



Published in final edited form as:

Ethics Behav. 2012 ; 22(6): . doi:10.1080/10508422.2012.730787.

Research Challenges and Bioethics Responsibilities in the Aftermath of the Presidential Apology to the Survivors of the U. S. Public Health Services Syphilis Study at Tuskegee

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Abstract

In 1997 President William Clinton issued an apology to the living male survivors of the U.S. Public Health Syphilis Study at Tuskegee. While the apology became the focus for many, little attention has been paid going forward to two very important recommendations by President Clinton that accompanied the apology. President Clinton pointed out that it is through the remembering of the shameful past of the Syphilis Study at Tuskegee that we can build a better present and a better future for the *nation*. Second, President Clinton directed the Secretary of Health and Human Services to work in partnership with higher education to prepare training materials for medical researchers as well as postgraduate fellowships to train bioethicists to build on core ethical principles of respect for individuals, justice, and informed consent, and how to use these principles effectively in racial/ethnic minority populations, especially African Americans. This article examines bioethical research challenges left in the wake of the U.S. Public Health Syphilis Study at Tuskegee and the presidential apology. This manuscript raises for consideration the inclusion of these issues in health care reform and the implementation of the Affordable Care Act. It asks: What is the right or good thing to do? What are our obligations to one another? Two challenges are examined: 1) Conducting research with African Americans without knowledge of bioethics specific to this population; and 2) The ethical dilemma of conducting research that does not adequately take into account the diversity within the Black population that is a contributing factor in health disparities. Training and policy recommendations responsive to President Clinton's Apology are presented.

Keywords

Tuskegee; presidential apology; affordable care act; population health ethics; research ethics training

“The eight men who are survivors of the syphilis study at Tuskegee are a living link to a time not so very long ago that many Americans would prefer not to remember, but we dare not forget. It was a time when our nation failed to live up to its ideals, when our nation broke the trust with our people that is the very foundation of our democracy. It is not only in remembering that shameful past that we can make amends and repair our nation, but it is in remembering that past that we can build a better present and a better future. “... we commit to strengthen researchers’ training in bioethics... So I am directing Secretary Shalala to work in partnership with higher education to prepare training materials for medical researchers. They will be available in a year. They will help researchers build on core ethical principles of

respect for individuals, justice and informed consent, and advise them on how to use these principles effectively in diverse populations...to increase and broaden our understanding of ethical issues and clinical research, we commit to providing postgraduate fellowships to train bioethicists especially among African Americans and other minority groups. HHS will offer these fellowships beginning in September of 1998 to promising students enrolled in bioethics graduate programs.”

(President William Jefferson Clinton, Apology, 1997)

In 1997 former President Clinton on behalf of the federal government issued an apology to the male survivors of the Tuskegee Study of Untreated Syphilis in the Negro Male (Chelala, 1997) and their families. This long overdue apology for unethical treatment of African American men in a study conducted by the federal government was both a historic moment and a moment of hope for change in the accountability of researchers working with African American participants. Clinton called for us not only to remember the Tuskegee study, which began in 1932 and only ended in 1972, but to learn from its ethical failures in order to build a better present and future. In his role as president, he directed the then Secretary of Health and Human Services Shala to develop ethics training materials that would educate biomedical researchers about core ethical principles to prevent similar research abuses from occurring in African American populations. In his speech he focused in on “principles of respect for individuals, justice and informed consent” and advice on how to use these principles effectively in racial/ethnic minority populations. The year 2012 represents the 15th anniversary of President Clinton’s call for creating a better present and future, an appropriate time to reflect on whether we have met his call for change.

In the last decade, scholarly efforts to examine the legacy of the Tuskegee Study of Untreated Syphilis in the Negro Male (the study’s formal name) have focused on documenting the rates of participation in research by African Americans and their mistrust of the research enterprise. Much of this investigation was a response to the reported difficulties of clinical researchers with recruiting and participation of African Americans for human studies, particularly HIV-related clinical and behavioral trials (Mays 2012 in this issue). This focus on mistrust and clinical trial participation has distracted from efforts to develop core bioethical principles for health research specific to African Americans. This in turn has slowed efforts to develop science-based trainings that address the ethical dilemmas specific to research with Black Americans (Mays, 2001). Starting with the leadership of then Health and Human Services Secretary Shala, NIH did commission through its T15 grant mechanisms course development of research ethics but little was focused specifically on African Americans. While many of the T15 courses were developed and some publically shared (<http://grants2.nih.gov/training/t15.htm>), no NIH policy or consensus developed from this work that provided guidance specifically on ethical approaches for working with African Americans. It is the case that President Clinton’s call for change has elicited only a partial response.

