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Increasing the Awareness of Black Women to Promote Medical Research Engagement

by

Stephanie Malone

A Dissertation Submitted in Partial Fulfillment of the Requirements for the Degree

Of

Executive Doctorate in Business

In the Robinson College of Business

Of

Georgia State University

GEORGIA STATE UNIVERSITY

ROBINSON COLLEGE OF BUSINESS

2023

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ACCEPTANCE

This dissertation was prepared under the direction of the *STEPHANIE MALONE* Dissertation Committee. It has been approved and accepted by all members of that committee, and it has been accepted in partial fulfillment of the requirements for the degree of Doctor of Philosophy in Business Administration in the J. Mack Robinson College of Business of Georgia State University.

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“Get wisdom, get understanding; forget it not; neither decline from the words of my mouth. Forsake her not, and she will preserve thee; love her, and she shall keep thee. Wisdom is the principal thing; therefore, get wisdom; and with all thy getting, get understanding.”

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ABSTRACT

Raising the Awareness of Black Women to Increase Engagement in Medical Research

by

Stephanie Malone

August 2023

Chair: Denish Shah

Major Academic Unit: Doctorate in Business Administration

Medical research in the United States has drastically improved over the past forty years with the implementation of policies and procedures through government regulation and significant technological advancements. Despite these measures, there are still low participation rates among minority groups, especially Black women, who have proven to suffer the most drastic effects from underrepresentation in medical research. Despite their willingness to participate in medical research, a leading barrier to participation is the need for more knowledge and awareness about how to engage in medical research.

This research is a field experiment conducted at a Black Women's Health Symposium in urban Atlanta to explore the research question, "Does awareness improve Black Women's intent to engage in medical research?" During the symposium, a workshop focusing on the importance of participating in medical research was conducted to increase the knowledge and awareness of Black women. The intent is to encourage engagement and reduce health disparities to improve health equity for Black women.

INDEX WORDS: *African American Women; Black women; health disparities;*

underrepresentation; clinical research; medical research; knowledge, awareness; health equity

I INTRODUCTION AND RESEARCH QUESTION

As a non-clinical healthcare industry professional for over twenty years, I have been blessed with the ability to obtain almost any healthcare information I need. With convenient access to medical experts across multiple disciplines throughout the country, I have always been able to find answers or overcome any knowledge barriers faced when seeking healthcare. However, I am also compassionate towards the many Black women who are not so fortunate. I witness the disheartening impact of the many health disparities Black women face daily. Statistics and reports consistently reveal Black women at the bottom of the list due to the intersectionality of their race and gender in many areas. As an educated, Black woman in the healthcare industry, I wanted my dissertation to contribute to advancing the health equity of Black women through the lens of medical research.

The phrase "medical research" is interpreted and processed as diversely as the population required for its success and generalizability. For some, it is a welcome intrusion into their DNA to contribute to society's greater good. For others, the social norm places it in the category of cultural taboo, despised as the cover for trial-and-error experiments at the devaluation, dehumanization, and potential demise of their race. African Americans fall into the latter group with solid and deep historical scars from unethical experiences with the medical research community. Medical research has not been a welcome visitor to our environment. The respectful, obligatory mentions of the past grievances of the Tuskegee Syphilis Study, Henrietta Lacks, Vertus Hardman, and so many others, known and unknown, are still etched in the generational hand-me-downs of what-not-to-do. "While it is important to acknowledge and understand the "haunting legacy" of the painful and unethical relationship between the African American community and the United States Medical system, the historical forms of ethical mistrust and

mistreatment must be forgiven. We must forge ahead to conquer the African American community's "historical reluctance to assist scientific discovery." Acknowledging every aspect of the multigenerational barriers for Black Americans to enrolment in clinical trials is critical to moving forward." (Manning, K.D. 2020) We must cautiously dive into the medical research environment and explore how we can replace the ruptured relationship with the medical research community with one with respect and reciprocity. We need to know the laws and regulations around medical research and willingly engage to benefit ourselves and future generations. However, one of the first steps is awareness and access to raise our hand to volunteer for participation.

Although African Americans make up 12% of the United States population, they, on average, represent only 4 to 5% of all clinical trial participants. This representation is even smaller for Black women. A widely believed assumption is that Black women are unwilling to participate in medical research. However, recent studies prove this is an inaccurate assumption (Brewer L.C. et al., 2014). In fact, some research has shown that African Americans are more than any other racial and ethnic group to have an interest in participating in medical research. So, what is the problem? One of the most cited barriers by Black women to engaging in medical research is a lack of information and awareness of how to participate in medical research. Dr. Sharonne Hayes, cardiologist, and professor of cardiovascular medicine at the Mayo Clinic states that "the number one reason that women do not participate in medical research is that they were never asked." (Hawkins, L, 2022) With this knowledge, further studies must continue investigating the research question, "Does providing information and increasing awareness override trust in impacting the intent of Black women to engage in medical research?"

Recognizing that lack of information is a multifaceted issue that also challenges healthcare providers and researchers, this study focuses on closing the information and knowledge gap of Black women. I hope that closing the knowledge gap of Black women will help improve representation in medical research and contribute to closing the knowledge gap of medical researchers, allowing medical scientists to improve the generalizability of their research and help reduce health disparities of Black women.

I.1 Definitions and Terminology

There are several distinct types and forms of medical research, however, most people associate the term with clinical trials, Clinical trials sometimes involves experimental testing of medications or physically intrusive procedures that may or may not impact their current state of health. However, there are many other forms of physically non-intrusive medical research, ranging from responding to surveys, wearing health tracking devices, and biobanking, which involves donating blood samples and tissue for researchers to help understand certain conditions and diseases in specific populations. We are encouraging Black women to consider participation through biobanking.

While all women are important, this study uses Black women to describe non-white, non-Hispanic women. The term “women of color” is often used as a catch-all category to describe non-white ethnicities, further suppressing, and diminishing the plight of non-Hispanic Black women. The woman is also defined as the gender assigned at birth.

II LITERATURE REVIEW

The literature review for this study focuses on three areas. First, it is important to understand the status and implications of the underrepresentation of Black women in medical research. Secondly, it is imperative to understand the intersectionality of non-Hispanic Black women in medical research and their unique position of oppression in a structural and systemic context. The third area of focus is an evaluation of successful strategies used to improve underrepresentation to reduce health disparities and improve the health outcomes of Black women.

II.1 Implications of Underrepresentation of Black Women in Medical Research

Healthy People 2020 defines a health disparity as "a particular type of health difference linked with social status; gender; age; mental health; cognitive, sensory, or physical disability; sexual orientation or gender identity; geographic location; or other characteristics historically linked to discrimination or exclusion." Health disparities are pervasive and prevent us from achieving health equity, defined as the "attainment of the highest level of health for all people. Achieving health equity requires valuing everyone equally with focused and ongoing societal efforts to address avoidable inequalities, historical and contemporary injustices, and eliminating health and health care disparities" (CDC, 2020). Black women suffer the most drastic effects from underrepresentation in medical research, contributing to higher mortality rates than their peers in other populations facing the same diagnoses. For example, black women are 41% more likely to die from breast cancer than White women, despite a lower incidence of the disease. (cancer.org).

One of the most significant disparities facing Black women is maternal mortality. The most recent Centers for Disease Control and Prevention (CDC) report shows that in 2021, Black

women's maternal mortality rates rose from fifty-five to almost seventy deaths per 100,000 live births. While Black women gave birth less in 2021, they still died at higher rates, according to the data. Why are so many Black women dying from the same conditions and diseases treatable or cured in other minority populations?

Science has proven gender and race differences in how ethnic minority groups respond to medical therapies. Medical therapies developed using White males do not consider all the nuances due to the biological differences of women and, to a lesser degree, Black women. In 1993, the United States Congress enacted the National Institute of Health Revitalization Act of 1993 to encourage women and minority participation in clinical trials. (Reifstein, K., Adare, M. 2018) Sadly, the underrepresentation of Black women continues in medical research. Black women are disproportionately excluded from many studies, creating a knowledge gap in how specific medical therapies will work in underrepresented minority groups. Are Black women destined to be the new 'therapeutic orphans' as coined by Dr. Harry Shirkey in 1963?

