



African Americans and Trust:  
Examining Clinical Research Trust Levels Based on Age

by

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## Abstract

African American mistrust in clinical research has been cited as a barrier to participation. The decision not to participate often depends on personal knowledge or experiences that shape one's views toward research. This lack of participation limits the generalizability of research results for African Americans.

Using an established instrument to measure trust and qualitative analysis, this study sought to determine whether there were differences in trust level towards clinical research based on age for African Americans. Furthermore, the study examined whether the level of education, type of employment, knowledge of the Tuskegee Syphilis study, experience with cultural prejudice or racism, or perceived health status had influence on age-specific trust levels. Analysis of four age groups (18-30, 31-40, 41-50, 51-74) showed that there were distinct differences in trust level and attitudes toward clinical research. The 41-50 year-old age group was the least trusting of clinical research overall.

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## Chapter 1: Introduction and Background

On June 10, 1993, the National Institutes of Health (NIH) Revitalization Act was signed into law, mandating NIH-funded research projects to include women and minorities unless the nature of the research justifiably excludes these groups (National Institutes of Health [NIH] Guide, 1993). On March 9, 1994, the NIH issued guidelines outlining appropriate adherence to the new law and has since updated those guidelines to ensure the ethical justice is maintained, and gender and race are balanced in clinical research (NIH Guide, 1994; NIH Guide Amendment, 2001). Despite this effort, African Americans still represent a low percentage (3%-20%) of the clinical trial participant population (Adams-Campbell, et al., 2004; Swanson & Ward, 1995).

The following causes for the lack of African American participation in clinical research have frequently been established in literature: lack of knowledge, limited access to health care, racial/ethnic discrimination, and fear (Shavers-Hornaday, Lynch, Burmeister, & Torner, 1997). Other commonly cited barriers are broader health care system issues, negative public perception towards research and researchers (Freimuth et al., 2001), a lack of minority investigators (Diaz et al., 2008), and religion (Advani et al., 2003). Additionally, much of the current literature points to a lack of trust in the medical field or in physicians in general as the primary reason for low rates of participation for African Americans (Bird & Bogart 2001; Corbie-Smith, Thomas, Williams, & Moody-Ayers, 1999; Corbie-Smith, Thomas, & St. George, 2002; Doescher, Saver, Franks & Fiscella, 2000; Hall et al., 2004). This lack of trust has been found to have roots in various places, but nonetheless creates a difficult barrier for researchers to overcome for African American recruitment.

Barriers to clinical research participation can be barriers to effective treatment, mainly because purpose of clinical research is to test new medical standards of care (Emanuel, Wendler, & Grady, 2000). It also tests the safety and efficacy of new drugs and devices (Meinert, 1986). Treatment for specific conditions cannot be generalized to a large, ethnically diverse group without adequate representation of that group in clinical research (Advani et al., 2003; Diaz, Mainous, McCall, & Geesey, 2008). This is partly because differences in the pathogenesis of disease and response to treatment is thought to exist for various ethnic groups (Doherty, Tang, & Detrano, 1999). For example, African Americans have been found to respond poorly to several classes of antihypertensive agents, putting them at greater risk for complications from the medication. Their representation in experimental studies can help to address these differences to ensure safety and efficacious treatment (Armstrong, Crum, Reiger, Bennett, & Edwards, 1999; Evelyn et al., 2001; Savitt, 1978).

Because of these pathogenetic differences, African Americans are affected by diseases such as cancer, hypertension, atherosclerosis, diabetes, and end state renal disease in unique ways (Doherty et al., 1999; Freedman et al., 1997; Freedman, Tuttle & Spray, 1995; Fregene & Newman, 2004; Kizer et al., 2004). A study by Fregene and Newman (2005) revealed that African American women and women from sub-Saharan Africa suffer disproportionately compared to white women from an aggressive form of breast cancer, prompting speculation that heredity factors can potentially explain the trending similarities for this group of women. Many of the countries in focus for this study are in Western Africa where the European slave trade originated in the 17<sup>th</sup> and 18<sup>th</sup> centuries. An estimated 66% of slaves brought to the United States during the slave trade were from West African countries; therefore, many African Americans and West Africans are currently thought to share similar genetic vulnerabilities (Fregene &



Newman, 2005; Ijaduola & Smith, 1998). A lack of clinical research participation by blacks therefore prevents further study surrounding effective treatment for these vulnerabilities.

Another reason that a lack of clinical research participation is harmful to African Americans is that the mortality risk of various diseases affects this group at disproportionate rates. Blacks account for 33% and 37% of all patients being treated for HIV and AIDS in the United States, respectively. However, they represent only 23% of patients in clinical trials for these diseases (Gifford et al., 2002). African Americans make up only 6% of cancer clinical trials, but have higher mortality rates for breast, prostate, lung, and colorectal cancer than any other ethnic group (Newman et al., 2005). More African Americans (10.6%) have diabetes than their White counterparts (6.4%), which has implications for the higher rates of kidney failure and coronary artery disease (Carter, Pugh, & Monterrosa, 1996; Perneger, Brancati, Whelton, & Klag, 1994).

*Mistrust: Where is did it begin?* Trust can be defined as one party's confidence that they will not be harmed or put at risk by the actions of another party, or confidence that no party will exploit the other's vulnerability (Jones & George, 1998). According to that definition, a lack of trust in someone or something would mean that one was fearful of harm or exploitation by another. Many African Americans have these fears toward clinical research. From where does the lack of trust within African Americans originate? Historians and medical anthropologists alike have amassed a convincing amount of evidence suggesting that the origin of mistrust spans many centuries. This evidence has been preserved and re-circulated through time by historical documents, public records, and oral accounts and can be attributed to the extreme caution that surrounds many African American ideas about clinical research.

Perhaps the origin of this fear and mistrust sprouted in the eighteenth and nineteenth centuries, long before the transformation of medicine as a useful science. Medicine in the Southern United States at this time was harsh, ineffective, and spontaneously experimental (Washington, 2006). Slavery was an established normalcy in American society and was largely based on the control and manipulation of blacks for capital gain. Many historical records reveal that slaves were medically neglected and abused because they were powerless and invisible under the law (Savitt, 1978). The immense emotional, psychological, and physical trauma that slavery had on the African American people is beyond the scope of this project; however, the historical accounts of this time can only begin to paint a portrait of mistrust for this group.

What if the origin of mistrust was inscribed in the self-recorded notes of Dr. James Marion Sims, the renowned “father of American gynecology”? Dr. Sims pioneered the technique of fixing vaginal fistulas suffered by women post partum, but did so at the expense of 11 slave women purchased solely for experimentation. He operated on these women without the use of anesthesia, claiming that the operation was not painful enough to make the effort. However, he was found to have always used anesthesia when performing the painful technique on white women (Washington, 2006).

What if the origin was the agony of a slave named Fed who endured unthinkable temperatures as a subject in a heat stroke study. Fed was secured in an in-ground pit that was covered and heated in order to test which medications effectively enabled him (and eventually other slaves) to withstand the Southern heat. The test would end only after Fed passed out and had to be revived (Harris, Gorelick, Samuels & Bempong, 1996).

An additional theory could have originated with the accounts of “night doctors” that stole black bodies from cemeteries and morgues in the late 1800s and early 1900s (Gamble, 1997). These stories were dismissed by Whites as folklore and fairytale until proof of grave robberies began to surface; most notably, the 1989 discovery of over 10,000 human bones and skulls underneath the basement floor of the Medical College of Georgia (Blakely & Harrington, 1997). Seventy-five percent of the bones were from African Americans, although they only consisted of 42% of Augusta, Georgia’s, population. The bones were thought to have been used between 1835 and 1912.

Or, it could have been knowledge about the North Carolina Eugenic Commission that sterilized 8,000 mentally handicapped people in the 1930s. Five thousand of the 8000 were black (Washington, 2006). Maybe it was knowledge about the cruelty inflicted upon Holmesburg Prison inmates in the early 1900s at the hands of dermatologist Dr. Albert Kligman. Kligman later invented the popular acne treatment, RetinA, largely based on experimental data from mostly black prisoners (Washington, 2006).

The origin of mistrust could have very well sprouted from the most notorious case of medical abuse: The Tuskegee Syphilis Study at the Tuskegee Institute in Macon County, Alabama (Armstrong et al, 1999; Brandon, 2005; Bates, 2004; Freimuth et al., 2001; Gamble, 1997). The experiment spanned forty years, even after regulatory staples such as the Henderson Act of 1943, the Nuremberg Code of 1947, and the Declaration of Helsinki in 1964 deemed the study’s protocol unfit (Emanuel et al., 2000). This study was sponsored by the United States Public Health Service (PHS) and included a study team that consisted of both Black and White health professionals. Over 400 black men were admitted to this study over its forty-year life under the guise that they would receive treatment for syphilis. The intent of the study was to

research the long-term effects of the syphilis by keeping the men in the study until they succumbed to the disease (Shavers-Hornaday et al., 1997). They were watched and monitored closely by study staff, most notably Eunice Rivers, a black nurse who gained the participants' trust. Some believe her relationship with the participants contributed to the high retention rate of the study (Gamble, 1993). The men never received proper treatment for syphilis, even after wide-spread use of penicillin in the 1940s revolutionized the treatment of bacterial infections. Once information about the study began to surface in medical conference minutes, many of the attempts to end the study by both white and black professionals were unsuccessful. In fact, the study did not cease until it was leaked to the press in 1972, 40 years after its initiation (Shavers-Hornaday et al., 1997; Dennis & Neese, 2000). Only after public knowledge of the study drew outcry and scrutiny was there an attempt to reconcile wrong-doing of the researchers in the form of a government act, The Belmont Report of 1979. This report established guidelines for protection of human subjects in research (Emanuel et al., 2000).