The goal of this article is to refocus discussions about the legacy of the U.S. Public Health Syphilis Study at Tuskegee away from blaming African Americans for their mistrust of the research system and toward developing a science-based bioethics for conducting research in African Americans populations. This paper examines the challenges faced in research endeavors as a function of not having a bioethics health research guide for working with African American populations.

In the face of the tremendous health disparities that African Americans experience, research efforts that are efficacious and provide solutions need to be fast tracked to reduce premature loss of life (Woolf, Johnson, Fryer, Rust, & Satcher 2004; Satcher et al., 2005). In an article by Satcher and colleagues examining Black/White mortality disparities for 1991–2000, age-

adjusted mortality rates for White males and females were a quarter to almost a third lower compared to African American males and females (Woolf, Krist, Johnson, & Stenborg, 2005). They estimate that if during this period the two racial/ethnic groups were comparable it would have prevented the deaths of 886,202 Black Americans. On a yearly basis they estimate that if Black/White mortality disparities did not exist it would save 83,570 Black Americans (Satcher et al., 2005). This same racial/ethnic pattern of health disparities is evidenced in proportionally greater number of cases of HIV, diabetes, or cardiovascular disease (CVD) that are adding to the morbidity in Black Americans (Karlamañgla, Merkin, Crimmins, & Seeman 2010; Macinko & Elo, 2009). The greatest disparities exist in the receipt of health care services. The IOM Report, as well as a number of reviews (Nelson, 2002; Smedley, Stith, Nelson 2003); Escarce, Epstein, Colby, & Schwartz 1993; Giacomini, 1996; Mayberry, 2000; Johnson, Lee, Cook, Rouan, & Goldman, 1993; Canto et al., 2000; Peterson, Wright, Daley, & Thibault 1994; Franks, May, Wenger, Blount, & Eaker, 1993; Abreu, 1999; Gomes & McGuire, 2001; Schulman et al., 1999; Van Ryn, 2000) have cited instances of differences in services. A study of Medicare beneficiaries' utilization data for 1986 found that African Americans were less likely than Whites to receive 23 different services, including such procedures as cardiac surgery. The more advanced, invasive or expensive the technology the less likely it was used in the care of African Americans. More recent studies demonstrate that compared to Whites, African Americans are less likely to be admitted to the hospital when they come into emergency rooms with complaints of chest pain to receive care in coronary care unit, thrombolytic therapy, coronary angiography, or bypass surgery. They are more likely to be sent home and told to monitor their conditions and come back if the symptoms continue. They receive less aggressive care and intervention to reduce morbidity and mortality. While research was able to count and document differences in equities it is research that understands more the context of the behavior and the social determinants of the inequity that is needed for solutions.

Research is needed to understand the mechanisms by which racial health disparities persistently occur. But before such research can begin, researchers who are unfamiliar with the cultural and contextual contributions that are embodied in African American population level health inequities would greatly benefit from training that could increase their research skills for increasing the participation of adequate numbers of African American in research. Study results are statistically valid in specific populations only if adequate numbers of subjects are enrolled. Given the severity of health disparities experienced by Black Americans, failing to equip oneself with adequate training to ensure African American participation in research may be as unethical as allowing African Americans to participate in studies that will not result in findings for their specific racial/ethnic group. Even when African Americans participate in a research study if analyses are not conducted due to inability to power such studies it raises equity issues of population benefits for the African American community in participating in research activities. One pathway for better research outcomes in the recruitment and participation of African Americans in biomedical and behavioral research may be through culturally specific bioethical training of investigators that equips them with skills to design research that will attract and retain African Americans. There are two questions that are the domain of bioethics that while challenging can serve in developing guidelines for working with racial/ethnic minority populations. They are: "What is the right or good thing to do?" and "What are our obligations to one another?"

