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Dark Medicine: How the National Research Act Has Failed to Address Racist Practices in Biomedical Experiments Targeting the African-American Community

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Dark Medicine: How the National Research Act Has Failed to Address Racist Practices in Biomedical Experiments Targeting the African- American¹ Community

Anietie Maureen-Ann Akpan*

I. INTRODUCTION

It is dangerous to be an American Negro male. America has never wanted its Negroes to be men, and does not, generally, treat them as men. It treats them as mascots, pets, or things.²

- James Baldwin

1943. Rural Alabama. The rays of the sun stream down mercilessly hot on your back, and perspiration darkens your shirt. It had been another long day of work, and you finally made your way home. As you approach your home, you see a letter tucked between the doorframes. It is a letter from a

¹ The author acknowledges that the terms “African-American” and “Black” are used frequently throughout this article. These words are not used interchangeably, but are deliberately placed in specific portions of the text to reflect each of the terms varying historical connotations.

* JD, 2013, St. Mary’s University School of Law. I would like to thank my loving family, my parents, Boni and Imoh Akpan, and my sisters, Mayen and Idara, for always encouraging me and telling me to reach for the stars. I love you all so much. Thanks to my associate editor, Ling Han and my comment advisor, Vicky Wu for supporting me while I was writing this piece and for always believing in me. Much thanks to my *Scholar* family, especially Kate Meals and Francisca Parra, for their support. I am greatly indebted to the editorial board of the Seattle Journal for Social Justice for their careful editing and excellent suggestions. I want to extend a special thank you to my article editor, Liberty Upton, for her tireless dedication to make this piece presentable. Finally, to the men of the Tuskegee Syphilis Experiment, I can only hope that this piece can introduce your story to a new generation. Thank you for your bravery.

² JAMES BALDWIN, *THE CROSS OF REDEMPTION: UNCOLLECTED WRITINGS* 26 (Randall Kenan ed., 2010).

health clinic informing you to come in for a “special procedure”³ in order to appease your illness. “This examination is a very special one,” the letter reads, “and after it is finished you will be given a special treatment if it is believed you are in a condition to stand it.”⁴ As someone who is poor and unable to afford health care treatment, you take the clinic up on its offer.

Two nurses take you to a back room upon your arrival at the clinic the following morning. They instruct you to remove your shirt while a nurse pulls out a large syringe. “You will be receiving a ‘special shot,’” she says, and they proceed to administer an excruciatingly painful spinal tap on you. This is done with no anesthesia, and no drugs to ease the insufferable pain shooting through your body.⁵ Days later, you begin to feel a strange numbness⁶ in your legs and causing you to crawl on your hands and knees to move about your house. The cause of this pain was from the “special shot” you received. However, you were never told that this “special shot” was in fact a spinal tap. You were never informed that you would be given a spinal tap, neither through the letter you received, nor upon your arrival at the clinic. You were not even properly informed of what you were being treated for.⁷ All you had been told was that you suffered from “bad blood”⁸

³ JAMES H. JONES, *BAD BLOOD: THE TUSKEGEE SYPHILIS EXPERIMENT—A TRAGEDY OF RACE AND MEDICINE* 127 (1981).

⁴ *Id.*

⁵ *See id.* at 123.

⁶ *Id.*

⁷ *Quality of Health Care: Human Experimentation, 1973: Hearing on S. 878, S. 974, and S.J Res. 71 Before the Subcomm. on Health of the Comm. on Labor and Public Welfare, 93rd Cong. 1036–43, 1210–14 (1973)* [hereinafter *Hearings*] (statement of Sen. Edward Kennedy over widespread concern with abuse in human experimentation), reprinted in *TUSKEGEE TRUTHS: RETHINKING THE TUSKEGEE SYPHILIS EXPERIMENT* 137 (Susan M. Reverby ed., 2000).

Senator Kennedy: During this time, did they indicate to you what kind of treatment they were giving you, or that you were involved in any kind of test or experiment?

Mr. Pollard: No, they never did say what it was.

and nothing more. You were never told of how the bad blood came to be; nor were you informed of how the treatments you received would fix it.

This narrative was very much the reality for many of the men selected to participate in the Tuskegee experiment. This horrendous experiment was just one example of the continuing narrative of institutionalized racism against the Black community. The brutal violence imposed by the Ku Klux Klan, segregation in the Jim Crow South, and the criminalization of Blacks are perhaps more well-known historical examples of this kind of racism. But through the clever guise of “science,” the Anglo majority was able to impose prejudice in a new way.

The US Public Health Service (USPHS) initiated the Tuskegee syphilis experiment in Macon, Alabama, in 1943, with the intent to observe untreated syphilis in African-American males.⁹ USPHS officials chose four hundred syphilitic African-American men as part of the experiment, as well as two hundred uninfected men who “served as controls.”¹⁰ The initial purpose of the study was to “explore possibilities of mass treatments”¹¹ for the illness. The subjects selected were between the ages of twenty-five and

Senator Kennedy: What did you think they were doing, just trying to cure bad blood?

Mr. Pollard: That is all I knew of.

Id.

⁸ The term “bad blood” became an allegory of sorts in representing the horrors of the Tuskegee study. It was a trigger phrase for deceitfulness, guilefulness, and racial discrimination. In this way, the term “syphilis” almost took on a taboo-esq eminence among government doctors. By not mentioning syphilis at all to the participants, it maintained the furtiveness necessary for them to conduct their procedures. MICHAEL V. USCHAN, *FORTY YEARS OF MEDICAL RACISM: THE TUSKEGEE EXPERIMENTS* 24 (2006) (“[D]octors used that term because they thought that uneducated blacks would not know the disease’s proper name.”).

⁹ See JONES, *supra* note 3, at 1.

¹⁰ *Id.*

¹¹ Allan M. Brandt, *The Case of the Tuskegee Syphilis Experiment*, in *TUSKEGEE TRUTHS: RETHINKING THE TUSKEGEE SYPHILIS EXPERIMENT* 18 (Susan M. Reverby ed. 2000).

sixty,¹² and they underwent a series of medical tests to see if they qualified for the study.¹³ The majority of the subjects selected were poor, illiterate sharecroppers and farmers who were promised free health care and therapy for their willingness to participate.¹⁴ USPHS officials induced these men into becoming a part of their study by cloaking their “ailments” nebulously under the guise of “bad blood.”¹⁵ In reality, the doctors never had any “intention of providing any treatment for the infected men”¹⁶ throughout the duration of the study.

History has illuminated how the relationship between the Black community and the American legal system has historically sustained institutionalized, racist parameters that have hindered Black people’s ability to be perceived equally against their White counterparts. From the very first interaction with the White community, Blacks were considered to be inherently inferior quasi-humans whose existence was appropriated only to serve and be subject to inhumane cruelty.¹⁷ American law was used as a powerful tool to bolster Blacks in this position. However, American legislation has played an integral role in maintaining a second-class citizenry among Black people as evidenced by Slave Codes first established in 1705,¹⁸ the Three-Fifths Compromise (which established that, in the eyes

¹² *Id.* at 21.

¹³ *See id.* (explaining that subjects underwent “a thorough physical examination including x-rays . . . and a spinal tap to determine the incidence of neuro-syphilis.”).

¹⁴ *Id.*

¹⁵ USCHAN, *supra* note 8.

¹⁶ *Id.*

¹⁷ *Anthropology in Slave Narratives*, EXISTENCE & ANTHROPOLOGY BLOG (Aug. 29, 2012), <http://existenceandanthropology.blogspot.com/2012/08/anthropology-in-slave-narratives.html>. “[T]he Africans inevitably lived close to their masters so that they could not possibly be treated just as tools; rather, they had to be granted a quasi-human level of life.” *Id.*

¹⁸ Slave codes delineated the limits to the rights of slaves in the United States. *See Slave Life and Slave Codes*, USHISTORY.ORG, <http://www.ushistory.org/us/27b.asp> (last visited Feb. 10, 2013). Although the codes may have slightly differed pending on the state, the overall objective was the same: devalue and belittle the Black race. *Id.*

of the law, Blacks qualified as three-fifths of a person),¹⁹ and Jim Crow laws enacted from 1876 to 1965 mandating racial segregation.²⁰

Blacks have been treated as an underclass for many years, and only recently has the trend begun to change. The humanization of Black people is a somewhat recent development.²¹ By asserting that the humanization of Black people is new, scholars are not purporting an over-exaggerated

¹⁹ U.S. CONST. art. I, § 2, cl. 2.

Representatives and direct Taxes shall be apportioned among the several States which may be included within this Union, according to their respective Numbers, which shall be determined by adding to the whole Number of free Persons, including those bound to Service for a Term of Years, and excluding Indians not taxed, three fifths of all other Persons.

Id. The Three-Fifths Compromise was a negotiation made at the Philadelphia Convention of 1787, where delegates decided that slaves would be apportioned as three-fifths of one person for the purpose of “political representation in the House.” *The “Three-Fifths” Compromise*, AFR. AM. REGISTRY, http://www.aaregistry.org/historic_events/view/three-fifths-compromise (last visited Apr. 17, 2013). Quantifying a person as less-than-whole implies that enslaved persons were not considered “human” enough to quantify as “whole.” See *Race in Constitutional Convention: Looking at the Past Through the Lense of Race*, SHMOOP, <http://www.shmoop.com/constitutional-convention/race.html> (last visited Apr. 17, 2013). (“[T]he clause only recognized a fraction of their humanity, thereby dehumanizing them all the more, and that the fraction it *did* recognize not only gave them no rights or liberties but actually worked to further their masters’ political influence, the stability of the institution, and therefore their status as chattel.”) The Three-Fifths Compromise essentially devalued the lives of Black people, sustaining Whites’ history of dehumanizing the darker-hued race. *Id.* The passing of this statute further solidified the perception that Blacks were no more than quasi-human chattel. *Id.*

²⁰ Just as “bad blood” was synonymous with the Tuskegee study, “Jim Crow” was synonymous with the cruel discrimination the Black community endured. See Ronald L.F. Davis, *Creating Jim Crow: In-Depth Essay*, VOYAGER, <http://voyager.dvc.edu/~mpowell/afam/creating2.pdf> (last visited Feb. 10, 2013). The Jim Crow character was birthed from a minstrel show where White entertainers would cover their faces in coal or rubber and act in a stereotypical caricature of a Black man. *Id.* Living as a Black person in the Jim Crow era essentially was like living as a second-class citizen. *Id.* The stripping of their humanity continued fervently through this time and hindered Blacks from being viewed equally as Americans. The passing of Jim Crow laws was essentially equated to legalized terrorism against Black people. *Id.*

²¹ See CORNEL WEST, HOPE ON A TIGHTROPE: WORDS & WISDOM 43 (2008) (“The very discovery that black people are human beings is a new one.”).

attempt to depict the historical narrative of Black people in the United States. Rather, this assertion reflects a dark and tragic truth to the way Black people have been treated throughout their experiences as a prominent underclass. This social structure is most likely derived from a long history of “othering” Black people.²²

“Othering” is an institutionalized phenomenon utilized to affirm the Eurocentric social power structure that differentiates between communities in order to assert one population’s superiority over another.²³ The Black community’s transition from “humans” to “others” primarily happened as a result of examinations on Black people’s anatomy and intelligence, as discussed in Part II of this article.

With Black peoples’ cemented inferior position in the American social structure as “othered” pseudo-property, they were perfectly suited to be subjects for medical studies by inquisitive White physicians. Scientific racism²⁴ has been utilized as a mechanism to oppress and manipulate Black people for a number of years.²⁵ In more contemporary times, this racialized

²² Teresa J. Guess, *The Social Construction of Whiteness: Racism by Intent, Racism by Consequence*, 32 CRIMINAL SOCIOLOGY 4, 649, 651–52 (2006), available at http://diversity.umsl.edu/documents/W07_Guess_article_s6.pdf.

Racism by consequence, operates at the macro level of society, and represents an historical evolution. It constitutes a gradual shift away from a conscious, almost personalized conviction of the inferiority of an “othered” “race.” Such conviction expresses itself in attitudes of prejudice and is acted out in discriminatory behavior. In its place follows social practices that are essentially depersonalized through institutionalization.

Id.

²³ Sara Rismyhr Englund, *Introductory Essay: “The Other” and “Othering,”* NEW NARRATIVES, <http://newnarratives.wordpress.com/issue-2-the-other/other-and-othering-2/> (last visited Feb. 10, 2013).

²⁴ Nancy Leys Stepan & Sander L. Gilman, *The Racial Economy of Science, Appropriating the Idioms of Science: The Rejection of Scientific Racism*, in THE “RACIAL” ECONOMY OF SCIENCE: TOWARD A DEMOCRATIC FUTURE 170 (Sandra Harding ed., 1993).

²⁵ See generally Amanda Thompson, *Scientific Racism: The Justification of Slavery and Segregated America*, 1 GAINES JUNCTION 1 (2003), available at <http://pat.tamu.edu>

view of science has yielded many incidents of illegal human experimentation on Black people.²⁶ However, the most horrific and notorious instance of the barbarism of this scientific racism was the infamous Tuskegee syphilis study sponsored by USPHS.²⁷

This article will focus on the National Research Act (NRA)²⁸—a renowned legislative response to the horrors of Tuskegee—and how its provisions have ineffectively and inefficiently addressed racist scientific practices that have targeted Black people. Part II will outline the history of how the Black community has been dehumanized over time. From their first footsteps on Western soil, the Black community was “othered” through the racist examining of their physical features as well as their social, cultural, and religious practices.²⁹

Part III will focus on how the NRA was developed and will entail its current provisions. This section will also discuss the NRA’s inefficiencies, and the necessary amendments that need to be made to ensure the Act has an impactful legacy by highlighting these needs through a constitutional law analysis.

Part IV will discuss how the USPHS physicians were legally liable for their behavior regardless of explicit legislation prohibiting such conduct (at

/journal/vol-1/thompson.pdf (explaining how scientific racism justified “the American system of ante-bellum slavery and post-bellum segregated education”).

²⁶ See *infra* Part VI.

²⁷ Brandt, *supra* note 11, at 15. Although hardly possible to believe, another government-funded syphilis experiment took place in conjunction with the atrocities of Tuskegee. Between 1946 and 1948, as funded by the National Institute of Health, US government scientists infected prison inmates, psychiatric patients, and prostitutes with venereal diseases such as gonorrhea and syphilis to study the effects of penicillin. See, e.g., Donald G. McNeil Jr., *U.S. Apologizes for Syphilis Experiment in Guatemala*, N.Y. TIMES, Oct. 1, 2010, <http://www.nytimes.com/2010/10/02/health/research/02infect.html>; see also *US Scientists ‘Knew Guatemala Syphilis Tests Unethical,’* BBC NEWS, <http://www.bbc.co.uk/news/world-latin-america-14712089> (last updated Aug. 30, 2011) (stating that at the end of the testing, at least 83 individuals had died).

²⁸ National Research Act, 42 U.S.C. § 201 (2012).

²⁹ *Infra* Part II.

the time). Not only will this contention be made evident through a criminal law analysis, but it will also serve as a backdrop for creating sanctions for present-day physicians who contribute to studies analogous to the Tuskegee studies.

Part V addresses the significance of adequate compensation for wronged patients; this section will offer instructions for how to construct proper compensatory remedies while also examining case law (*Skinner v. Oklahoma*³⁰ and *Moore v. Regents of the University of California*,³¹ for example) that has set constitutional precedent as to the right of privacy for one's body. Part VI of this article will discuss post-Tuskegee experimentations in the Black community, verifying why a properly amended NRA is so vital.