There is an inverse relationship between medical therapy effectiveness and population diversity. The effectiveness of traditional medical therapies decreases as our population diversity increases. The United States is becoming more diverse, with the 2020 U.S. Census finding that the number of people who identify as white has decreased for the first time since the census began in 1790. (Bibbins 2022). By 2045, it is anticipated that half of the U.S. population will self-identify as ethno-racially diverse (Census, 2018), so it is imperative that medical research become as diverse as possible. As this diversity trend continues, we must improve the generalizability of medicine to ensure therapy equality for all populations, especially Black women.

More diverse representation is needed to improve therapy equality and generalizability across all populations. "The participation of racial/ethnic minorities and other underrepresented groups in medical research is a critical link between scientific innovation and improvements in healthcare delivery and health" (Ford, J., Howertonk M.W., Lai, G.Y., Gary, T.L, Bolen, S, Gibbons, Tilburt, J., Baffi, C., Tanpitukpongse, T.P, Wilson, R.F. Powe, N.R. and Bass; E.B., 2007)

The recent world pandemic revealed the depth and validity of the problem of minority underrepresentation in medical research. COVID-19 re-emphasized the importance of and the blatant lack of diversity in medical research as researchers could not generalize findings in response to inquiries regarding the effect of vaccines on African Americans, primarily due to their lack of representation in clinical research. The lack of African American representation in the medical research for the covid-19 vaccine left researchers and the medical community at a loss for words when African Americans questioned the efficacy and side effects of the vaccine for their demographic. The repeated mantra of "I do not know what is in it" was rampant in the Black community. Ironically, many exercised daily drug therapy for conditions disproportionately plaguing the Black community, such as high blood pressure and diabetes but were less concerned about the ingredients of their prescriptions. Other concerns were around fear, miseducation, and mistrust which fed a revival of the historical record of medical abuse in the African American population.

African Americans are grossly underrepresented in clinical research. This lack of participation contributes to them experiencing some of the highest health disparities in diseases that disproportionately affect the African American community. The pandemic presented the

opportunity for researchers and healthcare advocates to raise the visibility of this issue and its impact on the health disparities in the African American community with real-time applicability.

With justified apprehension due to the damaged relationship between Black people and the medical research community, research is proving that Black women are willing to cautiously engage in medical research with a determination not to let history repeat itself. As research proves that Black women are just as willing as any other race to participate in medical research, why does this knowledge gap continue?

Despite their willingness to participate in medical research, a leading barrier to Black women's participation in medical research is the lack of knowledge and awareness of how to engage in medical research. In a study describing the factors associated with the decisions of older African American women to join a cancer screening trial, 92% stated that no healthcare provider had ever talked to them about joining a study. (Trauth, J., et al, 2005). According to a 2022 report from The BECOME (Black Experience of Clinical Trials and Opportunities for Meaningful Engagement) Project, which is sponsored by the Metastatic Breast Cancer Alliance (MBC), most Black women with metastatic breast cancer do not get enrolled into clinical trials. More than 90% indicated they would be interested in learning about clinical trials, and 83% said they were somewhat or very likely to consider participating. However, only 54% were aware of clinical trials happening, and only 36% said they received as much information as desired from their oncologist and care team. In addition, 40% of Black respondents reported that no one on their care team had discussed clinical trials for MBC.

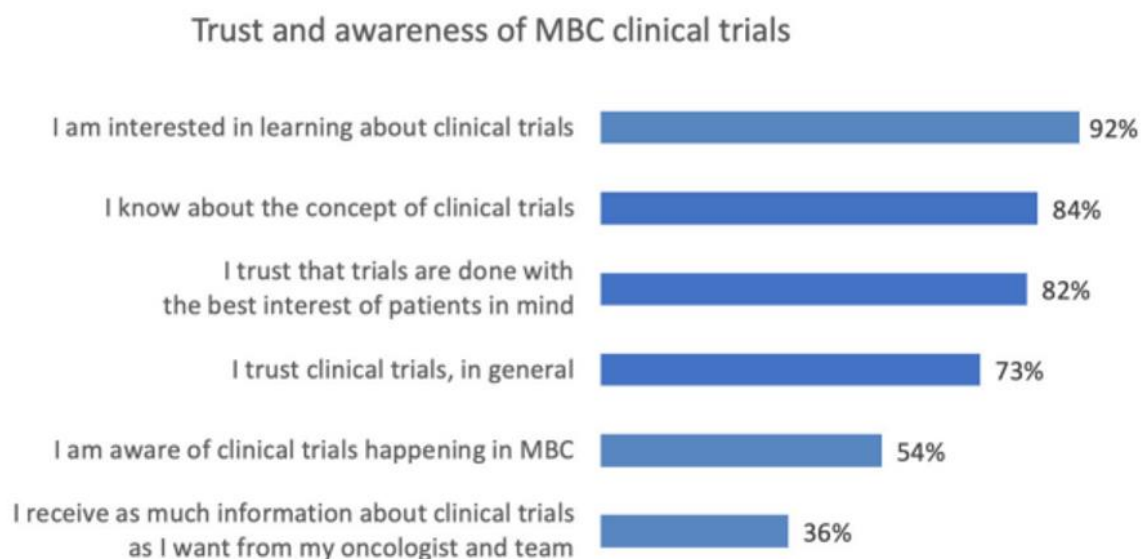


Figure 1 <https://www.mbcalliance.org/wp-content/uploads/2022.06.01-BECOME-Summary-Report.pdf>



Figure 2 <https://www.mbcalliance.org/wp-content/uploads/2022.06.01-BECOME-Summary-Report.pdf>

One factor has been revealed to be physician bias. One study revealed that “physicians are biased concerning who they believe will comply with difficult therapy regimes and suggested that physicians did not believe that their African American patients would adhere to the prescribed protocol.” (Fisher, J., Kalbaugh, C., 2011) Whether by implicit or explicit bias,

healthcare providers are missing the opportunity to eliminate health disparities and diversify their medical research by not asking Black women to participate. Without equity in social and economic conditions, health equity is unlikely to be achieved, and one cost of health inequity has been the lives of Black women. (Chinn, J. et al, 2021)

II.2 Implications of Intersectionality of Black Women in Medical Research

The intersectionality of Black women is a term coined by Kimberle Crenshaw that raises the visibility of oppressed groups and individuals who live at the margins of society with inequitable access to resources. Black women are multidimensional matriarchs and “one of the few demographic groups that must advocate for themselves to receive consistent and high-quality care. In addition, black women are characterized by incredible resilience in the face of adversity and continue to experience improvements in health, even with the socioeconomic contexts that allow disparities to persist.” (Chinn, J. et al., 2021). In 2019, a report from the Pan American Health Organization identified “structural racism” as a key driver of health inequity. Structural factors impacting Black women's enrollment in medical research include concerns related to health and research systems and economic issues. Often, the cost and duration of some studies, along with the time commitment and travel problems, are a burden on minority groups without health insurance, transportation, or the luxury of time to commit to participating in medical research.