Challenge 1. The conduct of research in African American populations without bioethics health research training specific to African Americans

Each of us who engages in research funded by the federal government and increasingly other entities such as foundations are required to complete research ethics training. One of the major instruments for this training is the Collaborative Institutional Training Initiative

(CITI) which began in 2000 and has since that time flourished as a source for research ethics training (<https://www.citiprogram.org/aboutus.asp>). This proliferation of attention to research ethics training is one of the impacts of President Clinton's 1997 Apology. In this CITI training, we learn some of the facts such as who, when, where and what happened in Tuskegee but little of the broader contextual bioethical issues. The training fails to instruct how the metaphor of this event is not really over for some African Americans who as a result of health disparities, poverty and other societal conditions enter research studies as a way to access unaffordable tests or care, receive incentives or access a resource for themselves or family that normally would be beyond their means such as school based testing for a child or retina scans to check diabetes status. The content and message of the training is that an abusive incident has left African Americans distrustful of medical research. The training says little about how the Tuskegee study robbed the African American community of longer lives and maybe even different legacies for the men who died from tertiary syphilis. Little is learned about the stigma experienced by the generations of families of the survivors described in the Wimberly (2012), article in this issue, or the betrayal suffered by undocumented Latinos who were able to participate in research studies but not be eligible based on the Affordable Care Act for the population-level health benefits that were developed from those research studies because of their undocumented status described by Carcari-Stone and Avila (2012) in this issue. The training never underscores the underlying message of the Tuskegee study: that the abusive treatment of the African American men conveyed to Black America that White America did not value the lives of these men beyond their use as research subjects and a vehicle for data collection for scientific publications. The training ignores the fact that Black America sees in the disparities of the current health care system the type of mortality disparities described by Satcher and his colleagues (Satcher et al., 2005; Woolf, Krist, Johnson, & Stenborg, 2005). For those who take the CITI training, the Tuskegee study is a historical event from the long ago past. It is true that the Syphilis Study was begun 80 years ago has been stopped for 40 years and does not currently exist. However, there is little in the training that helps research investigators accomplish the goals of respect and justice that Clinton calls for in his Apology (Carmack, Bates, & Harter, 2008). It is in the not knowing that, despite the ending of the Syphilis Study that, its replacement exists in the form of the health care treatment bias described in the IOM Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care Report (Smedley, Stith & Nelson 2003). The papers in this volume hopefully will help researchers have a greater appreciation of the types of ethical violations that fail to employ culturally specific research designs to address respect and justice at the individual and population levels in the IOM's Unequal Treatment Report, we learned that even when insurance status, income, age, and severity of conditions are comparable health care is not (Nelson, 2002; Smedley, Stith, & Nelson, 2003). We learned that differences in health care for racial/ethnic minority groups occur as a function of their economic and social status vulnerability that persists within a broader historic and contemporary context of inequality fueled by prejudice, bias, racial/ethnic discrimination and stereotyping (Nelson, 2002). The very depth of the inequity in health disparities in the African American community coupled with the persistence of non-minority researchers who continue to be funded despite failing to recruit and retain African Americans is a part of the continuing neglect of equal benefit in the research and evidenced-based treatment process. The IOM Unequal Treatment Report indicated that one solution to the disparities in health was that treatment should be practiced-based on the best available science (Nelson, 2002). Yet when research fails to enroll minorities sufficiently in studies to have power to detect racial/ethnic differences then solutions to health disparities in health care are difficult if not impossible. In their review of the literature about evidenced-based mental health treatments for racial/ethnic minority youth, Huey & Polo (2008) found "probably efficacious" or "possibly efficacious" but no "well-established" treatments for anxiety-related problems, attention-deficit/hyperactivity disorder, depression, conduct problems, substance use problems, trauma-related syndromes,

and other clinical problems. As Huey & Polo (2008) point out in their discussion, the sample sizes of many of the youth treatment studies often may not have been sufficient to test true differences. While studies may indicate findings of no difference in the treatment approaches, no difference does not necessarily indicate group equivalence—it may really reflect a lack of adequate statistical power to detect the difference. Huey & Polo (2008) explain that studies intended to test Treatment \times Ethnicity interaction effects are often underpowered, which decreases the likelihood of detecting moderator effects. To detect an interaction effect if ethnicity is really a moderator in the treatment process requires much larger sample sizes (Huey & Polo, 2008) than are often collected. Therefore, providing equal health benefits to racial/ethnic minority's demands that they be sufficiently present in number in the research studies to detect treatment differences related to race/ethnicity and social status.

