

TESTING THE EFFECT OF CULTURALLY TARGETED, NORMATIVE
MESSAGING ON BLACK WOMEN'S INTENTIONS TO PARTICIPATE IN A
BREAST CANCER CLINICAL TRIAL

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DEDICATION

For my beautiful girl, who was here to encourage me to start this journey, and who—although she had to go before it was done—sent angels to stay by my side. You are my muse, and I still hear you singing. RIH.

For my husband, who has been my scaffolding, holding me fast, helping me climb, and never swaying. Thank you for trusting and accepting the plan God had for me. I have never known love like this before.

For my father, who taught me everything I ever needed to know, and from whom I am still learning.

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Katherine Ellen Ridley-Merriweather

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Despite increasing disease incidence and remarkably high mortality rates, Black women are underrepresented in breast cancer (BC) clinical trials (CTs), likely limiting the generalizability of BC research findings to Black patients. Evidence demonstrates that the BC research community could exert more effort to ensure the recruitment of Black women into CTs. Although Black and white women have similar BC incidence rates, Black women are 40% more likely than all other races and ethnicities to die of the disease. Clear disparities exist even after controlling for socioeconomic inequalities. Black participation in CTs has been declining, which is particularly unfortunate given the increasing health problem of a lack of Black representation in medical research. Successfully swelling the percentages of Black women who participate in BC research is important and likely reliant on increasing group members' motivations to surmount existing historical, cultural, and social barriers. Guided by normative and cultural theoretical frameworks, this study examined the effects of culturally informed messaging on Black women's intention to participate in a CT focused on BC prevention. Six hundred thirty-five Black women aged 18 and over were recruited through Qualtrics to participate in an online, posttest only, control-group design message testing study using random assignment to condition (the control or one of four injunctive-, descriptive-, and/or legacy norm-focused messages). They answered survey questions designed to measure the messages' effects on the women's intention to participate in the CT. The

study employed univariate and multivariate logistic regression and yielded statistically nonsignificant results; none of the four hypotheses were supported. However, the findings trended overall toward having higher probability of intending to perform the behavior (overall intention $M = 3.35$). All conditions had means higher than three (out of a five-point scale). A practical implication is that message content is affected by the medium through which it is delivered. Theoretical implications include the importance of overlaying cultural factors onto normative theories. Given that previous successful recruitment methods to this CT for this population were grounded in research practices involving face-to-face, interpersonal interactions, future research should consider employing a multi-level approach in testing these messages.

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CHAPTER ONE

Introduction

Racially minoritized subpopulations comprise nearly 40% of the United States population (U. S. Census Bureau, 2022) but are underrepresented in clinical trials (Hamel et al., 2016), meaning that a substantial subset of Americans are not fully benefiting from clinical and biomedical developments. As further evidence of this significant disparity, people of color are substantially underrepresented in breast cancer clinical trials. Breast cancer clinical trials are research studies to evaluate the safety and effectiveness of propitious new treatments for myriad types of breast cancer among human volunteers. As such, these breast cancer clinical trials are critical to the advancement of new breast cancer medications and treatment protocols for all individuals suffering from breast cancer.

The underrepresentation of Black women in breast cancer clinical trials has been broadly documented and criticized, and particular concerns about this group's increasing disease incidence rate and remarkably high mortality rate have been noted (Yedjou et al., 2019). A primary concern is that the generalizability of breast cancer research findings to Black patients may be limited by underrepresentation of Black participants in breast cancer clinical trials (U.S. National Library of Medicine, 2021). However, some evidence exists demonstrating that minimal effort is made by the breast cancer research community to ensure the recruitment and representation of Black women into those clinical trials (Ridley-Merriweather, 2019).

Although work focused on how to best recruit Black women to participate is increasing, more studies are needed to explore the role of unique social and cultural

aspects of Black women that may play a role in motivating intentions and behavior in this context. In particular, researchers should increase employment of culturally targeted efforts to examine how more effective norms messaging could help recruit Black women to clinical trials.

This project addresses these concerns by creating and testing normative messaging culturally targeted to recruit Black women to participate in an unconventional preventive breast cancer clinical trial. Although the messages created for this dissertation are specifically geared toward a particular clinical trial, these processes can be readily adapted to help increase minoritized populations' recruitment to clinical trials studying other cancers, diseases, or medical processes (such as organ donation).

Background and Literature Review

Black Women, Breast Cancer, and Clinical Trials

Breast Cancer Statistics

According to recent statistics, Black women (124.3 per 100,000) and white¹ women (128.1 per 100,000) are diagnosed with breast cancer at similar incidence rates, although much higher than other racial groups (American Cancer Society, 2020).

However, non-Hispanic Black women under 50 are 111% more likely than non-Hispanic white women, and more than 40% more likely overall, to die of breast cancer (CDC,

¹ Within the last two years the choice was made by most academic and popular press to capitalize the B in Black (Ridley-Merriweather et al., 2021). Around that same time, the APA determined that for any cultural group who labeled their own race or ethnicity as a color, that color would be capitalized. However, because of the knowledge that white people's skin color can correspond with systemic inequalities and injustices (<https://blog.ap.org/announcements/why-we-will-lowercase-white>) and increasing resistance from communication studies (Thompson & Harrington, 2021), in this dissertation I will not be capitalizing the word white when referring to the racial group or any individual group member.

2012; Hendrick et al., 2021). In addition, breast cancer tumors in Black women are often discovered at a younger age, more advanced stage, and higher grade, which often reduces the choice of possible treatments (Hendrick et al., 2021). The breast cancer incidence rates of Black or African American women before age 45 are the highest of all women (Shoemaker et al., 2018). In addition, about 21% of Black women who develop breast cancer are diagnosed with triple negative breast cancer, a subtype that is particularly aggressive and more challenging to treat (American Cancer Society, 2020).

These figures translate to Black women in the United States being twice as likely as white women to develop triple negative breast cancer (McDowell, 2019). Women diagnosed with triple negative breast cancer tumors experience comparatively poor outcomes and cannot be treated with any targeted therapies, as they do not yet exist (Mehanna et al., 2019). Recurring research hypotheses attribute clear disparities like these more to socioeconomic standing than solely to minority status (San Miguel et al., 2020), but as discussed in the next section, those assumptions are not fully supported by evidence.

Black Women and Breast Cancer Disparities

The differences in poor breast cancer outcomes between Black and white women in the United States are partially explained by the higher prevalence of socioeconomic disadvantages in Black communities. These outcome differences, for example, are reflected by variations in the patterns of delivered cancer care (Newman & Kaljee, 2017). However, several other reputable studies exist evidencing that, even after accounting for socioeconomic variables, the statistical gaps between the racial (predominantly Black and white) differences in breast cancer stages remain statistically significant (Newman &

Kaljee, 2017; San Miguel et al., 2020). In other words, clear breast cancer disparities still exist after socioeconomic variables are controlled.

The fact remains that Black women in the United States are significantly more likely to die of the disease and have worse treatment outcomes than white women, regardless of socioeconomic standing. These remarkable and ubiquitous statistics starkly demonstrate the importance of increasing the participation rates of Black women in breast cancer clinical trials in order to fully understand and address outcome inequities. In acknowledgment of the significance of increasing inclusion of minoritized populations in cancer research, the National Institutes of Health attempted to mandate researchers to prioritize increased participation of Black and Brown people.

NIH Revitalization Act of 1993. Including appropriate percentages of minorities in medical research projects was considered so important by the National Institutes of Health (NIH), that in 1993 as part of their Revitalization Act, inclusion of proportional numbers of marginalized group members into research was mandated as a necessary factor for all NIH-funded clinical research (NIH, 1993; Oh et al., 2015). Later, when it became clear that the mandate was ineffective, the NIH modified their Revitalization Act (Duma et al., 2018) to require the actual reporting of study participants' race/ethnicity percentages to the NIH. Not only was the modified version also ineffective, minority recruitment rates actually declined afterward (Duma et al., 2018). Although many minority women exhibit low levels of intention to participate in breast cancer clinical trials, they have expressed some interest in doing so (Haynes-Maslow et al., 2014).

Importantly, research shows that possessing broad knowledge of the methods and purpose of breast cancer clinical trials increases minority women's participation

intentions (Ferrera et al., 2016; Hann et al., 2017; Licqurish et al., 2017; Ridley-Merriweather & Head, 2017). Given these positive and hopeful findings and considering that research has outlined so many potentially effective actions that could positively affect recruitment rates, one might wonder why the participation of Black people is declining (Duma et al., 2018). Scientists who are serious about increasing the levels of participation of Black people in their research projects must actively work to employ methods for stimulating and enhancing the group members' intention to become involved.

Stimulating and enhancing Black and Brown individuals' involvement in clinical trials, which is possible through targeted health messaging, will translate to increased participation of minorities in medical research and clinical trials. Unfortunately, as is made clear in the next section, the situation is getting worse rather than better.

Black Women's Low Participation in Clinical Trials

According to Duma (2018), the number of Black people participating in clinical trials has been declining for the past 14 years. Most recently, the COVID-19 pandemic that began in the United States in early 2020 caused tremendous disturbance to the processes of cancer clinical trials (Boughey et al., 2021). A survey taken at the end of March 2020 reported a delay or cessation of screening and enrollment of patients to clinical trials from at least 60% of investigators. This phenomenon is expected to cause even more disparity in clinical trial enrollment of minoritized populations, given the higher rates of COVID-19 infection among Black and Brown people (Boughey et al., 2021).

Researchers would like to know more about why this is happening, as lack of representation of minority populations in medical research, including clinical trials, is an increasing health problem (Langford et al., 2019; Niranjana et al., 2019). Successfully increasing the percentages of Black women who take part in breast cancer research helps to address that problem by accelerating the development of new technologies, treatments, and services that can be effective for this subpopulation. However, any increase in research participation is likely reliant on increasing the group members' motivations to surmount the current barriers facing them.

Black Women's Barriers to Research Participation

Black women in particular have been historically underrepresented in medical research and clinical trials (Duma et al., 2018; Tanner et al., 2015). Up until now, researchers have mostly approached this problem by identifying and attempting to mitigate the cultural and social barriers faced by members of racial and ethnic minority groups who might consider participating in cancer clinical trials. Several categories of studies have revealed multiple participation barriers, including systematic literature reviews (Ford et al., 2008; Rivers et al., 2019), reviews targeting recruitment obstacles (Salman et al., 2016) and single studies (Tanner et al., 2015). The barriers identified in these studies included—but were not limited to—lack of awareness and understanding of clinical trials, such as time and effort required for participation; structural barriers such as transportation, childcare, and access to health care; and psychological barriers such as misperceptions, distrust, and fear.

The most commonly identified obstacles particular to Black women's clinical trial participation in medical research are fear (Peng et al., 2019), negative personal

involvements with the healthcare system, and mistrust of medical research and the researchers themselves (T. B. Hughes et al., 2017; Rivers et al., 2013). Other factors frequently linked to low participation rates in clinical trials among Black women are perceived disinterest by the medical community concerning diseases prevalent among Black populations (Kenerson et al., 2017), and potential participants' lack of awareness and/or access to scientific research opportunities (Frierson et al., 2019; Heller et al., 2014). Another often-documented barrier to clinical trial participation for Black people is the pervasive lack of knowledge about medical research, discussed in the next section.

Black Women's Lack of Knowledge about Breast Cancer Research. Brown et al. (2000) found that lack of knowledge and awareness of available trials were among the most common barriers inhibiting Black women from participation in breast cancer clinical trials. These findings are supported by more recent research demonstrating that members of racial and ethnic minority groups exhibit a paucity of knowledge about breast cancer and clinical trials (Hann et al., 2017; Licqurish et al., 2017) and may not understand the potentially positive impact that participation in a clinical trial could have on their communities and possibly their own families (Jones, 2015; Ridley-Merriweather & Head, 2017). Because Black women are far less likely to be approached about clinical trials by their physicians, the cumulative findings of all of these studies suggest a need to provide information to, and educate Black women about, available trials (Brown et al., 2000; Ridley-Merriweather et al., 2019).

Rivers et al., (2019) also found an existing lack of cultural relevance in education and outreach materials for Black communities, resulting in a void of cancer clinical trial information targeted to members of Black communities. Findings from focus groups

involving Black women suggested numerous outlets through which to get word about cancer clinical trials into Black communities, including physician's offices, churches, health fairs, newspapers, and radio ads (Rivers et al., 2019). In other words, a long-identified barrier is still solidly in place, even in light of strong evidence suggesting solutions that could be relatively easily implemented.

In an important and recently published study, Swaby et al., (2021) clearly describe the findings of their systematic review examining articles published between 2010 and 2020 that were inclusive of the search terms “cancer,” “clinical trials,” “African American,” and “minority.” The authors excluded studies focused on screening, quantifying participation rates, and all narrative and systematic reviews. Their findings confirmed myriad previously identified barriers Black people face regarding participation in cancer clinical trials, but focused primarily on the solutions. According to Swaby et al. (2021), although the research participation obstacles faced by Black people are numerous, the solutions are clear, can be easily enacted through channels already in place, and can be drawn from the very same research institutions that offer the cancer clinical trials. Suggested solutions include offering biomedical education to potential participants and investing in increasing the diversity of the clinical trial biomedical research and healthcare teams. Swaby et al. (2021) report that “enhancing the level of communication and education of cancer patients from minority communities will build trust between the patient and oncology team and has the potential to improve participation rates in clinical trials among this population” (p. 9).

When used to inform Black women about the importance of participation in breast cancer clinical trials, the findings of the current proposed study will be applied

toward the very educational health communication practices suggested by Swaby et al. (2021). Clinical researchers clearly have not heeded these perspectives and proposed solutions coming directly from the population they continually purport to seek as research participants. Cancer healthcare and health research teams should take strong and immediate action, although some seem not to know how to do so. An important part of working to increase clinical trial participation in Black women is developing methods for both the potential study participants and their healthcare teams to navigate these and other barriers.

Navigating the Barriers. Clearly, addressing the multiple existing barriers discussed in the previous section requires implementation of various strategies (Heller et al., 2014). However, Black individuals' attitudes toward medical research and clinical trials are inarguably justifiable considering the history of atrocities committed against them, such as the Tuskegee Syphilis Study (Frazier, 2020) and the taking of Henrietta Lacks' cervical cancer cells without her consent (Wolinetz & Collins, 2020). Other historical brutalities, such as the work of J. Marion Sims, who earned his unofficial title as "father of modern gynecology" by perfecting surgical procedures (usually without anesthesia) on three slave women he kept captive (Cronin, 2020), and the "night doctors" who kidnaped Black children during the night in Baltimore to perform surgical experiments on them (PBS NewsHour, 2016) are lesser known outside of Black families and cultural groups.

Beyond these larger examples of mistreatment of Black people by medical researchers, the everyday systemic racism within the healthcare system also contributes to negative attitudes. The popular press is redolent with current examples of everyday

atrocities happening to these group members, such as disproportionately high rates of death from COVID-19 (Lee, 2021) and childbirth (Population Reference Bureau, 2021).

Therefore, rather than place the onus on Black women to change their attitudes, as several research teams have done (Niranjan et al., 2019), this study seeks to amplify these women's voices, listen and appropriately respond to what they have to say, and use that data to create messaging that could ultimately lead to both reduced health disparities and increased trust. Proliferating and propagating the trust of these group members is only possible through learning to acknowledge and honor their cultural norms.

Black Women's Cultural Norms and Behavioral Intentions

Previous research has established that to better serve Black women who have developed breast cancer, as well as those who could benefit from risk-lessening preventive measures, there is a need to increase their breast cancer clinical trial participation rates. However, examination of the literature yields extensive evidence and descriptions of perceived cultural and social barriers held by these and other racial and ethnic minority group members regarding their low clinical trial participation rates (Hamel et al., 2016; Tanner et al., 2015).

A few studies even focused on identifying the influences and attitudes of those who do decide to become involved in medical research (Rivers et al., 2013, 2019), but those studies declined the opportunity to take the next step of suggesting ways to apply their discoveries toward increasing the participation of other group members to do the same. I perceive this identification of a problem without suggestion of appropriate follow-up to be somewhat of a failure on the part of the researchers performing this work. In other words, as social scientist researchers, we must actually respect the idea that fully

listening to members of this subpopulation, and suggesting action based on what we learn from them, can make a difference for the research problem we purport to care about. Many of the studies I have highlighted here have not fully focused on exploring and applying the potential power of cultural norms to increase clinical trial participation among members of a minoritized community.

The Komen Tissue Bank

Consider the Komen Tissue Bank (KTB)², a unique biorepository and clinical trial that collects healthy breast tissue from women with no signs of cancer. The tissue (along with whole blood, serum, and plasma) is collected from volunteer donors at clinical collection events, annotated with the participant's medical data, and stored. Breast cancer researchers around the world request and receive the samples for study or use as controls in their own research studies.

The mission of the KTB is to focus on preventing breast cancer and facilitating the development of targeted treatments where none currently exist, such as for triple negative breast cancer. Despite the fact that tissue donation to the KTB is a completely altruistic, non-incentivized action on the part of the tissue donors, there is no shortage of women who choose to donate. However, the vast majority of those women, over 81% at the time of this writing, are white (Komen Tissue Bank & LifeOmic, 2023). The KTB samples from racial and ethnic minority women that do exist are the result of targeted recruitment efforts over the past decade or so.

² The Komen Tissue Bank (or KTB) is the shortened name of the Susan G. Komen Tissue Bank at the IU Simon Cancer Center. The KTB is part of Indiana University and is located in Indianapolis, Indiana.

Growing the research participation rates of Black or African American women in the KTB and in other breast cancer clinical trials is essential. New developments in breast cancer prevention and/or treatments for Black women are desperately needed. Therefore, for the past decade, the KTB has been developing language to increase successful recruitment of Black women through the creation of culturally based appeals (Ridley-Merriweather et al., 2019; Ridley-Merriweather & Head, 2017).

Effective Culturally Informed Messaging

Studies have combined the word “culture” with varied other terms to help effectively describe their processes of considering and including the role of culture in their methods. For example, Whitbeck et al. (2012), who reviewed three categories of American Indian/Alaska Native substance abuse prevention programs, often sought methods that were “culturally specific.” Chiong-Rivero et al. (2021) tested the feasibility of a “culturally appropriate” narrative film that utilized “culturally tailored” messaging to create “culturally relevant” interventions. Additionally, Elk et al. (2020) considered the “cultural values and preferences” of rural Black people throughout the feasibility study of a “culturally based” tele-palliative care consult program.

A “culturally informed” study comprises all of these other terms. In their study using cultural interventions to treat addictions in Indigenous populations, Rowan et al. (2014) defined culturally informed as including Indigenous spiritual or healing practices or traditions, because they determined those cultural factors to be most inherent to the group under study. Despite slightly different terminology, the terms all refer to the need to consider a group’s traditions, religions, mores, customs, beliefs, and cultural identity

when trying to engage group members in health practices and interventions (Burrage et al., 2021; Williams et al., 2013), and then to use those constructs to *inform* the work.

Research shows that successful recruitment of Black people to cancer clinical trials should develop and use culturally based appeals. However, most current recruitment efforts into clinical trials still fail to recognize the different cultural, historical, and sociological factors that are important to minorities (Shiyanbola et al., 2018). These can be particularly critical oversights when trying to encourage Black women's participation in cancer research (Peng et al., 2019; Ridley-Merriweather & Head, 2017).

Triple negative breast cancer is a particularly aggressive form of the disease that disproportionately affects Black women, who are 20% more likely than white women to develop this form of the disease (Centers for Disease Control and Prevention, 2022). Clinicaltrials.gov is a database, provided by the U.S. National Library of Medicine, of privately and publicly funded clinical studies conducted around the world. A textual analysis was performed in spring 2019 to examine the recruitment language of all 105 triple negative breast cancer clinical trials available on clinicaltrial.gov (Ridley-Merriweather, 2019). Despite decades of well-demonstrated evidence that triple negative breast cancer primarily, measurably, and significantly adversely affects women of African descent (Centers for Disease Control and Prevention, 2022), not a single study included a request for Black women to participate. In fact, these risk factors were not at all addressed in the formal inclusion language (Ridley-Merriweather, 2019). Careful development of culturally informed messages will help safeguard against these kinds of

omissions and increase the likelihood of creating messaging that will motivate Black women to participate in clinical trials.

Need to Increase Intentions

Working to increase Black women’s intentions to participate in breast cancer research intended to benefit them and others in their community could lead to new developments to improve their health; however, studies concentrating on actually stimulating this minoritized group’s intentions are rare. This study will follow the guidance of Williams (2022), who suggests that in the pretesting and planning of research, researchers should take into consideration a group’s cultural characteristics “including cultural considerations, selection/translation of instruments, recruitment, collection of data, and analysis and interpretation of findings,” because “these adaptations have a cumulative effect of rendering individual projects culturally sensitive and of building culturally informed research” (para. 1).

Specifically, this work hypothesizes that applying effective sociopsychological and health communication strategies toward these goals, with a specific focus on the role of social norms influences, will lead to an increase in intentions for Black women’s participation in a breast cancer clinical trial. The next chapter explains how this work can be guided by thoughtful application of normative theoretical frameworks and health communication message design tactics.

CHAPTER TWO

Theoretical Structure

Theory in health communication research is used to understand, clarify, and forecast people's health beliefs, attitudes, intentions, and behaviors. Appropriate and rigorous application of well-chosen theories will likely help researchers develop well-framed, clearly conducted studies. Additionally, according to Head and Noar (2014), when engaged in applied research, theories can also help us understand how the theories themselves should be adapted or changed.

Sometimes, when a specific theoretical variable has been shown to be particularly effective or beneficial to behavioral examination, the justified application of multiple theories in a single study is warranted (Lundy, 2008). This need for complex theoretical guidance in a study can be particularly applicable when examining behavior motivation (Rickles, 2010). In fact, combining multiple theoretical frameworks can help in improving existing theories or even in developing new ones.

This study will focus particularly on the role of culture and, more specifically, cultural social norms within Black women's lives and how these may affect intentions to participate in breast cancer clinical trials. An applied normative framework guides the current study. This normative focus will be informed by the PEN-3 model (Airhihenbuwa, 1995), which addresses the need to think about norms in a way that more fully considers individuals' cultural impact.

The next section first describes social norms and the various theoretical frameworks that explicate social norms' role in behavior and behavioral intentions. Next, the utility of the PEN-3 model is explained and demonstrated and how it can be applied

as a filter through which to think about the role of culture in identifying and applying social norms in this study is described. Finally, the literature relevant to social norms messaging and pilot data on Black women's participation in breast cancer clinical trials informing the current study are presented.

Theoretical Framework

Social Norms

The roles of descriptive and injunctive norms have been widely studied. In fact, many behavioral models and theories, including (but not limited to) the theory of reasoned action (Fishbein, 1967), the theory of planned behavior (Ajzen, 1991), the theory of normative conduct (Cialdini et al., 1991), the theory of normative social behavior, a.k.a. social norms theory (Rimal & Real, 2005), and the integrated behavioral model (Kasprzyk et al., 1998), focus to some extent on the effects of norms on intention and behavior. Below, these theories are briefly reviewed and previous work that has specifically explored the role of these two normative influences is highlighted.

Social norms are unwritten, mainly socially learned group characteristics that create group members' behavioral standards or expectations for what are "appropriate" and "normal" feelings, thoughts, and actions (Stok & de Ridder, 2019). Social norms are present in several theories common to the fields of health communication and health-related behavior change. Although social norms are often not laid out in writing, they are usually deeply institutionalized and fully internalized by group constituents. In other words, individuals will usually reflect and adhere to relevant social groups' norms even when other members are not in the vicinity (Stok & de Ridder, 2019).

People likely conform to social norms because of a combination of psychological processes. (Cialdini et al., 1991) brought to our attention that although the label of “norms” is shared, human motivations are evidenced differently when comprehending what others commonly do and what others commonly approve. Therefore, a need exists to label these types of norms differently. Consequently, norms that characterize the perception of what most people or group members *actually do* are labeled as “descriptive” norms, and of what most people or group members *approve or disapprove of* as “injunctive” norms.