These barriers preventing the health equity of Black women include “lack of health insurance coverage, cultural attitudes, and beliefs, lack of experience with medical research, mistrust of the healthcare system and the failure of physicians to refer patients.” (Trauth, J. et al., 2005) In 2001 the Center for Disease Control and Prevention (CDC) declared racism a public health threat leading to the National Institutes of Health (NIH) launch of an “Ending Structural

Racism” initiative with funding to address racism. One study suggests that “efforts should focus on how to reduce the additional burden that participation in clinical trials may impose.” (Bierer, 2022)

“Black women are also subject to higher levels of racism, sexism, and discrimination not experienced by Black men or White women.” (Chinn, J., 2021) The intersection of race and gender discrimination has profound impacts on the well-being of Black women. Black women were overlooked during the recent pandemic, proven by an analysis of COVID-19 deaths by race and sex in Georgia which found that Black women died at more than three times the rates of white men and Asian men. The only other group more likely to die from the disease was Black men. Without data to examine the intersection of race and gender, the blanket claim that women with Covid-19 fare better than men made the high death rate among Black women invisible. (Rushovich, T., Richardson, S., 2023). Without proper recognition and representation, Black women could become an extinct relic of humanity. It is time to disrupt the white-male trend, improve the lifespan of Black women, and close the knowledge gaps in research. "Intervention research is needed to address the barriers posed by intersectionality and capitalize on the solidarity and social support that people with similar identities share." Turan, J. (2019)

II.3 Community-Based Participatory Research to Address Underrepresentation

Current scholarly conversations suggest strategy after strategy to address and mitigate the various barriers that prevent minority populations from participating in medical research. There is an overwhelming repository of scholarly literature that summarizes and analyzes the multitude of strategies being implemented to address the issue of the underrepresentation of minority populations in medical research. For Black women, the most used is community-based participatory research (CBPR). Community-based participatory research is a partnership with the

community to collaborate to address issues and solutions for positive outcomes. They employ community-based participatory research as a research protocol that involves a balance of research and social action in the pursuit of knowledge and social justice. Community mistrust of the healthcare system and lack of understanding present a pronounced need for community education. The community and researchers work together to identify problems and questions to address, actively participate in the research, and use the outcomes to address the root causes of the programs and health equity. A major strength of the method is that it is informed by the experiences of the people and communities who are being considered and is conducted in the environment in which interventions will be implemented, assuring real-world application of the research findings. “Community-Based Participatory research inherently addresses ethics in health research works with vulnerable populations as collaborative partners and holds promise for reducing health disparities.” (Rogers, J., Kelly U., 2011)

The National Institute on Minority Health and Health Disparities (NIMHD) focuses on health disparities among racial and minority groups. Their mission is to lead scientific research to improve minority health and reduce health disparities by planning, coordinating, evaluating, and reviewing NIH minority health and health disparities research and activities. They also conduct and support research in minority health and health disparities and foster innovative collaborations and partnerships, including the *All of Us* Research Program, which spawned from President Barack Obama’s 2015 Precision Medicine Initiative. The *All of Us* Research Program is a historic effort to collect and study data from one million or more people living in the United States with the goal of better health for all populations. The ten-year program began enrollment in 2018 and currently consists of over 600,000 participants to create a voluntary national research cohort in collaboration with other agencies and stakeholders. This diverse database will

be able to inform thousands of studies on a variety of health conditions by enrolling a large group of people reflecting the diversity of the United States. This project includes minority populations that have not taken part in or have been left out of health research, like Black women.

Delta Sigma Theta Sorority, Inc. (Delta) is the most prominent African American Women's organization in the world, with a membership of over 350,000 college-educated Black women. The first public service activity was participation in the Women's Suffrage March in 1913. Delta has always leveraged the power of its membership to impact change in social, political, education, and health initiatives. In 1967, Delta established the Delta Research and Educational Foundation (DREF) as a public charity supporting scholastic achievement, public service programs, and research initiatives focused on African American women. DREF received funding from the NIH for the health initiative Research Matters for *All of Us* Program to focus on community engagement, empowerment, research, and enrollment. In addition, DREF is leading the national effort to educate Black people about the significant role biomedical research plays in addressing health disparities with an awareness campaign entitled "Research Matters: Creating Possibilities to Achieve Health and Wellness for *All of Us*."

The Black Greek Letter Consortium (BGLC) comprises the nine National Pan-Hellenic Council (NPHC) organizations, including Delta Sigma Theta, Inc. It is also known as the Divine Nine (D9). These historically Black Fraternities and Sororities support the mission of the *All of Us Research Program* to advance health equity for those considered underrepresented in biomedical research through community-based participatory research.

III THEORETICAL FRAMEWORK

There are several conceptual models of health behavior, such as the health belief model, the theory of planned behavior, and the social cognitive theory. The health belief model outlines the requirements needed before there is a change in behavior. The theory of planned behavior posits that individuals act in accordance with their attitudes and social norms towards a particular behavior (Bandura, 1998). Social cognitive theory posits a multifaceted causal structure in which self-efficacy beliefs operate together with goals, outcome expectations, and perceived environmental impediments and facilitators in the regulation of human motivation, behavior and well being. (Bandura, 2004) Among the successful strategies and interventions that positively impact the engagement of healthy Black women in medical research, few, if any, have tackled the issue of minority underrepresentation in medical research through a pure lens of social cognitive theory (SCT). Developed by Albert Bandura, one of the most cited academics in the world, social cognitive theory is an action-oriented approach that has been applied across a diverse array of health-compromising behaviors and used successfully with many different intervention models. SCT helps facilitate theory-based interventions to improve health status and inequities. Social cognitive theory consists of personal, behavioral, and environmental constructs facilitating theory-based interventions to improve health status and outcomes.

Personal or cognitive factors include the knowledge, attitudes, and outcome expectations that influence a person's behavior. Gaining knowledge increases the comfort level of Black women when deciding whether to participate in medical research. As previously discussed, the paradigm of Black women is shifting away from resistance despite the scarred past. They demand thorough and complete knowledge to facilitate successful outcomes when they participate in medical research. A benefit of education is to promote equality and empowerment;

however, through the lens of medical research, Black women are underprivileged in both areas. Once labeled one of the most educated ethnic groups in the United States, Black women have the lowest representation in medical research, despite their willingness to learn and increase their knowledge about participating in medical research. The barriers of lack of communication and awareness about or how to participate in clinical research contribute to the lack of participation in clinical research by Black women. Providing Black women with the opportunity to learn and increase their self-efficacy around medical research participation will improve awareness and comfort with the medical research process. This will lead to higher representation in medical research and improve parity with the goal of reducing disparities due to underrepresentation.

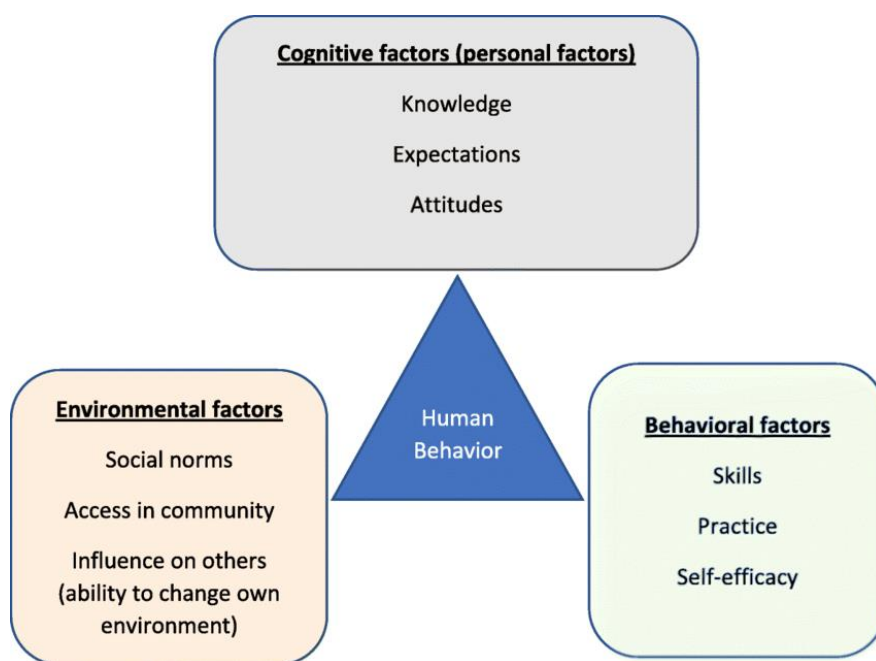


Figure 3 Social Cognitive Theory

https://www.researchgate.net/figure/Banduras-Social-Cognitive-Theory-adapted-from-the-lead-authors-PhD-thesis_fig6_339415831

Behavioral factors involve the capability and skillset to perform a behavior. Being confident in their ability to succeed. After acquiring the knowledge and skillset needed to perform a specific behavior, Black women must be confident in their ability to perform a behavior.

