A Review of the Facing Our Risk of Cancer Empowered (FORCE) Peer Navigation Program

by

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Abstract

Peer navigation programs in the cancer community were created approximately 30 years ago to provide education and support to patients. Peer navigation programs are significant in public health, as they address health inequities and remove barriers to access of care in underserved communities. Through one-on-one peer relationships, peer navigation programs can supply patients with compassion and guidance to help them navigate their journey through disease and healing. The literature has shown there are benefits of peer navigation to participants, such as improved mental health.

Despite research suggesting that peer navigation programs can improve health outcomes in underserved populations, few digital-based peer navigation programs exist and have been assessed by researchers. Facing Our Risk of Cancer Empowered (FORCE) created a peer navigation program in 2016 in which participants can sign up on the FORCE website to be matched to a navigator who will communicate with them online or on the phone. This essay analyzes participant and navigator demographics, interests, and health information collected from January 2018 to August 2022. These data were obtained from surveys completed on the FORCE website by patients and caregivers signing up for the peer navigation program, or cancer previvors or survivors signing up to volunteer as a navigator. From this analysis, findings show that Black and Male patients, who are underrepresented in this program and the hereditary cancer community, generally are interested in receiving information that most participants are also interested in.

However, it was found that a significant number of Black participants have not had genetic testing, and several Black participants were interested in receiving information about paying for genetic counseling and testing. This may suggest that this population would benefit from receiving more information regarding health insurance and accessibility to genetic services. It is recommended that FORCE implement a post-experience survey to gather information about what services patients would like to receive. Additionally, it was found that participants with less common cancers or genetic mutations may not match to a navigator with the same health history. This finding suggests that targeted recruitment efforts should be created to meet the needs of these patients.

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1.0 Peer Navigation Programs in the Literature

Peer navigation programs are used to provide support and resources to patients. These programs involve structured, one-on-one relationships in which cancer survivors and caregivers serve as volunteers to provide information, comfort, and stories about their own experiences to patients and families who are newly affected by cancer (Flora et al., 2020). The American Cancer Society is credited for creating the first peer navigation program in the United States approximately 30 years ago. Since then, several peer navigation programs have been implemented by private organizations and supported by the United States government, the National Cancer Institute, and the National Institutes of Health (Dohan & Schrag, 2005). Several cancer peer navigation programs also exist in Canada. Per the Canadian Partnership Against Cancer (2012), there are eight peer navigation programs across the country as of 2011 that assist female cancer patients, Chinese cancer patients, and high-needs cancer patients with complex tumors. While the peer navigation programs in the United States were created to address health disparities for underserved populations, Canadian peer navigation programs are more focused on addressing barriers to care, as their healthcare system is more universal (Lorhan et al., 2013). Peer navigation programs were started in the Canadian provinces of Newfoundland, Ontario, and British Columbia through cancer centers and volunteer networks. The volunteers who served as peer navigators played a role in effecting program development based on the specific needs of patients who reside in these provinces (Lorhan et al., 2013).

Peer navigation programs allow patients to speak with someone who has gone through a similar diagnosis and treatment process (Giese-Davis et al., 2006). Additionally, peer navigation programs are used to provide health promotion and cancer education (Lorhan et al., 2013). This

type of intervention is widely accepted, as cancer survivors who serve as navigators are viewed as knowledgeable and can also share their lived experiences to provide feelings of hope (Mollica et al., 2014). Furthermore, peer navigation programs are intentionally designed so patients are often matched to navigators who have similar racial and ethnic backgrounds (Sheehan et al, 2018).

Peer navigation programs are beneficial in multiple stages of cancer care, from preventive screening to end-of-life care (Dohan & Schrag, 2005). Peer navigation programs were created to address health disparities and barriers to accessing treatment (Lorhan et al., 2013). Social barriers, such as income, education, age, gender, ethnicity, and place of residence are connected to survival outcomes of cancer patients (Varcoe et al., 2015). Based on a model of cancer health disparities, minority and low socioeconomic status patients can experience poor health outcomes, such as decreased quality of life and survival rates. However, this model suggests that a navigator can help address patient barriers in health literacy, transportation, insurance, and communication. Navigators can also assist in patient adherence to cancer screening and treatment, promote patient self-management, and connect patients to community resources (Hendren et al., 2011). Therefore, through peer navigation, underserved and minority communities can receive equitable support and empowerment throughout their cancer journey (Moadel-Robblee et al., 2021).