Descriptive Norms

People’s thoughts, feelings, and actions are motivated by descriptive norms, which, because individuals understand that others are thinking, believing, and/or doing these things, provide evidence of what might be effective and desirable (Cialdini et al., 1991). Descriptive norms (also sometimes referred to as “subjunctive” norms) are individuals’ perceptions of how other people are actually behaving, without regard to whether the behavior has the group’s approval. This presumption makes it easy for advertisers to sell products through suggesting that everyone in a target circle is a fan or user of whatever they are selling (Cialdini et al., 1991).

Individuals can usually choose to do something well by emulating others, as long as they are careful about whom to imitate, but there are some clear drawbacks. Descriptive norms describe perceptions of what members of social groups are actually doing; therefore, health campaigns that focus on warning against an undesirable or harmful behavior, such as eating or drinking to excess, may not significantly affect the targeted group members if they are surrounded by people regularly performing the

behaviors against which the messaging is warning (Farrow et al., 2020). Implications from much of the formative research for the current study, however, suggest that many Black women, when fully informed of all options, will make decisions to participate in research that may not be as strongly influenced by descriptive norms.

Injunctive Norms

Contrary to descriptive norms, which indicate what *is* done, injunctive norms indicate what *ought to be* done. Ajzen (1980) defines injunctive norms as group members' perceptions about the significance of others' beliefs and their enthusiasm for complying with those beliefs. A group's moral rules inform their injunctive norms, which in turn motivate actions through governing whether the group's response will be praise or informal sanctions. In other words, injunctive norms are influential because of an assumption that they are at least partially guided by a need to behave appropriately (Rimal & Real, 2005). Individuals' instinctive need to lower their voices in a library, or drink alcohol only at certain times of day, are examples of injunctive norms.

Health communication researchers should always keep in mind that people are individuals with individual thoughts and ideas; therefore, mutually incompatible norms will often exist simultaneously within social groupings. Several authors argue that most human response only sometimes conforms to the dominant social norms. For example, some group members may promote personal health privacy and others promote openness (Vayena & Gasser, 2016), and men are able to assemble and portray masculine identities in female-dominated occupational situations, such as nursing (J. McDonald, 2013).

In summary, from a social norms perspective, people can exhibit a behavior because of their belief that they are expected to do so by those close to them, or because

failing to perform the behavior will result in social repercussions. The common thread here is that behavior is guided by the viewpoints of others' beliefs, and a deep understanding of both descriptive and injunctive norms is critical to successful application of normative theories.

The next sections briefly describe several theories considered to be helpful as guidelines to this project, as they all feature social norms as a component. These theories include: the theory of reasoned action (TRA), the theory of planned behavior (TPB), the integrated behavioral model (IBM), the focus theory of normative conduct (FTNC), and the theory of normative social behavior (TNSB).

The Theory of Reasoned Action

The TRA asserts that behavior is powered by intention, which in turn is a function of beliefs about the likelihood that performing a particular behavior will lead to a specific outcome. The beliefs fueling this system are divided into two parts: behavioral and normative (Fishbein, 1967; Fishbein & Ajzen, 1975). According to Fishbein and Ajzen (1975), other external variables are important, but only to the degree that they might influence those attitudes and/or norms. In defining the TRA through clarification of behavioral and normative beliefs, intentions, and behavior, the theory developers demonstrated the importance of having high levels of correspondence between measures of attitude, norm, perceived control, intention, and behavior in terms of performing an action (Ajzen, 1980, 1991; Fishbein & Ajzen, 1975).

Kan and Zhang (2018) successfully applied the TRA as a framework to examine how family encouragement and subjective norms influenced the vaccination behaviors of elderly people. Their findings suggested that family members should also be included in

all interventions with their elders. As a theory, the TRA was integral to the study of normative behavior and communication. Development of this framework continued, and its developers eventually added an additional construct to the TRA, thereby creating the theory of planned behavior (TPB).

The Theory of Planned Behavior

The TRA, which posits and assumes that behavioral intention is the most significant in determining behavior, is successful in explaining behavior only if people are able to exercise great degrees of control over the behavior (Montano et al., 2008). This however cannot be guaranteed, and there is not surety that the elements of the TRA are sufficient behavioral predictors should volitional control be absent.

The TPB, an outgrowth of the TRA, takes notice of situations wherein individuals may not have total control over their behavior, and therefore adds perceived control as a construct (Ajzen, 1991). The TPB presupposes that when attitude and norm are held constant, perceived control can independently determine behavioral intention (Montano et al., 2008). Both the TRA and TPB presume that behavioral, normative, and control beliefs are causally linked through attitudes, norms, and perceived control to intentions and behaviors (Ajzen, 1980, 1991, 2006).

The TPB was used to guide an interesting and strong normative study examining the cannabis-use behaviors of cancer patients in Canada, once a legal access system had been designed for nonmedical purposes (McTaggart-Cowan et al., 2021). The authors sought to reveal factors that influence cancer survivors' decisions about whether or not to self-medicate with cannabis as a complementary therapy to relieve and lessen their cancer symptoms. In looking at normative influences, some participants indicated that physician

support, along with approval and validation from family and friends, were important factors in their decision making (McTaggart-Cowan et al., 2021).

The Integrated Behavioral Model

As a health behavior model, the IBM comprises constructs from the theory of reasoned action, the theory of planned behavior, social cognitive theory, the theory of interpersonal behavior, and the health belief model (Kasprzyk et al., 1998). The IBM is defined by three construct categories: attitude toward the behavior, perceived norms, and personal agency (individuals' beliefs that they are capable of enacting a behavior, Montano et al., 2008). The variables in the model are shown to provide a fuller prediction of behavioral intention than the TRA or TPB alone. When applying the IBM, perceived injunctive and descriptive norms denote the social pressure one feels to carry out or resist carrying out a particular behavior (Kasprzyk et al., 1998).

Likely due to its composition from the constructs of several other behavior theories, the IBM's range and scope as a framework to guide formative health communication research is a major strength. Head and Iannarino (2017) made use of this strength when they applied the IBM to guide their interviews with 22 former high school football players (N=22). This qualitative study served as formative research to help with understanding the psychosocial influences on high school football players' weight-gaining behaviors. Head and Iannarino (2017) found strong descriptive and injunctive normative influences in a culture of high school football that supported bulking up, formative findings that can assist in the development of health communication interventions targeting players, coaches, and parents.

The Focus Theory of Normative Conduct

The FTNC is particularly important to this section because it focuses solely on norms. This theory, which provides clarification that offers a fuller understanding of the distinction between descriptive and injunctive norms, hypothesizes that norms direct behavior only when they are made salient (Cialdini et al., 1991). In addition, if more than one norm is activated, the most salient norm is the one that governs in a given situation (Mackie & Moneti, 2014). Therefore, individuals whose attention is temporarily directed toward, and focused on, normative matters are decidedly more likely to act in ways consistent with the norms on display.

The FTNC is best explained through a short description of the study used to develop it. People walking through open, outdoor environments—some very clean and some well-littered—were handed a flyer by a study volunteer, then observed to determine if they would litter by throwing the flyer on the ground or keep it to dispose of later (Cialdini et al., 1991). The participants' responses differed based on whether they observed someone in front of them choosing to litter. Cialdini et al. (1991) posits that whether or not a particular norm will influence an individual's response relies on the degree to which that individual's attention is actually focused on that norm.

Jonas et al. (2008) employed the FTNC in a study to further explore and understand the concept of mortality salience (the awareness by people of the inevitability of death) and its effect on individuals' social judgments. Their findings helped to demonstrate the predictive power of the FTNC and also supplemented the theory by suggesting that the degree to which salient norms have an impact on people's attitudes and behavior at least partly depends on certain motivational factors (Jonas et al., 2008).

The Theory of Normative Social Behavior

The TNSB (also known as social norms theory) was developed by Rimal and Real (2005) and is another theoretical framework that distinguishes descriptive norms from injunctive norms. Social norms are the collective, accepted behaviors for a specific situation, but social theorists such as the developers of the TNSB have focused not as much on the norms as on the beliefs developed through these norms.

The TNSB suggests that descriptive norms are related to behavior and/or behavioral intent, and that relationship is moderated by other, outside influences (Bute & Jensen, 2010). Rimal and Real (2005) explained that expected outcomes (beliefs that certain behaviors will bring about benefits) coupled with group identity (an individual's perception of belonging to a group of similar others) and injunctive norms are collectively called normative mechanisms. The effect of descriptive norms on an individual's behavior is potentially increased or decreased through the influence of one or more normative mechanisms. Although they may have some direct bearing on behavior, normative mechanisms can be better described in health communication as agents that can reduce, reinforce, or intensify descriptive norms' effects.

The TNSB is most widely used to explore alcohol drinking norms and habits, including how behaviors are influenced by perceived norms (Rimal & Real, 2005), peer communication and how friends talk to friends about drinking (Real & Rimal, 2007), and perceived historical drinking norms and current drinking behavior (Carciooppolo & Jensen, 2012).

However, the theory can also be a helpful and effective guide for studying several other health communication concerns. For example, offering a framework that physicians

can use to embed a social norm perspective within integrated health interventions could allow them to better address the multiple factors that sustain and even promote damaging behaviors (Cislaghi & Heise, 2019), and the effects of perceived social norms on students' handwashing behavior (Dickie et al., 2018).

Health communication researchers have found each of the five normative theoretical frameworks described above to have been valuable tools studying and manipulating normative behavior. All of these theories provide effective guidance for examining participants' responses to the experiment and/or the effects on their intention to perform—or stop performing—certain behaviors. However, each of the theories described here are lacking an important construct that is crucial to the success of the current study. Despite so much evidence of the role of norms on behavior and behavior intention provided by each of the norms-focused theories outlined and summarized in this chapter, none of them, as they now stand, specifically address and account for cultural influences on behavior, particularly regarding sub-population norms.

The Role of Culture in Norms

Communication researchers should recognize that culture is not a research “add-on”; rather, it is integral to our work and should be at the forefront of our scholarship, particularly in consideration of relatively recent cultural events such as the Black Lives Matter movement (Canella, 2018). Consider the impact of the labels we use to describe Black and African American people. In their essay exploring the role of the labels “Black” and “African American,” Ridley-Merriweather et al., (2021) posit that a disconnect exists between researchers and individuals of African descent regarding perceptions of the labels “Black” and “African American.” Academic researchers assume

the terms to be interchangeable. Furthermore, academic scholars consider "African American" to be a more proper, and in fact better, choice (Ridley-Merriweather et al., 2021).

In actuality, research shows that descendants of the African diaspora, who often have a preference as to which label is used to describe them, could be offended by use of the other moniker. In fact, neglecting to use their preferred identification label may be a further barrier to Black or African American people's participation in research (Ridley-Merriweather et al., 2021).

While identity preference is just one example, it suggests that researchers should be exploring other ways that culture may influence norms research. In the next section, the addition of a third type of norm influenced by culturally informed formative research with Black women is proposed: legacy norms.

Introducing the Legacy Norm

Throughout the formative research informing the current study, how a specific group of women culturally discuss their role in clinical trials was observed and heeded, leading to the discovery of a new kind of norm. To clarify, by applying a cultural lens to understanding Black women's perspectives of participating in a clinical trial and a tissue donation study, a new norm was found that was unidentified in other literature that had previously studied these kinds of behaviors (Ridley-Merriweather & Head, 2017).

Therefore, the third type of norm explored in this dissertation is the "legacy" norm.

Ridley-Merriweather and Head (2017) described the legacy norm as driving a motivation for these women to "participate as a tissue donor in order to help other women in the future. They feel like their actions will be good for, and result in better outcomes

for, their daughters, grand-daughters, and future [population] members” (p. 1576). A scale development for the legacy norm has not yet been performed. For this reason, and for the purposes of the current study, an expansion of the legacy norm will be conceptually defined. Injunctive and descriptive norms are about how the perceived behaviors of others affect an individual, and are not necessarily bound by time; however, the legacy norm is based on how the individual’s behavior can affect others in the future. Before attempting to create items to measure the legacy norm, it was necessary to break down this definition to examine and identify its constructs. Included in this new norm are ideas of altruism, care of others, personal sacrifice, and awareness of the effects of current actions on future possibilities.

Altruism. In their manuscript dedicated to describing and defining altruism, Kerr et al., (2004) posit that the ubiquity of the term can promote ambiguity as well as a lack of scientific exactitude. They opined that social scientists everywhere are overlaying their own views over its definition, resulting in a term that is no longer precise. Through mathematical processes, Kerr et al., (2004) present three different interpretations of altruism based on cost and benefit.

The “focal-complement” interpretation revolves around the idea that altruism is costly to self but is a benefit to others. The “multilevel” interpretation conceptualizes that in a mixed group (altruists and non-altruists), the altruist is always less “fit” than the non-altruist, and that the higher the number of altruists, the more productive the group. Like the “multilevel,” the final interpretation—“individual-centered”—also finds the altruist to be less “fit,” but benefits for both altruists and non-altruists increase with the addition of more altruists (Kerr et al., 2004). All of these interpretations presume altruism to be

behavior that advantages others at a personal cost to the individual performing the behavior. Though similar, this concept differs from the idea of caring for others.

Care for Others. According to Foucault (2019), happiness is only accomplished through having dependent relationships with others. Foucault, a renowned French philosopher and psychologist, posited that caring for others is a prime element of living a worthwhile and happy life. By acknowledging our responsibility toward others, we are caring for them and being stewards of the environment (Cherrier & Munoz, 2007). There is great benefit to self to be found through caring for others.

Personal Sacrifice. Several theoretical lenses could be useful for examining self-sacrifice; the ideas of importance of significance and importance of family may be most appropriate for the current study. Dugas et al., (2016) suggest that individuals are motivated by a sense of self-worth when they self-sacrifice for a cause. The quest for personal significance theory posits that humans' yearning for meaning or personal significance is often reflected in people's need to "make a difference," in ways described by society (Kruglanski et al., 2009).

Perhaps more likely in terms of health and health decisions, self-sacrifice is an important and often innate factor of social life in general and family lifestyle in particular (Bahr & Bahr, 2001). The giver gives because a need is discerned; however, meaning is centered on how the giving and the need affect each other. Givers can possibly experience their own growth through the sacrifice by fostering the growth of another or perhaps shame and loss through turning away (Bahr & Bahr, 2001).

Awareness of the Future. It can be important to understand how people perceive and are conscious of the future, particularly in terms of their health or health-related

concerns. According to Lalot et al., the term “futures consciousness” refers to the human ability to grasp, foresee, prepare for, and accept the future (Lalot et al., 2020).

Comprehending the idea that time is passing and tomorrow will come are prerequisites for being conscious and aware of the future.

A fundamental aspect of futures consciousness is time perspective, which accentuates the importance of looking and thinking ahead long-term thinking and looking ahead (Ahvenharju et al., 2021). Psychologists make note of and assess the differences in time perspectives demonstrated by disparate individuals, often using a tool called the Consideration for Future Consequences scale (Strathman et al., 1994) which has been found to positively predict numerous several long-term behaviors long-term-oriented (Lalot et al., 2020).

Legacy Norm Constructs. It is important to understand that the legacy norm is a more sophisticated and complex concept than simple altruism or self-sacrifice. The amalgamation of the nuances of an individual really caring about others rather than simply wanting to do something good and being aware that actions performed now could positively affect the future, are key to its essence.

The Futures Consciousness scale was designed to quantitatively measure differences in individuals’ perception of the future (Lalot et al., 2020, 2022). The scale comprises five dimensions, including Time Perspective, Agency Beliefs, Openness to Alternatives, Systems Perception, and Concern for Others. Together, six of the eight items contained in two of these dimensions, Time Perspective and Agency Beliefs, are centered around the four constructs of the legacy norm. Therefore, an adapted version of

the Futures Consciousness scale, comprising these six items, will be employed in the current study to measure the legacy norm.

Discovery of this new norm exemplifies a need to really think about and be more sensitive to culture when trying to recruit minoritized populations into medical research. The next section outlines how discovery of the legacy norm was guided by culturally aware formative research for the current project.

Formative Research

In this section, in addition to Ridley-Merriweather et al. (2021), two more studies are presented as formative research. These projects serve as evidence and support that the messages designed for the current study are based on research and are projected to succeed in raising the intentions of the participants to perform the desired behavior. The findings of these studies, both guided by normative theory, provide abundant material from which to craft targeted KTB messaging for Black and African American women.

Rigorous formative research holds clear importance in health communication intervention design for Black and Brown people. For example, to help identify gaps in their intentions to discuss care options for Black patients with advanced cancer, Rhodes et al. (2020) first developed education and counseling interventions for this high-risk population. Also, Cunningham-Erves et al. (2020) incorporated multiple community engagement approaches into their formative research processes to facilitate enrichment of the cultural-appropriateness of programs designed to promote cancer clinical trial participation among Black people and Latinx groups. These examples demonstrate the importance of formative research in designing and developing the content, delivery, and specific focus of messaging.

Black Women, Clinical Trials, and the Legacy Norm. Guided by the IBM, Ridley-Merriweather and Head (2017) recruited 71 Black women (N=71) who were previous breast tissue donors to respond to an online questionnaire. The purpose of this study was to better understand Black women’s perceptions of donating their healthy breast tissue for purposes of research and the potential influence of their race on the decision to participate. Findings from this work illuminated a new “legacy” norm.

The legacy norm is identified as the propensity for some group members (e.g., Black women as in the source citation) to be willing to sacrifice for the betterment of their children, their children’s children, and other group members in the future. This legacy norm ignites the motivation for these women to donate healthy tissue so they can help other women in the future (Ridley-Merriweather & Head, 2017), and reappears in findings of the authors’ other work on influencing Black women to participate in medical research.

Ridley-Merriweather and Head (2017) identified three uniquely nuanced instrumental attitudes demonstrated by their participants, all of whom were Black women. First, many of the women in this study reported perceptions of breast cancer research as being something with which it was generally important to help:

I wish everyone would donate. This research is so important to help find a cure. If a treatment is found to help breast cancer it maybe could be used to cure other cancer. I pray that any and all research is a [potential] cure for all cancer, not just breast cancer. I wish more people realized just how important this is. (p. 1575)

Second, participants demonstrated positive instrumental attitudes in their wish to specifically help Black women, thereby evidencing the newly identified legacy norm:

Looking around and seeing a minimal number of African American women donating [made me] become passionate in spreading the word to my fellow sistahs and encouraging them to at least consider becoming a donor. I also share with them the disparity in donating tissue as well as that of the death rate between Caucasian and African American women to breast cancer. (p. 1566)

They also considered the representation of the Black or African American race in breast cancer research to be important:

The Black community does not know about donating. Now if you would like more studies of African American women, please advise, communicate, and educate. Every Black women I have spoken to, [including] women preachers who have traveled the world, state they did not even know that they could donate [their breast tissue] (p. 1566).

Finally, the women wanted to honor or support someone who has or has had breast cancer. Additionally, results of preliminary studies examining the reasons for Black women's decisions to participate in the KTB clinical trial identify altruism, high levels of cultural identification and evidence of a "legacy norm" that, when stimulated, is a powerful influencer (Ridley-Merriweather & Head, 2017).

Black Women's Clinical Trial Motivations. In another IBM-guided study, Ridley-Merriweather et al. (2019) interviewed 14 Black breast cancer patients or survivors (N=14) in five states, who participated or were currently participating in a

clinical trial. The purpose of this study was to better understand the motivations of Black women to become involved in medical research and participate in a clinical trial.

Findings again supported that in addition to desiring to help themselves, Black women's altruistic desires to serve others and their communities are greatly influenced by the need to leave a "legacy" of improved treatments for other Black women (Ridley-Merriweather et al., 2019). One participant articulated, "I had no problem [participating] because if it would work on me, then I'm hoping it would work on someone else . . . whatever I can do to help someone else." Another clearly demonstrated evidence of the legacy norm by saying, "if it would be a help to others that will follow me and it would be a help to my children, because I have two daughters, then I'm all for it."

The participants in this study mostly learned about the clinical trials in which they participated through communicating with family, friends, or other breast cancer patients and survivors. Many of the women were positively influenced and encouraged to participate by other Black breast cancer patients they knew. This is a strong indicator that social norms messaging may effectively alert and inform other Black women about continuing disparity in breast cancer clinical trial participation.

As evidenced by one woman who asked, "how are people going to get new medicines if you don't do a study?," most of these participants knew and understood that taking part in research was a form of helping themselves *but also helping others*. The findings from this work reveal important normative reasons Black women chose to participate in breast cancer clinical trials and offer important ideas for the development of culturally targeted normative messaging, particularly surrounding the emerging evidence

that when influenced by culturally based motivators, Black women are clearly willing to be involved in medical research (Ridley-Merriweather et al., 2019).

Formative Research Conclusions. In summary of these formative work findings, there are many valuable lessons to glean about how and why Black women are motivated to donate their healthy breast tissue and participate in the KTB clinical trial. In addition to having knowledge about trials and how Black women are more likely to develop and die from more aggressive breast cancers, these women are also strongly motivated by normative influences and pro-social reasons, specifically: (1) receiving encouragement from other group members, (2) receiving targeted information about disparities relevant to their racial subgroup, (3) receiving culturally informed messaging, (4) perceiving high levels of legacy norm, (5) recruitment by friends or family, (6) understanding the reasons behind the need for their participation, (7) connection to people who have breast cancer or are survivors, (8) understanding the donation procedure, and/or (9) being asked.

Other Cultural Norms

As previously discussed, social norms are determined by individuals' beliefs of what they should or should not do as members of their particular society, and also by what other members of their societal circles actually do (Kasprzyk et al., 1998). Adding the influences of culture further defines the parameters of societal norms, as different cultures have different norms resulting from their own unique traditions, lifestyles, religious beliefs, etc. (Airhihenbuwa, 1995). In other words, a more robust understanding of individuals' social norms can only be gained by including and accounting for the strong cultural influence in these people's lives.

For example, Zhao Martin et al. (2019) examined the role of Latinas' bond with their urban, ethnic neighborhood storytelling networks (residents, local/ethnic media, and community organizations) in forming their descriptive normative perceptions about cervical cancer screening. The authors specifically focused on exploring communication mechanisms underlying Latinas' exposure and attention to media information about Pap tests. This included the women's discourses about Pap tests with health-care professionals, their normative perceptions about Pap tests for women in their culture, and cervical cancer screening guidelines compliance.

The authors found that neighborhood storytelling resources informed health communication outcomes influencing normative descriptive outlooks and Pap test compliance, and that health messages needed to travel through neighborhood "noise" to reach an intended audience, suggesting a need to pay attention to the amount, type, and framing of health stories being related through the network. Other results pointed to a need for interventions that were able to increase positive health storytelling (Zhao Martin et al., 2019). Additionally, the identification of the legacy norm is an example of how approaching research from a cultural lens can allow us to better understand different norms from different subgroups, and how those normative outlooks and practices might inform lessening health disparities in those groups. These examples evidence the clear need for application of a cultural lens when examining norms.

Need for a Cultural Model

It is particularly important to acknowledge that individuals from different cultural backgrounds possess differing cultural norms that will influence their normative behaviors (Airhihenbuwa, 2007). In the case of Black women, some of the unique and

important cultural factors relating to this group and their participation in clinical trials are previously explained in Chapter 1.

So far, this chapter has reviewed the role of social norms and the importance of gaining a deep cultural understanding of a group to determine the types of norms that are relevant to them. Therefore, for this research project, the PEN-3 model is applied as a supplemental, guiding framework, to help enhance the attention to Black women's cultural identities, cultural empowerment, and the extended families, neighborhoods, and communities that influence them (Airhihenbuwa, 1995, 1999).

The PEN-3 Model

The recent and ongoing COVID-19 pandemic has affected, among other things, the way the United States looks at the individuals' health through the lenses of race, ethnicity, and the accompanying cultures (Turner-Musa et al., 2020). As a result, many Americans are currently in the midst of working harder to comprehend the impact of culture on health. The PEN-3 model was developed specifically to help examine and understand culture's influence on health (Airhihenbuwa, 1989) and places culture in the center of health development, beliefs, and behaviors.

The model posits that individual insights and actions concerning health are shaped and clarified through culture in a cyclical manner; those insights and actions inform the composition of a population's health beliefs, which in turn re-inform their cultural beliefs (Airhihenbuwa, 1995, 2007). Interestingly, this is exactly what our communication theories should do. The theory informs the research, which in turn, must re-inform and improve the theory itself. According to Ogden (2003), this cycle is not happening like it should.

