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### Predictors of barriers to participation in clinical research in adults living in the Southeastern United States

Jennifer Scanlon

[jennifer.scanlon@pop.belmont.edu](mailto:jennifer.scanlon@pop.belmont.edu)

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Predictors of barriers to participation in clinical research  
in adults living in the Southeastern United States

Jennifer Scanlon

Belmont University

Scholarly Project Advisor: Dr. Linda Wofford

Scholarly Project Team Members: Dr. David Phillippi & Dr. Alecia Fair

Date of Submission: April 17, 2020

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### Abstract

Research is the necessary foundation for health care advancement and understanding. Significant challenges exist, however, with recruiting and engaging underrepresented populations in clinical research. The purpose of the scholarly project was to determine how stakeholder race, trust, and level of education influence participation barriers in clinical research. The project utilized secondary, cross sectional survey data that were collected between 2014 and 2016 through the former Mid-South Clinical Data Research Network (CDRN), currently known as the STAR-CRN. Descriptive statistics and spearman rank correlations were performed between level of education, level of trust, and each attitude statement for each racial category. A total of 2,149 survey responses were used in the data analysis. The mean age of respondents was 52 years old ( $SD=15.65$ ) with majority being female (69.0%,  $n=1496$ ), white (77.7%,  $n=1701$ ), insured (76%,  $n=1610$ ), and working full time (50.4%,  $n=1078$ ). Overall, the respondents had favorable attitudes towards research participation. Trust was associated with agreement in each attitude statement from both white and AA respondents ( $p<.001$ ), while correlations with education level was more variable depending on racial grouping. Trust level was negatively associated with agreement towards the statement “Researchers don’t care about me” in White ( $CC=-.492$ ;  $p=.000$ ), AA ( $CC=-.188$ ;  $p=.000$ ), Asian ( $CC=-.429$ ;  $p=.041$ ), and Middle Eastern ( $CC=-.864$ ;  $p=.003$ ) respondents. The results support the importance of trust within the patient and provider relationship. Generally, education level is not a largely predictive variable in its influence of research participation, although it shows stronger evidence of influence depending on race and attitude statement.

*Keywords:* trust, race, education, participation, clinical research, underrepresented, adults

Predictors of barriers to participation in clinical research  
in adults living in the Southeastern United States

**Introduction and Background**

At the turn of the 21<sup>st</sup> century, the Institute of Medicine (IOM) released the article, *Crossing the Quality Chasm*, which emphasized the need for an effective, equitable, and patient-centered health care delivery system (Agency for Healthcare Research and Quality [AHRQ], 2018). Effective health care refers to providing appropriate medical services based on scientific knowledge to those who could benefit, while refraining from services that are likely nonbeneficial (AHRQ, 2018). Equitable health care does not vary in quality based on patient-specific characteristics like race, socio-economic status, or geographic location (AHRQ, 2018). Patient-centered care (PCC) views a patient holistically and is grounded in the idea of mutuality between the patient and medical provider. The goal is to ultimately attain the best health outcomes for the patient (Beattie, Shepherd, Howieson, 2012). In order to provide effective and equitable care to all individuals, health care research in the domain of patient centeredness is necessary (Beattie et al., 2012).

Health care research is a general term that includes a variety of research methodologies that ultimately develop or provide knowledge regarding disease, risk factors, outcomes of treatment, public health interventions, functional abilities, patterns of care, and health care usage (Beattie et al., 2012). For example, a medical provider may decide to treat a young African American woman with hypertension differently compared to an older Caucasian woman based on what research shows to be most effective. It is through research that the goal of equitable, effective, and patient centered health care can be attained.

Although research is the necessary foundation for health care advancement and understanding, significant challenges exist with recruiting and engaging underrepresented populations into health care research. The National Institutes of Health (NIH) recognize African Americans (AA), American Indians (AI), Alaskan Natives (AN), Hispanics, Native Hawaiians (NH), and other Pacific Islanders (PI) as underrepresented populations in research studies (National Institutes of Health [NIH], 2018). Although increasing minority participation in clinical trials has been a priority in the country since the NIH Revitalization Act of 1993, participation rates in minority populations remain low compared to the percentage of minorities in the entire United States' (US) population (Reifenshtein & Asare, 2018).

In 2017, the FDA reported 81% of clinical trial participants as Caucasian, 14% AA, 2.7% Asian, and the remaining 2.3% were Hispanic, PI, AI, AN, and NH populations (Food and Drug Administration [FDA], 2017). The participants were not representative of the entire US population in that 61% were Caucasian, 18% were Hispanic or Latino and 15% were African American, 5% were Asian, and 2% were AI or PI (United States Census Bureau, 2017). Although minority populations are underrepresented in clinical research, they face the greatest health disparities (AHRQ, 2015).

The 2015 National Healthcare Quality and Disparities Report documents that minority populations receive poorer quality of care and face greater barriers in accessing care compared to white populations (AHRQ, 2015). In addition, AA, AI, and Hispanics have greater rates of preventable hospitalizations and higher mortality rates compared to white populations (AHRQ, 2015). Incidence of specific diseases, cancers, and reactions to medications and treatments differ between races and ethnicities. For example, AA men have a greater incidence of prostate cancer compared to Caucasian men. AA women have the same incidence of breast cancer as Caucasian

women, however, have higher mortality rates (Ahaghotu, Tyler, & Sartor, 2015; Reifenstein & Asare, 2018). In addition, Hispanics and AAs have the greatest prevalence of diabetes and adolescent obesity compared to Caucasians (CDC, 2015). Similarly, almost half of all AA adults have some form of cardiovascular disease compared to about one third of Caucasian adults (Reifenstein & Asare, 2018). In addition to health disparities, the effectiveness of treatment modalities differs between races. Clopidogrel, an antiplatelet drug is highly effective for Caucasians but has no greater affect than a placebo in 75% of Pacific Islanders (Wu, White, Oh & Buchard, 2015). Due to the disparities present, it is necessary to recruit and engage diverse populations in order to create equitable health systems. However, engaging and recruiting participants to accurately represent the diversity of the population is challenging process (Cunningham-Erves et al., 2017).

### **Problem Statement**

Research participants, also referred to as stakeholders in patient centered research studies, are needed from diverse populations (i.e. racial ethnic minorities, sexual gender minorities, variation in geographic locations and differing abilities) in order to identify relationships between numerous socio-cultural and biologic variables, ensure reliable data, and to ultimately determine equitable, effective, and patient-centered health outcomes and solutions for all patients (Centers for Disease Control [CDC], 2013; Cunningham-Erves et al., 2017; FDA, 2018; Lin & Kelsey, 2000). Although there is a great need in engaging diverse samples of participants for research as mentioned previously, recruiting and engaging participants remains a challenge.

In 2014, the National Patient-Centered Clinical Research Network was established by the Patient-Centered Outcomes Research Institute (PCORI) with the goal of transforming the culture of clinical research through patient-centered engagement and recruitment (Unertl et al., 2018).

Utilizing the multiple healthcare facilities and millions of patients in the network, the STAR-CRN (Stakeholders, Technology, and Research CRN, n.d.), formally known as the Mid-South Clinical Data Research Network (CDRN), a sub-unit of the National Patient-Centered Clinical Research Network, aims to increase the number of research participants through their diverse patient network. In order to effectively engage patients in the diverse STAR-CRN network, it is necessary to identify the barriers that these specific patients encounter at any point in the research process.

### **Purpose and Hypothesis**

The purpose of the scholarly project was to determine how stakeholder race, trust, and level of education influence participation barriers in clinical research. Improved understanding of predictors will offer insight on how to effectively engage and educate patients living in the southeastern United States who receive healthcare services through facilities associated with the STAR-CRN. Based on the reviewed evidence, the researchers hypothesize that race, trust level, and level of education are predictors of barriers to participation in clinical research.

### **Review of Evidence**

Extensive literature exists regarding participation barriers in research and variables that can influence a stakeholder's willingness to participate. Barriers identified include the participant's level of trust, access to research information, fear of the unknown or adverse effects, inconvenience, and reputation of researchers and research institutions (George, Duran, & Norris, 2014; Williams et al., 2010).

### **Trust**

The concept of trust is discussed and examined in health care literature specifically due to relationship dynamics between healthcare professionals and patients (Dibben, Morris, & Lean,



2000; Hall et al., 2001; Hupcey, Penrod, Morse, & Mitcham, 2001; Goudge & Gilson, 2005).

Trust is defined as the degree to which the patient relies, depends, and is confident in the provider (Armstrong, Ravenell, McMurphy, & Putt, 2007). Trust is present in situations of risk, uncertainty, or unequal status where there is a level of dependence on another individual (Kerasidou, 2017; Thielmann & Hilbig, 2015) creating a relationship of vulnerability (Hall et al., 2001). In the case of a patient and medical researcher, an asymmetrical relationship exists between the researcher's authority and patient role.

