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Changing Landscapes: Perspectives of Young African American Women of Population-Wide  
Testing for Hereditary Breast Cancer Mutations

A dissertation submitted in partial fulfillment of the requirements for the degree of Doctor of  
Philosophy at Virginia Commonwealth University.

by

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*“The nature of this flower is to bloom.”*

-Alice Walker

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## **Abstract**

Changing Landscapes: Perspectives of Young African American Women of Population-Wide Testing for Hereditary Breast Cancer Mutations

By Alesha Henderson, MA

A dissertation submitted in partial fulfillment of the requirements for the degree of Doctor of Philosophy at Virginia Commonwealth University.

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Virginia Commonwealth University, 2020

INTRODUCTION: Young African American women continue to die from breast cancer at higher rates than White women. In an effort to promote breast cancer prevention, population-wide testing (PWT) for all women in the U.S. starting at age 30 is a potential future initiative that is garnering a lot of attention. The decreasing cost of genetic testing may make this a possible reality in the future. However, African American women currently utilize genetic testing for hereditary breast cancer at lower rates than White women. Therefore, if young African American women are not prioritized in a future roll out of PWT, then existing breast cancer and genetic testing disparities will likely continue to widen.

**PURPOSE:** The purpose of this dissertation was to conduct a sequential exploratory mixed methods study to understand young African American women's (18-30 years) perspectives towards hereditary breast cancer mutations, direct to consumer testing, PWT, as well as health communication preferences. This study also aimed to explore the factors that influence intentions to participate in such a service in the future.

**METHODS:** Seven focus groups were conducted with 39 young women residing in a southern community and attending two local universities. A thematic analysis was conducted using MAXQDA qualitative software to identify themes and subthemes. A survey was developed based upon focus group findings and tested using two rounds of cognitive interviews (n=10). The survey was distributed via Qualtrics Online Sample (n=170) to examine the factors that influence intentions to participate in PWT. Simple and multiple regressions were conducted to understand which factors were significantly associated with intentions.

**RESULTS:** Focus group participants had limited to no knowledge about hereditary breast cancer mutations. Participants indicated that it was important for PWT to be accessible to everyone, normalized in American society, and to be thoroughly researched before it is presented as a viable option to the general public. Motivators to participate in PWT included having a family history of breast cancer, access to equitable healthcare quality, and concerns for future offspring. Barriers to intended participation in PWT included medical mistrust and concerns about affordability. Moreover, survey findings indicated that participants had moderate knowledge of hereditary breast cancer mutations and moderate levels of medical mistrust. Separate unadjusted

and adjusted multiple regressions indicated that both subjective norms and motivators to participate in direct to consumer testing remained significant predictors of intentions to participate in PWT after accounting for sociodemographic variables.

CONCLUSION: This was the first study to preemptively explore young African American women's perspectives and intentions to participate in future PWT. As discussions continue about the potential for this new service, it will be imperative for researchers and public health practitioners to prioritize the needs and preferences of young African American women when designing interventions and potential health promotion strategies. This study findings provide potential avenues for future research, public health programming, trainings, and public campaigns in this area.

## **Chapter 1: Introduction**

### **Background**

African American women are more likely to die from breast cancer than any other racial group (Desantis et al. 2019). Despite White women having the highest incidence of breast cancer, African American women are most likely to be diagnosed at earlier ages, later stages, and more likely to be diagnosed with triple negative breast cancer that lacks proper treatment and is associated with the presence of a hereditary breast cancer mutation. This disparity worsens when examining young African American women (>40 years). Young African American women, who are younger than the recommended mammography screening age, not only have the highest incidence and mortality rates of breast cancer but are also most likely to be diagnosed with triple negative breast cancer. Studies have also consistently found a high rate of hereditary breast cancer mutations amongst young African American women breast cancer survivors but that African American women tend to utilize genetic counseling and testing for hereditary breast cancer mutations at lower rates than White women (Armstrong, Micco, Carney, Stopfer, & Putt, 2005; Jones et al., 2016; Pal et al., 2015). To promote breast cancer prevention amongst all women in the United States, population-wide testing (PWT) for hereditary breast cancer mutations is being proposed for all women starting at age 30. However, given the current low participation rates of African American women in genetic counseling and testing for hereditary breast cancer mutations, the benefits of such a proposed initiative may not reach this group and in turn only widen existing breast cancer disparities. Understanding young African American women's perspectives and intentions to participate in PWT for hereditary breast cancer

mutations, may help to design interventions and health promotion programming to ultimately increase participation in this potential new service.

### **Genetic Counseling and Testing and African American women**

Genetic counseling and testing (GCT) for hereditary breast cancer mutations could provide a unique pathway to prevention and treatment of breast cancer among African American women (Force, 2019). Current statistics estimate that the breast cancer gene 1 and breast cancer gene 2 (*BRCA1/2*) account for between 5-10 percent of all breast cancers (Force, 2019). Genetic testing for *BRCA1/2* was recently expanded to multi-gene panel testing to account for other hereditary breast cancer genes, including *PALB2*, *ATM*, *TP53*, *PTEN* and a host of others (Afghahi & Kurian, 2017). These additional genes are said to account for between 5 and 6 percent of all breast cancers (Afghahi & Kurian, 2017). Given that African American women utilize genetic counseling and testing at lower rates than White women (Armstrong et al., 2005; Jones et al., 2019; McCarthy et al., 2016), researchers know considerably less about the prevalence of hereditary breast cancer mutations in this group. Malone et al. found that 4% of all breast cancers amongst African Americans had a *BRCA1/2* mutation present (Malone et al., 2006). Pal et al. found that 20% of African American women with triple negative breast cancer in the study sample had a *BRCA1/2* mutation and that those diagnosed with triple negative breast cancer at younger ages had an even higher percentage of *BRCA1/2* mutations (Pal et al., 2015). Further, they found that 22 percent of African American women under the age of 35 had a *BRCA1/2* mutation (Pal et al., 2015). When examining rates in multi-gene panel testing, Churpek et al. (2015) found that among the 65 African American women in their sample with a hereditary

breast cancer mutation, the sample consisted of 57 different types of hereditary breast cancer mutations (Churpek et al., 2015). Further, 20 percent of African American women with a hereditary breast cancer mutation were carriers of non-BRCA 1/2 genes from the multi-gene panel test (Churpek et al., 2015). These study findings point to the potential interconnectedness of some African American women's experiences with breast cancer and the presence of hereditary breast cancer mutations as well as the need to ensure that this group also reaps the benefits of PWT for hereditary breast cancer mutations.

The presence of hereditary breast cancer mutations in African American women is of concern because mutation carriers have an elevated risk (40-80%) of developing breast cancer over their lifetime (Institute, 2018 ; Petrucelli, Daly, & Feldman, 2010), compared to the average risk of 12% (DeSantis, Ma, Goding, Newman, & Jemal, 2017; Institute, 2018 ; Petrucelli et al., 2010). These mutations are hereditary in nature and are passed down from one family member to another (Petrucelli et al., 2010). The risk of having a hereditary breast cancer mutation among children and siblings of a mutation carrier is 50%, while nieces and nephews of a mutation carrier have a hereditary breast cancer mutation risk of 25% (Petrucelli et al., 2010). Getting tested not only has implications for understanding their own risks for breast cancer but also that of their families. Current recommendations from the National Comprehensive Cancer Network advise women who have a family history of breast cancer that is suggestive of a hereditary breast cancer mutation to undergo genetic counseling and testing beginning at 18 years old (NCCN, 2018). Several prevention strategies are available to women who find out that they are hereditary breast cancer mutation carriers, including preventive double mastectomy,

chemoprevention, and more frequent screening schedules than women who are not carriers (Force, 2019).

### **Barriers and Motivators to Genetic Counseling and Testing for African American women**

Most extant research has focused on the perspectives and knowledge levels around hereditary breast cancer of African American women (<40) with a family or personal history of breast cancer suggestive of a hereditary breast cancer mutation (Adams, Christopher, Williams, & Sheppard, 2015; Hughes, Fasaye, Lasalle, & Finch, 2003; Kessler et al., 2005; Sheppard et al., 2014; Sheppard, Mays, Tercyak, & LaVeist, 2013). Prior studies have indicated that lack of knowledge, high cost of testing, medical mistrust, limited access to healthcare, perceived familial approval of testing, and lack of physician recommendation are all barriers to the utilization of genetic counseling and testing services (Adams et al., 2015; McCarthy et al., 2016; Sheppard et al., 2014; Sheppard et al., 2013; Thompson et al., 2012). For example, Sheppard et al. 2014 found that African American women at high risk for hereditary breast cancer mutations were worried about how their genetic data would be stored and used against them in the future, potential high cost of testing, as well as issues surrounding access to healthcare services (Sheppard et al., 2014). African American women at high risk for breast cancer listed motivators to participate in genetic counseling and testing including, the potential benefit of disclosing their status to family members so that they can also be aware of their future breast cancer risk, the ability to have the counseling and testing covered by insurance, and the ability to help other individuals in the Black community (Sheppard et al., 2014).



Studies focusing on the perspectives of African American women without a family or personal history of breast cancer have been limited. Adams et al. (2015) employed intercept interviews with African American women without a family history suggestive of hereditary breast cancer at public places in Washington, D.C. to understand perspectives of hereditary breast cancer mutations (Adams et al., 2015). Study participants mentioned similar advantages and disadvantages of hereditary breast cancer mutations as African American women at high risk for the mutations including, cancer prevention and the ability to inform family members of their breast cancer risk, medical mistrust, and potential emotional distress caused by knowing their status (Adams et al., 2015). However, many of the women indicated that they would participate in testing if offered to them (Adams et al., 2015). Currently, there is only one study that includes African American women's perspectives about and perceived acceptability of PWT but the mean age of participants was 37.7 years (Rubinsak et al., 2019). If PWT is implemented in the future, it will be imperative to understand whether African American women approaching the proposed screening age (18-30) for PWT mirror those of older African American women.

### **The Push for Population-wide testing**

In 2014, the founder of hereditary breast cancer mutations, Mary-Claire King, and colleagues called for PWT for *BRCA1/2* mutations for all women regardless of their family history of breast cancer beginning at age 30. The call for PWT was prompted by a study that indicated that up to 50 percent of hereditary breast cancer mutations are missed with current screening criteria (King, Levy-Lahad, & Lahad, 2014) . Furthermore, King et al. 2014 expressed concerns about genetic counseling and testing not being used until after a woman has been

diagnosed with breast cancer instead of being used as a form of breast cancer prevention (King et al., 2014). Furthermore, making the switch to PWT would eliminate the current model that hinges on physicians as gatekeepers to genetic counseling and testing for the mutations. Prior research has shown that physicians lack knowledge about genetic counseling and testing for hereditary breast cancer mutations. Moreover, Bellcross et al. 2011 found that less than 20 percent of primary care physicians knew all of the increased-risk for hereditary breast cancer mutations scenarios provided in the study (Bellcross et al., 2011). The elimination of the need for physician recommendation for genetic counseling and testing could be beneficial to all women but could be transformative for breast cancer prevention amongst African American women given that formative research has consistently indicated that lack of physician recommendation is a major barrier to participation in genetic counseling and testing.

As can be expected of any new preventive service, there are several oppositions to PWT. Opponents, of PWT argue that it is hard to justify implementing PWT in more diverse and larger populations, such as the United States, that may prove to not be cost effective based upon current *BRCA1/2* risk estimates (Foulkes, Knoppers, & Turnbull, 2016; Long & Ganz, 2015). Furthermore, the research supporting PWT is largely based upon studies with Ashkenazi Jews, who are known to have a high prevalence of hereditary breast cancer mutations (Foulkes et al., 2016). Therefore, given that the United States has a more diverse population, there will also be increased risk for false positives as well as the identification of variants of unknown significance that cause unnecessary psychological distress, especially in minority populations (Foulkes et al., 2016; Yurgelun, Hiller, & Garber, 2015). Despite the challenges to implementation of PWT,

recent studies indicating the cost-effectiveness of PWT and the acceptability of this initiative to women provide strong support for this initiative to become a reality in the future (Manchanda & Gaba, 2018; Rubinsak et al., 2019). Given the potential challenges of implementing PWT as it relates to minority populations, it is important to proactively understand the potential challenges and barriers that may impact African American women's uptake of PWT.

### **Potential Population-wide testing and Young African American women**

African American women from the millennial generation are an important target population for this study given that, if implemented, PWT would begin at 30 years for all women in the United States. The perspectives of younger African American women, who are approaching the proposed screening age for PWT, are important because they are approaching eligibility to use this service as a pathway to breast cancer prevention if PWT was to be implemented. African American women are disproportionately impacted by the breast cancer disparity and currently utilize genetic counseling and testing for hereditary breast cancer mutations at lower rates than White women, therefore it is imperative that researchers preemptively gather the perspectives of young African American women towards PWT. Their perspectives would provide insights into recommendations for public health practitioners at both local and state health departments to reach and raise awareness in this group around PWT for hereditary breast cancer mutations. Moreover, their participation in counseling and testing could provide a better understanding of variants of unknown significance found in this population. Some may argue that capturing this population's perspectives would be premature since this is still an ongoing debate but it is critical that we preemptively explore the perspectives and needs

of populations that are underrepresented in genetic counseling and testing services as well as those that are disproportionately impacted by breast cancer when thinking about rolling out PWT. If the tides do shift towards PWT for hereditary breast cancer mutations in the United States, disparities in both breast cancer and genetic counseling and testing utilization among younger African American women will continue if we do not proactively seek out their perspectives of this potential shift.

Younger African American women's perspectives towards genetic counseling and testing for hereditary breast cancer mutations may be vastly different from older African American women, given that they have been exposed to the proliferation of direct to consumer genetic services that provide information about the connection between their genes and health to their front door without the need for a physician recommendation (Bowen & Khoury, 2018; Estrada, 2017). The millennial generation of African American women born between 1982 and 2004 came of age during the technology revolution and most recently during the rise of direct to consumer genetic testing used to provide answers about ancestry and health. Direct to consumer genetic testing services (DTC testing), such as Ancestry.com and 23andMe, are steadily increasing in popularity in the United States (Bowen & Khoury, 2018). To date, there have been a limited number of studies that provide insight into DTC testing uptake and the perspectives of racial minorities on DTC testing (Bloss et al., 2010; Carroll et al., 2019; Hensley Alford et al., 2011; Landry et al., 2017). Studies have found that African Americans use DTC testing at similar rates as Whites and are more interested in using these services to learn about ancestry than disease information (Carroll et al., 2019; Landry et al., 2017). However, none have focused

specifically on young African American women's perspectives of DTC testing services. There are distinct differences between DTC testing and population-wide testing in that DTC testing is largely handled by private companies whereas PWT would be implemented by the healthcare system. Despite these differences, young African American women's perspectives on an already widely available genetic counseling and testing service, such as DTC testing, could provide further insight into their perspectives about PWT in the future.

### **Research Aims and Hypotheses**

To date, few, if any studies have focused on the knowledge gaps and perspectives of African American women (18-30 years) from the millennial generation towards hereditary breast cancer mutations and PWT for hereditary breast cancer mutations. Given the current proposal for PWT for hereditary breast cancer mutations, it is imperative that as researchers preemptively assess the needs and perspectives of young African American women given the known breast cancer disparity. Therefore, the purpose of this dissertation is to conduct a sequential exploratory mixed methods study to understand young African American women's perspectives towards hereditary breast cancer mutations, PWT, DTC testing, and health communication preferences if PWT became available in the future. This study also aims to understand the factors that impact intentions to participate in PWT for hereditary breast cancer mutations in the future. The specific aims research aims and hypotheses are as follows:

**Aim 1:** Identify knowledge gaps and attitudes (perceived disadvantages, advantages, subjective norms, medical mistrust) towards genetic counseling for hereditary breast cancer mutations,

motivators and barriers to participating in PWT for hereditary breast cancer mutations, health communication preferences for PWT for hereditary breast cancer mutations among African American women aged 18-30 years old, and perspectives about DTC genetic testing services.

**Aim 1 Approach:** African American women between the ages of 18 and 30 will be recruited from Virginia Commonwealth University, Virginia Union University, and the Greater Richmond area to participate in six focus groups (N~40) about knowledge and perspectives of hereditary breast cancer mutations, willingness to participate in PWT, health communication preferences for PWT, as well as perspectives about DTC genetic testing services.

**Aim 2:** Examines the factors that influence young African American women's intentions to participate in PWT for hereditary breast cancer mutations.

**Aim 2 Approach:** African American women between the ages of 18 and 30 (N~ 160) will be recruited using Qualtrics Online Sample to complete a survey about their knowledge and perspectives of genetic counseling and testing for hereditary breast cancer mutations, intentions to participate in PWT for hereditary breast cancer mutations, health communication preferences, as well as perspectives about DTC genetic testing services.

**Hypothesis 1:** Participants will have low levels of knowledge about hereditary breast cancer mutations and low levels of medical mistrust.

**Hypothesis 2:** There will be a positive relationship between participants' attitudes towards DTC testing and intentions to participate in PWT.

***Hypothesis 3:*** There will be a positive relationship between participants' subjective norms and intentions to participate in PWT.

***Hypothesis 4:*** There will be a negative relationship between participants' individual medical mistrust and intentions to participate in PWT.

***Hypothesis 5:*** There will be a negative relationship between participants' group-based medical mistrust and intentions to participate in PWT.

***Hypothesis 6:*** There will be a positive relationship between participants' perspectives towards hereditary breast cancer mutations and intentions to participate in PWT.

***Hypothesis 7:*** There will be a positive relationship between perceived risk of hereditary breast cancer mutations and intentions to participate in PWT.

***Hypothesis 8:*** There will be a negative relationship between participants' perceived severity of breast cancer and intentions to participate in potential population-wide testing.

### **Dissertation format**

This aims of this study are presented in a three-paper format. All the papers provide an understanding of the literature relevant to the aim, methods used, as well as a results and discussion section.

(Aim 1): The first paper (Chapter 2) presents findings from the qualitative analysis of focus groups with young African American women (students and community residents) that aimed to explore their perspectives towards PWT in the U.S.

(Aim 2): The second paper (Chapter 3) provides insight into the factors that would impact young African American women's intentions to participate in PWT if offered in the future. These findings were gathered through a quantitative analysis of an online survey distributed through the Qualtrics Online Sample.

(Aim 3): The third paper (Chapter 4) utilizes health communication related findings from Chapters 2 and 3 to create a data brief. The data brief, "Population-wide testing for Hereditary Breast Cancer Genes: Recommendations for Public Health Practitioners to Reach and Raise Awareness Amongst Young African American Women," presents programming, training, and public health campaign recommendations that public health practitioners at health departments can use to best target and raise knowledge around PWT amongst young African American women (18-30 years). The chapter provides an overview that presents the importance of closing the translation gap between research and practice as well as the rationale for the brief. While other chapters of this dissertation will be submitted to traditional academic journals, this brief will be provided to key stakeholders at the Virginia Department of Health. It will also be disseminated via Facebook through the Black Ladies in Public Health private Facebook group that consists of over 10,000 public health practitioners.

The final chapter (Chapter 5) synthesizes the study findings as well as provides implications for future research and practice.



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## **Chapter 2**

### **Paper 1**

Young African American women's perspectives of the potential shift towards population-wide testing for hereditary breast cancer mutations: "We can do it, but just don't take from us."