Part VII asserts a property rights argument by addressing the issue of commercializing the human body, and whether one can assert property rights to his or her own biological materials. Using the tragic story of Henrietta Lacks, a poor, rural Black woman, whose body was used as a springboard in progressive scientific research, it will be made evident why a property rights assertion must also be integrated into the NRA.³²

II. ANIMALIS AFRICANUS

A. How the Dehumanization of the Black Body Set the Backdrop for Its Use for Scientific Experimentation

Racism served as the primary reason for the collective dehumanization of the Black body as White majority's perceptions are what governed normality. As Whiteness was perceived as the model to measure

³⁰ See generally *Skinner v. Oklahoma*, 316 U.S. 535 (1942) (describing how compulsory sterilizations were held as unconstitutional).

³¹ See generally *Moore v. Regents of the Univ. of Cal.*, 499 U.S. 936 (1991) (explaining a plaintiff's struggle to acquire property rights for his body tissue).

³² 42 U.S.C. § 201.

immaculateness in terms of physical appearance, intelligence, and so on, Black people's "differences" placed them in the bottom-rung of the social hierarchy.³³ Biased human experimentation represents an institutionalized process of targeting communities who do not fit these socially constructed ideals of normality. The majority of these scientific "studies" constituted nothing more than government-sponsored medical warfare against disenfranchised communities.

The horrors of one such study, the Tuskegee syphilis study that took place from 1932 to 1972,³⁴ inspired the birth of the NRA. The study represented a continuation of the narrative of the world's racialized view on science, medicine, and health regarding the Black community. The Tuskegee study served as a continuance of that historical narrative, and was essentially rooted in how the Black corporal body had intrinsically been tied to White ideologies of intelligence and progression throughout history.³⁵

The dehumanization of African slaves is the most fundamental example of how Blacks were "othered" to the point of dehumanization. Scholars offer a multi-pronged analysis as to why Africans were deliberately selected to be slaves; this examination was tied to both skin color and a bigoted view of Africans' social and religious practices.³⁶ At the commencement of the

³³ Mikhail Lyubansky, *Beauty May be in Eye of Beholder but Eyes See What Culture Socializes*, PSYCHOL. TODAY (May 16, 2011), <http://www.psychologytoday.com/blog/between-the-lines/201105/beauty-may-be-in-eye-beholder-eyes-see-what-culture-socializes>. "[S]tandards of beauty are essentially "White" standards . . ." *Id.* See Audrey Thompson, *Summary of Whiteness Theory*, PAUAHTUN.ORG, <http://www.pauhtun.org/Whiteness-Summary-1.html> (last visited Apr. 17, 2013) (discussing how Whiteness has historically been used as the yardstick to measure against other racial identities in terms of intelligence and beauty).

³⁴ See Brandt, *supra* note 11, at 15 (discussing how USPHS initiated experiment in 1932). It was not until 1972 that the whistle was blown and the project shut down after investigations, thus proving the forty-year length of the experiment. *Id.*

³⁵ See Renschler & Monge, *infra* note 45 (addressing how the cranium size of Africans was examined to determine their "inferior" intelligence).

³⁶ BETTY WOOD, *THE ORIGINS OF SLAVERY* 23 (1997) ("The negative connotations that the English had long attached to the color black were to deeply prejudice their assessment

Trans-Atlantic slave trade, concomitant with the transport of Africans to the Americas, also went the Euro-based constructs of Africans' inferiority.³⁷ With the new African presence in the United States, anthropologists and scientists began to examine the biological make up of Africans, studying their "differences" to elucidate the innate inferiority of Africans as a race.³⁸ Scholars made conclusions about the Black body, not only from a social-religious backdrop, but also, more prominently, from an allegedly more scientific, empirical one.³⁹ Their genealogical criticism was primarily based in craniometry, the study of cranial size to determine human characteristics, such as intelligence.⁴⁰

This dehumanizing narrative continued well into the twentieth century, where Black health began to be viewed as a separate phenomenon from the health of Whites.⁴¹ This was no different from earlier scientists' fascination

of West Africans. If, as the English believed, the color black epitomized sin and evil, then presumably those same defects must attach to the black-skinned person." Aristotle asserts that approximating slaves with animals is not only based on their functional purposes, but that their roles within their environments inherently implied that they themselves were chattel. See David Brion Davis, *The Problem of Slavery*, THE GILDER LEHRMAN CENTER FOR THE STUDY OF SLAVERY, RESISTANCE & ABOLITION, <http://www.yale.edu/glc/forum/davis.html> (noting Aristotle's discussion on differentiating chattel slavery from other forms of slavery). This contention was one of the primary examples of how Africans were first classified as quasi-human, only helping to formulate the backdrop in which the historical demoralization of Blacks commenced. *Id.* at 22.

³⁷ Andrew Tholen, *African History Terms*, MINNESOTA ST. U., MANKATO, <http://andrewtholen.efoliomn.com/lejn> (last visited Apr. 17, 2013).

³⁸ See generally Audrey Smedley, *Origin of the Idea of Race*, ANTHROPOLOGY NEWSLETTER, Nov. 2007, available at http://www.pbs.org/race/000_About/002_04-background-02-09.htm (explaining how craniometry was utilized by anthropologists to assert Anglos' racial superiority over people of color).

³⁹ WOOD, *supra* note 36, at 22–23.

⁴⁰ HARRIET A. WASHINGTON, *MEDICAL APARTHEID: THE DARK HISTORY OF MEDICAL EXPERIMENTATION OF BLACK AMERICANS FROM COLONIAL TIMES TO THE PRESENT* 35 (2006); Stephan Jay Gould, *Morton's Ranking of Races by Cranial Capacity: Unconscious Manipulation of Data May Be a Scientific Norm*, 200 SCI. 503, 503–04 (1978).

⁴¹ Brandt, *supra* note 11, at 16.

with “othering” the Black body, but these new fascinations dealt with examining the correlations made between the Black body and sexuality.⁴²

B. The Tuskegee Syphilis Experiment

A central justification for the development of the Tuskegee syphilis study was the racialization of health by White physicians. Fascination of the intersection between Blacks, sex, and disease underscored the experiment. The Anglo view on Blacks’ sexuality is based on the theory that Blacks developed degeneratively from their White counterparts; as a result, Blacks were inherently, primitively hypersexual.⁴³ Attacks on “defenseless white women,”⁴⁴ and arbitrary studies on genital organs and cranium sizes (a method used by anthropologists of the eighteenth and nineteenth

⁴² WASHINGTON, *supra* note 40, at 45.

But whites ascribed black women’s sexual availability not to their powerlessness but to a key tenet of scientific racism: Blacks were unable to control their powerful sexual drives, which were frequently compared to those of rutting animals. This lack of control made black men dangerous and made black women sexually aggressive Jezebels who habitually enticed white men into inappropriate sexual relations.

Id.

⁴³ *Id.* at 82–85. Author discusses the tragic story of Sara Baartman, further illustrating how the exoticizing and sexualizing of the Black community was due to their physical attributes. *Id.* A Khoi woman put into servitude was later handed over to Dr. William Dunlop, a naval surgeon from England. *Id.* Her anatomy was of particular interest to Dr. Dunlop and he concluded that her “dramatically endowed figure” as a Khoi woman was an evident indicator of hypersexuality not inherent in her White counterparts. *Id.* at 84. She was grossly exhibited as a circus-esqe attraction to be publicly demeaned and humiliated, her “voluptuousness” perceived as intriguingly bizarre and foreign. *Id.* If that was not a flagrant enough display of dehumanization, upon Baartman’s death she was skinned and dismembered for further scientific observation. *Id.* at 85. Doctors perverted a mere anatomical characteristic and utilized it as a way to continue “othering” the Black race. *Id.*

⁴⁴ Brandt, *supra* note 11, at 17.

centuries⁴⁵), yielded hypotheses by the White medical community that the Black male was over-sexualized and thus more prone to venereal diseases.⁴⁶

Based on these suppositions, the doctors who conducted the Tuskegee syphilis experiment performed various studies on the subjects. Although taking blood with syringes⁴⁷ was the most common way physicians extracted material to study, these procedures escalated to become much more invasive and dangerous—spinal taps, for instance, became a frequent way to measure the growth of syphilis in the subjects.⁴⁸

⁴⁵ Emily S. Renschler & Janet Monge, *The Samuel George Morton Cranial Collection: Historical Significance and New Research*, 50 EXPEDITION 30, 37 (2008), available at <http://www.penn.museum/documents/publications/expedition/PDFs/50-3/reuschler.pdf> (discussing the works of Samuel Morton, who was previously mentioned about his notorious studies that examined the cranial capacities of different racial communities).

⁴⁶ Brandt, *supra* note 11, at 17 (“lust and immorality . . . made [B]lacks especially prone to venereal diseases”).

⁴⁷ See, e.g., JONES, *supra* note 3, at 176–77 (depicting in photos 5 and 11 how blood was drawn with syringes).

⁴⁸ See *id.* at 122 (discussing how doctors used spinal taps to detect neurosyphilis in the subjects). Dr. Vonderlehr spearheaded this effort to ensure that these severe forms of syphilis developing in the subjects were observed. *Id.* Dr. Vonderlehr, however, was more concerned with the effects of Tuskegee if the spinal taps yielded negative effects. *Id.* Some of the aftereffects included headaches, numbness, or even paralysis. *Id.* If these aftereffects became known nationwide, “the spirit of cooperation and voluntarism” that the doctors had become so dependent on in order to conduct this study would be diminished. *Id.* at 123. Hoping to expand these activities, Dr. Vonderlehr drafted letters seen as so “imposingly official” as to deceitfully entice men to the hospital to partake in the lumbar punctures:

Dear Sir,

Some time ago you were given a thorough examination and since that time we hope you have gotten a great deal of treatment for bad blood. You will now be given your last chance to get a second examination. This examination is a very special one and after it is finished you will be given a special treatment if it believed you are in a condition to stand it. . . . You will remember that you had to wait for some time when you had your last good examination, and we wish to let you know that because we expect to be so busy it may be necessary for you to remain in the hospital over one night. If this is necessary you will be furnished your meal and a bed, as well as the examination and treatment

The most prominent issue with this research was the fact that it was not based in evidence, but rather based in pseudo-scientific ideas of race, science, and health. Thus, the study has historically been viewed as being racially motivated, and even semi-eugenic, rather than as a legitimately conducted experiment.⁴⁹

III. THE BIRTH OF THE NATIONAL RESEARCH ACT (NRA)

A dark-haired legislator by the name of Edward “Ted” Kennedy sits behind a desk, his hair slightly touched with whispers of gray—indicative of the inherent stress and strain of his career.⁵⁰ Across from him sit two elderly African-American men. The young legislator settles himself behind his desk, taps his microphone gently, clears his throat, and asks, “Would you tell us a little about how you heard about this study, how you came to be involved?”⁵¹ This triggers a series of questions that forces the older gentlemen to recall very painful and agonizing periods in their lives.⁵²

The beginnings of the NRA were first yielded from the hearings conducted by Senator Ted Kennedy,⁵³ who was an adamant advocate for the survivors of the Tuskegee syphilis study.⁵⁴ Senator Kennedy spearheaded the movement for medical bioethics legislation by the conduction of a series

without cost. REMEMBER, THIS IS YOUR LAST CHANCE FOR A SPECIAL FREE TREATMENT.

Id. at 127. The anecdote mentioned at the introduction is modeled after this very letter. To so guilefully utilize phrases such as “special treatment” and “thorough examination” to manipulate an unknowing community only further chronicles manipulation of the Black community through this study. *Id.*

⁴⁹ See Elizabeth Landau, *Studies Show ‘Dark Chapter’ of Medical Research*, CNN HEALTH (Oct. 1, 2010, 6:08 PM), <http://www.cnn.com/2010/HEALTH/10/01/guatemala.syphilis.tuskegee/index.html> (discussing the racist context of the Tuskegee syphilis experiment).

⁵⁰ USCHAN, *supra* note 8, at 84–85.

⁵¹ *Id.*

⁵² *Id.*

⁵³ *Id.* at 84–85.

⁵⁴ *Id.*

of hearings in the early 1970s in which survivors of the study testified to their experiences.⁵⁵ Through these hearings, Senator Kennedy learned from the survivors of the study that the nature of these experiments was nebulously conveyed; therefore, the survivors were unable to properly assess whether or not they should participate.⁵⁶ The Senators were alarmed by the survivors' testimony detailing the lack of consent,⁵⁷ the menial

⁵⁵ *Id.* at 85.

⁵⁶ *Hearings, supra* note 7, at 137–38, 142 (discussing the Senate hearings where three Tuskegee survivors – Charles Pollard, Herman Shaw, and Lester Scott – gave testimony to Senator Kennedy in 1973 about their experiences as participants). Pollard would later bring a private suit to gain compensation for himself and other survivors. *Pollard v. U.S.*, 384 F.Supp. 304 (N.D. Ala. 1974). Both Pollard and Scott discussed the issue of not ever being properly informed of why they underwent the procedures administered to them. *Id.* “If they had told me [I had syphilis], I would have gone to a family doctor and got treated,” states Lester Scott. *Id.* This reflects that if properly informed, participants would have more than likely removed themselves from the study. *Hearings, supra* note 7, at 142.

⁵⁷ *Id.* *Natanson v. Kline*, 350 P.2d 1093 (Kan. 1960). Lack of informed consent played an integral role in USPHS doctors' ability to guilefully conduct the Tuskegee experiment. *Id.* Again, there is no legal doctrine that explicitly states doctors' liability for malpractice (intentional or not); however, the doctrine of informed consent is underlined with the principle of individual autonomy and thus the right to be informed should be highly exalted. *Id.* at 1103–04. “Anglo-American law starts with the premise of thorough-going self-determination. It follows that each man is considered to be master of his own body, and he may, if he be of sound mind . . .” *Id.* *Natanson* discusses the issue of informed consent, principally addressing physicians conducting procedures without fully exhausting information about risks. *Id.* Such case law has functioned as the building blocks of examining patient-physician issues through a legal analysis. In examining informed consent in the context of Tuskegee, it is important to understand that the issue of omission in particular is what analogizes so well with *Natanson's* above contention. When it came to informing the Tuskegee participants of what ailment they were being treated for, the subjects were told they were infected with “bad blood.” *Brandt, supra* note 11, at 22. “Bad blood,” however, was not an actual ailment but rather a euphemism used in place of an actual diagnosis of syphilis. *Id.* By deliberately choosing to withhold this diagnosis, the conduct of these physicians took away the participants' right to make a well-informed decision of “intelligent consent.” *Natanson*, 350 P.2d at 1103–04; *see also* *Moore v. Regents of the Univ. of Cal.*, 793 P.2d 479 (Cal. 1990) (discussing how plaintiff, a cancer patient, had bodily fluids patented by defendants without his content); *Scaria v. St. Paul Fire & Marine Ins. Co.*, 227 N.W.2d 647 (Wis. 1975) (suing for negligence after plaintiff becomes paraplegic due to an unconsented procedure performed by doctors); Paula Walter, *The Doctrine of Informed Consent: To Inform or Not to*

compensation received by the participants,⁵⁸ and the lack of compensation for their spouses and children who caught syphilis due to the subjects remaining untreated for a number of years.⁵⁹

Backed by the testimony at these hearings, Kennedy commenced his expedition to introduce the concept of scientific experiments conducted on humans into the narrative of American law. He first introduced a bill to create a National Human Experimentation Board⁶⁰ to regulate biomedical research, but unfortunately, it was unsuccessful.⁶¹ At the wake of his first bill's failure, Kennedy introduced another bill that would be known as the NRA, which was signed into law by President Nixon on July 12, 1974.⁶² The NRA created the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research (the Commission).⁶³ The purpose of the Commission was to serve as an advisory body that creates

Inform?, 71 ST. JOHN'S L. REV. 543, 546 (1997) (discussing that the physician thus has an obligation to "respect the autonomy of the patient" and thus his actions should be guided through benevolence with the purpose to help rather than harm).