While the Syphilis Study was stopped 40 years ago as of 2012, the legacy of unequal benefit from research continues unabated. Our current bioethics research training fails to equip researchers to understand how well-meaning research, conditions of health care and health policies are the modern day manifestation of the Syphilis Study at Tuskegee. The real legacy of the Syphilis Study may be the persistence of societal norms that maintain the vulnerability of particular racial/ethnic minority populations—norms that that allowed the Syphilis Study to move to death as the variable of interest. Where were the African American principal investigators then and unfortunately a recent study of the PIship of NIH grants raises the same question now (WGDBRW, 2012). In a recent analysis of the review and award process of NIH grants no matter the type of grant program or mechanism, African Americans were the least likely of all racial/ethnic groups to receive research awards (Ginther et al., 2011).

The US Public Health Service Syphilis Study began as well-intentioned and lost its way. It moved from an outcome of searching for ways to save lives to studying the path to the end of life at the expense of African American men. This continues to happen today as investigators competing for a very small number of funded NIH applications submit proposals to which they already know the answers as they have done this same research in other populations, other context or age groups. It is not really about making a difference in the lives of African Americans but about staying funded. Risky or complicated, high risk high impact grant opportunities are infrequent and as long as review committees lack senior well-funded African Americans in sufficient numbers as part of review panels, there is less chance of high risk high impact studies of African Americans being funded in this tight funding climate. It raises yet again the fundamental biomedical ethical questions: What is the right or good thing to do? What are our obligations to one another?

There have been a number of African Americans professionals and others who have argued that it is a wrong assumption to believe that we all share the same ethical values in America (Randell, 2012; Flack & Pellegrino, 1992; Prograis & Pellegrino, 2007; Gbadegesin, 2007). Rather, our experiences as filtered by race/ethnicity, culture, gender and our history in this country shapes our perspectives on some of the basic and essential areas of bioethics such as personhood, bodily integrity in how we handle body parts, tissues, fluids and genetic information, our moral compasses, even how we define, wellness, or a long, fulfilling and useful life (Wiredu 1992ab; Thomas, 1992; Harris, 1992; Pellegrino, 1992; Peterson, 1992; Bowman, 1992; Branson, 1992; Dula, 1992; Dula, 2007; Peniston, 2007). Also there is no monolithic African American view of biomedical ethics because of the rich diversity that exists within African, African American and other subgroups that make up the Black population in the United States (Wiredu, 1992ab; Peniston, 2007). So even in the constructing of a guide to African American bioethics it is necessary to be either exclusive

of who it addresses within the Black population or inclusive to address the ethnic diversity of Black Americans.

One reason that research bioethics informed by African American perspectives becomes so important and necessary is that there are not sufficient African American research scientists distributed around the country that can ensure adequate protections. It is therefore a greater imperative that bioethics training for the general population of researchers incorporates these perspectives. As long as we are all certified as competent to conduct research on African American but without adequate training then we are continuing down an unethical path.

Before we can train others about African American bioethics it is important to provide a population level context that is broader than individual consent and individual reparations but is focused on the deeper legacy of the U.S. Public Health Syphilis Study at Tuskegee. For the White researcher, the legacy is that of mistrust that African Americans have about not participating in their research. For African Americans, the legacy is being as vulnerable to today as when the actual study took place. If African Americans value as an aspect of their racial/ethnic identity their connectedness to other African Americans including those who lived in the past and were wronged historically, research participation and its outcomes is not just about the consent of the individual but issues are raised that the actions of one have implications for the welfare of others. So until we can strongly convey that African American bioethics is not just about the rights and wrongs of an individual but that every wronged person regardless of when it occurred impacts the legacy of the future generation, we will not get the teaching of bioethics right.

Challenge 2: Culture and subpopulation differences in African Americans as a part of ethical responsibility in the analyses of data

In conducting research within the Black population in contrast to other racial ethnic groups less attention is paid to subpopulation differences. Yet data accumulated over a period of years have shown us that culture and racial/ethnic are important in accounting for health attitudes, behaviors, and approaches to treatment. It has become standard practice to assess subpopulations differences within Asian and Other Pacific Islanders and Latinos and to ask Native Americans if they have a tribal affiliation. Yet researchers working within Black populations tend to classify all individuals as Black or African American. In rare cases, researchers record whether Black research participants are U.S.-or foreign-born. Not knowing about ethnic diversity within the Black population can amplify health disparities; this was seen in the case of a publicity campaign designed to inform Californians about a new state law that established the right to a language interpreter in medical settings.