The third construct of social cognitive theory is environmental factors beyond our control that often impact our ability to succeed in many areas, including healthcare. Healthcare is an area that sometimes presents these unsurmountable structural and systemic barriers. Accessibility can mean either meeting all the qualifications to be included in a medical research study or physically being able to access the geographic location of the study.

III.1 Research Methodology

Engaged scholarship aims at overcoming the hurdles of relevance and rigor when researchers attempt to contribute to solving complex problems in the real world. (Van de Ven, 2007). Through deliberate interventions and their reflections on the problem, researchers can gain an in-depth understanding of the investigated phenomenon and deliver the insights to help solve the problems. This research is tackling the real problem of underrepresentation of Black women in medical research by breaking down the awareness barrier.

Action research is a cognitive process emphasizing the social interactions among researchers, stakeholders (i.e., practitioners), and their surroundings (Baskerville and Wood-Harper, 1998). Unlike other research methods, action researchers are regarded as key participants in the research process; they collaborate with other stakeholders to bring about change or improvement in a problem context (Baskerville & Wood Harper, 1998). Action-intervention research involves an intervention to address the problem through which the researcher aims to contribute to academic knowledge. It emphasizes an iterative process of deliberative intervention and diagnosis of responses to the intervention.

This research will use a mixed methods approach. The quantitative research included a pre-test and post-test survey to assess the impact on awareness after attending an educational intervention. The goal is to assess whether a community educational intervention aimed

towards African American women helps break down the barrier of lack of communication and awareness by increasing knowledge about medical research and whether it positively affects intent to engage. In other words, does awareness and information increase the likelihood of engaging in medical research?

III.2 Data Collection

Both Georgia State University and Emory University Institutional Review Boards approved the research protocol. Quick Response codes were used for registration and the program agenda and to collect survey responses from voluntary participants during the symposium.

III.3 Research Setting

The research consisted of a field experiment conducted during a community-based participatory research event. The Stone Mountain-Lithonia Alumnae Chapter of Delta Sigma Theta Sorority, Incorporated hosted the inaugural Black Women's Health Symposium. The structure of the symposium facilitated workshops on various health issues Black women face. As a member of the Chapter, I had the opportunity to develop a workshop focusing on the *All of Us* Research program to address the topic of the underrepresentation of Black women in medical research in collaboration with the Black Greek Letter Consortium (BGLC). The timing for this symposium was the perfect opportunity to gather data. One of the public service initiatives of the Five Point Programmatic Thrusts is physical and mental health which promotes a healthy lifestyle focusing on the total woman: mind, body, and spirit. With a unique position to impact not only the well-being of the membership but also the families and communities served, the Deltacare wellness initiative promotes self-care through physical and emotional wellness and awareness/advocacy.



Figure 4 Deltacare Initiative Diagram

To support this initiative, the local chapter sponsored the symposium to provide health and wellness resources and information to the community. The symposium was a free Saturday morning event held at a local middle school in the community. Culturally appropriate advertising materials were disseminated to elementary, middle, and high schools and churches, and other Black-owned establishments in the area. Advertising also consisted of digital and print flyers and social media blasts from the sponsor via Facebook and Instagram, and Twitter accounts. The event was also advertised daily on the school marquis two weeks before the event. The symposium began at 9:00 am with a Town Hall type forum discussing health issues faced by Black women ranging from menopause to mental health to medical research. The panel was comprised of eleven Black women's specialists representing multiple disciplines actively practicing in metropolitan Atlanta. Each gave a quick speech sharing motivations that led them to their respective specialties and insights into their encounters with some of the most pressing issues facing Black women. One of the physicians, who also serves as a Professor of Medicine as well as the Associate Chair of Diversity, Equity, and Inclusion for the Department of Medicine at Emory University, shared a very inspiring account of her experience as a Covid-19 vaccine clinical trial participant. As a third-generation graduate of Tuskegee University, home of one of the most egregious medical research abuses against Black men, she acknowledged her anxiety

during the process and the valid apathy and mistrust around participating in medical research. She also made a rousing plea for Black women to get educated and get involved, which was met with strong nods of agreement and a loud applause of gratitude and appreciation for her transparency and vulnerability. There was also a question-and-answer session where attendees could ask questions for the benefit of the whole. The goal of this symposium is to create an interactive and informative bi-directional dialogue between the community and panelists about issues impacting Black women's health.

Before leaving the town hall, all attendees were encouraged to scan a QR code to complete the pre-workshop survey to gauge overall awareness about medical research before being exposed to the content presented in the workshop. The pre-test questions consisted of nine questions to gather data on awareness and knowledge around medical research.

IV FINDINGS AND ANALYSIS

Descriptive data analysis included the computation of frequencies and percentages along with a thematic grouping of qualitative data.

A total of fifty-eight women completed the pre-survey after the town hall. The first question asked them to use a 5-point Likert scale to rate their awareness of how to participate in medical research. Only 38% stated that they were “aware” or “very aware” of how to participate in medical research.

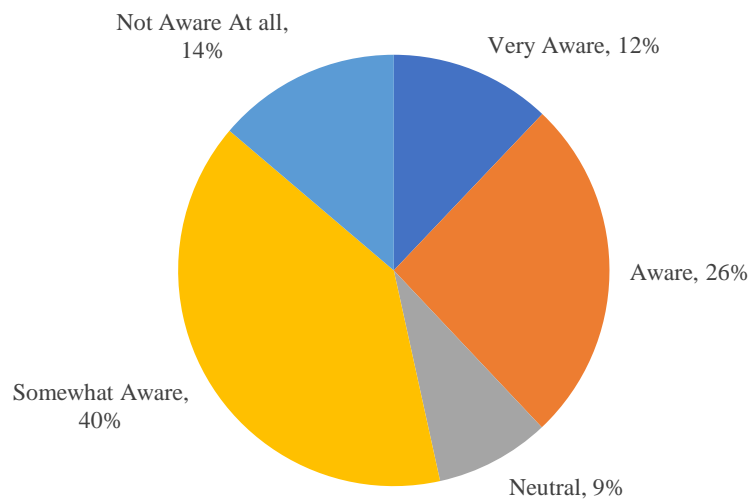


Figure 5: How would you rate your level of awareness on how to participate in research? (Pre-Workshop)

Using a 5-point Likert scale again, they were asked how likely they were to want to participate in medical research. While 56% responded that they were either “*likely or very likely*” to want to participate in medical research, this number fell to 48% when asked if they were likely to encourage their friends and family to participate in research.

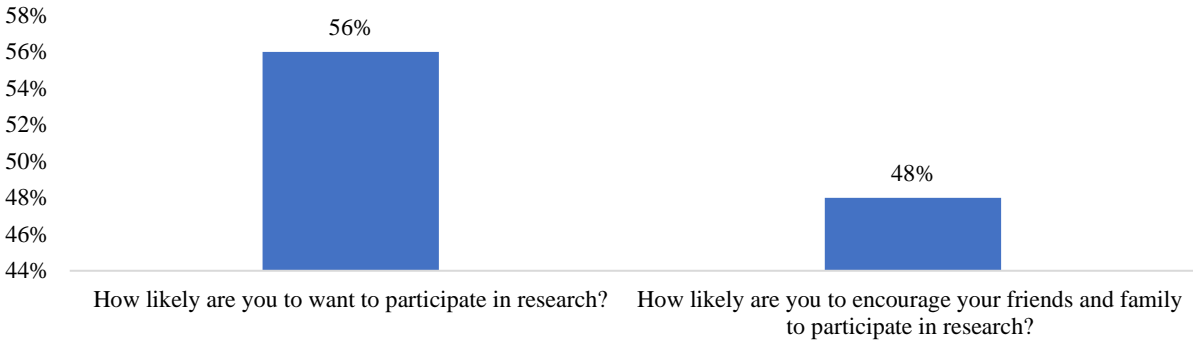


Figure 6: Likelihood to Participate and Encourage Friend & Family to Participate in Research

Most of the women had not heard of the *All of Us* Research Program (74%) and were not familiar with the term “precision medicine” (79%).