⁵⁸ *Hearings*, *supra* note 7, at 138–39 (statement of Senator Edward Kennedy over widespread concern with abuse in human experimentation).

⁵⁹ Christopher Agulanna, *The Requirement of Informed Consent in Research Ethics: Procedure for Implementing a Crucial Ethical Norm in African Communal Culture*, 44 EUR. J. OF SCI. RES. 204, 207 (2010), available at http://www.eurojournals.com/ejsr_44_2_04.pdf. For some Tuskegee participants, the aftereffects of untreated syphilis unfortunately did not end with them. *Id.* Not only did the men who served as lab rats for this experiment endure the consequences of untreated syphilis, but for those who were married, their wives became infected with the disease as well. *Id.* There were even children who were born with the congenital syphilis as a result of this study. *Id.* In this way, we see how the legacy of Tuskegee continues to unfairly affect innocents. *Id.*

⁶⁰ The National Research Act, Pub. L. No. 93-348, 88 Stat. 342 (1974).

⁶¹ *The Development of Human Subject Research Policy at DHEW*, ACHRE REPORT, http://www.hss.doe.gov/healthsafety/ohre/roadmap/achre/chap3_2.html ("Senator Kennedy introduced an unsuccessful bill to create a National Human Experimentation Board . . .").

⁶² THE NAT'L COMM'N FOR THE PROTECTION OF HUMAN SUBJECTS OF BIOMEDICAL AND BEHAVIORAL RESEARCH, RESEARCH ON THE FETUS 3 (1975), available at http://videocast.nih.gov/pdf/ohrp_research_on_fetus.pdf.

⁶³ The National Research Act § 201.

the ethical and moral framework for medical professionals and scientists conducting experiments that involve human subjects.⁶⁴

Several components of the NRA cover the training of research personnel,⁶⁵ which regulates⁶⁶ how institutes select members for advisory councils.⁶⁷ The NRA also clearly delineates how funds are allocated to research institutions⁶⁸—only institutions that conduct medical research relating to “the cause, diagnosis, prevention and treatment of the disease or other health problems”⁶⁹ are eligible to receive government grants.

A. The NRA's Objectives and Provisions

The NRA also discusses the central role of the secretary of the US Department of Health, Education, and Welfare (now known as the secretary of US Department of Health and Human Services) in ensuring that the provisions of the NRA are properly executed. For example, the secretary is responsible for assessing “current training programs available for the training of biomedical and behavioral research personnel.”⁷⁰ One of the most important responsibilities of the secretary is the selection of the members of the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research.⁷¹ The careful selection of these members is imperative, as it is the Commission that both “identif[ies] the basic ethical principles which should underlie the conduct of biomedical and behavioral research”,⁷² and “develop[s] guidelines which should be

⁶⁴ *Id.*

⁶⁵ *Id.*

⁶⁶ *Id.* §§ 217(f), 217(a).

⁶⁷ *Id.* §§ 201(B)(1), 211(F)(1).

⁶⁸ *Id.* § 472(A)(1).

⁶⁹ *Id.*

⁷⁰ *Id.* § 473(a)(2)(A).

⁷¹ *Id.* § 201(B)(1).

⁷² *Id.* § 202(a)(1)(A)(iii)(I).

followed in such research to assure that it is conducted in accordance with such principles.”⁷³

The unfortunate aspect of this provision (and a large contributing factor to the NRA’s deficiencies to be addressed later) is that it never clarifies those guidelines. The NRA also gives the secretary of Health and Human Services power to select members for the National Advisory Council for the Protection of Subjects of Biomedical and Behavioral Research (the Council).⁷⁴ Similar to the Commission, the Council functions as an advising entity regarding “the protection of human subjects of biomedical and behavioral research.”⁷⁵ Although the Commission and the Council fundamentally serve the same purpose, the Commission establishes the moral framework for those conducting experiments, whereas the Council evaluates changes in policies and regulations regarding biomedical research.⁷⁶

The passage of the NRA was historical because it was the first piece of national legislation that recognized the need to protect human subjects in medical and scientific experiments.⁷⁷ The fact the NRA’s passage was

⁷³ *Id.* § 202(a)(1)(A)(ii).

⁷⁴ *Id.* §§ 211(a), 217(F)(1).

⁷⁵ *Id.* §§ 211(a), 217(F)(2)(A).

⁷⁶ *Id.* §§ 211(a), 217(F)(2)(B).

⁷⁷ John Harkness, Susan Lederer, & Daniel Wikler, *Laying Foundations for Clinical Research*, Vol. 79 BULL. OF THE WORLD HEALTH ORG. 365 (2001). Authors discuss Dr. Henry K. Beecher as a trailblazer to the discussion of bioethics in medical research involving human subjects. He “identified ethical lapses in research carried out by physician-scientists in renowned universities and published in the world’s leading journals.” *Id.* His prominent 1966 article published in the *New England Journal of Medicine* discussed examples of “unethical research” practices on human subjects with the purpose of exposing an unknown dark side to the medical-scientific community. Tamar W. Carroll & Myron P. Gutmann, *The Limits of Autonomy: The Belmont Report and the History of Childhood*, 66 J. OF THE HIST. OF MED. AND ALLIED SCI. 1, 87 (2001), available at <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2998285/pdf/jrq021.pdf>. Although Beecher may have been one of the first prominent speakers on this subject, it was not until the early 1970s, at the termination of the Tuskegee experiment, that the Kennedy-sponsored legislation came to fruition and put Beecher’s ideals into legislation.

sparked largely by the mistreatment of African-Americans—coupled with its passage during the mid-1970s, when racial tensions were significantly high—illustrates an attempt by lawmakers to protect communities that have historically been seen as more expendable than others.⁷⁸ While the creation of the NRA was noble and trailblazing, it unfortunately has both an overflow of provisions that are unnecessary, and a lack of provisions that would ensure the actualization of its intended impact.

The main objective of the NRA is to regulate medical research involving human subjects, and based on the legislative intent of the NRA, it is clear that it is used as a tool to preempt future violations.⁷⁹ However, due to its failure to thoroughly address past atrocities, it continues to be inefficient in its execution. There are several components that must be integrated into the NRA in order for it to have its intended impact.

B. The NRA's Inefficiencies

The NRA, though noble in its creation, lacks the necessary provisions to have the impact it seeks. In order to prevent the horrors that it was created to prevent, there are numerous amendments that need to be integrated into the NRA.

Up until the passing of the National Research Act, no other law that focused specifically on the biomedical research involving human subjects existed. *Id.* at 83.

⁷⁸ Marcia McCormick, *Race Discrimination 1970s Style*, EXAMINER.COM (Feb. 26, 2009), <http://www.examiner.com/article/race-discrimination-1970s-style>; *White House History Timelines: African Americans and the White House*, WHITE HOUSE HIST. ASS'N, http://www.whitehousehistory.org/whha_timelines/timelines_african-americans-04.html (last visited Apr. 17, 2013) (“Racial tensions were high in 1970, as [B]lacks became frustrated with economic conditions that did not improve despite advancements in civil rights.”); see *Racial Tensions Rise*, LJWORLD.COM, <http://www2.ljworld.com/stories/2010/apr/20/1970-a-year-turmoil/racial-tensions-rises/> (last visited Apr. 17, 2013) (noting an example of racial tensions at a high school in the South in 1970).

⁷⁹ *The Belmont Report*, AM. THORACIC SOC'Y, <http://www.thoracic.org/clinical/critical-care/critical-care-research/institutional-review-board.php> (last visited Apr. 17, 2013) (discussing how the purpose of the NRA and its provisions is to “prevent [future] exploitation” of “vulnerable” communities).

1. Absence of the Tuskegee Study

One of the most important and glaringly obvious omissions from the NRA and its notes is the mention of Tuskegee. Although this omission may not seem significant, acknowledging the circumstances that prompted the creation of the legislation plays an integral role in the NRA having a lasting effect, while also appropriately acknowledging those participants in the study who were wronged.

The absence of Tuskegee in the preliminary provisions of the NRA makes for a lack of context as to why the NRA was initially drafted. The NRA was written to protect human subjects targeted due to their race, yet it makes no mention of ensuring that subjects are not selected based on their identification to a specific social group.⁸⁰ Until such a provision is written into the NRA, it can never truly give reverence to those who suffered, nor can it reprove the behavior of USPHS officials or others who may conduct future analogous experiments.

2. Absence of Framework for Human Subject Selection

Further, the NRA does not discuss the significance of setting a framework to guide the selection of subjects for any future studies. While it is necessary for doctors to target specific communities when conducting clinical studies, such as a breast cancer study in women where such studies are based on empirical, scientific assertions and not on socialized views of a particular community like the Tuskegee syphilis study, legitimacy in selection of subjects is established.⁸¹ The NRA must address the

⁸⁰ See generally National Research Act, Pub. L. No. 93-348, 88 Stat. 342, 349 (1974) (illustrating how the Tuskegee Syphilis Study is absent from the text of the NRA).

⁸¹ See Borgna Brunner, *The Tuskegee Syphilis Experiment*, INFOPLEASE, <http://www.infoplease.com/spot/bhmtuskegee1.html> (“The study’s other justification—for the greater good of science—is equally spurious. Scientific protocol had been shoddy from the start.”). See generally D.L. Chandler, *Tuskegee Syphilis Experiment: America Apologizes for Racist Study 15 Years Ago Today*, NEWSONE (May 16, 2012), <http://newsone.com/2015752/tuskegee-syphilis-study/> (noting how the

specificities of how to select subjects, ensuring that selection is not based on biased notions, but rather based on empirically founded hypotheses. Here, the main contention is that the process of selecting subjects must be evidence-based.⁸² Such a process ensures that the research being conducted is done so without bias, racial or otherwise, as illustrated by Tuskegee.

3. Absence of Clear “Guidelines” and “Boundaries”

The purpose of the Commission, derived from the NRA, is to “develop guidelines which should be followed in such research to assure that it is conducted in accordance with such [basic ethical] principles.”⁸³ It is not enough to assume that careful, unbiased subject selection falls under these vague “principles,” which the Commission must enforce. Rather, guidelines and principles must be clearly and explicitly defined in order to avoid possible future problems.

One can assume that the reasoning behind the broad language used in constructing the NRA was to create an over-inclusive, all-encompassing overtone, ensuring that all similarly situated persons receive its legislative protection. However, comprehending the context in which this act was written, its general, broad language is more harmful than helpful. If the focal point of the NRA is to ensure that humanity is maintained while conducting medical studies or experiments,⁸⁴ then specificities must be explained in order to ensure that this objective is upheld.

Tuskegee syphilis study was widely understood to be an act of institutionalized racism against the Black community, rather than a legitimate scientific study).

⁸² David L. Sackett, et al., *Evidence-Based Medicine: What It Is and What It Isn't*, 321 BRIT. MED. J. 71–72 (1996), available at <http://www.ncope.org/summit/pdf/Footnote1.pdf>. Evidence-based medicine is the “conscientious, explicit, and judicious use of current best evidence in making decisions about the care of individual patients.” *Id.*

⁸³ The National Research Act, Pub. L. No. 93-348, § 202(1)(A), 88 Stat. 342(1974).

⁸⁴ *Research & Economic Development: Office of the Chancellor*, U. MISSOURI-KANSAS CITY, [SEATTLE JOURNAL FOR SOCIAL JUSTICE](http://ors.umkc.edu/research-compliance/institutional-review-board-(irb)/history-</p>
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In particular, section 202 of the NRA exemplifies this glaring lack of specificity.⁸⁵ By generally referring to broad “guidelines” and “boundaries,” this portion of the NRA does little to clarify the authors’ intentions. If a bright line “boundary” is not defined, it cannot be guaranteed that medical researchers will be aware of crossing it. It then becomes easy to escape liability if negative aftereffects occur.

Section 202 also tasks the Commission with developing guidelines to create the moral framework for physician-scientists to conduct their work.⁸⁶ However, there is no discussion in the NRA of exactly *how* these guidelines will be developed.⁸⁷ What will the Commission look to in deciding what the guidelines will be; and how they will be defined?

The NRA also refers to examining the “boundaries between biomedical or behavioral research involving human subjects and the accepted and routine practice of medicine.”⁸⁸ This again is lacking the specificity necessary in a properly written provision of legislation. While today’s doctors have ethics included in their educations,⁸⁹ it is unwise to assume that they (or society overall) fully comprehends what such a statement objectively means. An “accepted and routine practice of medicine”⁹⁰ is by no means subjective; it is defined by a series of objective and internationally revered set of doctrines.⁹¹ Allowing that portion of the

of-research-ethics (last visited Apr. 17, 2013) (“The National Research Act codified the requirement that human subjects in research must be protected . . .”).

⁸⁵ See generally National Research Act, Pub. L. No. 93-348, § 202, 88 Stat. 342 (1974) (outlining the duties of the Commission).

⁸⁶ *Id.* § 202 (A).

⁸⁷ See *id.* (noting how there are no provisions addressing the method in which guidelines to assure “accordance with such principles” are developed).

⁸⁸ *Id.* § 202(A)(1)(B)(1).

⁸⁹ Govind C. Persad et al., *The Current State of Medical School Education in Bioethics, Health Law, and Health Economics*, 36 J.L. MED. & ETHICS 89 (2008).

⁹⁰ National Research Act § 472(A)(1).

⁹¹ USCHAN, *supra* note 8.

statement to remain as it is welcomes laxity in defining the propriety of physician-scientists' conduct.

The Commission consists of an assortment of experts who all contribute to the task of creating ethical boundaries for biomedical research. The individuals of the Commission are described as people distinguished in various fields of expertise, including medicine, law, theology, as well as behavioral and social sciences.⁹² However, the NRA fails to discuss to what extent each expert contributes in creating these boundaries. This Commission may consist of “not more than five”⁹³ members involved in the biomedical industry. This language is significant because it leaves undecided the question of who the remaining individuals will be in regards to their expertise.⁹⁴ If a limit has been placed on the quantity of *these* particular types of experts, then there should be a clear statement as to how many individuals in law or theology, or any of the mentioned fields of expertise, should or should not be included in the makeup of the Commission as well. Through this type of change, one can ensure that the recommendations made by the Commission are balanced and fair. A well-balanced Commission warrants a well-balanced set of standards, thus at least somewhat guaranteeing that the communities, intended by the NRA, are indeed protected. By eliminating the broad language in sections 201 and 202, the NRA will perform more efficiently in meeting the effects of its objective, and thereby better protecting communities most in need of its legislative protection.

However, there are several other inadvertences that will help make the NRA a stronger remedy for victims of human experimentation. One solution to strengthen remedial measures in the NRA is to force researchers

⁹² National Research Act § 201(A)(B)(1).