More recently, the HeLa cell controversy has also become an account of history that has raised considerable questions about the motives of research. In 1951, Henrietta Lacks, a young mother, went to her doctor complaining of inter-menstrual bleeding. Upon examination, her doctor found purple lesion, unlike anything he had ever seen. He biopsied the mass, which would later prove to be a biologically unique and cancerous tumor. The cancer was resistant to radiation and grew very aggressively in culture as well as in Mrs. Lacks, who died eight months after her initial biopsy. This uniqueness in growth and resistance to radiation attracted many researchers, all racing to find a cure for cancer. Thus, the HeLa cell line was formed and the cells were distributed to biomedical companies to be massed produced. These cells led to a revolution in cellular and molecular biology both intellectually and financially. The problem was that Mrs.

Lacks never gave her consent for the distribution of her cells nor has her surviving family received any financial compensation for any revenue generated by HeLa cell research (Jones, McKusick, Harper, & Wu, 1971). One of Mrs. Lacks' daughters expressed her feelings about financial compensation after seeing her mother's cells under a microscope: "People always gonna be makin money from them cells, nothing we can do about that. But we not gonna get any of it" (Javitt, 2010).

Wherever the origin of mistrust has its roots and whatever portrait has been painted in the minds of African Americans, many the aforementioned historical events and the knowledge thereof are relative to each individual. Some may know more about the history of clinical and medical research abuse than others. There are African Americans who know very little, if anything, about clinical malpractice but are still less trusting of clinical research than the average participant (Corbie-Smith, Thomas, Williams, & Moody-Ayers, 2002; Mouton, Harris, Rovi, Solozarno & Johnson, 1997). Hence, the origin of mistrust could lie within the confines of an unfavorable personal experience that tainted one's view of what clinical research is truly supposed to represent. Whether the unfavorable experience was on the job, in the classroom, or at a hospital, the fact remains that broken trust must be mended and redeemed.

#### *Problem Statement, Justification, and Significance*

Much of the innovation and technology that will help develop the cures for currently incurable diseases are being tested in clinical trials. Research and development for new drugs and therapies consists of intensive testing before they are incorporated as part of the gold standard of care for patients (Meinert, 1986). African Americans represent a range of 3%-20% of clinical trial participation (Adams-Campbell et al., 2004; Swanson & Ward, 1995). It is critical

that African Americans participate in clinical research so that results can be generalized to this group (Advani et al., 2003; Diaz et al., 2008).

A majority of the literature references historical events and personal experiences as precursors to participant apprehension and lack of trust. Personal experience with or remembrance of historical events implies that there could be a link to the origin of mistrust with the age of the individual. There is little research that intricately examines the characteristics of African Americans who may have had negative attitudes or a lack of trust in the clinical research process. Age is a particularly important area of interest given the strong link to history's influence on trust. Other than clinical trials or research studies involving the elderly cancer population or clinical trials related to diseases that target the very young or the very old, there were few studies focusing on the attitudes and beliefs of specific age groups regarding clinical research trust levels.

#### *Study Purpose and Objective*

This study was conducted to determine whether different age groups of African Americans have different levels of trust in the clinical research process and to examine differences for those reasons. Trust levels were determined using the Trust in Medical Researchers Scale (Mainous, Smith, Geesey & Tilley, 2006). The secondary objectives were to determine whether or not there was a correlation between type of employment, education level, knowledge of the Tuskegee Syphilis Study, or experience with cultural prejudice/racism with resulting trust levels.

*Research Questions*

Different age groups have different events that define their generation and often have unique and multidimensional perspectives on life due to their varying experiences. With this in mind, this research project aimed to answer the following questions: Do different age groups of African Americans have similar perspectives and opinions about clinical research? Are younger African American adults more trusting of the clinical research process, given their upbringing in a less historically negative time period? Do level of education, perceived health status, and type of employment predict trust levels?

## Chapter 2: Review of Related Literature

A review of the extant literature pertaining to African American trust and research reveals that little data intricately examine the age characteristics of African Americans who may have had negative attitudes or a lack of trust in the clinical research process, unless the study focused on patients ages 65 and older. A study by Comis, Miller, Aldige, Krebs, and Stoval (2003) attempted to assess public attitude toward clinical trials and found that younger adults were more likely to hold positive views about cancer clinical trial participation. This was the only study reviewed that broke down age groups in 10-year increments and compared attitudes pertaining to willingness to participate in cancer trials. These data were helpful; however, they did not go into detail as to why the individuals felt as they did, nor were data presented comparing race differences.

Other studies offered age breakdowns, but they were specific to diseases, not trust in clinical research (Lear, 1995; Hoover, Carfiolo & Moench, 2000). One age-specific analysis protocol did not analyze trust but factors influencing the clinical research participation of African American college students (Diaz et al., 2008). The study found that young African Americans preferred an African American investigator over other races. Additionally, a study by Crandall et al. (2006) presented a breakdown of age effects of lifestyle modification on diabetes prevention, but race was controlled and there was no survey of attitudes toward research participation.

Dr. Vanessa Northington Gamble's extensive work on African American trust in clinical research has helped to provide a framework for the widespread mistrust of African Americans toward clinical research. Although an abundance of research points to the Tuskegee experiment



as a sole contributor to mistrust, Gamble emphasizes that the origin of mistrust predates public knowledge about the Tuskegee experiment (Gamble, 1997). She does not ignore Tuskegee's influence, however, delving deeper in to the "shadows of Tuskegee" than many other scholars have gone.

Arch Mainous and colleagues (2006) developed the Trust in Medical Researchers Scale that specifically assesses participant trust towards clinical research staff. Other authors developed trust scales, some citing Mainous in preparation, but these scales addressed trust in physicians specifically, which does not necessarily indicate trust in clinical research or researchers.

Harriet Washington, medical ethicist and journalist, provided the first comprehensive historical account of medical experimentation on African Americans. In the book, *Medical Apartheid: The Dark History of Medical Experimentation on Black Americans from Colonial Times to the Present*, Washington made the Tuskegee experiment appear tame with accounts of other medical monstrosities practiced in the name of research. This publication provided powerful evidence that the origin of clinical research mistrust for all ages of African Americans can be as multidimensional and complex as the wrongs committed against this race of people throughout history.

The most extensive and informative data linking age with trust and participation involve cancer clinical trials. For example, one study found a high rate of elderly African American women cancer trial enrollment using a cancer cooperative database to recruit participants (Hutchins et al., 1999). This study did not, however, gauge trust or attitudes toward participation. Although effective recruitment strategies for any age group are helpful, addressing differences in response to African American recruitment by age could be helpful as well. Over 60% of cancer cases in the United States occur in the elderly ( $\geq 65$ ) population (Aapro, 2005),

and it is important to expand age specific focus to younger groups so that comparisons can be made regarding what is appropriate practice and what is not.

### Chapter 3: Research Design and Methodology

The target population in this study consisted of African American adults over the age of 18. However, all races were welcome to participate.

Prior to the distribution of the questionnaire, a Request for Approval of Research Involving Human Subjects was submitted to the Eastern Michigan University College of Health and Human Services Human Subjects Review Committee (HSRC) for review and approval. The study was approved on August 24, 2009 (Appendix A).

A survey was created incorporating questions that would enable a comparison of age to the level of education, knowledge of the Tuskegee Syphilis Study, experience with cultural prejudice/racism, and trust. A brief introduction to the survey described the purpose of the this research project, extent of study involvement, what would happen with the results, insurance of confidentiality and protection of privacy, explanation of risks, and researcher contact information should a problem arise. The participants were informed that by completing the questionnaire, they were giving permission for their answers to be used in analysis of the study, but they were also informed that their participation was completely voluntary and that they could stop their participation at any time. Demographic information was then collected including age, race, hometown, education status, level of education, employment status, and perceived health. An information section was included to inform those who might have been unfamiliar with common clinical research terms. The following items were defined: clinical research/clinical study, clinical trial, informed consent, principal investigator, participant, subject, and trust. The questions varied in form including short answer questions, multiple choice, yes/no, Likert scale responses (5=very likely, 4=somewhat likely, 3=neutral, 2=somewhat

unlikely, 1=not likely), and Likert scale responses that included a short answer explanation. The survey is presented in Appendix B.

Embedded in the larger survey was a smaller 12-item survey: the Trust in Medical Researchers (TMR) Scale (Mainous et al., 2006). This is a previously established instrument to measure trust specifically in the medical researcher and not in a general construct of medicine as other models have done (Hall, Zheng, & Dougan et al., 2002). For this study, the questions were answered on a 5-point Likert scale, thus trust was measured by the total score of the participant after answering all twelve questions. A higher score represented more trust in the medical researcher. There were two scores that comprised one trust score. One score pertained to the participants' belief that they will be deceived or misled in research (Participant Deception Score). The other score pertained to the participants' confidence that researchers are honest while conducting their research.