Figure 7: Before today, have you heard of the All of Us Research Program?

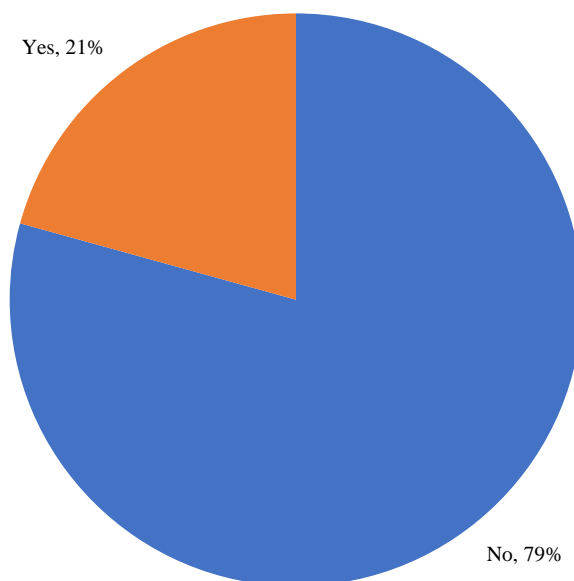


Figure 8: Before today, have you heard of the term 'precision medicine'?

The responses to the question "*What are your biggest concerns about participating in medical research,*" were grouped into themes where possible. If multiple reasons were cited by the same respondents, they were grouped accordingly. Surprisingly, concerns about side effects were mentioned most frequently as opposed to mistrust. Knowledge and honesty/transparency were the next concerns mentioned most frequently.

Table 1: Concerns about Participating in Research (Pre-Workshop)

<i>Concern</i>	<i>#</i>	<i>Comments</i>
Side Effects	10	<ul style="list-style-type: none"> – “Medications and long-term effects of procedures” – “Not knowing how I will be affected.” – “Not knowing how my body would react to what’s being studied.” – “Adverse side effects later in life” – “Worsened condition”
Knowledge/Unknowns	8	<ul style="list-style-type: none"> – “When I am approached by unknown companies collecting data, I need to know the legitimacy of the research organizations.” – “Knowledge of its purpose and what will be revealed.” – “Need to be educated about the process.” – “The entire process of gathering and organizing the data.” – Use/purpose of the information being gathered. – “Lack of information on how to participate”
Honest/Transparency	8	<ul style="list-style-type: none"> – Dishonest Researchers – Not being told all the information that is needed or being deceived.” – “Not know all the information/not understanding everything about the process. I want it to be as clear as possible”
Confidentiality	6	<i>Safety of personal information</i>
Fear	4	<i>‘I’m scared!’</i>
Trust	3	<ul style="list-style-type: none"> – “Being able to trust that research will help Black people.” – “Can you trust them with your information/DNA?”
Incorrect Diagnosis/ Possible Outcome	2	<i>N/A</i>
Cost	2	<i>N/A</i>
Being Dismissed	1	<i>N/A</i>
Not for Black People	1	<i>N/A</i>

Twelve respondents identified themselves as healthcare professionals providing services, all twelve had heard of the *All of Us* Research Program, and eleven were familiar with "precision medicine." However, only two healthcare professionals had talked to their patients or colleagues about participating in the All of Us Research program.

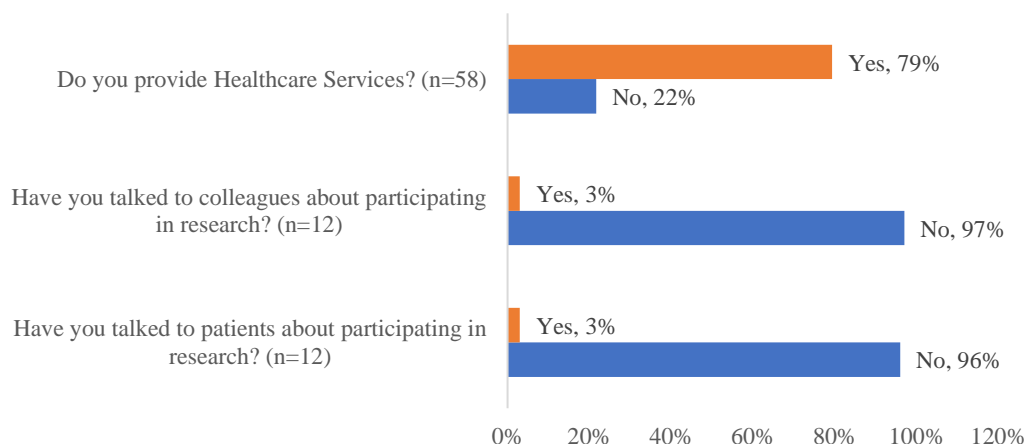


Figure 9: Do you provide healthcare services, and if so, have you talked to your patients and colleagues about participating in research?

The remainder of the symposium included the option of various workshops to attend. In addition, several vendors and health resources were also onsite, including a local co-op farmers market and the opportunity to receive free mammograms and Covid-19 initial and booster vaccines.

As you will notice in the workshop participant demographics presented in Table 2, most of the workshop attendees were mature, educated, and insured Black women between the ages of 26-59 years of age and over half of the workshop participants had at least a bachelor's Degree or higher (71%). Three workshop participants responded that they needed health insurance. (8%)

Table 2 Workshop Demographics (n=38)

Age		Education		Insured		Healthcare Service Provider
18-25	8%	H.S. Diploma/GED	13%	Yes	92%	21%
26-35	21%	Some College	13%	No	8%	79%
36-45	24%	Associate degree	3%			
46-59	29%	Bachelor's Degree	26%			
60-65	11%	Master's Degree	32%			
70+	8%	Doctorate/PhD	13%			

After attending the workshop, 97% of the women felt that their awareness about how to participate in medical research was “*improved or very improved.*”

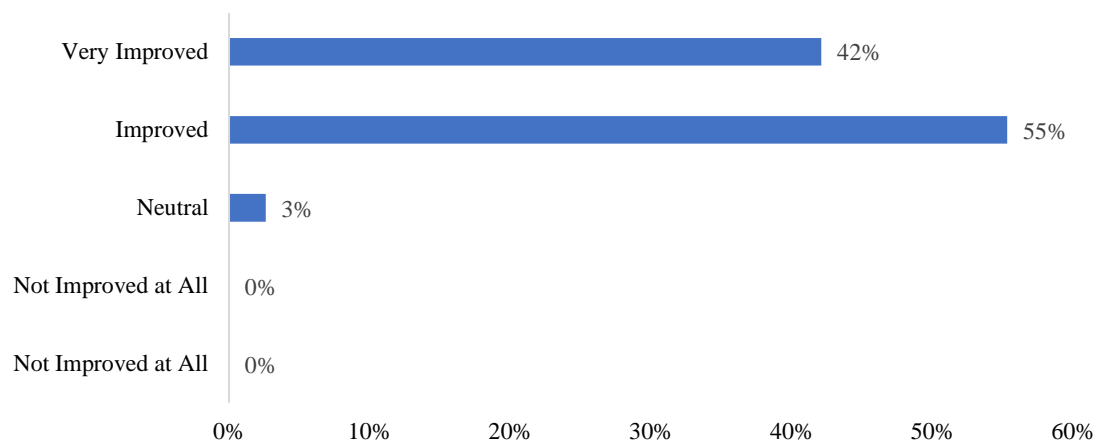


Figure 10: After participating in this workshop, how would you rate your overall awareness about how to participate in medical research?

The women stated positive intentions to participate in medical research (79%), with the same percentage or very likely to encourage their friends and family to participate in research.

There was an incentive to win one of four Visa gift cards if they attended the workshop, and 60% of the women stated that incentives were also important in their decision to participate in medical research.