## *Abstract*

Young African American women (<50 years) are twice as likely than their White counterparts to die from breast cancer. To promote breast cancer prevention, population-wide testing for hereditary breast cancer mutations was proposed for women in the U.S. starting at age 30. However, African American women currently utilize genetic testing for hereditary breast cancer at lower rates than White women. The purpose of this study is to examine the perspectives of African American women ages 18-30 towards population-wide testing for hereditary breast cancer mutations with the goal of understanding how to prevent the current utilization gap from widening if the new testing guidelines are adopted and to inform future health promotion campaigns. We conducted seven focus groups with 39 young women residing in a southern community and attending two local universities. Data was analyzed using a thematic analysis approach. Findings indicate participants had limited knowledge of hereditary breast cancer mutations but asserted that it was important for population-wide testing to be accessible to everyone, normalized in American society, and to be thoroughly researched before it is presented as a viable option to the general public. Motivators to participate in population-wide testing included having a family history of breast cancer, access to equitable healthcare quality, and concerns for future offspring. Barriers to intended participation in population-wide testing included medical mistrust and concerns about affordability. Future health promotion campaigns and research should determine how to normalize population-wide testing and increase geographic and economic accessibility for young African American women

*Key words:* **Health Disparities**, African American women, genetic counseling and testing, population-wide testing, hereditary breast cancer

### *Introduction*

African American women continue to die from breast cancer at a higher rate than White women. They are more likely to be diagnosed at earlier ages, with more advanced stages, and with triple-negative breast cancer which is a highly aggressive form of the disease that lacks targeted treatment (DeSantis et al., 2016; DeSantis, Ma, Goding, Newman, & Jemal, 2017; Dietze, Sistrunk, Miranda-Carboni, O'Regan, & Seewaldt, 2015). Furthermore, African American women under 40—who are younger than the recommended mammography screening age—not only have the highest incidence of breast cancer, but they also have the highest mortality rate of all racial groups (Anders, Johnson, Litton, Phillips, & Bleyer, 2009; Bleyer, O'Leary, & Ries, 2006). Finding ways to reduce these disparities is a pressing public health concern.

Genetic testing for hereditary breast cancer mutations provides a unique pathway to prevention and treatment of breast cancer, especially among African American women (Force, 2019). Hereditary breast cancer accounts for between 5 and 10 percent of all breast cancers (Force, 2019). However, African American women who meet the current hereditary breast cancer mutation counseling and testing profile utilize genetic counseling services at lower rates than their White women, making prediction of rates in this population difficult (Peterson et al., 2020). Researchers found that 20% of African American women with triple negative breast cancer had a *BRCA1/2* mutation (Breast cancer 1 and Breast cancer 2 mutations) and that those diagnosed with triple-negative breast cancer at younger ages had an even higher percentage of *BRCA1/2* mutations (Pal et al., 2015). Further, they found that 22 percent of the African

American women under the age of 35 had a *BRCA1/2* mutation (Pal et al., 2015). Another retrospective cohort study with young women with early onset of breast cancer found that African American women had the highest prevalence of hereditary breast cancer mutations (18.2%) in their sample (Jones et al., 2019). The presence of hereditary breast cancer mutations in African American women is important because mutation carriers have an elevated risk of developing breast cancer from 40-80% over their lifetime, compared to the average lifetime risk of 12% (DeSantis et al., 2017; Kuchenbaecker et al., 2017; Petrucelli, Daly, & Feldman, 2010). Hereditary breast cancer mutation carriers are also typically diagnosed with breast cancer at early ages, and *BRCA1* mutation carriers, specifically, are largely diagnosed with triple-negative breast cancer (Chen et al., 2018).

Current recommendations for genetic counseling and testing for hereditary breast cancer mutations from the National Comprehensive Cancer Network (NCCN) states the necessity of either a family or personal cancer history suggestive of having a hereditary breast cancer mutation (Force, 2019; Institute, 2018 ). However, given recent study findings indicating that the current screening criteria are not capturing all women with hereditary breast cancer mutations, there has been a call for population-wide testing (PWT) for all women in the United States starting at age 30 (King, Levy-Lahad, & Lahad, 2014). This potential shift in screening recommendations would remove the need to rely on an individual's knowledge of their family history and the need for physician recommendation for testing for hereditary breast cancer mutations (King et al., 2014). Lack of physician recommendation for screening has consistently



been cited as a major contributor to African American women's lower rates of utilization of genetic testing for hereditary breast cancer mutations (Armstrong, Micco, Carney, Stopfer, & Putt, 2005; McCarthy et al., 2016; Peterson et al., 2020). Therefore, if implemented, the potential benefits of PWT need to be communicated to all women, but especially to younger African American women, given the breast cancer disparity that disproportionately impacts them.

Existing research has focused on the perspectives and knowledge levels about hereditary breast cancer mutations of African American women (<40) with a family or personal history of breast cancer suggestive of a mutation (Adams, Christopher, Williams, & Sheppard, 2015; Hughes, Fasaye, Lasalle, & Finch, 2003; Hurtado-de-Mendoza, Jackson, Anderson, & Sheppard, 2017; Kessler et al., 2005; Sheppard et al., 2014; Sheppard, Mays, Tercyak, & LaVeist, 2013). Lack of knowledge, high cost of testing, medical mistrust, limited access to healthcare, and lack of physician recommendation fuels their lower utilization of genetic counseling services (Adams et al., 2015; Hurtado-de-Mendoza et al., 2017; McCarthy et al., 2016; Sheppard et al., 2014; Sheppard et al., 2013; Thompson et al., 2012). However, not much research has focused on capturing the perspectives of hereditary breast cancer mutations of African American women without a family history suggestive of a hereditary breast cancer mutation (Adams et al., 2015), and only one study has captured their attitudes about PWT for hereditary breast cancer mutations (Rubinsak et al., 2019). Further, to date, no studies have focused on the perspectives of young women, particularly young African American women, about this potential shift towards PWT

despite their heightened risk for early onset of breast cancer and triple negative breast cancer compared to other racial groups.

The millennial generation of African American women born between 1982 and 2004 came of age during the technology revolution and, most recently, during the rise of direct-to-consumer genetic testing that can be used to provide answers about their ancestry and health without the need for a physician recommendation. Direct-to-consumer genetic testing services (DTC testing), such as Ancestry.com and 23andMe, are steadily increasing in popularity in the United States (Bowen & Khoury, 2018). To date, there have been a limited number of studies that provide insight into DTC testing uptake and the perspectives of racial minorities on DTC testing (Bloss et al., 2010; Carroll et al., 2019; Hensley Alford et al., 2011; Landry et al., 2017). These studies have found that African Americans use DTC testing at similar rates as their White counterparts and are more interested in using these services to learn about their ancestry than disease information (Carroll et al., 2019; Landry et al., 2017). However, none have focused specifically on young African American women's perspectives of DTC testing services in relation to genetic counseling and testing for hereditary breast cancer mutations. There are distinct differences between DTC testing and population-wide testing in that DTC testing is largely handled by private companies whereas PWT would be implemented by the healthcare system. Despite these differences, young African American women's perspectives on an already widely available genetic counseling and testing service, such as DTC testing, could provide further insight into their perspectives about PWT in the future.

Understanding why people do or do not engage in health protective behaviors should be informed by appropriate theoretical frameworks. The Integrative Behavioral Model provides a robust framework to best understand young African American women's perspectives of DTC testing, genetic counseling and testing for hereditary breast cancer mutations, and PWT in the future (Fishbein & Cappella, 2006). This theory posits that the most salient determinant for an individual to perform a health behavior is behavioral intention (Glanz, Rimer, & Viswanath, 2015). Furthermore, it states that an individual's intentions to perform a behavior are influenced by their perceived norms, attitudes, environmental constraints, knowledge, habits, perceived importance of the behavior, and their personal agency (Fishbein & Cappella, 2006; Glanz et al., 2015). The purpose of this paper is to address this significant gap in the literature by using the Integrative Behavioral Model to examine the perspectives of African American women from the millennial generation (ages 18-30) towards PWT for hereditary breast cancer mutations who, if PWT was implemented, would be coming of age during this shift.

### *Methods*

Focus groups were conducted as part of a larger sequential exploratory mixed methods study to inform the development of a survey on the same topic. To obtain a more representative sample to inform the development of the larger online survey, focus group participants included women who were university students and community-based residents not attending college. A multi-prong convenience sampling approach using flyers, social media, emails, and word of mouth was used to recruit focus group participants in the Greater Richmond Area, including at Virginia Commonwealth University and Virginia Union University. The recruitment messages

provided information about the opportunity to discuss African American young women's perspectives of hereditary breast cancer mutations and their health communication preferences. Participant inclusion criteria included: a) women who self-identified as African American and/or Black; b) between the ages of 18 and 30; c) residence in the Greater Richmond area, and/or) enrolled in undergraduate or graduate studies at either Virginia Commonwealth University or Virginia Union University. We conducted seven focus groups (n=39). Four focus groups were conducted with community residents and three with students from Virginia Commonwealth University or Virginia Union University. This study was approved by the Institutional Review Board at Virginia Commonwealth University (HM200015881).

### *Procedure*

Upon arrival to the focus group, participants were provided an information sheet which included the study purpose, voluntary nature of their participation, minimal risks associated with their participation, payment for participation, and encouraged participants to ask any questions. Focus groups were conducted by the first author. The first author, an African American female, who is currently a PhD candidate in Social and Behavioral Sciences, has extensive training and experience in conducting focus groups. Focus groups were conducted between July and October 2019 and lasted approximately 30 to 45 minutes. The focus groups were hosted in the afternoons to best accommodate both students and community members' schedules. Participants also completed a demographic survey after reading the study information sheet. The demographic survey included questions about residency, age, racial and ethnic background, marital status, employment status, college enrollment status, and family history of breast cancer. Both

community and student focus groups were held in private rooms at Virginia Commonwealth University and Virginia Union University. Participants received a \$15 Target gift card upon completion of the focus group.

### *Instrumentation*

Using semi-structured questions developed informed by the Integrative Behavioral Model, the focus group guide elicited participants' knowledge of hereditary breast cancer mutations as well as their perspectives towards DTC testing, genetic counseling and testing for hereditary breast cancer mutations, and PWT in the future. The moderator guide began the group by reading a short introductory question: "*Companies, such as 23andme and Ancestry.com, now offer genetic testing to the public for a small fee that provide information about the links between their genetic information and their health: What do you think of these services?*" Examples of questions included in this analysis are: "*What, if anything, have you heard about the hereditary breast cancer mutations? What do you think are the advantages of undergoing genetic counseling and testing for hereditary breast cancer mutations? What do you think are the disadvantages of undergoing genetic counseling and testing for hereditary breast cancer mutations?*" Participants were also asked about their perspectives and motivations about participating in any future potential shift towards PWT for hereditary breast cancer mutations including: "*What do you think about the potential shift towards PWT for hereditary breast cancer mutations? What would motivate you to participate in PWT for hereditary breast cancer mutations? What would deter you from participating in PWT for hereditary breast cancer*"

*mutations?* All focus groups were audio-recorded and transcribed verbatim by a professional transcription service, Rev.com.

### *Data Analysis*

SPSS was used to analyze quantitative demographic data. Focus groups were analyzed by the first author (AH) and a graduate student, both of whom are trained in qualitative analysis. Coders conducted a thematic analysis of the data using MAXQDA software (Braun & Clarke, 2006). The primary author created a preliminary codebook by reading and re-reading the transcripts to search for patterns in the data and subsequently created initial codes. These patterns and initial codes were organized around the focus group questions. After the creation of the preliminary codebook, both coders read and assigned codes to each transcript independently. Coders met weekly to refine existing codes, add any additional codes emerging from the data, finalize the codebook, and reach consensus on any coding discrepancies. Overarching themes were created using the constant comparative method of grouping and ordering codes.

### *Results*

The majority of the participants identified themselves as Black or African American (97.4%) with only one participant identifying as Black and Hispanic (2.5%), and the majority lived either in Richmond City (59%) or Henrico County (23%). Most participants were unmarried (94.9%), had full-time employment (76.9%), and were enrolled in college (64.0%). Most were either college freshmen (12.8%), juniors in college (10.3%), seniors in college (15.4%), or graduate students (17.9%). Lastly, there were slightly more participants without a family history of breast cancer (53.8%) than participants with a family history (46.2%).

Five overarching themes emerged from the focus group discussions: 1) perceived benefits and barriers to participating in direct to consumer testing (DTC testing); 2) limited knowledge about hereditary breast cancer mutations; 3) perceived advantages and disadvantages of testing for hereditary breast cancer mutations; 4) motivators and barriers to participating in PWT; and 5) concerns prior to rolling out PWT to the general public.

*Benefits and barriers to participating in direct to consumer testing.* Participants expressed benefits including helping them to connect with family members and providing information about their health risks to participating in DTC testing services, such as Ancestry.com and 23andMe. Some participants described these services as a helpful resource to connect them with other family members. One participant commented:

*“I used Ancestry.com, and I really liked knowing some type of association of where my family history was. I did like being able to see what types of tribes were mixed in my blood, and mixed and mingled. It allowed me to connect with family members I had no idea existed.”*

Other participants mentioned the utility of using these online testing services to provide them with information about their health and risk factors for disease. One participant stated:

*“I think in theory, that’s super helpful, and I have a history of breast cancer in my family, so for me it feels like if I’m genetically predisposed. Then I agree there are external factors that influence our health for sure, but to know that, oh, okay, there’s something in my body that leaves me more likely, than I feel like I would want to know.”*

Participants also expressed environmental constraints surrounding DTC testing.

Participants expressed concerns about both the accuracy and confidentiality of their results. One participant commented: *But personally I wouldn't try it because ... I'm a really paranoid person. "So yeah, they say it goes... but do we really know? And could the results even be that accurate?"* Another participant indicated that she had doubts about who would be reviewing the results: *"So you and I feel like it's not really guaranteed that there's a specific doctor looking at those tests. Like you're sending it to somebody on the internet."*

Participants also highlighted concerns about the confidentiality of their genetic information if sent to a DTC testing company. One participant stated:

*"Yeah I've always heard about the 23andMe, the whole government thing. I guess they're watching you, they're keeping track of what you're doing, putting you in the system. So I've always been kind on the fence about it, but being a biology major, I feel like it could be good."*

Another participant connected her concerns about the confidentiality of her genetic information to how it could be used to negatively impact her in the future as Black person in America: *"My thing like the way black people are being set up like, "Oh, we found your DNA at this scene." I'm like, how? I wasn't there."*

*Limited knowledge about hereditary breast cancer mutations.* Many participants either had no knowledge or limited knowledge about hereditary breast cancer mutations. Some participants responded that they had not heard anything about the hereditary mutations including this participant: *"I honestly have not heard anything about it."* Many participants highlighted



hearing about the hereditary nature of the mutations and having a partial understanding of the mutations. A participant commented:

*“I haven’t heard much of it, honestly. I just know that breast cancer can sometimes be hereditary in your family and some family members take precautions with their children at young ages to make sure that they don’t go through that.”*

Other women highlighted what they have learned from either their own or a friend’s family history of breast cancer. One woman stated:

*“Yeah, I don't really know what that means to be honest. I'm not even gonna lie. I've never heard of mutation, or I don't know what that is, but I've just heard my grandmother had breast cancer and so when I was like 17 or 18, we all go to the same doctor, me, my grandmother and my mom. So my doctor would always tell me ... She would always like, you know, when you get your Pap, she would check my breasts and tell me how to do it at home. But as far as the mutation, I don't really know.”*

Interestingly, despite having limited knowledge about the hereditary breast cancer mutations, a few participants referenced the heightened risk of breast cancer amongst African American women. A participant said:

*“Breast cancer doesn't run in my family, but I have friends whose moms have had it. So they get tested often. I've got people I know that it's literally been like "Grandma had it. So my aunt had it." And so I do know that black, well this might be incorrect, but black women can get some of the most aggressive forms of breast cancer.”*

*Perceived advantages and disadvantages of testing for hereditary breast cancer mutations.* Many participants mentioned many advantages to testing for hereditary breast cancer mutations including early detection, being informed, and potential lifestyle changes. Participants consistently highlighted the importance of early detection of breast cancer as an advantage of genetic counseling and testing for hereditary breast cancer mutations. One participant commented:

*“But you go to the eye doctor and they ask you to do that extra test. That extra test can save you from glaucoma and stuff like that. So that extra test for breast cancer mutations, can help you for your future instead of later on down the road. You’re now sick and can’t really do anything.”*

In a similar vein, these participants also cited the importance of being informed about their risk for breast cancer in the future as an advantage of genetic counseling and testing for hereditary breast cancer mutations. One participant commented:

*“I really think it’s just a matter of being better informed because, I mean science is advancing at a rate that’s out of this world these days. But I feel like there’s still a lot of things that go under the radar in terms of scans and all of those things that just go unseen and I think genetic testing would just give a leg up in terms of knowing a little bit more when it comes to things that may be going on that you can’t see.”*

Some also noted the importance of being informed about their hereditary breast cancer mutation status as it relates to their future childbearing decisions. One participant stated: *“So with the breast cancer, not so much the partner part, but as far as okay, I know I carry this gene. So if I*

*have a child it may pass on to my child. Do I want to do that? It lets you have options at least upfront.”*

Participants also pointed to the lifestyle changes that could be made based upon their knowledge of the hereditary breast cancer mutation status. One participant commented: *“Now I would want to make sure that I’m living a certain lifestyle in order to prevent certain things to enter into my body, or for our body to mutate in any other way. I feel like that kind of information would be important to me.”*

Participants cited multiple disadvantages to undergoing genetic counseling and testing for the hereditary breast cancer mutations. Some women mentioned the fear that they have around getting testing for hereditary breast cancer mutations. One participant commented:

*“I feel like it could definitely scare somebody a lot. Yeah, we said it would be informative to let your kids know and stuff like that, but a lot of people could go about that as completely changing their lives, and just never fully living to the best of their ability because they’re like, Oh, what if I die because of breasts... You have that in the back of your head the whole time.”*

Others mentioned the potential impacts of finding out that they have a hereditary breast cancer mutation on their mental health. One participant stated: *“It may make me live a healthier lifestyle. But I could totally see just slipping into depression about my fate and all of that. Yeah because I would worry all the time too.”*

Medical mistrust of genetic counseling and testing for hereditary breast cancer mutations were constraints for some participants. Some participants expressed mistrust of the accuracy of

the test results and concerns about the privacy of their genetic information. One participant stated: *“What if they make a mistake? They were wrong or something. I’ve chopped off both my breasts. Can’t take that back. So it definitely would impact your life from now on.”* Another participant mentioned being afraid that her genetic information would be used to create a “clone” in the future.