⁹³ *Id.* § 201(b)(1).

⁹⁴ *See id.* (explaining that “the Commission shall be composed of eleven [total] members”).

to address a study's, or experiment's, definitive purpose. One of the most tragic parts of the Tuskegee study is that the finite objective to the study—examining possible cures for syphilis—never came to be.⁹⁵ A requirement of a finite objective would serve as the most impactful addition made to the NRA. It would ensure that the research entity or agency conducting the study states a definitive and expressly defined purpose to the study. The change would require this purpose to be strictly adhered to. Although it was contended that the rationale behind the Tuskegee study was significant in how it could improve public health, this objective never came to fruition.⁹⁶ Over time, a shift occurred in the purpose of the Tuskegee experiment being conducted—from finding a cure for syphilis to examining the effects of syphilis going untreated.⁹⁷

Due to this shift in objectives, the intentions of the USPHS physicians conducting the Tuskegee study went from scientifically-based—with a purpose to benefit general public health—to racially-based, putting one

⁹⁵ Brandt, *supra* note 11, at 18.

⁹⁶ USCHAN, *supra* note 8, at 9.

Because syphilis was such a menace, the U.S. Public Health Service (PHS) was anxious to study ways of controlling the disease. In fact, what became known as the Tuskegee study, was the successor to another study whose intent was to learn how to reduce the frequency of syphilis outbreaks in a population—blacks in the rural South—who appeared particularly vulnerable to infection with the disease. But at some point the purpose changed from controlling a dreaded disease to documenting the effects of the illness.

Id. The objective, however, of “documenting the effects of the illness” was moot, as many of the USPHS physicians were already aware of syphilis’ negative aftereffects that included “heart failure, loss of muscular control, blindness, insanity, and, ultimately, death.” *Id.*

⁹⁷ *U.S. Public Health Service Syphilis Study at Tuskegee*, CENTERS FOR DISEASE CONTROL & PREVENTION, <http://www.cdc.gov/tuskegee/timeline.htm> (last updated June 15, 2011) (“In truth, they did not receive the proper treatment needed to cure their illness.”); *About the USPHS Syphilis Study*, TUSKEGEE U., http://www.tuskegee.edu/about_us/centers_of_excellence/bioethics_center/about_the_usphs_syphilis_study.aspx (last visited Apr. 17, 2013) (“The intent of the study was to record the natural history of syphilis in Blacks.”).

particular community's health in danger. The NRA must include a provision declaring that any research initiated must present a finite, objective purpose to mitigate any possible abuses by researchers. If a change exists in the objectives due to new developments in the experiment, the researching entity must present that new objective and garner the approval of the Commission. This new objective (just as the primary one) must function to benefit the general public and not be used as a way for physician-scientists or researchers to fortify their own personal inquiries.⁹⁸

One of the most glaring omissions from the NRA is its failure to discuss any reprimands for doctors who violate it.⁹⁹ Failure to practice medical research in a careful and cautious way is a direct breach of the medical standard of care.¹⁰⁰ For the survivors of the Tuskegee study, breach of

⁹⁸ *Scaria v. St. Paul Fire & Marine Ins. Co.*, 227 N.W.2d 647 (Wis. 1975).

[A] physician has a duty to make a reasonable disclosure to his patient of the significant risks in view of the gravity of the patient's condition, the probabilities of success, and any alternative treatment or procedures if such are reasonably appropriate so that the patient has the information reasonably necessary to form the basis of an intelligent and informed consent to the proposed treatment or procedure. The patient then has a right to give or withhold his consent to the proposed treatment or procedure.

Id. at 653. See Alina Selyukh, *U.S. Researchers Broke Rules in Guatemala Syphilis Study*, REUTERS (Aug. 29, 2011, 7:10 PM), <http://www.reuters.com/article/2011/08/29/us-usa-guatemala-syphilis-idUSTRE77S3L120110829> (stating that “[t]oo often people become absorbed with the merit of a scientific question and can lose sight of the ethics in answering it,” further explaining that the purpose of a medical or scientific objective can sometimes get lost among medical professionals, as illustrated in Tuskegee).

⁹⁹ See generally National Research Act, Pub. L. No. 93-348, 88 Stat. 342 (1974) (noting lack of discussion of reprimand for violation of the Act's objectives).

¹⁰⁰ Since there were no laws that called to monitor any “experimentation” by medical or scientific professionals, members of these communities were given a *carte blanche* as to how to conduct their studies or experiments. Dick C. Strauss & J. Meirion Thomas, *What Does the Medical Profession Mean By “Standard of Care?”*, 27 J. OF CLINICAL ONCOLOGY 32, 192–93 (2009), available at <http://jco.ascopubs.org/content/27/32/e192.full.pdf+html>. However, even though there was not legislation that addressed the concept of experimentation specifically, there was still a standard of care that medical

medical care resulted in an atrocious aftermath. Wives of the subjects (as well as many of their children) contracted the disease because it went untreated.¹⁰¹ These results were irreversible,¹⁰² yet despite these facts, no record exists showing that the physicians involved were ever held legally liable for their work or punished in any way.¹⁰³

Although it is true that there are alternative avenues to rebuke doctors and their agencies (e.g., suing for medical malpractice), it is unfair that victims of these past atrocities, as well as the victims of any later breaches of the NRA, were forced to partake in a roundabout path to ensure that medical practitioners were held accountable for their harmful conduct.

Although doctors were held to an ethical standard, this standard during Tuskegee was evidently not strictly enforced or regulated. Lack of regulation, however, by no means releases these physicians from having to conduct themselves ethically. Some scholars suggest that the enforcement of criminal sanctions on physicians is highly unlikely because our dependence on medical professionals is too significant to permit a sudden

professionals had to follow. *Id.* See also *Richie v. West*, 23 Ill. 385 (Ill. 1860) (first legal decision that outlined the medical standard of care is for a physician).

¹⁰¹ USCHAN, *supra* note 8, at 56 n.50. “In addition, forty men had infected their wives with the disease, and nineteen children had been born with congenital syphilis, which had been passed on to them by their unsuspecting parents.” *Id.* at 10.

¹⁰² *Id.* at 76.

As the years passed, many of the men in the Tuskegee Study of Untreated Syphilis in the Negro Male became sicker and sicker from the disease. They suffered from heart disease; problems with their eyesight, including blindness; loss of muscular control; and a variety of psychological problems cause by lesions formed on their brains. Many of the men died from syphilis.

Id.

¹⁰³ *The Tuskegee Syphilis Study*, UCSB DEP’T OF HIST., <http://www.history.ucsb.edu/faculty/marcuse/classes/33d/projects/medicine/The%20Tuskegee%20Syphilis%20Study.htm> (last visited Apr. 17, 2013) (inferring that USPHS officials were not held criminally liable for the study when stating, “white doctors responsible for the study should be prosecuted”).

lack of doctors.¹⁰⁴ It is probable that the medical profession has become so idolized that adjudicators are more resistant to convict.¹⁰⁵ It is also suggested that American law should create motivations for physicians to

¹⁰⁴ Larry I. Palmer, *Paying for Suffering: The Problem of Human Experimentation*, 56 MD. L. REV. 604, 622 (1997). The idea that criminal sanctions enforced against doctors would be highly unlikely because society would suffer from a sudden lack of medical professionals is nothing more than a romantic dramatization for the author to make his argument. *Id.* I am not suggesting that Palmer's contention is uncommon. *Id.* Perhaps it might be difficult to imagine criminalizing a doctor because "people do not expect criminal behavior from a doctor." L. Song Richardson, *When Human Experimentation Is Criminal*, 99 J. CRIM. L. & CRIMINOLOGY 89, 95 (2009), available at http://digitalcommons.wcl.american.edu/cgi/viewcontent.cgi?article=1133&context=facsch_lawrev. A second author offers a case that further evidences the aforementioned contention of physicians "immunity" from liability:

The courts' idealization of the medical profession persists even in cases involving researchers who act in bad faith. For instance, *Heinrich v. Sweet* was a class action lawsuit filed on behalf of terminally ill brain cancer patients who were subjects in radiation experiments without their knowledge. The patients thought they were receiving treatment and were unaware of the deception until a government report uncovering the experiments were published over forty years later. The patients thought they were receiving treatment and were unaware of the deception. . . . The plaintiffs sued in battery, alleging that the defendants 'intentionally injected the class' decedents with toxic substances and irradiated the class' decedents without consent.' The researchers acted in bad faith. The victims had not agreed to become research fodder, or to be injected with the experimental radioactive substance. However, despite evidence of intentional deceit, the court dismissed the battery claim and held that the action should be treated as a form of medical malpractice or negligence.

Id. at 99. This parallels directly with the Tuskegee study in that doctors utilize omission to cleverly abstract themselves from any form of liability. Similar to the doctors in *Heinrich*, the Tuskegee physicians acted with "intentional deceit" to further aid the work they were conducting. *Id.* at 98. Also similar to the doctors in *Heinrich*, it is safe to assume that the doctors in Tuskegee escaped adjudication due to the idealized view of medical professionals. A unique element to Tuskegee however (unlike *Heinrich*), was the racial undertone in which the experiment took place, suggesting that the races of the doctors and of the test subjects in a socially prejudiced environment may have also suggested such adjudicative laxity. *Id.* See also *Heinrich v. Sweet*, 308 F.3d 48 (1st Cir. 2002).

¹⁰⁵ See Palmer, *supra* note 104.

“see themselves as institutionally embedded.”¹⁰⁶ By doing so, doctors would be encouraged to properly analyze the interconnection between “law, medicine, and science as they constantly revisit the challenges of modern medicine.”¹⁰⁷

In response to these proposals, I contend the following: first, criminal sanctions should be imposed on anyone (regardless of their profession) who deliberately endangers someone, as the doctors of Tuskegee did. Physicians are in a position of power and should be held legally liable for conducting any type of study or experiment that takes advantage of that power and would unfairly manipulate or target a specific community over another. Reverence for their profession does not grant medical professionals immunity from legal liability. Second, Professor Larry I. Palmer of Cornell Law School proposes that an institutional analysis is necessary to properly evaluate the issue of human experimentation as opposed to examining individual behavior as “bad professionals.”¹⁰⁸ I understand this proposal to mean that the behavior and work of physicians should be evaluated as a corporate body, rather than an individual body.

I do believe it is important to examine the work of medical institutions as a whole (as we see in the example of the USPHS as an agency sponsoring the Tuskegee study) to ensure that medical groups and entities are not conducting themselves in a questionable way. But to propose that physicians are incapable of having even a minor understanding of the nexus between law, morals, and practicing medicine without first seeing themselves as “institutionally embedded”¹⁰⁹ seems a bit overreaching. Yes,

¹⁰⁶ *Id.*

¹⁰⁷ *Id.*

¹⁰⁸ *Id.*

¹⁰⁹ *Id.* Palmer suggests that once the medical community is framed in a more institutionalized manner, medical schools would be in a better position to facilitate discourse on “law, medicine, and science.” *Id.* This presents the inquiry of whose responsibility it is to properly educate medical students on issues of bioethics. Bioethics as of late has been an integral part of the curriculum for medical students nationwide. The

the projects of *institutions* should be examined, but it is individual *persons* who create the ideas that fuel the projects to begin with. Therefore, individual behavior should be examined in determining legal responsibility. Palmer suggests that supervising the conduct of individual physicians is a job best suited for Congress.¹¹⁰ I could not agree more with this contention, as this article addresses how properly constructed *legislation* (in this case, the National Research Act) can shape the behavior of medical personnel to conform to ethical protocol.

Although legislation establishing a universal medical standard of care currently does not exist, one can look to other doctrines that have created a framework for examining human experimentation in a more humane and ethical way. The principles established in the Physician's Oath,¹¹¹ and the

National Research Act, Pub. L. No. 93-348, § 202(1)(A)(ii), 88 Stat. 342 (1974). There is concern however regarding at what point in a medical student's education that bioethics is being touched upon. "[T]he instruction of bioethics occurs in the first two years of preclinical training, before medical students experienced actual dilemmas related to patient care. This time distribution precludes consideration of bioethical issues at the time when students are most engaged with the actual issues, so-called 'teachable moments.'" Govind C. Persad et al., *The Current State of Medical School Education in Bioethics, Health Law, and Health Economics*, 36 J.L. MED. & ETHICS 89, 92 (2008), available at <http://www.bioethics.nih.gov/publications/fellows/persadjlme2008.pdf>.

¹¹⁰ See generally Palmer, *supra* note 104.

¹¹¹ EILEEN WELSHOME, *THE PLUTONIUM FILES: AMERICA'S SECRET MEDICAL EXPERIMENTS IN THE COLD WAR* 212 (1999). The Hippocratic Oath states:

I swear . . . I will apply dietetic measures for the benefit of the sick according to my ability and judgment; I will keep them from harm and injustice. I will neither give a deadly drug to anybody if asked for it, nor will I make a suggestion to this effect. . . . Whatever I may see or hear in the course of the treatment in regard to the life of men, which on no account one must spread abroad, I will keep to myself holding such things shameful to be spoken about. If I fulfill this oath and do not violate it, may it be granted to me to enjoy life and art, being honored with fame among all men for all time to come; if I transgress it and swear falsely, may the opposite of all this be my lot.

Lisa R. Hasday, *The Hippocratic Oath as Literary Text: A Dialogue Between Law and Medicine*, 2 YALE J. HEALTH POL'Y L. & ETHICS 299 (citing LUDWIG EDELSTEIN, *THE HIPPOCRATIC OATH* 3 (1943)). Although the Physician's Oath carries no legal weight, it

Nuremburg Code,¹¹² should be incorporated into the NRA so that the legislation contains a provision that explicitly explains *why* physicians should be held liable for illegal medical research involving human subjects. No provision is written in the NRA that explains the type of ethical standard that medical professionals should be held to when conducting medical research. While it may be true that most medical professionals hold themselves to strict ethical standards, even without the threat of legal consequences, not having any legally binding provisions that ensure adherence to a certain standard of care would be unwise.

These doctrines are held with well-regarded reverence, and it is expected that all physicians who swear to them will adhere to them. Therefore, it is important that a shift takes place from these doctrines holding no legal weight to those doctrines being the very legal framework by which

is still regarded as a doctrine that has “sacred reverence attached to it,” and therefore, is expected to be adhered to by all physicians who swore to it. Joyce Arthur, *Hypocrisy and the Hippocratic Oath*, JOYCE ARTHUR (1999), <http://mypage.direct.ca/w/writer/hippo.html>.

¹¹² The Nuremburg Code was a ten-point doctrine established after the Nuremburg Trials, which responded to the horrors conducted by physicians in Nazi Germany. *The Nuremburg Code*, JEWISH VIRTUAL LIBRARY (1947), available at http://www.jewishvirtuallibrary.org/jsource/Holocaust/Nuremburg_Code.html. Since Nazism provided a framework to create racially motivated, quasi-eugenic medical experimentation, it was its aftermath that provided a dialogue to create doctrines to prevent such atrocities from occurring again. The Nuremburg Code functioned as “the primary precondition to performing human experimentation requir[ing] that ‘voluntary consent of the human subject is absolutely essential’ as a precondition to the performance of experiments on human beings. This requirement precludes the possibility of conducting research on human beings without first obtaining their informed consent.” Mark Ernest Trigilio, *The Convention on Human Rights and Biomedicine: Allowing Medical Treatment and Research Without Consent on Persons Unable to Give Informed Consent*, 22 SUFFOLK TRANSNAT’L L. REV. 641,644 (1999). The Declaration of Helsinki and the Universal Declaration of Human Rights were other doctrines that established an all-encompassing doctrine to ensure that human rights were properly preserved. See generally *The Declaration of Helsinki*, WORLD MED. ASS’N (1964), available at <http://www.wma.net/en/30publications/10policies/b3/17c.pdf>. First adopted in 1964, the Declaration of Helsinki is a set of ethical principles created by the World Medical Association that addressed the ethics of using human subjects for medical research. *Id.*

physicians will be held accountable. Making such doctrines law could yield a universal standard of care to which physicians would be held liable.

