	9	N	at Tuskegee-1948	1	n	92-01
N	17	10	N	Correspondence of Dr. J. D.	1	n	92-01
N	17	11	N	Miller	1	n	92-01
N	17	12	N	Proposed Biopsy of Lymphnode	1	n	92-01
N	17	13	N	Purchase Orders	1	n	92-01
N	17	14	N	Use of Tuskegee VA Hospital	1	n	92-01
N	17	15	N	for Patient Follow Up	1	n	92-01
N	17	16	N	Patient Observation Procedures	1	n	92-01
N	17	17	N	and Forms	1	n	92-01
N	17	18	N	Correspondence of Dr. Anne R.	1	n	92-01
N	17	19	N	Yobs	1	n	92-01
N	17	20	N	Interviews With Patients 1972	1	n	92-01
N	17	21	N	Proceedings of Conference on	1	n	92-01
N	17	22	N	VD Washington, D. C. 1936	1	n	92-01
N	17	23	N	Field Investigation Progress	1	n	92-01
N	17	24	N	Report 1952	1	n	92-01
N	17	25	N	Analysis of Current Status of	1	n	92-01
N	17	26	N	Tuskegee Study 1970	1	n	92-01
N	17	27	N	Purposed Patient	1	n	92-01
N	17	28	N	Certificate-25th Year of Study	1	n	92-01

RESTRICTED	BOX_NUMBER	FOLDER_NO	BLD_ISS	TITLE	NO_FOLDERS	CRISPINDING	ACC_NO
n	17	17	n	Chamblee Conference 1951	1	n	92-01
n	17	18	n	Notes on Cardiovascular Syphilis	1	n	92-01
n	17	19	n	Autopsy, X-ray, and Fluoroscopy Examinations 1952	1	n	92-01
n	17	20	n	Treatment History and Cause of Death 1952-1972	1	n	92-01
n	17	21	n	Patient Deaths 1971	1	n	92-01
n	17	22	n	Trip Report-Tuskegee Alabama 1970	1	n	92-01
n	17	23	n	Autopsy Information	1	n	92-01
n	17	24	n	Patient Information Requests	1	n	92-01
n	17	25	n	Funds for Panel Services 1972	1	n	92-01
n	17	26	n	Injection Therapy	1	n	92-01
n	17	27	n	Long-Term Studies in Untreated Syphilis	1	n	92-01
n	17	28	n	Miscellaneous Correspondence	1	n	92-01
n	17	29	n	Annual Visit to Tuskegee 1968	1	n	92-01
n	17	30	n	Drugs Used in the Chemotherapy of Syphilis	1	n	92-01
n	17	31	n	Control of Syphilis in Southern Rural Areas	1	n	92-01
n	17	32	n	Southern Medical Journal 1931	1	n	92-01
n	17	33	n	Follow Up of Macon County Study Participants	1	n	92-01
n	17	34	n	Early Warning Test for Syphilis	1	n	92-01
n	17	35	n	Follow Up of Spouses and Children	1	n	92-01
n	17	36	n	Patient Follow Up-Tuskegee Medical Care Program	1	n	92-01
n	17	37	n	Effect of Syphilitic Infection on Life Expectancy	1	n	92-01
n	17	38	n	Neurologic Investigation	1	n	92-01
n	17	39	n	Problems in Tuskegee Study	1	n	92-01
n	17	40	n	Review of Procedures in Tuskegee Study	1	n	92-01
n	17	41	n	Tuskegee Visit Report 1951	1	n	92-01