Airhihenbuwa (1995) describes the PEN-3 as a tool for placing culture at the core of a community's health around which health problems and solutions can be arranged and defined. Furthermore, the solutions are structured to compensate positive, more sustainable values rather than negative ones (Airhihenbuwa, 2007). Guidance from the PEN-3 model will facilitate the ability to more fully consider the importance of acknowledging that the norms of Black or African American people will likely reflect those of their cultural identity.

Three Domains

The PEN-3 comprises three principal domains (Airhihenbuwa, 1995, 1999), each of which contains three components forming the PEN acronym (Iwelunmor et al., 2014). All three domains focus on characteristics of the health behavior.

Cultural Identity Domain. The *cultural identity* domain, which addresses the multiple identities that are the reality of people of African descent, contains person, extended family, and neighborhood as its components (Airhihenbuwa, 1995, 1999; Airhihenbuwa & Webster, 2004). According to Iwelunmor et al. (2014), this domain focuses on the health intervention point of entry; in other words, where the intervention initiates or begins. "PEN" acknowledges that point of entry could happen at the "person" level (e.g., close family or healthcare providers), "extended family" members (e.g., cousins, grandmothers. etc.), or "neighborhoods" (e.g., communities, social groups, etc.).

Relationship and Expectations Domain. The *relationship and expectations domain* includes perception, enablers, and nurturers as its three categories. This domain frames and examines attitudes and/or perceptions about health issues, the social and fundamental resources (e.g., health care services) that may positively or adversely affect

an individual's health seeking customs, and the effects of close family and other relatives' impact on decisions concerning effective management of health issues.

Cultural Empowerment Domain. Finally, the three categories in the domain of *cultural empowerment* are positive, existential, and negative. Health problems are first explored in this domain by recognizing and investigating which beliefs and practices are positive and which have no harmful health consequences, and only then identifying negative health applications (Iwelunmor et al., 2014). Through this method, emphasis is first placed on identifying and encouraging the cultural beliefs and norms that are beneficial health issue solutions and acknowledging those that are benign, prior to attacking and dealing with harmful health practices that will likely cause negative health repercussions. Direction from these three domains within the application of the PEN-3 have successfully guided several studies, including some examining cultures surrounding communities other than those of African descent.

PEN-3 in Health Literature

The PEN-3 Model is a cultural framework, and a strong, deep body of evidence exists supporting the idea that cultural factors influence group health. This makes the model an important tool, particularly when applied to health literature.

Melancon et al. (2009) applied the PEN-3 to assess the Type 2 Diabetes Mellitus (T2DM) disease knowledge of Mexican Americans who had developed T2DM. Additionally, the authors explored the attitudes and self-efficacy about the management of the disease and identified contributing factors to the promotion or prevention of developing and managing diabetes. This was a mixed methods study that required participants to complete a survey and attend one of several focus groups. In consideration

of the audience, the questionnaires were offered in both English and Spanish. Because this study examined knowledge, attitudes, and self-efficacy, and also explored the participants' beliefs and behaviors about the disease the methodology and results of this study could be salient to the current study.

Melancon et al. (2009) applied the PEN-3 domain constructs to their focus group analysis, and found lack of knowledge of the disease, fear, fatalistic views, strong family support, and increased family concern about the participant. They also found perceptions of stigmas and barriers to receiving care, primarily linked to lack of knowledge and understanding of English. The participants expressed strong desires to live, support from their churches, and a general perception that physicians in America do not address participants' needs (Melancon et al., 2009). The PEN-3 model was found to be a helpful framework for this study, particularly for focus group analysis.

Similar to the currently proposed dissertation study which is using a multi-theoretical approach, Scarinci et al. (2012) used a multi-theoretical approach by combining the PEN-3 with a second, widely-used framework, the Health Belief Model. The authors described their plans to combine methods from a previously successful program (Navarro et al., 1998) with cognitive-behavioral strategies in order to create a proposed intervention to promote cervical cancer prevention in underserved populations.

With the understanding that Latinos tend to rely deeply on their close and extended families, and that their communities often perform like families, this study identified specific significant family-oriented principles of Latino culture that are possibly salient to cervical cancer prevention (Scarinci et al., 2012). For example, members of this cultural group tend to trust individuals over organizations, feel more

comfortable when they receive personal, individualized consideration, and possess great levels of fatalism (Moreira et al., 2018). This study demonstrated that the PEN-3 provided theoretical guidance for a sociological approach to the development and application of their intervention.

Germane to the current study, the PEN-3 has often been used in work with African, Black, and African American populations. In their review of the PEN-3 model and its application in public health research and interventions, Iwelunmor et al. (2014) identified three main themes in their analysis of studies using the PEN-3 to analyze cultural effects on health behaviors. The first main theme was the importance of context. In support of this theme, and to strengthen our understanding of the precise ways that cultural context shapes health behaviors, Abernethy et al., (2005) highlighted the significance of understanding how, particularly in Black communities, traditional opinions of masculinity influence men's perceptions of their health.

The second theme, the role of family as an intervention point of entry, is demonstrated in a study about the role of Black women in a family's health. Black women typically are responsible for the family's health, are in charge of food preparation, and set standards for both healthy and unhealthy eating, which were reported to be crucial agents of cultural alteration (James, 2004).

Finally, the third identified main theme is the need to explore the positive aspects of culture on health behaviors. Embracing the PEN-3 tenet that community health research and interventions should first prioritize focusing on promoting positive values over changing negative ones, (Ochs-Balcom et al., 2011) applied the model to identify positive and negative themes pertinent to creating community partnership and increasing

successful recruitment of Black women in a breast cancer epidemiology study. The identified positive themes were the need for additional breast cancer information and the potential benefits of participation to younger generations (Ochs-Balcom et al., 2011).

Negative themes included lack of knowledge about research participation and breast cancer research in general, both of which are repeatedly revealed in other research about Black women and cancer research. Focusing on the benefits, a method the current study will apply when creating the targeted messaging, Ochs-Balcom et al. (2011) reinforced positive themes and reviewed negative ones.

In summary, the wide range of examples provided here supports the suggestion that the addition of the PEN-3 model to the norms-focused project improves its attention to culture and therefore its usefulness in guiding the current study. Inherent in this idea is that this dissertation, or any work looking at culturally informed norms, will be focused on a particular group in order to develop messages that are, by definition, targeted to that group. The employment of the PEN-3 model overlaying normative theoretical frameworks facilitates the targeting of the messages tested in this dissertation.

For example, relevant to the current study, Black women tend to understand the prevalence of breast cancer in their population. When questioned later, Black women who had already participated in the KTB said it was very important to them to know that they were being sought out because they were Black, and that they could help others who looked like them by participating (Ridley-Merriweather & Head, 2017). Including this kind of information in the messaging being tested in this study is salient to effective targeting of this group.

As another example, recent literature explains that researchers should not default to assuming that minoritized population members are too distrustful of or biased against medical research to consider participating in clinical trials. However, remembering the tenets of the PEN-3 model helps us understand that when these group members are respectfully informed and offered the opportunity to take part, not only will they often be open to the idea, but in doing so, they can affect the future cultural outlook on performing the behavior.

Finally, each of the message conditions contained language designed to bring the participants' close family and other relatives to mind, which is particularly important to Black women. Women reading these messages are called upon to reflect about their relationships with and influences of the people nearest and dearest to them. Also, as occurred in Ridley-Merriweather and Head (2017), these participants—strongly influenced by the desire to ignite cultural factors described in the PEN-3 relationship and expectations domain—could themselves become the influencers in their close social and family circles and choose to encourage open-mindedness and information-seeking desires in others. All together, these examples illustrate the utility of the PEN-3 model in targeting the messaging to be tested.

Targeted Health Messaging

Targeted health communication is adapted for a specific population based on shared characteristics (Noar et al., 2011), such as identity, culture, or lifestyle factors. Message targeting comprises characterizing a population subgroup based on common features and providing information in a manner that embodies those characteristics (Schmid et al., 2008). This method assumes that if group members possess enough

similar characteristics and inspirations, they will be influenced by the same message. Knowledge of the subgroup's features is obtained through the process of audience segmentation, rigorous formative research, and gives permission to message creators to allocate campaign resources economically and strategically by targeting their germane audience (Schmid et al., 2008).

Although tailored messaging (fitting a message to meet individual, personal needs and characteristics) is theoretically more effective than targeted messages, some research advocates that well-fitting targeted communication can be as effective as tailored messages (Kreuter et al., 2000). To effect behavioral change, health messages must accomplish a certain level of personal relevance. Although message tailoring is considered best for complex behaviors, many health communication scholars posit that message targeting is best when the behavior is relatively simple, such as performing a one-time behavior, and/or if resources are not available to do individual assessment (Schmid et al., 2008). Both of these situations (performing a one-time behavior and resources limited to individual assessment) apply here, making targeted messaging the best choice for the current study.

The Current Study

Many researchers have recently become driven to learn more about breast cancer subtypes such as triple negative, which as explained earlier, disparately affects Black women and at least partly accounts for their significantly elevated breast cancer mortality rate over white women. It is a particular feature of the current project that improved recruitment of minority participants is approached through targeting their normative

responses to increase motivations to participate that they may already possess, rather than focusing on working to break through their social and cultural barriers.

This study shifts the research paradigm through addressing the need to increase participation of Black women in clinical trials in general as referenced by a wealth of published research (Arriola et al., 2005; Aycinena et al., 2017; Heller et al., 2014; Tanner et al., 2015), and identifying novel approaches for increasing participation of Black women in breast cancer research and clinical trials in particular (Banda et al., 2012; Bolen et al., 2006; Robinson et al., 2017). The current message-testing experiment will employ the theoretical tenets of social normative influences, assisted by the PEN-3 model as a sensitizing cultural lens, to develop and test culturally targeted normative messages to increase intentions of Black women to participate in a preventive breast cancer clinical trial.

To clarify, this pilot message testing project is not intended to further contribute to the already abundant repository of research concerning the cultural and social barriers minority group members must confront when considering taking part in medical research. Rather, driven by strong formative research, it seeks to test messages targeted to Black women, with the overall goal of increasing intention to participate.

Based on the literature review and the formative research presented here, the current study proposed to test the effectiveness of culturally targeted normative messaging on Black women's intentions to donate their healthy breast tissue. An informational control recruitment message was composed for the current study. The control comprised only brief general information about the breast cancer clinical trial and a general statement about why women should donate. Culturally targeted messages were

designed and inserted into the control message to manipulate each of the normative variables (injunctive, descriptive, and legacy). In consideration of the expected effects of these conditions on Black women's intention to participate in the clinical trial, the following hypotheses are submitted:

H1: Black women who view culturally informed injunctive normative messages about the KTB will report higher intentions to donate healthy breast tissue than Black women who view the control message.

H2: Black women who view culturally informed descriptive normative messages about the KTB will report higher intentions to donate healthy breast tissue than Black women who view the control message.

H3: Black women who view culturally informed legacy normative messages about the KTB will report higher intentions to donate healthy breast tissue than Black women who view the control message.

A search of the literature yields some support for combining the different types of normative messages. For example, to promote household energy conservation, Schultz et al. (2007) combined injunctive and descriptive normative messages to successfully eliminate a previously discovered boomerang effect. In addition, Habib et al. (2021) recently combined low descriptive norms with high injunctive norms, therefore highlighting and emphasizing the divergence between what people think they should do and what they actually do. This synonymous use of both types of recognized social norms resulted in higher numbers of organ donor registrations in the field than employing either of the social norms separately; therefore:

H4: Black women who view culturally informed messages about the KTB which include all three normative approaches (i.e., injunctive, descriptive, and legacy) will report higher intentions to donate healthy breast tissue than Black women who view the control or any of the other normative messages.

The norms of any particular group are defined by the group itself (Cialdini et al., 1991). We know that injunctive and descriptive norms are different from each other (Montano et al., 2008), so it makes sense that their impact on behavioral intention would also differ. However, which normative influences are more powerful in motivating intention and behavior? In their meta-analysis of conservation behavior, Niemiec et al. (2020) found that descriptive norms are stronger; however, Zou and Savani (2019) discovered that injunctive norms appear to have more power when individuals are making risk recommendations to others.

So, the answer varies and is likely situational. The formative research suggests that when focusing on normative health behavior messaging within the Black community, descriptive norms are more likely than injunctive to have higher impact on intention due to the clearly evident, high levels of altruism held by these group members. The legacy norm, however, was generated from formative work (Ridley-Merriweather & Head, 2017), and therefore not yet measured or tested. Therefore, in addition to measuring the impact on intentions of each normative message, perceived injunctive, descriptive, and legacy norms were measured in a post-test, and the following research question was asked:

RQ: Which of the culturally targeted normative messages has the strongest effect on intention to perform the behavior?

In sum, this study was proposed as an experiment to test the impact of three different normative messages (both individually and combined) on Black women's behavioral intention to participate in the KTB clinical trial. The next chapter outlines the methods used for the experiment.

CHAPTER THREE

Methods

The current study represents the next (and first quantitative) step in a larger, mixed-methods design research project comprising formative qualitative research followed by a series of quantitative message testing studies. I engaged Black women as participants in an online, posttest only, control-group design message testing study using random assignment to condition. As described in the previous chapter, I have previously conducted rigorous qualitative formative work which served as the foundation for the control and comparative message conditions I composed and adapted for use in this experiment. In this chapter, I will describe the inclusion and exclusion criteria for participants, recruitment methods, online survey and message testing procedures, measures, and analytic process.

Participants and Recruitment

A Qualtrics research panel of U.S. adults (www.qualtrics.com) was recruited to participate in the survey. Qualtrics, a cloud-based platform for creating and distributing web-based surveys, facilitates participant recruitment and online data collection. In total, 635 participants from 38 different states and Washington D.C. were recruited. A power analysis for having determined this sample size is described below.

Eligible participants were at least 18 years of age, assigned female at birth, lived in the United States, and self-identified as Black, African American, Afro-Caribbean, African, or of African descent. Although it is regular practice for Qualtrics to offer an incentive to each eligible participant who fully completes a study, the amount given is usually only \$2.50 to \$4.50 for a completed survey. In their study examining the

recruitment and retention of populations with high attrition rates into clinical trials, Barnett et al., (2012) found that, although it was not a main reason for participation, an incentive of a \$20 gift card was helpful and was seen as a nice gesture by most participants. Nicholson et al., (2015) reviewed recruitment and retention strategies in clinical studies of low-income and minority populations from 2004 – 2014, and discovered that although incentives did not have much of an effect on recruitment, they were reliably associated with an increase in overall retention rates.

In line with the findings of Barnett et al., (2012) and Nicholson et al., (2015), I believed that—particularly as my research is focused on helping to reduce health disparities—it would have been unethical of me to offer such a small amount of compensation to the Black women I was recruiting. Therefore, working with Qualtrics, I provided an increase of \$7.00 to the amount each participant received, the most I could budget from my grant funds and still have enough remaining to cover the rest of my expenses. This increased incentive amount, and the study protocol, were approved (protocol #14478) by the IRB at Indiana University-Purdue University Indianapolis in Indianapolis, IN.

Procedures

Participants recruited through Qualtrics who agreed to take part in the study were directed to the study link on the survey platform, where they first answered eligibility demographic questions. Women younger than 18, those who were not assigned female at birth, and/or those who had previously developed breast cancer, were excluded from the study. Any potential participants deemed ineligible were then diverted to a screen thanking them for their time and desire to help.

The survey can be found in Appendix B. Eligible participants continued on, sharing important contextual information through responses to six additional questions: familiarity with the KTB, trust of medical researchers, two questions determining whether the women had a personal connection to breast cancer, and two questions assessing their general awareness of Black women and breast cancer. Next, participants were randomized into one of five message conditions and continued with the survey and the post-test (control $n = 135$, injunctive $n = 121$, descriptive $n = 120$, legacy $n = 128$, combo $n = 131$).

At the end of the survey, participants were asked to provide responses to five additional demographic questions seeking information about participants' level of education, employment status and occupation, zip code, marital status, and income range. Responses to these questions reflected the complexity of participants' identities (J. L. Hughes et al., 2016). Survey items and message manipulations are described in the next sections. No significant differences were found by message condition on previous knowledge of the KTB or demographics (i.e., age, income, education level, or employment status); thus, randomization was successful.

Measures

The study survey codebook can be found in Appendix C. Survey items relevant to the hypotheses and research question are presented here in this section. These items include demographics, awareness of the connection between Black women and breast cancer, and trust of medical researchers. Additionally, I measured three perceived normative variables (injunctive norms, descriptive norms, legacy norms), and the dependent outcome variable, intention to participate in the KTB clinical trial.

Awareness

A four item scale adapted from Moodley et al (2019) was used to measure participants' awareness of Black women and breast cancer along with their feelings of connection to breast cancer ("I personally know someone currently living who has/had breast cancer," "I personally knew someone who died of breast cancer," "Black, African, African American, Haitian, or Afro-Caribbean women do not often develop breast cancer," "Black, African, African American, Haitian, or Afro-Caribbean women have a similar risk of death from breast cancer as white women"). Participants responded to each item on a 3-point Likert-type scale wherein 1 = true, 2 = false, and 3 = I don't know. The four items were summed and averaged to calculate a single awareness score wherein a lower score was associated with higher awareness.

Trust of Medical Researchers

A one item scale adapted from Mainous et al. (2006) was used to measure participants' trust of medical researchers ("Participants should be concerned about being deceived or misled by medical researchers"). Participants responded to this item on a 5-point Likert-type scale where 1 = strongly disagree to 5 = strongly agree. The item was reverse coded; a lower score was associated with higher trust.

Intention

A one item measure adapted from Head et al. (2022) was used to measure intention ("If I had received this letter, it is likely that in the next six (6) months I would accept an opportunity to donate my healthy breast tissue for research"). Participants responded to this item on a 5-point Likert-type scale where 1 = strongly disagree to 5 = strongly agree.

Injunctive Norms

A four-item scale including items adapted from Ajzen (2006), Kim et al. (2015), Park and Smith (2007), and Sieverding et al. (2010) was used to measure participants' injunctive norms. Two of the items, as described by Ajzen (2006), addressed injunctive norms' subjective quality ("Most people who are important to me would think that I should donate healthy breast tissue to be used in breast cancer research;" "Most people in my life whose opinions I value would think I should donate healthy breast tissue to be used in breast cancer research").

Research shows that Black people's health decisions are often influenced by their closest loved ones and their healthcare providers and even by their fellow church members (McNeill et al., 2018). Additionally, according to Park and Smith (2007), individuals' awareness of their reference group's expectation regarding participation in a behavior is assessed by direct measures of injunctive norms. Therefore, the other two items reflected these ideas ("Most people in my family would think I should donate healthy breast tissue to be used in breast cancer research;" "Most of my circle of friends would think I should donate healthy breast tissue to be used in breast cancer research"). Participants responded to each injunctive norm item on a 5-point Likert-type scale where 1 = strongly disagree to 5 = strongly agree. The six items were summed and averaged to calculate a single injunctive norms score.

Descriptive Norms

A six item scale including items adapted from Ajzen (2006), Goldstein et al. (2008), and Kim et al. (2015) was used to measure participants' descriptive norms. Ajzen (2006) guided the first set of three descriptive items ("Most people who are important to

me would donate healthy breast tissue to be used in breast cancer research;” “Many people like me would donate healthy breast tissue to be used in breast cancer research;” “The people in my life whose opinions I value would donate healthy breast tissue to be used in breast cancer research”). Participants responded to each item on a 5-point Likert-type scale where 1 = definitely inaccurate to 5 = definitely accurate. These first three descriptive items were summed and averaged to calculate the first descriptive norm score.

In their examination of the effects of descriptive norms on hotel towel conservation, Goldstein et al. (2008) found greater impact on normative adherence when individuals better identified with the reference groups. Therefore, a second three item scale adapted from Goldstein et al. (2008) was used to measure descriptive norms (“In your best estimate, what percentage of the women who are important to you do you think would donate healthy breast tissue if given the opportunity;” “In your best estimate, what percentage of the women in your personal life whom you admire do you think would donate healthy breast tissue if given the opportunity;” “In your best estimate, what percentage of your total circle of friends do you think would donate healthy breast tissue if given the opportunity?”)

For this second set of descriptive norm measurements, I used a draggable slider scale ranging from 0% to 100%. The three descriptive items were summed and averaged to provide a second descriptive score.

Legacy Norms

As a new and as of yet untested construct, the legacy norm has no validated scales or even guidelines for its measurement. Therefore, guided by Ridley-Merriweather and Head (2017), I incorporated measures from each of the legacy norm-related constructs

(i.e., altruism, care for others, self-sacrifice, and awareness of the future) identified earlier in the theoretical framework section. Lalot et al. (2020, 2022) developed and then adapted the Futures Consciousness scale to “precisely measure the nature and degree of how people apprehend the future” (Lalot et al., 2022, p. 1). The scale is based on the proposal by Ahvenharju et al. (2018) of a five-dimensional model of futures consciousness that included time perspective, agency beliefs, openness to alternatives, system perception, and concern for others. Ideas from all four legacy norm constructs were contained within two of the Futures Consciousness scale’s dimensions (time perspective and concern for others) which is described in detail in the next section. In the absence of a validated scale for the legacy norm, I adapted six of the eight items from the revised version of these two dimensions.

Futures Consciousness Time Perspective. The four items comprising Lalot and colleagues’ (2022) time perspective domain accentuate the significance of ongoing thinking and a forward gaze. Awareness of a potential tomorrow and comprehending the idea of passing time are the basic needs for being cognizant about the future (Ahvenharju et al., 2021). The first item, “I think about the consequences before I do something,” was adapted for the current study to “I would think about the consequences of donating breast tissue before I did it.” This statement addresses the legacy norm constructs of self-sacrifice and awareness of the future. The item is relatable to recent research revealing that in general, Black Americans possess a largely positive outlook on the competence and ability of medical researchers, but they do have concerns about the potential for misconduct (Nadeem, 2022). The second item, “I think about how things might be in the future,” was adapted to “I think about how breast cancer might be in the future.” This

statement addresses the legacy norm constructs of awareness of the future, particularly the future of breast cancer as a disease, and how it might affect them and others like them. Black women surveyed about their reasoning for donating their healthy breast tissue overwhelmingly agreed that they were aware of the risk of breast cancer in Black women, and that their participation was an effort to keep their loved ones safe from the disease in the future.

The third item, “I am willing to sacrifice my immediate happiness or well-being in order to achieve something in the future,” was adapted to “I am willing to sacrifice my immediate happiness or well-being by donating breast tissue in order to help others in the future.” This statement addresses the legacy norm constructs of self-sacrifice, awareness of the future, and altruism. This item helped to place a kind of measurement on the current study participants’ willingness to sacrifice present benefits for the possibility of increased future health of others. The fourth and final item, “I consider how things might be in the future and try to influence those things with my day to day behavior,” was adapted to “I consider what breast cancer might be like in the future, and would try to influence that by donating my healthy breast tissue.” This statement addresses the legacy norm constructs of how the actions chosen now can/will affect happenings in the future.

Futures Consciousness Concern for Others. Two items of the original four comprising Lalot and colleagues’ (2022) concern for others domain were considered fully appropriate to adapt to use to measure this construct of the legacy norm. Forward-thinking individuals should consider future generations as well as themselves, developing notions of empathy (Decety & Jackson, 2004) and an identification with all of humankind (McFarland et al., 2012), all of which is related to concern for others.

The first item, “I show concern and care for peers,” was adapted to “I can show concern and care for peers by donating healthy breast tissue.” This statement addresses the legacy norm constructs of altruism and concern for others. When asked about their motivations for potential future healthy breast tissue donation, Black women attending community events and focus groups have expressed a desire to honor their friends and family members with the disease. The second item, “When they are in need, I want to help people all over the world,” was adapted to “When they are in need, I want to help people all over the world by donating my healthy breast tissue.” This statement addresses the legacy norm constructs of altruism, self-sacrifice, and awareness of the future. Before being allowed to donate their tissue to the KTB, Black women are made fully aware of the protocols of the study. They know and understand that their samples could be requested and used by scientists around the world to be used as normal controls in their individual research projects.