Although the ethical standards outlined in these doctrines exemplify what the medical standard of care should be, that alone would not hold physicians legally liable. The only way to ensure that physicians, like those who conducted the Tuskegee study, can be held legally liable is to actually criminalize certain conduct. As no legislation exist that regulated physicians' conduct—illicit or otherwise—the only way to establish liability is by examining their behavior through a criminal law analysis.

IV. HOW REMEDYING EXPERIMENT SURVIVORS IN A PRE-CIVIL RIGHTS, RACIALLY BIASED LEGAL SYSTEM SETS THE BACKDROP FOR CRIMINAL SANCTIONS FOR DOCTORS OF TODAY

The highly racialized milieu of the Jim Crow South played an integral role not only in the backdrop of the Tuskegee experiment, but also in the lax reprimand given to the doctors that conducted the experiments in the first place.¹¹³ As the discussion of racial relations had yet to reach the fervent fruition it later would in the 1960s and the 1970s, the men of Tuskegee were subjected to a pre-civil rights America with much more assertively and strongly established racist parameters.¹¹⁴

Although the physicians who conducted the Tuskegee study have since passed on,¹¹⁵ it is important to conduct an analysis of how they *could* have

¹¹³ Douglas O. Linder, *The Emmett Till Murder Trial: An Account*, UMKC.EDU, <http://law2.umkc.edu/faculty/projects/frtrial/till/tillaccount.html> (last visited Apr. 17, 2013) (noting the story of the Emmett Till murder trial, an example of how criminal behavior by Whites against Blacks in the Jim Crow South were overlooked).

¹¹⁴ See *The 20th Century Ku Klux Klan in Alabama*, ALABAMA DEP'T OF ARCHIVES & HIST., <http://www.alabamamoments.state.al.us/sec46qs.html> (last visited Apr. 17, 2013) (explaining the conditions of pre-Civil Rights Alabama, a time when the Ku Klux Klan had a large presence in the Deep South).

¹¹⁵ See Dennis McLellan, *Ernest Hedon, 96; Tuskegee Syphilis Study's Last Survivor*, L.A. TIMES, Jan. 25, 2004, <http://articles.latimes.com/2004/jan/25/local/me-hendon25> (explaining that the last Tuskegee survivor passed away in 2004; although there is no

been held legally liable for their conduct. Through this analysis, a proper foundation can be set to delineate the type of criminal sanctions for which individuals such as the Tuskegee doctors might be held liable.

A. Criminalizing the Conduct of the Physicians

1. Homicide

To some, the unfortunate circumstances of the Tuskegee experience are considered a tragic, but well-understood, inherent risk in science.¹¹⁶ However, countless deaths and irreversible medical conditions afford more than a slap on the wrist. The actions of these physicians have an extremely uncomfortable undertone of homicidal conduct, and their punishment should rightly fit such reckless endangerment of others' lives.¹¹⁷

The following arguments outline proposed amendments that should be incorporated into the NRA to delineate what criminal sanctions physicians should be liable for if another Tuskegee-like study darkens our country's history.

a) Manslaughter

Whether done in the name of science or not, deaths at the hands of USPHS officials constitute crimes. Voluntary manslaughter would be the homicidal classification that best fits here. It is defined in the Model Penal Code as an act “[c]ommitted recklessly or a homicide which would otherwise be murder is committed under the influence of extreme mental or emotional

record of the ages of the USPHS physicians at the time of the experiment, one can infer that they were most likely around the same age as the subjects).

¹¹⁶ See generally RISK ASSESSMENT GUIDE, SOCIETYFORSCIENCE.ORG, available at <http://www.societyforscience.org/document.doc?id=40> (last visited Apr. 17, 2013) (discussing risk assessment in scientific experiments).

¹¹⁷ MODEL PENAL CODE § 210.1 (2011) (“A person is guilty of homicide if he purposely, recklessly or negligently causes the death of another human being.”).

disturbance for which there is reasonable explanation or excuse.”¹¹⁸ The definition of voluntary manslaughter would be a more appropriate framework to create sanctions for physicians, as opposed to *involuntary* manslaughter—an act that has the absence of malice.¹¹⁹ The deliberate, prolonged continuance of this study, coupled with the blatant disregard for the lives of the Tuskegee subjects, fits into the very definition of malicious conduct. Thus, voluntary manslaughter would serve as an appropriate crime for the physicians.

b) Hate Crime

Race served as an integral role in why this experiment was conducted in the first place. Although Blacks were targeted as subjects instead of Whites for allegedly scientific reasons, these justifications were both illusory and arbitrary. Not only were Blacks targeted for this experiment, but they were also targeted for over forty years. The fact that this study took place for so long only further perpetuates the blatant racism that was used to initiate the study to begin with.¹²⁰

The motivating factor as to why the subjects were selected was race.¹²¹ This factor, coupled with the fact that doctors had a deliberate disregard for their health, safety, and lives, constitutes a “hate crime.”¹²²

¹¹⁸ *Id.* § 210.3.

¹¹⁹ 28 C.F.R. § 2.20 (“Involuntary manslaughter” refers to the unlawful killing of a human being without malice in the commission of an unlawful act not amounting to a felony, or in the commission in a unlawful manner, or without due caution and circumspection, of a lawful act which might produce death.”).

¹²⁰ *See generally* Part II. A. (describing how racism was first utilized to dehumanize the Black community).

¹²¹ *Id.*

¹²² Rose Ochi, *Hate Crime: The Violence of Intolerance*, U.S. DEP’T OF JUSTICE, <http://www.justice.gov/crs/pubs/htecrm.htm> (“Hate crime is the violence of intolerance and bigotry, intended to hurt and intimidate someone because of their race, ethnicity, national origin, religious, sexual orientation, or disability.”). *Hate Crime Laws*, ANTI-DEFAMATION LEAGUE (2006), available at <http://www.adl.org/99hatecrime/federal.asp> (“a crime in which the defendant intentionally selects a victim, or in the case of a

Several states have proposed enhanced sentencing for criminal acts based on prejudice against minority groups.¹²³ *Wisconsin v. Mitchell* was a landmark Supreme Court case that sparked the dialogue on this very issue.¹²⁴ In *Mitchell*, a group of Black men brutally beat a White teen unconscious.¹²⁵ After being subjected to a Wisconsin penalty-enhancement statute for his actions, Mitchell, the defendant, argued that the penalty-enhancement statute violated his First Amendment right to express his thoughts, bigoted or otherwise.¹²⁶ The US Supreme Court held that Wisconsin's statute did not violate his First Amendment rights,¹²⁷ and, therefore, established a valid avenue for safeguarding individuals of particular protected classes. The Court's holding suggests that there is a heightened degree of cruelty in criminal behavior when the purpose behind the criminality is malevolence toward an individual of a particular social group.¹²⁸

property crime, the property that is the object of the crime, because of the actual or perceived race, color, religion, national origin, ethnicity, gender, disability, or sexual orientation of any person").

¹²³ Michael McGough, *There's Little to Like About Hate-Crime Laws*, L.A. TIMES, Dec. 3, 2006, <http://www.latimes.com/news/la-op-mcgough3dec03,0,3236383.story> (describing briefly California and Pennsylvania hate-crime law that allows for enhanced punishments for biased crimes). *See, e.g.*, *Wisconsin v. Mitchell*, 508 U.S. 476, 479 (1993) (addressing an incident in 1993 where "a group of young black men" who brutally beat a young white teen unconscious based on his racial identity); *see also* Michael Lieberman, *Hate Crime Laws: Punishment to Fit the Crime*, ANTI-DEFAMATION LEAGUE (July 8, 2010), http://www.adl.org/ADL_Opinions/Civil_Rights/DissentMagazine_Summer2010.htm.

¹²⁴ *Mitchell*, 508 U.S. at 479.

¹²⁵ *Id.*

¹²⁶ *Id.* at 483.

¹²⁷ *Id.* at 489–90.

¹²⁸ *Mitchell* upheld the Wisconsin statute that enhances punishment for victims of hate crimes. *Id.* at 479, 490. Their reasoning was based on observing the *motive* of those perpetrating the crime. Sandra D. Scott & Timothy S. Wynes, *Should Missouri Retain Its "Ethnic Intimidation" Law?*, 49 J. MO. B. 445, 447 (1993). In the same way, the motivation of the USPHS physicians should have been examined to verify how "greater individual and societal harm [was] inflicted by [their] bias-inspired conduct." *Id.* at 477.

I propose that a provision, analogous to Wisconsin's enhancement statute, would serve as a framework to create sanctions for researchers who violate the NRA. This enhancement would hold individuals legally accountable not only for their crimes, but also for their prejudiced reasoning behind the acts. This must be incorporated into the NRA to ensure that, first, researchers are aware that there *are* sanctions for partaking in human experimentation that deliberately and recklessly puts lives in danger and, second, and more importantly, these sanctions should be heightened in circumstances when human subjects are selected based on racial bias.

To properly acknowledge the horrors of Tuskegee, a hate crime component must be incorporated into the NRA to reprimand physicians, researchers, or doctors who deliberately target subjects based on an immutable trait such as race. The execution of such an amendment could be used as a preemptive tool in demarcating racialized scientific experimentation.

c) *Endangering Public Health (by Allowing People with Syphilis to Remain Untreated)*

Deliberate non-treatment of syphilis not only endangered the individual subjects, but also endangered their communities. This experiment clearly illustrates a public policy issue in addition to a criminal liability issue. The study blatantly disregarded the lives and safety of the public, as the Tuskegee subjects essentially were vessels of a disease that they easily (albeit unknowingly) passed on to other individuals in their communities. This shows a deliberate endangerment of the public by the doctors who refused to treat the subjects that were infected in the first place. Therefore, a public health/public policy stipulation should also be integrated into the

The adverse impact of "bias-inspired conduct" could be used as a factor to analyze the behavior of physicians and scientists conducting experiments with human subjects. *Id.*

NRA, as it would hold researchers accountable if their actions could have adverse impacts on the greater public.

For the foregoing reasons, it is clear that there are evident omissions in the NRA regarding the sanctioning of physicians who select subjects with malicious and prejudiced intentions. Once these provisions are incorporated into the NRA, it will be properly amended, it will finally give proper acknowledgement to those who have been adversely impacted as a result of Tuskegee, and it will also help to prevent any possible Tuskegee-like studies in the future.

V. THE SIGNIFICANCE OF COMPENSATION

For victims of human experimentation gone awry, particularly individuals who underwent experimentation without full consent or knowledge of what was occurring, multiple avenues could be taken to properly remedy their pain. Some examples include the following approaches: (1) seek compensation to mitigate health bills accumulated from the negative aftermath and aftereffects of the medical study; (2) seek punitive compensation for pain and suffering; and (3) seek therapy sessions to mitigate any mental, physical, or emotional turmoil accumulated as a result of the experimentation.

Why should reparations be inherently owed to the victims? Although there is no law that explicitly states one has the “right to their own body,” constitutional clauses and case law establishes that this right is an implicit privilege for all Americans.¹²⁹ By taking our analysis down this path, we can properly examine the rights of patients and human subjects and further articulate support for including compensatory provisions.

Establishing reprimands for physicians who breach the “guidelines” that the NRA establishes would assist in making it a more impactful legislative

¹²⁹ *Infra* note 152.

proposal as it would bring the nexus of racial conscientiousness and public health to the forefront of the attention of the greater society. Not only must physicians who partake in biased medical experimentation be reprimanded, victims of that experimentation must also be compensated. The NRA must establish provisions that contain compensatory measures in order for it to be regarded as a thorough piece of legislation.

The omission of addressing remedies for victims of inhumane medical research is glaringly evident in the NRA.¹³⁰ Although there may have been an international dialogue of human liberties due to universal doctrines,¹³¹ at the time of the Tuskegee study, no dialogue existed to utilize these principles, either to examine the work of USPHS or to indoctrinate these principles into the body of American law.¹³² As a result, irreversible damages were suffered. Thus, the NRA should include compensatory rewards for anyone who has undergone illegal or nonconsensual medical treatment (including, like in Tuskegee, *lack* of treatment). Victims should not have to make additional efforts in order to be compensated for something that they should have been owed in the first place.

The Equal Protection Clause is a constitutional provision that could be utilized as a mechanism to support a “right” to autonomy and control of one’s body.¹³³ The primary objective of the Equal Protection Clause is to

¹³⁰ See generally National Research Act, Pub. L. No. 93-348, 88 Stat. 342, 349 (1974) (showing how no remedial provisions are mentioned in the entire National Research Act).

¹³¹ *Id.* § 202(a)(1)(B)(i).

¹³² Amanda Cole, *Tuskegee Syphilis Study: Poor Ethics*, YAHOO! VOICES (June 25, 2008), <http://voices.yahoo.com/tuskegee-syphilis-study-history-poor-ethics-1554957.html?cat=70> (noting “[a]t the time of the study there were very few guidelines on how to handle research studies involving human subjects”).

“Further, in 1964, the World Health Organization created a set of guidelines for working with human subjects in medical experiments called the Declaration of Helsinki (World Health Organization, 2000). The Tuskegee Syphilis Study also violated several of these guidelines in order to continue their research.” *Id.* Here, the author explains that although doctrines governing ethical conduct of researchers and physicians were available during the time of Tuskegee, they were not adhered to by the USPHS officials.

¹³³ U.S. CONST., amend. XIV, § 1.

ensure that “no state shall . . . deny to any person within its jurisdiction the equal protection of the laws.”¹³⁴ Although the right to ethical medical treatment is not an explicit constitutional right, these communities were unfairly targeted and were in an unequal bargaining position of power. The Equal Protection Clause could serve as the primary framework in which the rights of the Tuskegee subjects could be formulated.

The Tuskegee experiments show that equal protection became an issue for a very distinct class—the Black rural poor. The focus of the Tuskegee study was to examine the development of untreated syphilis in Black males,¹³⁵ inherently creating a disparity between Blacks and Whites. Additionally, the majority of the subjects selected were rural, uneducated men.¹³⁶ Further inquiry illustrates that the USPHS created a separate class of people even within the *same* racial community as their subject selection was based on classist decisionmaking as well. The rural community was specifically targeted because it was easier to take advantage of, manipulate, and exploit.¹³⁷

The levels of professional and ethical decorum that doctors are expected to adhere to when administering to a patient was clearly not present in Tuskegee.¹³⁸ It could be argued that the Tuskegee subjects were not treated

¹³⁴ *Id.*

¹³⁵ USCHAN, *supra* note 8, at 30–31.