Peer navigation programs have had positive outcomes for underserved populations. Previous research has shown that African American women with breast cancer have had positive outcomes from peer navigation programs. One of these outcomes includes learning how to self-advocate and ask questions during follow-up appointments. Peer navigators have also empowered African American breast cancer patients to see their diagnosis from a positive perspective and use their story to help others (Mollica et al., 2014). Following the inception of the first patient navigation program in New York City, the number of poor African American and Latino women

living in this region presenting with late-stage breast cancer has decreased from 49% to 21%, and the number of patients in this population presenting with early-stage cancer has increased from 6% to 41%. While it is unclear if patient navigation is directly correlated to improved cancer outcomes, these findings indicate that navigation programs can play a role in reducing health disparities (Vargas et al., 2008).

1.1 Psychosocial Outcomes of Peer Navigation Programs

Studies have shown that peer navigation programs are beneficial for patients' mental health (Giese-Davis et al., 2006). In a study examining the impact of a peer navigation program on the mental illness of Latinos, it was found that empowerment and quality of life were improved among participants (Corrigan et al, 2018). Furthermore, it has been found that peer navigation programs have few negative effects on the individuals who serve as mentors. In a study examining the effects of peer navigation on newly diagnosed cancer patients and their navigators, it was found that some navigators report an increase in depression. Therefore, it is recommended that peer navigators meet with a mental health provider regularly to discuss strategies for coping with their own trauma, in addition to the trauma of the patients they are serving (Giese-Davis et al., 2006).

1.2 Digital Peer Navigation

Peer navigation programs have been successfully implemented and continue to receive support; the National Cancer Institute and other professional organizations have provided funding for new programs and future research (Dohan & Schrag, 2005). However, few digital peer navigation programs for cancer patients have been assessed by the literature. The literature has not compared outcomes for patients participating in a digital based peer navigation program to those for patients belonging to an in-person navigation program. One study conducted among adolescent and young adult cancer survivors in Canada determined that 82% of participants would want to speak to a peer navigator through a digital application where they could choose a peer navigator based on several criteria, such as age at diagnosis, stage of disease, and treatments received (Bender et al., 2022). Additionally, a study conducted among adolescents and young adults in the Los Angeles area compared the outcomes of a text-messaging-based peer navigation program to the outcomes found from receiving online educational materials only. It was found that participants who received peer navigation felt more confident in their ability to plan their cancer care than participants who received online education only. However, the participants in the aforementioned study who received the online educational component only with no peer navigation received better post-test scores in knowledge about cancer management and treatment. Researchers concluded that a program combining peer support and education would lead to better health outcomes for adolescents and young adults (Casillas et al., 2019). Based on the findings from these studies, a comprehensive examination of a digital peer navigation program for cancer patients is clearly needed that encompasses a more diverse patient and navigator population and covers additional geographic locations.

1.3 Peer Navigation Outcomes in Male Cancer Patients

Several underserved groups have benefited from peer navigation. Men are considered underrepresented in the hereditary cancer community, as most studies examining hereditary breast and ovarian cancer (HBOC) gene mutations have been conducted among women. Yet, men who carry a *BRCA2* mutation have an increased risk of being diagnosed with several cancers and carry a 7% and 20% lifetime risk for breast and prostate cancers, respectively (Strømsvik et al., 2009). In a pilot feasibility study conducted in Canada among 34 prostate patients and caregivers, participants reported receiving validation and emotional support from the peer navigation program in a post-experience survey, with these categories receiving overall satisfaction ratings of 7.8 and 7.6 (Bender et al., 2022). The study from Bender et al. (2022) consisted of 88% Caucasian participants. A study examining the perceived benefits of peer navigation for African American cancer patients is needed, as African American men have a higher incidence and mortality rate from cancer than Caucasian men (Palmer et al, 2022).

1.4 Peer Navigation Outcomes in African American Cancer Patients

Because African American cancer patients experience worse health outcomes than Caucasian patients, it is important to determine if peer navigation is an effective intervention to mitigate the health disparities experienced by this population. In a study conducted among African American men and women in Philadelphia, it was found that participants who had a perceived higher risk of cancer were less likely to enroll in a community-based navigation program (Halbert

et al, 2014). Therefore, more information is needed to determine why African American patients are reluctant to participate in such programs.

In one study examining community support for African American individuals experiencing illness, the results showed that patients were most interested in receiving emotional support through conversations and visits. Patients were least interested in receiving advocacy, with only 3% of participants wanting this type of support, such as accompaniment to a doctor's appointment. Furthermore, while 43% of community support teams were willing to provide cancer and palliative care services, only 5% of patients were interested in receiving those services (Hanson et al., 2013).

The aforementioned study was not specific to peer navigation programs. This study involved community support given to cancer patients through church or community groups comprised of six to ten volunteers trained in offering emotional and spiritual care, building and sustaining a team, addressing patient barriers, and identifying community resources, such as palliative care and hospice services. While other volunteers were trained separately for lay health advisor roles, which is equivalent to the role of a peer navigator, it was found that the team approach provided with community groups was better suited to the participants in this study, as they all suffered from advanced cancer and had complex needs (Hanson et al., 2013). Therefore, a gap in the literature exists that does not address how the care of African American cancer patients would be impacted by a one-on-one relationship with a peer navigator, or if African American patients would perceive more benefits from a one-on-one navigator relationship.