RESTRICTED	BOX_NUMBER	FOLDER_NO	BLD_JSS	TITLE	NO_FOLDERS	CRRSPNDG	ACC_NO
N	17	42	n	Results of Twenty Study	1	n	92-01
N	17	43	n	Report of Delegation II	1	n	92-01
				Tuskegee Syphilis Study Ad Hoc			
				Advisory Panel '972			
N	17	44	n	Criteria for Classout of	1	n	92-01
				Initial Phase			
N	18		N	UNTITLED FOLDER (BACKGROUND	1	N	
				MATERIAL/CORRESPONDENCE)			
N	18		N	UNTITLED FOLDER (DRAFT)	1	N	
N	18		N	UNTITLED FOLDER (FROM DRAWER	1	N	
				3)			
N	18		N	UNTITLED FOLDER (LEGAL)	3	N	
N	18		N	UNTITLED FOLDER (MEMO RE:	1	N	92-01
				FOLLOW UP)			
N	18		N	UNTITLED FOLDER (MISC	1	Y	92-01
				CORRESPONDENCE)			
N	18	4-21	N	UNLABELED FOLDER	1	N	92-01
				(MISCELLANEOUS CORRESPONDENCE)			
N	18		N	UNTITLED FOLDER (MISC	1	N	
				CORRESPONDENCE)			
N	18		N	UNTITLED FOLDER (MISC	3	N	
				CORRESPONDENCE)			
N	18	4-1	N	UNLABELED THREE RING BINDER	3	Y	92-01
				(KENNEDY HEARINGS)			
N	18		N	UNTITLED	1	N	92-01
N	18	8-20	N	UNTITLED	1	N	92-01
N	18	1	n	Hearing of Senate Health	1	n	92-01
				Subcommittee 1973			
N	18	2	n	Background Paper on Tuskegee	1	n	92-01
				Study			
N	18	3	n	Recommendation and Plans of Ad	1	n	92-01
				Hoc Advisory Panel 1972			
N	18	4	n	CDC Plans	1	n	92-01
N	18	5	n	Protocol for Medical	1	n	92-01
				Evaluation			
N	18	6	n	Implementation of Plan to	1	n	92-01
				Secure Medical Treatment			
N	18	7	n	Status of Implementation	1	n	92-01

RESTRICTED	BOX_NUMBER	FOLDER_NO	LABD_ISS	TITLE	NO_FOLDERS	CORRESPONDING	ACC_NO
n	18	8	n	Report	1	n	92-01
n	18	9	n	Second Meeting of Medical Consultants 1974	1	n	92-01
n	18	10	n	Final Report of the Ad Hoc Advisory Panel	1	n	92-01
n	18	11	n	Court Rulings	1	n	92-01
n	18	12	n	Drafts of Ad Hoc Advisory Panel Subcommittees 1973	1	n	92-01
n	18	13	n	Race, Prejudice, and Health Care Symposium	1	n	92-01
n	18	14	n	Medical Articles	1	n	92-01
n	18	15	n	List of Correspondence	1	n	92-01
n	18	16	n	Pollard vs United States	1	n	92-01
n	18	17	n	Legal Correspondence	1	n	92-01
n	18	18	n	X-ray Measurements of Heart and Aorta	1	n	92-01
n	18	19	n	Salary Information-Nurse Eunice Rivers	1	n	92-01
n	18	20	n	Salary Information-Elizabeth Kennebrew	1	n	92-01
n	18	21	n	Trip Report 1962	1	n	92-01
n	18	22	n	Initial Planning Conference	1	n	92-01
n	18	23	n	Clinical Status of Tuskegee Patients	1	n	92-01
n	18	24	n	Pulse of Pharmacy	1	n	92-01
n	18	25	n	Alabama Municipal Journal 1956	1	n	92-01
n	18	26	n	Carver Foundation Tuskegee Institute Annual Report 1953-54	1	n	92-01
n	18	27	n	Guidelines for the Examination of Participants	1	n	92-01
n	18	28	n	Correspondence A. Freeman Institute	1	n	92-01
n	18	29	n	Untreated Syphilis in the Adult Male Negro	1	n	92-01
n	19		n	UNTITLED FOLDER (RE: POLLARD VS US AND CONGRESSIONAL CORRESPONDENCE)	2	n	