Some participants wondered how they would be able to afford to get the testing and whether it would be included in their current insurance plans:

*“I feel like one, it just depends on how much they’re going to incorporate in people’s insurance plans. Are you going to have to come out of pocket? I’m just trying to do that cause, because at this point, I would like to but it’s like, I’m not really sure.”*

*Motivators and barriers to participating in potential PWT.* When asked about what would motivate them to participate in PWT, they identified multiple factors including, family history of breast cancer, healthcare quality, and being informed for themselves and their current and future family. Having a family history of breast cancer was a strong motivator to participate in PWT. One participant commented:

*“I would do it. My motivations are my health, and recognition of family history... and two people, it's not a lot of people, but it's more than enough people to feel like that they're not too many generations removed. So, if there is a genetic component to it, then I would want to know. I would be in the room shaking and probably, like, somebody hold my hand, but I think that would be enough motivation to get me to go.”*

Belief that they would receive quality health care would also be a motivator for some participants. One participant said:

*“I think if I was to know that I would be treated like an individual because a lot of time they like to branch us all into one cure all for everyone, and that's not the case because everybody is different. So, as long as I know somebody is going to cater to my needs, not a group of people.”*

Having children was also identified as a motivating factor in their participation in PWT for hereditary breast cancer mutations. One participant said:

*“I'm just a wild card out here in these streets. I think I'd probably be more motivated if I had children, if I'm being honest. If I had a little girl or a little boy, but more specifically a little girl, who I was raising, and I wanted to protect them at all costs... I think that would probably be a huge motivation for me; and it's probably currently a huge motivation for a lot of women in taking care of themselves and getting checked out.”*

Medical mistrust particularly related to health care quality, provider competence, accuracy of diagnosis, confidentiality, as well as appropriate usage of genetic information was mentioned by several participants as barriers to participating in population-wide testing. One participant stated:

*“I would just be more concerned kind of saying what you got to say is that the person who's doing it is skilled and educated enough to know what they're doing. Because if it is something so new, I'm sure people can be getting misdiagnosed all over the place.”*

Another participant pointed to the importance of African American's not being exploited during the roll out of PWT: *"I'm all for it. If it doesn't disenfranchise us. I'm over that. I think everyone at this [point] is over that. So we can do it, but just don't take from us."*

Affordability of the testing would be a major deterrent to their participation in PWT. One participant stated: *"If it comes with a cost that we cannot afford, don't offer me that. That's like a spit in my face."* Similarly, insurance coverage in their decision and ability to participate in PWT: *"If my insurance doesn't cover it and it's a lot of money, I probably wouldn't do it unless I absolutely needed to."*

*Concerns prior to rolling out PWT.* Participants also highlighted concerns about the roll-out of PWT to the general public that they believed should be considered. Many of the participants were concerned about potential access barriers including how inclusive and accessible the rollout would be to underrepresented ethnic and racial groups and socio-economically disadvantaged groups. For instance, one participant stated:

*"I mean you already know so much going on right now with healthcare, and it seems like the more and more that things become available to everyone, specifically for African Americans. And I'm not saying by any means like we should be exclusive, but I just see an issue arising with it not being the same. What's to say that if you say genetic counseling across every single state, Virginia is going to have the same set up as California? Are we going to have the same access to different resources?"*

Another participant pointed to the concern for access for individuals who are socio-economically disadvantaged: *"When you think of doctor visits, you have to think about people who have access*

*to health care. So in my mind, I'm wondering if certain populations will get more help with this type of thing than others. Because they have more access to go to the doctor and talk to someone."*

Some participants also pointed to the newness of genetic counseling and testing for hereditary breast cancer mutation and the need for additional research for them to be comfortable with participating. One participant commented:

*"Once again I don't know why my brain is going this way, but I think about the HPV shots. When the first came out, my mom was like "You're not getting that. It needs to be tested more, and this, this that and the other." And I think it's going to be the same way if that is brought up population-wide."*

Along this vein, participants also spoke about the need to integrate PWT in both the medical field and society at large if it is to be successful. One participant stated:

*"I think you could probably be like integrated more into your pediatric care. Like how your physician tells you, "Oh, you got to take this for if you're having sex or if you're sexually active and all that. But no one ever touches the topic of breast cancer at all. It's just never really talked about as you get older until, you reach a certain age, and it's like. "Oh, I guess I should get a mammogram."*

Other participants highlighted the need for PWT to become more of a "mainstream thing" first, before it is likely to have any traction amongst young black women.

## *Discussion*

This current study examined the perspectives of young African American women (ages 18-30) about genetic counseling and testing if there was to be a shift towards PWT in the United States. Given existing breast cancer and genetic counseling and testing utilization disparities, it is imperative to understand the perspectives of millennial African American women about this potential shift in testing guidelines. This group has largely been absent from conversations around genetic counseling and testing for hereditary breast cancer mutations unless they were breast cancer survivors themselves (Jones et al., 2016). The potential of PWT for genetic counseling and testing for hereditary breast cancer mutations for every woman regardless of family history, beginning at age 30, appears to be imminent (Buchanan et al., 2020; King et al., 2014). Therefore, the perspectives of African American women between the ages of 18 and 30 who have not been affected by breast cancer provide key insights into potential knowledge gaps, attitudes, and environmental constraints that can be addressed in the development of future PWT interventions with this population.

This is the first known study to explore young African American women's perceptions of seeking information about their health risks and ancestry through direct to consumer testing platforms such as, 23andMe and Ancestry.com. Participants in this study identified multiple benefits and barriers to utilizing existing DTC testing services. Similar to prior research findings, participants in this study also indicated that DTC testing services are useful to connect them with other family members and to learn about their health (Carroll et al., 2019; Landry et al., 2017). Consistent with prior research on African American women's perspectives of traditional clinical



genetic testing, cost and medical mistrust were major environmental constraints to DTC testing (Sheppard et al., 2013). Participants also expressed concerns about accuracy and confidentiality of their test results from DTC testing companies.

Consistent with prior studies, participants had limited knowledge of hereditary breast cancer mutations (Adams et al., 2015; Sheppard et al., 2014). If PWT is made available, this finding highlights the need for greater education in this group about hereditary breast cancer mutations. Hurtado de Mendoza et al. (2017) found that knowledge is a key factor impacting genetic counseling and testing engagement amongst African American women at high risk for being a hereditary breast cancer mutation carrier (Hurtado-de-Mendoza et al., 2017). Therefore, education about hereditary breast cancer mutations will need to be a key component in health communication messaging and the design of future PWT interventions with this group.

Participants had similar perceived advantages and disadvantages of current model of genetic counseling and testing for hereditary breast cancer mutations as African American women in prior studies (Adams et al., 2015; Sheppard et al., 2014; Sheppard et al., 2013). Benefits of testing, such as early detection, being informed about their carrier status, and potential lifestyle changes that they could make if they possess the gene, mirror those found in a previous study with African American women in Washington, D.C (Adams et al., 2015). Similar to past studies (Adams et al., 2015; Sheppard et al., 2013; Sutton, He, et al., 2019), the participants in this current study also indicated that medical mistrust would be a major barrier to their participation in traditional genetic counseling and testing for hereditary breast cancer mutation. These women expressed concerns not only about the accuracy of the test but also the

confidentiality of their test results. A recent study found that African American women had moderate levels of confidence in the Genetic Information Non-Discrimination Act (Sutton, Henderson, et al., 2019). However, the concerns surrounding data confidentiality expressed by participants may be related to a lack of knowledge of GINA and its protections amongst African American millennial women.

When asked specifically about the potential shift towards population-wide availability of testing for hereditary breast cancer mutations, participants were concerned about possible disparities in screening practices amongst underrepresented racial and ethnic groups and socio-economically disadvantaged groups that could occur if PWT becomes widely available. They were hyper-aware of the potential widening of disparities that could occur due to existing inequities as it relates to differential medical screening practices and quality of care based on race and socio-economic status. Given the current shortage of genetic counselors, access to these services would be an important concern, especially in underserved communities (Bookman & News, 2016). Similar to the disadvantages that participants highlighted in reference to the current model for genetic testing for hereditary breast cancer mutations, medical mistrust and affordability continue to be significant barriers to their participation in PWT for hereditary breast cancer mutations.

#### *Limitations and Future directions*

One limitation to the current study is that this was a convenience sample of primarily, college students at 31.6% of the community group were also college students. Therefore, the findings from this study may not represent the perspectives of non-college attending African

American women. This group may face additional barriers, including lack of access to a genetic counselor and competing priorities, that prevent them from participating in PWT. Future research should examine the perspectives of low income African American millennial women to explore whether their perspectives of PWT may differ from the women in this study. Another limitation was that the young women's intentions to participate in PWT was not directly assessed during the focus groups. However, factors that impact their willingness to participate according to the Integrative Behavioral Model were probed (i.e. motivators, barriers). Future research needs to examine the factors that influence young African American women's intentions to participate in PWT in the future.

### *Implications*

This study has implications for existing health care policies surrounding genetic counseling and testing for hereditary breast cancer mutations. Given the participants' concerns about the cost of PWT, policies will be need to be created that make PWT accessible for all. The Affordable Care Act currently addresses the cost of genetic counseling and testing for women who are considered to be at high risk for being *BRCA1/2* mutation carrier (Walcott & Dunn, 2015). However, the cost of genetic counseling and testing for women who do not meet the screening guidelines for traditional genetic counseling and testing for *BRCA1/2* is not covered (Walcott & Dunn, 2015). Policymakers will need to extend this policy to cover all women in the U.S. if PWT is implemented in the future. The Affordable Care Act currently lacks the provision of coverage for risk-reducing interventions including, chemoprevention, frequent mammography, and preventive double mastectomy, that are the recommended next steps for

patients who find out that they carry a hereditary breast cancer mutation (Walcott & Dunn, 2015). This is an important missing provision under the current guidelines, however if PWT is implemented in the United States, it will be critical that this provision is added and made available to all women but especially to young African American women who have concerns about the affordability of PWT in the future.

This study also has implications for genetic counselors who will be a part of the PWT process. Given the high levels of medical mistrust expressed by women in this study, genetic counselors will need to have cultural competency training as well as learn strategies to build trust with members of this population. Prior implicit bias simulation research by Schaa et al. (2015) with genetic counselors indicated that most genetic counselors in their study had either a moderate or strong pro-White bias (Schaa, Roter, Biesecker, Cooper, & Erby, 2015). This pro-White bias led to genetic counselors in the study not building rapport and being verbally dominant in conversations with simulated Black clients (Schaa et al., 2015). Addressing potential biases amongst genetic counselors will be particularly helpful in improving health communication and building trust with African American patients.

### *Conclusion*

African American women continue to be disproportionately impacted by breast cancer and are more likely to succumb to the disease than any other racial group. Population-wide testing is a potential pathway to breast cancer prevention for young African American women in the United States. However, if long standing barriers facing the African American community, such as lack of knowledge about hereditary breast cancer mutations, cost, and medical mistrust

are not addressed, then the genetic counseling and testing utilization gap will only continue to widen. Targeted health promotion programs will need to be implemented to increase knowledge of hereditary breast cancer mutations, the Genetic Information Non-Discrimination Act, and to help with visibility of PWT within this population. Policies will also need to be amended and created to provide insurance coverage for not only genetic counseling and testing but also any risk reducing interventions that are necessary for hereditary breast cancer mutation carriers. Furthermore, medical mistrust is a particularly important barrier that will need to be addressed by cultural competency trainings and the recruitment of African American students into the genetic counseling profession. Lastly, issues of access will also need to be addressed to determine how such a service could be economically and geographically accessible for all.

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## **Chapter 3**

### **Paper 2**

Predictors of young African American women's intentions to participate in potential population-wide testing for hereditary breast cancer mutations

Abstract:

Young African American women (<40 years) are twice as likely to die from breast cancer than White women. Preventive efforts, including population-wide testing for hereditary breast cancer mutations for all women in the United States beginning at age 30, are being considered as potential pathways to breast cancer prevention for all women. This paper examines factors that influence intentions to participate in potential population-wide testing in a sample of 170 African American women. Participants in this study were between the ages of 18 and 30 and did not have a known hereditary breast cancer mutation. Simple and multiple regression models assessed the relationship between factors and participants' intentions to participate in population-wide testing. Participants had moderate knowledge levels of hereditary breast cancer mutations and moderate to high levels of medical mistrust. Simple regressions indicated that subjective norms ( $B = .460$ ,  $p = .000$ ) and motivators to participate in direct to consumer testing ( $B = .217$ ,  $p = .004$ ) were positively associated with intentions to participate in potential population-wide testing. Subjective norms ( $B = .449$ ,  $p = .000$ ) and motivators to participate in direct to consumer testing ( $B = .204$ ,  $p = .009$ ) remained significant after accounting for sociodemographic variables. Findings suggest that family-based and social network interventions as well as public health campaigns that target social networks would be particularly well-suited for this population. Furthermore, it will be important to better understand the linkages between young African American women's current participation in direct to consumer testing and their intentions to participate in population-wide testing.

## Introduction

African American women are most likely to die from breast cancer at every age when compared to White women (DeSantis et al., 2019; Society, 2020). Breast cancer amongst young women is rare. However, young African American, who are younger than the recommended mammography screening age (< 40 years), are twice as likely to die from breast cancer, have the highest incidence of breast cancer of all racial groups, and the highest rates of an aggressive form of breast cancer, triple negative breast cancer (Anders, Johnson, Litton, Phillips, & Bleyer, 2009; Bleyer, O'Leary, & Ries, 2006; DeSantis et al., 2019; Dietze, Sistrunk, Miranda-Carboni, O'Regan, & Seewaldt, 2015). Triple negative breast cancer lacks proper treatment and is associated with the presence of a hereditary breast cancer mutation. Studies with young African American women with breast cancer have consistently indicated that they have a high prevalence of hereditary breast cancer mutations (Jones et al., 2019; Pal et al., 2015). African American women who meet current screening recommendations for hereditary breast cancer mutations utilize genetic counseling and testing services at lower rates than White women (Armstrong, Micco, Carney, Stopfer, & Putt, 2005; McCarthy et al., 2016). Recently, there has been a growing interest in expanding hereditary breast cancer mutation screening to all women beginning at age 30 in the United States to promote breast cancer prevention (King, Levy-Lahad, & Lahad, 2014); however, if implemented it is imperative to ensure that such screening does not widen existing breast cancer disparities impacting young African American women.

Hereditary breast cancer mutations account for approximately 5 to 10 percent of all breast cancers (Force, 2019). The average lifetime risk of breast cancer amongst women is 12%;

however, hereditary breast cancer mutation carriers have an increased lifetime risk of breast cancer of between 40 and 80 percent (Kuchenbaecker et al., 2017; Petrucelli, Daly, & Feldman, 2010). Similar to the experiences of African American women with breast cancer, hereditary breast cancer mutation carriers are typically diagnosed at younger ages and with triple negative breast cancer (Chen et al., 2018). Hereditary breast cancer mutation carriers have preventative options available to them including, more frequent mammography screening, chemoprevention, and mastectomy to reduce their risk of developing breast cancer (Force, 2019). However, given their lower rates of testing, African American women, who meet the current screening guidelines, have largely not been able to reap the preventive benefits of genetic counseling and testing for hereditary breast cancer mutations.

More recently, there has been an increasing call for population-wide testing (PWT) largely prompted by recent studies indicating that up to 50 percent of hereditary breast cancer mutation carriers are missed with current screening criteria (King et al., 2014; Manchanda, Loggenberg, et al., 2015). Current screening guidelines from the National Cancer Comprehensive Network (NCCN) requires a personal or family history suggestive of a hereditary breast cancer mutation to be eligible for genetic counseling and testing (Force, 2019; Institute, 2018 ). However, PWT would eliminate this current model that hinges on physicians as gatekeepers to genetic counseling and testing for the mutations (King et al., 2014). Prior studies have indicated that PWT is cost-effective given the decreasing prices of genetic testing and that there is high interest amongst women in in this potential initiative (Manchanda & Gaba, 2018; Manchanda, Legood, et al., 2015; Rubinsak et al., 2019). If PWT were to be implemented, this

potential shift could be transformative for breast cancer prevention among African American women given that formative data has consistently linked the lower utilization of genetic counseling and testing for hereditary breast cancer mutations by African American women, who meet current NCCN testing guidelines, to the lack of physician referral for genetic counseling and testing (McCarthy et al., 2016). Other commonly cited barriers to their participation in genetic counseling and testing are lack of knowledge about hereditary breast cancer mutations, cost, medical mistrust, and concerns about their families' negative perceptions towards participation in genetic counseling and testing (Adams, Christopher, Williams, & Sheppard, 2015; Hurtado-de-Mendoza, Jackson, Anderson, & Sheppard, 2017; Sheppard et al., 2014; Sheppard, Mays, Tercyak, & LaVeist, 2013). Prior to rolling out PWT, it will be important to preemptively understand and address any barriers that young African American women may experience to participating in PWT.

There is a lack of research focusing on the perspectives of young African American women, who do not have a family history suggestive of a hereditary breast cancer mutation, towards genetic counseling and testing for hereditary breast cancer mutations. Currently, only one study includes African American women's perspectives towards and acceptability of PWT; however, the mean age of participants in this study was 37.7 (Rubinsak et al., 2019). Moreover, there have not been any studies that focus on the factors that influence young African American women's intentions to participate in PWT if it becomes available in the future. Young African American women between the ages of 18 and 30 are unique in that they have come of age during the rise of direct to consumer testing (DTC) services, such as Ancestry.com and 23andMe, which

are already widely available genetic testing services that provides information about health without the need for a physician recommendation. Studies indicate that African Americans utilize DTC testing at similar rates as Whites, however none have explored whether young African American women's intentions to participate in PWT for hereditary breast cancer mutations are influenced by their perspectives toward DTC testing (Carroll et al., 2019; Landry et al., 2017). Understanding the potential factors that influence young African American women's intentions to participate in PWT will provide insight into behavioral interventions and public health campaigns for this group.

The Integrative Behavioral Model provides a comprehensive framework to understand the factors that influence young African American women's intentions to participate in PWT for hereditary breast cancer mutations. This theory indicates that the most important determinant for a person's intentions to perform a health behavior is behavioral intention (Fishbein & Cappella, 2006). Furthermore, it states that an individual's intentions to perform a behavior are influenced by their perceived norms, environmental constraints, knowledge, habits, attitudes, and their personal agency (Fishbein & Cappella, 2006). This current paper aims to examine the factors that influence young African American women's (ages 18-30) intentions to participate in PWT in the future. The main hypotheses for this study are:

*Hypothesis 1:* Participants will have low levels of knowledge about hereditary breast cancer mutations and low levels of medical mistrust.

*Hypothesis 2:* There will be a positive relationship between participants' attitudes towards direct to consumer testing and intentions to participate in PWT.

*Hypothesis 3:* There will be a positive relationship between participants' subjective norms and intentions to participate in PWT.

*Hypothesis 4:* There will be a negative relationship between participants' individual medical mistrust and intentions to participate in PWT.

*Hypothesis 5:* There will be a negative relationship between participants' group-based medical mistrust and intentions to participate in PWT.

*Hypothesis 6:* There will be a positive relationship between participants' perspectives towards hereditary breast cancer mutations and intentions to participate in PWT.

*Hypothesis 7:* There will be a positive relationship between their perceived risk of hereditary breast cancer mutations and intentions to participate in PWT.

*Hypothesis 8:* There will be a negative relationship between participants' perceived severity of breast cancer and intentions to participate in potential population-wide testing.

## **Methods**

### Survey Development

An online survey was administered to assess the factors that influence young African American women's intention to participate in PWT as a part of a larger sequential exploratory mixed methods study. This survey was developed based upon the results of seven focus groups with young African American women (n=39) in a southern urban city that focused on perspectives of hereditary breast cancer mutations and motivators and barriers to participating in PWT. Knowing that most participants may not know about PWT for hereditary breast cancer



mutations, high level definitions of commonly used terms such as DTC testing, genetic counseling, genetic testing, and PWT were included throughout the survey. An expert panel consisting of four academic scholars each with experience in survey development, hereditary breast cancer mutations, and breast cancer reviewed the survey developed by the first author. In an effort to increase survey validity, the first author conducted two rounds of cognitive interviews using the verbal probing method to test and obtain feedback from members of the target population (Peterson, Peterson, & Powell, 2017). All discrepancies in the survey were resolved by two coders at the end of the second round of cognitive interviews.