The survey was uploaded to the Survey Monkey website ([www.surveymonkey.com](http://www.surveymonkey.com)) where it was accessible to anyone who could retrieve the link to the survey. The link was posted to the social media websites Facebook and MySpace. Additionally, various participants obtained the link from either website and forwarded the link via email to associates and friends who were not part of an electronic social network or reposted the link on their personal page. The link was also forwarded via email to a large database of employees of a nationally recognized company. The completion of the questionnaires was solely online.

The SAS Data System was used to analyze the significance of trust scores in relation to the secondary variables: age, region of upbringing, education, employment, and perceived health.

Various short answer questions from the survey were qualitatively analyzed. The answers were grouped according to affirmative answers to the following questions: “Have you ever heard of the Tuskegee Syphilis Study? Does knowledge of this experiment have any influence on your opinions about clinical research OR whether or not you would participate in a clinical research study? Have had any experience with cultural prejudice or racism?” Once grouped, the answers that stood out and were similarly stated by three or more individuals were given a theme. If answer verbiage was similar across age groups, then the theme was kept consistent across the groups. Themes that were unique to one group were given distinguishable titles.

## Chapter 4: Presentation and Analysis of Data

A total of 163 people started the questionnaire. Out of this group, 74% were African American, 19.6% were white, and 6.25% were of either central/south Asian, American Indian/Alaskan, or of a mixed racial background. Due to the small sample size of the latter group, they were all combined into group classified as “Other.” One hundred and sixty-two respondents completed the demographic portion which included age, race, region of upbringing, education status, and perceived health. After this section, there were fewer total respondents per question and the response rate varied by question. In the end, 120 people received a complete set of trust scores. Therefore, only the answers submitted by these respondents were used in trust data analysis.

### *Demographic Information*

*Age.* The youngest participant in the sample was 18 years old and the oldest participant was 72 years old. Figure 1 represents the comparison of age groups by race. There were no respondents in the 51-74 age group for the Other section.

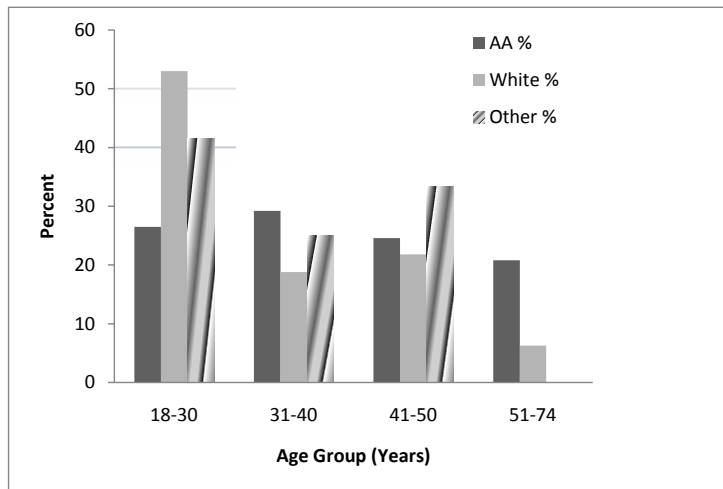


Figure 1. Age distribution of study sample by race (African American, n=120; White, n=30; Other, n=12)

*Region of upbringing.* Various regions of the country were represented in the study sample. Eighty-three percent of the respondents were from the Midwest (MI, IL, IN, OH, MO), 5% were from the South (FL, GA, TN, MS, AB, AR), 5% of respondents answered that they grew up in various regions of the country, 3.8% were from the Northeast (NY, NJ, PA), 1.3% were from the East coast (Washington D.C., VA), and 1.9% were from the west coast (CA, NM, AZ). It is important to note that four respondents indicated that they were not born and raised in the United States. Due to the differences in culture and traditional clinical research practices of the United States compared to other countries, these respondents were not included in the trust analysis but were still included in other qualitative measures.

*Education.* For the total sample, 34% of respondents had a bachelor's degree, 33.9% had a Master's degree, 9.4% had an associate's degree, 4.4% had a doctorate degree, and only 1.26% had no college education at all (See Figure 1). For the purpose of analysis, groups were combined into the following: high school education, some college, Associates degree; Bachelor

and Post-Baccalaureate Degree; Master’s and Doctoral Degree. The breakdown for the sample as a whole was 25.7%, 35.7%, and 37.5% respectively.

The education level for African Americans varied, with a majority of the group having obtained a Master’s or a doctoral degree (See Figure 2).

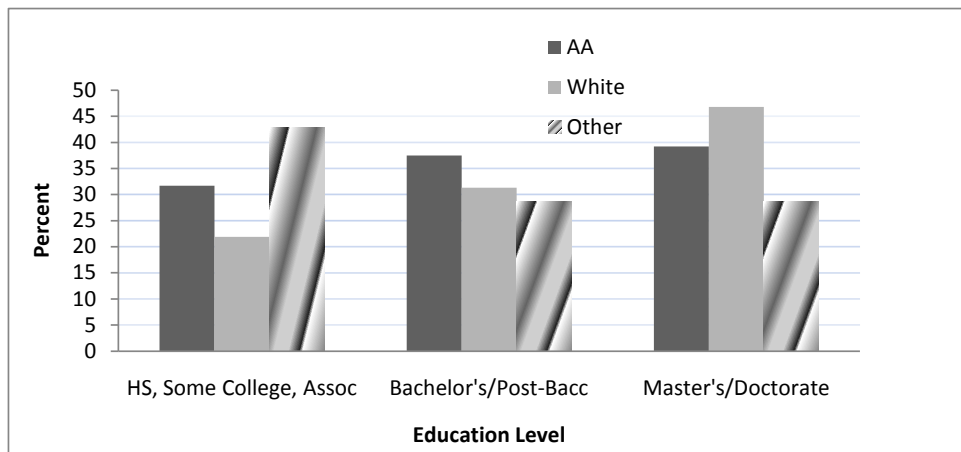


Figure 2: Education level by race (African American, n=120; White, n=30; Other, n=12)

Figure 3 shows the distribution of education as it pertains specifically to African Americans.

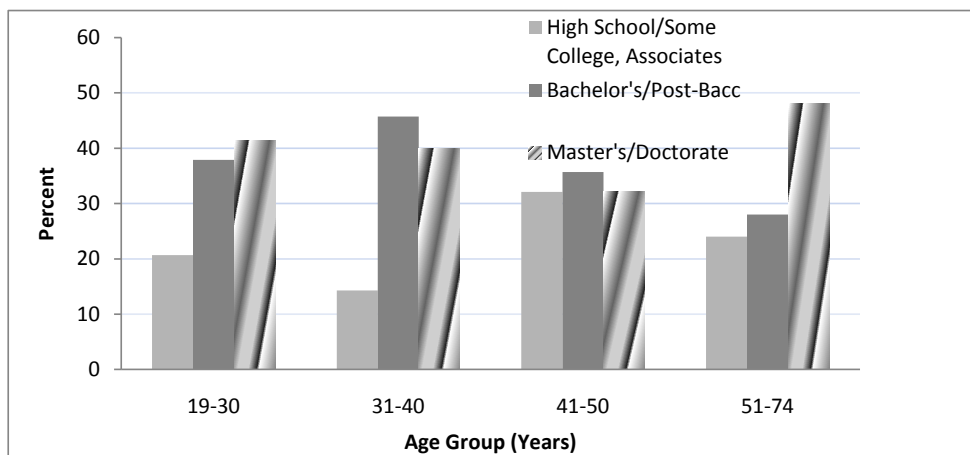


Figure 3. African American education by age (African American, n=120)

*Employment.* The employment distribution for the entire sample was as follows: 35.2% of respondents worked in the business field, 26.3% worked in education, 16.7% worked in health



care, 12.18 worked in the arts, technology, or trade, and 9.6% were unemployed. Figure 4 presents this data according to race.

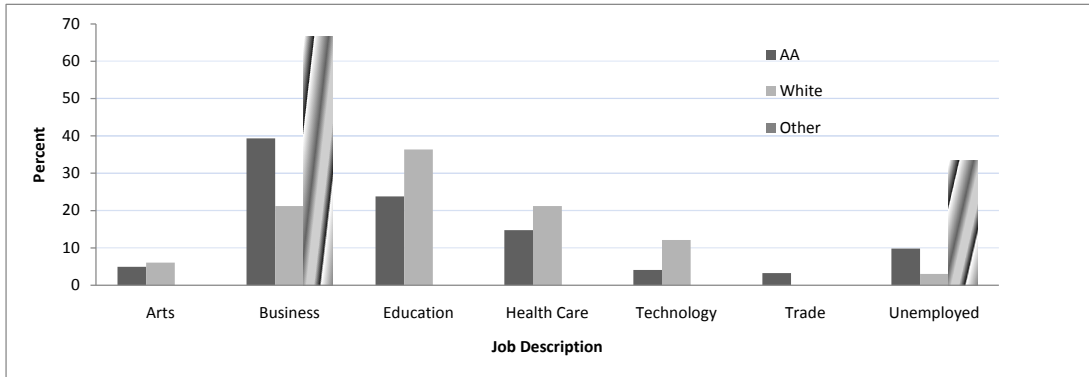


Figure 4. Job Classification by race (African American, n=120; White, n=30; Other, n=12)

*Perceived Health.* Forty-two percent of the survey population considered themselves to be in very good health, 32% in good health, 11% in excellent health, and 5% in fair/poor health.