A well-regarded foundation in California funded public campaigns in specific languages to ensure that the diverse populations of California were informed of the right to interpreters in medical care. However, no campaign was launched in languages specific to Black immigrant populations. Yet, California is second only to New York in the number and diversity of Blacks who immigrate to the state, and particularly to Los Angeles, where Africans, Haitians, Belizeans, Dominicans and others with French, African languages and others can be found. More than a quarter of the Black populations of Boston, New York and Miami are foreign born. The number of foreign-born Blacks in the United States is significant. In 2005, nearly two-thirds of the 2.8 million foreign-born Blacks in the United States were born in the Caribbean or some other Latin American country, one-third were born in Africa and the remaining small percentage come from Canada, Europe, and even Cuba.

In the last decade as a result of the National Survey of American Life (<http://rcgd.isr.umich.edu/prba/nsal.htm>), we have learned how profoundly important the differences are between Caribbean Blacks and African Americans in the United States and the differences that being U.S.-born versus foreign-born are in mental and physical health outcomes (Hammond et al., 2011; Griffith, Johnson, Zhang, Neighbors, & Jackson, 2011; Williams et al., 2012). Yet we continue to read studies in which questions of nativity and subpopulation identification are ignored in research on Black Americans. This happens because there continues to be a reliance on the minimum standards in both the collection and classification of data on race and ethnicity in researching Black populations (Mays, Ponce, Washington & Cochran, 2003).

At a gross level of racial classification, a person is Black or African American. Yet the cultural habits, behaviors, exposures and ethnic subpopulation origins of Southern Blacks with their African origins can be quite different than those in New England where they may be Cape Verdeans from West Africa and influenced by the Portuguese, or those in Southern California, where they may be of Egyptian origin. In my own case, though I have lived in California for many years, I am very clear that not only am I an African American but I am a Southern African American, as my parents were both from the South and were a part of the big migration from the South to Chicago in search of work. There are many things for me that were shaped by my Southern roots that range from the foods that I ate as a child through my early adulthood to the beliefs that I have about my interconnectedness to other African Americans being a part of a migration, or my sense of responsibilities around my privileged education and occupational status which come from knowledge of the sacrifices of others for my civil rights. When a Black in America is classified in research studies purely by race without some of these other important characteristics, science has failed at capturing the nuanced data that is often key to understanding the role of social determinants in health disparities.

As a member of the federal advisory committee responsible for health data and health statistics, National Committee on Vital and Health Statistics, its subcommittee on Populations produced reports and letters to the Secretary of Health and Human Services about the classification of race and ethnicity (NCVHS, 2005). There was encouragement for the federal government to produce data reports that go beyond the reporting of the minimum 5 race categories of Black or African American, White, American Indian or Alaska Native, Asian, Native Hawaiian or Other Pacific Islander and to report on subgroups when possible (i.e. Puerto Rican, Mexican American, Cuban). Information about Black subgroup differences is critical for efficacious interventions, according to theories on social determinants of health disparities. Given the growing numbers of foreign-born Blacks and the diversity of origin among African Americans, it is critical that health researchers identify subgroup differences in racial groups. Developing tools to educate researchers about the need to understand and search for evidence about subgroup differences is an appropriate response to the questions: What is the right or good thing to do? What are our obligations to one another? Clinton promised survivors a better educated researcher as a mean to prevent research abuses but we have lacked leadership in what the education should be. Too often, the legacy of the Syphilis Study has been defined through the lens of white researchers who have had problems with recruiting and retaining Black Americans in the research enterprise.