### Sample and setting

Surveys were distributed and administered in July 2020 by the online survey company, Qualtrics, to individuals in their existing online panels. Qualtrics randomly selected potential survey participants based on the demographic information in the profiles of users that were most likely to qualify for participation. Potential participants were sent an invitation to participate via email that informed them of the survey, survey length, incentives for participation, and the survey hyperlink. Potential participants who did not meet the established eligibility criteria were excluded from participation. Participant inclusion criteria included women who: 1) self-identified as African American or Black, 2) were between the ages of 18 and 30, and 3) did not have a known hereditary breast cancer mutation in their family. A power analysis was conducted using G\*Power to determine the sample size in which the analysis would have a small effect (Cohen's  $h=0.5$ ). The power analysis indicated a sample of 160 would be sufficient. Quota sampling was used to stratify participants by age to ensure an equal number in each of the age

ranges, 18 to 24 and 25 to 30 (Brown, 2016; Feild, Pruchno, Bewley, Lemay, & Levinsky, 2006). Survey respondents were required to answer all questions to avoid skipped or missed survey responses. Participants were provided with various incentives for participation in the study that were provided by Qualtrics. Due to the exempt nature of this study, all participants were provided with an information sheet prior to the survey that outlined the purpose of the study, voluntary nature of participation, and minimal risks associated with participation in the study. This study was approved by the Institutional Review Board at Virginia Commonwealth University (HM200015881).

#### Measures

#### Predictors

*Breast Cancer Genetics Knowledge* was assessed using a 11-item scale that measures knowledge about hereditary breast cancer mutations of women at risk for hereditary breast cancers (Erblich et al., 2005). All the items in the scale require true or false responses. This scale assessed the cancer risk associated with being a hereditary breast cancer mutation carrier, the prevalence of hereditary genes, familial patterns of hereditary breast cancer mutation inheritance, and various risk management options available to hereditary breast cancer mutation carriers. An overall score was created by summing the correct responses to the items. Higher scores indicated greater hereditary breast cancer mutations knowledge (scores range 0 to 11).

*Group-Based Medical Mistrust* was assessed using a 12 item, 5-point Likert scale, that asks the respondent to think about the relationship between individuals of their race and the medical system (Cronbach's alpha = .741) (Thompson, Valdimarsdottir, Winkel, Jandorf, &

Redd, 2004). It contains items, such as “Doctors have the best interests of people of my racial/ethnic group in mind” and “People of my racial/ethnic group cannot trust doctors and health care workers.” Responses range from strongly disagree to strongly agree. An overall score was created by summing item responses together with higher values indicating greater group-based medical mistrust (range 0-60).

*Individual medical mistrust* was assessed using a 7-item yes or no response scale that examined participants’ experiences with discrimination in the healthcare field (Bird & Bogart, 2001 ). The main question of this scale asks, “When getting health care, have you ever had the following things happen to you because of your race or ethnicity?” Respondents are then asked to respond yes or no to statements such as, “Been treated with less courtesy than other people” and “Received poorer service than others.” An overall score was created by summing item responses together with higher values indicating greater individual medical mistrust (scores range from 0 to 7) (Cronbach’s alpha = .818).

*Perceived Risk of Carrying a BRCA1/2 Mutation* was assessed by adapting a previously used Likert item, “How likely do you think it is that you carry a BRCA1/2 mutation (Sussner, Jandorf, Thompson, & Valdimarsdottir, 2013)?” In this current study, the item asked, “How likely do you think it is that you carry a hereditary breast cancer mutation?” This was adapted in order to account for other hereditary breast cancer mutations that are not necessarily *BRCA1/2* mutations. The possible responses to this Likert scale item ranged from not at all likely, somewhat likely, likely, very likely, and extremely likely.

*Perceived Severity* was assessed using a three item 5-point Likert scale that measures women's perceived severity of carrying a gene mutation. It contains the following three items: 1). "If I found out I carried a gene mutation, it would greatly disrupt my life," 2) "Finding out I carried a gene mutation would be very difficult for me," and 3) "If I found out I carried a gene mutation, I would worry much more about developing breast cancer (Wang, Gonzalez, Janz, Milliron, & Merajver, 2007)." The responses to these items range from strongly disagree to strongly agree (Cronbach's alpha = .787). An overall score was created by summing item responses with higher scores indicating greater perceived severity (scores range from 0 to 15).

*Attitudes towards hereditary breast cancer mutations* were assessed using a 13-item, 5-point Likert scale that measures women's perceived advantages and disadvantages to undergoing genetic counseling and testing for hereditary breast cancer mutations (Cronbach alpha=.662) (Thompson et al., 2002). It contains items such as "Testing is not worthwhile because it could yield inconclusive results about whether I carry the gene for breast cancer" and "If I were found to carry the gene for breast cancer, I would worry about passing the gene to my children." The possible item responses ranged from strongly disagree to strongly agree. An overall score was created by summing the correct responses together. Higher scores indicate greater perceived advantages of hereditary breast cancer mutations (scores range from 0 to 65).

*Subjective Norms* were assessed by adapting a 5 item, 5-point Likert scale that asks women to consider what close relatives and friends would think of them undergoing genetic counseling and testing for *BRCA 1/2*. Example items include, "My parents would approve of me getting genetic testing and counseling for *BRCA 1/2*" and "My friends would approve of me

getting genetic testing and counseling for *BRCA 1/2*. Possible item responses range from strongly disagree to strongly agree (Cronbach's alpha = .864). In this current study, scale items were reframed to focus on whether their friends, family, spouse, or other family member would approve of them getting genetic testing and counseling through PWT. An overall score was created by summing the items together. Higher scores indicate more positive subjective norms (scores range from 0 to 25).

*Attitudes towards Direct to Consumer Genetic Testing* were assessed using two scales to understand respondents' perspectives towards direct to consumer genetic testing (Mavroidopoulou, Xera, & Mollaki, 2015). The first 7-item, 5-point Likert scale explored respondents' motivations to participate in DTC testing (scores range from 0 to 35) (Cronbach's alpha = .829). An overall score was created by summing all the response items together. Higher scores indicated greater agreement with the potential reasons to participate in DTC testing. The second 4-item scale explored respondents' reasons for not wanting to participate in direct to consumer genetic testing (scores range from 0 to 20) (Cronbach's alpha = .612). An overall score was created by summing all of the response items. Higher scores indicated greater agreement with the potential reasons not to participate in DTC testing. Responses for both direct to consumer participation scales range from strongly disagree to strongly agree.

#### *Demographic Characteristics.*

The survey collected respondents' age, race, income, level of education, family history of breast cancer, marital status, health insurance status, employment status, and whether they had a regular physician. For the analysis, family history of breast cancer was dummy coded as yes/no.

Education level was categorized into three levels: 1) less than or equal to high school, 2) any college to a Bachelor's degree, and the referent category 3) graduate degree. Marital status was categorized into four levels: 1) married, 2) living together, 3) divorced, and the referent category 4) never married.

#### Outcome

*Intentions for potential population-wide testing for BRCA 1/2 scale* was assessed by adapting an item that has been validated by a prior study on intentions that asks "At the present time, which of the following statements describes you best?" The possible responses to this Likert scale item are: definitely will have genetic testing, probably will have genetic testing, considering genetic testing, and not considering/thought about genetic testing (Lerman et al., 1999). This item was adapted to ask, "Now try to imagine you are offered genetic testing and counseling for breast cancer susceptibility through a population-wide testing initiative at some point in the future, would you choose to have the test?" The possible responses to this Likert item are: no definitely not, no probably not, unsure, yes probably, and yes definitely.

#### **Statistical Methods**

Descriptive statistics were run to describe the variables of interest in this study. Total mean scores and standard deviations were computed for each of the continuous predictor variables. The dependent variable, intention, was assessed for normality. Unadjusted simple regressions were conducted to assess the relationship between each of the predictor variables (i.e. group-based medical mistrust, individual medical mistrust, perceived risk, perceived severity,

attitudes towards hereditary breast cancer mutations, subjective norms, and attitudes towards direct to consumer testing) and intentions to participate in population-wide testing. All assumptions were assessed and met for each of the unadjusted analyses. Variables were selected for separate adjusted multiple regression analyses based upon their significance in the initial unadjusted analyses. Each adjusted analysis accounted for potentially confounding variables, including family history, marital status, and level of education based upon findings from the initial focus groups. Multicollinearity was assessed for each of the adjusted analyses by conducting bivariate correlations. All analyses were conducted using SPSS 25.0.

## **Results**

Among the individuals recruited for participation in the survey by Qualtrics, 391 individuals opened the survey link and were presented the IRB approved information sheet. Of the 391 individuals who opened the link, 113 were ineligible to participate based upon the study's inclusion criteria and an additional nine participants were over-sampled. Another 99 failed to complete the survey. A total of 170 African American women between the ages of 18 and 30 are included in the study sample.

Most participants attended some college (62.3%), were employed either full-time or part-time (60.6%), never married (61.8%) and had an income less than \$40,000 (55.3%). Further, most of the women in the study had a regular physician (65.3%), health insurance (68.2%), and did not have a family history of breast cancer (81.2%). The scores on the knowledge of hereditary breast cancer mutations scale ranged from 2 to 10 with a mean score of 6.1 (standard deviation = 1.53). The individual medical mistrust scale total range of scores were from 0 to 7

with a mean score of 6.6 (standard deviation = 2.33). The group medical mistrust scale total range of scores were from 12 to 58 with a mean score of 35.9 (standard deviation = 6.51) (Table 1).

Table 1: Frequencies of Demographic Variables and Predictor Scale means

<b>Variables</b>	<b>N (%)</b>	<b>Mean (SD)</b>
<b>Demographic Variables</b>		
<b>Age</b>		23.7 (4.00)
18-24 years	85 (50%)	
25-30 years	85 (50%)	
<b>Marital Status</b>		
Married	20 (11.8%)	
Never married	105 (61.8%)	
Living together	28 (16.5%)	
Divorced	17 (10.0%)	
<b>Education level</b>		
Less than or equal to high school	64 (37.6%)	
Any College to a Bachelor's Degree	92 (54.1%)	
Graduate Degree	14 (8.2%)	
<b>Insurance Status</b>		
Yes	116 (68.2%)	
No	54 (31.7%)	
<b>Income</b>		
Less than \$20,000	53 (31.2%)	
\$20,000 -\$39,999	41 (24.1%)	



\$40,000-\$59,999	38 (22.4%)
\$60,000- \$79,999	13 (7.6%)
\$80,000-\$99,999	10 (5.9%)
\$100,000- \$119,999	7 (4.1%)
At least \$120,000	8 (4.7%)
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<b>Employment Status</b>	
Full time	69 (40.6%)
Part-time	34 (20.0%)
Unemployed	24 (14.1%)
Retired	4 (2.4%)
Unable to work	6 (3.5%)
Homemaker	11 (6.5%)
Student	22 (12.9%)
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<b>Family History of Breast Cancer</b>	
Yes	32 (18.8%)
No	138 (81.2%)
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<b>Regular Physician</b>	
Yes	111 (65.3%)
No	59 (34.7%)
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<b>Predictor Variables</b>	
Attitudes towards <i>BRCAl/2</i>	42.0 (6.7)
Subjective Norms	16.3 (4.4)
Individual Medical Mistrust	6.6 (2.3)
Group-based Medical Mistrust	35.9 (6.5)
Perceived Severity	9.7 (2.9)

Perceived Risk	2.1 (1.9)
DTC Motivations	24.9 (5.7)
DTC barriers	11.5 (3.1)

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The dependent variable, intention, was not normally distributed as indicated by the Shapiro-Wilks test with a p-value of .000. The majority of the responses to the intention to participate in PWT was “Unsure” (n = 75). There were not any statistically significant relationships between intention to participate in PWT and the simple regression models with group medical mistrust (B = -.075, 95% CI : [-.037, .012], p=.332), individual medical mistrust (B = .140, 95% CI: [-.005, .132], p = .070), reasons to not participate in direct to consumer testing scale (B = -.060, 95% CI: [-.073, .031], p=.436), perceived risk for hereditary breast cancer mutations (B =.066, 95% CI: [-.076, .194], p = .391), perceived severity (B = .124, 95% CI: [-.010,.101],p =.106), or attitudes towards hereditary breast cancer mutations (B = .070, 95% CI: [-.014, .038],p = .362) (Table 2). Subjective norms were positively associated with intentions to participate in PWT for hereditary breast cancer mutations (B =.460, 95% CI: [.077, .142], p < .000). Subjective norms accounted for 20.7% of the variation in respondents’ intentions to participate in PWT (F (1,168) = 44.99, p = .000). The relationship between subjective norms and intentions to participate in PWT remained statistically significant in the multiple regression model that accounted for family history of breast cancer, marital status, and level of education (B = .449, 95% CI: [.074, .141], p = .000). The overall adjusted model remained significant (F, (7, 162) = 6.60, p < .000). Motivations to participate in direct to consumer testing was also positively associated with intentions to participate in PWT for hereditary breast cancer mutations

in the simple linear regression ( $B = .217$ , 95% CI: [.013, .067],  $p = .004$ ). Motivations to participate in direct to consumer testing accounted for 4.2% of the variation of respondents' intentions to participate in PWT ( $F(1,168) = 8.32$ ,  $p = .004$ ). Despite the overall model not remaining significant ( $F(7,162) = 1.71$ ,  $p = .110$ ), the relationship between motivations to participate in direct to consumer and intentions to participate in PWT also remained statistically significant in the multiple regression model that accounted for family history of breast cancer, marital status, and level of education ( $B = .204$ , 95% CI: [.010, .066],  $p = .009$ ).

Table 2: Simple Linear Regressions with each of the Predictor Variables and Intentions for potential population-wide testing

<b>Dependent Variable</b>				
Intention to participate in population-wide testing				
<b>Predictor Variables</b>	Unstandardized beta	Standardized beta (p-value)	95% CI	Adjusted R <sup>2</sup>
Attitudes towards BRCA	.012	.070 ( $p = .362$ )	(-.014, .038)	-.001
Group-based medical mistrust	-.012	-.075 ( $p = .332$ )	(-.037, .012)	.000
Individual medical mistrust	.063	.140 ( $p = .070$ )	(-.005, .132)	.014
DTC Motivations	.040	.217 ( $p = .004$ ) *	(.013, .067)	.042
DTC Barriers	-.021	-.060 ( $p = .436$ )	(-.073, .031)	-.002
Perceived Risk	.059	.066 ( $p = .391$ )	(-.076, .194)	-.002

Perceived Severity	.046	.124 (p = .106)	(-.010, .101)	.010
Subjective Norms	.110	.460 (p = .000) *	(.077, .142)	.460

\*p < .05

Table 3: Multiple Regression models adjusting for marital status, level of education, and family history of breast cancer

<b>Model 1</b>	Beta	95% CI	P-value	<b>Model 2</b>	Beta	95% CI	P-value
Constant	.923	(.178, 1.667)	.015	Constant	1.68	(.789, 2.569)	.000
Subjective Norms	.449*	(.074, .141)	.000*	DTC Motivations	.204*	(.010, .066)	.009*
<b>Marital Status</b>				<b>Marital status</b>			
Married	.063	(-.267, .680)	.390	Married	.102	(-.185, .848)	.207
Living together	.003	(-.394, .409)	.970	Living Together	.027	(-.361, .516)	.728
Divorced	-.002	(-.506, .490)	.975	Divorced	-.031	(-.654, .439)	.698
Never Married <sup>a</sup>				Never Married <sup>a</sup>			
<b>Education Status</b>				<b>Education Status</b>			
Less than or equal to HS	.143	(-.261, .882)	.285	Less than or equal to HS	.139	(-.325, .927)	.344
Any College to a Bachelor's	.145	(-.246, .857)	.275	Any College to a Bachelor's	.173	(-.238, .969)	.233
Graduate degree <sup>a</sup>				Graduate degree <sup>a</sup>			

Family history of breast cancer	.044	(-.254, .493)	.528	Family history of breast cancer	.065	(-.238, .969)	.396
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\*p<.05

<sup>a</sup>Referent Group (coded 0)

### Discussion

This is the first known study aiming to understand the factors that influence young African American women’s (ages 18-30) intentions to participate in population-wide testing for hereditary breast cancer mutations. Preemptively understanding the factors that influence young African American women’s intentions to participate in PWT for hereditary breast cancer mutations is imperative given the existing breast cancer and genetic counseling and testing utilization disparities that exist in this population. Recent studies provide strong support for PWT to become a reality in the future (Manchanda & Gaba, 2018; Manchanda, Legood, et al., 2015; Rubinsak et al., 2019) citing cost-effectiveness, benefits for breast cancer prevention, and acceptability of this initiative. This study assessed African American women’s current knowledge of hereditary breast cancer mutations and their levels of medical mistrust. It also examined potential factors, such as attitudes and environment constraints, that could be associated with intentions to participate in PWT for hereditary breast cancer mutations if, and when, offered in the future.

Study participants indicated a moderate level of knowledge about hereditary breast cancer. The moderate knowledge of hereditary breast cancer mutations finding is particularly important given that knowledge has been found to be a significant predictor of genetic

counseling and testing uptake for hereditary breast cancer mutations amongst African American women (Hurtado-de-Mendoza et al., 2017). These findings are similar to a prior study with African American breast cancer survivors at risk for carrying a hereditary breast cancer mutation that have found that younger age was a significant predictor of having a higher knowledge of hereditary breast cancer mutations (Hurtado-de-Mendoza et al., 2017). Moderate knowledge levels amongst younger African American women could potentially be due to recent mainstream conversations about hereditary breast cancer mutations in the media (Leach, 2019). Discussions about hereditary breast cancer mutations have been included in popular television shows targeting young adults. In 2018, a popular show on ABC Freeform channel that targets young adults, *The Bold Type*, presented a storyline of a young 26-year-old woman getting tested and finding out that she had a hereditary breast cancer mutation and how being a mutation carrier impacted every aspect of her life throughout the season (Leach, 2019). Therefore, younger African American women may have been exposed to more information about hereditary breast cancer than older African American women who participated in past studies.

Subjective norms were positively associated with young African American women's intentions to participate in any future PWT. Our findings differ from a prior study exploring factors that impact young African American breast cancer survivors' with a slightly larger age range (ages 20-45) that found their uptake of genetic counseling and testing was not influenced by subjective norms (Jones et al., 2016). Differences between this current study may be due to the fact that participants in the prior study were diagnosed between the ages of 20-45 but participated in this study years later. Findings from this current study are consistent with studies

that have focused on the introduction of new preventive health behaviors to young adult women, such as HPV vaccination. Previous studies have consistently indicated that subjective norms are positive predictors of young adult women's intentions to get an HPV vaccination (Allen et al., 2009; Gerend & Shepherd, 2012). Study findings suggest that, if PWT is implemented, family-based and social network behavioral interventions will likely need to be conducted prioritizing young African American women as well as members of their social network. Family members can serve both as deterrents and motivators to African American women's participation in genetic counseling and testing for hereditary breast cancer mutations (Sheppard et al., 2014); therefore, social network intervention strategies are well-suited for this population given the potential diverse opinions of family members. Similarly, public health campaigns targeting young African American women will also need to reference social networks given the influence of families and friends. Lastly, though not examined in this study, it may also be important for future research to examine who exactly counts as social network members especially given the pervasiveness of social media engagement and social media influencer culture including the phenomenon of Facebook and Twitter friends and followers.