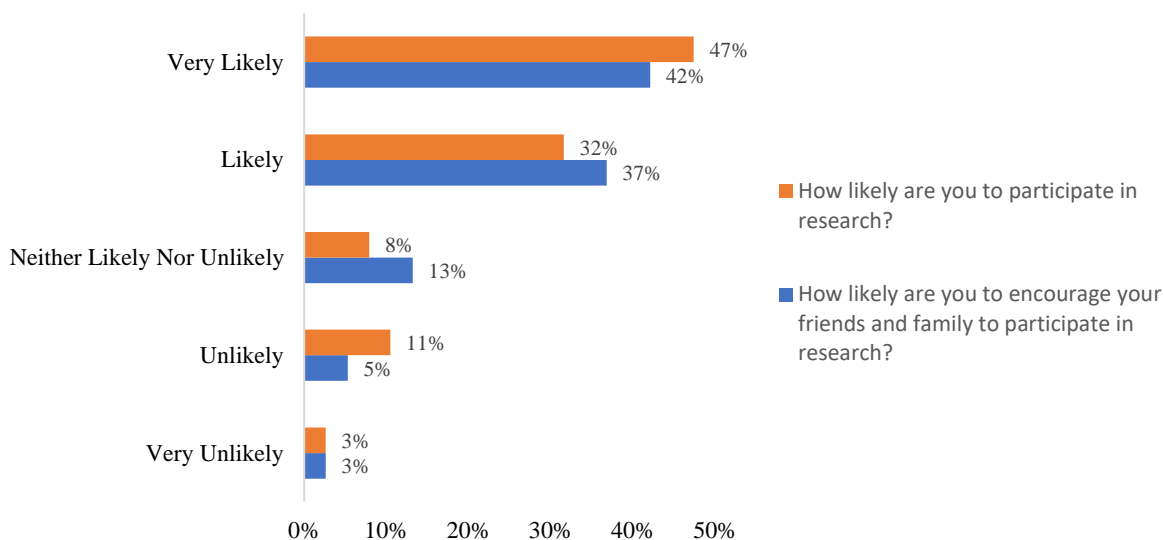


Figure 11: Likelihood to participate and encourage friends and family to participate in research (post-Workshop)

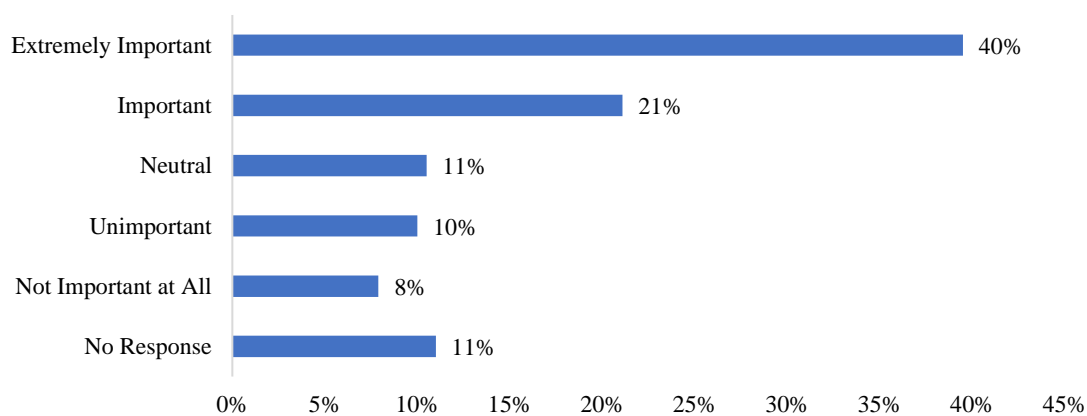


Figure 12: How important are incentives in your decision to participate in medical research?

As the research sought feedback on the workshop, participants were asked to rate a few aspects of the workshop. Ninety-seven percent agreed that the workshop was either *"informative or very informative,"* and all the women expressed positive satisfaction with the workshop content and materials and found the workshop informative (92%), with an even higher percentage

responding that the workshop either met or exceeded their expectations (97%). Everyone that attended the workshop agreed that they had a better understanding of the *All of Us* Research program, with 79% agreeing that the content was effective in changing their mind about participating in research.

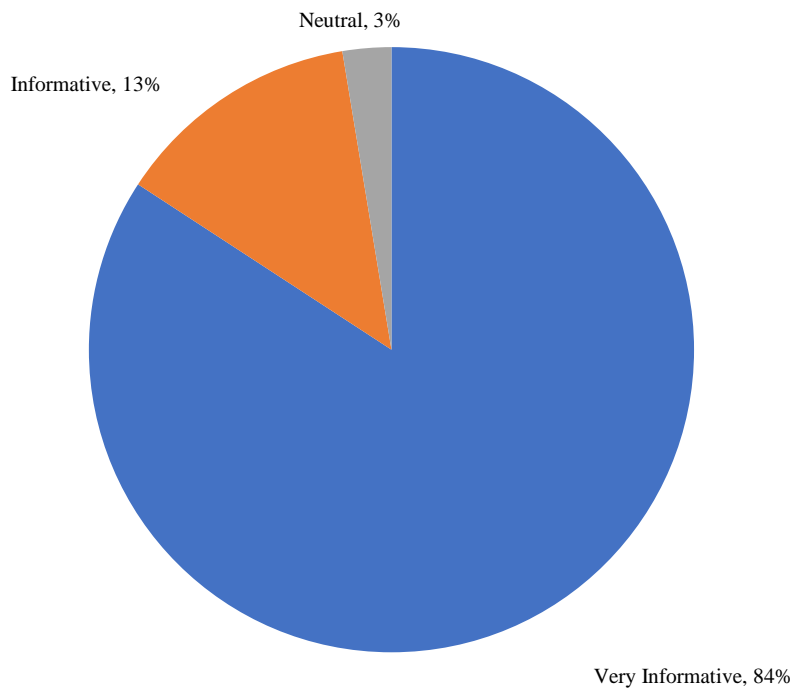


Figure 13:How informative did you find the workshop?

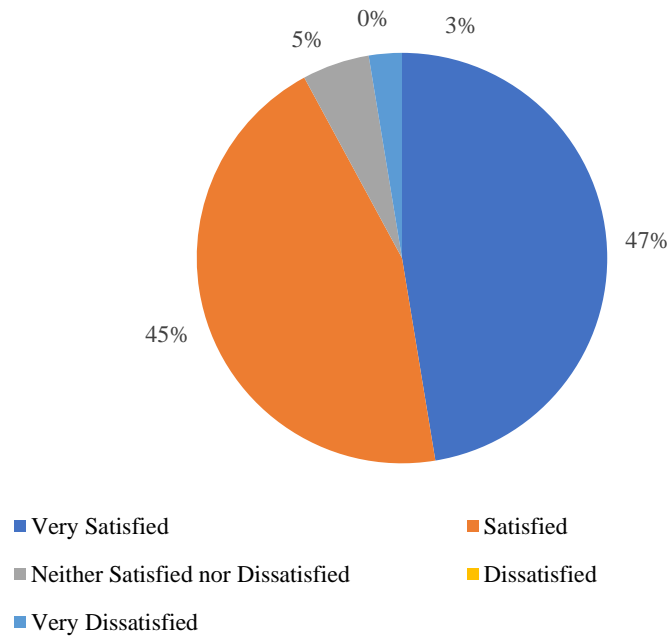


Figure 14: How satisfied were you with the workshop content and materials?

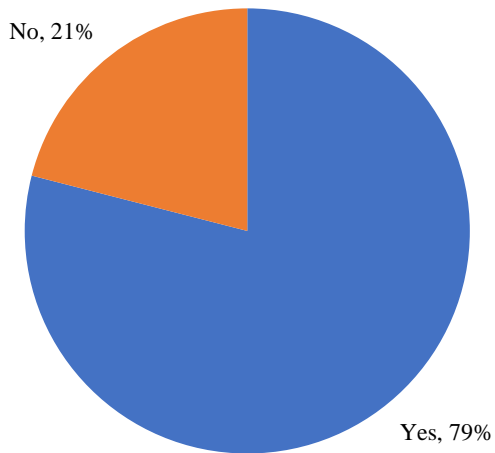


Figure 15: Was the workshop content effective in changing your mind about participating in research?