The Future: The Tuskegee legacy redefined to benefit people not research

It is time that we refocus the Legacy of the Tuskegee Study of Untreated Syphilis in the Negro Male by not letting its' primary legacy be that of White researchers telling America how mistrustful Black Americans are about participating in their research, as if that is a bad thing (Mays, 2011). The legacy should not be the numerous studies of how to get African

Americans to participate in research (see Mays, Coles & Cochran, 2012 in this issue). If there were many more Black researchers, creativity born of collaboration with Black communities would be a part of the dialogue about strategies to increase participation of African Americans in studies. If more racial/ethnic minority scientists were majority members on the review panels that fund research studies, successful methods that engage and retain racial/ethnic minorities in studies would be more prevalent. The spending of precious research dollars on how to address mistrust in non-minority researchers is not advancing research but rather serving as remedial education as do over attempts at the same study question in the hope of getting it right (Mays, 2011). Researchers without training or experience in community-engaged research—researchers who have never teamed with racial/ethnic minority colleagues or community-based organization CEO's as equal research collaborators—should receive continuing education mandated by their university's IRB in this area, even if they are senior in their careers. Despite Clinton's call for the federal government to remedy this lack of education, a majority of researchers lack sufficient knowledge of the intricacies of racial/ethnic minority populations, particularly African Americans to conduct research that is not only significant in its findings but that is on point with the experiences of the community.

Another approach is to refocus the legacy of the Tuskegee Study of Untreated Syphilis in the Negro Male to be a legacy of honor and lessons to be learned. First, let us as a nation come to learn what the scientific contributions are that the men in the study by being untreated taught us that helps everyday to save the lives of others (Mays, 2011). Let us tell the scientific legacy of the study of untreated syphilis in 399 untreated Negro men so that the families of the survivors of these men have their legacy of honor to share with their children and the world who has stigmatized them. We have yet to publicly share the legacy that those who are no longer here left that makes the world a healthier place. (The last study participant died in January 2004. The last widow died in January 2009). A book was published about a Black woman, Henrietta Lacks whose tumor cells were taken without her permission but yet changed medicine for the better (Skloot, 2010). We are now learning about Henrietta Lacks and the ways in which her contribution despite being taken without permission has kept many others alive and changed medicine.

We should tell the human stories of those men who were in the Syphilis Study at Tuskegee, to immortalize each and every one of the three hundred ninety-nine men as a way to make their inhuman sacrifice compel today's researcher to be more humane. It is important that as a part of the legacy of the Syphilis Study that America and the world know the human side of the men who gave their life under the banner of science. They are heroes much like those who in war give their lives to protect us. In a very similar way these men gave their lives so that others could medically benefit. Yet unlike the veterans of war we do not honor them through making them visible; instead, we spend more time making the experiment visible and the men invisible. Even when we talk about the study we call it the Syphilis Study and leave out the words of "untreated Negro male." Leaving out these words dehumanizes the experiment, making it more difficult for America to internalize the humanity of each of the 399 African American men who were untreated for syphilis. Leaving out the men also makes it easier for it to happen again in some other form. It may take us further in our efforts to make this study have the legacy of changing the behavior of researchers and establishing a set of bioethics guidelines for research if we understood in human terms what was lost in the name of science. Each man who participated in the study is a story, a connectedness back not just to the African American race but the human race for each of those men left a scientific legacy and also a human legacy. In talking with the families of the "untreated Negro males" it was clear that their stories should be a part of the legacy so that we know next time that subjects lives matter and that we must value the lives of all. What are our obligations to each other? One of them is to honor the lives of those who gave on

behalf of science by making their humanity come alive through the stories about them as told by their survivors and historical documents so that the unethical behaviors of Tuskegee do not happen again. Leadership by the federal government through NIH could accomplish this goal by funding from the National Library of Medicine which funds historical health books that contribute knowledge to biomedical public health efforts. In this issue, the ways in which this study continues to impact the family survivors of the men are discussed in the Wimberly article as well as that of Mrs. Head who is a survivor. So clearly our work is not done in addressing the legacy of the Syphilis Study

The NIH is in the best position to advance the promises of President Clinton to educate researchers to ensure that what happened 80 years ago does not happen again. At the same time, it is also those Committees that advise the President of the United States, the White House Office on Science and Technology Policy and the Presidential Commission for Bioethics that can also play a role in changing the required knowledge base of US researchers.

Acknowledgments

This work was supported by funding from the National Center on Minority Health and Health Disparities (MD000508) and the UCLA Chancellors Office for Faculty Development and Diversity. This manuscript is drawn from a talk given for the 11th Anniversary of the Tuskegee Apology at the Tuskegee Bioethics Center. I would like to thank the families of the men who participated in the U.S. Public Health Service Syphilis Study at Tuskegee who attended the event for generously sharing with me their thoughts and concerns about this historic study.

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