This is the first study to examine the relationship between young African American women's motivations to participate in DTC testing and intentions to participate in PWT for hereditary breast cancer mutations. Our findings suggest that young African American women may be more open to direct to consumer testing and may in turn influence their perspectives towards PWT. This could potentially be attributed to the rise of marketing of direct to consumer testing to consumers that began with Myriad Genetics in 2006 (Matloff & Caplan, 2008). Direct

to consumer testing marketing has become increasingly popular with companies such as, 23andMe and Ancestry.com, that advertise their services on all platforms (Estrada, 2017). Direct to consumer testing companies have not always effectively targeted African Americans in advertisements. Ancestry.com recently had to pull a controversial tv commercial, entitled “Inseparable”, after being accused of romanticizing the rape of an enslaved African American woman by her White slave owner (Kearns, 2019). Despite this missed opportunity to target African Americans, studies have consistently indicated that African Americans utilize DTC testing at similar to rates as Whites (Carroll et al., 2019; Landry et al., 2017). Future research should explore the linkages between young African American women’s intentions to participate in PWT and their current participation in already widely available genetic testing services offered through direct to consumer testing.

Medical mistrust is a known predictor of African American breast cancer survivors’ participation in genetic counseling and testing for hereditary breast cancer mutations (Sheppard et al., 2014; Sheppard et al., 2013; Sutton et al., 2019). Consistent with prior studies, young African American women in this study had moderate to high levels of medical mistrust. However, despite having moderate to high levels of medical mistrust, neither individual or group-based medical mistrust were associated with young African American women’s intentions to participate in PWT. This finding suggests that while participants may distrust the medical field, distrust may not negatively influence their health behaviors in the same ways as it has traditionally among older African American breast cancer survivors. Future research should



examine the impact of medical mistrust on young African American women's intentions to participate in PWT and subsequent uptake of PWT.

Other factors that have been typically found to be associated with intentions and uptake of genetic counseling and testing for hereditary breast cancer mutations in prior studies with breast cancer survivors both young and old were not significant in this current study (Jones, McCarthy, Kim, & Armstrong, 2017; Kessler et al., 2005; Wang et al., 2007). Different from prior studies with African American women at-high risk for hereditary breast cancer mutations, perceived risk and attitudes towards hereditary breast cancer mutations were not significant predictors of intention for young African American women that participated in this current study (Jones et al., 2017; Kessler et al., 2005). These findings suggest that there are potentially other important factors that were not included in this present study, such as cost, accessibility, and confidence in the accuracy of testing. Future research should explore other factors and how they can be best targeted and incorporated in behavioral interventions and public health campaigns.

#### Limitations

One limitation of this current study is that this was a highly educated sample with 62 percent of the sample having at least attended some college. Therefore, these findings may not be reflective of the experiences of individuals who have not attended college. Another limitation is that the survey sample is limited to individuals who are signed up to participate in online surveys distributed by Qualtrics. As a result, findings may not represent the experiences of young African American women in the general population or those with limited access to the internet. Future research should include non-college attending young African American women as well as young

African American women in the general population to understand if the factors that influence their intentions to participate in potential PWT are different from the women who participated in this study. Another limitation of this study was that the dependent variable, intention to participate in PWT, was not normally distributed. The majority of responses to the intentions to participate in PWT item was unsure. The non-normal distribution of the dependent variable may impact the significance of the findings from this study given the potential impact of non-normality on estimates of confidence intervals and standard errors in regression.

### Conclusion

The potential for population-wide testing for hereditary breast cancer mutation could serve as a pathway to breast cancer prevention for young African American women and reducing existing breast cancer disparities. However, young African American women will not reap preventive benefits of participation in a potential initiative if the factors that may influence their intentions (attitudes and environmental constraints) are not understood prior to the implementation of such a service. Without fully understanding these factors, the implementation of such an initiative will only lead to the widening of existing disparities in the utilization of genetic counseling and testing and subsequently increase disparities in breast cancer incidence and mortality.

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## Chapter 4

### Introduction

There is a long-standing delay in the translation of academic research findings into public health practice. Balas & Boren (2000) found that it takes 17 years on average for research evidence to make its way into practice (Balas & Boren, 2000). Most public health researchers and academics disseminate their findings primarily to academic journals. Journal publications carry a significant weight for academic researchers while they are on the job market and during the tenure and promotion process (Moore, Maddock, & Brownson, 2018). While worthwhile, this siloed dissemination strategy continues to contribute to significant lags in the sharing of evidence-based public health knowledge to key non-academic stakeholders, which includes public health practitioners, policy makers, and the community at large. Without academic researchers putting forth substantial efforts to utilize alternative dissemination strategies, public health research findings will continue to have challenges reaching non-academic audiences. Recent research has found that academic researchers are making efforts to close the translation gap. For example, a recent survey has indicated that approximately 58 percent of public health researchers associated with either federal agencies or universities disseminated their findings to local state health departments in the U.S (McVay, Stamatakis, Jacobs, Tabak, & Brownson, 2016).

Non-academic stakeholders experience barriers to both accessing and understanding research findings presented in peer-reviewed journals (Brownson, Eyler, Harris, Moore, & Tabak, 2018). Public health practitioners at local, state, and federal health departments

specifically lack access to journal articles, time, resources, and have the potential for information overload (Brownson et al., 2018). In turn, this leads to missed opportunities to use these findings to design evidence-based public health promotion programming and research, implement public health policies, as well as promote health behaviors to the general public.

Efforts to close the translation gap between academic researchers and non-academic audiences have taken different forms. More recently, academic researchers have disseminated public health research findings to the general public using more accessible formats including social media posts and websites, photovoice, and the creation of data briefs. (Brownson et al., 2018). Data brief reports, in particular, provide the opportunity for the researcher to disseminate research findings in an abbreviated format that also utilizes graphs and tables to illustrate study findings (Brownson et al., 2018). For example, the Center for Disease Control and Prevention has utilized data brief reports to disseminate findings from current public health topics ranging from suicide rates to racial and ethnic disparities in infant mortality rates ("NCHS Data Briefs ", 2018). Briefs are created with the intent of targeting a specific population which can range from the general public to public health practitioners (Brownson et al., 2018). This current paper introduces a data brief entitled, "Population-wide testing for Hereditary Breast Cancer Genes: Recommendations for Public Health Practitioners to Reach and Raise Awareness Amongst Young African American women." The target audience of this data brief are public health practitioners working in local or state health departments with disproportionate breast cancer burden amongst African American women. Public health practitioners working in these settings are particularly important because they are tasked with creating health promotion programming



and campaigns, connecting community members with health services, creating community partnerships, and ensuring that the health workforce is skilled and competent (Stover & Bassett, 2003). Furthermore, these public health practitioners are responsible for operationalizing academic research findings into practice (Stover & Bassett, 2003). Therefore, if PWT is implemented in the future, public health practitioners serving in local and state health departments in states with breast cancer disparities impacting African American women will need to have concisely presented recommendations to reach and raise awareness around PWT in this group. African American women in Virginia, specifically, are diagnosed at higher rates, more advanced breast cancer stages, and are more likely to die from breast cancer than White women (Health, 2016 ). Due to these existing breast cancer disparities in Virginia, this data brief will be provided to stakeholders in both the Office of Health Equity and the Cancer Division at the Virginia Department of Health. Furthermore, this data brief will be disseminated on the Black Ladies In Public Health Facebook group that consists of over 10,000 African American women who are public health practitioners in various organizations and health departments across the country.

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**POPULATION-WIDE  
TESTING FOR  
HEREDITARY BREAST  
CANCER GENES:**

**RECOMMENDATIONS FOR PUBLIC  
HEALTH PRACTITIONERS TO  
REACH AND RAISE AWARENESS  
AMONGST YOUNG AFRICAN  
WOMEN**

**2020  
REPORT**

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## **RECOMMENDATIONS FOR RAISING AWARENESS ABOUT POPULATION- WIDE TESTING AMONG YOUNG AFRICAN AMERICAN WOMEN**

- Develop health promotion programs that include members of young African American women’s social networks such as events that focus on mothers and daughters.
  - Create public health campaigns that display mothers or friends providing information about the new initiative and speaking favorably of participation in testing.
  - Use targeted social media platforms to communicate health communication messages to young African American.
  - Partner with Black breast cancer organizations.
  - Train healthcare workers to increase their cultural competency and improve patient-provider communication with young African American women patients.
- .....

Public health practitioners working at local and state health departments are perfectly positioned to target and raise awareness about population-wide testing for hereditary breast cancer mutations. Currently, population-wide testing is a prospective future initiative that is garnering a lot of attention. The decreasing cost of genetic testing may make this a possible reality in the near future. Therefore, it is imperative to proactively provide public health practitioners with recommendations for potential programming, training, and public health campaign strategies to reach young African American women, a group that is disproportionately impacted by breast cancer. Recommendations provided in this brief are based upon a research study that used focus groups and surveys with young African American women, ages 18-30 years, who are approaching the proposed screening age for population-wide testing.

### **What is population-wide testing?**

Population-wide testing would allow all women, regardless of their personal or family history of breast cancer, to utilize genetic counseling and testing services for hereditary breast cancer mutations. This initiative is being proposed for all women in the United States beginning at age 30 (King, Levy-Lahad, & Lahad, 2014; Pal et al., 2015). Currently, only women with a certain family or personal history of breast cancer can be recommended for genetic tests (NCCN, 2018). However, this approach typically leads to women lacking an understanding of their increased susceptibility for breast cancer until they have already been diagnosed (Jones et al., 2016; King et al., 2014). The goal of population-wide testing would be to create a pathway to breast cancer prevention.

### **Why is targeting young African American women important?**

Breast cancer is the second leading cause of cancer death for all women in the U.S (DeSantis et al., 2019). Young African American women are most likely to die from breast cancer and to be diagnosed with more aggressive forms of breast cancer (DeSantis et al., 2019). Moreover, young African American women breast cancer survivors have a high rate of hereditary breast cancer mutations, which substantially increase a women’s risk for breast cancer over her lifetime (Anders, Johnson, Litton, Phillips, & Bleyer, 2009; Pal et al., 2015). However, African American women utilize genetic counseling and testing for hereditary breast cancer at lower rates than White women (Armstrong, Micco, Carney, Stopfer, & Putt, 2005; Jones et al., 2016). To address these disparities, it is critical that future programming, trainings, and public health campaigns are designed with young African American women in mind.

***What do young African American women currently know  
about heredity breast cancer?***

- Young African American women have a limited to moderate knowledge of hereditary breast cancer mutations.

***"I haven't heard much of it, honestly. I just know that breast cancer can sometimes be hereditary in your family and some family members take precautions with their children at young ages to make sure that they don't go through that." – Focus Group Participant***

- Only 30 percent of participants knew that a woman with a sister with the gene did not have only a 1 in 4 chance of having the mutation herself.
- 50 percent of participants knew that women who test positive for breast cancer gene mutations are more likely to develop breast cancer at an early age.
- Nearly 69 percent of survey participants knew that 50 percent of inherited genetic information is passed down from a person's mother.
- Young African American women are aware that women in their racial/ethnic group have a heightened risk for more aggressive forms of breast cancer.

***"And so, I do know that black, well this might be incorrect, but black women can get some of the most aggressive forms of breast cancer." –  
Focus Group Participant***

## *What are young African American women's preferences for information sources about population-wide testing?*

**Who:** Young African American women want to receive information about population-wide testing from their mothers, breast cancer survivors, and other people that they trust including friends, relatives, and co-workers. They also want to hear from health care professionals, including OBGYNs, primary care providers, and nurses.

*"I mean, my mom has a lot more knowledge than I do because she actually had to go through and experience, she actually had to get a mastectomy. So, I feel like I would go to her first because she knows." - Focus Group Participant*

**How:** Social media platforms including, Instagram, Facebook, and Twitter would all be important information sources about population-wide testing.

*"Social media, for sure. I mean, it's a huge platform already; use it to your benefit. I think that social media probably takes up the majority of most people's time, so definitely social media and using that as a mechanism to communicate not only the importance of it, but the accessibility of it and how to get it done." - Focus Group Participant*



## ***Recommendations for Programming and Public Health Campaigns for Population-wide Testing***

Public health practitioners working at local and state health departments are in a unique position to develop and implement health promotion programming, clinician trainings, and public health campaigns, and to partner with community organizations in their area to promote awareness about this potential initiative.

### **Programming for Young African American Women**

- Create programming that includes not only young African American women, but also their mothers, other relatives, and peers. Providing educational programming for multiple members of their social networks could help to encourage additional conversations with these trusted information sources.
- Seek out partnerships with local African American breast cancer organizations when creating programs for this initiative. African American breast cancer survivors could help bring additional legitimacy through their sharing of personal breast cancer experiences to the severity of breast cancer amongst Black women.

### **Training for Healthcare Providers**

- Create trainings for healthcare providers that raise awareness about hereditary breast cancer mutations and their impact on racial minorities. Highlight the disparities in knowledge gaps around hereditary breast cancer mutations and tendencies to refer African American women for testing at lower rates than White women.
- Increase cultural competency and patient-provider communication to address medical mistrust and facilitate provider conversations with young African American women.

### **Public Health Campaigns**

- Develop health communication campaigns with scenarios displaying mothers or friends providing information about the potential new initiative and speaking favorably of participation in the service.
- Disseminate information about population-wide testing on popular social media platforms. Partner with well-known African American influencers, who young African American women follow to provide them with information about population-wide testing.

## *Data Sources and Methods*

Recommendations presented in this brief report are based on focus group and surveys with 209 young African American women between the ages of 18 and 30. Seven focus groups were conducted with 39 African American women who were either enrolled at one of two local colleges, Virginia Commonwealth University and Virginia Union University, or who were community residents in the Greater Richmond area. The majority were unmarried (94.9%), employed full-time (76.9%), were enrolled in college (64%), and did not have a family history of breast cancer (53.8%). Findings from this focus group were used to create a survey that was distributed to a larger online sample via Qualtrics Online Sample (n=170). Results from this study may not represent young African American women who do not participate in Qualtrics panels and more specifically, young women who have limited access to the internet.





## About the author

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## **Chapter 5**

### **Discussion**

Population-wide testing (PWT) could be a significant pathway to breast cancer prevention for young African American women. Preemptively exploring their perspectives towards PWT is an important first step towards ensuring that existing breast cancer and genetic testing utilization disparities are reduced if PWT is implemented in the future. Therefore, the purpose of this dissertation was to conduct a sequential exploratory mixed methods study to preemptively understand young African American women's (ages 18-30) perspectives and contributing factors towards hereditary breast cancer mutations and intended use of PWT if it were to be implemented in the future. The two main aims guiding this study were: 1) identify young African American women's knowledge gaps and attitudes towards genetic counseling and testing as well as direct to consumer testing (DTC); assess motivators and barriers to participating in PWT and determine health communication preferences for PWT for hereditary breast cancer mutations; and 2) examine the factors that influence young African American women's intentions to participate in PWT for hereditary breast cancer mutations.

Study findings were presented in the form of two manuscripts intended for peer review and a data brief aimed at public health practitioners at local and state health departments in urban cities with disproportionate breast cancer burden amongst African American women. The first paper presented findings from the focus groups conducted as a part of Aim 1 by examining young African American women's perspectives towards PWT. The second paper presented the survey findings and explored factors that influence intentions to participate in PWT for

hereditary breast cancer mutations. This study had eight main hypotheses that explored the influence of multiple factors (i.e. attitudes towards DTC, subjective norms, group-based medical mistrust, individual medical mistrust, perceived risk, perceived severity, and perspectives towards hereditary breast cancer mutation) on intentions to participate in PWT. The third paper was presented in the format of a data brief and included health communication-related findings from both Aims 1 and 2. Specifically, the brief presented recommendations for public health practitioners working at local and state health departments to best reach and raise awareness amongst young African American women about the new initiative. Taken together, this formative study provides insight into existing knowledge gaps and attitudes that can inform future public health campaigns, behavioral interventions, clinician trainings, and breast cancer prevention programming with young African American women.

Knowledge about hereditary breast cancer mutations varied between the focus groups and surveys. While the majority of focus group participants expressed having limited to no knowledge about hereditary breast cancer mutations, survey respondents indicated moderate knowledge. Survey findings are consistent with a prior study which found that younger age was a significant predictor of greater knowledge about hereditary breast cancer mutations amongst African American breast cancer survivors at high risk for the mutations (Hurtado-de-Mendoza, Jackson, Anderson, & Sheppard, 2017). Differences in study findings could be due to the open-ended way in which the question was asked in the focus group setting versus the true/false knowledge scale that was used in the survey. Another potential explanation is that the survey captured a larger sample, therefore ultimately providing insights about the knowledge level of a

larger sample. Knowledge is a particularly important indicator in that it has been found to predict genetic counseling and testing utilization amongst African American women (Hurtado-de-Mendoza et al., 2017). Therefore, this current study suggesting that participants have limited to moderate knowledge about hereditary breast cancer mutations may indicate the need for more specific education in this group.

Medical mistrust was a common thread in the focus groups and survey data. Overall, participants indicated that they had moderate to high levels of medical mistrust. In the focus groups, medical mistrust was a commonly cited disadvantage and barrier to participation in DTC testing, the current model of genetic counseling and testing, as well as PWT. Consistent with prior research (Adams, Christopher, Williams, & Sheppard, 2015; Sheppard et al., 2014; Sheppard, Mays, Tercyak, & LaVeist, 2013), participants were keenly aware of the differences in quality of care, potential exploitation by the medical field, as well as had concerns about the confidentiality of testing results. When asked specifically about PWT, participants indicated that more research would be needed for them to be comfortable with participating in PWT. High levels of medical mistrust might be attributed to mainstream conversations about Black maternal mortality, for example, in 2018, the near death experience during childbirth by top tennis player, Serena Williams due to her doctor not listening to her concerns (Haskell, 2018). Despite study participants high levels of medical mistrust, this variable was not associated with intentions to participate in PWT. This finding is particularly important given that medical mistrust has consistently been found to be a significant barrier to utilization of genetic counseling and testing amongst African American women at high risk for being a mutation carrier (Sheppard et al.,

2013). Findings from this current study suggest that even though participants may have high levels of medical mistrust, it may not have the same impact on their intentions to participate in PWT.

Cost was another commonly cited barrier to participation in all three genetic testing services explored in the focus groups. Cost has been consistently cited as a common barrier to African American women's participation in traditional genetic testing (Adams et al., 2015; Sheppard et al., 2014). In this study, participants were not only concerned about the affordability of testing for themselves but were also more broadly hyperaware of potential disparities in access to testing for underrepresented minorities and socio-economically disadvantaged groups.