RESTRICTED	BOX_NUMBER	FOLDER_NO	BLD_TSS	TITLE	NO_FOLDERS	CRRSPDING	ACC_NO
N	19		N	UNTITLED FOLDER (MISCELLANEOUS CORRESPONDENCE)	3	N	92-01
N	19		N	UNTREATED SYPHILIS IN THE MALE NEGRO - CARDIAC X-RAY AND BLOOD PRESSURE FINDINGS	1	N	92-01
N	19		N	UNTREATED SYPHILIS IN THE RURAL NEGRO - NOTES, LITERATURE AND TABLES FOR INCOMPLETED STUDY - SUM'	1	N	
N	19	2-24	N	UNTREATED	1	Y	92-01
N	19	8-35	N	USPHS ANNUAL REPORTS - RESEARCH 1928-1952	1	N	92-01
N	19	1	N	Heating of the Ad Hoc Advisory Panel 1973	1	N	92-01
N	19	3	N	Neurosyphilis Study 1953	1	N	92-01
N	19	4	N	Tuskegee Study Protocol	1	N	92-01
N	19	5	N	Tuskegee Study 1968	1	N	92-01
N	19	6	N	Postmortem Examinations in Untreated Syphilis	1	N	92-01
N	19	7	N	Syphilis Demonstrations in Six Southern States	1	N	92-01
N	19	8	N	Hoble Clinic Macon County, Alabama	1	N	92-01
N	19	9	N	Syphilis Demonstration Macon County	1	N	92-01
N	19	10	N	Bureau of the Budget Clearance Actions 1966	1	N	92-01
N	19	11	N	Gonorrheic Disease Control in the South 1940	1	N	92-01
N	19	12	N	Cooperative Project Agreement 1970-71	1	N	92-01
N	19	13	N	Correspondence of Dr. Austin V. Delbeil	1	N	92-01
N	19	14	N	Correspondence of Dr. Murray Smith	1	N	92-01
N	19	15	N	Results of Physical Examination	1	N	92-01
N	19	16	N	Criteria for Interpretation of	1	N	92-01

RESTRICTED	BOX_NUMBER	FOLDER_NO	LBD_TSS	TITLE	NO_FOLDERS	CRRSPNDING	ACC_NO
n	19	17	n	Blood Pressure Readings	1	n	92-01
n	19	18	n	Supplies for Tuskegee Survey 1968	1	n	92-01
n	19	19	n	Outline for Tuskegee Survey 1951	1	n	92-01
n	19	20	n	Clinical Studies in the Treatment of Syphilis	1	n	92-01
n	19	25	n	Contribution of Tuskegee Study to Medical Knowledge	1	n	92-01
n	19	26	n	Tuskegee Medical Care Program	1	n	92-01
n	19	27	n	Background Data	1	n	92-01
n	19	28	n	Incidence of Arteriosclerosis	1	n	92-01
n	19	29	n	Grants-Rosewald Family Fund	1	n	92-01
n	19	30	n	Research Papers of Dr. Joe Caldwell	1	n	92-01
n	19	31	n	Correspondence of Dr. Don W. Printz	1	n	92-01
n	19	32	n	Miscellaneous File	1	n	92-01
n	19	33	n	Milestones in VD Control	1	n	92-01
n	19	34	n	Results Expected From the Tuskegee Study	1	n	92-01
n	19	35	n	Research in Humans-PHS Policy 1972	1	n	92-01
n	19	36	n	Nurses Training School	1	n	92-01
n	19	37	n	Hypercholesteremia	1	n	92-01
n	19	38	n	Correspondence of Nurse Eunice Rivers Laurie	1	n	92-01
n	19	39	n	Correspondence of Dr. Sidney Olansky	1	n	92-01
n	19	2	y	Mortality Rates	1	n	92-01
n	19	2	y	Patient Histories	1	n	92-01
n	19	2	y	Congressional Correspondence	1	n	92-01
n	20		n	WORK SHEETS 1932- 1935 - TABULATIONS AND EXAMINATIONS AND AUTOPSIES	1	n	92-01
N	20		N	X-RAY MEASUREMENTS OF THE HEART AND GREAT VESSELS 1948	1	N	92-01
N	20	2-20	N	VD CLINIC (GC)	1	Y	92-01