Participants responded to each item on a 5-point Likert-type scale where 1 = not true of me at all to 5 = very true of me. The six items were summed and averaged to calculate a single legacy norms score. It is important to note that these legacy norm measures were untested, and it was imperative that I assess the reliability of these measures before including them in any analyses. I also spent time examining the pre-test survey and cognitive pretest feedback on these legacy norm items.

Message Manipulations

Based primarily on the collective conclusions from my own formative research and informed by previous research on message design and norms (Richards et al., 2021; Ryoo & Kim, 2021), I developed five message conditions encouraging the participants to

take part in the KTB clinical trial by donating their healthy breast tissue. See Appendix D for the control letter and all message manipulations.

The messages were made to look like letters or emails sent to participants. Condition 1, the control message, was written as a general recruitment letter for any audience and was based on much of the written text and spoken descriptions already in use to recruit women to participate in the KTB. I designed the control letter for the express purposes of this experiment, and although the content is indicative of language that has been used previously, it has never been actually used to recruit participants. It is important to note that the control message is *completely devoid* of cultural aspects. To create Conditions 2, 3, 4, and 5, I inserted the corresponding culturally informed experimental message manipulations into the control letter.

Condition 2 included four added, bulleted information points focused on injunctive norms informed by cultural aspects relevant to Black women in the breast cancer context. Condition 3 included four added, bulleted information points focused on descriptive norms influenced by cultural aspects relevant to Black women in the breast cancer context. Condition 4 four added bulleted information points focused on legacy norms influenced by cultural aspects relevant to Black women in the breast cancer context. The design of each manipulation message for Conditions 2, 3, and 4 was based on my formative research and enhanced through an application of the PEN-3 model. Guided primarily by the cultural themes found and described in a systematic review of the PEN-3 cultural model, which also focused on its application in public health research and interventions framed by the model (Iwelunmor et al., 2014), I structured the messages to reflect normative theoretical constructs overlaid by those of the PEN-3.

It was here, in the development of Conditions 2, 3, and 4, where application of the PEN-3 lens (which facilitated my ability to target the messages) proved both necessary and valuable. Before creating these three message conditions, I thoughtfully considered my formative research as well as what other researchers have opined about what factors regarding clinical trial participation are important to Black people, and these factors informed how I operationalized the normative message conditions. Of the three PEN-3 domains, I find that those concerned with cultural identity and cultural empowerment align most with the goals of the current study. The Cultural Identity Domain focuses on where the health intervention begins, and the Cultural Empowerment Domain emphasizes first identifying beneficial and benign cultural health beliefs and then dealing with health practices that are harmful.

For injunctive norm-focused Condition 2, the PEN-3 is applied in the inserted manipulation to point out the cultural importance of family as respected role models and communities as safe spaces. Next, the PEN-3 is used as a lens for the descriptive norm-focused Condition 3 to create messages that statistically inform about the differences in the effects of breast cancer on the lives of Black women as opposed to white, as well as the cultural importance of participating in breast cancer research. For legacy norm-focused Condition 3, the PEN-3 model helps amplify not only the rich cultural history and tradition that Black women leave for each other and their future generations, but also the possibility of added health knowledge and protection.

Condition 5 included three added, combined, bulleted information points: one injunctive-focused point chosen from Condition 2, one descriptive-focused point chosen from Condition 3, and one legacy-focused point chosen from Condition 4. I designed

Condition 5 to try to determine whether combining these manipulations together might make an even stronger impression and encourage greater behavioral change than any of the other conditions taken singly. The process of selecting these three points is explained more fully in the next section (“Cognitive Pre-testing”).

Finally, I focused on designing all message conditions to be as similar as possible by ensuring that the word count and Fry Readability Grade Level (Fry, 1968) were comparable for all three individual normative messages inserted into Conditions 2, 3, 4, and 5. Table 1 helps comprehensively explain the normative messages development discussed in this section.

Cognitive Pre-testing

After completing the design of my survey, I conducted cognitive pretesting with five participants from the target population, each of whom received a \$10 gift card as a thank you gift, to collect feedback concerning survey flow, survey design, messages, and responses. Cognitive testing helps to identify problems in survey questionnaires, therefore helping to limit associated errors in responses that may otherwise be difficult to illuminate (Willis, 2018). I met one-on-one with each of the five pretesting participants, all of whom fulfilled the eligibility requirements of the study. During the meeting I encouraged the participant to “think aloud,” a technique suggested by Lenzner et al, (2016) which I enhanced by having the respondent begin taking the survey by reading all instructions and questions out loud. This method seemed to facilitate saying out loud whatever the participant was thinking, and thereby heightened the richness of the feedback.

Cognitive pretesting yielded several valuable observations (see Appendix E). For example, typographical/structural errors, missing occupational categories, and lack of clarity in wording were all noted by the pre-testers. Each pre-tester was also instructed to voice an opinion about which of the injunctive, descriptive, and legacy normative bullet point they liked, and thought were most effective, thereby assisting in the development of the Condition 5 letter. Following each pretest, I applied the resulting information to make changes to the survey (Grimm, 2010; Tilley et al., 2014).

Once the cognitive pretesting was completed and the appropriate adjustments had been made, I performed a preliminary (soft) launch of the survey. After about 10% (N=60) of the responses had been collected, I paused the survey to review the results and check that all procedures were working properly. Several of the response times seemed to have been too fast to enable thoughtful consideration of survey question content. A speeding check of 3.5 minutes—measured as just over one-half the six-minute average time of the surveys completed during the soft launch—was added to the survey. This meant that anyone completing the survey in less than 3.5 minutes would be considered to have not responded thoughtfully, and their response would be rejected.

In addition to the speeding check, to facilitate better comprehension of the randomized letter, I asked Qualtrics to place a 1 3/4-minute timing hold on the randomized letter screen. A message reading, “So that you can take your time reading the letter closely, the ‘next page’ button will not be enabled right away.” alerted the participant of the delay, and the “Next Page” button did not appear until after the participant had spent at least 105 seconds reading the randomized letter. Following the installment of all these cautions and processes, I launched the full survey.

Table 1
Normative Messages

Type of Norm	Definition / Operationalization	PEN-3 Filter Application examples Iwelunmor et al., (2014)	Example from Literature	Message in Current Study	Word Count/ Reading Level
Injunctive	Group members' perceptions about the significance of others' beliefs and their enthusiasm for complying with those beliefs	<p>Cultural context: Black men get tested for hypertension in barber shops when they see others do it.</p> <p>Role of family: Black women who fear clinical trial participation decide to participate because family members have done so.</p> <p>Explore positive aspects of culture: Messages are shaped and clarified through use of program content that applies cultural norms for a cancer control intervention.</p>	Examined the effects of statistical and narrative messaging on decreasing intent to use tanning beds. (Greene & Brinn, 2003)	Black women decide to participate in breast cancer research because their friends and families have participated. Black women decide to participate in breast cancer research because community leaders or other people whose opinions they value have participated. Black women who donate healthy breast tissue are doing what their friends and family would want them to do. When Black women donate their healthy breast tissue they are admired by others.	69 / 6th grade
Descriptive	Individuals' perceptions of how other people are actually behaving, without regard to whether or not the behavior has the group's approval	<p>Cultural context: Bangladeshis accepted the concept of diabetes prevention despite commonly reporting a strong desire to comply with cultural norms.</p> <p>Role of family: Younger generations of Black and Brown families can be more open-minded about medical research participation than their elders.</p> <p>Explore positive aspects of culture: Accessing and developing indigenous leadership and cultural resources to influence both individual behavior and the prevailing community norms.</p>	College students' own exposure to health promotion media, which helps shape their general perception of media influence on others, is positively related to their general perception of media influence on others. (Hong & Kim, 2019)	Black women are 40% more likely than White women to die from breast cancer. Black women are 20% more likely to develop some of the most aggressive, hard-to-treat forms of breast cancer. Researchers need more Black women to donate their tissue so they can study it and learn why these things are true. Fewer than four out of every 1000 women who participate in a breast cancer clinical trial are Black.	71 / 6th grade
Legacy	The propensity for some group members (e.g., Black women as in the source citation) to be willing to sacrifice for the betterment of their children, their children's children, and other group members in the future	<p>Cultural context: Encouraging individuals whose cultural norms support and promote altruism to consider those norms in health contexts.</p> <p>Role of family: Black women develop a legacy norm that helps to motivate them to donate breast tissue for the good of their family, loved ones, and others like them.</p> <p>Explore positive aspects of culture: Promoting healthy behaviors (i.e., good dietary habits, regular screening and testing, etc.) through highlighting positive cultural aspects to help improve groups' health outcomes.</p>	Black women's decisions to participate in a preventive breast cancer study were strongly and primarily influenced by normative factors, including the legacy norm. (Ridley-Merriweather & Head, 2017)	Black women who donate their healthy breast tissue give hope to the women who come after them. Black women who participate in breast cancer research help find new treatments specifically designed to treat their daughters and granddaughters who might develop breast cancer. Black women who donate their breast tissue help create better medicines and protect other Black women from developing breast cancer in the future. If Black women do not participate in breast cancer research, they, their family members, or other people who look like them, won't be able to benefit.	91 / 6th grade

Statistical Methods and Planned Analysis

I contracted with Qualtrics to recruit eligible participants and facilitate distribution of the survey link. The suggested sample size was based on analysis through

G*power software, which offers the capability to calculate power for an extensive range of statistical tests and is widely employed in social and behavioral research (Faul et al., 2007). I planned to run a one-way ANOVA, which is frequently used by social science researchers, to analyze the post-test only message testing experiment. Using G*Power v3.1.9.7, F-test family, a priori analysis, 2.85 odds ratio (effect size), 0.05 significance level α , and 0.95 power, I calculated a total desired minimum sample size of 305 using a medium (0.25) effect size, for five conditions.

Given the available budget I had due to the grant for this project, the exploratory nature of this experiment, and the testing of different types of normative messages (including the new legacy norms messaging), I decided to double the sample size to reduce sampling error and increase the power of the study. This decision was supported by my committee. I eventually reached 635 participants before closing the survey. An explanation of funding can be found in Appendix A.

After the experiment was completed, and the survey had been closed, I engaged the services of a biostatistician to help run all the analyses and consequently discovered that, primarily to address H4 and the RQ, I should use logistical regression rather than ANOVA.³ Logistic regression can be applied to estimate the probability that an occurrence will result through using components or information considered to be related

³ The Indiana University Biostatistics community uses R package of pwr to determine power. The power calculation for logistic regression would have been based on R package of pwr, with 5% type I error, 80% power, effect size (odds ratio) of 2.85, resulting in a minimum sample size of 118 for using logistic regression. Using a higher power, based on R package of pwr, with 5% type I error, 95% power, effect size (odds ratio) of 2.85, resulting in a minimum sample size of 192 for using logistic regression. Based on R package of pwr, with the **actual study** sample size of 635, 5% type I error, 80% power, the required odds ratio is 1.56 by using logistic regression.

to, or to influence, such occurrences (Tolles & Meurer, 2016). Important for the current study, logistic regression can demonstrate which of the evaluated discrete factors has the strongest association with an outcome and provides an assessment of the potential influence. Additionally, logistic regression can “adjust” for confounding factors associated with other predictor variables as well as the outcome, “so the measure of the influence of the predictor of interest is not distorted by the effect of the confounder” (Tolles & Meurer, 2016, p. 533).

The biostatistician explained that logistic regression quantitatively connects one or more predictors (in this case, the different normative messages) considered to influence a particular outcome to the odds of that outcome. For this reason, in order to calculate a needed sample size for logistic regression analysis, I would need to decide/determine what odds ratio I sought. The odds ratio is “a measure of how strongly an event is associated with exposure. The odds ratio is a ratio of two sets of odds: the odds of the event occurring in an exposed group versus the odds of the event occurring in a non-exposed group” (Tenny & Hoffman, 2023, para. 1). The biostatistician suggested 2.85 as a standard and ran the calculation, resulting in a minimum sample size of 192 for using logistic regression. With a sample size of 635, the current study tested 3.3 times the suggested minimum sample size for logistic regression analysis.

Hypotheses Testing

The effects of the different normative influence message conditions (injunctive, descriptive, legacy, combination) on the intention outcome in comparison to the control were tested using univariate (referring to a single dependent variable) logistic regression. Because univariate regression tested each individual pair within the entire set of five

conditions, the resulting data allowed me to test all of my four hypotheses and also informed the response to my research question. Analyses were performed by a biostatistician using SAS Statistical Software. The effects of the normative recruitment messages (injunctive vs. descriptive vs. legacy) on these outcomes was evaluated and compared. Additional analysis of effects on outcome (intention) was performed controlling for variables such as age and whether participants personally knew someone who had developed or died from breast cancer. The results from this study are reported in the next chapter.

CHAPTER FOUR

Results

Participants and Descriptives

The participants for this study were 635 women who self-identified as Black ($n = 392$), African American ($n = 220$), African ($n = 12$), Afro-Caribbean ($n = 10$), or Other of African Descent ($n = 1$). Eligible participants lived in the United States and were at least 18 years of age (see Table 2 for these and other demographics).

The main outcome of Intention to donate breast tissue was on average relatively high across all conditions ($M = 3.35$, $SD = 1.19$) on the 5-point intention measure. The Control Message Condition ($M = 3.24$, $SD = 1.25$), Injunctive Message Condition ($M = 3.17$, $SD = 1.10$), Descriptive Message Condition ($M = 3.45$, $SD = 1.20$), Legacy Message Condition ($M = 3.45$, $SD = 1.18$), and Combination Message Condition ($M = 3.42$, $SD = 1.20$), were all above 3.0 (see Table 3).

Univariate Logistic Regression

Univariate logistic regression analysis allowed me to examine the association of the normative message conditions one by one, without adjusting for other variables. Through application of univariate regression, I determined the association of each condition with the outcome of the intention. The results of H1, H2, and H3 are all found in Table 4, which reported the parameter estimates (PE), odds ratios (OR), 95% Confidence Intervals (CI) for the ORs, and p -values.

Table 2

Participant Demographics

Total Participants = 635

Characteristic	n =
Self-Identified Race	
Black	392
African American	220
African	12
Afro-Caribbean	10
Other of African descent	1
Age Groups	
18 - 24	65
25 - 34	150
35 - 44	124
45 - 54	106
55 - 64	109
65 - 74	66
75 & over	15
Marital Status	
Married	170
Single	366
Divorced	66
Widowed	28
Prefer not to answer	5
Education	
Some elementary school	2
Some high school	23
High school or GED	168
Some college or associate degree	263
Bachelor's degree	117
Graduate degree(s)	62

Characteristic	n =
Employment Status	
Full time	248
Part time	96
Student	22
Not employed	259
Prefer not to answer	10
Household Income	
Less than \$10,000	85
\$10,000 to \$24,999	108
\$25,000 to \$49,999	185
\$50,000 - \$74,999	118
\$75,000 - \$99,999	60
\$100,000 - \$149,999	35
\$150,000 - \$199,999	15
\$200,000 or more	10
Prefer not to answer	19

The overall univariate logistic regression model predicting higher intention of Black women exposed to Injunctive normative messages to donate breast tissue (Hypothesis 1) was not significant (OR = .874, 95% CI [.563, 1.357], $p > .05$). Therefore, Hypothesis 1 was not supported. The overall univariate logistic regression model predicting higher intention of Black women exposed to Descriptive normative messages to donate breast tissue (Hypothesis 2) was not significant (OR = 1.404, 95% CI [.903, 2.183], $p > .05$). Therefore, Hypothesis 2 was not supported. The overall univariate logistic regression model predicting higher intention of Black women exposed to Legacy normative messages to donate breast tissue (Hypothesis 3) was not significant (OR = 1.398, 95% CI [.905, 2.158], $p > .05$). Therefore, Hypothesis 3 was not supported.

To give more context to the results of H1, H2, and H3, the Descriptive Message Condition regression analysis results (OR = 1.404) demonstrated slightly higher effect on intention than the Legacy Message Condition (OR = 1.398); however, these two

conditions showed similar results in all analyses. Both demonstrated higher (though not significant) odds to have higher intention than the Control Message Condition, which demonstrated slightly higher (though not significant) odds to have higher intention than the Injunctive Message Condition.

Results for H4—which predicted that the Combined Message Condition would lead to higher intention than the Control or any of the individual Norms Conditions—were analyzed two ways. The overall univariate logistic regression model predicting higher intention of Black women exposed to Combination normative messages to donate breast tissue (Hypothesis 4) was not significant (OR = 1.398, 95% CI [.905, 2.158], $p > .05$). As an additional analysis, the Control Message Condition was combined⁴ with the Injunctive Message Condition (Condition 2), the Descriptive Message Condition (Condition 3), and the Legacy Message Condition (Condition 4) into one variable called Message Conditions 1-4. Therefore, for this second analysis, two levels were created: Message Conditions 1-4 and the Combination Message Condition (see Table 5 and Table 6). The Combination Message Condition demonstrated higher (though not significant) odds to have higher intention to donate healthy breast tissue than Message Conditions 1-4. Therefore, Hypothesis 4 was not supported.

⁴ The method used to combine the four variables together is: If MessageCondition=1 or MessageCondition=2 or MessageCondition=3 or MessageCondition=4, then Message = “Conditions 1-4.” Message = “Combination Message Condition” Only if MessageCondition=5. Raw values, not means, were combined.

Table 3

Outcome Means

(Total Number of Participants = 635)

	N	Mean	Std. Deviation	95% Confidence Interval for Mean	
				Lower Bound	Upper Bound
Control Message	135	3.24	1.25	3.02	3.45
Injunctive Message	121	3.17	1.10	2.98	3.37
Descriptive Message	120	3.45	1.20	3.23	3.67
Legacy Message	128	3.45	1.18	3.25	3.66
Combo Message	131	3.42	1.20	3.21	3.63
Total	635	3.35	1.19	3.25	3.44

Table 4

Summary of Univariate Logistic Regression Analysis of Intention

Variable	Parameter Estimate	Odds Ratio	95% CI for Odds Ratio		p-value
Message Condition					0.1304
- Control Message	Reference				
- Injunctive Message	-0.1345	0.874	0.563	1.357	0.5487
- Descriptive Message	0.3392	1.404	0.903	2.183	0.1323
- Legacy Message	0.3348	1.398	0.905	2.158	0.1308
- Combo Message	0.2609	1.298	0.843	1.998	0.2359
Age	-0.0925	0.912	0.836	0.994	0.037
Race					0.1445
- Black	Reference				
- African American	0.2933	1.341	0.996	1.804	0.0529
- Other of African Descent	-0.0277	0.973	0.458	2.066	0.9426
Personally Knew Smon					0.0559
- True	0.2993	1.349	0.966	1.883	0.0786
- False	Reference				
- I don't know	-0.2678	0.765	0.404	1.448	0.4108
Personally Knew Smon 3					0.0241
- True	0.2168	1.242	0.93	1.66	0.1426
- False	Reference				
- I don't know	-0.5361	0.585	0.331	1.034	0.0649

To give more context to the results of H4, the overall Combined Message Condition regression analysis results (OR = 1.298) demonstrated lower (though not significant) odds to have higher intention than both the Descriptive (OR = 1.404) and

Legacy (OR = 1.398) Message Conditions, and higher (though not significant) odds to have higher intention than both the Injunctive (OR = 0.874) and Control Message Conditions.

Table 5

Summary of Univariate Logistic Regression Analysis of Intention (two levels: combo and others)

Variable	Odds Ratio	95% CI for Odds Ratio		p-value
Message Condition				0.4585
Control or Any of the Other				
Normative Message	Reference			
Combo Message	1.139	0.807	1.608	0.4585

The research question sought to know which of the Message Conditions would have higher effects on intention. Overall, the Control (reference) variable was not significantly associated with intention ($p = .1304$). Parameter estimates included in Table 4 help answer the RQ. These parameter estimates displayed the multivariate logistic regression results and summarized information that could be used to determine these findings. The Descriptive Message Condition (PE = .339) was calculated to trend toward having minimally higher effect than the Legacy Message Condition (PE = .335). Both suggested higher effects than the Combination Message Condition (PE = .261) when compared to the Control. The Injunctive Message Condition suggested a lower effect (PE = -.135) on intention when compared to the Control. In summary, the Descriptive Message Condition trended toward higher effects on intention, followed by the Legacy Message Condition and then the Combination Message Condition. The Injunctive Message Condition trended toward a positive but lower effect on intention than any of the other conditions, including the Control. No results were significant.

Table 6

Summary of Multiple Logistic Regression Analysis of Intention (two levels: combo and others)

Variable	Odds Ratio	95% CI for Odds Ratio		p-value
Message Condition				0.4945
- Control or Any of the Other Normative Message	Reference			
- Combo Message	1.129	0.797	1.598	0.4945
Age	0.906	0.829	0.99	0.029
Race				0.0964
- Black	Reference			
- African American	1.371	1.017	1.847	0.0385
- Other of African Descent	0.882	0.411	1.892	0.7463
Personally Knew Smon				0.2126
- True	1.333	0.939	1.892	0.1079
- False	Reference			
- I don't know	0.985	0.481	2.017	0.9675
Personally Knew Smon 3				0.0843
- True	1.211	0.892	1.642	0.2193
- False	Reference			
- I don't know	0.613	0.324	1.162	0.134

Multivariate Logistic Regression

The multivariate logistic regression model was applied to further and more fully answer the RQ, which involves predicting higher intention of Black women exposed to normative messages pertaining to the effect of multiple IVs on one DV. The multivariate regression parameter estimate value for the Descriptive Message Condition (PE = .422) was calculated to trend toward having a more noticeably higher effect than the Legacy Message Condition (PE = .379). As with univariate analysis, both suggested higher effects than the Combination Message Condition (PE = .3178). The Injunctive Message Condition still suggested a positive effect on intention, though less so (PE = -.011) when compared to the Control Condition (see Table 7).

Table 7

Summary of Multivariate Logistic Regression Analysis of Intention

Variable	Parameter Estimate	Odds Ratio	95% CI for Odds Ratio		p-value
Message Condition					0.1534
- Control Message	Reference				
- Injunctive Message	-0.0107	0.989	0.631	1.551	0.9627
- Descriptive Message	0.422	1.525	0.972	2.392	0.0662
- Legacy Message	0.3786	1.46	0.937	2.275	0.0943
- Combo Message	0.3177	1.374	0.887	2.13	0.1552
Age	-0.0872	0.917	0.838	1.002	0.0566
Race					0.0688
- Black	Reference				
- African American	0.3446	1.411	1.044	1.909	0.0253
- Other of African Descent	-0.0905	0.913	0.423	1.972	0.8177
Personally Knew Smon					0.2256
- True	0.2776	1.32	0.929	1.875	0.1211
- False	Reference				
- I don't know	-0.037	0.964	0.47	1.974	0.9195
Personally Knew Smon 3					0.0818
- True	0.2004	1.222	0.9	1.658	0.1984
- False	Reference				
- I don't know	-0.4855	0.615	0.322	1.175	0.141

Supplemental data tables for participants' occupations, connection to breast cancer, awareness of breast cancer, trust of medical researchers, and reliability statistics can be found in Appendix F.

CHAPTER FIVE

Discussion

Although Black and white women experience similar breast cancer incidence rates, Black women demonstrate a critically higher mortality rate than white women, as well as a higher likelihood to develop more aggressive forms of the disease. Social and cultural norms have proven to be important factors affecting Black women's intention to participate in medical research, which can be incredibly useful in discovering important medical advances to treat breast cancer in this population. Research shows that when informed and asked, Black women will participate in breast cancer clinical trials. The purpose of the current study was to test and relatively measure the effects of normative messages on the behavioral intention of Black women to donate their healthy breast tissue for research purposes in advancing breast cancer treatments.

The current study was guided by the concept of norms from several normative theoretical frameworks and overlaid by the PEN-3 cultural model as a lens for ensuring that cultural and community factors enjoyed ground-level consideration in this work. Six hundred thirty-five Black, female participants were recruited through Qualtrics to respond to an online, posttest only, control-group design message testing study using random assignment to condition.