Many variables identified throughout literature act as barriers and facilitators to participant trust in clinical research (George, Duran, & Norris, 2014). Barriers to trust include inadequate information regarding research studies, unethical behavior by the research team, and safety concerns (Ceballos et al., 2014; Cortes et al., 2017; Cunningham-Erves et al., 2016; George et al., 2014; Owens et al., 2013; Scharff et al., 2010; Williams et al., 2010). Many individuals believe that collected samples like blood, urine, saliva, or stool are unethically disposed of or used after the research study without permission (Ceballos et al., 2014; Kraft et al., 2018). In addition, study participants expressed fear of taking medications that would cause adverse effects (Cortes et al., 2017), receiving unnecessary surgery (Cortes et al., 2017), experiencing unintended consequences of the study (George et al., 2014), having personal information be used against the participant (Cortes et al., 2017; Scharff et al., 2010) and being treated like "guinea pigs" or "lab rats" (Cunningham-Erves et al., 2016, Durant et al., 2011, George et al., 2014; Owens et al., 2013; Scharff et al., 2010; Williams et al., 2010).

Facilitators to participant trust in clinical research include the patient's relationship with the research team (Burkett & Morris, 2014; Byrne et al., 2014; Cortes et al., 2017; George et al., 2014; Getrich et al., 2013; Gupta et al., 2014; Kraft et al., 2018; Owens et al., 2013; Paquette &

Derrington, 2018; Scharff et al., 2010; Williams et al., 2010), a thorough and educational research consent process (Cortes et al., 2017; George et al., 2014; Kraft et al., 2018, Owens et al., 2013), and extensive research study oversight (Kraft et al., 2018; Paquette & Derrington, 2018). Individuals are more likely to participate in a study if they feel well informed about the study and know they have the right to withdraw at any point (Cortes et al., 2017; George et al., 2014). Study participants report greater feelings of trust and willingness to participate in research knowing that researchers are being held accountable by leadership teams (Kraft et al., 2018; Paquette & Derrington, 2018). In addition, participants voiced wanting to know about the research funding and how the data library was being managed (Kraft et al; 2018; Williams et al., 2010). Participants' understanding of the research team behind the study facilitated greater trust by the participant (Kraft et al., 2018; Paquette & Derrington, 2018; Williams et al., 2010).

### **Race and ethnicity**

Race and ethnicity are variables that not only influence patient participation in research but also influence trust. Due to historic and recent events of segregation, racism, and unequal civil rights, African Americans report less willingness to participate in research compared to Caucasians (Dunlop, Leroy, Logue, Glanz & Dunlop, 2011; Durant et al., 2011; George et al., 2014; Kraft et al, 2018; Ma et al., 2012; Owens et al., 2013; Scharff et al., 2010; Westergaard et al., 2013; Williams et al., 2010). A variety of studies reference the Tuskegee Syphilis Study that was conducted from the 1930s to the 1970s that left the African American community fearful and distrusting in the process of research (Alsan & Wanamaker, 2018; Durant et al., 2011; George et al., 2014; Ma et al., 2012; Owens et al., 2013; Scharff et al., 2010; Williams et al., 2010). The study permitted hundreds of adult AA men with syphilis to go untreated despite the availability of effective treatment, Penicillin (Alsan & Wanamaker, 2018). In addition, the

treatment of Henrietta Lacks and her family in the 1950s continues to alter the perspectives of AAs towards healthcare institutions and American society (Kraft et al., 2018). Henrietta Lacks was an AA woman whose cells, collected from a cervical cancer biopsy, were later developed into the HeLa cell line. HeLa cells were commercialized and highly profitable in the healthcare world, however, the Lacks family did not gain any profit from her biospecimen (Lee et al., 2019).

Hispanic individuals also face specific cultural and racial variables that influence participation in clinical research (Ceballos et al., 2014; Kraft et al., 2018; Ulrich et al., 2013; Westergaard et al., 2013). Some study participants expressed their willingness to participate in research but have limited understanding of the healthcare system due to immigration to the United States later in their lives (Ceballos et al., 2014; Kraft et al., 2018; Ulrich et al., 2013). In addition, individuals expressed fear of racial discrimination (Ceballos et al., 2014; Ulrich et al., 2013; Westergaard et al., 2013) and misunderstanding due to language barriers (Ceballos et al., 2014; Westergaard et al., 2013).

### **Education**

An individual's education level is discussed within research literature in the context of research participation. Education level affects an individual's literacy and understanding (Asare, Flannery & Kamen, 2017), therefore theoretically affecting what a participant knows and understands about research. In one study measuring recruitment and participation in clinical research (n=5,154), individuals with increased levels of education, particularly college graduates, were more likely to participate (Baquet, Commiskey, Mullins & Mishra, 2006). The results were consistent with a different study where 97% of participants were college educated and reported favorable views of research and willingness to participate in clinical trials (Brewer et al., 2014).

In a study measuring African Americans' willingness to participate in research before and after a pre-consent education session (n=192), individuals with a high school level of education or less were significantly more likely to participate in a clinical trial after receiving pre-consent education (Dunlop et al., 2011). Although past literature explores the relationship between education level and an individual's participation in research, convincing evidence of the relationship between an individual's education level and perspectives on research participation is lacking.

### **Location**

Race, trust, and education are variables in this scholarly project because they are seen throughout literature as predictors to patient participation. Although barriers to research participation have been studied previously, further research is justified because there is geographic variation in research participation barriers throughout the United States (Armstrong et al., 2007). Individuals living in urban areas report greater distrust compared to those in rural areas, yet rural participants report lack of interest in participating in clinical trials compared to urban areas (Friedman, Bergeron, Foster, Tanner & Kim, 2013). In another study, participants living in rural Maryland were less likely to participate in research compared to participants living in urban Maryland (Baquet et al., 2006). Due to geographic variation, collecting data from patients who receive care from medical providers that belong in a specific healthcare network, specifically those affiliated with the STAR-CRN, can be beneficial for developing accurate implementation methods to engage that same population for research.

### **Theoretical Model**

The Social Cognitive Theory (SCT) by Albert Bandura (1971) provided the theoretical framework for the scholarly project. The Social Learning Theory was initially developed in the

1960s while Bandura was studying the learned behaviors of children. The theory was later updated into the Social Cognitive Theory in 1986 (LaMorte, 2019). The theory explains how individuals learn and maintain behaviors in the social context in which they live. The theory includes the construct of reciprocal determinism which considers the continual interaction between cognitive, environmental, and behavioral factors to ultimately determine human behavior (Ozyilmaz, Erdogan, & Karaeminogullari, 2018). Cognitive factors, also called personal factors, include an individual's knowledge, expectations, and attitudes. Environmental factors include societal and cultural norms, community access and resources, and the influence of others. Behavioral factors include skills, practice, and an individual's self-efficacy.

The triadic reciprocal relationship between cognitive factors, the environment, and human behavior explains the theorized relationship between variables in the scholarly project. Refer to Figure 1 for a model of the SCT in relation to the variables being examined. The independent variables of the scholarly project included the individual's level of trust towards clinical research, race, and level of education. Each independent variable was classified as a personal factor within the theory. Barriers to participating in research were the dependent variables of the scholarly project. One can assume if no barriers to participating exist, an individual would therefore participate in research. Participation in clinical research was classified as the behavior in the theoretical model. Environmental factors include the physical, social and cultural context in which an individual lives.

Although the scholarly project did not directly include environmental factors as study variables, literature consistently displays that environmental factors are closely tied to race and trust level. Current and historic racism and societal segregation create neighborhoods and cities with unequal opportunities and resources. When comparing communities with similar poverty

rates, neighborhoods that are predominantly African American or Hispanic have fewer grocery stores, parks, and gyms than predominately white neighborhoods (Brooks, 2014; Firebaugh & Acciai, 2016). In addition, African American men report greater perception of racial discrimination in health care compared to white men (Assari et al., 2017). As stated previously in the review of literature, past studies reveal that level of trust and willingness to participate in research varies geographically. Therefore, environmental factors, although not a variable that is being measured directly within the scholarly project, are directly tied to the variables of interest and require inclusion within the theoretical framework.

In the context of the scholarly project, the researcher can theoretically predict behavior, as in, participation in clinical research, with consideration of the various factors that influence that human behavior. An individual who does not understand research or has little trust in medical research may be less likely to engage in research. Comparatively, an individual with greater amounts of trust towards medical research and a higher level of education may be more likely to participate in research.