1.5 Essay Introduction and Purpose

The goal of this essay is to evaluate an existing peer navigation program to address current gaps in the literature. Previous research shows that Black/African American and male patients are underrepresented in the hereditary cancer community. Additionally, peer navigation programs previously studied in the literature show promise in improving health outcomes in historically underserved populations. While some research highlights peer navigation outcomes in male patients, most of the participants in these studies are White/Caucasian. This essay specifically focuses on survey responses from Black/African American males interested in participating in the FORCE peer navigation program. Data gathered from these underserved individuals can help FORCE find ways to improve the current landscape of the peer navigation program to meet the needs of Black/African American patients. Findings from this essay show that Black/African American participants are receptive to speaking with a peer navigator to receive information about hereditary cancer services.

2.0 Relevant Hereditary Cancer Syndromes

Of all cancers diagnosed, approximately 5% of those cancers are characterized as hereditary. Common hereditary cancer syndromes include Hereditary Breast and Ovarian Cancer Syndrome (HBOC), Lynch Syndrome, Li-Fraumeni Syndrome, Cowden Syndrome, Peutz-Jeghers Syndrome, and Hereditary Diffuse Gastric Cancer (American College of Obstetricians and Gynecologists, 2019). Hereditary cancer syndromes can be caused by a germline genetic mutation passed from one generation to the next via meiosis, a process in which cells divide to create daughter cells (Rahner & Steinke, 2008). Therefore, patients with a germline mutation associated with a hereditary cancer syndrome may present with a strong family history of cancer. In some cases, germline mutations found in hereditary cancer syndromes are de novo, which means the mutations are not inherited from a parent (Garcia-Casado et al., 2011). Patients carrying a genetic mutation associated with a hereditary cancer syndrome require long-term care, as they have an increased risk of developing cancer compared to the average population risk. These patients can undergo annual cancer screenings or opt for prophylactic surgeries prior to a cancer diagnosis. Furthermore, hereditary cancers are often diagnosed at a young age requiring extensive treatments and follow-up appointments (Kulkarni & Carley, 2016). Due to the range of treatment and management options available for patients with a hereditary cancer genetic mutation, these patients can find benefit in speaking with peers who are faced with the same diagnosis (Holdren, et al., 2023).

2.1 Hereditary Breast and Ovarian Cancer Syndrome (HBOC)

People affected by hereditary breast and ovarian cancer syndrome are predisposed to a higher lifetime risk of breast and ovarian cancer diagnoses due to inherited mutations in tumor suppressor genes (Kobayashi et al., 2013). Males and females of all races and ethnicities are affected by HBOC (National Organization for Rare Disorders, 2019). Additionally, 25-40% of breast cancer diagnoses among women under age 35 occur as the result of a genetic mutation (Lux et al., 2006). Mutations in the *BRCA1* and *BRCA2* genes are largely responsible for HBOC, with approximately 3% of all breast cancers and 10% of all ovarian cancers diagnosed being caused by a *BRCA* mutation (Centers for Disease Control and Prevention, n.d.). In a retrospective family study conducted among over 5,000 families analyzing the associations of *BRCA1* and *BRCA2* mutations with the risk of developing other primary cancers, it was found that *BRCA1* and *BRCA2* mutations are associated with a higher risk for male breast cancer, pancreatic cancer, stomach cancer, and prostate cancer (Li et al., 2022). In particular, *BRCA2* is estimated to be the cause of 76% of male breast cancers diagnosed (Mohamad & Apffelstaedt, 2008). *BRCA2* is also associated with a 60% lifetime risk for prostate cancer by age 85 (Petrucelli, et al., 1998). Additionally, increasing incidence of melanoma in *BRCA1* carriers and cervical cancer in *BRCA2* carriers was noted in a study conducted in over 1,000 individuals with either *BRCA1* or *BRCA2* mutations (Mersch et al, 2015). Another study conducted among 6,207 women in the United States and Canada estimated that the lifetime risk of melanoma is 2.5% for *BRCA1* carriers and 2.3% for *BRCA2* carriers (Narod et al., 2024). In a study conducted among 34 women with a *BRCA* mutation, it was found that participants experience uncertainty and associated psychosocial harms in the days leading up to a cancer screening, while waiting for test results, and while thinking of familial cancer experiences, such as the trauma their children may experience while watching a

parent suffer from cancer (Dean, 2016). While HBOC is most associated with *BRCA1* and *BRCA2* pathogenic variants, mutations in other genes can also contribute to an increased risk of HBOC, including but not limited to *CHEK2*, *ATM*, *PALB2*, *RAD51C*, and *BARD1* (National Organization for Disorders, 2019).