This study largely resulted in null findings. H1 was not supported; however, the mean values showed that the Injunctive Message Condition trended toward higher intention, although lower than the control. H2 was not supported however, the mean values showed that the Descriptive Message Condition trended toward higher intention when compared to the control. H3 was not supported, and the mean values showed that

the Legacy Message Condition trended toward higher intention when compared to the control. H4 was not supported; however, the OR values showed that the Combination Message Condition trended toward higher odds of intending to donate healthy breast tissue than the control and Message Conditions 1-4. In response to the RQ, results from both univariate and multivariate regression testing showed the Descriptive Message Condition trended toward higher effects on intention, followed very closely by the Legacy Message Condition, then the Combination Message Condition, the Control Message Condition, and finally the Injunctive Message Condition. All conditions trended toward higher odds of intending, although no results were significant.

Despite the null findings, the data still reveals relevant ideas about this important topic. The upcoming section will, over several paragraphs, delve into analysis of the results of this work by first looking at many examples in the literature that, when taken all together, help to disprove the long-held and firmly entrenched idea that Black and Brown people do/will not participate in medical research and/or clinical trials. The section after that will discuss some practical implications, followed by the theoretical implications of the study, and next an explanation of the broad study implications. The discussion section concludes with strengths and limitations of the study, and finally future research.

Study Analysis

The significant underrepresentation of Black participants in cancer clinical trials continues despite repeated appeals for higher inclusion (Aldrighetti et al., 2021; Awidi & Al Hadidi, 2021; Loree et al., 2019). In 2020, a task force mandated by the U.S. Congress and convened by National Institutes of Health studied the resulting long-term effects of the lack of underrepresentation of historically excluded populations in medical research.

Their findings revealed, among other things, that resulting research findings lacked generalizability for these populations, and the lack of inclusion preserved existing health disparities and distrust of medical research, researchers, and practitioners (Bibbins-Domingo & Helman, 2022). In other words, despite clear evidence that it is extremely important to prioritize enrolling Black people into medical research and clinical trials, scientists running these trials are, for the most part, not doing enough to create change.

The ubiquitous finding of medical distrust among Black individuals has historically dominated health communication research, particularly focusing on, but not limited to, previous scientific transgressions such as the Tuskegee Syphilis Study (Frazier, 2020), the brutal experiments of J. Marion Sims (Cronin, 2020), and the broadening awareness of the story of Henrietta Lacks (Wolinetz & Collins, 2020). Other widely and repeatedly noted reasons for substandard success of Black participant recruitment into cancer clinical trials include the population's supposedly lower levels of health literacy (Kripalani et al., 2021; Muvuka et al., 2020), education (Rivers et al., 2013), and socioeconomic status (Unger et al., 2013, 2016). This research has been done over and over but the findings of noted distrust, fear of being a "guinea pig," and social disparities such as lack of transportation and/or childcare do not vary. It is past time to start criticizing the perennial publication of repetitive, and singularly focused research on reasons why Black individuals may rightly not want to participate, and instead promote new work that will positively change the narrative.

Some studies have questioned and even challenged the validity of the conclusions in the previous paragraphs. The Black participants in a study by Riggan et al. (2023) felt the association between the research participation of Black individuals and medical

mistrust has been over simplified. They opined that a decision to participate in research studies hangs on more diverse social factors than just race and ethnicity, such as cultural perceptions that cancer trial participation is like a last-ditch long shot or “hail Mary” pass to be used only when all other options have failed. Additionally, Riggan et al. (2023) found their participants pointed to other disparate barriers, such as subpar quality of healthcare, as contributing to low awareness and subsequently low research participation. In effect, these participants are pointing out that although the most cited barriers are indeed solidly in place, their existence does not close the gate on their possible research participation. The next paragraphs highlight other recent studies supporting these findings and demonstrating that, when given the opportunity, Black people are no less likely than other groups to participate in cancer research.

Langford et al. (2014) examined the National Cancer Institute's Community Cancer Centers Program Clinical Trial Screening and Accrual Log, seeking information about racial and ethnic patients' differences in clinical trial enrollment and refusal rates, among several other factors. They employed logistic regression and, after controlling for region, site, age, sex, consent form length, and SMOG readability, found no overall racial or ethnic differences, particularly among Black and white patients, regarding enrollment in clinical trials (Langford et al., 2014). In other words, after controlling for several addressable factors, indications are that when informed and when asked, Black people do participate in clinical trials.

As further evidence, in an enlightening systematic review of 35 U.S. studies involving patient agreement to participate in cancer clinical trials when actually asked to do so, Unger et al. (2021) applied meta-analytical techniques to find that at least half of

the patients who were informed of and offered a clinical trial did participate. These findings, which held true regardless of whether the clinical trial focused on cancer treatment or control, offer significant contradiction to the commonly stated statistic of 3-8% adult patient participation in cancer clinical trials (Murthy et al., 2004; Tejeda et al., 1996; Unger et al., 2019). Additionally, there was no discernable difference among racial groups in the findings; the participation rates of Black, Hispanic, and Asian individuals were all at least as high as those of white patients.

Through examining the effectiveness of using community forums to increase HPV and cervical cancer knowledge, Teteh et al. (2019) discovered a significant post-forum increase in the perceived knowledge of Black people in attendance. The researchers found a positive relationship between perceived knowledge and trust in vaccines, and they credit the usefulness of sharing information through these forums for helping to educate about cancer prevention and trust building (Teteh et al., 2019). The results of their study not only support the effectiveness of community forums, but they also demonstrate the importance—and possible positive effects—of fully informing and enhancing the understanding of Black community members about medical research.

En masse, the recent studies outlined in the previous paragraphs find that Black individuals and other racial and/or ethnic groups, when given the availability of some kind of pipeline to information and a feeling of safety when asked, are no less likely to participate in research as compared to other groups. The results of the current study not only support this existing literature and add nuances of how to perform this work, but also seem to support the idea that informing target populations about what clinical trials are—as well as how, where, and/or whether they are available—can help surmount a

major and well-documented communication inequality in the recruitment and participation of Black people into cancer clinical trials. To state it more clearly, when researchers prioritize sound health communication practices with and for these community members, their efforts will result in high intentions—and ultimately participation—from these community members.

Although the current study's hypotheses were not supported, overall, the main outcome of intention garnered more positive than negative responses for the Injunctive ($M = 3.17$), Descriptive ($M = 3.45$), Legacy ($M = 3.45$), and Combination ($M = 3.42$) Norm Conditions (on a 5-point scale). In other words, the responses of the Black women in this study trended toward higher intention across all conditions, a finding in line with literature nationally surveying the intentions of Black people to donate to a biobank (McDonald et al., 2014). Of the participants who responded to the question, the great majority (>90%) had never heard of the Komen Tissue Bank, meaning the information imparted by the messages would have been new and/or unfamiliar. Each of the five condition messages, including the control, was broad and informative. Given that research shows that in addition to being asked, knowledge about a study and information about its availability are critical factors for Black people to consider participation in a cancer clinical trial (Cunningham-Erves et al., 2020; Skinner et al., 2019; Tete et al., 2019), the current study's trending positive results are hopeful.

It is interesting to unpack the results, focusing particularly on how and why the results for each message condition turned out the way they did. All conditions trended toward a higher likelihood of having higher intention to perform the behavior; however, it is provocative to hypothesize about the importance of the ranking order of their means

values. The mean values, which are rounded to two decimal places, appear to be the same for the Descriptive and Legacy Normative Conditions. Therefore, it is necessary to look at the odds ratios, which are traditionally calculated to three decimal places, to discern the slight difference and see that the descriptive norm (OR = 1.404) performed best.

This result fits with observations made in some of the formative research, wherein Black women displayed strong descriptive norms in their decisions to participate in breast cancer clinical trials (Ridley-Merriweather, 2022; Ridley-Merriweather et al., 2019). The legacy norm (OR = 1.398) was technically in second place, but the difference in the results is very small. Again, formative research illuminated clear and strong evidence of Black women's decisions to donate healthy breast tissue being led by legacy norms (Ridley-Merriweather & Head, 2017). The combination message was third highest (OR = 1.298), likely the result of having been influenced at least in part by both descriptive and legacy norms messaging.

Next is the control, which was the reference for all analyses. Later in this manuscript, the strong performance of the control is explored as a possible limitation of this study; however, it is also interesting to view the higher-than-expected accomplishment of the control as possible underperformance of the injunctive norm (OR = -0.0107). Although the Injunctive Message Condition trended toward having a likelihood of higher effect on intention, it resulted in lower likelihood to have higher effect and the control and ranked lowest of all the message conditions. Once again, formative research yielded more than a hint of this possibility. For example, in a study of fourteen Black female breast cancer patients and survivors who participated in breast cancer clinical trials, injunctive norms were shown to have much lower effect on their

decision making than descriptive norms (Ridley-Merriweather et al., 2019). A more detailed examination of other potential reasoning behind the performance of the injunctive norm occurs later, in the theoretical implications section of this manuscript.

In sum, although the results generated here were not statistically significant, knowledge was gained from this study showing that dissemination of culturally targeted, norms-based messaging to Black women could elicit positive intentions in their willingness to donate healthy breast tissue. These positive intentions are possibly attributable to the culturally targeted norms-based messaging designed for this study; however, similar work could be performed that focused on other cancers, other conditions such as diabetes, or other situations such as organ donation. Therefore, despite the clear existence of the social and cultural barriers facing this group, there seems to be a path to increasing Black women's intention to participate not only in this preventive breast cancer clinical trial, but also in other research studies. The next section discusses the practical implications of this work.

Practical Implications

The findings of the current study help increase knowledge not only for addressing disparities in the health communication field in general, but in this research focus in particular. The main difference between the premise of the current study and the aforementioned previous work (Ridley-Merriweather et al., 2022, 2019; Ridley-Merriweather & Head, 2017) is the lack of personal, face-to-face interaction. In the field of communication, the media through which messages are delivered are considered to be messages in and of themselves (McLuhan, 1964). Therefore, according to McLuhan (1964), the wrong medium can adversely affect the intended meaning and content of a

message, something that is important to consider here. Although the content of these recruitment messages has been shown to be successful in informal settings, measuring the effect of these messages when delivered through text-based, digital, and impersonal channels has caused the loss of something vibrant and necessary.

Previous successful recruitment methods to the KTB for this population have been grounded in research practices involving face-to-face, friend-to-friend, small group, and/or one-on-one interactions, usually in trusted social situations. Some examples include:

- Speaking with congregants at Black churches in the Indianapolis area as well as in other cities that host a KTB event. In the two to three months leading up to a KTB collection event, research team members visit different Black churches to either speak formally to the entire congregation, meet with smaller groups after service, or sit in a pre-determined area where congregants can come for one-on-one conversations.
- Presentations at Black sorority or other social club gatherings. These can be either formal information sessions with slides followed by a Q&A, or quicker, more frequent visits to develop a familiarity with the group members.
- Tasty Talks. These are small (usually 6 to fourteen in attendance), informative, low pressure conversations with community members over dinner, held in a private space at a local restaurant. Previous tissue donors are invited and placed among attendees who know little about the KTB. After a very brief introduction to the KTB, including the mission/purpose and a bare minimum about tissue collection procedures, the invitees talk amongst themselves, asking previous

participants about their experiences, expressing any concerns, and gathering information. Invitees are invited to attend Tasty Talks as many times as they like; however, they are asked to “bring one, send one”—bring someone with them the next time they come, or send a friend or colleague in their stead if they are unable to attend.

This pilot study and the messages that were tested were carefully designed and employed data from the literature regarding what is already known about how Black women want to be approached (Giusti et al., 2021; Ridley-Merriweather & Head, 2017). Additionally, the relatively high resulting intention outcome variables were promising. However, there is always some concern about results that lack statistical significance.

In sum, a practical implication and lesson learned from this work is that the content of a message cannot be separated from the medium used to communicate that message. This might be particularly true when making connections and trusting in the medium is of great importance, as it is when considering increasing the intention to perform particular behaviors such as participating in clinical trials. Dalski et al., (2022) investigated neural pathways formed while getting to know other people, and found that when compared to exposure to other types of media, face-to-face exposure yielded the strongest connections between subjects, possibly generating more trust. Other research suggests that visuals sent through face-to-face interaction, including even being able to see a communicator’s hands and body movements, enhances the delivery of important social information concerning motivations and goals (Ransom et al., 2022). Additionally, and possibly most salient to the current study, Roghanizad and Bohns, (2017) discovered that individuals are likely to overestimate their persuasive powers when communicating

through email, and underrate their ability to be persuasive when communicating face-to-face. Although participants felt equally confident about their email and face-to-face persuasive abilities, the face-to-face requests were 34 times more effective (Roghanizad & Bohns, 2017).

Coupled with more relational, face-to-face interactions, the current study may have been better positioned to test these hypotheses and see which normative message – *when paired with an appropriate medium* – is most effective at recruiting Black individuals to participate in clinical research. This study’s findings are interesting because of what was already known as the result of formative qualitative research and previous studies that focused on relational communication methods. However, it must be taken into account that interpersonal communication work is resource intensive, both personnel-wise and financially. In a resource-limited environment wherein options for multiple level messaging are restricted, the relatively high intention outcomes generated in the current study could translate to the potential success of well designed, text-based messages for increasing clinical trial participation. The next section explores the theoretical implications of this work.

Theoretical Implications

The current study’s findings have theoretical as well as practical implications for the creation of future breast cancer research recruitment messaging, especially about focusing on targeting normative influences of Black women.

Implications of the PEN-3 Model

The findings from the RQ suggest that considering that different messages trend toward appealing to different people, tailoring the messages to individuals, rather than

targeting them to groups, might be interesting to explore. The PEN-3-influenced cultural aspects were not included in the control message, but it performed just as well as the norms messages that *did* have cultural aspects. Therefore, it cannot be said here that the PEN-3 quantitatively enhanced these messaging strategies. However, we can qualitatively posit that adding cultural aspects to messages is important and something that future work should continue to explore. This was actually evidenced early in the experimental process, when conducting the cognitive pretesting. Two of the five pre-testers, Houston and Nina, vocalized robust opinions about the descriptive norm messages that strongly contradicted each other.

Houston, whose work focuses on racial and ethnic disparities, experienced a negative reaction to statements such as, “Black women are 40% more likely to die from breast cancer than white women,” and “Black women are 20% more likely to develop some of the most aggressive, hard to treat forms of breast cancer.” She expressed a great dislike of being constantly compared to white women and said it “put her off.” Nina, however, who possesses a PhD in organic chemistry, not only liked all the analytical statements very much, but thought more of them should be added. For her, the messages’ effectiveness was increased through the use of comparisons and statistical data. The differences in the reactions of these two women could signal the need to make further efforts to identify participants’ approach preferences. In this case, for example, Nina preferred a statistical message, while Houston was much more receptive to a narrative one. These women wanted to find themselves in the survey.

The nuances of this example provide support for the need to overlay the normative theoretical foundation of this experiment with constructs of the PEN-3 model.

Without the application of the PEN-3 lens to the message conditions, Nina and Houston would not have had much to discuss, and the findings of this work would have lost much of their value. The injection of Black cultural distinctions into the norms messaging helps make it clear that, although any woman can develop breast cancer, there is no dispute about the more deadly effects of the disease on Black women. As an example, one of the messages in the Injunctive Condition reads, “Black women decide to participate in breast cancer research because community leaders or other people whose opinions they value have participated.” In addition to clearly stating “Black women,” the word “community” speaks volumes here. Other than when referring to upscale housing developments, white people are rarely described as being in “communities.” The very word evokes images of places and areas where minoritized population members live.

The example of Nina and Houston also adds support for the practical implications discussed above, especially regarding the myriad complex cultural factors enmeshed in Black women’s breast cancer disparities. Consider what this means in reference to the finding that the injunctive norm demonstrated the lowest likelihood to have higher intention than all the other conditions as well as the control, although it was not statistically significantly lower. Houston’s strong reaction was to the wording on a descriptive norm item, but her objection was about an injunctive norm idea. Although Nina perceived the statement, “Black women are 40% more likely than white women to die from breast cancer” to be a simple, clear statistic, Houston perceived she was being compared to white women. The people to whom others are compared are salient to injunctive norms. Therefore, an implication of this study is that for the injunctive norm message design, using the wrong reference group (e.g., referencing family members or

friends rather than church members or sorority sisters) could have translated to a lower performance for this norm message for this population. Future research should explore other reference groups that may deliver higher impact for Black women. Application of a framework like the PEN-3 could be invaluable for designing a more relational, multi-level approach that might work best and be most effective for this population.

The racial identity labels preferred by participants in the current study are also evidence of the necessary addition of the PEN-3 to the theoretical scaffolding. Being Black was a criterion of eligibility for this study; giving the participants the honor of identifying themselves in a manner that helped them feel seen. The PEN-3 cultural identity domain, which acknowledges person, extended family, and neighborhood, takes into consideration the real world phenomenon that people of African descent must often have multiple identities (Airhihenbuwa & Webster, 2004). This is undeniable in the United States, as evidenced by most Black Americans' need and ability to code switch for personal, professional, and emotional safety (Macklin, 2021). The PEN-3 cultural identity domain is where any kind of health intervention must start, and it is in this domain where trust is first founded. The litany of normative theories serving as a foundation of this study are valuable but in reference to this need, cannot stand alone in support of this work, as evidenced in the main eligibility question of the current study's survey as an example.

Responses to the survey question "What is your race? (or, when asked what your race is, what is your response?)" yielded interesting information that could have an impact on future research. For decades, both academic and public media have pushed the term "African American" as the preferred, more "proper" term for this group, and style

guides have actually mandated its use (Ridley-Merriweather et al., 2021). In reality, a recent Gallup poll reveals that among the options “Black,” “African American” and “Does not matter” given to members of the African diaspora to choose from in a survey, Black and African American are evenly split, and just over half of the poll responses reflected no preference (McCarthy & DuPree’, 2020). Those who prefer being called “Black” often wonder why, over time, white people seemed to grow afraid of doing so. Many members of this population do have preferences about the identity label assigned to them and can even feel offended when their preferences are not honored, particularly when pertaining to group members’ health and health communication needs. When those in the Gallup poll who did not have a preference were asked a follow up question of whether they lean toward one term over the other, Black (52%) was preferred over African American (44%, McCarthy & DuPree’, 2020).

Concerns and offenses can occur when people default to calling any and all descendants of the African diaspora “African American,” as that term is specific to one nation. Immigration to the United States among Black people not born here, and guests coming for work or education purposes, have steadily increased post-1960s (Adams, 2020). Now the “African American” label is applied to Africans, Afro Caribbeans, and Black Europeans alike. These factors make it important for researchers to at least make an attempt at calling people what they want to be called, particularly in situations regarding their health (Ridley-Merriweather et al., 2021)

The participants in the current study were asked to identify themselves with the racial label they preferred. They chose one of five options as their racial identity: Black, African American, African, Afro-Caribbean, or Other of African Descent. Each option

garnered at least one response. As would be expected, most responses were divided between Black and African American, although not evenly. In fact, of the 635 participants, 220 called themselves African American (35%), and 392 chose to identify as Black (62%, see Table 2).

In tandem with the PEN-3 cultural identity domain, the model's cultural empowerment domain plays an important role in the discussion of these study results. This domain categorizes health situations as positive, existential (or benign), and negative. When referring to clinical trial participation as an example of a "health situation" for the current study's group members, encouraging feelings of physical and emotional safety are paramount (Kirkpatrick et al., 2022). The cultural empowerment domain emphasizes encouraging the cultural norms and beliefs that hold health benefits and acknowledging or watching those that are remediable. To consider donating healthy breast tissue, these participants would likely need to assess the behavior as something that was positive, or at least benign, with low likelihood of causing harmful health consequences. The descriptive and legacy norm conditions demonstrated positive effects on intention and might therefore be useful as messaging that would promote higher levels of donor empowerment.

Implications of the Normative Theories

The normative behavioral theoretical concepts applied in this study, primarily taken from the theory of reasoned action (TRA), the theory of planned behavior (TPB), the integrated behavioral model (IBM), the focused theory of normative conduct (FTNC), and the theory of normative social behavior (TNSB), are all well-conceived, well tested, and well used. Most have been updated and/or adapted over time. Two of them, the TRA

and the TPB, were regularly revisited, tweaked, and updated. Eventually, their concepts were merged with constructs from several other theories into the IBM. After decades of these theories informing and somewhat reciprocally benefiting from practice, they still claim only two normative constructs—descriptive and injunctive.

After qualitatively surveying Black women about their healthy tissue donation outlooks and experiences, Ridley-Merriweather and Head (2017) introduced the legacy norm as a suggested third theoretical normative construct. They found that the historical perceptions attributed to Black women of altruism, self-sacrifice, caring for and carrying the burdens of others, and focusing on adopting behaviors that would benefit their daughters and granddaughters in the future, were also present in their participants. Although the legacy norm is conceptually different and is not yet a validated scale, in the current study it performed as well as the descriptive and injunctive norms.

Some would say that the already existing normative theories do address culture in some ways (e.g., the IBM considers environmental constraints and habits). However, the addition of the legacy norm and the fact that it performs just as well as the others, supports the argument that the other normative theories may not adequately uphold or value the theoretical role of culture. The qualitative formative findings and the testing results of the current study suggest not only the legitimacy of and need to further study the legacy norm, but also that it should perhaps be considered and added to this body of theories, at least for this population.

Broad Implications

This was an important study to conduct; creating theory-guided, respectful, effective messaging for the recruitment of Black women into cancer clinical trials is a

ripe area for research. An implication of this study is that Black women really need culturally aware, norms-focused relational communication to enable an understanding that this is something in which they and others like them have interest and—despite other research that implies otherwise—really want to do, particularly after having been comprehensively informed (Statler et al., 2023).

At the time of this writing, 14% of KTB tissue donors are Black, compared to a national rate of 5% clinical trial participation from members of this group (Flores et al., 2021). While this might be seen as impressive, one could also present a sound argument for the need to oversample this population. The low national percentage of Black clinical trial participants quoted here does not make much sense, given the robust research studies demonstrating that Black people—when informed and asked—are active and willing clinical trial participants. A gross depth of literature promotes the trope that Black people will not participate in clinical trials (Statler et al., 2023). If this is the case, then it is at least partly because of institutional biases and preconceptions about Black patients that prevent providers and researchers from informing Black individuals about clinical trials and asking them to participate (Walker et al., 2022).

Despite the targeted messages it contained, the letter piloted in the current study likely would possibly not reach its full possible effect if disseminated only on its own. Research shows that the most successful recruitment strategies in Black communities when using flyers or letters occurs when the printed materials are paired with healthcare provider collaboration and/or the validation of community gatekeepers (Renert et al., 2013; Spratling, 2013). However, a letter containing messages like those in the current study could help do the groundwork prior to employing these kinds of strategies.

If Black individuals were first armed with a base of information about a study (such as what the study involves, why it is being done, and why it is important to the potential participant) they may be more open to the follow-up personal approach from providers, clinicians, or principal investigators who may want to further inform and hopefully recruit them (Namageyo-Funa et al., 2014). Diffusion of Innovation theory supports the premise that media is good for disseminating knowledge, but behaviors and/or opinions are changed by opinion leaders (Rogers, 1962). The process of diffusing the information is social and inherently interpersonal, and can include one person instructing another about the behavior along with the “ins and outs” of how it works (Head et al., 2021). The Tasty Talks, which were described earlier, offer an example of this diffusion process. In fact, given that the mean scores on intention were relatively high and that most participants in the current study had no prior knowledge (i.e., were starting from a place of unawareness about this behavior), a foundation exists to support the idea that these letters could help to lay a foundation that could then be diffused and built upon through face-to-face interactions.

To date, the bulk of the literature focusing on increasing the motivations of Black people to donate their healthy breast tissue and participate in other breast cancer research has been qualitative (Ridley-Merriweather et al., 2022, 2019; Ridley-Merriweather & Head, 2017). Applied findings from those previous studies have been measurably successful at increasing the participation of Black women in the Komen Tissue Bank, and have mostly included creating grassroots, community interactions in the Black community (e.g., presentations at churches, “Tasty Talks” where individuals are invited to learn more about the KTB over dinner, etc.). Future research should involve designing

innovative, multiple messaging approaches (e.g., combinations of text based plus face-to-face based media) and seek to appropriately evaluate the relative effectiveness of those individual and combined techniques.