### **Project Design**

The scholarly project utilized secondary, cross sectional survey data that were collected between 2014 and 2016 through the former Mid-South Clinical Data Research Network (CDRN), currently known as the STAR-CRN. The surveys were handed out throughout clinics within the former Mid-South CDRN after receiving approval from the Vanderbilt University Institutional Review Board (IRB). To utilize the de-identified data for the scholarly project, the Belmont University IRB approved the project as exempt in April 2019.

**Clinical Setting**

The former Mid-South CDRN conducted research across numerous healthcare delivery sites throughout the Southeastern US. The major medical sites associated with the former Mid-South CDRN included Vanderbilt University Medical Center, Meharry Medical College, the Vanderbilt Healthcare Affiliated Network, Greenway Health, and the Carolinas Collaborative.

Although the former Mid-South CDRN, now known as the STAR-CRN, is expansive throughout the southeast, the survey was specifically distributed to patients visiting a Vanderbilt University or Meharry/Metro General hospital or clinic. Practice settings of the former Mid-South CDRN included, Vanderbilt University Medical Center, Vanderbilt University Children's Hospital, Vanderbilt University Stallworth Rehabilitation Hospital, Vanderbilt University Psychiatric Hospital, Meharry/Metro General Hospital, and Matthew Walker Community Health Center.

**Project Population**

The research participants were adults (18 years old and older) living in the Southeastern United States who received care at least one time from a provider at one of the aforementioned clinical sites. There were no further inclusion or exclusion criteria.

**Data Collection Instruments**

Between 2014 and 2016, approximately 5,000 patients in the CDRN were surveyed to identify barriers that impede patient involvement in research. Two parallel surveys were administered using a random process (Cunningham-Erves, Villalta-Gil, Wallston, Boyer, & Wilkins, 2019). The surveys differed by tools that measured the concept of trust. One survey included the tool, Hall-Trust in Medical Research (Hall et al., 2006) while the other included Mainous-Trust in Medical Research (Mainous, Smith, Geesey, & Tilley, 2006). The Scholarly

Project only utilized data collected from the survey containing the tool, Trust in Medical Research (items 67-78) by Hall et al. (2006). All surveys were administered using REDCap (Harris et al., 2019). Refer to appendix A for a copy of the survey.

Race, ethnicity, and level of education were collected in the demographic portion of the survey (items one through 24). The tool *Trust in Medical Research* (items 67 to 78) by Hall et al. (2006) was used to measure the respondent's level of trust in medical research. The trust tool was developed initially through a pilot study with a 25-item questionnaire. It was then simplified by following an item-reduction procedure to develop the current 12-item tool (Hall et al., 2006). The Cronbach alpha coefficient was 0.87 and the response pattern was normally distributed (Hall et al., 2006).

Questions to assess barriers to participation in medical research (items 54 to 66) were taken from a previous study by Mouton, Harris, Rovi, Solorzano, & Johnson (1995) using a five-point Likert scale for each statement ranging from strongly agree to strongly disagree. The specific questions were created from a literature review of barriers to participation in research. A panel of four experts reviewed the 12- question instrument for clarity, content validity, and cultural sensitivity. The content validity and cultural sensitivity both scored as 1.0 (Millon-Underwood, Sanders, & Davis, 1993).

### **Data Collection Process**

Participants were recruited in person at the aforementioned clinics. Prior to receiving a survey, participants were informed of the purpose, time commitment, risks and benefits, and compensation. Compensation included a \$25.00 gift card with the completion of the survey.

The results of the survey were stored in a secure dataset through the Meharry Vanderbilt Alliance (MVA). In order for the project leader to access the secondary data, the Belmont



University IRB approval was obtained in April 2019. Next, a data-usage agreement through MVA was signed by the project leader. The project leader obtained the dataset in August 2019.

### **Statistical Analysis**

The dataset was organized and cleaned in Microsoft Excel. Initially, the dataset included 4,700 respondents from two different surveys. The researcher removed the respondents from the dataset that did not obtain the survey that was used for the scholarly project. A total of 2,149 respondents remained after deletion. The percentage of missing data was calculated for each survey measure. Each measure had less than 5% missing data. A response mean for each measure was calculated to fill in missing data.

IBM SPSS Statistics, version 26 was used for the statistical analysis. Descriptive statistics were performed on the variables of level of education, trust level, race, and each attitude statement in the barriers to participation scale. Next, a spearman rank correlation was performed between level of education, level of trust, and each attitude statement for each racial category.

### **Results**

A total of 2,149 survey responses were used in the data analysis. Sociodemographic characteristics of survey respondents are shown in Table 1. The mean age of respondents was 52 years old ( $SD=15.65$ ) with majority being female (69.0%,  $n=1496$ ), white (77.7%,  $n=1701$ ), insured (76%,  $n=1610$ ), and working full time (50.4%,  $n=1078$ ). The mean trust score was 39.85 ( $SD=6.7$ ). Trust scores by racial grouping are shown in Table 2. Middle Easterners reported the least amount of trust ( $M=36.11$ ,  $SD=5.8$ ) compared to other groups. The majority of respondents had at least two years of college education (85.3%,  $n=1836$ ). Education levels are separated by racial groupings in Table 3. Very few respondents in each racial grouping had less than an 8<sup>th</sup> grade education.

Overall, the respondents had favorable attitudes towards research participation. Percentage of respondent agreement towards attitude statements are displayed in Table 4. The majority of participants agreed that research benefits society and that participation in research means better care. Oppositely however, only 3.3% ( $n=51$ ) of respondents agreed that research conducted in the United States is ethical. Attitudes towards researchers were generally positive in that only a few, 5.5% ( $n=119$ ), agreed that “Researchers don’t care about me” and “Scientists cannot be trusted” (2.4%,  $n=51$ ).

Spearman correlations were performed using the racial groupings of White, AA, Hispanic, Native American, Asian, and Middle Eastern. As mentioned previously in the project design section, the correlations utilized education, trust level, and attitudes regarding participating in research. Correlation results are displayed in Table 5. Correlations were not performed for the Native Hawaiian grouping due to a small sample size ( $n<5$ ). Trust was significantly associated with agreement in each attitude statement from both white and AA respondents ( $p<.001$ ), however association with education level was variable. Trust level was negatively associated with agreement towards the statement “Researchers don’t care about me” in White ( $CC=-.492$ ;  $p=.000$ ), AA ( $CC=-.188$ ;  $p=.000$ ), Asian ( $CC=-.429$ ;  $p=.041$ ), and Middle Eastern ( $CC=-.864$ ;  $p=.003$ ) respondents. Trust level was strongly associated with specific attitude statements for Native American respondents but there was less evidence of associations involving their education level. Conversely in Asian respondents, education level was positively associated with the statements “Participation in research is morally wrong” ( $CC=.540$ ;  $p=.008$ ), “Scientists cannot be trusted” ( $CC=.568$ ;  $p=.005$ ), “Research conducted in the US is ethical” ( $CC=.453$ ;  $p=.030$ ), and “It is better to be treated by doctors who are researchers” ( $CC=.418$ ;  $p=.047$ ).

## Discussion

The purpose of the scholarly project was to determine how stakeholder race, trust, and level of education influence participation barriers in clinical research. Although the respondent's attitude scores towards research participation is not the exact determination of whether the participant will or will not engage in clinical research, the attitude score may be considered a proxy for the act of engaging in clinical research.

Overall, this cross-sectional survey of adults in the Southeastern US demonstrates favorable attitudes towards research participation. The data suggest that attitudes are positive in regard to perceived societal benefit and the belief that research leads to better medical care. The attitudes towards research are consistent with both the findings of Mouton et al (1995) and Brewer et al (2014). In addition, the research of Kraft et al (2018) displayed similar themes during focus group interviews of AAs, Chinese, Hispanic, White, and Asians who agreed that research would benefit society and in general, improve medical care. Although favorable attitudes towards research participation are seen within the data, the relationship of attitudes and an individual's race, trust, and education is important to consider in the context of the theoretical framework of the project and implications for future clinical practice.

### **Race and Ethnicity**

No statistical tests were performed to analyze the correlation between race and attitudes towards research participation within the scholarly project. As explained previously in the methods section, the data was separated by racial groupings in order to consider race within statistical tests that do not allow for nominal variables. The scholarly project results display variability between racial groupings in education level, trust level, and attitudes towards

participating in research. One cannot assume, however, statistically correlated relationships between a respondent's race and attitudes towards participating in research.

The difference of trust and education between White, AA, Hispanic, NA, Asian, and MEs support the theoretical underpinnings of the scholarly project. The Social Cognitive Theory considers an individual's personal factors like race and ethnicity, however, the predictive weight of the personal factor in direct correlation to participating in research is uncertain.