¹³⁶ *Id.* at 18. “Macon County, Alabama, the most primitive of the communities studied and the most poverty ridden.” *Id.* at 22. Known as part of Alabama’s “black belt,” Macon County’s conditions were especially conducive for USPHS’ deceitful intentions. Most of the Black population in Macon County was considered “poorly educated.” *Id.* Poverty affected health of the Black community, and it was also problematic that the majority of their diets consisted mostly of grains and meat; fresh produce and dairy were not as available. *Id.* Water was often contaminated in these rural communities. *Id.* All of these factors contributed into manifesting poor public health for rural Blacks. *Id.*

¹³⁷ *Id.* at 58. “Many of the white doctors involved in the study considered the black participants ignorant and inferior.” *Id.* This reflected an institutionalized perception of the Black community, particularly those in the poor rural South. This perception was used as a mechanism to justify utilizing the Black community for the experiment.

¹³⁸ Cole, *supra* note 132.

with the same level of professionalism from USPHS as a medical entity because they belonged to a sociologically constructed underclass as rural, poor people of color with little to no education. An equal protection issue arises when one class of people is unfairly denied professional medical care, and a more privileged class, in a similar situation, would likely not have to undergo the same atrocities. In other words, it was highly unlikely that either of these studies would have taken place in a predominantly White, middle-class suburb.¹³⁹

It is in this way—deliberately selecting who underwent these medical experimentations—that two separate classes of community members were indirectly created: one was a community of color, in contrast to the White community; and the other one was comprised of the uneducated poor, in contrast to the wealthy, college-educated professionals. Although the treatment of one class of people (based on race) was an evident reflection of the social environment of that time, there existed a classist undertone that had also biased the way that medical agencies viewed the communities who underwent these medical procedures.

¹³⁹ JONES, *supra* note 3, at 21 (“To some extent physicians merely echoed the arguments white middle-class Americans made against the poor regardless of race. Ethnicity, class, and life style were perceived as inseparable identifications.”). Jones asserts how the unique intersection of the above mentioned social identities continue to perpetuate the separatism of poor people of color from White Middle America. Through this separatism, syphilis became increasingly reinforced as a “black disease.” *Id.* Black people had been so vigorously socialized as scientific anomalies that when harboring the same disease as a White man, it was equally critiqued as a separate phenomenon:

I think that such a study as you have contemplated would be of immense value. It will be necessary of course in the consideration of the results to evaluate the special factors introduced by a selection of the material from negro males. Syphilis in the negro is in many respects almost a different disease from syphilis in the white.

Brandt, *supra* note 11, at 20.

Skinner v. Oklahoma was one of a series of Supreme Court cases that addressed the right to govern one's own body.¹⁴⁰ In this 1942 case, Jack Skinner had been convicted of multiple crimes "amounting to felonies involving moral turpitude."¹⁴¹ According to a eugenics-based law, Oklahoma's Habitual Sterilization Act of 1935,¹⁴² any individual convicted of two or more "felonies involving moral turpitude" would be imposed to a sentence of compulsory sterilization.¹⁴³ The Court ruled that this statute was unconstitutional under the Equal Protection Clause because it excluded

¹⁴⁰ *Skinner v. Oklahoma*, 316 U.S. 535 (1942). Although the "right to privacy" is not explicitly written in the Constitution, there are several examples of case law that have established that there are limits to how far the government can interfere with one's privacy. *Griswold v. Connecticut* was a 1965 case that involved a Connecticut law that criminalized the use of birth control. *Griswold v. Connecticut*, 381 U.S. 479, 485 (1965). The Supreme Court ruled that such a law was a direct violation of privacy. *Id.* Although the invasiveness of Tuskegee dealt primarily with science and research, it still paralleled the issues of spousal privacy in *Griswold*. The fact that the syphilis went untreated eventually affected the wives of some of the participants, ultimately analogizing to the similar issue of invading the "sacred precincts of marital bedrooms." *Id.* Another parallel between *Griswold* and Tuskegee is issue of bodily privacy, *Griswold* with the use of contraceptives to prevent conception, Tuskegee with continuous intrusive medical procedures. *Id.* at 480–86. Other "right to privacy" cases famously included *Bowers v. Hardwick*, a 1986 Supreme Court case that upheld a Georgia statute that criminalized homosexual sex. *Bowers v. Hardwick*, 478 U.S. 186, 188 (1986). The Court stated that "[t]he issue presented is whether the Federal Constitution confers a fundamental right upon homosexuals to engage in sodomy and hence invalidates the laws of the many States that still make such conduct illegal and have done so for a very long time." *Id.* at 190. The Court ultimately sustained Georgia's sodomy statute that outlawed homosexual sex. *Id.* at 190. This was eventually overturned by 2003 Supreme Court case, *Lawrence v. Texas*, that overruled *Bowers*. *Lawrence v. Texas*, 539 U.S. 558, 588 (2003). Justice Kennedy in his opinion of the Court stated, "Liberty presumes an autonomy of self that includes freedom of thought, belief, expression, and certain intimate conduct." *Id.* at 562. Here I find a parallel once more to the Tuskegee study due principally to the discussion of "autonomy." The Tuskegee participants lost their right to self-autonomy because of the issue of non-consent. They were unaware of the intentions of the USPHS officials, and by participating in the study, they unknowingly released their rights to govern their own body. *Id.*

¹⁴¹ *Skinner*, 316 U.S. at 536.

¹⁴² OKLA. STAT. ANN. 57 § 171.

¹⁴³ *Skinner*, 316 U.S. at 537.

criminals who conducted crimes considered more “white collar,” such as embezzlement.¹⁴⁴ Skinner, on the other hand, was convicted of chicken-stealing and armed robbery.¹⁴⁵ Thus, the law unfairly protected a class of criminals who were equally liable for their crimes.¹⁴⁶

The Court also looked at the irreversibility of sterilization and how it deprives citizens of “a basic liberty.”¹⁴⁷ The Court astutely recognized that the unapologetic invasiveness of Oklahoma’s statute created “invidious discriminations . . . against groups or types of individuals in violation of the constitutional guaranty of just and equal laws.”¹⁴⁸ Although the men of Tuskegee did not undergo punitive sterilization as Skinner did, they did similarly experience the battle of being in an inferior bargaining position in articulating the welfare of their bodies. Ironically, the holding in *Skinner* took place in the midst of the Tuskegee study in 1942, but had no effect in the administration of the experiment by the USPHS, which continued for another thirty years.¹⁴⁹ The social environment at the time of the study was not particularly conducive to creating dialogue on the rights of the Black community.¹⁵⁰ However, it was significant in commencing a discourse in a

¹⁴⁴ *Id.* (“[E]mbezzlement . . . shall not come or be considered within the terms of [the] Act.”)

¹⁴⁵ *Id.*

¹⁴⁶ *Id.*

¹⁴⁷ *Id.* at 541.

¹⁴⁸ *Id.*

¹⁴⁹ See *Remembering Tuskegee*, NPR (July 25, 2002), <http://www.npr.org/programs/morning/features/2002/jul/tuskegee/> (explaining that the Tuskegee syphilis experiment commenced in 1932 and continued for forty years).

¹⁵⁰ USCHAN, *supra* note 8, at 21–22.

In the first half of the twentieth century, blacks were denied many of their basic civil rights. Racism was strongest in southern states. . . . [Jim Crow] laws determined where blacks could live, eat, shop, attend school. . . . Blacks were also denied the right to vote in elections, which meant they had no opportunity to gain political power so they could stop the discrimination. [M]ost blacks were relegated to a life of poverty because they were allowed to hold only the most menial and low-paying positions. . . . [M]ost blacks had little choice of

legal paradigm as to the rights of one's own body, to be further discussed below in Part VII.

Community uproar occurred when the atrocities of Tuskegee became known.¹⁵¹ *Pollard v. U.S.* came about when one of the survivors of the study, Charles Pollard, filed a lawsuit in 1974 “on behalf of the survivors of the Study and the heirs and representatives of the participants who had since died.”¹⁵² The federal government provided compensation to the participants in the study as a result of the suit,¹⁵³ however, the result should not be seen as a way to release those involved in this government-funded study from liability.

Legislative protection should exist to compensate victims from physicians conducting illegal medical studies, and such protection may deter private suits from being filed in the first place. Therefore, by including a compensatory provision in the NRA, the need for private suits would be eliminated. Acknowledging that protection is needed for non-majority communities, however, is a foundational step that must occur before any remedying takes place.

Examining the two fundamental characteristics of the Tuskegee subjects—race and social-class—within the context of the NRA,

occupation. They either did menial labor or became sharecroppers, tenant farmers who grew crops on land rented from whites.

Id.

¹⁵¹ Carol A. Heintzelman, *The Tuskegee Syphilis Study and Its Implication for the 21st Century*, SOCIALWORKER.COM (2003), <http://www.socialworker.com/tuskegee.htm> (discussing the “[h]idden within the anger and anguish of those who decried the experiment [was] a plea for government authorities and medical officials to hear the fears of people whose faith has been damaged”).

¹⁵² Palmer, *supra* note 104, at 609.

¹⁵³ *Id.* at 610. After numerous pre-trial maneuvers, the lawyers for the plaintiffs and for the US Government reached a monetary settlement in which each surviving subject received \$37,500, each heir or representative of a deceased subject received \$15,000, each of the “controls” received \$16,000, and the heir or representative of each control received \$5,000 from the \$10 million settlement paid by the federal government.

Id.

specifically section 202 that refers to “protected” classes, are essential to understanding how the NRA applies to the Tuskegee survivors. Section 202 of the NRA addresses the necessity of investigating research that specifically involves communities perhaps considered to be in a disadvantaged bargaining position. “[C]hildren, prisoners, and the institutionalized mentally infirm,” for example, are listed as the communities in need of ultra-sensitive protection in this section of the NRA.¹⁵⁴ Considering those communities perceived as disenfranchised is the core focus of this article, and while I do laud the legislators for addressing this somewhat, this list is under-inclusive.

More specifically, section 202 looks to protect these groups by overseeing the following:

[T]he adequacy of the information given them respecting the nature and purpose of the research, procedures to be used, risks and discomforts, anticipated benefits from the research, and other matters necessary for informed consent; and the competence and the freedom of the persons to make a choice for or against involvement in such research.¹⁵⁵

In this way, the authors of the NRA acknowledge that there *are* communities within society that are at a disadvantage to being able to self-govern in terms of medical autonomy and, therefore, be aware of their own rights. The NRA was not specifically written for the victims of Tuskegee, but rather as a reactionary response to what happened to them. Therefore, I find it ironic that although these particular communities in the NRA are listed, there is no discussion of any of the social identities of the Tuskegee subjects—people of color and members of the working-class with little to no primary education. Applying the parameters of section 202 to certain racial or ethnic groups may prove difficult, as it could be argued that race is

¹⁵⁴ The National Research Act, Pub. L. No. 93-348, § 202(1)(C)(2), 88 Stat. 342 (1974).

¹⁵⁵ *Id.* § 202(1)(C)(2).

not always an indicator of marginalization.¹⁵⁶ In this way, the fact that the Tuskegee subjects were Black may arguably not add any leverage to the development of the NRA because the analysis to examine this idea could be considered too subjective.

However, the second prong of the Tuskegee subjects' identity—poverty-stricken rural habitants—deserves a closer examination and presents a much stronger argument. In addition to the communities already acknowledged in the NRA, section 202 should include a hyper-protected provision for people who identify as lower or working-class. Socio-economic class, unlike race, is more of a quantitative character, as it is objectively defined by money.¹⁵⁷

In order to properly understand why socio-economic class must be included as one of the protected communities in the NRA, one must first examine the historical correlation between poorer communities and access to proper medical care. Barriers to proper health care for working-class individuals can be due to “life styles that tend to provide poor nutrition, unsanitary or inadequate living conditions and poor healthcare-seeking habits.”¹⁵⁸ This clearly illustrates that people living in poverty are already in a disadvantaged position for proper nutrition and medical treatment. This also illustrates why it is understandable that the working-class community

¹⁵⁶ Peter Beinart, *A Quiet Campaign of Violence Against American Muslims*, THE DAILY BEAST (Aug. 20, 2012, 1:00 AM), <http://www.thedailybeast.com/newsweek/2012/08/19/a-quiet-campaign-of-violence-against-american-muslims.html> (outlining the abuse endured by *Islam-practicing communities* in the United States after the September 11 attacks); Scott Keyes, *Mexican Restaurant in South Carolina Under Fire for Racist ‘How to Catch An Illegal Immigrant’ T-Shirt*, THINKPROGRESS (Jan. 7, 2013, 12:30 PM), <http://thinkprogress.org/justice/2013/01/07/1407561/racist-mexican-shirt/?mobile=nc> (illustrating an example of the displeasing experiences of Mexicans in the United States based on their *immigration status*).

¹⁵⁷ *A Profile of the Working Poor, 2010*, U.S. DEP'T OF LABOR & U.S. BUREAU OF LABOR STATISTICS 1 (Mar. 2012), available at <http://www.bls.gov/cps/cpswp2010.pdf> (“The specific income thresholds used to determine people’s poverty status vary. . . . [T]he poverty threshold is determined by their family’s total income.”).

¹⁵⁸ Walter L. Stiehm, *Poverty Law: Access to Healthcare and Barriers to the Poor*, 4 QUINNIPIAC HEALTH L.J. 279, 279 (2001).

deserves at least legislative protection from agencies that may take advantage of their position in seeking subjects for medical studies.

In the case of Tuskegee, subjects were offered incentives to participate in the study, such as free medical care for minor ailments and hot meals.¹⁵⁹ Ironically, of course, no treatment was offered to mitigate the very disease for which they were being observed.¹⁶⁰ For some, the mere suggestion of being told one was ill by a White doctor could have been enough to provoke participation.¹⁶¹ Working-class communities are very much in need of legal protection from human experimentation and research because they represent a population that could be easily manipulated into medical studies, without the ability to recognize that they are unfairly being taken advantage of.

VI. THE AFTERMATH OF TUSKEGEE—THE CONTINUING NARRATIVE OF EXPERIMENTATION ON THE BLACK COMMUNITY POST-TUSKEGEE

A. “*Ain’t I a Woman?*”¹⁶²

Wall, chilern, whardar is so much racket dar must be somethin’ out o’ kilter. I tinkdat ’twixt de niggers of de Souf and de womin at de Nork, all talkin’ ’bout rights, de white men will be in a fix pretty soon. But what’s all dis here talkin’ ’bout?

Dat man oberdar say dat womin needs to be helped into carriages, and lifted ober ditches, and to hab de best place

¹⁵⁹ USHCAN, *supra* note 8, at 50–51.

¹⁶⁰ *Id.* Penicillin was a new drug, made available to the public in the late 1940s, that had the ability to cure many diseases, including syphilis. *Id.* Although penicillin was available, PHS officials refused to administer it to the participants of the Tuskegee study as it would contaminate their study. *Id.* at 67–68 (“[t]he longer the study, the better the ultimate information”).

¹⁶¹ Thomas Parran, *Shadow on the Land*, in TUSKEGEE TRUTHS: RETHINKING THE TUSKEGEE SYPHILIS EXPERIMENT 61 (Susan M. Reverby ed., 2000).

¹⁶² Jone Johnson Lewis, *Ain’t I a Woman?: Sojourner Truth, 1851: Account by Frances Gage, 1881*, ABOUT.COM, http://womenshistory.about.com/od/sojournertruth/a/aint_i_a_woman.htm. (last visited Feb. 10, 2013).

everywhar. Nobody eber helps me into carriages, or ober mud-puddles, or gibs me any best place. . . . And a'n't I a woman?¹⁶³

The purpose of Truth's speech was to relay how the intersection of race, gender, and class not only shapes an individual's experience, but also how it can powerfully influence society's perception of that individual's expendability.¹⁶⁴ Truth's viewpoint is especially evident, as the cruelty of human experimentation in the Black community did not end in Macon County, Alabama.¹⁶⁵ The lack of necessary amendments to the NRA permitted the invasive experimentations on the Black community to continue with a vengeance, as illustrated in the North Carolina sterilizations.