Figure 5 presents this data according to race.

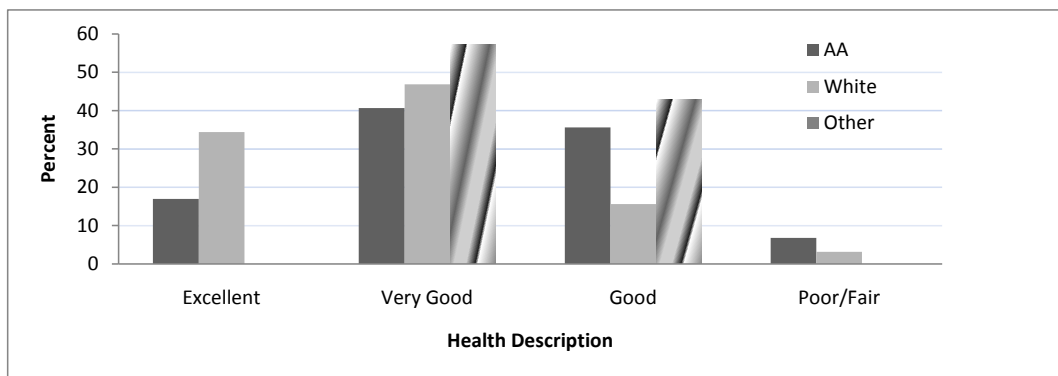


Figure 5. Perceived health by race (African American, n=120; White, n=30; Other, n=12)

*Survey*

As stated previously, after the demographic section of the questionnaire, the response number per question, especially by non-African American participants, varied slightly. Thus, the resulting sample of White and other ethnic groups were too small in many cases to analyze

properly. Where the numbers were large enough per question, there are detailed results of all three groups. If only the data from African American participants were analyzed, it is explained and justified.

Question 1 (survey section) of the questionnaire asks participants to list what comes to mind when they hear the term “clinical research.” There were very similar responses across all age groups for the entire sample with the most common terms and phrases cited as: cures, lab testing, research about diseases/health, research done to enhance health, experiments, and medical testing. The majority of the entire sample listed these relatively positive, general statements. A total of 6 participants (total n=162), all African American, simply listed “guinea pig,” “test rat,” “test dummies,” or “Tuskegee” as their response. This response trend was meaningful, because overall, the sample had a neutral first thought about what clinical research meant to them.

However, as detailed in subsequent discussion, other questions gave more opportunity for the expression of opinion and this neutral response turned less positive, particularly for African Americans.

*Tuskegee and Experience with Racism.* Survey questions incorporating knowledge of the Tuskegee Syphilis Study and racism prompted the participants to share their opinions and beliefs more so than any other short answer question. Due to the low number of responses from non-African American participants, only African American responses were analyzed; however, significant responses by White and Other ethnics groups will be noted.

Table 1 consists of the percentage of affirmative responses across the four age groups of African Americans that seemed to correspond with the trust score pattern that will be discussed later.

Table 1

*Percentage of Respondents Answering “Yes” to Key Survey Questions By Age Group for African Americans*

Question	Age Group			
	18-30	31-40	41-50	51-74
1a: Have you ever been <u>asked</u> to participate in a research study?	63.6%	57.1%	42.1%	61.1%
1b: Have you ever participated in a research study?	59%	39.3%	31%	50%
1c: Have you ever heard of the Tuskegee Syphilis Study?	68.2%	82.1%	94.7%	83.3%
1d: Does knowledge of this experiment have any *influence on your opinions about clinical research OR whether or not you would participate in a clinical research study? (*strong to moderate influence)	46.7%	60.9%	61.1%	60%
1e: Have had any experience with cultural prejudice or racism?	81.8%	89.3%	68.4%	100%
1f: Does your experience with cultural prejudice or racism have an effect on your willingness to trust health care or clinical research staff?	13.6%	7.1%	15.8%	27%

A closer look into respondent answers for questions 1d from Table 1, 1d part B (not listed in the table) “If so, can you briefly explain why you are influenced?” and question 1e also in Table 1 revealed many similarities in opinion about clinical research, trust, and racism across age groups as well as unique differences. It is important to note that among individuals who had a trust score, experience with cultural prejudice or racism was measured as a significant predictor of lower trust ( $p$ -score=0.0328).

Table 2 compares the significant statements for questions 1d and 1d part B. The responses from these questions were placed into themes. The first column shows the only theme that was present in all four age groups, Theme 1: “No drugs, no injections.” In addition, “No drugs, no injections – Especially no flu shot” present in the older two age groups was listed under theme 1 due to the similarity of the topic. Theme 2, “The Unknown,” was present in

three age groups. The third and fourth column show two different themes that were present in two age groups: Theme 3, “Another Tuskegee is unlikely, but...” and Theme 4, “The right versus the wrong group.” Table 3 shows the themes that were unique to each age group.

Table 2  
*Significant Short Answer Themes for Questions 1d/ 1d part B from Table 1, by Age Group for African Americans*

	4 Groups	3 groups	2 groups	
Age	Theme 1a: No injections, no drugs	Theme 2: The Unknown	Theme 3: Another Tuskegee is unlikely, but...	Theme 4: The right versus the wrong group
18-30	"No experiment would be invasive to my body..." "I choose not to participate in medical research. Only social science"	X	"[Tuskegee] was run by the government. Federal funding from the government funds most studies these days" "It happened once. It can happen again"	X
31-40	"I am not sure if I would ingest anything" "I realize that any data can be manipulated...I am not a fan of taking drugs for any research project..."	"[Tuskegee influences me] because one never knows..." "It's hard to get all of the facts" "I have wondered about things that I have done and how they will affect me long term. To the best of my knowledge they were safe, but who knows"	X	"If I was given clear assurance that I would receive the real sample I may participate" "if there was a chance for me to be in the 'wrong group' on these studies, I will not participate"
41-50	"[Tuskegee] has caused a mis trust in... trials as well as any 'vaccines' that the government is pushing for" <b>Theme 1b: No injections, no drugs - Especially no flu shot</b> "[Tuskegee] allows me not to take flu shots or to be involved in any type of studies" "any research that involved any drug or injection...I would not participate in"	"I would never voluntarily expose myself due to the lack of full disclosure associated with research"	"Even though these are different times, I still feel like there is no way for a person to know what is really being done to them" "[Tuskegee] makes me cautious about what anyone says about what is good for me"	X
51-74	"I do not receive injections or flu shots" "I am mistustful of the H1N1 vaccine"	"I have no way of being assured that I would receive truthful information...pertaining to research"	X	"you could be treated with a placebo for terminal cancer...[I will not participate] due to this uncertainty"

Table 3  
*Unique Short Answer Themes Per Group for Question 1d/ 1d part B by Age Group for African Americans*

		Age			
		18-30	31-40	41-50	51-74
<b>Theme 5: We're treated like animals</b>	<b>Theme 7: I'm not a testing ground</b>			<b>Theme 8: Alterior Motive</b>	<b>Theme 3: AA lives are viewed as inferior, worth less</b>
<i>"Tuskegee has little influence because I am already aware of how white people view and treat AA as animals"</i>	<i>"I would never allow anyone to use my body as a testing ground for an experimental drug"</i>			<i>"People are generally selfish...thinking about what benefits them...I would have trouble reaching a comfortable trust level"</i>	<i>"the heart of some humans can't be trusted...blacks are still considered inferior to whites that are largely in charge of research"</i>
<i>"It seems as though AA are used as guinea pigs"</i>	<i>"it's hard to trust organizations that fight for the rights of rabbits to not have mascara tested...but will stand quietly by when people are at risk"</i>			<i>"The US government performed experiments...under the guise of research...blacks used over whites is illustrative of the willingness to subject non-whites to inhumane treatment"</i>	<i>"the way this experiment was done makes me believe...clinical researchers don't believe AA people have any value or worth"</i>
<b>Theme 6: AA are given diseases/not cured on purpose</b>				<b>Theme 9: God</b>	
<i>"...I feel as though African-Americans are subjected to clinical research with negative ramifications. i.e. giving african-americans diseases and/ or using non-proven cures for pre-existing diseases"</i>				<i>"If God doesn't lead me...I will not participate"</i>	

The themes in Table 3 were numbered in succession with Table 2. Table 4 groups the responses to question 1e from Table 1 in a similar manner as Table 2. The themes are lettered in order to distinguish them from the numbered themes that were in response to question 1d. As with Tables 2 and 3, it is important to note that the responses found in Table 4 do not represent the entire set of answers to questions 1e; however, these responses stood out among the others and were specific examples of personally experienced racism.