### **Trust**

The findings of the scholarly project display strong evidence that an individual's trust in clinical research influences one's attitude towards research. In White, AA, Hispanic, NH, and ME respondents, trust is correlated more often to attitudes towards research than an individual's education level. The findings are consistent with past literature displaying the significant role that trust has in a patient's barriers and facilitators in participating in clinical research (George, Duran, & Norris, 2014). In addition, the findings support the original hypothesis that trust is predictive towards barriers in clinical research. As respondents agreed more to negative statements regarding participation like, "Researchers don't care about me", "Participation in research is risky", and "Participation in research is morally wrong", trust level was decreased. As respondents agreed more with the statements "Participation will mean better care", "Participation in research is enjoyable", and "Participation in research allows me to socialize", trust level expectedly also increased.

The relationship between trust and the respondent's attitude towards research also aligns with the theorized relationship of variables explained through the Social Cognitive Theory.

Through the theoretical model and the supporting data, stronger evidence exists to predict if an

individual has greater trust towards medical research, attitudes towards research are more favorable, and participation is more likely to occur.

### **Education**

Overall, less evidence supported correlations between a participant's level of education and attitude on research participation. These findings are generally inconsistent with past research regarding barriers to research participation. Past literature displays that low education levels can contribute to decreased research participation due to the difficulty of understanding the research information or the informed consent process (Asare, Flannery & Kamen, 2017; Baquet, Commiskey, Mullins & Mishra, 2006; Crosson, Eisner, Brown, & Ter Maat, 2001). In a qualitative survey of Hispanic beliefs about biomedical research participation, the researchers found that participants discussed not having a formal education which acted as a barrier for participating in research from fear of the unknown (Ceballos et al., 2014). However, the findings of the scholarly project display less evidence of a correlation between education level and attitudes towards research participation in Hispanic individuals.

The results of the scholarly project suggest that education level may hold a stronger influence on attitudes towards research for Asian respondents compared to the influence of trust. The results contradict what is commonly discussed in medical literature regarding Asian American reverence and respect to healthcare providers (Gaw, 2020). Past literature expresses how language barriers and health literacy are common barriers for Asian Americans when navigating the healthcare system (Kim & Keefe, 2010; Tu et al., 2005) which may align with an individual's education level, particularly if they were educated in the US.

Generally, education level is not a largely predictive variable in its influence of research participation unlike what was hypothesized. Although it shows stronger evidence of influence

depending on race and attitude statement, it is not as consistent as the influence of trust level. The dynamic, reciprocal relationship between personal and environmental factors of the Social Cognitive Theory is important to consider in regard to the relationship of education level on an individual's participation in research. Although education can have influence on an individual's behavior, a variety of personal and environmental factors exist that may hold stronger influence towards behavior. The inconsistency of an individual's education level on attitudes towards research participation within this scholarly project can ultimately highlight that numerous factors have the ability to play a role in research participation.

### **Implications for Practice and Future Directions**

The findings of the scholarly project have several implications. The variability in results support the Social Cognitive Theory in that numerous factors influence an individual's decision to participate in research. Clinicians must be aware of the factors that contribute to an individual's attitude toward research and educate accordingly. A staggering 97% (n=2,079) of respondents within the dataset agreed that research conducted in the US is unethical. The results of this study are even more than Brewer et al (2014) of which half of survey respondents agreed that research in the US is unethical. As the results show, an individual can believe that research benefits society while also perceiving research to be unethical. The fear of unethical treatment may outweigh the altruistic motivation of how research benefits society, therefore hindering the participants' engagement in research. Increased clinician education regarding the socio-cultural barriers that hinder patients from participating can enhance clinician-patient communication.

Utilizing multiple recruitment methods for engaging participants may also be helpful. Researchers may consider engaging with community representatives, community networks, and churches to engage individuals (Luebbert & Perez, 2016). A newer model of research

engagement, community-based participatory research (CBPR), displays encouraging recruitment results (Scharff et al., 2010). CBPR operates on long term community-research relationships (Scharff et al., 2010) and can improve knowledge gaps within communities regarding disclosure and transparency, fear of research procedures, and societal impact in relation to research trials (Cortes et al., 2017). In one study, Chadiha et al., (2011) utilized a CBPR framework to build a research volunteer registry. The community-based recruitment initiatives increased the registry from 102 to 1,273 individuals enrolled (Chadiha et al., 2011). In addition, increased ethnographic research, particularly for highly underrepresented races and subgroups, may be helpful in recognizing barriers to participating in research that are not as culturally explicit (George, Duran, & Norris, 2014).

Due to the overall favorable attitudes towards participating in research displayed in the scholarly project, it warrants the question if individuals are being exposed to research participation opportunities through their medical providers. The data collected by Pinto et al (2014) found that medical providers with greater education and experience were more involved in the recruitment and facilitation of research specifically with underrepresented populations. Patients, although possibly willing to participate in research, may have little to no knowledge of the trials occurring if providers have a more limited lens on research opportunities. In outpatient clinical settings, providers state that time constraints, forgetting to recruit, and the small number of eligible individuals act as barriers in recruiting patients into research (Page, French, McKenzie, O'Connor & Green, 2011).

The findings from the scholarly project can be used to enhance the ongoing efforts of recruiting and engaging participants, specifically underrepresented populations, in clinical research. It would be beneficial to consider clinician's effectiveness with recruitment efforts

based on practice setting. The distribution of medical providers varies depending on rural and urban regions and specialty care settings (AHRQ, 2012). Currently, more physicians are practicing in urban, specialty areas compared to Physician Assistant's and Nurse Practitioners who are more commonly in rural and primary care settings (AHRQ, 2012). It is possible that providers who are working within academic or large medical centers in urban areas have greater exposure to research engagement opportunities for their patients compared to more community-based providers. In addition to provider exposure to research recruitment efforts, the scholarly project warrants greater exploration in the role of Doctor of Nursing Practice (DNP)-practitioners within the context of research. The DNP role functions to support the closure of the research-practice gap, specifically by exploring evidence-based research questions grounded in clinical practice (Weierbach, Glick, Fletcher, Rowlands, & Lyder, 2011). For DNPs, research initiatives or recruitment may be easier because the practitioner is trained with a greater lens for research.

### **Limitations**

In light of this study's strengths, several limitations are acknowledged. Sampling bias is possible in that individuals holding negative attitudes toward research participation were less likely to complete a survey and are therefore underrepresented in the sample. The data were collected between 2014 and 2016, therefore it is becoming more outdated. In addition, due to the nature of utilizing a secondary data source, a precise response rate is unable to be calculated. In order to understand the relationship between variables, Spearman's correlation was an appropriate statistical test. However, performing a correlation between every attitude score, trust level, and education level for each racial category allows for greater opportunities for false



positives. Cross-sectional research designs allow for correlational analyses; however, it is difficult to derive a causal relationship between variables.

### **Conclusion**

Engaging and recruiting participants, particularly from minority populations, in clinical research is a national priority. Research allows for increased knowledge in healthcare delivery and treatment which ultimately allows for effective, equitable, and patient centered care. Without diversity in research participants, the health disparities already occurring within minority populations will only worsen. The results of the scholarly project, aligned with past literature, support the importance of trust within the patient and provider relationship and that numerous variables contribute to a patient's attitude towards participating in research. Medical providers involved in recruiting and engaging participants in research must have heightened awareness, consideration, and appreciation of the complex relationships of personal and environmental factors that make a participant and their attitudes, specifically towards research, unique.

### Acknowledgements

This work was supported by the Meharry-Vanderbilt Alliance and The Patient-Centered Outcomes Research Institute under the following award number: R-1306-04869

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Figure 1.