¹⁶³ *Id.* Sojourner Truth's "Ain't I a Woman?" speech is significant as it asserts women's equality during a time where being a woman yielded second-class citizenry. See generally *id.* In the tone of Truth's speech, "woman" nearly becomes interchangeable with "human," continuing the discourse of the collective dehumanizing experience of Black people. Jim R. Bounds, *Woman Fights for Compensation for Forced Sterilization*, JACKSONVILLE.COM, Aug. 15, 2011, 3:25 PM, <http://jacksonville.com/news/health-and-fitness/2011-08-15/story/woman-fights-compensation-forced-sterilization>. Riddick's inquiry of quantifying her "worth" echoes Truth's narrative of the Black woman's experience. See also PATRICIA HILL COLLINS: INTERSECTING OPPRESSIONS 6, http://www.uk.sagepub.com/upmdata/13299_Chapter_16_Web_Byte_Patricia_Hill_Collins.pdf (last visited Feb. 23, 2013). "[A] black woman's epistemology recognizes this tension between common challenges and diverse responses which in turn is producing a growing sensibility that black women because of their gendered racial identity may be victimized by racism, misogyny and poverty." *Id.* (addressing why the concept of intersectionality is important to understand as the convergence of multiple social identities often plays an integral role in shaping an individual's role within social power structures).

¹⁶⁴ Autumn Bloom, *Rhetoric: Analysis of Sojourner Truth's Speech*, YAHOO! VOICES (Sept. 11, 2007), <http://voices.yahoo.com/rhetoric-analysis-sojourner-truths-speech-532353.html> (discussing how Sojourner Truth's identity as an African American female adversely impacted her ability to be perceived as equal to the Anglo male majority).

¹⁶⁵ *Infra* Part VI. B.

B. North Carolina Sterilizations: How Tuskegee's Legacy Adversely Impacts Black Women

The mass sterilizations of young North Carolinian women of color is one of the more recent illustrations of why a reformed NRA is so essential to eliminating the biases of expendability once and for all. Mandated by the Eugenics Board of North Carolina, these compulsory sterilizations primarily targeted young women of color.¹⁶⁶ The bulk of these sterilizations were based on the idea “that poverty, promiscuity and alcoholism” were genetic characteristics that could be inherited.¹⁶⁷ By performing these compulsory sterilizations, doctors believed they were cleansing the genetic pool from individuals considered anomalies of a normal society.¹⁶⁸ Initially, these sterilizations centered on the “feeble-minded,” reflecting the early works of eugenicist Harry Laughlin.¹⁶⁹ Feeble-mindedness was still used as a justification for sterilization, but promiscuity soon became a frequently used

¹⁶⁶ Sheryl Huggins Salomon, *An Outrage: NC Black Women Were Sterilized*, THE ROOT, (Nov. 7, 2011, 3:15 PM), <http://www.theroot.com/buzz/outrage-nc-black-women-were-sterilized> (“It began as a way to control welfare spending on poor white women and men, but over time, North Carolina shifted focus, targeting more women and more blacks than whites.”).

¹⁶⁷ Michelle Kessel & Jessica Hopper, *Victims Speak Out About North Carolina Sterilization Program, Which Targeted Women, Young Girls and Blacks*, ROCKCENTER (Nov. 7, 2011, 9:09 AM), http://rockcenter.msnbc.msn.com/_news/2011/11/07/8640744-victims-speak-out-about-north-carolina-sterilization-program-which-targeted-women-young-girls-and-blacks.

¹⁶⁸ Kim Severson, *Payment Set for Those Sterilized in Program*, N.Y. TIMES, Jan. 10, 2012, http://www.nytimes.com/2012/01/11/us/north-carolina-sterilization-victims-get-restitution-decision.html?_r=0 (discussing how North Carolina’s sterilization program “was intended to . . . cleanse the gene pool of undesirable characteristics”).

¹⁶⁹ *Buck v. Bell*, 274 U.S. 200 (1927). The Black community was not the only disenfranchised group targeted for human experimentation. The mentally ill in the United States were also seen as unfit beings. HARRY HAMILTON LAUGHLIN, *EUGENICAL STERILIZATION IN THE UNITED STATES* 446 (1922). Laughlin’s Model Law presented the idea that the mentally ill were “socially inadequate” and therefore their ability to procreate should be terminated, as it would increase the number of unfit persons in society. *Id.* The mentally ill were targeted because they were seen as deviants from what was determined as normal. *Id.*

rationale for the horrendous act as well.¹⁷⁰ This “abnormal” trait of promiscuity was primarily used to justify sterilization of Black women.¹⁷¹ The North Carolina experiment and the Tuskegee study seem comparable, especially when considering the following characteristics: targeting of people of color, lack of informed consent,¹⁷² invasion of privacy,¹⁷³ and lack of evidence in the rationale for the experiments.

The North Carolina sterilizations introduced a deeper problem to the issue of medical experimentation—as the aftereffects of these atrocities impacted women differently from their male counterparts—because sterilization wrongfully deprived women of their right to bear children.¹⁷⁴

¹⁷⁰ Kevin Bogos, *Lifting the Curtain on A Shameful Era*, in *AGAINST THEIR WILL: NORTH CAROLINA’S STERILIZATION PROGRAM*, <http://extras.journalnow.com/againsttheirwill/> (last visited Feb. 10, 2013). This sexualization of young Black women echoes the story of Sara Baartman and continues the narrative of sexuality continuously being used as a way to dehumanize Black people. Young Black women in the South were often victims of rape, and thus many unwanted pregnancies occurred. Lutz Kaelber, *Eugenics/Sexual Sterilizations in North Carolina*, U. OF VT., available at <http://www.uvm.edu/~lkaelber/eugenics/NC/NC.html> (last updated Oct. 21, 2012) (“Black women were presumed to have uncontrollable sexual behavior, and as these racial stereotypes were reinforced, Black women became an even larger target for controlled reproduction through sterilization.”).

¹⁷¹ *Id.*

¹⁷² John Railey & Kevin Bogos, *Still Hiding*, *AGAINST THEIR WILL: NORTH CAROLINA’S STERILIZATION PROGRAM*, <http://extras.journalnow.com/againsttheirwill/parts/one/story2.html> (“Jessie, who lives in Atlanta now, got no explanation before or after the operation.”).

¹⁷³ *Id.* (“It is the most degrading thing, the most humiliating thing a person can do to a person is to take away a God-given right.”) Railey and Bogos quote sterilization survivor Elaine Riddick once more. Here she discusses how the ability to reproduce is a “God-given right.” Or in other words, a right with which a person is inherently born. This is a direct parallel to the main issue in *Skinner v. Oklahoma*, that the “freedom from unwanted medical attention is unquestionably among those principles ‘so rooted in the traditions and conscience of our people as to be ranked as fundamental.’” See *Cruzan v. Mo. Dep’t of Health*, 497 U.S. 261, 305 (1990) (citing *Snyder v. Mass.*, 291 U.S. 97 (1934)).

¹⁷⁴ Martha Waggoner, *No Money For Forced Sterilization Victims in North Carolina*, *HUFFINGTON POST* (June 6, 2012, 10:46 PM), http://www.huffingtonpost.com/2012/06/27/no-money-for-forced-steri_n_1630417.html.

This could possibly afford a strong constitutional argument in favor of women, utilizing the holding of *Skinner* to argue that the enforcement of sterilizations deprives the victims of their fundamental liberty to produce offspring.

Sterilizations impact women differently than the male community. A woman's sterilization, to further explain, does not hinder her partner's ability to have a child. Although both women and men would still be able to bear a child through alternate medical routes,¹⁷⁵ and options such as adoption¹⁷⁶ are always available, the issue is not what alternatives sterilized women have to mitigate their circumstances, it is that they were placed in those circumstances to begin with.

Although the sterilizations prompted legislative proposals for restitution in North Carolina, none of the proposals were adopted into law,¹⁷⁷ further

¹⁷⁵ See *Surrogacy*, BETTER HEALTH CHANNEL, http://www.betterhealth.vic.gov.au/bhcv2/bhcarticles.nsf/pages/Surrogacy_the_issues (last updated Oct. 26, 2012) (explaining surrogacy as “a form of assisted reproductive treatment in which a woman conceives and carries a child . . . for another person or couple”).

¹⁷⁶ See Rachel Gurevich, *How to Have a Baby When You've Been Trying to Conceive for Awhile, Be Aware of Alternative Options*, ABOUT.COM, http://infertility.about.com/od/tryingtoconceive101/ss/How-To-Have-A-Baby-When-You-Ve-Been-Ttc-For-Awhile_8.htm (last updated Jan. 25, 2013) (listing options for couples unable to conceive).

¹⁷⁷ H.B. 21, 2009 Gen. Assemb., Reg. Sess. (N.C. 2009).

An act to provide counseling benefits to eugenics survivors, to direct the Department of Health and Human Services to establish a database of eugenics program participants and verify the status of persons contacting the state to determine their participation in the state program, to erect a historical marker about the program, to direct the State Board of Education to include information about the program in its K–12 history curriculum, to recommend creation of an ethics training module for state, county, and local government employees, and to direct the Department of Cultural Resources to digitize existing records for preservation and study purposes, as recommended by the House Select Committee on Compensation for Victims of the Eugenics Sterilization.

Id. “Any person who, as a result of the eugenic sterilization program in this State, was sterilized between the years of 1929 and 1975 shall receive compensation as provided for

illustrating the need for a properly amended NRA. One of the sterilization survivors, Elaine Riddick, sought an appeal with the US Supreme Court, after a trial jury determined that her sterilization had not “unlawfully or wrongfully deprived her [of the] right to bear children as a proximate result of the actions of the defendants.”¹⁷⁸ Her experience, and the collective experiences of the other victims of the North Carolina sterilizations, offers additional proof as to why the NRA must be properly amended to include provisions for compensatory action. Without such amendments, we cannot be sure that victims would ever receive the proper restitution they deserve. The compensatory component of the proposed amendments would function positively in the amendments providing benefits to these women who have yet to come across any form of restitution. The experiences of these women bring to light that human experimentation is very much prevalent, and their experiences reassert why a well-constructed NRA is so important for reparations.

VII. ASSERTING PROPERTY RIGHTS FOR ONE’S OWN BODY

The historical narrative of Blacks perceived as quasi-property is a concept that has been fervently echoed throughout this article. But this argument has served as more than a sociological analysis as to the Black body’s dehumanization. It also functions as a means of creating legal reparations for individuals who have been targeted for human experimentation. While the idea of having to assert protective rights to one’s own body appears both unnerving and unnecessary, it is essential to have such rights clearly delineated in response to a society where the lines in bioethics are often nebulous.

in this section if the person submits a claim before June 30, 2012.” S.B. 179, 2009 Gen. Assemb., Reg. Sess. (N.C. 2009).

¹⁷⁸ Allen G. Breed, *North Carolina Eugenics Victim, Son Fighting Together for Justice; At the Age of 14, the State Deemed Elaine Riddick Unfit to Procreate*, LEGAL NEWS (Aug. 15, 2011), <http://www.legalnews.com/detroit/1035511>.

Although the importance of compensation has been argued expansively in this article, I suggest that additional forms of compensation be given to individuals whose bodies, body tissue, or any type of biological materials are utilized by the scientific community to assist in studies used for the betterment of society. The NRA makes no mention of these circumstances, which, once more, illustrates debility in the way in which it was written.

A. The Immortal Henrietta Lacks and the Commercialization of the Human Body

The tragic story of Henrietta Lacks sparked the dialogue of asserting one's body as tangible personal property. Her story is an example of one of the most troubling and highly racist forms of scientific research conducted in the United States.

Henrietta was a poor Southern woman who worked on the same tobacco farm of her enslaved ancestors.¹⁷⁹ On January 29, 1951, Henrietta went to the doctor after being in pain from a mysterious knot in her stomach.¹⁸⁰ She later learned that she had cervical cancer.¹⁸¹ Henrietta eventually saw cervical cancer expert Richard TeLinde, who, along with his colleague George Gey, played an integral role in "immortalizing" Henrietta.¹⁸²

TeLinde's practice was similar to those of the Tuskegee physicians. He used "patients from the public wards for research"¹⁸³ with the understanding that a large Black population meant clinics were well supplied with research material.¹⁸⁴ TeLinde supplied samples of Henrietta's cervical cancer tissue to Gey, who cultured the cells from the samples.¹⁸⁵ Gey's lofty ambition

¹⁷⁹ REBECCA SKLOOT, *THE IMMORTAL LIFE OF HENRIETTA LACKS* 18–21 (2010).

¹⁸⁰ *Id.* at 13.

¹⁸¹ *Id.* at 17.

¹⁸² See generally *id.* at 27–41 (discussing TeLinde and Guy's discovery of Henrietta's "HeLa" cells).

¹⁸³ *Id.* at 29.

¹⁸⁴ *Id.* at 30.

¹⁸⁵ *Id.* at 29–30.

was to “grow the first immortal human cells: a continuously dividing line of cells all descended from one original sample—cells that would constantly replenish themselves and never die.”¹⁸⁶

After thirty years of failed studies before obtaining Henrietta’s cells, Gey was shocked to find that Henrietta’s cells not only survived outside her body, but also grew at an astonishing rate,¹⁸⁷ making her cells the first “immortal” human cells grown in culture.¹⁸⁸ Henrietta was never informed of Gey’s study, leaving her clueless to the fact that her cells were being grown in a laboratory for scientific research.¹⁸⁹ Gey sent out her cells—donned with the name “HeLa”—to countless researchers across the United States and internationally. Tubes of the HeLa cells made their way from one research lab to another around the world, making HeLa a household name in the research community.¹⁹⁰ These HeLa cells were used in studies to cure cancer,¹⁹¹ cure polio,¹⁹² and research AIDS,¹⁹³ as well as to study the impact of radiation and toxic substances.¹⁹⁴

The most disturbing aftermath of these circumstances is that no one in Henrietta’s family has been compensated.¹⁹⁵ The grossness of Henrietta’s circumstances represents a three-pronged problem: (1) she represents an individual who underwent a guileful medical procedure; (2) the general public benefitted from the medical procedure; and (3) no restitution was

¹⁸⁶ *Id.* at 30.

¹⁸⁷ *Id.* at 40–41.

¹⁸⁸ *Id.* at 41.

¹⁸⁹ *Id.* at 42.

¹⁹⁰ *Id.* at 57–58, 127.

¹⁹¹ *Id.* 127–29.

¹⁹² *Id.* 93–95.

¹⁹³ *Id.* at 214–15.

¹⁹⁴ Van Smith, *Wonder Woman: The Life, Death and Life After Death of Henrietta Lacks, Unwitting Heroine of Modern Medical Science*, CITY PAPER, Apr. 17, 2002, <http://www2.citypaper.com/news/story.asp?id=3426>.

¹⁹⁵ Bruce Goldfarb, *Remembering Henrietta Lacks*, WELCOME TO BALTIMORE, HON! (Aug. 9, 2010), <http://welcometobaltimorehon.com/henrietta-lacks>.

provided as a result of those benefits incurred. Henrietta's experience clearly raises the issue of whether one is owed compensation in such circumstances.