Table 4  
*Significant Short Answer Themes for Question 1e from Table 1, by Age Group for African Americans*

Age	3 groups	2 groups		Theme D: Racial Profiling	Theme E: Too much to count
	Theme A: Work Place Racism	Theme B: Stereotyped and more by my doctor	Theme C: The N word		
18-30	X	X	"Nigger was painted on the lockers of the predominantly white high school I attended"	"It all boils down to people thinking you are up to something just because of the number of black men in a single group"	X
31-40	"I work in corporate America. I experience [racism] on a daily basis"	"My husband was given a vasectomy without my consent...[my doctor] stated...more AA men were likely to undergo the procedure at that hospital"	X	"I was pulled over while parked in front of my house because the police officer didn't believe it was my kind of neighborhood"	"too many to list"; "Too many to name"; "too many and not enough target for being a shop lifter" time"
	"discriminated against when it came to promotions...there was a trend in the office"	"...doctors assuming I didn't have a husband or insurance, assuming I'm on assistance"		"I'm a black man that fits every description of a wanted person for questioning"	
41-50	"by-passed for promotions"; "always on my job, I'm 1 of 2 blacks"	"I suffered a serious depressive episode due to a white doctor prescribing a beta-blocker without notifying me of the side effects...a black physician brought attention to it...led to my removal of the medication"	X	X	X
	"...on more than one occasion I have received disparaging treatment in the workplace"	"...stereotypical diagnoses...!you're pregnant, or have a yeast infection from tight jeans'...I was not sexually active and don't own jeans"			
51-74	"everyday at work demonstrates a lack of diversity in leadership"	X	"white kids [called my kids] the n word... they were hurt because the teacher did nothing"	X	"[Racism] is too broad...we just live with it...it just is"
	"I have been passed over for positions, ignored in some business situations..."		"I was at the park and a young male asked me why I didn't go to a 'nigger' park"		

Table 5 represents unique responses for each age group pertaining to whether participants had experienced cultural prejudice or racism (See Questions 1e, Table 1). The 31-40 year-old age group shared all of its themes with the other three age groups and did not produce a significantly unique response to question 1e.

Table 5  
*Unique Short Answer Themes Per Group for Question 1e by Age Group for African Americans*

18-30	Age		
	31-40	41-50	51-74
<b>Theme G: Childhood memories</b>		<b>Theme H: I've seen it happen to others</b>	<b>Theme I: The South</b>
<i>"I wasn't invited to a birthday party because I was black"</i>	X	<i>"I work in education..and have seen how inner-city schools were treated unfair compared to white schools"</i>	<i>"I'm black, raised in the South, you figure it out"</i>
<i>"I attended friend's birthday party where everyone else was staying over for the night...but I was informed that I could not."</i>		<i>"My father called people much younger than him no sir or no ma'am...this was done to make a better life for his children"</i>	<i>"I grew up in the south during segregation"</i>

*Trust Scores*

As noted earlier, only the respondents with a complete set of trust scores were included in trust score analysis. Overall, African Americans had lower trust scores than the other two groups. There were cases where the Other group had similar scores; however, the small sample size of the group (n=11) made it difficult to compare the results to the much larger sample of African Americans (n=87). As Table 6 shows, African Americans had a significantly lower trust score regarding participant deception than did their white counterparts.



Table 6

*Trust Scores by Race (African American, n=87; White, n=22; Other, n=11)*

	Participant Deception	Researcher Honesty	Total
AA	20.6	24	22.5
White	31	26.2	28.5
Other*	23.6	21.6	22.6

\*Small Sample Size

The differences in trust level among the ethnic groups also varied by age (see Table 7).

Table 7

*Participant Deception and Researcher Honesty Trust Scores by Race and Age (African American, n=87; White, n=22; Other, n=11)*

Race	Participant Deception				Researcher Honesty			
	18-30	31-40	41-50	51-74	18-30	31-40	41-50	51-74
AA	22.2	21.6	17.2	20.8	25.5	26.8	22.0	22.7
White	33.7	29.0	26.0	30*	27.3	29.5	19.6	32*
Other*	25.7	16.0	29.2	n/a	26.9	26	20	n/a

\*Small Sample Size

Combining the participant deception and researcher honesty scores gives one composite trust score. The composite scores also varied significantly by race and age (see Table 8); however, African Americans still amassed the lowest total trust scores in each age group of all counterpart groups.

Table 8

*Total Composite Trust Score by Race and Age*

	Age			
	18-30	31-40	41-50	51-74
AA	23.6	24.7	19.8	21.7
White	30.5	29.3	22.8	31*
Other*	26.3	37*	24.6	n/a

\*Small Sample Size

## Chapter 5: Summary, Conclusions, Inferences, and Recommendations for Further Research and Action

Not all of the data collected in the questionnaire warranted pertinent information relative to the initial research questions posed. The demographic information, questions pertaining to the Tuskegee Syphilis Study, racism, and the trust scores obtained from the study sample proved to correspond in a manner that not only answered the research questions but provided supplementary insight into other issues plaguing the African American community regarding trust and clinical research participation. Additional survey questions pertaining specifically to trust in clinical research were also helpful in analysis, mainly those probing “what comes to mind...” or “how likely are you to...”.

### *Research Questions Addressed*

*Do different age groups have similar perspectives and opinions about clinical research?*

According to Table 1, an average of 44% of African American respondents had ever participated in a clinical trial, with the highest percentage in the 18-30 year-old age group and the lowest percentage in the 41-50 year-old age group. Whites had a comparable participation rate at 48% and the Other group had a participation rate of 83%. Research suggests that only 3%-20% of African Americans participate in clinical trials, so even though they lagged behind their counterparts, their participation exceeded the average rate.

Question 1d from Table 1 and 1d part B (see questions 7 and 8 in Appendix B) were initially gauging knowledge of the Tuskegee experiment and the strength of its influence thereof. Although many African American participants responded accordingly, others used this question as an opportunity to explain how they felt about clinical research in general. Table 2 lists

recurring themes across age groups. “No injections, no drugs” was the most generalizable barrier to participation for African Americans, and it was knowledge of the Tuskegee study that prompted thoughts of injections or drugs.

The Tuskegee Syphilis Study, as horrific as it was, actually did not involve the injection of syphilis or the initiation of the infection. The intent of the study was to monitor the long-term effects of syphilis on those who already had the disease – which is why the men were not treated even after penicillin became an acceptable and effective treatment in the early 1940s. Notwithstanding, of the 31% of African American individuals who were strongly or moderately influenced by Tuskegee, 26% of these people incorrectly noted that the men of the study were injected with syphilis. Another 55% did not indicate injection but purposeful infection or exposure of the men to syphilis, which by protocol of the study is still an inaccurate interpretation. Many also noted that the men were given a drug that didn’t cure them. That leaves only 18% of the influenced with an accurate account of what actually happened in the Tuskegee study.

The most common answer given for apprehension towards clinical research participation based on Tuskegee’s influence (no matter how small or strong) was the distrust of injections and/or drugs. An inaccurate account of a historical event is currently carrying significant weight in the minds of those who are aware that the study existed, thus creating a barrier to clinical research participation in a small group who might otherwise participate in research. Corbie-Smith et al. (2002) insists that knowledge of negative events through wide dissemination carries enough weight to adversely affect the ability to overcome distrust. Eighty-one percent of the African Americans indicating that they were strongly or moderately influenced by Tuskegee had similar, inaccurate interpretations of the study. It is uncertain whether or not the views of these

people would change if they knew that the Tuskegee men were not injected or intentionally exposed to syphilis. However, the significant weight of these views, accurate or inaccurate, were nonetheless a barriers to clinical research participation for all ages in this study.

Implied fear of the “unknown” was also an influence of Tuskegee and a common theme. All age groups expressed this fear with the exception of the 18-30 group. One of the key statements from the 41-50 age group implied that research does not fully disclose its intentions. Another statement implies that the full “truth” about research cannot be known, thus it is safer not to participate. Even white respondents mentioned “hope” that research practices had changed since Tuskegee. Hope is not certainty. Therefore, fear of what *could* happen based on what *did* happen is driving a lack of participation as well.

Table 3 lists other significant themes present in less frequency with regard to the Tuskegee experiment. These themes (Theme 3 and 4) are only present in two age groups but still represent similarities in opinion about not just Tuskegee but clinical research in general. Theme 3 represents both optimism and skepticism for the 18-30 and 41-50-year-old age groups. “Another Tuskegee is unlikely, but...” takes into account that some African American participants believe that another study similar in practice to Tuskegee is unlikely in current times. However, even with that belief, many expressed doubts about other areas pertaining to research.

The youngest participant in the study sample (18 years old) noted the connection between government allowance of Tuskegee and the notion that many research studies today are funded by the government to strengthen their point that research is not safe simply because of government rules. In response to question 1d (Table 1) that same participant stated, “[Tuskegee] was run by the government. Federal funding from the government funds most studies these

days,” almost as if to say that the government provides no protection. Additionally, the entire study sample, not just African Americans, indicated that out of sample institutions that could conduct a study, mainly colleges and universities (see Question 11 in Appendix B), they were the least trusting of the government. White participants even indicated that they would be more trusting of a study run by a Historically Black College or University (HBCU) than a government-run study.