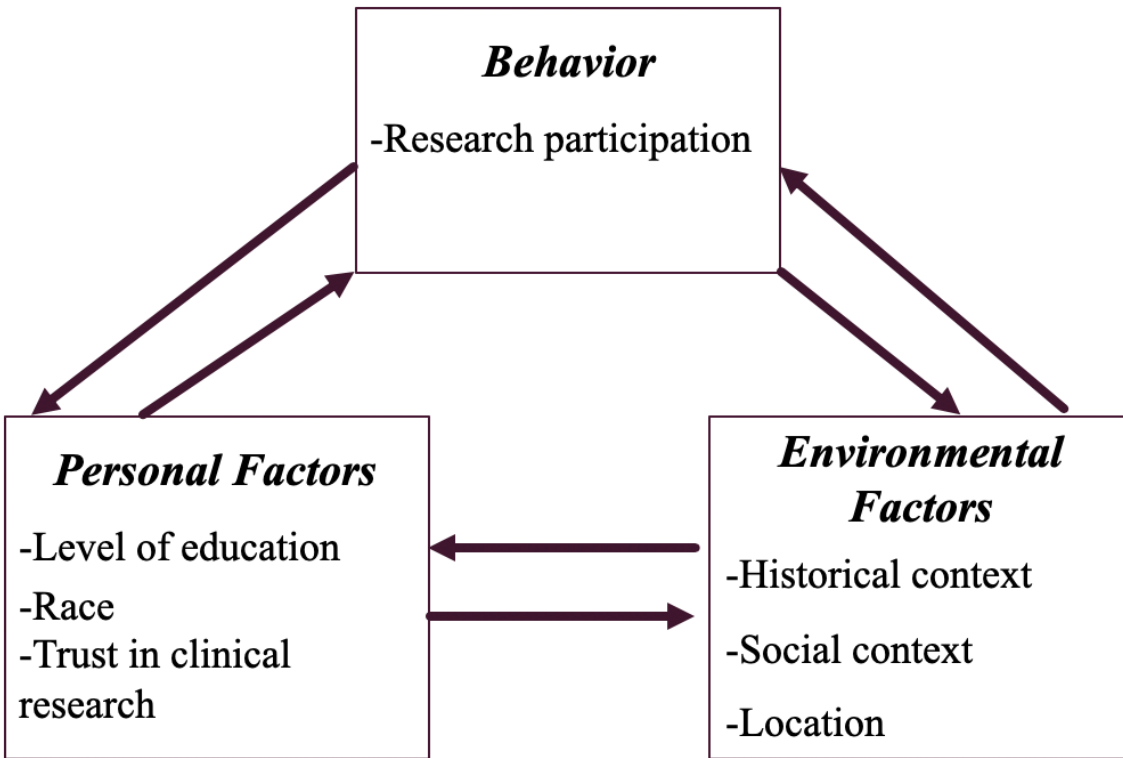


Figure 1. Core concepts of the Social Cognitive Theory with variables used in the scholarly project.

## Appendix 1.

The first set of questions tells us about you and your background.

1. What is the year of your birth	<input type="checkbox"/> Year _____
2. What is your race or ethnicity (Check all that apply) Other, please specify	<input type="checkbox"/> Asian (i.e. Asian Indian, Chinese, Filipino, Japanese, Korean, Vietnamese, Hmong, Laotian, Thai, Pakistani, Cambodian, etc.) <input type="checkbox"/> Black, African American, African, or Afro-Caribbean <input type="checkbox"/> Hispanic, Latino, Spanish origin <input type="checkbox"/> Middle Eastern/North African <input type="checkbox"/> Native American, American Indian, Alaskan Native <input type="checkbox"/> Native Hawaiian, Samoan <input type="checkbox"/> White <input type="checkbox"/> Some other race, please specific <input type="checkbox"/> Prefer not to answer
3. What is your sex If other, please specify:	<input type="checkbox"/> Male <input type="checkbox"/> Female <input type="checkbox"/> Other <input type="checkbox"/> Prefer not to answer
4. What is your marital status?	<input type="checkbox"/> Now married <input type="checkbox"/> Living with a partner or significant other <input type="checkbox"/> Widowed <input type="checkbox"/> Divorced <input type="checkbox"/> Separated <input type="checkbox"/> Never married <input type="checkbox"/> Prefer not to answer
5. What is the highest degree or level of school you completed?	<input type="checkbox"/> 8 <sup>th</sup> grade or less <input type="checkbox"/> Some high school, but did not graduate <input type="checkbox"/> High school graduate or GED <input type="checkbox"/> Some college or 2 year degree <input type="checkbox"/> Prefer not to answer
6. Are you currently:	<input type="checkbox"/> Employed Full Time (32+ hours a week) <input type="checkbox"/> Employed Part Time (less than 32 hours per week) <input type="checkbox"/> Unemployed <input type="checkbox"/> Volunteer <input type="checkbox"/> Stay-at-home parent <input type="checkbox"/> Retired <input type="checkbox"/> Receiving disability <input type="checkbox"/> Other, Please Specify ____

<b>7. How many people live in your home (including yourself)?</b>	<input type="checkbox"/> _____
<b>8. Have you visited your doctor in the past year?</b>	<input type="checkbox"/> Yes <input type="checkbox"/> No
<b>9. If yes, please select the clinic</b>	<input type="checkbox"/> Vanderbilt University Medical Center <input type="checkbox"/> Vanderbilt University Children's Hospital <input type="checkbox"/> Vanderbilt University Stallworth Rehabilitation Hospital <input type="checkbox"/> Vanderbilt University Psychiatric Hospital <input type="checkbox"/> Vanderbilt University Outpatient Practices <input type="checkbox"/> Meharry/Metro General Hospital <input type="checkbox"/> Matthew Walker Community Health Center <input type="checkbox"/> Prefer not to answer <input type="checkbox"/> Other, _____
<b>10. Do you have a cell phone?</b>	<input type="checkbox"/> Yes <input type="checkbox"/> No
<b>11. How often do you text?</b>	<input type="checkbox"/> Not at all <input type="checkbox"/> Not often <input type="checkbox"/> Somewhat often <input type="checkbox"/> Often <input type="checkbox"/> Very Often
<b>12. Can you access the internet using your phone?</b>	<input type="checkbox"/> Yes <input type="checkbox"/> No
<b>13. Do you have access to the internet at home?</b>	<input type="checkbox"/> Yes <input type="checkbox"/> No
<b>14. How confident are you using computers?</b>	<input type="checkbox"/> Very confident <input type="checkbox"/> Confident <input type="checkbox"/> Fairly Confident <input type="checkbox"/> Not Confident <input type="checkbox"/> Prefer not to say
<b>Many patients have trouble understanding the medical information they get at the hospital or doctor's office.</b>	
<b>15. How confident are you filling out medical forms by yourself?</b>	<input type="checkbox"/> Extremely <input type="checkbox"/> Quite a bit <input type="checkbox"/> Somewhat <input type="checkbox"/> A little bit <input type="checkbox"/> Not at all
<b>16. How often do you have someone help you read hospital materials?</b>	<input type="checkbox"/> All of the time <input type="checkbox"/> Most of the time <input type="checkbox"/> Some of the time <input type="checkbox"/> A little of the time <input type="checkbox"/> None of the time

- |            |   |  |
|------------|---|--|
| <b>17.</b> | <b>How often do you have problems learning about your medical conditions because of difficulty understanding written information?</b> | <input type="checkbox"/> All of the time<br><input type="checkbox"/> Most of the time<br><input type="checkbox"/> Some of the time<br><input type="checkbox"/> A little of the time<br><input type="checkbox"/> None of the time |
|------------|---|--|

**The next few questions ask about your experience and feelings about working with numbers.**

- |            |  |   |
|------------|--|---|
| <b>18.</b> | <b>How good are you at working with fractions?</b> | <input type="checkbox"/> Not at all good/Not at all often<br><input type="checkbox"/> Pretty good/Somewhat often<br><input type="checkbox"/> Good/Often<br><input type="checkbox"/> Very good/Very Often<br><input type="checkbox"/> Extremely good/extremely often |
|------------|--|---|

- |            |  |   |
|------------|--|---|
| <b>19.</b> | <b>How good are you at figuring out how much a shirt will cost if it is 25% off?</b> | <input type="checkbox"/> Not at all good/Not at all often<br><input type="checkbox"/> Pretty good/Somewhat often<br><input type="checkbox"/> Good/Often<br><input type="checkbox"/> Very good/Very Often<br><input type="checkbox"/> Extremely good/extremely often |
|------------|--|---|

- |            |  |   |
|------------|--|---|
| <b>20.</b> | <b>How often do you find numerical information to be useful?</b> | <input type="checkbox"/> Not at all good/Not at all often<br><input type="checkbox"/> Pretty good/Somewhat often<br><input type="checkbox"/> Good/Often<br><input type="checkbox"/> Very good/Very Often<br><input type="checkbox"/> Extremely good/extremely often |
|------------|--|---|

**How familiar are you with the following words or phrases?**

- |            |                        |   |
|------------|------------------------|---|
| <b>21.</b> | <b>Genetic Testing</b> | <input type="checkbox"/> Not at all familiar<br><input type="checkbox"/> Slightly familiar<br><input type="checkbox"/> Somewhat familiar<br><input type="checkbox"/> Moderately familiar<br><input type="checkbox"/> Extremely familiar |
|------------|------------------------|---|

- |            |   |   |
|------------|---|---|
| <b>22.</b> | <b>Biological Indicators/Biomarkers</b> | <input type="checkbox"/> Not at all familiar<br><input type="checkbox"/> Slightly familiar<br><input type="checkbox"/> Somewhat familiar<br><input type="checkbox"/> Moderately familiar<br><input type="checkbox"/> Extremely familiar |
|------------|---|---|