Lastly, most of the women stated that they did not have any concerns about participating in research, but 42% of the women still had concerns about participating in research. The concerns were categorized by themes, with knowledge questions receiving the most mentions. While trust was not explicitly mentioned as a concern, it was mentioned as a topic suggestion to improve the workshop.

Hearing from actual researchers was the comment most suggested to improve the workshop, followed by the ability to take advantage of free medical research resources.

Suggestions to Improve Workshop	
Suggestion	Mentions
Including Actual Researchers	4
Free Research Resources	3
Symposium focused on Research	2
Testimonials from Participants	2
Informed Consent /Confidentiality	2
Overcoming the Trust Factor	1
Partnership with Ancestry.com	1
Celebrity Spokesperson	1

Figure 16: Suggestions to Improve Workshop

Eight health professionals attended the workshop. Four of them stated that they were "likely or very likely" to talk to their patients about enrolling in medical research, and five responded that they would talk to their colleagues about medical research as well.

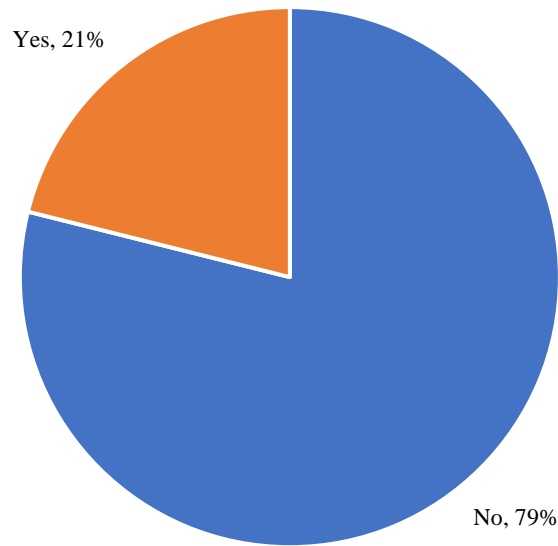


Figure 17: Are you a healthcare professional who provides healthcare services? (n=38)

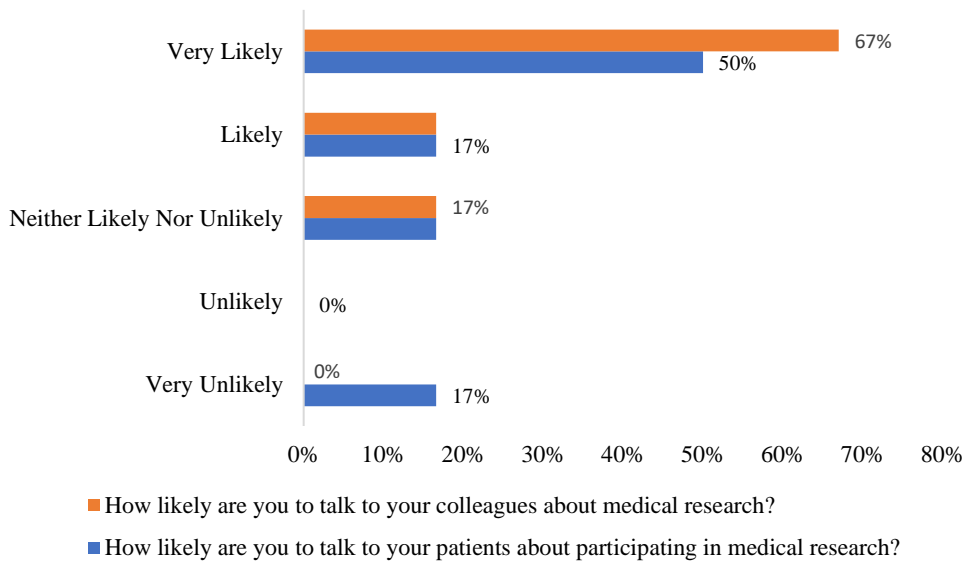
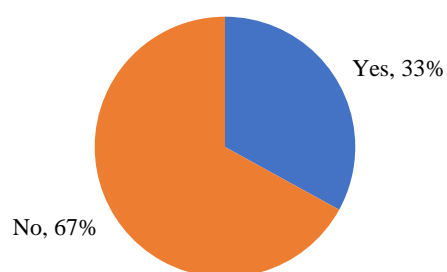


Figure 18: Healthcare Professional: How likely are you to talk to your patients and colleagues about participating in research? (n=6)

Only four of the healthcare professionals were interested in formal training (CE/CME) to learn how to talk to their patients about participating in medical research. “Minority physicians are interested in participating in clinical trials. However, multiple barriers, including lack of awareness and access to clinical research coordinators, continue to exist and must be addressed. Clinical training programs alone are not enough.” (Powell, J.H. et al., 2008)

Are you interested in formal training (CE/CME) on talking to patients about participating in medical research?



V DISCUSSION AND CONCLUSIONS

This research is important because not only is the focus on healthy volunteers, but it is empirical data that sets the baseline for future studies. This direct interaction and observed behavior provided valuable insight for future programming in the community. We have heard the concerns and can address them in future workshops and serve as a trusted community resource for information. The goal is to increase awareness about the importance of participating in medical research and providing resources to facilitate the enrollment of Black women along with other minority populations in the community.

The most valuable result is observing and witnessing the scholarly research live in action, both in conversation and on paper. This research did answer the question of whether awareness impacts the intent of Black women to enroll in medical research and yielded other unexpected insights. In the pre-test, less than sixty percent of the women stated positive attitudes toward engaging in medical research. This percentage jumped to over 80% among the women involved in the intervention.

Troubling is the fact that during the pre-workshop survey, out of the eight women who said they were healthcare providers and expressed positive intent to engage in medical research and were likely to encourage their friends and family to participate in research, only two stated that they had actually spoken to their patients or colleagues about medical research confirming Dr. Hayes statement that women are not asked to participate in medical research. While there is a definite need for education in patient and volunteer populations, raising awareness and knowledge of healthcare providers is also essential. “Globally, very few patients are informed by their doctors or consultants of clinical research studies which they might be eligible for, simply because many practitioners do not have this knowledge themselves.” Taking advantage of

opportunities to learn how to talk to patients about medical research could help raise awareness and engagement. Educating patients about their potential for clinical trial involvement should be an obligation of physicians – and it is part of a broader industry responsibility to give them the talking points, materials, and encouragement to do so. Doctors with long-standing patients who have built high levels of trust could be an effective strategy in encouraging Black women to participate in research.

V.1 Key Insights

Key insights gained were the importance of the same-gender, same-sex researchers. As a part of the symposium, two African Americans fielded questions and distributed materials from a table marketing the *All of Us* research program to steer women toward our workshop. There was also a table from Emory for the same purpose but managed by two Caucasians. While observing the women as they scanned the vendor tables, hardly any stopped at the Emory table, while they were more willing to stop and engage at the *All of Us* table. As this was a partnership between the two organizations, both had the same goal, and it appears that when sending representatives to these types of events, there needs to be a consideration for the audience preferences and perceptions of credibility. During the workshop, we asked the women about the two tables and whether they engaged at the Emory table. Some responded that they really did not know why Emory was there. Since they are partners in improving diversity in medical research, they often work on some of the same events and request to be located near each other for support. One woman stated that she thought the *All of Us* table was there to “feed” research participants to the hospital.

There is still much to be gained around the knowledge factor as it was the second most mentioned concern and overlaps with the focus of this study which is awareness. One workshop

participant suggested that “more metrics on how programs move things forward, and more numbers and visual presentations of the benefits of participating in medical research would be helpful” in deciding to participate in medical research.