Theme 4, “The right versus the wrong group,” was present in the remaining age groups. Two of the three participants quoted under Theme 4 (Table 2) had participated in clinical research. One participated in a diabetes study and the other participated in a clinical device study. Even though they had participated in research before, their comments indicated that they were skeptical of research that had more than one group for participants to be placed. Unfortunately, many clinical trials are set up with more than one group (commonly called arms). Randomized trials produce objective results because the researchers are not placing participants into the study arms. They are randomized into them and most studies of this type have at least two arms. The number of arms and the treatment thereof depends on the type of study, but the objectivity of the data depends on the randomization procedures (U.S. National Library of Medicine: [ClinicalTrials.gov](http://ClinicalTrials.gov)).

The participant who had not participated in research described a study that she was asked to participate in. She stated, “Two groups were randomly selected: one group to walk and use a pedometer and the other group to continue as normal (no walk, no exercise). The group on the walking program would benefit physically but the other group would not even though it is a proven fact that exercise is good for you. So instead of being encouraged to walk, you are almost encouraged not to for the benefit if the study.” She later went on to say, “If there was a

chance for me to be in the ‘wrong group’ on these studies, I will not participate.” In her first comment, she clearly articulated the random selection of the two groups, yet expressed her displeasure with the fact that one group would not get the same benefits as the other group. Therefore, since she believed that exercise was proven to be beneficial, she did not participate because she was not guaranteed enrollment into the pedometer group. A pattern emerged when combining her explanation of her experience with her knowledge of the Tuskegee Study. She indicated that Tuskegee’s “goal was to determine if patients were better off not being treated.” She chose not to participate in a study where she thought that she could be in the group that was not being “treated” with exercise even after her acknowledgement of the randomization process.

Many research studies rely on the comparison of data across different groups, and sometimes the randomization process is unavoidable. Notwithstanding, Theme 4 demonstrates that there could be trust issues surrounding a fundamental component of some research studies, due to historical recollection that one group will not receive the same benefits as the other(s).

Table 3 lists the themes that were unique to each age group with regard to Tuskegee’s influence. The 18-30 age group believed that African Americans are treated and viewed as animals and are intentionally given or not cured from diseases (Themes 5 and 6). Similarly, the 51-74 age group expressed views of African American lives as inferior to whites or less valued. Gamble (1997) explains that when African Americans feel devalued by whites, their relationships with medical professionals are influenced and mistrust is fueled. This belief’s shared influence on both the youngest and eldest age group suggests that these thoughts are impartial to the age of the individual.

The 31-40-year-old age group expressed their disdain for being used as testing objects because of potential risk. The 41-50 age group was the most candid in expressing outright distrust for the clinical research process, citing the selfishness of people and the “guise” of research as reasons to rightfully be negatively influenced in terms of clinical research opinion. As will be discussed later, the latter age group was also compositely the less trusting age group.

Table 4 lists select participant experiences with racism. As previously stated, racism was a statically significant predictor of a lack of trust in clinical research ( $p$ -score= 0.038). However, even though the 41-50 age group was the least trusting by total trust score, they had the least experience with racism of all groups. One would have expected the 51-74 age group (100% experience with racism,  $n=36$ ) to have been the least trusting overall based on experience with racism alone, but a lack of trust can originate from several factors. The 41-50 age group had the lowest participation rate (31%) in clinical research when compared to the 18-30, 31-40, and 51-74 age groups (59%, 39.3%, and 50%, respectively). Over 94% of the 41-50 age group had heard of the Tuskegee study and had the highest percentage of strong to moderate influence due to this knowledge (29%,  $n=38$ ). The level of education has also been cited to correlate negatively with a lack of trust (Hall, Camacho, Lawlor, DePut, Sugarman, & Weinfurt, 2006). The 41-50 age group had the most participants whose highest level of education was high school, some college, or an associate’s degree. Additionally, this group had the lowest percentage of participants reaching a Master’s or doctoral level of education of all African American age groups (See Figure 3) . All of these factors could explain the lower trust score despite the lesser experience with racism.

One of the most significant themes as it relates to the clinical setting is Theme B, “Stereotyped and more by my doctor.” This theme was represented in the 31-40 and 41-50 year-

old age groups. Negative views of hospital staff have been found to be a barrier to trust. African Americans have been found to be less trusting of their physicians and to be more passive in encounters (Franks, Muennig, Lubetkin & Jia, 2006; Bird & Bogart, 2001). A telephone survey revealed that African Americans were more likely than Whites to report that their doctors did not inquire sufficiently about their pain, did not give a time frame for their medication to work, and did not explain the seriousness of injury or illness (Blendon, 1989; Gamble, 1997). Additionally, physicians have been found to perceive and treat African American patients differently than their white counterparts (Franks et al., 2006). The cringe-inducing accounts of the experiences in this current research study are evidence of not only stereotypes in health care, but potential seeds of mistrust. One participant described her experience with what she thought was a stereotypical diagnosis by her doctor. She stated, "I have had several occurrences where I would mention certain symptoms that I am experiencing...and the physician would make a stereotypical diagnosis/guess of my condition without performing an examination...until I insist that they examine me before trying to guess." She went on to state that she was told she was pregnant or had a yeast infection from tight jeans when she was not sexually active and did not own a pair of jeans.

Just like the perpetuation of stereotypes in other areas of our lives can be harmful to those around us, so too can it be in health care and clinical research. Surprisingly, none of these participants indicated that they would not participate in clinical research indefinitely. Instead, they all stated that careful understanding of potential research studies, personal assumption of responsibility for knowing what the study entails, and careful background research of the study in question were necessary prior to participation. These individuals, whose stories were highlighted in Theme B (Table 4), represent a group of African Americans who are cautious of



research due to a negative medical experience but have not yet excluded clinical research participation all together.

Table 5 listed unique experiences by age group, and the themes for three of the four groups were somewhat indicative of the age of the individuals. Keeping in mind that racism was a statistically significant predictor of trust in clinical research, the 18-30-year-old age group often referenced distant childhood memories in their experiences with racism which could be indicative of why this group was less influenced and participated more in clinical research than any other age group. The 41-50 and 51-74 age group, which have the lowest two participation rates and trust scores of all groups, referenced more recent and frequent encounters with racism at their place of work. The recall of more recent memories or situations (e.g. going to the same job every day where they were passed up for a promotion, working every day with the same colleagues who make racist remarks) could explain why the older age groups were less trusting of and participated in research less than the 18-30 age group.

*Are younger African American adults more trusting of and more willing to participate in the clinical research process given their upbringing in a less historically negative time period?*

While little explicit data were available to answer this question, a few implicit details emerged through the short answer responses of the participants. Younger African American adults in the 18-30-year-old age group did participate in clinical research at a higher rate than the 31-40, 41-50, and 51-74 age groups (59% had participated in clinical research compared to 39.3%, 31%, and 50%, respectively). Across all age groups, this was an extremely high rate of participation. Newman et al. (2006) found that due to the difficulty in obtaining adequate minority samples, researchers tend to settle for general population demographics when conducting their studies. African Americans represent approximately only 13% of the United

States population (McKinnon, 2003), thus, the participation rates of the individuals in this study would be expected to hover around this percentage. The doubling and a tripling of this percentage could be attributed to the general geographic location of residence for the study sample. Over 70% of the respondents indicated that they were either born or raised in Southeast Michigan, which is home to over 5 major public institutions of higher education, two of which are world leaders in clinical research (Universities Research Association, Inc.). The proximity of the universities could provide increased access to research studies for this group of African Americans.

The 18-30-year-old age group and the 31-40-year-old age group both had higher composite trust scores than the corresponding older age groups, suggesting more trust in clinical researchers. The 18-30 age group had a participant deception score of 22.6, a researcher honesty score of 25.5, and a composite score of 23.6. These were the highest scores for all four age groups, meaning that the youngest age group was the most trusting of clinical researchers. The 31-40 age group was in the same area, with a participant deception score of 21.6, a researcher honesty score of 26.8, and a composite score of 24.7. The closest score to the two younger groups was the participant deception score of the 51-74-year-old age group, which was 20.8. The remaining scores for the older two groups were at least 2.8 points lower than the younger group. The 41-50 age group averaged a participant deception score of 17.3, which was the lowest of all trust scores for any age or race. This group frequently cited a lack of full disclosure and “withhold[ing] of the truth” as a barrier to participation, so it was expected that this group would unanimously believe that researchers attempt to deceive participants in some way.

*Do level of education, perceived health status, and type of employment predict trust levels?*

Although research suggests that education can be a predictor of low clinical research participation and trust (Hall et al., 2006), this study did not find a significant correlation between education and trust. In addition, this study did not find a correlation between perceived health and trust either.

The African American study sample was more educated than not only the average African American, but the average White American as well. Over 60% of the entire African American sample held at least a bachelor's degree, with 37% having obtained a master's or doctoral degree. According to a United States Census Bureau report in 2004, only 17% and 29% of African Americans and Whites, respectively, had obtained at least a bachelor's degree. This is an unusual sample by most standards and could be attributed to the general sampling area (Southeast Michigan is home to over 5 major universities) and the manner in which the sample was obtained (all respondents answered the questionnaire online via computer and internet access).