- |            |                           |   |
|------------|---------------------------|---|
| <b>23.</b> | <b>Precision Medicine</b> | <input type="checkbox"/> Not at all familiar<br><input type="checkbox"/> Slightly familiar<br><input type="checkbox"/> Somewhat familiar<br><input type="checkbox"/> Moderately familiar<br><input type="checkbox"/> Extremely familiar |
|------------|---------------------------|---|

- |            |                         |   |
|------------|-------------------------|---|
| <b>24.</b> | <b>Pharmacogenetics</b> | <input type="checkbox"/> Not at all familiar<br><input type="checkbox"/> Slightly familiar<br><input type="checkbox"/> Somewhat familiar<br><input type="checkbox"/> Moderately familiar<br><input type="checkbox"/> Extremely familiar |
|------------|-------------------------|---|

**To help guide future research and healthcare, how important are the following to you?**

- |  |  |
|--|--|
| 25. My healthcare is specific to me. No two cases are the same.  | <input type="checkbox"/> Not at all important<br><input type="checkbox"/> Slightly important<br><input type="checkbox"/> Somewhat important<br><input type="checkbox"/> Moderately important<br><input type="checkbox"/> Extremely Important   |
| 26. My genes can be used to determine the best treatment for me.   | <input type="checkbox"/> Not at all important<br><input type="checkbox"/> Slightly important<br><input type="checkbox"/> Somewhat important<br><input type="checkbox"/> Moderately important<br><input type="checkbox"/> Extremely Important   |
| 27. My genes and other health information can be used to help prevent or treat health conditions in my family.             | <input type="checkbox"/> Not at all important<br><input type="checkbox"/> Slightly important<br><input type="checkbox"/> Somewhat important<br><input type="checkbox"/> Moderately important<br><input type="checkbox"/> Extremely Important   |
| 28. My health information is kept private and secure   | <input type="checkbox"/> Not at all important<br><input type="checkbox"/> Slightly important<br><input type="checkbox"/> Somewhat important<br><input type="checkbox"/> Moderately important<br><input type="checkbox"/> Extremely Important   |
| 29. I have access to my own health records and can decide which health care providers and researchers have access to them. | <input type="checkbox"/> Not at all important<br><input type="checkbox"/> Slightly important<br><input type="checkbox"/> Somewhat important<br><input type="checkbox"/> Moderately important<br><input type="checkbox"/> Extremely Important   |
| 30. I can add information about my health to my health records.  | <input type="checkbox"/> Not at all important<br><input type="checkbox"/> Slightly important<br><input type="checkbox"/> Somewhat important<br><input type="checkbox"/> Moderately important<br><input type="checkbox"/> Extremely Important   |
| 31. Do you have any of the following? Check all that apply   | <input type="checkbox"/> No health conditions<br><input type="checkbox"/> High Blood Pressure<br><input type="checkbox"/> Heart Disease<br><input type="checkbox"/> Heart Attack<br><input type="checkbox"/> Overweight or obese<br><input type="checkbox"/> Diabetes<br><input type="checkbox"/> Asthma<br><input type="checkbox"/> Sickle Cell Disease<br><input type="checkbox"/> Other<br><input type="checkbox"/> Prefer Not to Say |
| 32. Household income   | <input type="checkbox"/> Less than \$10,000<br><input type="checkbox"/> \$10,000-\$14,999<br><input type="checkbox"/> \$15,000-\$44,999  |

	<input type="checkbox"/>	\$25,000-\$34,999
	<input type="checkbox"/>	\$35,000-\$49,999
	<input type="checkbox"/>	\$50,000-\$74,999
	<input type="checkbox"/>	\$75,000-\$994,999
	<input type="checkbox"/>	\$100,000-\$149,999
	<input type="checkbox"/>	\$150,000 or more
<b>33. Health Insurance Category</b>	<input type="checkbox"/>	Insured
	<input type="checkbox"/>	Uninsured (No Insurance)
	<input type="checkbox"/>	Medicaid (TennCare)
	<input type="checkbox"/>	Medicare
	<input type="checkbox"/>	Self Pay
	<input type="checkbox"/>	Other
<b>The next set of questions tells us about your experience with research.</b>		
<b>34. Prior to today, have you ever been asked to participate in research?</b>	<input type="checkbox"/>	Yes
	<input type="checkbox"/>	No
<b>35. Prior to today, have you ever participated in health-related research?</b>	<input type="checkbox"/>	Yes
	<input type="checkbox"/>	No
<b>36. If yes, how would you describe the research?</b>	<input type="checkbox"/>	A study comparing treatments or prevention methods (clinical trial)
	<input type="checkbox"/>	Testing to determine if you are high risk for a certain disease
	<input type="checkbox"/>	Testing to determine if a condition has been passed down in your family (inherited)
	<input type="checkbox"/>	In person-focus group, facilitated discussion or survey of attitudes, beliefs, or behaviors
	<input type="checkbox"/>	An online questionnaire or survey of attitudes, beliefs or behaviors
	<input type="checkbox"/>	Blood, tissue, or other body fluid was collected for use in any current or future research
	<input type="checkbox"/>	Other
<b>37. In general, what would be the preferred contact methods to learn about potential research studies? Select all that apply.</b>	<input type="checkbox"/>	Email
	<input type="checkbox"/>	Cell phone text
	<input type="checkbox"/>	Social media (Facebook or twitter)
	<input type="checkbox"/>	Letter or postcard in the mail
	<input type="checkbox"/>	A computer created phone message
	<input type="checkbox"/>	Personal phone call from research staff or my doctor
	<input type="checkbox"/>	Talking face to face
	<input type="checkbox"/>	Other



- I am not interested in being contacted about future research studies

**If a research study was studying a condition or health problem that you care about, would you participate if it required....**

- |  |   |
|--|---|
| <b>38. Completing a survey two or more times</b>   | <input type="checkbox"/> Not Interested<br><input type="checkbox"/> Somewhat Interested<br><input type="checkbox"/> Very Interested   |
| <b>39. Giving a blood sample</b>   | <input type="checkbox"/> Not Interested<br><input type="checkbox"/> Somewhat Interested<br><input type="checkbox"/> Very Interested   |
| <b>40. Taking part in a study that involves by phone or over the internet (for example, to get advice about your health)</b> | <input type="checkbox"/> Not Interested<br><input type="checkbox"/> Somewhat Interested<br><input type="checkbox"/> Very Interested   |
| <b>41. Taking part in a study that involves meeting at a local community center or school</b>                                | <input type="checkbox"/> Not Interested<br><input type="checkbox"/> Somewhat Interested<br><input type="checkbox"/> Very Interested   |
| <b>42. Taking part in a study that involves you and other people in your family</b>  | <input type="checkbox"/> Not Interested<br><input type="checkbox"/> Somewhat Interested<br><input type="checkbox"/> Very Interested   |
| <b>43. Taking part in a study in which you would stay in the hospital for one or more days</b>                               | <input type="checkbox"/> Not Interested<br><input type="checkbox"/> Somewhat Interested<br><input type="checkbox"/> Very Interested   |
| <b>44. What sources do you most often use to find information about health or medical topics? Check all that apply.</b>      | <input type="checkbox"/> Family<br><input type="checkbox"/> Friend/Co-worker<br><input type="checkbox"/> Doctor or other health care professional<br><input type="checkbox"/> Internet<br><input type="checkbox"/> Radio, newspaper or magazine<br><input type="checkbox"/> Telephone, information number of disease-focused group such as the American Cancer Society or the American Heart Association<br><input type="checkbox"/> Complementary, alternative or unconventional practitioner<br><input type="checkbox"/> I have never looked for information about health or medical topics<br><input type="checkbox"/> Other, please describe_____ |

**In general, how much do you trust information about health or medical topics from each of the following?**

- |                   |                                     |
|-------------------|-------------------------------------|
| <b>45. Doctor</b> | <input type="checkbox"/> Not at all |
|-------------------|-------------------------------------|