Another insight gained was around the idea of role models as posited by Albert Bandura’s social cognitive theory). During the workshop, the BGLC Program lead shared her experience as a participant in the *All of Us* program. She had won two battles with breast cancer, and in each episode, she was never presented with the option of participating in medical research by her healthcare providers. Acting as her own advocate, she discovered the All of Us research program by doing her research and ultimately enrolled. She had lost several women in her family to breast cancer, and her foremost motivation to engage was to learn what she could do to increase the longevity of her life while contributing to finding a solution and then transferring heritage knowledge to her daughters and granddaughters. She also mentioned that a surprise benefit of being involved in the program was the ability to trace her DNA back to the Republic of Côte d’Ivoire in West Africa. Although commonly done through other organizations like Ancestry.com, the aspect of contributing to science and receiving individualized knowledge at the same time was indeed an added benefit. This revelation piqued the women's interest and a sense of relaxation in the atmosphere as they began to chat among themselves and share their own experiences, manifesting the social learning tenet of social cognitive theory. Seeing people like oneself succeed through sustained effort raises observers' beliefs that they, too, possess the capabilities to master comparable activities to succeed. Modeling influences do more than provide a social standard against which to judge one's own capabilities. Through their behavior and expressed ways of thinking, competent models transmit knowledge and teach observers effective skills and strategies for managing environmental demands. (Bandura, 1996) One of the

women suggested a partnership between *All of Us* Research and Ancestry.com. However, AncestryHealth was discontinued in 2022.

The overall top concerns mentioned were around knowledge about the definition of medical research. During small group break-out sessions in the workshop, discussions were responding to the question, "What is medical research?" There was a general understanding of medical research that it "provides evidence for methodology" and "allows us to understand how to treat people with certain illnesses and conditions" To take the next step, there needs to be education about the informed consent process. Many people need to be made aware of Institutional Review Boards (IRB) and how they function to provide ethical oversight for all proposed and ongoing research studies in hospitals and universities.

When asked how they would encourage their family and friends to participate in research, one woman said she would "encourage them just to be open to the possibility." A gentle nudge to get them thinking about participating. Medical research should be seen as the social good that it is. The first step in tackling this challenge is regularly getting the public to consider participating in medical research. People need to consider how they can help advance the prevention, diagnosis, and treatment of disease. (Alvins, 2007)

Another responded that she would "try to explain all known benefits but would not ignore any concerns about any negative possibilities." A final response that received general agreement with head nods from the other women was, "I would encourage by explaining it as if it's a way of giving back." There was general agreement around the statement, "I would continue to research to educate myself and share the information with others."

During my doctoral journey, family and friends would often ask about my topic and wince in either disapproval or sympathy once they heard the focus. They would immediately

begin to reference all the negative history associated with medical research and use “scare tactics” and conspiracy theories to discourage others from engaging in the conversation. We would debate back and forth, each convincingly trying to get the other to see their point of view about the topic until one got tired. A more effective way to win this argument is to acknowledge concerns and encourage them to consider participating in medical research. Efforts to increase minority participation in health research should focus on ensuring access to health research for all groups rather than changing minority attitudes. (Wendler, D., et al, 2006)

V.2 Contribution to Theory

The results of this study add to the validation of social cognitive theory as a practical framework for designing interventions to promote changes in behavior.

V.3 Implications for Black Women

The result of this research serves as a Call to Action for Black women to continue to advocate for equal and better healthcare to eliminate disparities and improve outcomes. The women in this workshop had the right mindset and were on the right track. We encouraged them to continue their self-advocacy by researching, asking questions, and demanding better healthcare for themselves and their families and friends and coming back to the symposium next year to see how we listened and incorporated their feedback.

V.4 Implications for Researchers

When designing interventions, race considerations need to be made when assembling the teams involved in conducting the intervention. This research can be applied to other minority populations using this same format as the *All of Us* program's focus is to replicate the diversity of the United States. They should use relatable content and materials for advertising. When designing interventions for other minority populations, you should consider role models that the

audience can relate to or are highly respected. For this research, hearing the initiative President Obama introduced added credibility. President Obama was the first Black person elected president of the United States and is highly respected in the African American community. Those who came to the workshop and saw the video recalled watching President Obama's initial initiative announcement but did not pay attention to it at the time. However, seeing it again motivated them to get involved.

Increasing the self-efficacy of African American women will increase their confidence in initiating and engaging in meaningful conversations with physicians and researchers when evaluating their decision to engage in clinical research. The fact that trust was not the leading concern for this group of women could cautiously signal a shifting paradigm, at least among this demographic. With caution not to overclaim, could knowledge be the key factor to mitigate

V.5 Implications for Healthcare Providers

Increased awareness might facilitate communication between healthcare providers and patients, which is a crucial component of quality healthcare". (Kaihlanenm, A., Heitapakka, L., and Heponiemi, T., 2019) This study confirmed the need for more communication about medical research to and between healthcare providers. Individuals who provide healthcare services should have added accountability to improving the health and quality of life for the patients they serve. Whether the issue is their tendency to regulate medical research participants or their lack of knowledge, it needs to be addressed within the medical community. There should be a common goal of tackling and improving minority representation in medical research.

V.6 Implications for Policy

To ensure training and knowledge gain among healthcare providers, there should be a requirement for continuing education or continuing medical education (CM/CME) courses

focusing on medical research. An annual requirement would be needed as technology changes fast and new developments occur every day. While there are already laws and regulations aimed at improving representation, the lack of oversight nulls the intentions of the legislation. There should be stronger oversight of governmental and non-profit agencies with penalties to enforce compliance with the standards. Medical research be accessible to anyone who wants to participate.

V.7 Limitations and Future Research

There were many great lessons learned and opportunities to improve this workshop for the next round of this research.

A limitation of this study is that most of the women had received higher education and were insured. For future studies, there should be a more intentional focus outreach to women with lower levels of education who are uninsured in more rural areas and provide those resources onsite at the symposium.

Also, we were unable to confirm actual enrollment in the *All of Us* Research program, so the participation intention is based on self-reported responses. The researchers that attended the symposium and the workshops may have skewed the results that would have been received from less knowledgeable women. However, we were appreciative of the interest and engagement during the workshop.

There are limitless opportunities for ongoing research.

- 1) The Black Women's Health Symposium was the first of what is planned to be an annual event along with an annual men's mental health symposium where this research could be replicated with Black men.
- 2) A dedicated medical research symposium focusing on medical research to bridge the gap between researchers, physicians, and healthy volunteers is being developed for 2024.
- 3) A longitudinal study to measure awareness and other health-related issues over time is another opportunity for future research.

- 4) Another opportunity is the development of a workshop tailored to focus on the informed consent process and confidentiality, along with clarification on the distinct types of medical research.
- 5) More investigation on the issue of information and awareness of healthcare providers and the barriers preventing them from sharing information about medical research with their patients and colleagues

V.8 Conclusion

This research makes a difference because, unlike most other studies, it focuses on healthy volunteers. It also validates the importance of increasing the knowledge and awareness of Black women to eliminate this barrier to engaging in medical research. It also advances knowledge because it reveals that customization of the content and materials influences decisions about engaging in medical research, which should be addressed. Gathering information from the community while raising awareness of Black women could continuously increase engagement and yield more positive outcomes in the overall health of Black women.

This study provided me with the unique opportunity to increase the awareness and importance of the representation of Black women in medical research. My key takeaway is that there is still apprehension about participating in medical research and growing appreciation for the topic. I will continue to educate on this issue to close the knowledge gaps of Black women to increase participation and close the knowledge gaps of researchers. In addition, I look forward to encouraging and aiding Black women in their self-advocacy efforts to ensure that we are represented in the journey to health equity for all.

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VITA

Dr. Stephanie Malone has an extensive background in healthcare management with diverse experience in healthcare management. Dr. Malone's cross-functional areas of expertise include:

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- Health Equity
- Quality Management
- Regulatory and Compliance
- Scholarly Research & Writing
- Strategic Planning

Dr. Malone has worked alongside Sr. Leadership executives and physicians as a liaison with external auditors to ensure compliance with national quality standards and state-specific rules and regulations.

Dr. Malone is a results-driven professional with 26 years of experience in the healthcare industry focused on the detailed areas of quality management, including population health management, network management, credentialing, utilization management, and member experience.

In 2023, Dr Malone earned a Doctorate in Business Administration (DBA) from J. Mack Robinson College of Business at Georgia State University. In addition, she holds a Bachelor of Science in Business Administration (Marketing) from the University of South Carolina along with a Master's in healthcare management from Mercer University. Additionally, Stephanie is Lean Six Sigma Green Belt certified.