Strengths and Limitations

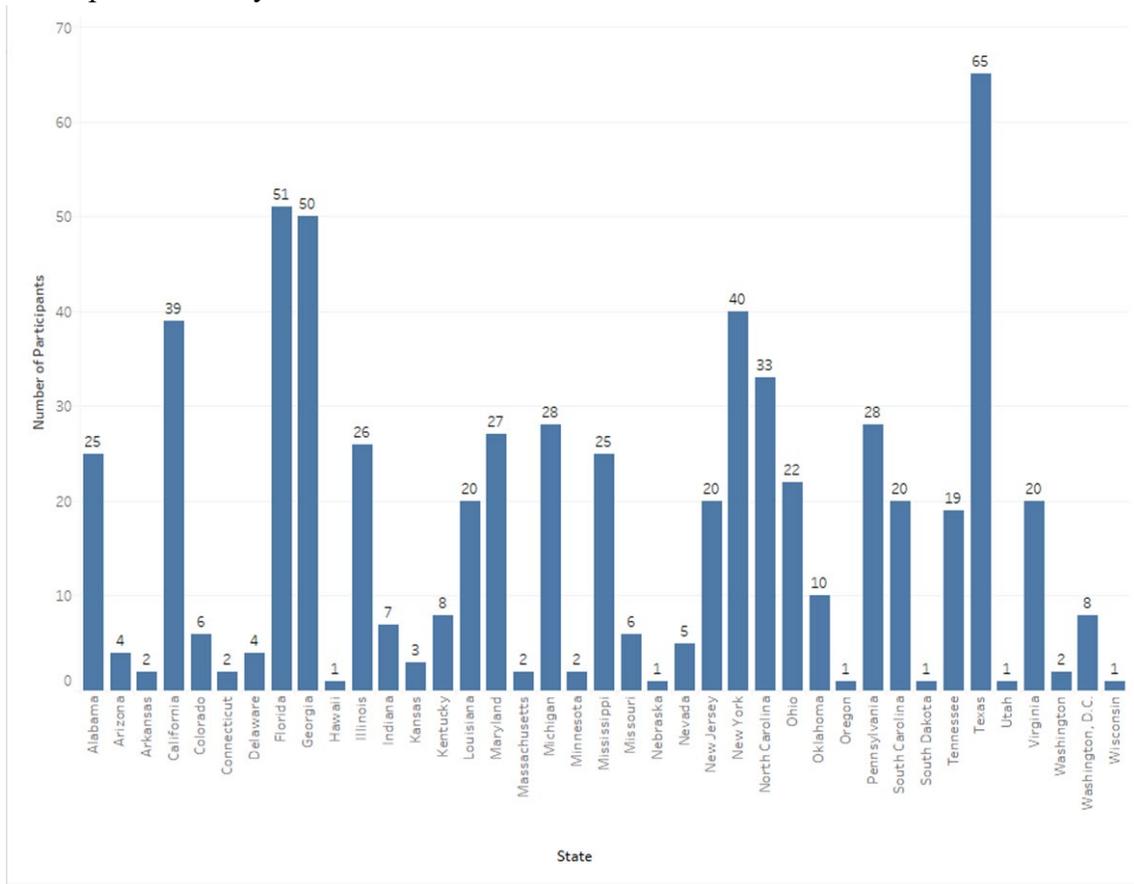
This study was a solid intervention prefaced by a strong body of background work and rigorous formative research. The availability of grant funding afforded the ability to provide incentives that seemed to have been deemed appropriate by the participants, given the short time period (five days) within which participants were accrued and the desired sample size was reached. Additionally, the study was strengthened by doubling the calculated power. Successful checks and balances were in place (e.g., cognitive interviews, speed checks, helpful assistance from Qualtrics personnel) ensuring smooth execution of the survey. However, there were several limitations of this study.

First, there were limitations in the geographic reach of the survey; participants did not represent all of the United States. Participant geographic location was determined through analyzing zip codes using Excel and can be viewed in Figure 1.

The women in this study lived in 38 states and Washington D.C.—certainly a clear majority—but it is preferable that data is also gathered from the other twelve states, and that the respondents represent similar per capita levels. Those missing states likely represent widely varying cultures and habits because geography can play a part in how Black women think and/or feel about clinical trials. In their study of differences in interest in participation in cancer clinical trials in the U.S., Caston et al., (2022) found clear disparities between urban and rural populations. Zip codes were collected for the current study, and it could have been determined whether the participants were from

urban or rural areas. This was not done for the current set of analyses. The lack of reach to all states may have impeded furthering the research started by Caston et al. (2022) and similar studies. Furthermore, when comparing one state to another, the actual numbers of respondents were widely dissimilar, ranging from one respondent in several states to Georgia (n = 50), Florida (n = 51), and Texas (n = 65).

Figure 1
Participant Count by State



It is interesting, however, to note that within this limitation, some comparisons between the U.S. Black population and this cohort are strikingly similar:

- The median age group for the current study is 35 – 44; the median age of Black Americans is 35.5 (Schneider, 2023).

- The median household income group for the current study is \$25K - \$49,999; the median household income of Black Americans is \$46,400 (*Household Income of Black Families U.S. 2021, 2023*)
- Twenty-eight percent of the participants in the current study, and 28% of all Black Americans, hold Bachelor's (or higher) degrees (U.S. Census Bureau, 2023);
- The percentages of divorced, widowed, or single participants in the current study differ somewhat from the corresponding categories for Black women in the United States; however; 27% of the women in both groups are married (*Black Married-Couple Families U.S. 2021, 2023*)

Although it is always best in a study like the current one to have participant representation from all available different geographic spaces, this cohort of Black women is relatively representative of Black people in the United States.

Second, a likelihood exists that there were additional differences within each state surrounding which of the potential participants had access to computers and plentiful internet service. Lack of these amenities would disrupt potential participants' ability to respond to a Qualtrics survey, translating to missing demographics among Black women. Although there are no statistically significant differences in smartphone or tablet ownership between Black people and whites, Black adults are still less likely to have the tools, such as laptops or broadband access, often required to be able to fully participate in survey platforms (Atske & Perrin, 2021).

Third, as was already pointed out earlier, more informative data may have been gathered through application of a multi-level intervention, with some type of added interpersonal factor. This adjustment of format may have been more effective at

mimicking relational interactions that are known from formative research to be successful at increasing intention.

Fourth, a biostatistician could have, and likely should have, been proactively consulted before beginning data gathering rather than waiting until after the survey was closed. There were no discernable adverse effects in the current study of a post-data gathering switch from ANOVA to logistic regression analysis. If, however, the secondarily determined sample size had not represented an adequate number that was appropriate to satisfy the logistic regression, the result could have been invalid study results.

Fifth, although Cronbach's Alpha was an appropriate 0.768 and the variable behaved well in comparison to others, the legacy norm is not yet a validated measure. Creating a valid scale for this important and exciting new norm should be a priority for use in future work. However, it is important to point out that none of the norms measures, including the legacy norm measure, were included in the analyses for the hypotheses and research questions in this dissertation project. Those measures may become useful and important in any post-hoc analyses of the data, and therefore it's important to acknowledge this limitation now.

The sixth limitation was noticed during the final edits of this manuscript and involves the wording of one of the adapted legacy norm measure items. The fourth item in Lalot and colleagues' (2022) revised scale, "I consider how things might be in the future and try to influence those things with my day-to-day behavior" was adapted to "I consider what breast cancer might be like in the future and would try to influence that by donating my healthy breast tissue." The adapted wording failed to aptly convey the

equivalent of the phrase “day to day” in the original item. The importance of doing something now to prevent an occurrence later was not fully conveyed. This omission could be addressed through the addition of the word “now” at the end of the adapted statement.

Finally, the seventh limitation arises from using a different gaze to view the participants’ trend toward a higher probability of having higher intention, which is an important and valuable positive finding of the current study. All five conditions, with the lone exception of the injunctive norm, but including the control, demonstrated this trend. Through employing an alternate gaze and reflecting on an idea that, at its very best, a control should be neutral—neither positive nor negative—the control message could be considered to be too strong and too persuasive. As others researchers have also surmised, a very strong control message could limit the possibility of achieving statistically significant differences (Marcus et al., 2007; Pbert et al., 2016). It is possible that, because it contained strong information about the KTB, the message employed here may not even be considered a true control message, which should be information only. The control used here might better be characterized as a comparison condition, because—although it did not contain any cultural language at all—there were statements that could be considered at least somewhat persuasive rather than strictly informative.

Future Research

In research, learning what is not effective can be just as important as knowing what is (Rudestam & Newton, 2014). The trends noted in this quantitative work were interesting and useful and could be valuable for informing further qualitative and

quantitative norms research in health communication studies. This study generates three main areas for future research.

First, consider the valuable information discovered in the current study, regarding the hopeful, positive trends toward higher likelihood of having higher intention to participate in breast cancer clinical trials. The findings illuminate important information regarding the need to include cultural influences and relational communication-informed findings in norms messaging for Black women. Effective health-related norms messages targeting Black women should enable the participants to recognize themselves within the message design. In other words, for greatest effect, the women need to believe the message is specifically about them and salient for them and people like them. This study's results showed promising trends toward higher levels of intention; however, moving forward may require designing multiple messaging approaches incorporating responses to the need for these women to see themselves.

Mixed methods studies, such as pre-test/post-test experiments that include interpersonal, face-to-face interventions, may be more successful at gathering data informed by and benefitting from relational communication. This kind of methodological design could apply one-on-one interventions involving individual interviews or question and answer sessions, or through several small focus groups involving interaction prior to taking individual surveys wherein group interaction may generate a more comfortable atmosphere. These methodological ideas could result in a combination of the positive factors resulting from the current study and the benefits of face-to-face interactions such as the Tasty Talks or church group Q&A sessions.

Performing multi-level interventions, such as combining tailoring of the culturally informed messages to each participant and adding an interpersonal feature to the experiment, could result in a more nuanced experience for the participants and higher possibilities of statistical significance in the survey results. As an example, please recall again the strongly contrasting emotional reactions to the descriptive norms survey questions experienced by Nina and Houston, two of the cognitive pre-testers, as described at the end of the practical implications section. It could be predetermined that Nina objected to constant comparisons to white women, but Houston seemed to have a deep appreciation for statistical data regardless of nuances. Adding in a video or short in person interaction might help the message fit to their comforts and successfully avoid powerful negative reactions.

The second suggestion for future research generated from this study is that health communication scholars must begin to change the narrative by placing more weight on examining the motivations of Black individuals to participate in research and less focus on the existence of the barriers that are perennially perceived to keep them from doing so. The aforementioned example from the current study of the differences of opinion perceived by Nina and Houston illuminates something important: these two Black women were focused on what would *encourage* them *to* participate. Rather than perceiving their difference of opinion about the feelings invoked by the message wording to be an immovable barrier, researchers should be thinking of ways to make each of them feel motivated, perhaps in different ways.

The discussion section in this study revealed some of the depth of researchers' single-mindedness pertaining to barriers facing Black people who might consider clinical

trial participation. Certainly, it is important to fully know and understand these obstacles. A recent, unique, and important systematic review of the barriers to clinical trial participation facing Black women examines the pertinent literature published between 2000 and 2021 (Le et al., 2022). The authors' findings, which are grouped into three broad categories including weak relationships with the medical and research community, high participation costs, and other personal circumstances, are not unexpected. However, Le et al., (2022) also posited that the most salient barriers pertained to participants' relationships with clinicians, providers, and/or researchers. Health communication researchers who focus more on how to educate and inform practitioners and the healthcare systems in which they work could perhaps learn how to change discouragement into encouragement, disrespect into honor, and a patient's negative outlook into a positive one. When these factors are in place, minoritized population members can be more open to their documented facilitators, such as wanting to do something to help others (T. B. Hughes et al., 2017; Ridley-Merriweather & Head, 2017).

Finally, it may be important to return to this data look for different effect modifiers or interaction effects. For example, exploring whether participants' geographic locations made a difference on some of the outcomes, or examining the effects of age or their self-identification choices of Black or African American, could yield potentially valuable information about this cohort, and could therefore be worthy of further study.

In sum, future research should involve designing innovative, multiple messaging approaches to normative message testing employing individual and combined techniques that relationally inform quantitative research. Research design should focus on including and acknowledging the need for employing cultural frameworks as, in addition to, or on

top of other theoretical guides. Finally, promoting the increase of motivations and a lessened focus on barriers could be helpful in moving this important research forward.

Author Self-Reflection Statement

At the time of this writing, I am the Communication, Outreach, and Recruitment Manager of the Komen Tissue Bank, and am responsible for increasing the number of healthy Black and Brown breast tissue donors to the bank. As such, there is no doubt that my positionality as author is likely strongly related to the current study's origin, ideas, design, and even its conclusions, because the bias of an author under these circumstances is inevitable. My entire education track and the majority of my body of work has resulted from a passion for the work and the job I, myself, created. Having been hired at the KTB in January of 2011 as an administrative assistant, I knew little to nothing about the causes of research disparities. However, as the only Black female employee, I found that I was asked for my opinion about the lack of banked samples from Black and Brown women.⁵ At the time, all I knew was that although the white women were literally registering in droves to participate, and although I myself had developed some comfort with the idea of potentially donating, there was very little chance that most of the Black women I knew would consider participation without having a lot more information.

As someone who began as a non-academic, I possessed a unique lens through which to view the identified problem of increasing participation. I did not know the “right” way from the “wrong” way, I just understood my people. My lack of expertise, combined with my openness to experimentation, enabled me to see beyond the published literature to a new way of thinking and framing of this research problem. My approach

⁵ Until November 2022, the KTB collected specimens only from women.

and ideas were completely based in my own identity as a Black woman who had grown up around Black people doing Black things and thinking the way Black people think. I knew of the depth of altruism within members of the Black community, particularly among the women. I understood that there was very little these group members would not do for each other, their families, their friends, and their extended community if they were treated with respect, given valid information, given time, and asked. I also knew that I could help these population members understand that their participation in medical research was the most valuable weapon they had with which to improve generational health; only through their participation would these group members be able to gain the benefits of improved understanding of their particular health challenges and concerns. With this point of view that I set out to do my best to reach my community.

Conclusion

This work focused on the effectiveness of normative messages derived from qualitative empirical research on Black women eligible to participate in a breast cancer prevention clinical trial. The email messages included persuasively worded information about the trial. After being randomized into one of five different message conditions, participants responded to survey questions measuring their intention to donate healthy breast tissue. The results showed that overall, although the messages trended toward increasing intention, they fell short of reaching statistical significance.

Overall, the survey question addressing the main outcome of intention garnered more positive than negative responses; participants trended toward higher intention across all conditions. However, after reading the message conditions, overall, the participants seemed not to feel negatively toward donation of healthy breast tissue, and

overall, displayed a positive outlook toward participation. The results of the current study seemed contraindicative to the researcher's body of work. However, the results could be helpful and informative for moving knowledge in the field forward, not only for addressing disparities in the health communication field in general, but in this research focus in particular.

The main difference between the premise of the current study and previous work is the lack of personal, face-to-face interaction. Previously, qualitatively derived evidence of positive impact of messages like these on KTB participants of color have been identified. In consideration of this evidence, the results of the current study show that, although this experiment on its own may not be the best test of these normative concepts, ideas such as the pairing of well-designed, text-based messaging with interpersonal methods may yield stronger results in the future.

Appendix A

Grant Information

The Catherine Peachey Fund is headquartered in Indianapolis, Indiana, and is part of the Heroes Family Foundation. The Catherine Peachey Fund focuses on helping to financially support breast cancer research, particularly research performed at Indiana University and/or through the IU Simon Comprehensive Cancer Center. I was awarded a grant in the amount of \$14,000 to fund this research. The funds were applied toward expenses to procure Qualtrics participant panels, additional participant incentives, and the services of a biostatistician.

Appendix B

Survey

Instructions Thank you for agreeing to take this survey. Please begin by answering some demographic questions.

Race What is your usual response when someone asks you your race?

- Black (1)
- African American (2)
- African (3)
- Afro-Caribbean (4)
- Other of African Descent (5)
- None of these (6)
- Rather not say (7)

*Skip To: End of Block If What is your usual response when someone asks you your race?
= None of these*
*Skip To: End of Block If What is your usual response when someone asks you your race?
= Rather not say*

Age What is your age?

- Under 18 (1)
- 18 - 24 (2)
- 25 - 34 (3)
- 35 - 44 (4)
- 45 - 54 (5)
- 55 - 64 (6)
- 65 - 74 (7)
- 75 and over (8)

Skip To: End of Block If What is your age? = Under 18

Gender What gender was assigned to you at birth (what is your biological sex)?

- Female (1)
- Male (2)
- Other (4)
- Prefer not to say (5)

Skip To: End of Block If What gender was assigned to you at birth (what is your biological sex)? != Female

Page Break

Familiarity with KTB **Have you ever heard of the Komen Tissue Bank in Indianapolis, Indiana?**

- Yes (1)
 - No (2)
 - I've heard the name but don't know what it is. (3)
-

Q79 Have you ever been diagnosed with breast cancer?

- Yes (1)
- No (2)
- Not sure (3)

Skip To: End of Block If Have you ever been diagnosed with breast cancer? = Yes
End of Block: Qualtrics Surveys Question Demo

Start of Block: Consent

Study Information

This study is a research survey about breast cancer clinical trial recruitment messaging. You do not need special knowledge of this topic to participate. The study is being conducted by a researcher at Indiana University.

What is the purpose of the study?

This study will test the effectiveness of health-related messaging. You may not benefit personally from completing this survey. We anticipate few risks or discomforts involved from being in this study.

Why are you being invited to take part in this study?

You have been invited to take part in this study because you fulfil the following criteria: (1) identify as a Black, African, African American, or Afro-Caribbean person who was assigned female at birth; (2) over the age of 18; (3) do not currently have, or have previously had, breast cancer; and (4) live in the United States.

What will the study involve?

Our online survey assesses Black women's perceptions about breast cancer clinical trial recruitment messages and the influence of these messages on intentions to participate. The survey should take no longer than 15 minutes. All information that is collected will

be kept strictly confidential and will only be accessible to members of the research team. Your answers will be anonymous.

Informed Consent **If you would like to participate in this study, please select CONTINUE below.**

- Continue (1)
- I do not wish to participate in this study (2)

Skip To: End of Block If you would like to participate in this study, please select CONTINUE below. = I do not wish to participate in this study

End of Block: Consent

Start of Block: Experience and Awareness of BC

Instructions In this section, we will collect some information from you about your awareness of and experience with breast cancer and perceptions about medical research. This information will help us more fully understand your responses. Please remember that all your answers are anonymous.

Connection to BC I personally know someone currently living who has, or has had, breast cancer.

- True (1)
- False (2)
- I don't know (3)

Skip To: Connection to BC 3 If I personally know someone currently living who has, or has had, breast cancer. = False

Skip To: Connection to BC 3 If I personally know someone currently living who has, or has had, breast cancer. = I don't know

Connection to BC 2 **Who do you know who has, or has had, breast cancer?** Please select all answers that apply.

- Grandmother (1)
 - Mother (2)
 - Aunt (3)
 - Daughter (4)
 - Sister (5)
 - Other Family Member (6)
 - Friend (7)
 - Coworker (8)
 - Other (9)
 - Prefer not to answer (10)
-

Page Break

Connection to BC 3 **I personally knew someone who died of breast cancer.**

- True (1)
- False (2)
- I don't know (3)

Skip To: Q41 If I personally knew someone who died of breast cancer. = False
Skip To: Q41 If I personally knew someone who died of breast cancer. = I don't know

Connection to BC 4 **Who did you know who died of breast cancer?** Please select all answers that apply.

- Grandmother (1)
 - Mother (2)
 - Aunt (3)
 - Daughter (4)
 - Sister (5)
 - Other family member (6)
 - Friend (7)
 - Coworker (8)
 - Other (9)
 - Prefer not to answer (10)
-

Page Break

Q41 In this section of the survey you will answer some questions pertaining to **Black, African, African American, or Afro-Caribbean women and breast cancer.** Remember that you are answering only for yourself. This is **your** opinion.

Q37 **Black, African, African American, Afro-Caribbean, or other women of African descent do not often develop breast cancer.**

- True (1)
 - False (2)
 - I don't know (3)
-

Q38 Black, African, African American, Afro-Caribbean, or other women of African descent have a similar risk of death from breast cancer as white women.

- True (1)
 - False (2)
 - I don't know (3)
-

Q39 Participants in clinical trials should be concerned about being deceived or misled by medical researchers.

- Strongly disagree (1)
- Disagree (2)
- Neither agree nor disagree (3)
- Agree (4)
- Strongly Agree (5)

End of Block: Experience and Awareness of BC

Start of Block: Letter Message Testing

Instructions Now we will have you **carefully read** the content from a sample email or flyer a woman might receive concerning participating in a breast health study. Please **spend some time reading the entire content** of the email, and then click the arrow at the bottom of the page to proceed to the last set of questions.

So that you can take your time reading the letter closely, the “next page” button will not be enabled right away.

Letter 1 Letter 1

Letter 2 Letter 2

Letter 3 Letter 3

Letter 4 Letter 4

Letter 5 Letter 5

Letter Timer Timing

First Click (1)

Last Click (2)

Page Submit (3)

Click Count (4)

End of Block: Letter Message Testing

Start of Block: Post-Test: Intention

Instructions We would like you to **carefully consider the email you have just read**. While thinking of the content of that email, please now read the statement below and indicate how accurate or inaccurate it is by selecting the appropriate response.

	Strongly disagree (1)	Somewhat disagree (2)	Neither agree nor disagree (3)	Somewhat agree (4)	Strongly agree (5)
<p>If I had received this letter, it is likely that in the next six (6) months I would accept an opportunity to donate my healthy breast tissue for research.</p> <p>(1)</p>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

End of Block: Post-Test: Intention

Start of Block: Post-Test: Norms

Page Break

Group A In this section, **please think carefully about the email you just read**, then respond to each question. Read each statement and indicate how much you agree or disagree with it by selecting the appropriate response. You must respond to each question to move forward in the survey.

	Strongly Disagree (1)	Disagree (2)	Neither agree nor disagree (3)	Agree (4)	Strongly agree (5)
<p>Most people who are important to me would think that I should donate healthy breast tissue to be used in breast cancer research. (1)</p>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<p>Most people in my family would think that I should donate healthy breast tissue to be used in breast cancer research. (2)</p>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<p>Most people in my life whose opinions I value would think that I should donate healthy breast tissue to be used in breast cancer research. (3)</p>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

**Most of my
circle of
close
friends
would think
that I should
donate
healthy
breast tissue
to be used in
breast cancer
research. (4)**

Page Break

Group B In this section, **please think carefully about the email you just read** and then respond to each question. Read each statement and indicate how much you agree or

disagree with it by selecting the appropriate response. You must respond to each question to move forward in the survey.

	Strongly Disagree (1)	Disagree (2)	Neither agree nor disagree (3)	Agree (4)	Strongly agree (5)
<p>Most people like me would donate healthy breast tissue to be used in breast cancer research. (1)</p>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<p>Most of my close friends would donate healthy breast tissue to be used in breast cancer research. (2)</p>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<p>Most people in my family would donate healthy breast tissue to be used in breast cancer research. (3)</p>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Page Break



Group B (cont.) Please **continue to carefully think about the email you just read**, then respond to each question. Read each statement and use the slider to indicate how much you agree or disagree with it by selecting the appropriate response. You must respond to each question to move forward in the survey.

0 10 20 30 40 50 60 70 80 90 100

In your best estimate, what percentage of women like you do you think would donate healthy breast tissue if given the opportunity? ()	
In your best estimate, what percentage of the women in your close circle of friends do you think would donate healthy breast tissue if given the opportunity? ()	
In your best estimate, what percentage of the women in your family do you think would donate healthy breast tissue if given the opportunity? ()	

Page Break

Group C In this section, please think carefully about the email you just read, then respond to each question. Read each statement and indicate how much you agree or disagree with it by selecting the appropriate response. You must respond to each question to move forward in the survey.