*Conclusions and Recommendations*

Given the information obtained in this research project, it is reasonable to conclude that different age groups of African Americans are apprehensive about participation and less trusting of clinical research for different reasons.

This study shows that even highly educated and employed African Americans can be distrustful of the clinical research process, contrary to other studies that indicated a lack of education and low socioeconomic status are barriers to clinical research trust and participation (Fouad et al., 2000; Shavers et al., 2002). The African American study sample surpassed not only

the national average for Blacks receiving at least a bachelor's degree, but for Whites as well. This study showed that a lack of trust correlated significantly with experience with racism. Other studies have reported that institutional racism can be a barrier, but few studies have specifically analyzed experiences with racism with regard to age. The ability to link one or multiple experiences with trust or lack thereof is an important step in determining how to move beyond racism as a barrier to African American participation.

Additionally, there is a lot of research that debates the significance of knowledge of the Tuskegee Syphilis Study on African American participation in research. There is research that suggests that it shaped a generation of thoughts toward clinical research (Gamble, 1993; Fairchild & Bayer, 1999). Evidence from this study supports this theory, mainly by the low trust scores and high knowledge rates of the Tuskegee experiment in the 41-50 and 51-74 age groups. However, there is also research that suggests that African Americans are willing to participate in clinical research and actually have favorable views towards it (Gifford et al., 2002). Evidence from this study supports this theory as well with the high participation percentage of African Americans when compared to their representation in the United States. The latter theory is also supported by the expression of "advice" that many participants gave regarding the pursuit of knowledge about a study before participation can begin, implying that participation was possible with and only with full knowledge of the study protocol.

To successfully reach out to African Americans, researchers must take into account the various reasons behind their mistrust. Focus groups that include research staff and African American adults of various ages could provide an opportunity for both parties to gain a better understanding of the other's perspective on research. These focus groups should center on investigator attitudes toward minority recruitment and reasons behind participant mistrust.

There were some limitations of this study. First, the questionnaire was only available online. This could have prohibited some from completing the questionnaire due to a lack of access to the internet. Second, the questionnaire link was primarily distributed on Facebook and MySpace. Many people do not have a Facebook or MySpace account, which limited the initial response to a select number of individuals. While it is not certain how many people responded via social networking sites or who responded via the emails forwarded to a company list-serve, the limited access of the survey created a barrier to participation. Last, additional demographic information such as gender and the institution of high education would have all been helpful in defining the characteristics of the study sample.

The study's strengths were its qualitative approach to attitudes about clinical research based on age. The resulting themes of the open-ended questions provide additional information to the literature as to what could be perpetuating mistrust of clinical research for African Americans. The division of age groups provided unique information pertaining to their thoughts and apprehensions about clinical research. The use of Trust in Medical Researchers scale enabled analysis of trust specifically in the medical researcher and not in general health care or primary care providers. This specificity strengthens the trust score's relevance to the research questions posed.

Evidence presented in this study also adds to the current literature by further exploring specific trust level differences in African Americans. Age specific barriers to trust could have future implications for trust-building and effective clinical research recruitment for specific age groups. Future outreach efforts should attempt to gauge the age-specific apprehension of African Americans in order to tailor appropriate recruitment and retention strategies towards them.

Last, as evident in Theme B from Table 4, principal investigators and their staff members must be trained in cultural sensitivity and cultural competency to help prevent irrational assumptions and stereotypes from impacting their outreach efforts to the African American population. Newman et al. (2006) report that many investigators are reporting deficiencies in developing culturally competent protocols. As difficult as it can be to recruit African Americans, the effort must be made to develop culturally competent protocols that will enable better recruitment and retention. This is particularly important in addressing younger people who have higher participation rates currently and, with effective outreach, can change the future enrollment statistics of African Americans. Additionally, the willingness of respondents in this study to participate in clinical research even after a culturally insensitive experience reflects the capacity of some African Americans to fully educate and inform themselves about their personal pursuit of research. Increased education for researchers in this area can facilitate the outreach to those who are not as willing to participate.

The results of this study provide a unique perspective on age-based trust that targets all adult ages, not just the elderly. Given that ethnic diversity in clinical research is critical, the results of this study provide important insights that could ensure that African Americans will feel more comfortable about clinical research participation. These insights include the importance of mending of broken trust for African Americans, the maintenance of trust that does exist, and the effort to specifically address their age-related issues in clinical research.

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APPENDIX A: Permission Letter



**EASTERN MICHIGAN UNIVERSITY**

August 24, 2009

Keri Kirk  
c/o Steve Sonstein  
Eastern Michigan University  
School of Health Sciences  
Ypsilanti, Michigan 48197

Dear Keri Kirk,

The CHHS Human Subjects Review Committee has reviewed the revisions to your proposal entitled: "African American and Trust: Examining Clinical Research Trust Levels Based on Age" (CHHS 09-054).

The committee reviewed your proposal and its revisions and concluded that the risk to participants is minimal. Your study is approved by the committee.

Good luck in your research endeavors.

Sincerely,

A handwritten signature in cursive script that reads "Gretchen Dahl Reeves".

Gretchen Dahl Reeves, Ph.D.  
Interim Chair, CHHS Human Subjects Review Committee



# EASTERN MICHIGAN UNIVERSITY

August 24, 2009

Keri Kirk  
c/o Steve Sonstein  
Eastern Michigan University  
School of Health Sciences  
Ypsilanti, Michigan 48197

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Sincerely,

A handwritten signature in cursive script that reads "Gretchen Dahl Reeves".

Gretchen Dahl Reeves, Ph.D.  
Interim Chair, CHHS Human Subjects Review Committee

## 1. Consent to Participate

Study title:

African Americans and Trust: Examining Clinical Research Trust Levels Based On Age

The purpose of this research project is to learn whether or not different age groups are or are not trusting of the clinical research process for different reasons based upon their age. Although African Americans are the target population, all racial and ethnic groups are welcomed and encouraged to participate in the study. You must be at least 18 years old to participate.

The study involves the completion of a brief survey that will take you approximately 15 -30 minutes to finish. You will be asked a series of questions about your personal feelings and experiences with regard to clinical research. This is not a test and there are no right or wrong answers.

The results of this study could be used in a research publication that will be accessible to the public. Your right to confidentiality is of great importance; therefore this study does not require that you give your name or other personal information. With your permission, responses to the open ended questions could be used as data, however, you will not be identified in any way. The data collected is only for use of the investigator for research purposes. Your privacy will be protected at all times.

Since no names or contact information are requested in this study, there will be a space at the end of the survey for you to provide your email address should you wish to be informed of the study results. This information will be kept securely in a password protected database and will only be used to distribute results of the study.

There are no risks associated with participating in this study. However, there is the possibility that as you respond to the questions you may feel some distress through identifying personal experiences. If you feel any discomfort, you have the right to stop at any time. If such distress is felt after the survey has been completed, you may contact Dr. Deb deLaski -Smith, Administrative Co-Chair of the Eastern Michigan University Human Subjects Review Committee (contact info below).

Taking part in this study is completely voluntary. You do not have to participate if you do not want to. You may stop your completion of the questionnaire at any time. If you stop taking the survey before it is finished, there will be no penalty to you.

If you have any additional questions or concerns, please contact the researchers listed below to:

- Obtain more information about the study
- Ask a question about the study procedures
- Express a concern about the study

Stephen Sonstein, PhD

Email address: sonsteinff@comcast.net

This research protocol and informed consent document has been reviewed and approved by the Eastern Michigan University Human Subjects Review Committee for use from to . If you have any questions about the approval process, please contact Dr. Deb de Laski -Smith (734.487.0042, Interim Dean of Graduate School and Administrative Co-chair of UHSRC, human.subjects@emich.edu).

By completing the questionnaire, you will give the researcher your permission to obtain, use, and share information that you provide for this study. This permission is required in order for you to take part in the study.



## 2. Demographic Information

Please enter the following demographic information.

To protect your privacy, all of your responses to this questionnaire will remain anonymous.

### 1. Age

Age

Where were you born?

Where were you  
primarily raised?

### 2. Ethnicity

- Hispanic or Latino
- Non-Hispanic or Latino

### 3. Race

- American Indian/Alaskan Native
- African American/Black
- Caucasian/White
- Central or South Asian
- Middle Eastern/Arab American
- Native Hawaiian/Pacific Islander

Other (please specify)

### 4. Are you currently enrolled in college?

Yes

No

## 5. What is the highest level of education you completed?

- Elementary School
- Middle School
- High School/GED
- Some College
- Associates Degree
- Bachelors Degree
- Post Baccalaureate Degree
- Master's Degree
- Doctoral Degree

## 6. Did you attend a Historically Black College or University?

- Yes
- No

## 7. What type of job do you have?

- Arts
- Business
- Education
- Health Care
- Technology
- Trade
- Unemployed

## 8. In general, how would you describe your health?

- Excellent
- Very Good
- Good
- Fair
- Poor

### 3. Survey

These questions will allow the researcher to gain a better understanding about your attitude towards clinical research and why you feel the way that you do.