Focus group participants indicated several benefits and motivators to participating in DTC testing, the current model of genetic testing, and PWT. Similar to prior studies that explore African American's perspectives towards DTC testing (Carroll et al., 2019; Landry et al., 2017), participants indicated that DTC testing was beneficial for learning more about ancestry and about personal risk for disease. Perhaps indicating the proliferation of direct to consumer testing, among survey participants, motivations to participate in direct to consumer testing was associated with intentions to participate in PWT. Similar to other research, advantages of the current model of genetic testing in a prior study (Adams et al., 2015), such as early detection, being informed, and the opportunity to make lifestyle changes, were also expressed by focus group participants. There was no association between participants' attitudes towards hereditary breast cancer mutations and intentions to participate in PWT, despite perceived benefits of genetic counseling and testing being a predictor of genetic counseling and testing utilization in a

prior study with older African American women at high risk for a hereditary breast cancer mutation (Jones, McCarthy, Kim, & Armstrong, 2017). When focus group participants were asked about potential motivators to participate in PWT, they cited common motivators such as having children and a family history of breast cancer that may put them at high risk (Adams et al., 2015). Furthermore, given the distrust of the medical field, participants noted the importance of access to quality healthcare as a motivator to participate in the potential new initiative.

In the survey, we explored the impact of subjective norms, perceived severity, and perceived risk on intentions to participate in PWT. Different from a prior study found that subjective norms did not influence genetic testing amongst African American women who had been diagnosed with breast cancer at a young age (Jones et al., 2016), this current study found that subjective norms was a significant predictor of intentions to participate in PWT. Differences between this current study may be due to the fact that participants in the prior study were diagnosed between the ages of 20-45 but participated in this study years later. Findings from this current study suggest that young African American women would be influenced by members of their social network including, family and friends, to participate in PWT. Neither perceived risk for breast cancer nor perceived severity was associated with intentions among survey participants.

### **Strengths, Limitations and Future Directions**

This current study addresses a significant gap in the existing literature by exploring young African American women's (18-30 years) perspectives about PWT and contributing factors that influence their intentions to participate in PWT. A strength of this study is that it

explores the perspectives of those who would be approaching the proposed screening age for PWT if it is implemented in the future. The majority of existing studies have focused solely on those African American women who have a family or personal history suggestive of a hereditary breast cancer mutation (Hurtado-de-Mendoza et al., 2017; Jones et al., 2016; Sheppard et al., 2014; Sutton et al., 2019). There are limited studies on attitudes towards PWT (Rubinsak et al., 2019) and currently no studies that specifically focus on young African American women. Another strength of this study is that it used a sequential exploratory mixed methods study approach starting with qualitative research which allowed for an in-depth exploration of potential factors that were salient for this specific population and were then included in the larger survey. Lastly, the use of cognitive interviews was another strength of this current study given that they helped to increase the validity of the survey instrument prior to distribution.

However, there are a various limitations. Overall, this study may also not be representative of non-college attending and low income young African American women who may experience additional barriers, such as competing priorities and lack of employment-based health insurance, that may impact intentions to participate in PWT for hereditary breast cancer mutations. Another limitation of this study was that the dependent variable, intention to participate in PWT, was not normally distributed. The majority of women indicated that they were unsure about their intentions to participate in PWT. Future studies should be conducted with low income and non-college attending young African American women to explore whether their knowledge of hereditary breast cancer mutations, attitudes, and motivators and barriers to participating in PWT differ from the study participants.

There are several other potential research directions that could stem from this research. Family and peer interventions could be beneficial in this group given the influence they have on participants intentions to participate in PWT. Furthermore, health communication related findings from this study suggest that interventions on social media platforms, such as Twitter and Instagram, may be well-suited for this group. Additional research should also determine what other factors may influence intentions to participate in PWT. Other factors that may be important for this group include, genetic counseling and the testing experience, preference for the type of medical professional providing the testing, and accessibility of testing, all of which may impact intentions to participate in PWT. Future research should focus on testing interventions with clinicians including primary care physicians and gynecologists, to not only raise knowledge about hereditary breast cancer mutations but also to improve their health directed messaging with young African American women. It will also be important for future research efforts to prioritize African American women who are older than 30 who may also be able to utilize PWT as a pathway to breast cancer prevention given that African American women shoulder a disproportionate burden of breast cancer mortality at every age (DeSantis et al., 2019). Lastly, African American women's perspectives of PWT as it relates to ovarian cancer should be explored given that hereditary breast cancer mutations also substantially heighten a woman's risk for ovarian cancer over her lifetime (Srivastava et al., 2017). Moreover, similar to existing breast cancer disparities, African American women tend to be diagnosed with ovarian cancer at more advanced stages and have higher mortality rates than White women (Srivastava et al., 2017).

### **Implications for Practice**



There are several implications of this research for practice that can be implemented by public health practitioners. First, is the use of social media as a strategy to develop targeted public health campaigns about PWT. Social media has become an integral part of the everyday lives of many individuals and is increasing becoming a significant source of health-related information (Li, Wang, Lin, & Hajli, 2018; Zhou, Zhang, Yang, & Wang, 2018). For example, the social media platform, Instagram, is a prime source for disseminating public health campaigns because users typically represent diverse socio-economic backgrounds and tend to be younger (Perrin & Anderson, 2019). Black users worldwide represent a greater percentage of Instagram users than Whites (Perrin & Anderson, 2019). Despite the potential utility of social media platforms, prior studies have consistently found that public health organizations underutilize social media as a conduit of health communication (Basch & MacLean, 2019; Miller, Guidry, & Fuemmeler, 2019). Second, potential health promotion strategies might include partnerships with influencers on both Twitter and Instagram. Partnerships with popular influencers that have a large following on social media may provide an entryway for public health messages about such an initiative using popular hashtags, such as #BlackTwitter that have the potential to quickly circulate information to members of the African American community. Public health campaigns on both social media and traditional platforms will need to not only target young African American women but also members of their social network and will need to emphasize the importance of key members of their social network, such as parents and friends.

This study also has implications for public health programming. Similar to public health campaigns, findings suggest that it may be beneficial to create programming that targets not only

the young woman but also key social network members. One example of potential programming could be a mother- daughter event that increases awareness amongst the dyad about PWT. The goal of this type of programming would be to spark additional conversations after the event about the importance of PWT. Study findings suggest that it may be important to partner with Black breast cancer organizations to create programming. These organizations are regarded as highly credible and their support may enhance the importance of breast cancer prevention efforts, such as PWT, amongst young African American women.

Findings also suggest that it may be important to develop trainings for healthcare providers in an effort to help promote the participation of young African American women patients in PWT. Given that healthcare professionals lack knowledge about hereditary breast cancer mutations (Christensen et al., 2016; Hauser, Obeng, Fei, Ramos, & Horowitz, 2018), it may be important to develop trainings to increase knowledge about hereditary breast cancer mutations and PWT among these professionals. Furthermore, additional training focusing on both cultural competency and patient-provider communication could be beneficial to assuaging medical mistrust amongst young African American women.

## **Conclusion**

PWT for hereditary breast cancer mutations for all women beginning at age 30 has been proposed as a viable potential pathway to breast cancer prevention for all women (King, Levy-Lahad, & Lahad, 2014). This was the first study to preemptively explore young African American women's perspectives and intentions to participate in PWT. Findings from this study provide insights about young African American women's current knowledge gaps about

hereditary breast cancer mutations, potential motivators, and barriers to their participation in PWT, and recommendations for future research and practice. Ultimately, if PWT is implemented, preemptively prioritizing this group will be imperative to reducing existing breast cancer disparities impacting young African American women.

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## **APPENDICES**

## **Appendix 1: Chapter 2**

### **Recruitment Email**

To whom it may concern,

My name is Alesha Henderson and I am a doctoral candidate in the Department of Health Behavior and Policy at Virginia Commonwealth University. I am writing to invite you to participate in a research study that focuses on young African American women's perspectives of hereditary breast cancer mutations and their health communication preferences. This study calls for the participation of African American women between the ages of 18 and 30 from the Greater Richmond Area.

Participation in this study involves:

- Answering questions about hereditary breast cancer mutations and health communication preferences
- 60-minute focus group in a private room on VCU's campus or at a library in the Greater Richmond Area
- Compensation will be provided

If you are interested in participating in this study, please call Alesha Henderson at 804-614-8304 or email her at [hendersonan2@mymail.vcu.edu](mailto:hendersonan2@mymail.vcu.edu). She is currently a doctoral candidate in the Department of Health Behavior and Policy at Virginia Commonwealth University.

### **Social media recruitment**



## Research study about Hereditary Breast Cancer Mutations and Health Communication Preferences

**Purpose:** We want to examine young women's perspectives about hereditary breast cancer mutations and potential population-wide testing for hereditary breast cancer mutations.

We are looking for young African American women to participate in a focus group.

### **Who can participate?**

- African American women in the Greater Richmond Area between the ages of 18 and 30.

### **What does participation involve?**

- Answering questions about hereditary breast cancer mutations and health communication preferences
- 60-minute focus group in a private room on VCU's campus or at a library in the Greater Richmond Area
- Compensation will be provided

If you are interested in participating in this study, please call Alesha Henderson at 804-614-8304 or email her at [hendersonan2@mymail.vcu.edu](mailto:hendersonan2@mymail.vcu.edu). She is currently a doctoral candidate in the Department of Health Behavior and Policy at Virginia Commonwealth University.



**Eligibility Screening for Focus Groups**

1. Do you identify as Black or African American women?  Yes  No
2. Are you between the ages of 18 and 30 years old?  Yes  No
  - a. If so, what is your age? \_\_\_\_\_
3. Do you live in the Greater Richmond Area?  
 Yes  No
  - a. If yes, what is your city and county of residence?  
\_\_\_\_\_
4. Do you have a known hereditary breast cancer mutation?  
 Yes  No
5. Are you currently enrolled at Virginia Commonwealth University?  
 Yes  No
  - a. If yes, what degree program are you pursuing?  
\_\_\_\_\_
6. Are you currently enrolled at Virginia Union University?  
 Yes  No
  - a. If yes, what degree program are you pursuing?  
\_\_\_\_\_

**RESEARCH PARTICIPANT INFORMATION SHEET**

**TITLE: Changing Landscapes: Perspectives of Young African American women of Population-Wide Testing for Hereditary Breast Cancer Mutations**

**VCU IRB NO.: HM20015881**

**PRINCIPAL INVESTIGATOR:** Alesha Henderson, M.A.  
Department of Health  
Behavior & Policy Virginia  
Commonwealth University  
Phone: 804-614-8304  
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0149  
Phone: (804) 628-2929  
Fax: (804) 828-5440

**PURPOSE OF THE STUDY**

You are being invited to participate in this research study about population-wide testing for hereditary breast cancer mutations and your health communication preferences. The results of this study will be used to develop a survey that will be distributed to a larger sample of young African American women. In this study, you will be asked to visit a conveniently located room at a library in the Greater Richmond Area or on Virginia Commonwealth University's campus to participate in a 60-minute focus group about hereditary breast cancer mutations and health communication preferences.

**VOLUNTARY PARTICIPATION AND WITHDRAWAL**

Your participation in this research study is voluntary. You do not have to participate in this study. If you choose to participate, you may stop at any time without any penalty. You may also choose not to answer particular questions that are asked in the study. Discontinuing your participation or withdrawing from the study will not result in any loss or benefits to which you are otherwise entitled. If you decide to join the study, you may withdraw at any time and for any reason without penalty or loss of benefits.

## **RISKS AND DISCOMFORTS**

There are minimal risks associated with participation in this study. Questions posed in the focus groups should not cause any distress to you given that they are not personal in nature but if they do, you can choose to skip any question that you do not feel comfortable with and can discontinue your participation in this study at any time. There is also a risk of a loss of confidentiality or privacy. Other members of the focus groups will be able to see that you are in the study and hear your responses, but we will not share any other information you provide to us with other members of the group.

## **PAYMENT FOR PARTICIPATION**

As a display of our appreciation for your participation in this study, you will receive a \$15 gift card when you complete the focus group.

## **QUESTIONS**

If you have any questions, concerns, or complaints about this study now or in the future, please contact Alesha Henderson at 804-614-8304 or email her at [hendersonan2@mymail.vcu.edu](mailto:hendersonan2@mymail.vcu.edu). She is currently a doctoral candidate in the Department of Health Behavior and Policy at Virginia Commonwealth University.

## Appendix 2 Chapter 3



### Research study about Hereditary Breast Cancer Mutations and Health Communication Preferences

**Purpose:** We want to get young African American women's feedback on a survey that will be distributed to a larger sample of young African American women.

We are looking for young African American women to participate in an interview.

#### Who can participate?

- African American women between the ages of 18 and 30 who are community residents in the Greater Richmond Area.

AND

- African American women between the ages of 18 and 30 that attend Virginia Commonwealth University or Virginia Union University

#### What does participation involve?

- Participating in a 60 minute telephone interview
- Review an online survey on your cellphone or computer
- Providing feedback on its' design and questions
- Incentives will be provided.

If you are interested in participating in this study, please call Alesha Henderson at 804-614-8304 or email her at [hendersonan2@mymail.vcu.edu](mailto:hendersonan2@mymail.vcu.edu). She is currently a doctoral candidate in the Department of Health Behavior and Policy at Virginia Commonwealth University.

To whom it may concern,

My name is Alesha Henderson and I am a doctoral candidate in the Department of Health Behavior and Policy at Virginia Commonwealth University. I am writing to invite you to participate in a research study that focuses on young African American women's perspectives of hereditary breast cancer mutations and their health communication preferences. This study calls for the participation of African American women between the ages of 18 and 30 from the Greater Richmond Area. We are specifically looking for students enrolled at either Virginia Commonwealth University or Virginia Union University. African American women between the ages of 18 and 30 who are community residents in the Greater Richmond area are also eligible to participate.

Participation in this study involves:

- Participating in a 60 minute telephone interview (\$10 gift card for participation)
- Review an online survey on your cellphone or computer
- Providing feedback on its' design and questions

If you are interested in participating in this study, please call Alesha Henderson at 804-614-8304 or email her at [hendersonan2@mymail.vcu.edu](mailto:hendersonan2@mymail.vcu.edu). She is currently a doctoral candidate in the Department of Health Behavior and Policy at Virginia Commonwealth University.

**Eligibility Screening for Cognitive Interviews**

1. Do you identify as Black or African American women?  Yes  No
2. Are you between the ages of 18 and 30 years old?  Yes  No
- a. If so, what is your age? \_\_\_\_\_

3. Do you live in the Greater Richmond Area?
- Yes  No
- a. If yes, what is your city and county of residence?
- 

4. Do hereditary breast cancer mutations run in your family?
- Yes  No
5. Are you currently enrolled at Virginia Commonwealth University?
- Yes  No
- a. If yes, what degree program are you pursuing?
- 

6. Are you currently enrolled at Virginia Union University?
- Yes  No
- a. If yes, what degree program are you in?

- 7, Do you have access to the internet via either a cellphone or computer?
- Yes  No

## RESEARCH PARTICIPANT INFORMATION SHEET FOR VERBAL CONSENT

**TITLE: Changing Landscapes: Perspectives of Young African American women of Population-Wide Testing for Hereditary Breast Cancer Mutations**

**VCU IRB NO.: HM20015881**

**PRINCIPAL INVESTIGATOR:**

**Alesha Henderson, M.A.**

**Department of Health**

**Behavior & Policy Virginia**

**Commonwealth University**

**Phone: 804-614-8304**

**Email: [Hendersonan2@mymail.vcu.edu](mailto:Hendersonan2@mymail.vcu.edu)**

**Maghboeba Mosavel, PhD**

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**Behavior & Policy Virginia**

**Commonwealth University**

**Richmond, Virginia 23298-**

**0149**

**Phone: (804) 628-2929**

**Fax: (804) 828-5440**

### **PURPOSE OF THE STUDY**

You are being invited to participate in this research study about population-wide testing for hereditary breast cancer mutations and your health communication preferences. The results of this study will be used to develop a survey that will be distributed to a larger sample of young African American women. In this study, you will be asked to participate in a 60-minute cognitive telephone interview to review provide feedback on an online survey. Interviews will be audio-recorded and transcribed so that they are accurately reported.

### **VOLUNTARY PARTICIPATION AND WITHDRAWAL**

Your participation in this research study is voluntary. You do not have to participate in this study. If you choose to participate, you may stop at any time without any penalty. You may also choose not to answer particular questions that are asked in the study. Discontinuing your participation or withdrawing from the study will not result in any loss or benefits to which you are otherwise entitled. If you decide to join the study, you may withdraw at any time and for any reason without penalty or loss of benefits.

## **RISKS AND DISCOMFORTS**

There are minimal risks associated with participation in this study. The questions asked in this study should not cause any distress. However, in the case that you feel that you need mental health services, Therapy for Black Girls is a great online resource to find local therapy services provided by African American women. There are also mobile apps, such as Betterhelp and Talkspace, that provide online therapy services.

## **PAYMENT FOR PARTICIPATION**

As a display of our appreciation for your participation in this study, you will receive a \$10 gift card via mail after you complete the cognitive interview.

## **QUESTIONS**

If you have any questions, concerns, or complaints about this study now or in the future, please contact Alesha Henderson at 804-614-8304 or email her at [hendersonan2@mymail.vcu.edu](mailto:hendersonan2@mymail.vcu.edu). She is currently a doctoral candidate in the Department of Health Behavior and Policy at Virginia Commonwealth University.



## Welcome and Introduction

Hello! Welcome to today's cognitive interview session and thank you for taking the time to be here with me. My name is Alesha Henderson and I will be conducting the interview today. I am a fourth-year, social and behavior sciences, doctoral candidate in the Department of Health Behavior & Policy in the School of Medicine at Virginia Commonwealth University.

*Purpose:* I've invited you here today to ask you to complete a survey so that I can get your perspectives on a survey that will be distributed to other African American women between the ages of 18 and 30. The survey broadly focuses on your knowledge of and perspectives towards hereditary breast cancer mutations, potential population-wide testing for hereditary breast cancer mutations, and your health communication preferences for messages about population-wide testing.

*Process:* I will ask you to respond verbally and on the online survey platform to questions from a previously developed online survey. There are no right or wrong answers to the questions that I ask you. After asking certain questions, I will ask you additional questions about your experience understanding and responding to the question. Again, there are no right or wrong answers. Your responses will help to create a better version of the survey to be distributed to a larger online sample.

This session is expected to last no more than 60 minutes and you will receive a \$10 gift card for compensation for your participation at the end of the survey. In-person participants will be handed their compensation upon completion of the interview. Individuals who participate in the second round of cognitive interviews will receive their compensation via mail. The session will be audio-recorded. The recordings will not contain any names or personal information and will only be used for research purposes.

*In Case of Distress:* The interview questions are not specific to your personal lives; however, you may choose not to answer particular questions that are asked in the study. Your participation in this session is completely voluntary. If at any time you feel uncomfortable or distressed, please don't hesitate to stop me at any time without any consequence. Also, please note that, for your safety, I will have to break confidentiality if you mention that you have been harmed, are harming oneself, or have/will harm(ed) others. As part of VCU's policy and procedures, I will have to report this to the appropriate outlets.

At this time, we ask that you please take a moment to read the informed consent document.

### **Instructions for interviewer:**

**→ Current probing questions begin at the description of direct to consumer testing.**  
**(highlighted in red)**

- There are interview instructions for each question ( highlighted in grey )
- Probes have been created and listed under each of the questions of interest (highlighted in yellow)
- Be sure to go through each question with each cognitive interview participants

### Survey Begins Here:

Survey Introduction: I am currently conducting research on the perspectives of young African American women between the ages of 18 and 30 on hereditary breast cancer mutations and the potential for population-wide testing for hereditary breast cancer mutations for all women in the United States among young women like yourselves. Questions will focus on your knowledge of and perspectives towards hereditary breast cancer mutations, potential population-wide testing for hereditary breast cancer mutations, and your health communication preferences for messages about population-wide testing.