RESTRICTED	BOX_NUMBER	FOLDER_NO	LEAD_ISS	TITLE	NO_FOLDERS	CRSPNDING	ACC_NO
N	20	3-8	N	M & C FOLLOW UP APPROVED	1	N	92-01
N	20	2-15	N	WORK SHEETS	1	Y	92-01
N	20	4-11	N	VD	1	Y	92-01
N	20	4-9	N	WIDOWS OUTSIDE ALABAMA/GEORGIA	1	N	92-01
N	20	8-42	N	WITNESS LIST	1	N	92-01
Y	20	3-10	N	TUSKEGEE STUDY	1	Y	94-02
N	20	4-8	Y	WORKING FILE	2	N	94-02
N	20	8-6	Y	WORK SHEETS	1	N	92-01
Y	21	1-20	N	WORKING FILE	2	N	92-01
Y	21	3-26	N	1945	1	Y	92-01
Y	21	5-10	N	1938	1	Y	92-01
Y	21		N	1952	1	Y	94-02
Y	21		N	365	1	Y	94-02
Y	21		N	ALABAMA UNTREATED SYPHILIS -	1	Y	92-01
Y	21		N	MISCELLANEOUS ROUGH DRAFTS	1	Y	92-01
Y	21	9-34	N	AUTOPSIES - GENERAL	1	Y	92-01
Y	21	1-44	N	1951	1	Y	92-01
Y	21	2-32	N	ALABAMA - MACON COUNTY -	1	Y	92-01
Y	21	2-16	N	AUTOPSIES	1	Y	92-01
Y	21	2-3	N	ALABAMA UNRX'D STUDY	1	Y	92-01
Y	21	1-18	N	ALABAMA UNRX'D E - 1952	1	Y	92-01
Y	21	1-52	N	1940	1	Y	92-01
Y	21	1-12	N	1941	1	Y	92-01
Y	21	1-64	N	1962	1	Y	92-01
Y	21	1-38	N	1937	1	Y	92-01
Y	21	1-32	N	1952	1	Y	92-01
Y	21	1-1	N	1953	1	Y	92-01
Y	21	1-55	N	1958	1	Y	92-01
Y	21	1-11	N	1962	1	Y	92-01
Y	21	1-10	N	1972	1	Y	92-01
Y	21	1-4	N	1973	1	Y	92-01
Y	21	2-33	N	ALABAMA UNRX'D E 1949	1	Y	92-01
				AUTOPSY DIAGNOSES - DIAG.			
				FIRST AND SECOND PHYS. SET UP			
				FOR MCB IN 1947			
Y	21	1-31	N	1935	1	N	92-01
Y	21	1-32	N	1945 (107 CYS)	1	N	92-01
Y	21	1-50	N	1946	1	N	92-01

APPENDIX N

IRB CONSENT FORM



University of Pittsburgh

*School of Information Sciences
Department of Library and Information Science*

633 LIS Building
135 N. Bellefield Avenue
Pittsburgh, Pennsylvania 15260
412-624-9435
Fax: 412-648-7001

Approval Date: 7/2/03
Renewal Date: 6/15/04
University of Pittsburgh
Institutional Review Board
IRB Number: #0305120

CONSENT TO ACT AS A PARTICIPANT IN A RESEARCH STUDY

TITLE: The Tuskegee Syphilis Study: Access and Control over Controversial Records

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Why is this study being done?

The purpose of this research study is to evaluate the efficacy of the National Archives and Records Administration's (NARA) access policy toward the Tuskegee Syphilis Study records, which are in its custody.

Who is being asked to take part in this study?

Approximately fifteen individuals with varied backgrounds who have consulted the records or know about them will be interviewed for this study.

What are the procedures of this study?

If you agree to participate in this research study, you will be interviewed and asked a series of questions. You will be interviewed by the principal investigator. The interview will take approximately 1½ - 2 hours to complete. The investigator will ask questions that concern access to the records, including any problems with access to specific material. You will be asked questions about the kind of information sought, how important are the records, and should all the records be made available to the public, including the medical files? You may refuse to answer any questions if you do not feel comfortable doing so. The principal investigator will also collect and analyze documents to supplement the interviews.

What are the possible risks and discomforts of this study?

The primary risk associated with participation is that the identities and job titles of those interviewed in this study will appear in the final research project, which could affect job security. The primary investigator will go over the questions with the participants and if there are questions that make the participant uncomfortable he/she does not have to answer them. In addition, the participant may choose not to participate at all in the interview.

Will I benefit from taking part in this study?

You will receive no direct benefit from participating in this study.

Are there any costs to me if I participate in this study?

There are no costs to participants in this research study.

How much will I be paid if I complete this study?

You will not be paid for participating in this study.

Will anyone know that I am taking part in this study?