B. Viewing Commercial Exploitation of Human Tissue Through a Racial Lens

Henrietta's unfortunate story is analogous to plaintiff John Moore's story in *Moore v. Regents of the University of California*, a case in which Moore underwent treatment for leukemia, only to have his cancer cells later developed into a cell line that was used for commercial purpose.¹⁹⁶ The Supreme Court ultimately held that Moore did not have any rights to anything that was developed from his discarded body parts as a result of his treatment.¹⁹⁷ The Supreme Court justices were concerned that if a "property interest" in body parts was created, it could prevent the research community from accessing body parts that could be used to help propel scientific studies forward.¹⁹⁸ Be that as it may, a balance must be achieved to ensure that research can continue, but also that an individual's property interest in his or her own body is protected.

I believe the circumstances surrounding Henrietta's descendants' case present a very strong argument in which the *Moore* holding should be overturned. It is a breach of fiduciary duty and lack of informed consent in itself to take biological materials from someone without the patient's knowledge. The failure to inform the patient of the value of his or her bodily substances presents a level of immorality at its highest. The *Moore* holding essentially stated that even though one might have property interest in his or her own body, an individual does not have an interest in anything

¹⁹⁶ *Moore v. Regents of the Univ. of Cal.*, 793 P.2d 479, 486 (1990).

¹⁹⁷ *Id.* at 124.

¹⁹⁸ *Id.* at 146 ("In deciding whether to create new tort duties we have in the past considered the impact that expanded liability would have on activities that are important to society, such as research.").

that might be *commercialized* from their bodies.¹⁹⁹ Such a conclusion is nonsensical. By using Henrietta’s biological materials, she inherently acted as a “contributing” party to the works of researchers; the use of her cells sparked multi-million dollar investments in tissue research for example. Her role as a contributing party is no different than an individual who has offered an idea or added an important element to a new invention that is later patented.

The NRA does not address this issue of human subjects’ property interest in their own bodies as tangible personal property. In order for this to occur, I would assert that the *Moore* case must not only be overturned, but also its holding should be re-analyzed through a lens of racial sensitivity.

The reason why this additional step must be taken is based in the well-founded view that Henrietta’s story continues the gross historic narrative of the Black body’s commercialization.²⁰⁰ Moore’s circumstances were both unfortunate and unfair, but the underlying history of racism behind Henrietta’s circumstances is not evident in Moore’s. For years, the Black body not only endured a collective dehumanization process, but it also endured commercialization process as well. The purchasing, selling, and transporting of Black bodies is a well-known component of slavery in the

¹⁹⁹ See *id.* at 185 (explaining the Court’s holding that the plaintiff did not have conversion rights to his body parts).

²⁰⁰ See *Transatlantic Slave Trade*, UNESCO, <http://www.unesco.org/new/en/culture/themes/dialogue/the-slave-route/transatlantic-slave-trade/> (last visited Apr. 17, 2013) (explaining how the enslavement of Africans characterized as a global “commercial and economic enterprise”); *The Slave Trade*, PORT CITIES BRISTOL, <http://discoveringbristol.org.uk/slavery/routes/places-involved/africa/slave-trade/> (last visited Apr. 17, 2013) (noting how Europeans introduced a “commercialised” [sic] form of slavery at the commencement of the Trans-Atlantic Slave Trade in which Africans were categorized as chattel); David Kroll, *The Henrietta Lacks Genome: Consent, Trust, and Common Decency*, FORBES (Mar. 24, 2013, 8:46 AM), <http://www.forbes.com/sites/davidkroll/2013/03/24/the-henrietta-lacks-genome-consent-trust-and-common-decency/> (showing how scholars qualify Henrietta Lack’s cells as “commercial product”).

United States, a course of action that is dangerously analogous to the purchasing, selling, and transporting of Henrietta's bodily materials.

I do not suggest that African-American complainants in cases analogous to *Moore* should receive *special* treatment. I suggest that their cases must be carefully examined to ensure that their circumstances are not a *result* of identifying and exploiting African-American test subjects. This would ensure that they were not deceitfully stripped of their bodily materials based on any preconceived, racialized views of their community.

VIII. CONCLUSION: AMERICA'S METAPHOR FOR RACISM²⁰¹

The horrors of the Tuskegee syphilis study will remain seared into our nation's history as one of its darkest chapters. Science did not fuel this study—racism did. The initial purpose of Tuskegee may have been benign. However, once the focus shifted to observing the aftereffects of the untreated illness in *one* population, any scientific credibility was diminished. It then became about deliberate harm to one community and not to another. Formal apologies have been made on behalf of the Tuskegee participants,²⁰² but the only way to truly “end the silence”²⁰³ on the issue of discrimination—particularly through scientific practices—is to have well-balanced, well-constructed legislation that protects all communities *equally*.

²⁰¹ USHCAN, *supra* note 8, at 90.

²⁰² *Id.* at 88. President Clinton stated:

The United States government did something that was wrong—deeply, profoundly, morally wrong. It was an outrage to our commitment to integrity and equality for all our citizens. To the survivors, to the wives and family members, the children and the grandchildren, I say what you know: No power on Earth can give you back the lives lost, the pain suffered, the years of internal torment and anguish. What was done cannot be undone. But we can end the silence. We can stop turning our beads away. We can look at you in the eye and finally say on behalf of the American people, what the United States government did was shameful, and I am sorry.

Id.

²⁰³ *Id.*

If this legislation is not put in place, the question hanging ominously in the air is, *could Tuskegee happen again?*²⁰⁴ This inquiry must be carefully examined, especially in light of questionable conduct of physicians and researchers occurring worldwide.²⁰⁵ Whether such horrors repeat will depend on (1) the collective moral beliefs of our medical community and (2) what legal boundaries have been created to both reprimand doctors for illegal behavior and protect victims from that behavior.

In order for the NRA to be fully impactful, the need for specific boundaries to protect communities, especially those that are disenfranchised, must be emphasized. The motivation behind the NRA was chiefly to regulate the ethical boundaries of researching agencies. Setting recommendations for punishment—holding physicians liable for their conduct, ensuring that a well-balanced Commission is selected, providing

²⁰⁴ Susan Reverby, *Tuskegee: Could It Happen Again*, 77 POSTGRADUATE MED. J. 533, 533–54 (2001).

²⁰⁵ *Id.* at 553:

Consider what a recent series in the Washington Times reported. A drug company begins a clinical trial of a new drug in Nigeria in the midst of a meningitis epidemic, but does not provide the usual standard of care when a subject's condition worsens. Even though there is another international group of physicians nearby providing treatment, the patient dies. Placebo trials in HIV vertical transmission take place in Thailand, the Ivory Coast, and Uganda even though zidovudine (AZT) is given in the West to HIV positive pregnant women. The infants born to these women in the placebo arm develop AIDS. Local doctors and nurses in Eastern Europe, Latin America, Asia and Africa are rewarded with money, trips, and other research positions as they enroll illiterate patients in questionable circumstances, with little informed consent, and under coercive governmental support in more and more international drug company sponsored trials.

Id. By displaying the above declarations, I am not suggesting by any means that deceitful and dishonest behavior by physicians is a newly materialized concept. However, through Reverby's restatements of the Washington Post, it is clear to see that deception in medical research has become globalized. It is not necessarily the burden of the United States to solve this, but through properly amending the NRA, perhaps a model can be properly set for other nations to frame their legal reprimands for physicians who breach the standard of care.

compensatory benefits, and establishing an objective, well-defined, beneficial purpose to each researching endeavor—would exemplify a definite step toward offering the victims of biased and illegal human experimentation the restorative reparations they deserve, as well as hopefully prevent future “Tuskeeges” from occurring.

Truthfully speaking, proposing that Tuskegee has functioned historically as a “metaphor for racism” hardly confers the true tragedy of what occurred. Tuskegee also represents a dark legacy, a horrid curse with a powerful omniscience that has influenced the lives of Black people years after the termination of the experiment.²⁰⁶ As a result, there has been an immense, pervasive impact of Tuskegee for the contemporary Black community. In the aftermath of the Tuskegee experiment, the Black community birthed a zealous distrust of the medical and public health care system.²⁰⁷ As a result

²⁰⁶ Tom Junod, *Deadly Medicine*, in *TUSKEGEE TRUTH’S: RETHINKING THE TUSKEGEE SYPHILIS STUDY 511* (Susan M. Reverby ed., 2000).

Continuance, then, was Tuskegee’s curse. It wasn’t supposed to die, and it has not died in the places where racial memory matters. The transaction between doctor and patient has always depended on trust, and Tuskegee is trust’s toxin. . . . There are black men and women with AIDS who won’t take AZT because of Tuskegee. People are dying because of Tuskegee. Penicillin killed the old scourge, killed syphilis. It cannot kill the new scourge, however. It cannot kill AIDS, and it cannot kill Tuskegee.

Id.

²⁰⁷ Vernellia R. Randall, *Bioethics and Law Symposium Deconstructing Traditional Paradigms in Bioethics-Race, Gender, Class, and Culture: Slavery, Segregation and Racism: Trusting the Health Care System Ain’t Always Easy! An African American Perspective on Bioethics*, 15 ST. LOUIS U. PUB. L. REV. 191, 191–92 (1996).

[F]ear and distrust of the health care system is a natural and logical response to the history of experimentation and abuse. The fear and distrust shape our lives and, consequently, our perspectives. That perspective keeps African Americans from getting health care treatment, from participating in medical research, from signing living wills, and from donating organs. That perspective affects the health care that African Americans receive. This fear and distrust is rarely acknowledged in traditional bioethical discourse.

Id.

of this study, a history of being corporally demoralized, and the historic stripping of autonomy, there is fervent anxiety within the Black community to protect their bodies.²⁰⁸ Individualism and the governing of self have both

Just like the rest of America, the African American community is facing a number of bioethical issues. . . . African Americans view these issues through an additional screen of fear and distrust. It is this fear and distrust that causes us to believe that the principles of bioethics: autonomy, beneficence, nonmaleficence, and justice, won't protect our community from mistreatment and abuse.

Id. at 204. Pete Clark, *Prejudice and the Medical Profession: A Five Year Update*, 37 J.L. MED. & ETHICS 118, 122 (2009). "For many in the African American community, news of the study confirmed what they had long suspected: that the medical profession and the federal government used various forms of contamination to commit genocide." *Id.* Fueled by the collective retracting of their autonomy, the Black community's distrust is not limited to the medical community, but extends to the government as well. Perhaps the most renowned (and most controversial) assertion is that HIV/AIDS is an epidemic created by the US government for a genocidal purpose with the Black community in mind. Darryl Fears, *Study: Many Blacks Cite AIDS Conspiracy*, WASH. POST, Jan. 25, 2005, <http://www.washingtonpost.com/wp-dyn/articles/A33695-2005Jan24.html>.

More than 20 years after the AIDS epidemic arrived in the United States, a significant proportion of African Americans embrace the theory that government scientists created the disease to control or wipe out their communities. . . . Nearly half of the 500 African Americans surveyed said that HIV, the virus that causes AIDS, is man-made. . . . More than one-quarter said they believed that AIDS was produced in a government laboratory, and 12 percent believed it was created and spread by the CIA. A slight majority said they believe that a cure for AIDS is being withheld from the poor. Forty-four percent said people who take the new medicines for HIV are government guinea pigs, and 15 percent said AIDS is a form of genocide against black people.

Id. Juliet Lapidus, *Jeremiah Wright's Paranoia, In Context*, SLATE (Mar. 19, 2008, 5:51 PM), http://www.slate.com/articles/news_and_politics/explainer/2008/03/the_aids_conspiracy_handbook.html. "[T]he Rev. Jeremiah Wright . . . blamed the government for creating a racist state and 'inventing the HIV virus as a means of genocide against people of color.'" *Id.* This sentiment is also expressed in popular culture, for example, by Kanye West when he says, "This the real world, homie, school finished. They done stole your dreams, you dunno who did it. I treat the cash the way the government treats AIDS, I won't be satisfied til all my n*ggas get it, get it?" KANYE WEST, GORGEOUS (Roc-a-Fella Records 2010).

²⁰⁸ *Supra* Part II.

functioned as the building blocks of the most fundamental of liberties.²⁰⁹ Tuskegee permitted those liberties to become tainted by racialized perceptions of expendability, rather than allowing the liberties to remain as a neutral, unbiased covenant that should have been obtainable by all.

By no means do I assert that the NRA is a poorly written doctrine, or that it is inefficient in the provisions that had originally been authored. However, in order to ensure the protection of vulnerable groups from being victims of future Tuskegee-like incidents, the proposed amendments must be made and then fervently enforced. The occurrences of human experimentation are essentially rooted in ideals of expendability and structures of power.²¹⁰ If a dominant entity determines that the life value of one community is insignificant, it then becomes easy to associate those community members as sub-class, quasi-humans, and justify their treatment as such. We see this evidenced in the genocidal killings of the Holocaust,²¹¹ the compulsory sterilizations of people with mental illnesses, like Carrie Buck,²¹² and the unremorseful laxity of Tuskegee.

One can only be hopeful that as time has progressed, the ideals and ethics of our medical professionals have progressed as well. Professionals must remove themselves from the backwards, antiquated belief that human experimentation is permissible—depending on who is being experimented on. It should not be necessary to create laws mandating the conduct of

²⁰⁹ *Natanson v. Kline*, 350 P.2d 1093, 1103–04 (Kan. 1960) (“Anglo-American law starts with the premise of thorough-going self determination. It follows that each man is considered to be master of his own body.”).

²¹⁰ See Scarlett C. Taylor, *Should Medical Experimentation on Humans Be Permitted When the Subject is Not Informed?*, U. OF DAYTON, <http://academic.udayton.edu/health/05bioethics/01taylors.htm> (last updated Mar. 10, 2010) (proposing that “abuse of certain groups such as minorities and women” occurs through human experimentation as “these groups [are] disposable”).

²¹¹ *Introduction to the Holocaust*, U.S. HOLOCAUST MEMORIAL MUSEUM, <http://www.ushmm.org/wlc/en/article.php?ModuleId=10005143> (last updated May 11, 2012).

²¹² *Skinner v. Oklahoma*, 316 U.S. 535 (1942).

physicians or scientists, as their roles in society have universally been understood to be benevolent. But as indicated by the establishment of the Nuremburg Code,²¹³ the Universal Declaration for Human Rights,²¹⁴ and the NRA itself, creating legal parameters for medical professionals is necessary to protect communities from exploitation.

It is my hope that, through these recommendations, professionals in the medical world can hold themselves with the altruism their profession inherently possesses, and perhaps brings an end to the practice of dark medicine once and for all.

The differences between black and white folk are not blood or color, and the ties that bind us are deeper than those that separate us. The common road of hope which we all traveled has brought us into a stronger kinship than any words, laws, or legal claims.²¹⁵

- Richard Wright

²¹³ *Scaria v. St. Paul Fire & Marine Ins. Co.*, 227 N.W.2d 647 (Wis. 1975).

²¹⁴ UNITED NATIONS, UNIVERSAL DECLARATION FOR HUMAN RIGHTS 1948 (1948), available at <http://www.jus.uio.no/lm/un.universal.declaration.of.human.rights.1948/portrait.a4.pdf>.

²¹⁵ CORNEL WEST, RACE MATTERS 11 (2006).