This survey should take approximately 20-25 minutes to complete.

If you have any questions about the survey, please email Alesha Henderson at hendersonan2@vcu.edu.

**Direct To Consumer Testing:** Direct-to-consumer genetic tests are marketed directly to customers via television, print advertisements, or the Internet, and the tests can be bought online or in stores. Customers send the company a DNA sample and receive their results directly from a secure website or in a written report. Direct-to-consumer genetic testing provides people access to their genetic information without necessarily involving a healthcare provider or health insurance company in the process (Retrieved February 4, 2020 from <https://ghr.nlm.nih.gov/primer/dtcgenetictesting/directtoconsumer>).

**Cognitive Interviewer questions start here!!!**

Question Instructions for Interviewers:

Please Ask the following questions about the paragraph about direct to consumer testing above:

1. Paraphrase: Would you please repeat that to me in your own words?
2. Comprehension: What does the term “genetic test” mean to you?

3. Comprehension: What does direct to consumer testing mean to you?

4. General probe: Was that easy or hard for you to read?

1. Do you know or have you heard of genetic tests that are provided directly to consumers via the internet?
  - a. Yes
  - b. No
  
2. Have you ever done a genetic test which is provided directly to consumers via the internet?
  - a. Yes
  - b. No

**Below are several statements describing why some people may do *direct to consumer genetic testing*. Please indicate how much you agree each statement. For what reason/motivation would you do *direct to consumer genetic testing*?**

	Strongly Disagree	Disagree	Neither Agree or Disagree	Agree	Strongly Agree
3. To know more about my health.	1	2	3	4	5
4. So that the doctor can monitor my health.	1	2	3	4	5
5. To change my lifestyle (e.g. dietary habits, exercise) in case the genetic test shows that I have an increased risk for a certain disease.	1	2	3	4	5
6. To inform my children about their possible increased risk for a disease.	1	2	3	4	5
7. Out of curiosity.	1	2	3	4	5
8. Out of scientific/ research interest	1	2	3	4	5
9. For fun.	1	2	3	4	5

Question Instructions for Interviewers:

Please ask the following questions related to the scale above:

1. Paraphrase: Would you please repeat the main question in your own words?
2. General Probe: Can you take me through the steps of how you came to your answers for questions 12 through 18?
  - a. Allow the respondent to provide their rationale/ decision making process for scale responses 12-18.
3. General probe: Were these questions easy or hard for you to answer?

**Below are several statements describing why some people may not do *direct to consumer genetic testing*. Please indicate how much you agree each statement. For what reason would you not like to do direct to consumer genetic testing?**

	Strongly Disagree	Disagree	Neither Agree or Disagree	Agree	Strongly Agree
10. The results are unreliable.	1	2	3	4	5
11. The information will not be useful.	1	2	3	4	5
12. I wouldn't like to know the risk I have to develop a certain disease.	1	2	3	4	5
13. I worry about my personal data and private life.	1	2	3	4	5

**Question Instructions for Interviewers:**

Please ask the following questions related to the scale above:

1. Paraphrase: Would you please repeat the main question in your own words?
2. General Probe: Can you take me through the steps of how you came to your answers for questions 19 through 22?
  - a. Allow the respondent to provide their rationale/ decision making process for scale responses 19-22.

3. General probe: Was that easy or hard for you to answer?

Question Instructions for Interviewers:

Probe about both direct to consumer scales:

4. General probe: Do you feel as if the description of direct to consumer testing provided sufficient information to answer those two questions?

The next set of questions is to find out how much you may already know about genes for cancer.

	True	False	Don't know
14. 50% (or half) of inherited genetic information (about breast cancer risk) is passed down from a person's mother.	01	02	3
15. 25% of inherited genetic information (about breast cancer risk) is passed down from a person's father.	01	02	3
16. There is more than one gene that can increase the risk of breast cancer.	01	02	3
17. A woman who has a sister with a breast cancer gene mutation has a 1 in 4 chance of having a gene mutation herself.	01	02	3
18. One in ten women has a breast cancer gene mutation.	01	02	3
19. Women who test positive for breast cancer gene mutations are more likely to develop breast cancer at a young age.	01	02	3

20. If a woman tests positive for a breast cancer gene mutation, her male relatives' risk for developing prostate cancer are lowered	01	02	3
21. A woman may be at a greater risk for developing ovarian cancer if she has several close relatives with breast cancer.	01	02	3
22. A woman who has her healthy ovaries removed will definitely not get ovarian cancer.	01	02	3
23. A woman who has her breasts removed will definitely not get breast cancer.	01	02	3
24. Screening for ovarian cancer often does not detect a tumor until it's more advanced.	01	02	03

**Genetic Counseling:** Genetic counseling is a communication process between a specially trained health professional and a person concerned about the genetic risk of disease. The person's family and personal medical history may be discussed, and counseling may lead to genetic testing.

#### Question Instructions for Interviewers:

Ask the following questions about the paragraph about genetic counseling above:

1. General probe: Was that easy or hard for you to read?

2. Comprehension: In your own words, what is genetic counseling?

25. Have you ever heard about genetic counseling for hereditary breast cancer genes (e.g., *Breast cancer gene*)?

- a. Yes
- b. No (skip pattern here)

26. If yes, how did you hear about genetic counseling for hereditary breast cancer genes (e.g., *Breast cancer gene*)? Please check all that apply:

- TV
- Newspaper
- Internet

- Friends
- Family
- Physician
- Other health professional:
  - i. Please specify \_\_\_\_\_

27. Has your healthcare provider ever talked to you about genetic counseling for hereditary breast cancer mutations?
- a. Yes
  - b. No (Skip pattern to Question 29)

28. Did she/he give you a referral for genetic counseling?
- a. Yes
  - b. No

**Genetic Testing:** Genetic testing for hereditary breast cancer looks for a mutation in your genes. Genetic testing may or may not involve genetic counseling or meeting with a genetic counselor.

#### Question Instructions for Interviewers:

Ask the following questions about the paragraph about genetic testing above:

1. General probe: Was that easy or hard for you to read?
2. Comprehension: In your own words, what is genetic testing?

29. Have you ever heard about genetic testing for a hereditary breast cancer gene (e.g. *BRCA*)?
- a. Yes
  - b. No (skip pattern to Question 31)
30. If yes, how did you hear about genetic testing for hereditary breast cancer mutations? Please check all that apply:
- TV
  - Newspaper
  - Internet

- Friends
- Family
- Physician
- Other health professional:
  - i. Please specify \_\_\_\_\_

**The next questions focus on your perspectives of hereditary breast cancer mutations.**

	Strongly Disagree	Disagree	Neither Agree or Disagree	Agree	Strongly Agree
31. If I were found to carry the gene, it would help members of my family like daughter(s) or sister(s) decide whether to undergo genetic testing.	1	2	3	4	5
32. Knowing that I carry the gene would help me decide whether to go for more frequent mammograms.	1	2	3	4	5
33. Knowing whether or not I carry the gene would increase my sense of personal control.	1	2	3	4	5
34. Knowing that I do not carry the gene would greatly improve my quality of life.	1	2	3	4	5
35. My concerns about developing breast cancer would be reduced if I knew I did not carry the gene.	1	2	3	4	5
36. My concerns about developing breast cancer would increase if I knew that I carried the gene.	1	2	3	4	5
37. Knowing that I do not carry the gene would not be helpful since I could still develop breast cancer.	1	2	3	4	5
38. If I were found to carry the gene, it would jeopardize my insurance	1	2	3	4	5



coverage or lead to problems with my employers.					
39. If I were found to carry the gene, it would cause others to view me negatively.	1	2	3	4	5
40. If I were found to carry the gene, it would lead to marital or family problems.	1	2	3	4	5
41. Testing is not worthwhile because it could yield inconclusive results about whether I carry the gene for breast cancer.	1	2	3	4	5
42. If I were found to carry the gene for breast cancer, I would worry about passing the gene to my children.	1	2	3	4	5
43. If I were found to carry the gene, I would worry that the results would not stay confidential.	1	2	3	4	5

#### Question Instructions for Interviewers:

Please ask the following questions related to the scale above:

1. General Probe: Can you take me through the steps of how you came to that answer for each of the perspectives towards hereditary breast cancer mutations listed in questions 40-52?

a. Allow the respondent to provide their rationale/ decision making process for scale responses in questions 40-52.

2. General probe: Were questions 40-52 easy or hard for you to answer?

3. General probe: Do you feel as if the description of genetic counseling and testing provided sufficient information to answer this question?

44. How likely do you think it is that you carry a *hereditary breast cancer mutation*?

a. Not at all likely

- b. Somewhat likely
- c. Likely
- d. Very Likely
- e. Extremely likely

**Question Instructions for Interviewers:**

Please ask the following questions about the question above:

1. Paraphrase: Would you please repeat the question that I just asked you in your own words?
2. General Probe: Can you take me through the steps of how you came to that answer?
3. Specific Probe: Do you think it would be hard for other people to answer that question?

**The next set of questions ask you to imagine the reaction you would have if you were to be told you have a hereditary breast cancer mutation.**

	Strongly Disagree	Disagree	Neither agree or disagree	Agree	Strongly agree
45. If I found out I carried a gene mutation, it would greatly disrupt my life.	1	2	3	4	5
46. Finding out I carried a gene mutation would be very difficult for me.	1	2	3	4	5
47. If I found out I carried a gene mutation, I would worry much more about developing breast cancer.	1	2	3	4	5

**Question Instructions for Interviewers:**

Please ask the following questions related to the scale above:

1. General Probe: Can you take me through the steps of how you came to your answers for questions 54-56?
  - a. Allow the respondent to provide their rationale/ decision making process for scale responses 54-56.
2. General probe: Were those questions easy or hard for you to answer?
3. Specific Probe: Do you think it would be hard for other people to answer that question?

**When getting health care, have you ever had the following things happen to you because of your race or ethnicity?**

	Yes	No	Unsure
48. Been treated with less courtesy than other people.	01	02	888
49. Been treated with less respect than other people.	01	02	888
50. Received poorer service than others.	01	02	888
51. Had a doctor or nurse act as if he or she thinks you are not smart?	01	02	888
52. Had a doctor or nurse act as if he or she is afraid of you?	01	02	888
53. Had a doctor or nurse act as if he or she is better than you?	01	02	888
54. Felt like a doctor or nurse was not listening to what you were saying?	01	02	888

Question Instructions for Interviewers:

Please ask the following questions related to the scale above:

1. Paraphrase: Would you please repeat the main question in your own words?

2. General Probe: Can you take me through the steps of how you came to your answers for questions 57-63?

a. Allow the respondent to provide their rationale/ decision making process for scale responses 57-63.

3. General probe: Was that easy or hard for you to answer?

**Thinking about the relationship between various racial/ethnic groups and the American medical system, please rate how strongly you agree or disagree with the following statements. Please note, we are referring to your general feelings...**

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree	Unsure
55. Doctors and health care workers sometimes hide information from patients who belong to my racial/ethnic group	1	2	3	4	5	888
56. Doctors have the best interests of people of my racial/ethnic group in mind	1	2	3	4	5	888
57. People of my racial/ethnic group should not confide in doctors and health care workers because it will be used against them	1	2	3	4	5	888
58. People of my racial/ethnic group should be suspicious (distrustful) of information from doctors and health care workers	1	2	3	4	5	888
59. People of my racial/ethnic group cannot trust doctors and health care workers	1	2	3	4	5	888
60. People of my racial/ethnic group should be suspicious of modern medicine	1	2	3	4	5	888

61. Doctors and health care workers treat people of my racial/ethnic group like “guinea pigs”	1	2	3	4	5	888
62. People of my racial/ethnic group receive the same medical care from doctors and health care workers as people from other groups	1	2	3	4	5	888
63. Doctors and health care workers do not take the medical complaints of people of my racial/ethnic group seriously	1	2	3	4	5	888
64. People of my racial/ethnic group are treated the same as people from other groups	1	2	3	4	5	888
65. In most hospitals, people of different racial/ethnic groups receive the same kind of care	1	2	3	4	5	888
66. I have personally been treated poorly or unfairly by doctors or health care workers because of my racial/ethnic group.	1	2	3	4	5	888

**Question Instructions for Interviewers:**

Please ask the following questions related to the scale above:

1. Paraphrase: Would you please repeat the main statement in your own words?
2. General Probe: Can you take me through the steps of how you came to that answer for each of your potential race-based experiences listed in questions 64-75?
  - a. Allow the respondent to provide their rationale/ decision making process for scale responses 64-75.
3. General probe: Was that easy or hard for you to answer?

**The next questions ask about the ways you may or may not have relied on religion to deal with life stressors.**

	Not at all	Very little	Somewhat	A great deal	Not Applicable
67. Looked for a stronger connection with God.	1	2	3	4	999
68. Sought God's love and care.	1	2	3	4	999
69. Sought help from God in letting go of my anger.	1	2	3	4	999
70. Tried to put my plans into action together with God.	1	2	3	4	999
71. Tried to see how God was trying to strengthen me in this situation.	1	2	3	4	999
72. Asked forgiveness for my sins.	1	2	3	4	999
73. Focused on religion to stop worrying about my problems.	1	2	3	4	999
74. Wondered whether God had abandoned me.	1	2	3	4	999
75. Felt punished by God for my lack of devotion.	1	2	3	4	999
76. Questioned God's love for me.	1	2	3	4	999
77. Wondered whether my church had abandoned me.	1	2	3	4	999

78. Decided the devil made this happen to me.	1	2	3	4	999
79. Questioned the power of God.	1	2	3	4	999

**Population-based testing for hereditary breast cancer mutations:** There is a current proposal about to offer genetic counseling and testing for hereditary breast cancer mutations to all women in the United States starting at age 30. Please answer the next questions with this in mind.

Question Instructions for Interviewers:

Please ask the following questions about the paragraph above about population-based testing:

1. General probe: Was that easy or hard for you to read?
2. Comprehension: In your own words, what is population-based testing?

80. Now try to imagine that you are offered genetic testing and counseling for breast cancer susceptibility *through a population-based testing initiative* at some point in the future, would you choose to have the test

- a. No, Definitely not (1)
- b. No, Probably not (2)
- c. Unsure (3)
- d. Yes, probably (4)
- e. Yes, definitely (5)

Question Instructions for Interviewer:

Please ask the following about the question above:

1. Paraphrase: Would you please repeat the question in your own words?
2. General Probe: Can you take me through the steps of how you came to that answer?

3. General probe: Was that easy or hard for you to answer?

The next questions ask you to imagine what members of your social circle would think of you participating in population-based testing if it becomes available.

	Strongly Disagree	Disagree	Neither Agree/Disagree	Agree	Strongly Agree	Unsure	Not applicable
81. My friends would approve of me getting genetic testing and counseling <i>through population-based testing.</i>	01	02	03	04	05	888	999
82. My spouse would approve of me getting genetic testing and counseling <i>through population-based testing.</i>	01	02	03	04	05	888	999
83. My parents would approve of me getting genetic testing and counseling <i>through population-based testing.</i>	01	02	03	04	05	888	999
84. My siblings would approve of me getting genetic testing and counseling <i>through population-based testing.</i>	01	02	03	04	05	888	999
85. My other family member would approve of me getting genetic	01	02	03	04	05	888	999



testing and  
counseling *through*  
*population-based*  
*testing.*

Question Instructions for Interviewers:

Please ask the following questions related to the scale above:

1. Paraphrase: Would you please repeat the main statement in your own words?
2. General Probe: Can you take me through the steps of how you came to your answers for questions 90-94 ?
  - a. Allow the respondent to provide their rationale/ decision making process for scale responses 90-94.
3. General probe: Was that easy or hard for you to answer?

86. Would you be willing to pay out of pocket for genetic testing for breast cancer risk through population-based testing?

- Up to \$50 (1)     Up to \$200 (3)     More than \$500 (5)  
 Up to \$100 (2)     Up to \$500 (4)     I would not be willing to pay any money (6)

Question Instructions for Interviewers:

Please ask the following questions related to the question above.

1. Paraphrase: Would you please repeat the question in your own words?
2. General Probe: Can you take me through the steps of how you came to that answer?

87. Imagine you had a strong need to get information about *population-based testing for hereditary breast cancer mutations*. Where would you go first to get information? (Mark only one)
- Printed materials (for example, newspapers, magazines)
  - Health care provider (doctor, nurse, social worker)
  - Conversations with people you trust (friends, relatives, or co-workers)
  - Internet (Google or another search engine, WebMD or another medical website)
  - Social Media (Facebook, Instagram, Twitter)
88. Imagine you had a strong need to get information about *population-based testing for hereditary breast cancer mutations*. Which of the following would you most trust as a source of information about population-based testing for hereditary breast cancer mutations? (Mark only one)
- Printed materials (for example, newspapers, magazines)
  - Health care provider (doctor, nurse, social worker)
  - Conversations with people you trust (friends, relatives, or co-workers)
  - Internet (Google or another search engine, WebMD or another medical website)
  - Social Media (Facebook, Instagram, Twitter)

Thanks for completing the survey. The next questions ask you to provide demographic information about yourself.

### Demographic Survey

- What is your age? \_\_\_\_\_
- Do you have a family history of breast cancer?
  - Yes
  - No
- Are you Hispanic or Latino?
  - Yes, Hispanic or Latino
  - Not, Hispanic or Latino

4. Please tell me which category best describes your racial background?
  - a. Black or African American
  - b. White
  
  - c. Asian
  - d. American Indian/ Alaskan Native
  - f. Native Hawaiian or Other Pacific Islander (6)
  - g. More than One Race
  - h. Other: please specify \_\_\_\_\_
  
5. What is your highest grade or level of schooling you have completed?
  - a. Less than high school
  - b. High School or general equivalency degree
  - c. Some college or technical school
  - d. Bachelor's degree
  - e. Graduate Degree
  
6. Do you have health insurance?
  - a. Yes
  - b. No
  - c. Not sure
  
7. Do you have a regular physician or health care provider?
  - a. Yes
  - b. No
  
8. What is your income?
  - a. Less than \$20,000
  - b. \$20,000-\$39,999
  - c. \$40,000- \$59,999
  - d. \$60,000- \$79,999
  - e. \$80,000- \$99,999
  - f. \$100,000- \$119,999
  - g. At least \$120,000
  
9. What is your employment status?
  - a. Full-time
  - b. Part-time
  - c. Unemployed
  - d. Retired
  - e. Unable to work

- f. Homemaker
- g. Student

10. What is your marital status?

- a. Married
- b. Living Together
- c. Divorced
- d. Widowed
- e. Separated
- f. Never Married

# Dissertation Survey 7.16

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Start of Block: Block 1

Q30 What is your age?

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*Skip To: End of Block If Condition: What is your age? Is Less Than 18. Skip To: End of Block.*

*Skip To: End of Block If Condition: What is your age? Is Greater Than 30. Skip To: End of Block.*

---



Q33 Please tell me which category best describes your racial background?

- Black or African American (1)
- White (2)
- Asian (3)
- American Indian/ Alaskan Native (4)
- More than One Race (5)
- Other: please specify (6) \_\_\_\_\_

*Skip To: End of Block If Please tell me which category best describes your racial background? != Black or African American*

---



Q41 What is your gender?