All records pertaining to your involvement in this study will be kept by the primary investigator. Your name and job title, however, will be identified within the final research project. At the end of this study, any records that personally identify you will remain stored in locked files and will be kept for a minimum of five years. Your identity will be revealed in any description or publications of this research. In unusual cases, your research records may be released in response to an order from a court of law. It is also possible that authorized representatives from the University of Pittsburgh Research Conduct and Compliance Office, the University of Pittsburgh IRB may review

your data for the purpose of monitoring the conduct of this study. Also, if the investigators learn that you or someone with whom you are involved is in serious danger of potential harm, they will need to inform the appropriate agencies, as required by Pennsylvania law.

Is my participation in this study voluntary?

Your participation in this study is completely voluntary. You may refuse to take part in it, or you may stop participating at any time, even after signing this form.

How can I get more information about this study?

If you have any further questions about this research study, you may contact the investigators listed at the beginning of this consent form at the phone numbers given. If you have any questions about your rights as a research subject, please contact the Human Subjects Protection Advocate at the University of Pittsburgh IRB Office, 412.578.8570.

PARTICIPANT'S CERTIFICATION

- I have read the consent form for this study and any questions I had have been answered to my satisfaction.
- I understand that I am encouraged to ask questions about any aspect of this research study during the course of this study, and that those questions will be answered by the researchers listed on the first page of this form.
- I understand that my participation in this study is voluntary and that I am free to refuse to participate or to withdraw my consent and discontinue my participation in this study at any time.
- I agree to participate in this study.
- A copy of this consent form will be given to me.

Participant's Signature

Date

CERTIFICATION of INFORMED CONSENT

I certify that I have explained the nature and purpose of this research study to the above-named individual(s), and I have discussed the potential benefits and possible risks of study participation. Any questions the individual(s) have about this study have been answered, and we will always be available to address future questions as they arise.

Printed Name of Person Obtaining Consent

Role in Research Study

Signature of Person Obtaining Consent

Date

APPENDIX O

INTERVIEW SAMPLE

September 20, 2001

Interviewee

CR: Charles Reeves, Director Archival Operations, National Archives and Records Administration Southeastern Regional Center

Interviewer

TW: Tywana Whorley

TW: How many administrative boxes are there?

CR: There are 38.

TW: Are there any other boxes?

CR: Yes, but they are separated from the administrative files.

TW: Can you give me a list of those?

CR: Yes and I can give you a list of those series here. For instance the patient medical records there are 47 boxes of those. Now it says there is actually the administrative records it says here

boxes 1-38 plus 32a. If you really want to know we can walk back and look on the shelf to find out.

TW: Are the restricted records near the administrative files or are they in a separate place.

CR: Some of the administrative files are restricted and they are shelved with the administrative files. The others are in a different location.

TW: What is considered restricted information?

CR: The restricted information is any patient identifier; name and social security numbers. I haven't seen any of those addresses specific enough that we think you could trace it back and find out who was living there or names of next of kin because...One of the reasons these records are restricted even though the patients most of them are dead is to protect the next of kin.

TW: Tell me why you can't get back to the administrative files that have restricted information.

CR: We went through them years ago and those that could fairly easily be redacted we redacted. The ones that we did not just had so many patient identifiers that you would have more holes than you would have. I haven't looked at them recently but that was sort of a judgment call when we did it and again we could always go through them again and we might be able to release a few more but its just more trouble than we thought it was worth.

TW: I reviewed the agreement between the CDC and NARA in the accession record. It says that no one, including researchers would not have access to the medical files. Is that in the spirit of FOIA?

CR: You looked at that agreement more recently than I have because I did redact some of the medical files,

TW: At the time of the agreement it seems that it's not in agreement with FOIA.

CR: Obviously it could be challenged and you would see what would happen. CDC has some statutory provisions. Even now some of the records are being created cannot be released and they have to do that to be able to do their job and ask the questions they do and gather the information they do.

TW: Have you received calls requesting to see the medical records?

CR: As far as I know you are probably the first person who has looked at those medical records and it I had read that agreement again you might not have looked at them.

TW: Have you released records with sensitive information upon death?

CR: Yes other records.