	Not true of me at all (1)	Neither true of me nor untrue of me (2)	Somewhat true of me (3)	Very true of me (4)
I would think about the consequences of donating healthy breast tissue before I did it. (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I think about whether breast cancer will still be here in the future. (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am willing to sacrifice my immediate happiness or well-being by donating healthy breast tissue in order to help others in the future. (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I consider what breast cancer might be like in the future, and would try to influence that by donating my healthy breast tissue. (4)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I can show concern and care for peers by donating healthy breast tissue. (5)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

When they are
in need, I want
to help people
all over the
world by
participating in
research studies.
(6)

End of Block: Post-Test: Norms

Start of Block: Additional Demographics

Q70 In this final section, we will collect some additional demographic information from you. Please remember that all your answers are anonymous.

Education What is the highest level of formal education you have completed?

- Some elementary school (1)
 - Completed eighth grade (7)
 - Some high school (8)
 - High school or GED (2)
 - Some college or associate degree (3)
 - Bachelor's degree (4)
 - Graduate degree(s) (5)
 - Other/prefer not to answer (6)
-

Employment **Are you employed?**

- Yes, full time (1)
- Yes, part time (2)
- No, I am a student (3)
- No, I am not employed (4)
- Prefer not to answer (5)

Skip To: Geography If Are you employed? = No, I am a student
Skip To: Geography If Are you employed? = No, I am not employed
Skip To: Geography If Are you employed? = Prefer not to answer

Occupation **Please check the category that best describes the field you work in.**

- Academia (34)
- Agriculture (36)
- Architecture (1)
- Arts, Design, and/or Entertainment (2)
- Building and/or Grounds Cleaning (3)
- Building Maintenance (38)
- Business and/or Financial Operations (4)
- Community and/or Social Service (5)
- Computer, IT, and/or Mathematical (6)
- Construction and/or Extraction (7)
- Customer Service (39)
- Educational Instruction or Library (8)
- Engineering (37)
- Factory and/or Warehouse (40)
- Farming, Fishing, and/or Forestry (9)
- Food Preparation and/or Serving (10)
- Healthcare (General) (20)
- Healthcare Practitioners (11)
- Healthcare Support (12)
- Home and Family Management (13)

- Installation, Maintenance, and/or Repair (14)
 - Law Enforcement, Security, First Response, or Protective Services (41)
 - Legal (15)
 - Life, Physical, or Social Science (16)
 - Management (17)
 - Media (32)
 - Military (18)
 - Office and Administrative Support (19)
 - Personal Care and Service (22)
 - Public Health (33)
 - Production (23)
 - Protective Service (24)
 - Research (25)
 - Sales or Sales Related (26)
 - Science, Research, or Pharmaceuticals (30)
 - Sports and/or Leisure Related (31)
 - Technology (27)
 - Transportation and/or Material Moving (28)
 - Volunteer Services (29)
 - Other Occupational category (please fill in) (21)
-



Geography What is your **5-digit** home zip code?

Marital Status What is your marital status?

- Married (1)
- Single (2)
- Divorced (3)
- Widowed (4)
- Prefer not to answer (5)

Income Approximately how much was your household income last year (2021)?

- Less than \$10,000 (1)
- \$10,000 to \$24,999 (2)
- \$25,000 to \$49,999 (3)
- \$50,000 - \$74,999 (4)
- \$75,000 - \$99,999 (5)
- \$100,000 - \$149,999 (6)
- \$150,000 - \$199,999 (7)
- \$200,000 or more (8)
- Prefer not to answer (9)

End of Block: Additional Demographics

Start of Block: Thank you

Thank you Thank you for taking part in this study. Remember that once you submit your responses, you cannot recall or change them. **Please click the "next page" arrow below** to submit and automatically log your responses.

End of Block: Thank you

Appendix C

Code Book

A.	Eligibility	5
B.	Study Information / Consent	1
C.	Research and Breast Cancer Awareness	7
D.	Letter Message Testing	Participants only see 1 condition
E.	Post-Test: Intention	1
F.	Post-Test: Injunctive/Descriptive/Legacy Norms	16
G.	Additional Demographics	6
	Total	36

123

Item #	Construct	Item	Response Options	Survey Logic	Source/Notes
PART A: Eligibility					
A00	Instructions	Thank you for agreeing to take this survey. Please begin by answering some demographic questions.			
A10	Race	What is your race? <i>(or, when asked what your race is, what is your response?)</i>	1 = Black 2 = African American 3 = African 4 = Afro-Caribbean 5 = other of African descent 6 = None of these	If B10 = 6 or 7, send to ineligibility/thank you screen.	

			7 = Rather not say		
A20	Age	What is your age?	1 = under 18 2 = 18-24 3 = 25-34 4 = 35-44 5 = 45-54 6 = 55-64 7 = 65-74 8 = 75 and over	If B20 = 1, send to ineligibility/thank you screen.	
A30	Gender	What gender was assigned to you at birth (what is your biological sex)?	1 = female 2 = male 3 = I am non-gendered 4 = other 5 = rather not say	If B30 = 2, 3, 4, or 5, send to ineligibility/thank you screen.	
A40	Familiarity with KTB	Have you ever heard of the Komen Tissue Bank in Indianapolis, Indiana?	1 = yes 2 = no	If B40 = 1, send to ineligibility/thank you screen.	
A50	BC patient or survivor	Have you ever been diagnosed with breast cancer?	1 = yes 2 = no 3 = not sure	If B50 = 1, send to ineligibility/thank you screen.	

Item #	Construct	Item	Response Options	Survey Logic	Source/Notes
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PART B: Study Information/ Consent

00	Study Instructions	<p>This study is a research survey about breast cancer clinical trial recruitment messaging. You do not need special knowledge of this topic to participate. The study is being conducted by a researcher at Indiana University.</p> <p>What is the purpose of the study? This study will test the effectiveness of health-related messaging. You may not benefit personally from completing this survey. We anticipate few risks or discomforts involved from being in this study.</p> <p>Why are you being invited to take part in this study? You have been invited to take part in this study because you fulfil the following criteria: (1) identify as a Black, African, African American, or Afro-Caribbean person who was assigned female at birth; (2) over the age of 18; (3) do not currently have, or have previously had, breast cancer; and (4) live in the United States.</p> <p>What will the study involve? Our online survey assesses Black women's</p>			
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		<p>perceptions about breast cancer clinical trial recruitment messages and the influence of these messages on intentions to participate. The survey should take no longer than 15 minutes. All information that is collected will be kept strictly confidential and will only be accessible to members of the research team. Your answers will be anonymous.</p>			
B10	Consent	<p>If you would like to participate in this study, please select CONTINUE below.</p>	<p>1=Continue 2=I do not wish to participate in this study</p>	<p>If A10=1, proceed to Section B. If A10=2, proceed to “thank you” screen.</p>	

Item #	Construct	Item	Response Options	Survey Logic	Source/Notes
PART C: Awareness of BC					
C00	Instructions	In this section, we will collect some information from you about your awareness of and experience with breast cancer and perceptions about medical research. This information will help us more fully understand your responses. Please remember that all your answers are anonymous.			Outcomes of this section will help describe participants' general knowledge about BC incidence and evidence of feeling a personal connection to BC
C10	Connection to BC (Awareness)	I personally know someone currently living who has / has had breast cancer.	1=True 2=False 3=I don't know	If C10 = 1, proceed to C10a. If C10 = 2 or 3, proceed to C20	Moodley, et al. (2019)
C10a		Whom do you know who has breast cancer?	1=Grandmother 2=Mother 3=Aunt 4=Daughter 5=Sister 6=Other family member 7=Friend	Allow more than one choice.	

			8=Coworker 9=Other 10=Prefer not to answer		
C20	I personally knew someone who died of breast cancer.	1=True 2=False 3=I don't know		If C20 = 1, proceed to 20a. If C20 = 2 or 3, proceed to C30	Moodley, et al. (2019)
C20a	Whom did you know who died of breast cancer?	1=Grandmother 2=Mother 3=Aunt 4=Daughter 5=Sister 6=Other family member 7=Friend 8=Coworker 9=Other 10=Prefer not to answer		Allow more than one choice.	
	Instructions	In this section of the survey you will answer some questions pertaining to Black, African, African American, or Afro-Caribbean women and breast cancer. Remember that you are answering only for yourself. This is your opinion.			

C30	Awareness about BW & BC	Black, African, African American, Afro-Caribbean, or women of African descent <u>do not</u> often develop breast cancer.	1=True 2=False 3=I don't know		modified Moodley, et al. (2019)
C40		Black, African, African American, Afro-Caribbean, or women of African descent have a similar risk of death from breast cancer as White women.	1=True 2=False 3=I don't know		modified Moodley, et al. (2019)
C50	Trust of medical researchers	Participants should be concerned about being deceived or misled by medical researchers.	1=Strongly disagree 2=Disagree 3=Neither agree nor disagree 4=Agree 5=Strongly agree	reverse scored	modified Mainous, et al. (2006)

Item #	Construct	Item	Response Options	Survey Logic	Source/Notes
PART D: Letter Message Testing					
D00	Instructions	Now we will have you read over the content from a sample email or flyer a woman might receive concerning participating in a preventive breast health study. Please spend some time reading the entire content of the email/flyer, and then click the arrow at the bottom of the page to proceed to the last set of questions.		Qualtrics will randomize to ONE condition (letters 1-5): • Letter 1 Basic Control KTB Info (D10)	

		So that you can take your time reading the letter closely, the “next page” button will not be enabled right away.		<ul style="list-style-type: none"> • Letter 2 Injunctive Norm KTB Info (D20) • Letter 3 Descriptive Norm KTB Info(D30) • Letter 4 Legacy Norm Info (D40) • Letter 5 Combination Norm KTB Info (D50) 	
D10		Control			
D20		Control + Injunctive Norm Manipulation			
D30		Control + Descriptive Norm Manipulation			
D40		Control + Legacy Norm Manipulation			
D50		Control + Combined Norm Manipulation			

Item #	Construct	Item	Response Options	Survey Logic	Source/Notes
PART E: Post-Test: Intention					
E00	Instructions	We would like you to carefully consider the email you have just read. While thinking of the content of that email, please now read the statement below and indicate how accurate or inaccurate it is by selecting the appropriate response.	Design as a matrix		
E11	Intention		1=Strongly disagree		

		If I had received this letter, it is likely that In the next 6 months I would accept an opportunity to donate my healthy breast tissue for research.	2=Disagree 3=Neither agree nor disagree 4=Agree 5=Strongly agree		Head et al., 2022
PART F: Post-Test: Injunctive/Descriptive/Legacy Norms					
	Study Info	The order of the section blocks of normative measures (injunctive, descriptive, legacy) will be randomized.			
F00	Instructions	In this section, please think about the letter you just read, then respond to each question. Read each statement and indicate how much you agree or disagree with it by selecting the appropriate response. You must respond to each question to move forward in the survey.	Design as a matrix		
F01	Injunctive Norm	Most people who are important to me would think that I should donate healthy breast tissue to be used in breast cancer research.	1=Strongly disagree 2=Disagree 3=Neither agree nor disagree 4=Agree 5=Strongly agree		Ajzen (2006); Sieverding et al. (2010); Kim et al. (2015)
F02	Injunctive Norm	Most people in my family would think that I should donate healthy breast tissue to be used in breast cancer research.	1=Strongly disagree 2=Disagree 3=Neither agree nor disagree 4=Agree		Ajzen (2006); Sieverding et al. (2010); Kim et al. (2015)

			5=Strongly agree		
F03	Injunctive Norm	Most people in my life whose opinions I value would think that I should donate healthy breast tissue to be used in breast cancer research.	1=Strongly disagree 2=Disagree 3=Neither agree nor disagree 4=Agree 5=Strongly agree		Ajzen (2006); Sieverding et al. (2010); Kim et al. (2015)
F04	Injunctive Norm	Most of my circle of close friends would think that I should donate healthy breast tissue to be used in breast cancer research.	1=Strongly disagree 2=Disagree 3=Neither agree nor disagree 4=Agree 5=Strongly agree		Ajzen (2006); modified Park & Smith (2007)
F10	Descriptive Norm - Instructions	In this section, please think carefully about the email you just read and then respond to each question. Read each statement and indicate how much you agree or disagree with it by selecting the appropriate response. You must respond to each question to move forward in the survey.	Design as a matrix		
F11	Descriptive Norm	Most people like me would donate healthy breast tissue to be used in breast cancer research.	1=Strongly disagree 2=Disagree 3=Neither agree nor disagree 4=Agree 5=Strongly agree		Ajzen (2006); Kim et al. (2015)
F12			1=Strongly disagree		Ajzen (2006);

	Descriptive Norm	Most of my close friends would donate healthy breast tissue to be used in breast cancer research.	2=Disagree 3=Neither agree nor disagree 4=Agree 5=Strongly agree		Kim et al. (2015)
F13	Descriptive Norm	Most people in my family would donate healthy breast tissue to be used in breast cancer research.	1=Strongly disagree 2=Disagree 3=Neither agree nor disagree 4=Agree 5=Strongly agree		Ajzen (2006); Kim et al. (2015)
F14	Descriptive Norm - Instructions	Please read each statement and indicate your response by dragging the slider to your selection.	Design as matrix	Draggable slider format will be used to allow selection from 0%-100%	
F15	Descriptive Norm	In your best estimate, what percentage of women like you do you think would donate healthy breast tissue if given the opportunity?	0% -----100%		Ajzen (2006); modified Goldstein et al. (2008)
F16	Descriptive Norm	In your best estimate, what percentage of the women in your close circle of friends do you think would donate healthy breast tissue if given the opportunity?	0% -----100%		Ajzen (2006); modified Goldstein et al. (2008)
F17	Descriptive Norm	In your best estimate, what percentage of the women in your family do you think would donate healthy breast tissue if given the opportunity?	0% -----100%		Ajzen (2006); modified Goldstein et al. (2008)

F20	Legacy Norm	In this section, please think carefully about the email you just read, then respond to each question. Read each statement and indicate how much you agree or disagree with it by selecting the appropriate response. You must respond to each question to move forward in the survey.	Design as a matrix		
F21	Legacy Norm	I would think about the consequences of donating breast tissue before I did it.	1=Not true of me at all 2=Neither true of me nor untrue of me 3=Somewhat true of me 4=Very true of me		modified Lalot et al. (2020); modified Lalot et al. (2021)
F22	Legacy Norm	I think about whether breast cancer will still be here in the future.	1=Not true of me at all 2=Neither true of me nor untrue of me 3=Somewhat true of me 4=Very true of me		modified Lalot et al. (2020); modified Lalot et al. (2021)
F23	Legacy Norm	I am willing to sacrifice my immediate happiness or well-being by donating breast tissue in order to help others in the future.	1=Not true of me at all 2=Neither true of me nor untrue of me 3=Somewhat true of me 4=Very true of me		modified Lalot et al. (2020); modified Lalot et al. (2021)
F24	Legacy Norm	I consider what breast cancer might be like in the future and would try to	1=Not true of me at all		modified Lalot et al. (2020);

		influence that by donating my healthy breast tissue.	2=Neither true of me nor untrue of me 3=Somewhat true of me 4=Very true of me		modified Lalot et al. (2021)
F25	Legacy Norm	I can show concern and care for peers by donating healthy breast tissue.	1=Not true of me at all 2=Neither true of me nor untrue of me 3=Somewhat true of me 4=Very true of me		modified Lalot et al. (2020); modified Lalot et al. (2021)
F27	Legacy Norm	When they are in need, I want to help people all over the world by participating in research studies.	1=Not true of me at all 2=Neither true of me nor untrue of me 3=Somewhat true of me 4=Very true of me		modified Lalot et al. (2020); modified Lalot et al. (2021)
PART G: Additional Demographics					
G00	Instructions	In this final section, we will collect some additional demographic information from you. Please remember that all your answers are anonymous.			
G10	Education	What is the highest level of formal education you have completed?	1 = some elementary school 2 = completed eighth grade 3 = Some high school 4 = high school or GED 5 = some college or associate degree		

			6 = bachelor's degree 7 = graduate degree(s) 8 = other / prefer not to answer		
G20	Employment	Are you employed?	1 = yes, full time 2 = yes, part time 3 = no, I am a student 4 = no, I am not employed 5 = prefer not to answer	If G20 = 3, 4, or 5, skip the next question.	
G30	Occupation	What is your occupation?	Academia Agriculture Architecture Arts, Design, and/or Entertainment Building and/or Grounds Cleaning Building Maintenance Business and/or Financial Operations Community and/or Social Service Computer, IT, and/or Mathematical Construction and/or Extraction Customer Service Educational Instruction or Library Engineering Factory and/or Warehouse Farming, Fishing, and/or Forestry		

				Food Preparation and/or Serving Healthcare (General) Healthcare Practitioners Healthcare Support Home and Family Management Installation, Maintenance, and/or Repair Law Enforcement, Security, First Response, or Protective Services Legal Life, Physical, or Social Science Management Media Military Office and Administrative Support Personal Care and Service Public Health Production Protective Service Research Sales or Sales Related Science, Research, or Pharmaceuticals Sports and/or Leisure Related Technology Transportation and/or Material Moving		
--	--	--	--	---	--	--

			Volunteer Services Other Occupational category (please fill in)		
G40	Geography	What is your 5-digit home zip code?	open response field (limit 5 digits)		
G50	Marital status	What is your marital status?	1 = married 2 = single 3 = divorced 4 = widowed 5 = prefer not to answer		
G60	Income	Approximately how much was your household income last year (2021)?	1=Less than \$10,000 2=\$10,000 to \$24,999 3=\$25,000 to \$49,999 4=\$50,000 - \$74,999 5= \$75,000 - \$99,999 6= \$100,000 - \$149,999 7=\$150,000 - \$199,999 8= \$200,000 or more 9= Prefer not to answer		
G70	Closing	Thank you for taking part in this study. Remember that once you submit your responses, you cannot recall or change them. Please click the "next page" arrow below to submit and automatically log your responses.			

Appendix D

Message Conditions



Hello!

Did you know that 1 in 8 women in the United States develops breast cancer during her lifetime? Only lung cancer kills more women than breast cancer each year.

The Komen Tissue Bank (KTB) is the only tissue bank in the world that collects normal, healthy breast tissue from women with no sign of breast cancer. The focus of the KTB is preventing and finding new treatments for breast cancer.

Studying normal breast tissue has already helped us develop new treatments. **You are a perfect candidate to donate healthy breast tissue to the KTB.** In fact, the research cannot move forward without you!

Why normal breast tissue? Good question. By donating a very small, unnoticeable portion of your tissue, you can help fight breast cancer. Researchers worldwide use tissue donations like yours to learn how breast cancer develops and to discover new, better treatments.

Tissue donation requires making an appointment at a tissue collection event that is attended by dozens of other participants. The tissue donation process takes about an hour. You first have an opportunity to speak with a consultant to have all of your questions answered. Next, your height, weight, and medical history are taken, and a small amount of blood is drawn. Finally, your breast is numbed, and a small pea-sized amount of tissue is taken.

Specifically, here are some reasons why **your** participation is important:

- **INSERT MANIPULATION BULLET POINTS HERE**

Manipulation paragraphs are inserted here.

Please consider participating by donating your healthy breast tissue to the KTB at our next tissue collection event. You can be a part of the cure! If you have any questions, please contact me at 555-555-5555, or email info@ktb.org. Thank you.

Regards,

A handwritten signature in black ink that reads "Kathi Ridley-Merriweather".

Kathi Ridley-Merriweather,

Communication, Recruitment, and Outreach Manager

Komen Tissue Bank

Komen Tissue Bank | 550 University Boulevard AOC Room 6042 | Indianapolis, IN 46202 PH 317.274.2366 | FX 317.274.6746 | komentissuebank.iu.edu

Manipulation Paragraphs

Condition 2 – Injunctive Norm

- Black women decide to participate in breast cancer research because their friends and families have participated.
- Black women decide to participate in breast cancer research because community leaders or other people whose opinions they value have participated.
- Black women who donate healthy breast tissue are doing what their friends and family would want them to do.
- When Black women donate their healthy breast tissue they are admired by others.

(69 words; 6th grade reading level when inserted into control message)

Condition 3 – Descriptive Norm

- Black women are 40% more likely than White women to die from breast cancer.
- Black women are 20% more likely to develop some of the most aggressive, hard-to-treat forms of breast cancer.
- Researchers need more Black women to donate their tissue so they can study it and learn why these things are true.
- Fewer than four out of every 1000 women who participate in a breast cancer clinical trial are Black.

(71 words; 6th grade reading level when inserted into control message)

Condition 4 – Legacy Norm

- Black women who donate their healthy breast tissue give hope to the women who come after them.
- Black women who participate in breast cancer research help find new treatments specifically designed to treat their daughters and granddaughters who might develop breast cancer.
- Black women who donate their breast tissue help create better medicines and protect other Black women from developing breast cancer in the future.
- If Black women do not participate in breast cancer research, they, their family members, or other people who look like them, won't be able to benefit.

(91 words; 6th grade reading level when inserted into control message)

APPENDIX E

Cognitive Pretesting Notes

To facilitate ease of talking out loud, I asked all interviewees to read the entire questionnaire out loud as they went through it, and to speak whatever was crossing through their minds as they took the survey. This was easier for some than others, but all five got into the rhythm of doing this pretty quickly.

In general, I waited until after all five interviews before making most changes (which is why there are so many adjustments following the fifth cognitive interviews), but there were exceptions. If a suggestion made so much sense that I thought others would say the same thing, I changed it immediately. Similarly, if a suggestion quickly came up in two or three interviews, I changed it before moving forward. I also made some adjustments based on my own internal thoughts between interviews.

The names of the cognitive pre-testers are pseudonyms.

1) **Chaka** – Friday, 8/12/22

- Noticed that a full paragraph was repeated in the instructions.
- Said the study information was too long and made her not want to continue. She asked whether it could be shortened.
- At the first demographics question, she said she was so tired of having to label herself. She wants to be able to choose everything that she is as her race, thereby including her white grandmother.
- Knew more than one person with BC but survey restricted her to choosing only one.
- Using dedicatedly correct grammar, and therefore the use of “whom,” made her have to stop and reread the questions using that format. She suggested I make those questions more readable, despite incorrect grammar.
- In BW & BC section, noted that the third question was about “participants” but did not clarify who these participants were.
- Randomized into the legacy norm letter and after reading, commented that it “really made you want to donate b/c you’re looking out for your children & grandchildren,” and said the letter is very convincing.
- Wondered whether “family” in DN questions referred to immediate or extended.
- Wondered whether “consequences” in LN questions referred only to bad ones.
- Recognized her own job description as “personal care”
- For combo plate question, 1st/2nd choices were: IN #2/#1, DN #1/#3, LN #1/#2

Following this interview, I:

- Changed both questions about who you know who has BC to be able to check more than one answer.
- Made both questions regarding w knowledge of people with or who had died from BC more readable by changing “whom” to “who.”

2) **Houston** - Tuesday, 8/16/22

- Suggested some rearrangement of the study instructions language.

- Suggested removal of “I am non-gendered” from response options for gender question.
- Suggested some rewording of the first question in the BW & BC section.
- Noticed the appropriateness of the reading level and noted that was important.
- Randomized into IN letter; did not like the wording of the first bullet point.
- Acknowledged that if she had not been asked to read out loud, she would have skipped over all instructions and just answered the questions.
- Had some questions about the meaning of the 2nd & 4th statements on the LN measurement, said the wording was unclear.
- Suggested adjustment of final LN measurement question for clarity.
- For combo plate question, 1st/2nd choices were: IN #2/#4, DN #4/#2, LN #2/#1

Following this interview, I:

- Removed “I am non-gendered” from response options for gender question.
- Made adjustment of final LN measurement question.

3) **Nina** - Tuesday, 8/16/22

- Complained that the study instructions were too long and repetitive.
- Said she would have chosen both Black and AA for race, and that she was used to the option being only “Black/African American”
- Noticed several technical glitches.
- Suggested further edits of “who do you know who has BC” questions to aid in clarity.
- Randomized into combo norm letter.
- Suggested that anytime a number was used, that is was always written out in both words and (numerical value).
- Pointed out some redundancies in the control letter (*not acted on, as no one else made this comment, and I did not see it as a problem.*)
- Had a hawk eye for any typos and/or extra spaces, etc. Nneka is a scientist and is careful about details.
- Asked for a “thermometer” so she would know how much of the survey was completed.
- Did not find an occupational field she was happy with and made other suggestions about the readability of the occupational categories list.
- For combo plate question, 1st/2nd choices were: IN #2/NA, DN #1/NA, LN #4/#1.