	<input type="checkbox"/> A little <input type="checkbox"/> Some <input type="checkbox"/> A lot
46. Other healthcare provider (nurse, pharmacist, or other professional who provides care)	<input type="checkbox"/> Not at all <input type="checkbox"/> A little <input type="checkbox"/> Some <input type="checkbox"/> A lot
47. Family or friend	<input type="checkbox"/> Not at all <input type="checkbox"/> A little <input type="checkbox"/> Some <input type="checkbox"/> A lot
48. Online community for patients or caregivers dealing with the same health condition	<input type="checkbox"/> Not at all <input type="checkbox"/> A little <input type="checkbox"/> Some <input type="checkbox"/> A lot
49. Disease-focused groups such as the American Cancer Society or the American Heart Association	<input type="checkbox"/> Not at all <input type="checkbox"/> A little <input type="checkbox"/> Some <input type="checkbox"/> A lot
50. Your health insurance company	<input type="checkbox"/> Not at all <input type="checkbox"/> A little <input type="checkbox"/> Some <input type="checkbox"/> A lot
51. Internet	<input type="checkbox"/> Not at all <input type="checkbox"/> A little <input type="checkbox"/> Some <input type="checkbox"/> A lot
52. Television, radio, newspaper, or magazines	<input type="checkbox"/> Not at all <input type="checkbox"/> A little <input type="checkbox"/> Some <input type="checkbox"/> A lot
53. Government health agencies	<input type="checkbox"/> Not at all <input type="checkbox"/> A little <input type="checkbox"/> Some <input type="checkbox"/> A lot

Please indicate to what degree you agree or disagree with the following statements regarding participation in research

54. Please indicate to what degree you agree or disagree with the following statements regarding participation in research	<input type="checkbox"/> Strongly disagree <input type="checkbox"/> Disagree <input type="checkbox"/> Neither agree nor disagree <input type="checkbox"/> Agree <input type="checkbox"/> Strongly Agree
Participation in clinical research benefits society	
55. Participation will mean better care	<input type="checkbox"/> Strongly disagree <input type="checkbox"/> Disagree <input type="checkbox"/> Neither agree nor disagree <input type="checkbox"/> Agree <input type="checkbox"/> Strongly Agree
56. Participation in research is risky	<input type="checkbox"/> Strongly disagree

	<input type="checkbox"/> Disagree <input type="checkbox"/> Neither agree nor disagree <input type="checkbox"/> Agree <input type="checkbox"/> Strongly Agree
<b>57. Researchers do not care about me</b>	<input type="checkbox"/> Strongly disagree <input type="checkbox"/> Disagree <input type="checkbox"/> Neither agree nor disagree <input type="checkbox"/> Agree <input type="checkbox"/> Strongly Agree
<b>58. Participation in research is enjoyable</b>	<input type="checkbox"/> Strongly disagree <input type="checkbox"/> Disagree <input type="checkbox"/> Neither agree nor disagree <input type="checkbox"/> Agree <input type="checkbox"/> Strongly Agree
<b>59. Participation in research allows me to socialize</b>	<input type="checkbox"/> Strongly disagree <input type="checkbox"/> Disagree <input type="checkbox"/> Neither agree nor disagree <input type="checkbox"/> Agree <input type="checkbox"/> Strongly Agree
<b>60. Participation in research is against my religion</b>	<input type="checkbox"/> Strongly disagree <input type="checkbox"/> Disagree <input type="checkbox"/> Neither agree nor disagree <input type="checkbox"/> Agree <input type="checkbox"/> Strongly Agree
<b>61. Participation in research is morally wrong</b>	<input type="checkbox"/> Strongly disagree <input type="checkbox"/> Disagree <input type="checkbox"/> Neither agree nor disagree <input type="checkbox"/> Agree <input type="checkbox"/> Strongly Agree
<b>62. Transportation is a problem for people who participate</b>	<input type="checkbox"/> Strongly disagree <input type="checkbox"/> Disagree <input type="checkbox"/> Neither agree nor disagree <input type="checkbox"/> Agree <input type="checkbox"/> Strongly Agree
<b>63. Scientists cannot be trusted</b>	<input type="checkbox"/> Strongly disagree <input type="checkbox"/> Disagree <input type="checkbox"/> Neither agree nor disagree <input type="checkbox"/> Agree <input type="checkbox"/> Strongly Agree
<b>64. It is better to be treated by doctors who are researchers</b>	<input type="checkbox"/> Strongly disagree <input type="checkbox"/> Disagree <input type="checkbox"/> Neither agree nor disagree <input type="checkbox"/> Agree <input type="checkbox"/> Strongly Agree
<b>65. Which of the following are barriers for you when considering participating in research? Check all that apply</b>	<input type="checkbox"/> Technical language on study materials (i.e. flyers, brochures, text messages, consent form, etc.) <input type="checkbox"/> Cultural appropriateness of study materials (i.e. flyers, brochures, text messages, consent form, etc.)

- 
- Burden to yourself or your family (i.e. time, cost, social acceptance)
  - The feeling of being undervalued or poorly treated by health care system
  - Limited access to research studies
  - Personal attitude towards research in general
  - Limited resources to participate in research (i.e. transportation, phone, internet, etc.)
  - Lack of sensitivity from the researcher
  - Lack of trust/mistrust/distrust
  - Lack of motivation/willingness
  - Fear
  - Religious/spiritual beliefs
  - Lack of awareness of studies (i.e. poor advertisement in your environment)
  - The feeling that your health condition is stigmatized by society/health system/health providers (i.e. obesity, mental health, etc.)
  - Restricted eligibility criteria (i.e. being turned away because you did not fit the screening criteria)
  - Other

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**66. In my opinion, research in the United States is**

- Ethical
- Not Ethical
- Don't know
- Other

**The following 12 questions ask about your views on research. There are no right or wrong answers. For each statement below, please indicate how strong you agree or disagree with it.**

**67. Doctors who do medical research care only about what is best for the patient**

- Strongly disagree
- Disagree
- Neutral
- Agree
- Strongly Agree

**68. Medical researches treat people like "guinea pigs"**

- Strongly disagree
  - Disagree
  - Neutral
  - Agree
-

	<input type="checkbox"/> Strongly Agree
<b>69. It's safe to be in a medical research study</b>	<input type="checkbox"/> Strongly disagree <input type="checkbox"/> Disagree <input type="checkbox"/> Neutral <input type="checkbox"/> Agree <input type="checkbox"/> Strongly Agree
<b>70. Some doctors do medical research for selfish reasons</b>	<input type="checkbox"/> Strongly disagree <input type="checkbox"/> Disagree <input type="checkbox"/> Neutral <input type="checkbox"/> Agree <input type="checkbox"/> Strongly Agree
<b>71. Doctors tell their patients everything they need to know about being in a research study</b>	<input type="checkbox"/> Strongly disagree <input type="checkbox"/> Disagree <input type="checkbox"/> Neutral <input type="checkbox"/> Agree <input type="checkbox"/> Strongly Agree
<b>72. A doctor would never ask me to be in a medical research study if the doctor thought there was any chance it might harm me.</b>	<input type="checkbox"/> Strongly disagree <input type="checkbox"/> Disagree <input type="checkbox"/> Neutral <input type="checkbox"/> Agree <input type="checkbox"/> Strongly Agree
<b>73. There are some things about medical research that I do not trust at all.</b>	<input type="checkbox"/> Strongly disagree <input type="checkbox"/> Disagree <input type="checkbox"/> Neutral <input type="checkbox"/> Agree <input type="checkbox"/> Strongly Agree
<b>74. A doctor would never recommend something that is not the best treatment just so he or she can study how it works</b>	<input type="checkbox"/> Strongly disagree <input type="checkbox"/> Disagree <input type="checkbox"/> Neutral <input type="checkbox"/> Agree <input type="checkbox"/> Strongly Agree
<b>75. Medical researchers have no selfish reasons for doing research studies</b>	<input type="checkbox"/> Strongly disagree <input type="checkbox"/> Disagree <input type="checkbox"/> Neutral <input type="checkbox"/> Agree <input type="checkbox"/> Strongly Agree
<b>76. Medical researchers do not tell people everything they really need to know about being in a research study</b>	<input type="checkbox"/> Strongly disagree <input type="checkbox"/> Disagree <input type="checkbox"/> Neutral <input type="checkbox"/> Agree <input type="checkbox"/> Strongly Agree
<b>77. The only reason doctors do medical research is to help people</b>	<input type="checkbox"/> Strongly disagree <input type="checkbox"/> Disagree <input type="checkbox"/> Neutral <input type="checkbox"/> Agree <input type="checkbox"/> Strongly Agree
<b>78. I completely trust doctors who do medical research</b>	<input type="checkbox"/> Strongly disagree <input type="checkbox"/> Disagree <input type="checkbox"/> Neutral <input type="checkbox"/> Agree <input type="checkbox"/> Strongly Agree