There are a few important terms that the researcher would like you to be familiar with before you begin the survey:

Clinical Research - Also known as medical research which requires the collaboration of a number of persons, perhaps not all of them doctors.

Clinical studies (or clinical research) - medical research studies in which people participate as volunteers. Clinical research studies (sometimes called trials or protocols) are a means of developing new treatments and medications for diseases and conditions. There are strict rules for clinical trials, which are monitored by the National Institutes of Health and the U.S. Food and Drug Administration.

Clinical trial - a scientific study of how a new medicine or treatment works in people. Through clinical studies, doctors find new and better ways to prevent, detect, diagnose, control, and treat illnesses.

Testing in humans is permitted only if that person volunteers for participation and understands the risks and benefits of taking part in a study. This informed consent to participate must be based on the volunteer's understanding of what is involved in the study, including potential risks and benefits.

Principal investigator (study doctore) - In biomedical research, the person who directs a research project or program. The principal investigator (also known as the PI) usually writes and submits the grant application, oversees the scientific and technical aspects of the grant, and has responsibility for the management of the research.

Participant - One that participates, shares, or takes part in something.

Subject - The object of observation, treatment, or research.

Trust - assured reliance on the character, ability, strength, or truth of someone or something; one in which confidence is placed.

**1. In your own words, please explain what comes to mind when you hear the term "clinical research".**

**2. If you were to participate in a clinical research study, would you prefer to be referred to as a:**

Participant

Subject

Doesn't matter

**3. Have you ever been asked to participate in a research study?**

No

Yes

#### 4. Have you ever participated in a research study?

No

Yes

#### 5. If so, what kind of study? Please check all that apply.

Drug clinical trial or research study

Device clinical trial or research study (example of a device pacemaker or podometer)

Heart/Hypertension study

Arthritis study

Diabetes

HIV/AIDS study

Cancer study

Psychology study

Sleep study

Depression study

Other (please specify)

#### 6. Have you ever heard of the Tuskegee Syphilis Experiment?

No

Yes

If yes, please describe what you know about this study.

## 7. Does knowledge of this experiment have an influence on your opinions about clinical research?

	Strong Influence	Moderate Influence	Neutral	Little Influence	No Influence	No Knowledge
Strength of Influence	jn	jn	jn	jn	jn	jn

If so, could you briefly explain why you are influenced?

## 8. Does knowledge of this experiment have any influence on whether or not you would participate in a clinical research study?

	Strong Influence	Moderate Influence	Neutral	Little Influence	No Influence	No knowledge
Strength of influence	jn	jn	jn	jn	jn	jn

If so, could you briefly explain why you are influenced?

**9. How likely is it that you would trust a clinical study doctor and staff if they were primarily**

	Very Likely	Somewhat Likely	Neutral	Less Likely	Not Likely
Caucasian/White?	jn	jn	jn	jn	jn
Black/African American?	jn	jn	jn	jn	jn
Asian?	jn	jn	jn	jn	jn
Hispanic/Latino?	jn	jn	jn	jn	jn
Middle Eastern or Arab American	jn	jn	jn	jn	jn
Other?	jn	jn	jn	jn	jn
A mixture of races?	jn	jn	jn	jn	jn
Men?	jn	jn	jn	jn	jn
Women?	jn	jn	jn	jn	jn

**10. How likely is it that you would participate in a clinical study if:**

	Very Likely	Somewhat Likely	Neutral	Less Likely	Not Likely
You knew the doctor or clinical study staff member	jn	jn	jn	jn	jn
You were told about the study by a friend	jn	jn	jn	jn	jn

**11. How likely is it that you would participate in a clinical reserach study if the study was sponsored by:**

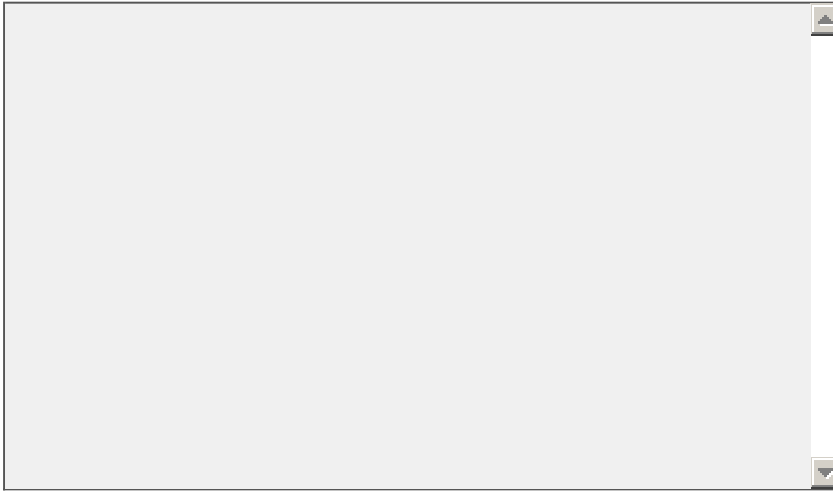
	Very Likely	Somewhat Likely	Neutral	Less Likely	Not Likely
A large, well-known univeristy or college?	jn	jn	jn	jn	jn
A small, less-know univeristy or college?	jn	jn	jn	jn	jn
A predominantly white university or college?	jn	jn	jn	jn	jn
A historically black university or college?	jn	jn	jn	jn	jn
The government?	jn	jn	jn	jn	jn
Other institution?	jn	jn	jn	jn	jn

**12. Have you had any experience with cultural prejudice or racism?**

No

Yes

If so, can you provide a brief explanation of what occurred?

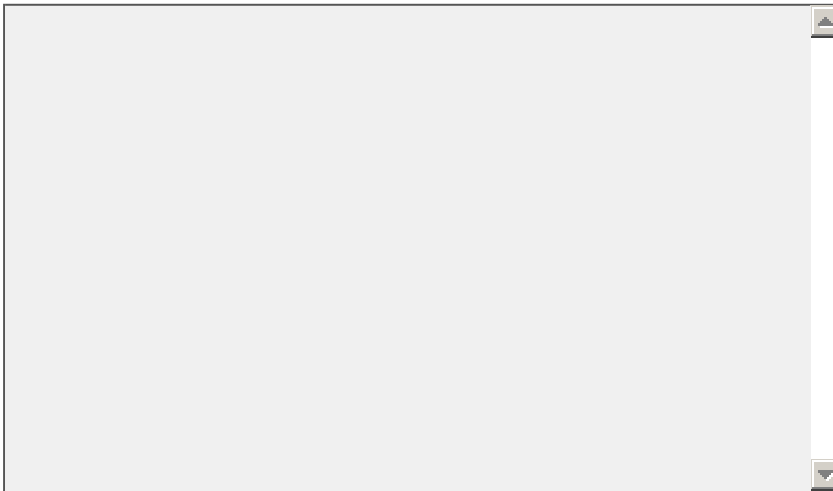


**13. Does your experience with cultural prejudice or racism have an effect on your willingness to trust health care or clinical research staff?**

No

Yes

If so, can you provide a briefly explain why?



**14. Do you know someone other than yourself who has experienced cultural prejudice or racism?**

No

Yes

If so, does their experience with prejudice and/or racism effect whether or not you will participate in clinical research studies? Enter NA if no effect.

**15. If you answered 'yes' to the question above, what is that person's relationship to you?**

- Parent
- Sibling
- Son/Daughter
- Husband/Wife
- Partner
- Other relative
- Friend
- Co-worker
- Roommate
- Professor

Other (please specify)



## 4. Survey (cont)

### 1. Please select whether or not you agree or disagree with the following items.

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
To get people to take part in a study, medical researchers usually do not explain all of the dangers about participation.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Participants should be concerned about being deceived or misled by medical researchers.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Usually, researchers who make mistakes try to cover them up.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Medical researchers act differently toward minority subjects than toward white subjects.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Medical researchers unfairly select minorities for their most dangerous research studies.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

**2. Please select whether or not you agree or disagree with the following items.**

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
Some medical research projects are secretly designed to expose minority groups to diseases such as AIDS.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
In general, medical researchers care more about doing their research than about the participants' medical needs.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Researchers are more interested in helping their careers than in learning about health and disease.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Medical researchers are generally honest in telling participants about different treatment options available for their conditions.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Usually, medical researchers tell participants everything about possible dangers.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
All in all, medical researchers would not conduct experiments on people without their knowledge.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Most medical researchers would not lie to people to try to convince them to participate in a research study.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

**3. Do you think that President Obama should urge people to participate in clinical research?**

No

Yes

**4. Do your religious beliefs influence whether or not you would be trusting of clinical research studies?**

No

Yes

**5. What (if anything) makes you uncomfortable about the idea of participating in clinical trials?**

**6. Is there anything else that you would like to share that you have not yet shared already?**

## 5. Study Results

**1. The results of this study could potentially be used in a resesrach publication. Your responses will be used as data to explain your feelings about trust and clinical research.**

**Does the researcher have permission to use your responses as data in this research study?**

Yes

No

**2. If you would like to receive information about the results of the study, please enter an active email address where the information can be sent.**

**This information will be kept secure in a password protected database and will only be used to distribute results of this study.**

Email Address:

## 6. Thank You

**Thank you for you participation!**

### **Definition References**

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