Following this interview, I:

- Edited, shortened, and rearranged the study information
- Fixed tech problems.

4) **Meshell** – Wednesday, 8/17/22

- Complete the survey on a mobile phone.
- Seemed to flow well through the edited study instructions.
- She noticed a tendency to think about others as she answered the Black identity questions and had to remind herself she was not answering for others. Suggested adding language to instructions to help with that.
- Randomized into the control condition, and said she found it to be persuasive.
- Had some questions about the meaning of the 2nd & 4th statements on the LN measurement (as did Hadya before).
- Commented that the survey worked very well on her mobile device; flowed well, good sized font, spaced out well, and easy to navigate.
- For combo plate question, 1st/2nd choices were: IN #1/#3, DN #1/#2, LN #2/#4.

Following this interview, I:

- Further adapted the questions in the LN measurement for clarity.

5) **Della** – Friday, 8/19/22

- In study instructions, suggested the first eligibility criterion be divided into two separate items for clarity. Also suggested a re-wording of the identity protection section.
- Said the last paragraph of the study instructions was wordy and unclear.
- In BW w/BC section, noted that the third question was about “participants” but did not clarify who these participants were (repeated earlier by others.)
- Thought that the letter had been tailored b/c the instructions for the BW & BC section called her “Black.”
- Randomized into the LN letter and after reading, commented that it was not compelling enough (contrary to CC’s response after reading the same letter).
- Strongly suggested that “donation” in the letter was changed to “donation process” to clarify that the time spent was not just for the actual donation (*very helpful that she has donated tissue and could point this out!*)
- Also noticed lack of a progress bar.
- Commented on the response options to highest level of formal education and noted that there was an option for having had some elementary school, but no option for having completed elementary school.
- Noted that ethically, there should be a reminder that clicking submit meant that data from the responses could not be recalled.

Following this interview, I:

- Made further edits to the study instructions section.
- Separated the first eligibility criterion into two separate items for clarity, creating a final list of five (5) eligibility criteria.
- Adjusted the wording of the first question in the BW & BC section by adding the word “usual” before response, to facilitate ease of choosing the label most comfortable for the participant.

- clarified who the participants were in the third question of the BW & BC question.
- For consistency, edited the BW & BC instructions to include all of the identity options so that everyone would find their particular identity choice listed there.
- Made edits to “who do you know who has BC” questions to clarify that the person could either currently or previously had BC.
- Added clearer instructions about using the slider for the second DN question.
- Reworded the first question in the BW & BC section for clarity.
- Made several changes to the actual letters as suggested by all interviewees, including wording changes, corrections for clarity, and changing the combo norm letter bullet points to the ones chosen by this condition as most effective.
- Fully edited, added to, and re-ordered the list of job categories to be more concise, consistent, and inclusive.
- Added both “completed 8th grade” and “some high school” to the formal education options for consistency.
- Edited the thank you message at the end to include a reminder that submitting responses meant there were no options to recall the data.
- Added a progress bar so participants could tell how far along in the survey they were.

APPENDIX F

Supplementary Tables

Occupations of Participants (Participant Responses = 323)

Occupation	# of Participants
Agriculture	8
Architecture	1
Arts, Design, and/or Entertainment	24
Aviation	1
Building and/or Grounds Cleaning	4
Building Maintenance	10
Business and/or Financial Operations	9
Community and/or Social Service	19
Computer, IT, and/or Mathematical	21
Customer Service	22
Factory and/or Warehouse	2
Food Preparation and/or Serving	8
Government	3
Healthcare (General)	13
Healthcare Practitioners	44
Home and Family Management	15
Installation, Maintenance, and/or Repair	5
Law Enforcement, Security, First Response, or Protective Services	2
Legal	0
Life, Physical, or Social Science	16
Management	6
Marketing Research	3
Media	6
Military	5
Ministry	1
Non-Profit	4
Office and Administrative Support	2
Personal Care and Service	3
Protective Service	4
Public Health	2
Real Estate	1
Sales or Sales Related	4
Science, Research, or Pharmaceuticals	2
Sports and/or Leisure Related	4
Technology or Tech Related	34
Transportation and/or Material Moving	11
Volunteer Services	4

Black Women's Awareness of Black Women and Breast Cancer
 (Total Number of Participants = 635)

Personally Know Someone who Has/Had Breast Cancer

Yes	449
No	148
Not Sure	38

Relationship to Person (optional response)

Grandmother	29
Mother	20
Aunt	38
Daughter	1
Sister	14
Other family member	50
Friend	106
Coworker	22
Other	24
Prefer not to answer	3

Personally Know Someone Who Died from Breast Cancer

Yes	305
No	286
Not Sure	44

Relationship to Person (optional response)

Grandmother	35
Mother	4
Aunt	39
Daughter	0
Sister	10
Other family member	59
Friend	62
Coworker	15
Other	22
Prefer not to answer	0

Black Women's Awareness of Black Women and Breast Cancer (Total Number of Participants = 635)

Black, African, African American, Afro-Caribbean, or women of African descent do not often develop breast cancer.	True	False	I don't know
# of Participants	49	76	510
approx. % of Participants	7.7	12	80.3
Black, African, African American, Afro-Caribbean, or women of African descent have a similar risk of death from breast cancer as White women.	True	False	I don't know
# of Participants	345	183	107
approx. % of Participants	54.3	28.8	16.9

Black Women's Trust of Researchers (Total Number of Participants = 635)

Participants should be concerned about being deceived or misled by medical researchers.	Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree
# of Participants	44	100	241	154	96
approx. % of Participants	6.9	15.7	38	24.23	15.1

Reliability Statistics

Reliability Statistics

Injunctive Norm

Cronbach's Alpha 0.928

N of Items 4

Descriptive Norm

Cronbach's Alpha 0.863

N of Items 3

Legacy Norm

Cronbach's Alpha 0.768

N of Items 6

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Zou, X., & Savani, K. (2019). Descriptive norms for me, injunctive norms for you: Using norms to explain the risk gap. *Judgment & Decision Making*, 16(6), 644–648.

Curriculum Vitae
Katherine Ellen Ridley-Merriweather

Education

Doctor of Philosophy, Health Communication

Indiana University-Purdue University Indianapolis, July 2023

Minor: Applied Methods Addressing Racial & Ethnic Disparity

Dissertation Project: *Testing the Effect of Culturally Targeted, Normative Messaging on Black Women's Intentions to Participate in a Breast Cancer Clinical Trial*

Doctoral and Dissertation Committee: Katharine J. Head (chair), Krista Hoffmann-Longtin, Maria Brann, Leslie Ashburn-Nardo

Master of Arts, Applied Communication

Indiana University-Purdue University Indianapolis, December 2016

Emphasis: Health Communication

Thesis Project: *Asian American Women's Perspectives on Donating Healthy Breast Tissue: Implications for Recruitment Methods and Messaging*

Thesis Committee: John Parrish-Sprowl (chair), Jennifer J. Bute, and Katharine J. Head

Bachelor of Arts, General Studies

Indiana University-Purdue University Indianapolis, December 2000

High Honors

Concentration: Arts and Humanities

Minor: German

Research Interests

- Illuminating the voices and perspectives of racial and ethnic minority women affected by breast cancer;
- Changing the conversation currently focused on cultural barriers toward identifying and increasing the motivations of women from racialized and minoritized populations to participate in breast cancer clinical trials;
- Designing well researched, communication-focused and culture-relevant persuasive health messaging to educate women from racialized and minoritized populations about breast cancer prevention and clinical trial participation; and
- Applying rigorous qualitative communication-focused research theories and methods to design reproducible recruitment processes that will ultimately help reduce racial disparities in breast and other cancer research.

Professional Work Experience

- Biospecimen Collection and Banking Core, IU Simon Comprehensive Cancer Center, Indianapolis, IN
 - Communication, Recruitment, and Outreach Manager, August, 2021 – Present,

- Susan G. Komen Tissue Bank at the IU Simon Comprehensive Cancer Center
 - Communication and Minority Outreach Coordinator; January 2011 – August, 2021, Indianapolis, IN
- St. Richard’s Episcopal School, Indianapolis, IN
 - Director of Aftercare and Summer Camps Programs, September 2003 – December 201025
- Indy Youthworks, Indianapolis, IN
 - Co-Founder, Owner, Executive Director, June 2001 – May 2018

Peer-reviewed Journal Articles

- Ridley-Merriweather, K. E., Head, K. J., Younker, S. M., Evans, M. D., Moore, C. M., Lindsey, D. S., Wu, C. Y., & Wiehe, S. E. (2022). A novel qualitative approach for identifying effective communication for recruitment of minority women to a breast cancer prevention study. *Contemporary Clinical Trials Communications*, 27, 1-9. <https://doi.org/10.1016/j.conctc.2022.100910>
- Kikut, A., Sanyal, M., Vaughn, M., Ridley-Merriweather, K.E., Head, K.J., Salowe, R., Lomax-Reese, S., Lewis, M., Ross, A.G., Cui, Q.N., Addis, V., Sankar, P.S., Miller-Ellis, E., & O’Brien, J. M. (2022). Learning from Black/African American Participants: Applying the Integrated Behavioral Model to Assess Recruitment Strategies for a Glaucoma Genetic Study. *Health Communication*, 37(4), 515-524. <https://doi.org/10.1080/10410236.2020.1853897>
- Ridley-Merriweather, K. E., Hoffmann-Longtin, K., & Owusu, R. K. (2021). Exploring how the terms “Black” and “African American” may shape health communication research. *Health Communication*, 1-7. <https://doi.org/10.1080/10410236.2021.1993533>
- Hoffmann-Longtin, K., Brann, M., Ridley-Merriweather, K., & Bach, B. W. (2020). Rethinking graduate student socialization and identification: How the communication discipline can help. *Communication Education*, 1-3. <https://doi.org/10.1080/03634523.2020.1811361>
- Ridley-Merriweather, K. E. & Head, K. J. (2017). African American women’s perspectives on donating healthy breast tissue for research: Implications for recruitment. *Health Communication*, 32, 1571-1580. <https://doi.org/10.1080/10410236.2016.1250191>

Book Chapters / Encyclopedia Entries

- Head, K.J., Ridley-Merriweather, K.E., (in press) *Media and Health*. In Handbook of Language in G. Martínez, P. Ortega, M. Lor, & S. Ramírez (Eds.). Public Health and Healthcare.
- Ridley-Merriweather, K. E., (2022). Clinical Trials Recruitment: Underrepresented Groups. In *The International Encyclopedia of Health*

Communication (pp. 1–7). John Wiley & Sons, Ltd.
<https://doi.org/10.1002/9781119678816.iehc0905>

- Head, K. J., Bute, J. J., & Ridley-Merriweather, K. E. (2021). Everyday interpersonal communication about health and illness. In T. L. Thompson & N. H. Harrington (Eds.), *Handbook of Health Communication* (3rd ed., pp. 149-162). Routledge.

Scholarly Conference Sessions and Presentations (competitively selected)

- Ridley-Merriweather, K. E., Okoruwu, O. P., Storniolo, AM. (2022, December 6-10). *Examining recollections of Black women with breast cancer who participated in clinical trials: A grounded practical theory study of patient-provider communication*. Poster presented at the 2022 AACR San Antonio Breast Cancer Virtual Symposium, San Antonio. TX.
- Ridley-Merriweather, K. E., (2022, September 16-19). *Examining recollections of Black women with breast cancer who participated in clinical trials: A grounded practical theory study of patient-provider communication*. Poster presented at the AACR Disparities in Cancer Research Virtual Conference, Philadelphia, PA.
- Ridley-Merriweather, K. E., (2022, April 8-13). *Identifying effective communication for recruitment of minority women to a breast cancer prevention study: A novel focus group approach*. Poster presented at the AACR Annual Meeting, New Orleans, LA.
- Ridley-Merriweather, K. E., (2022, April 7-9). *Examining Recollections of Black Women with Breast Cancer Who Participated in Clinical Trials: A Grounded Practical Theory Study of Patient-Provider Communication*. Paper presented at the Kentucky Conference on Health Communication, Lexington, KY.
- Ridley-Merriweather, K. E., Owusu, R. K., Hoffmann-Longtin, K. (2021, April 22-24). *Exploring how the terms “Black” and “African American” may shape health communication research*. Paper presented at the D.C. Health Communication Virtual Conference.
- Ridley-Merriweather, K. E., Head, K. J., Brann, M., Giron, A. (2020, December 8-11). *“I’m willing to be that woman”: Exploring Black women’s decisions to participate in breast cancer clinical trials*. [Abstract nr PS7-48]. Poster presented at the 2020 AACR San Antonio Breast Cancer Virtual Symposium, San Antonio. TX.
- Ridley-Merriweather, K. E. (2020, October 2-5). *Putting their money where their mouths are: A review of the literature concerning health research and grant funding organizations and the recruitment of Black women to breast cancer clinical trials*. Poster presented at the AACR Disparities in Cancer Research Virtual Conference.

- *Kikut, A., Sanyal, M., Vaughn, M., Ridley-Merriweather, K.E., Head, K.J., Salowe, R., Lomax-Reese, S., Lewis, M., Ross, A.G., Cui, Q.N., Addis, V., Sankar, P.S., Miller-Ellis, E., O'Brien, J.M. (2020, May 21-26). *Learning from the perspectives of African American participants: Assessing how a recruitment campaign motivated participation in a genetic research study*. Paper presented at the International Communication Association Virtual Conference.
 - *awarded top paper, Health Communication
- Ridley-Merriweather, K. E., Head, K. J., Brann, M., Giron, A. (2020, April 2-4). "I'm willing to be that woman:" Exploring Black Women's Decisions to Participate in Breast Cancer Clinical Trials through the Integrated Behavioral Model. Paper presented at the Kentucky Conference on Health Communication, Lexington, KY.
- Ridley-Merriweather, K. E. (2019, September). *What About Me? A Content Analysis of Triple Negative Breast Cancer Clinical Trial Inclusion Eligibility Criteria*. Poster presented at the AACR Disparities in Cancer Research Conference (San Francisco, CA).
- Ridley-Merriweather, K. E. (2019, September). *Motivation through Relational Communication: Examining the Normative Social Behavior of African American Women Who Participate in Breast Cancer Clinical Trials*. Poster presented at the AACR Disparities in Cancer Research Conference (San Francisco, CA).
- Ridley-Merriweather, K.E. (2018, April). *An Interactive Focus Group Approach to Examining Effective Communication for Recruitment of Hispanic and Asian American Women to a Breast Cancer Prevention Study*. Paper presented at the Kentucky Conference on Health Communication, Lexington, KY.
- Harris, C., Ridley-Merriweather, K.E., Arnold, R. (2018, March). *Diversity by Design: Strategies to Engage Minority Communities in Bio-Medical Research*. Webinar presented on the National Cancer Institute ENRICH Forum.
- Ridley-Merriweather, K.E. (2017, September). *Asian American women's perspectives toward donating healthy breast tissue: Implications for recruitment methods and messaging*. Poster presented at the AACR Disparities in Cancer Research Conference (Atlanta, GA).
- *Ridley-Merriweather, K. E. & Head, K. J. (2016, April). *African American women's perspectives on donating healthy breast tissue for research: Implications for recruitment*. Poster presented at the Kentucky Conference on Health Communication (Lexington, KY).
 - *awarded top poster honorable mention at KCHC 2016

- *Ridley-Merriweather, K. E. & Head, K. J. (2016, May). *African American women's perspectives on donating healthy breast tissue for research: Implications for recruitment*. Poster presented at the IU Simon Cancer Center Annual Cancer Research Day, Indianapolis, IN
 - *awarded third place in Behavioral and Population Science category

Invited Speaker

- Ridley-Merriweather, K.E. (2023, April 28) *Identity and Legacy; Keys to Recruiting Black Women to Preventive and Clinical Breast Cancer Clinical Trials*. Keynote Speaker. Equity in Action: Strategies to Advance Diversity, Justice, and Inclusion in Research Symposium, UM Miller School of Medicine, Sylvester Comprehensive Cancer Center.
- Ridley-Merriweather, K.E. (2021, May 10-11) *Exploring How the Terms "Black" and "African American" May Shape Health Communication Research*. University of Wroclaw Communication & Culture Virtual Conference.
- Ridley-Merriweather, K.E. (2021, May). *Recruiting Black and Brown Women to the Komen Tissue Bank: A Motivational Roadmap*. Speaker at International Society for Biological and Environmental Repositories 2021 Virtual Annual Meeting & Exhibits.
- Ridley-Merriweather, K.E (2021, April 13). *Identifying Effective Communication for Recruitment of Minority Women to a Breast Cancer Prevention Study: A Novel Focus Group Approach*. Seminars in Medical Humanities and Health Studies, Indiana University-Purdue University Indianapolis, Indianapolis, IN.
- Ridley-Merriweather, K.E. (2020, October 28). *"I'm Willing to Be That Woman": Exploring Women's Decisions to Participate in Cancer Clinical Trials, and Examining the Effects of Novel Communication Methods on Recruitment of Hispanic and Asian American Women to a Breast Cancer Prevention Study*. Healthcare inequity And Racism in medicine (HEAR) series. Indiana University School of Medicine, Indianapolis, IN.
- Ridley-Merriweather, K.E. (2020, April – canceled for pandemic). *Recruiting Racial and Ethnic Minority Women to the Komen Tissue Bank: A Motivational Roadmap*. Speaker at International Society for Biological and Environmental Repositories 2020 Annual Meeting & Exhibits, Co, Research Centers in Minority Institutions (RCMI) Translational Science 2017: Innovate, Translate, Collaborate, Engage, Community, Washington D.C.
- Rufenbarger, C. & **Ridley-Merriweather, K.E.** (2017, October). *The Komen Tissue Bank*. Co-Speaker at pre-conference, Research Centers in Minority Institutions (RCMI) Translational Science 2017: Innovate, Translate, Collaborate, Engage, Community, Washington D.C.

Non-Refereed Publications

- Ridley-Merriweather, K. E., (2018). The Komen Tissue Bank White Paper. ResearchGate.
- Ridley-Merriweather, K. E., Moore, C. M., Wiehe, S. E. (2016) *The Komen Tissue Bank Minority Recruitment Booklet*. Retrieved from https://komentissuebank.iu.edu/wp-content/uploads/2017/03/Minority-Women_english.pdf

Applied Scholarship

- Ridley-Merriweather, K. E., (2015, updated semi-annually). *The Komen Tissue Bank Recruitment Flyer*. <https://komentissuebank.iu.edu/docs/media-resources/general-minority-flyer.pdf>
- Ridley-Merriweather, K. E., (2016, updated annually). *The Komen Tissue Bank Minority Recruitment Team Handbook*. https://komentissuebank.iu.edu/docs/media-resources/komen_book_final_rv2_read.pdf

Grants Awarded

- Testing The Effect of Culturally Targeted, Normative Messaging on Black Women's Intentions to Participate in a Breast Cancer Clinical Trial. (July 2021). Received from the Catherine Peachey Fund / Heroes Foundation. Award Amount \$14,000. Description: This project focuses on creating and testing normative messaging culturally targeted to recruit Black women to participate in an unconventional preventive breast cancer clinical trial. Although the messages created for this dissertation are specifically geared toward a particular clinical trial, these processes can be readily adapted to help increase minoritized populations' recruitment to clinical trials studying other cancers, diseases, or medical processes (such as organ donation.)
- CRES Conversations About Faith & Science Series. (July 2019 – July 2020). *A Faith Leader & a Scientist Walk into a Bar*. Received from Consortium for the Study of Religion, Ethics, and Society Seminar Series. Co-PI, with Krista Hoffmann-Longtin, Jason Organ, & Melvin Wininger. Award Amount \$6,000. Description: Develop a six-seminar series for faculty members, religious leaders, and community members designed to encourage empathy between scientists and members of faith communities, as empathy is a critical component of collaborative relationships and productive conversations.
- Identifying the Motivations of Minority Women to Donate Healthy Breast Tissue. (June 2020). Received from the Catherine Peachey Fund / Heroes Foundation. Award Amount \$1,380. Description: This project's goal is to identify why Black, Hispanic/Latina, and Asian women choose to donate healthy breast tissue to the Komen Tissue Bank at the IU Simon Cancer Center. To accomplish this, the research team will conduct guided interviews with minority tissue donors to better

understand the determinants and considerations that led these women to donate healthy breast tissue.

- We Need to Know study. (May 2019). Received from the Catherine Peachey Fund / Heroes Foundation. Award Amount \$2,700. Award was applied to incentive purchases. Description: This project involved holding and interactive focus group with Black women and completed a three-phase set of focus groups and was phase 3 of a three-part series. The first two focus groups were held with Asian and Hispanic women. The study sought, through interactive activities, to better understand the determinants and considerations that would influence Black women without knowledge of the Komen Tissue Bank to donate healthy breast tissue.

Academic Teaching

University of Indianapolis, August 2015-present

Courses taught as instructor of record:

COMM 100: Public Speaking (Fall and Spring semesters)

Fall 2015: 1 section (18 students)	Spring 2016: 1 section (18 students)
Fall 2016: 2 sections (32 students)	Spring 2017: 1 section (18 students)
Fall 2017: 1 section (17 students)	Spring 2018: 1 section (15 students)
Fall 2018: 1 section (15 students)	Spring 2019: 1 section (17 students)
Fall 2019: 1 section (14 students)	Spring 2020: 1 section (15 students)
Fall 2020: 2 sections (36 students)	Spring 2021: 2 sections (40 students)

Guest Lecturer / Invited Presenter:

- Health Campaigns; November 2, 2022, IUPUI Dept. of Communication Studies, Katharine Head PhD, Associate Professor.
- Health Promotion; Feb.4, 2021, University of Oregon School of Journalism and Communication, Autumn Shafer, PhD, Associate Professor.
- Patient-Provider Communication; March 17, 2021, IUPUI Dept. of Communication Studies, Katharine Head PhD, Associate Professor.

Fellowships, Awards, Recognition

- IUPUI Department of Communication Studies, Travel Grant Award, Spring Semester 2022.
- IUPUI Top-Ranked Outstanding Graduate Research and Creative Project, (April 2020). *Communication Program Plan Proposal – Increasing Indianapolis Black Women’s Intention to Participate in Medical Research*. Awarded by the Graduate Program in Communication, IUPUI.
- IUPUI Elite 50, March 2020, Awarded by Indiana University-Purdue University Indianapolis

- IUPUI Outstanding Graduate Paper Award, (April 2019). *Communication Program Plan Proposal – Increasing Indianapolis Black Women’s Intention to Participate in Medical Research*. Awarded by the Graduate Program in Communication, IUPUI.
- Academic Achievement for Communication Studies 2017, January 2017, \$250, Awarded by the Department of Communication Faculty, IU School of Liberal Arts, IUPUI.
- IUPUI Outstanding Graduate Paper Award, (April, 2015). *African American Women’s Perspectives on Donating Healthy Breast Tissue for Research: Implications for Recruitment*. Awarded by the Graduate Program in Communication, IUPUI.
- Graduate Travel Award, November 2015, \$500, Awarded by the Graduate Program in Communication, IUPUI.
- NCA Travel Award, November 2015, \$200, Awarded by the NCA travel grants committee, Washington, D.C.

Departmental & University Service

- Mission, Vision, Goals, and Values Subcommittee Member, IU Simon Comprehensive Cancer Center, February-May 2022. Chair: Rachel Katzenellenbogen
- Search Committee Member; IUPUI Visiting Lecturer in Applied Theatre, May-July 2019. Chair: Krista Hoffmann-Longtin, PhD.
- Presenter Host; 2019 Joseph T. Taylor Symposium hosted by IUPUI Department of Communication Studies, February 20, 2019, IUPUI Campus Center.
- Committee Member; Department of Communication Studies Graduate Program Orientation Committee, August 2019.

Service to Profession

- Academic Journal Peer Reviewer, *Health Communication* (March 2021, Sept. 2021)

Professional & Service Organizations

- American Psychological Association, Member 2019 – Present
- American Association for Cancer Research, Member 2015 – Present
- National Communication Association, Member: 2015 – Present
- Actors Equity Association, Member: 1986 – Present
- Alpha Kappa Alpha Sorority Inc., Member: 1979 – Present

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