Table 1  
*Sociodemographic characteristics of survey respondents (N=2,149)*

Characteristic	<i>n</i>	%
<b>Gender</b>		
Male	640	29.0
Female	1496	69.0
Other	6	0.3
<b>Race</b>		
White	1701	77.7
African American	341	15.6
Hispanic	57	2.6
Native American	40	1.9
Asian	23	<1
Prefer not to answer	14	<1
Middle Eastern	9	<1
Native Hawaiian	4	<1
<b>Education</b>		
8 <sup>th</sup> grade or less	17	0.8
Some high school did not graduate	59	2.7
High school graduate or GED	214	9.9
Some college or 2-year degree	543	25.2
College degree	622	28.8
More than a college degree	671	31.3
Prefer not to answer	16	0.7
<b>Employment</b>		
Full Time	1078	50.4
Part Tim (<32hr)	193	9.0
Unemployed	108	5.0
Volunteer	22	1.0
Stay at home parents	87	4.1
Retired	351	16.4
Receiving disability	158	7.4
Other	143	6.7
<b>Insurance</b>		
Insured	1610	76.0
Uninsured	68	3.2
Medicaid	73	3.4
Self-Pay	318	15.0
Other	37	1.7
<b>Household Income</b>		
<\$10,000	142	7.5
\$10,000-\$14,999	72	3.8
15,000-24,999	136	7.2
25,000-34,999	197	10.4
35,000-49,999	233	12.3

50,000-74,999	356	18.7
75,000-99,999	288	15.1
100,000-149,999	260	13.7
150,000 or more	218	11.5

Table 2

*Trust statistics by racial grouping*

Race	Trust	
	<i>M</i>	<i>SD</i>
All	39.85	6.7
White	40.33	6.6
African American	37.79	6.7
Hispanic	37.92	7.3
Native American	37.85	6.8
Asian	40.26	4.9
Prefer not to answer	40.36	6.6
Middle Eastern	36.11	5.8
Native Hawaiian	40.22	9.4

*Note.* *n* = frequency; *M* = Mean; *SD* = standard deviation

Table 3  
*Education level by racial grouping*

Education Level	Race																	
	Total (N=2149)		White (n=1701)		African American (n=341)		Hispanic (n=57)		Native American (n=40)		Asian (n=23)		Middle Eastern (n=9)		Native Hawaiian (n=4)		Prefer not to answer (n=14)	
	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%
8 <sup>th</sup> grade or less	17	0.8	4	0.2	12	3.5	-	-	-	-	-	-	-	-	-	-	-	-
Some high school did not graduate	59	2.8	19	1.1	35	10.3	3	5.3	1	42.5	-	-	-	-	-	-	-	-
High school graduate or GED	214	9.9	149	8.8	61	17.9	5	8.8	6	15.0	-	-	-	-	-	-	-	-
Some college or 2-year degree	543	25.2	440	25.9	80	23.5	11	19.3	16	40.0	6	26.1	1	11.1	1	25.0	5	35.7
College degree	622	29.0	515	30.3	76	22.3	23	40.4	7	17.5	7	30.4	2	22.2	3	75.0	3	21.4
More than a college degree	671	31.1	567	33.3	72	21.1	13	22.8	10	25.0	9	39.1	6	66.7	-	-	5	35.7
Prefer not to answer	16	0.7	7	0.4	5	1.5	2	3.5	-	-	1	4.3	-	-	-	-	1	7.1



Table 4

*Percentage of survey respondents reporting agreement with each attitude statement*

Research participation attitude statement	Agreement (N=2149)	
	<i>n</i>	%
Participation in research benefits society	1954	90.9
Participation in research will mean better care	1649	76.7
Participation in research is risky	532	24.8
Researchers don't care about me	119	5.5
Participation in research is enjoyable	731	34.0
Participation in research allows me to socialize	379	17.6
Participation in research is against my religion	35	1.6
Participation in research is morally wrong	33	1.5
Transportation is a problem for research participants	357	16.6
Scientists cannot be trusted	51	2.4
Research conducted in the US is ethical	70	3.3
It is better to be treated by doctors who are researchers	687	31.9

*Note:* Agreement combines the responses: "agree" and "strongly agree."

Table 5

*Spearman correlations between attitude statements, trust score, and education level by each racial category*

Statement	White (n=1701)		African American (n=341)		Hispanic (n=57)		Native American (n=40)		Asian (n=23)		Middle Eastern (n=9)	
	Trust	Education	Trust	Education	Trust	Education	Trust	Education	Trust	Education	Trust	Education
Participation in research benefits society	<b>CC .281**</b> .000	<b>CC .182**</b> .000	<b>CC .225**</b> .000	<b>CC .293**</b> .000	CC .96 .140	CC .241 .071	CC .137 .392	CC .289 .071	CC .193 .377	CC .067 .760	CC -.087 .823	CC .207 .593
Participation in research will mean better care	<b>CC .333**</b> .000	CC .024 .323	<b>CC .331**</b> .000	CC :.037 .499	<b>CC .388**</b> .003	CC .146 .278	<b>CC .443**</b> .004	CC .114 .483	CC .181 .409	CC .019 .930	CC -.276 .472	CC .245 .524
Participation in research is risky	<b>CC -.238**</b> .000	<b>CC -.082**</b> .001	<b>CC -.154**</b> .004	<b>CC .139*</b> .010	CC -.021 .877	CC -.218 .104	<b>CC -.311*</b> .048	CC .115 .481	CC -.245 .260	CC .115 .601	CC -.315 .410	CC .000 1.0
Researchers don't care about me	<b>CC -.492**</b> .000	CC -.035 .154	<b>CC -.188*</b> .000	CC -.068 .208	<b>CC -.305*</b> .020	CC .140 .300	<b>CC -.567**</b> .000	CC .067 .681	<b>CC -.429*</b> .041	CC .346 .106	<b>CC -.864**</b> .003	CC .245 .525
Participation in research is enjoyable	<b>CC .312**</b> .000	<b>CC .054*</b> .025	<b>CC .249**</b> .000	CC -.007 .903	<b>CC .445**</b> .000	CC -.085 .530	<b>CC .429**</b> .005	CC -.203 .208	CC .057 .796	CC .123 .575	<b>CC .678*</b> .045	CC .371 .325
Participation in research allows me to socialize	<b>CC .165**</b> .000	<b>CC -.108**</b> .000	<b>CC .222**</b> .000	CC -.083 .126	<b>CC .283*</b> .031	CC -.085 .530	<b>CC .416**</b> .007	CC -.226 .161	CC -.074 .738	CC .028 .897	CC .180 .644	CC -.491 .179
Participation in research is against my religion	<b>CC -.201**</b> .000	<b>CC -.144**</b> .000	<b>CC -.117*</b> .029	<b>CC -.122*</b> .024	CC -.056 .676	CC -.176 .191	CC .149 .352	CC .032 .843	CC -.248 .255	CC .235 .280	CC .000 1.0	CC -.546 .129
Participation in research is morally wrong	<b>CC -.230**</b> .000	<b>CC -.152**</b> .000	<b>CC -.119*</b> .026	<b>CC -.128*</b> .018	CC -.144 .280	<b>CC -.342**</b> .009	<b>CC .314*</b> .046	CC -.064 .696	CC -.279 .198	<b>CC .540**</b> .008	CC -.052 .894	CC -.124 .751

BARRIERS TO PARTICIPATION

Transportation is a problem for research participants	<b>CC -.222**</b> .000	CC .018 .464	<b>CC -.146**</b> .006	CC -.036 .506	CC .041 .757	CC -.152 .260	CC -.285 .071	CC -.146 .369	CC .067 .761	CC -.381 .073	CC .347 .361	CC -.220 .569
Scientists cannot be trusted	<b>CC -.395**</b> .000	<b>CC -.163**</b> .000	<b>CC -.236**</b> .000	CC -.105 .052	CC -.233 .092	CC -.173 .198	CC -.303 .054	CC .102 .532	CC -.148 .501	<b>CC .568**</b> .005	CC -.663 .052	CC -.161 .680
Research conducted in the US is ethical	<b>CC -.328**</b> .000	<b>CC -.116**</b> .000	<b>CC -.171**</b> -.001	<b>CC -.236**</b> .000	<b>CC -.497**</b> .000	CC .144 .284	CC .001 .995	CC .256 .110	CC -.124 .572	<b>CC .453*</b> .030	CC -.522 .150	CC .371 .325
It is better to be treated by doctors who are researchers	<b>CC .101**</b> .000	CC .041 .089	<b>CC .106*</b> .047	CC -.010 .850	CC .115 .390	CC .084 .535	CC .049 .759	CC -.240 .137	CC -.246 .258	<b>CC .418*</b> .047	CC .518 .153	CC -.068 .862

Note: CC is Spearman Correlation Coefficient.

Second value is p value. \*p<.05, \*\*P<.01

Attitude statements are scored toward agreement, level of trust is scored such that higher scores indicate greater respondent trust in medical research