- Male (1)
- Female (2)
- Other/Non-binary (3)

*Skip To: End of Block If What is your gender? != Female*

---



Q42 Do hereditary breast cancer mutations run in your family?

- Yes (1)
- No (2)
- I don't know (3)

**End of Block: Block 1**

---

**Start of Block: Block 2**

**Q43 RESEARCH PARTICIPANT INFORMATION SHEET**

**TITLE: Changing Landscapes: Perspectives of Young African American women of Population-Wide Testing for Hereditary Breast Cancer Mutations**

**VCU IRB NO.: HM20015881**

**PRINCIPAL INVESTIGATOR: Alesha Henderson,  
M.A.**

**Department of Health Behavior & Policy  
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Phone: 804-614-8304  
Email: Hendersonan2@mymail.vcu.edu**

**Maghboeba Mosavel, PhD  
Department of Health Behavior & Policy  
Virginia Commonwealth University  
Richmond, Virginia 23298-0149  
Phone: (804) 628-2929  
Fax: (804) 828-5440**

**PURPOSE OF THE STUDY**

You are being invited to participate in this research study about population-wide testing for hereditary breast cancer mutations and your health communication preferences. The results of this study will be used to develop a survey that will be distributed to a larger sample of young African American women. In this study, you will be asked to complete a 15-minute online survey on the Qualtrics survey platform focusing on hereditary breast cancer mutations and potential population wide testing for hereditary breast cancer mutations.

**VOLUNTARY PARTICIPATION AND WITHDRAWAL**

Your participation in this research study is voluntary. You do not have to participate in this study. If you choose to participate, you may stop at any time without any penalty. You may also choose not to answer particular questions that are asked in the study. Discontinuing your participation or withdrawing from the study will not result in any loss or benefits to which you

are otherwise entitled. If you decide to join the study, you may withdraw at any time and for any reason without penalty or loss of benefits.

## **RISKS AND DISCOMFORTS**

There are minimal risks associated with participation in this study. The questions asked in this study should not cause any distress. However, in the case that you feel that you need mental health services, Therapy for Black Girls is a great online resource to find local therapy services provided by African American women. There are also mobile apps, such as Betterhelp and Talkspace, that provide online therapy services.

## **PAYMENT FOR PARTICIPATION**

You will be compensated the amount you agree upon before you entered into the survey.

## **QUESTIONS**

If you have any questions, concerns, or complaints about this study now or in the future, please contact Alesha Henderson at 804-614-8304 or email her at [hendersonan2@mymail.vcu.edu](mailto:hendersonan2@mymail.vcu.edu). She is currently a doctoral candidate in the Department of Health Behavior and Policy at Virginia Commonwealth University.

End of Block: Block 2

---

Start of Block: Default Question Block

Q1 Survey Introduction: I am currently conducting research on the perspectives of young African American women between the ages of 18 and 30 on hereditary breast cancer mutations and the potential for population-wide testing for hereditary breast cancer mutations for all women in the United States among young women like yourselves. Questions will focus on your knowledge of and perspectives towards hereditary breast cancer mutations, potential population-wide testing for hereditary breast cancer mutations, and your health communication preferences for messages about population-wide testing. This survey should take approximately 15 minutes to complete. If you have any questions about the survey, please email Alesha Henderson at [hendersonan2@vcu.edu](mailto:hendersonan2@vcu.edu).

---

**Q2 Direct To Consumer Testing:** Direct-to-consumer genetic tests are marketed directly to customers via television, print advertisements, or the Internet, and the tests can be bought online



or in stores. Customers send the company a DNA sample and receive their results directly from a secure website or in a written report. Direct-to-consumer genetic testing provides people access to their genetic information without necessarily involving a healthcare provider or health insurance company in the process.

---



Q3 1. Do you know or have you heard of genetic tests that are provided directly to consumers via the internet?

Yes (1)

No (2)

---



Q4 2. Have you ever done a genetic test which is provided directly to consumers via the internet?

Yes (1)

No (2)

---



**Q5** Below are several statements describing why some people may do *direct to consumer genetic testing*. Please indicate how much you agree with each statement. For what reason/motivation would you do *direct to consumer genetic testing*?

	Strongly disagree (1)	disagree (2)	Neither agree nor disagree (3)	agree (4)	Strongly agree (5)
3. To know more about my health. (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
4. So that the doctor can monitor my health. (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
5. To change my lifestyle (e.g. dietary habits, exercise) in case the genetic test shows that I have an increased risk for a certain disease. (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
6. To inform my children about their possible increased risk for a disease. (4)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
7. Out of curiosity. (5)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
8. Out of scientific/research interest (6)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
9. For fun. (7)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>



**Q6 Below are several statements describing why some people may not do *direct to consumer genetic testing*. Please indicate how much you agree with each statement. For what reason would you not like to do direct to consumer genetic testing?**

	Strongly disagree (1)	disagree (2)	Neither agree nor disagree (3)	agree (4)	Strongly agree (5)
10. The results are unreliable. (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
11. The information will not be useful. (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
12. I wouldn't like to know the risk I have to develop a certain disease. (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
13. I worry about my personal data and private life. (4)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>



**Q7 The next set of questions is to find out how much you may already know about genes for cancer.**

	True (1)	False (2)
14. 50% (or half) of inherited genetic information (about breast cancer risk) is passed down from a person's mother. (1)	<input type="radio"/>	<input type="radio"/>
15. 25% of inherited genetic information (about breast cancer risk) is passed down from a person's father. (2)	<input type="radio"/>	<input type="radio"/>
16. There is more than one gene that can increase the risk of breast cancer (3)	<input type="radio"/>	<input type="radio"/>
17. A woman who has a sister with a breast cancer gene mutation has a 1 in 4 chance of having a gene mutation herself. (4)	<input type="radio"/>	<input type="radio"/>
18. One in ten women has a breast cancer gene mutation (5)	<input type="radio"/>	<input type="radio"/>
19. Women who test positive for breast cancer gene mutations are more likely to develop breast cancer at a young age. (6)	<input type="radio"/>	<input type="radio"/>
20. If a woman tests positive for a breast cancer gene mutation, her male relatives' risk for developing prostate cancer are lowered (7)	<input type="radio"/>	<input type="radio"/>
21. A woman may be at a greater risk for developing ovarian cancer if she has several close relatives with breast cancer (8)	<input type="radio"/>	<input type="radio"/>

22. A woman who has her healthy ovaries removed will definitely not get ovarian cancer (9)

23. A woman who has her breasts removed will definitely not get breast cancer (10)

24. Screening for ovarian cancer often does not detect a tumor until it's more advanced. (11)

---

**Q8 Genetic Counseling:** Genetic counseling is a communication process between a specially trained health professional and a person concerned about the genetic risk of disease. The person's family and personal medical history may be discussed, and counseling may lead to genetic testing.

---



Q9 25. Have you ever heard about genetic counseling for hereditary breast cancer genes (e.g., *BRCA*)?

Yes (1)

No (2)

*Skip To: Q11 If 25. Have you ever heard about genetic counseling for hereditary breast cancer genes (e.g., BRCA... = No*

---



Q10 26. If yes, how did you hear about genetic counseling for hereditary breast cancer genes (e.g., *BRCA1* and *BRCA2*)? Please check all that apply:

- TV (1)
  - Newspaper (2)
  - Internet (3)
  - Friends (4)
  - Family (5)
  - Physician (6)
  - Other Health Profession: Please Specify (7)
- 



Q11 27. Has your healthcare provider ever talked to you about genetic counseling for hereditary breast cancer mutations?

- Yes (1)
- No (2)

*Skip To: Q13 If 27. Has your healthcare provider ever talked to you about genetic counseling for hereditary bre... = No*

-----





Q12 28. Did she/he give you a referral for genetic counseling?

Yes (1)

No (2)

---

Q13 **Genetic Testing:** Genetic testing for hereditary breast cancer looks for a mutation in your genes.

---



Q14 29. Have you ever heard about genetic testing for hereditary breast cancer genes (e.g. *BRCA*)?

Yes (1)

No (2)

*Skip To: Q17 If 29. Have you ever heard about genetic testing for hereditary breast cancer genes (e.g. BRCA)? = No*

---



Q15 30. If yes, how did you hear about genetic testing for hereditary breast cancer mutations.  
Please check all that apply:

- TV (1)
  - Newspaper (2)
  - Internet (3)
  - Friends (4)
  - Family (5)
  - Physician (6)
  - Other Health profession: Please Specify (7)
-



**Q17 The next questions focus on your perspectives of hereditary breast cancer mutations.**

	Strongly disagree (1)	disagree (2)	Neither agree nor disagree (3)	agree (4)	Strongly agree (5)
31. If I were found to carry the gene, it would help members of my family like daughter(s) or sister(s) decide whether to undergo genetic testing. (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
32. Knowing that I carry the gene would help me decide whether to go for more frequent mammograms. (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
33. My concerns about developing breast cancer would be reduced if I knew I did not carry the gene. (5)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

34. Knowing whether or not I carry the gene would increase my sense of personal control. (3)

35. Knowing that I do not carry the gene would greatly improve my quality of life. (4)

36. My concerns about developing breast cancer would increase if I knew that I carried the gene. (6)

37. If I were found to carry the gene, it would jeopardize my insurance coverage or lead to problems with my employers. (8)

38. If I were found to carry the gene, it would cause others to view me negatively. (9)

39. If I were found to carry the gene, it would lead to marital or family problems. (10)

40. Knowing that I do not carry the gene would not be helpful since I could still develop breast cancer. (7)

41. Testing is not worthwhile because it could yield inconclusive results about whether I carry the gene for breast cancer. (11)

42. If I were found to carry the gene for breast cancer, I would worry about passing the gene to my children. (12)

43. If I were found to carry the gene, I would worry that the results would not stay confidential. (13)



Q18 44. How likely do you think it is that you carry a *hereditary breast cancer mutation*?

- Not at all likely (1)
  - Somewhat Likely (2)
  - Likely (3)
  - Very Likely (4)
  - Extremely Likely (5)
- 



**Q19 The next set of questions ask you to imagine the reaction you would have if you were to be told you have a hereditary breast cancer mutation.**

	Strongly disagree (1)	disagree (2)	Neither agree nor disagree (3)	agree (4)	Strongly agree (5)
45. If I found out I carried a gene mutation, it would greatly disrupt my life. (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
46. Finding out I carried a gene mutation would be very difficult for me. (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
47. If I found out I carried a gene mutation, I would worry much more about developing breast cancer. (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>





**Q20 When getting health care, have you ever had the following things happen to you because of your race or ethnicity?**

	Yes (1)	No (2)
48. Been treated with less courtesy than other people. (1)	<input type="radio"/>	<input type="radio"/>
49. Been treated with less respect than other people. (2)	<input type="radio"/>	<input type="radio"/>
50. Received poorer service than others. (3)	<input type="radio"/>	<input type="radio"/>
51. Had a doctor or nurse act as if he or she thinks you are not smart? (4)	<input type="radio"/>	<input type="radio"/>
52. Had a doctor or nurse act as if he or she is afraid of you? (5)	<input type="radio"/>	<input type="radio"/>
53. Had a doctor or nurse act as if he or she is better than you? (6)	<input type="radio"/>	<input type="radio"/>
54. Felt like a doctor or nurse was not listening to what you were saying? (7)	<input type="radio"/>	<input type="radio"/>



**Q21 Thinking about various racial/ethnic groups and their interaction with the American medical system, please rate how strongly you agree or disagree with the following statements. Please note, we are referring to your general feelings...**

	Strongly disagree (1)	disagree (2)	Neutral (3)	Agree (4)	Strongly Agree (5)
55. Doctors and health care workers sometimes hide information from patients who belong to my racial/ethnic group (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
56. Doctors have the best interests of people of my racial/ethnic group in mind (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
57. People of my racial/ethnic group should not confide in doctors and health care workers because it will be used against them (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
58. People of my racial/ethnic group should be suspicious (distrustful) of information from doctors and health care workers (4)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

59. People of my racial/ethnic group cannot trust doctors and health care workers (5)

60. People of my racial/ethnic group should be suspicious of modern medicine (6)

61. Doctors and health care workers treat people of my racial/ethnic group like “guinea pigs” (7)

62. People of my racial/ethnic group receive the same medical care from doctors and health care workers as people from other groups (8)

63. Doctors and health care workers do not take the medical complaints of people of my racial/ethnic group seriously (9)

64. People of my racial/ethnic group are treated the same as people from other groups (10)

65. In most hospitals, people of different racial/ethnic groups receive the same kind of care (11)

66. I have personally been treated poorly or unfairly by doctors or health care workers because of my racial/ethnic group. (12)



**Q22 The next questions ask about the ways you may or may not have relied on religion to deal with life stressors.**

	Not at all (1)	Very Little (2)	Somewhat (3)	A Great deal (4)
67. Looked for a stronger connection with God. (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
68. Sought God's love and care. (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
69. Sought help from God in letting go of my anger. (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
70. Tried to put my plans into action together with God. (4)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
71. Tried to see how God was trying to strengthen me in this situation. (5)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
72. Asked forgiveness for my sins. (6)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
73. Focused on religion to stop worrying about my problems. (7)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
74. Wondered whether God had abandoned me. (8)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
75. Felt punished by God for my lack of devotion. (9)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>



76. Questioned God's love for me. (10)
77. Wondered whether my church had abandoned me. (11)
78. Decided the devil made this happen to me. (12)
79. Questioned the power of God. (13)
- 

**Q23 Population-based testing for hereditary breast cancer mutations:** There is a current proposal to offer genetic counseling and testing for hereditary breast cancer mutations to all women in the United States starting at age 30. Please answer the next questions with this in mind.

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Q24 80. Now try to imagine that you are offered genetic testing and counseling for breast cancer susceptibility *through a population-based testing initiative* at some point in the future, would you choose to have the test

- No, Definitely not (1)
- Not, Probably not (2)
- Unsure (3)
- Yes, probably (4)
- Yes, definitely (5)



**Q25 The next questions ask you to imagine what people close to you would think of you participating in population-based testing if it becomes available.**

	Strongly Disagree (1)	Disagree (2)	Neither Agree/ Disagree (3)	Agree (4)	Strongly Agree (5)
81. My friends would approve of me getting genetic testing and counseling through population-based testing. (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
82. My spouse would approve of me getting genetic testing and counseling through population-based testing. (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
83. My parents would approve of me getting genetic testing and counseling through population-based testing. (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
84. My siblings would approve of me getting genetic testing and counseling through population-based testing. (4)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

85. My other family member would approve of me getting genetic testing and counseling through population-based testing.  
(5)



Q26 86. Would you be willing to pay out of pocket for genetic testing for breast cancer risk through population-wide testing?

- Up to \$50 (1)
- Up to \$100 (2)
- Up to \$200 (3)
- Up to \$500 (4)
- More than \$500 (5)
- I would not be willing to pay any money (6)



Q27 87. Imagine you had a strong need to get information about *population-based testing for hereditary breast cancer mutations*. Where would you go first to get information? (Mark only one)

- Printed materials (for example, newspapers, magazines) (1)
  - Health care provider (doctor, nurse, social worker) (2)
  - Conversations with people you trust (friends, relatives, or co-workers) (3)
  - Internet (Google or another search engine, WebMD or another medical website) (4)
  - Social Media (Facebook, Instagram, Twitter) (5)
- 



Q28 88. Imagine you had a strong need to get information about *population-based testing for hereditary breast cancer mutations*. Which of the following would you most trust as a source of information about population-based testing for hereditary breast cancer mutations? (Mark only one)

- Printed materials (for example, newspapers, magazines) (1)
  - Health care provider (doctor, nurse, social worker) (2)
  - Conversations with people you trust (friends, relatives, or co-workers) (3)
  - Internet (Google or another search engine, WebMD or another medical website) (4)
  - Social Media (Facebook, Instagram, Twitter) (5)
- 

Q29 Thanks for completing the survey. The next questions ask you to provide demographic information about yourself.

---

X→

Q31 1. Do you have a family history of breast cancer?

- Yes (1)
  - No (2)
- 

X→

Q32 2. Are you Hispanic or Latino?

- Yes, Hispanic or Latino (1)
  - Not, Hispanic or Latino (2)
- 

X→

Q34 3. What is your highest grade or level of schooling you have completed?

- Less than high school (1)
  - High school graduate (2)
  - Some college or technical degree (3)
  - Bachelor's degree (4)
  - Graduate degree (5)
- 

X→

Q35 4. Do you have health insurance?

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



Q36 5. Do you have a regular physician or health care provider?

- Yes (1)
  - No (2)
- 



Q37 6. What is your income?

- Less than \$20,000 (1)
  - \$20,000-\$39,999 (2)
  - \$40,000- \$59,999 (3)
  - \$60,000- \$79,999 (4)
  - \$80,000- \$99,999 (5)
  - \$100,000- \$119,999 (6)
  - At least \$120,000 (7)
-





Q38 7. What is your employment status?

- Full-time (1)
  - Part-time (2)
  - Unemployed (3)
  - Retired (4)
  - Unable to work (5)
  - Homemaker (6)
  - Student (7)
- 



Q39 8. What is your marital status?

- Married (1)
- Living Together (2)
- Divorced (3)
- Widowed (4)
- Separated (5)
- Never Married (6)

End of Block: Default Question Block

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## Vita

Alesha Nicole Henderson was born on January 1, 1991 in Petersburg, Virginia. Alesha graduated from the International Baccalaureate Program at Henrico High School in Henrico, Virginia in 2009. She received her Bachelors of Art from Spelman College in 2013. She spent a year in between graduating from Spelman applying to graduate schools and then joined the Sociology doctoral program at Rutgers University. Upon receiving her Master of Arts from Rutgers in 2016, she transferred to the Department of Health Behavior & Policy at Virginia Commonwealth University to do more applied health disparities research. She was a recipient of a Southern Regional Education Board Doctoral Scholars Institutional Award that supported her studies. As a student in this program, she has had the opportunity to collaborate with other students and faculty on manuscripts, conduct community engaged research in the city she was born, and present her research at research conferences. She is currently working as a Behavioral Scientist on the Public Health team at the United Network for Organ Sharing in Richmond, Virginia.

### Scholarly Activity

Henderson, A., Miller, C.A., Guidry, J. #TripleNegativeBreastCancer: Exploring how Triple Negative Breast Cancer is discussed on Instagram. *Health Education and Behavior*. (Under Review).

Miller, C.A., Henderson, A., Guidry, J., & Fuemmeler, B. (2020). Pinning Pink: Messages about Hereditary Breast Cancer Risk on Pinterest. *Journal of Cancer Education*.

Sutton, A., Henderson, A., Hurtado de Mendoza, A., & Sheppard, V. (2019). An Exploration of African American Women's Confidence in the Genetic Information Non-Discrimination Act. *International Journal of Environmental Research and Public Health*.

Sutton, A., He, J., Tanner, E., Edmonds, M., Henderson, A., Hurtado de Mendoza, A., Sheppard, V. B. (2019). Understanding Factors Related to At-Risk Black Women's Feelings of Medical Mistrust and Genetic Counseling and Testing. *Journal of Health Disparities Research and Practice*.

Hurtado de Mendoza, A., Cabling, M.; Dilawari, A.; Turner, J.; Fernandez, N.; Henderson, A....Sheppard, V. (2018). Providers' Perspectives on Adherence to Hormonal Therapy in Breast Cancer Survivors. Is there are Role for the Digital Health Feedback System? *Health & Technology*.