TW: What is the actual policy when it comes to sensitive information that are contained in records that NARA has in its custody? Do you work out an agreement with the agency first before you decide what your policy will be?

CR: We don't deal with sensitive information all that much when the agency offers to transfer their records. They can site FOIA and we typically will examine the records, examine the FOIA law, call our access people in Washington and make a case by case judgment.

TW: What is your written policy?

CR: The NARA regulations and whatever all those different section of the [audible] and privacy act.

TW: When I requested to look at the medical files, did you contact the people in D.C.?

CR: I don't know, that I probably did not.

TW: You made a judgment?

CR: I probably made a judgment myself.

TW: So other than the regulations on the WEB-Site do you have specifically a booklet on how to deal with other requests or you basically go by the regulations?

CR: I go by the regulations. There are all kinds of regulations and we try to follow those.

TW: How are the Tuskegee Syphilis Study records handled or treated differently?

CR: Well they are treated differently basically because of the agreement between NARA. We would in this case protect the privacy of the dead and their heirs. That is the major difference between you know the general policy is that privacy ends with death but in this instance there is an exception. If I were looking at other records and if there was some indication that people had a disease such as syphilis or AIDS, we would probably treat those in a similar way or at least we would seek guidance.

TW: Who are you protecting?

CR: Well the idea with Tuskegee I've been told is such a small community and that people if you know that this guy was a part of the study and he had syphilis people there would know who are his children and who his grandchildren were. So that is another factor and obviously these aren't just your run of the mill records. They are studies is and has been controversial and so they sort of treat them a little bit differently then just normal records.

TW: How do you personally feel about the records?

CR: The only thing that gives me pause I guess is the way we treat the records. As you mentioned the names are out there and that doesn't mean we would release the medical records. The other records I sort of wondering why we are still protecting them but the medical records contain the kinds of information I can understand those are kept private.

TW: What about challenging the agreement between the CDC and NARA?

CR: Obviously anybody can file a FOIA request for records and we would send it or confer with our access officer in the National Archives and decide either to say yeah or neigh. If we say neigh then any citizen has a right to file in Federal Court.

TW: If you have a researcher asking to see certain documents, what is your response?

CR: The National Archives is in the job of making records available and most of what we have that's no problem. There are some exceptions with CDC records.

TW: Do you think you those records would have been transferred?

CR: Transfer dates are established if the agency is still using the records a lot of which happens all the time. They don't have to transfer them, they have an extension on the transfer and we don't particularly want records that the agency is still using heavily or anybody else is using heavily.

TW: Do you run into problems getting records from agencies? If so, how does NARA deal with it?

CR: Yeah, I mean we have no police obviously and some agencies are reluctant to transfer some of their records for various reasons and other agencies would like to transfer everything they can as quickly as they can partly because they don't have the time to do the reference work. The other thing it takes a certain amount of work to get the records ready to transfer and last week, two weeks ago one of our staff members went to a couple of Federal Court Offices one in Macon

and one in Valdosta picked up records simply because the courts didn't choose to spend the time to box them up and send them to us.

TW: How often have you contacted the Office of the General Counsel about the Tuskegee Syphilis Study records?

CR: I have contacted them a number of times about the records. Basically under what condition to grant access, what I could let them [public] see and what I couldn't let them see.

TW: Why not release the records. People need to know what happened.

CR: We should be able to release the records that tell what happened, what was done without releasing patient identifiers. We should be able to do that and I think we have. You can tell the story without telling the names of the people involved or at least the participants in the study. I'm sure there will always be people who are suspicious.

TW: How important are these records?

CR: This is a very important study and very important records so we to some extent want to advertise that we have them. On the other hand, if we have 40 people in a day come in and look at them, then we have more than we can handle. We're certainly not trying to conceal the fact that we have them and whenever we've do presentations to groups we usually mention that these are among the records that we have. The center can brag on them a little bit as important records in our holdings.

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¹ Much of this series is restricted by 5 U.S.C. (b)(6)-Personal information and information revealing the identities of participants in the study is restricted. For example, parts of the folder list are restricted to protect patient identities and medical information. As a result, the administrative files, which are boxes 1-20a are unrestricted, while boxes 21-35 and 1-3 remain restricted, which contain medical information.

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