Because HBOC affects people of diverse backgrounds and involves multiple cancer types and genetic mutations, individuals in this community could benefit from peer navigation. In a qualitative study conducted among Latina women in New York City with *BRCA* mutations, participants mentioned barriers such as medical jargon and distrust in the healthcare system that affect one's ability to receive access to genetic counseling and services. Therefore, peer navigation should be used to help individuals navigate the healthcare system and understand the importance of genetic education and services (Sussner, et al., 2015).

2.2 Lynch Syndrome

Hereditary nonpolyposis colorectal cancer, also known as Lynch syndrome, is caused by mutations in genes responsible for DNA mismatch repair. These genes include *MSH2*, *MLH1*, *MSH6*, *PMS2*, and *EPCAM* (Peltomäki, 2005). Approximately 1 in 279 individuals have a pathogenic mutation in a mismatch repair gene (Bucksch et al., 2020). Lynch syndrome is most associated with hereditary colorectal cancer, but individuals with Lynch syndrome have a higher risk of developing endometrial, stomach, liver, kidney, brain, and certain skin cancers as well. Additionally, Lynch syndrome causes more than 4,000 colon cancers and nearly 2,000 endometrial cancers per year (Centers for Disease Control and Prevention, n.d.). Lynch syndrome affects men and women of all ethnicities (Duquette et al., 2012).

Lynch syndrome has psychosocial and behavioral impacts on individuals and families. In a Canadian study conducted among several families, many barriers were found in Lynch syndrome management. These barriers include risk perceptions, decision-making, and the burdens associated with screening and the healthcare system (Watkins, et al., 2011). During interviews, study participants recognized the importance of screening for cancers associated with Lynch syndrome yet felt burdened, emotional, and anxious when it came time to complete screenings. Furthermore, participants felt that some providers communicated information poorly and did not have extensive knowledge of screening recommendations for Lynch syndrome. Due to this gap in care, patients noted that providers showed little concern about screening for extracolonic cancers, and screenings for colorectal cancer were not happening early enough (Watkins et al., 2011). Memorial Sloan Kettering Cancer Center created an advocacy group for patients with a pathogenic variant in any of the mismatch repair genes. Assessment of this peer network supports the need for peer navigation among Lynch syndrome patients, as members of the group were able to discuss stress and anxiety, coping strategies, developing a support network, communicating with family about Lynch syndrome, and decision-making surrounding genetic testing (Corines et al., 2017).

2.3 Cowden Syndrome

Cowden syndrome is a multi-organ cancer predisposition syndrome caused by multiple hamartomas (Farooq et al., 2010). Hamartomas are growths that are non-cancerous but may undergo malignant transformation (Ali & Mulita, 2023). Mutations in *PTEN*, a tumor suppressor gene, are associated with Cowden syndrome (Teresi et al., 2007). Patients with Cowden syndrome often develop cancers of the thyroid, endometrium, or breast (Garofola et al, 2023). According to

the literature, Cowden syndrome is predominantly seen in females, and most patients are Caucasian (Garofola et al, 2023). Women with a pathogenic *PTEN* variant have an increased risk of developing breast cancer of up to 87%. Additionally, cases of thyroid cancer from Cowden syndrome have been observed in patients as young as six years old (Mester & Eng, 2015).

Cowden syndrome is often difficult to diagnose, as clinical presentations can vary greatly among individuals. Misdiagnoses can also occur, which can delay management and treatment of Cowden syndrome. In one case, a patient presented with abnormal skin lesions, dysmorphic features, hamartomas, and a family history of breast and gynecologic cancer. Despite possessing a personal and family history of clinical features related to Cowden syndrome, the patient was misdiagnosed with Familial Adenomatous Polyposis (FAP) (Shaw et al., 2023). Once a diagnosis is made, screening recommendations are plentiful and include an annual mammogram starting at age 30, annual thyroid ultrasound starting at age of diagnosis, renal imaging every two years starting at age 40, annual transvaginal ultrasound starting at age 30, colonoscopy starting at age 35-40 with follow-ups dependent on polyp identification, and annual dermatologic exam starting from age of diagnosis (Mester & Eng, 2015). As Cowden syndrome presents individuals and families with several challenges before and after diagnosis, peer navigation could be a valuable tool for disseminating information and providing support to these people.

2.4 Li-Fraumeni Syndrome

Li-Fraumeni Syndrome (LFS) is a cancer predisposition syndrome associated with multiple cancers, including rhabdomyosarcoma, osteosarcoma, brain tumors, leukemia, and adrenal cortical carcinoma (Correa, 2016). Additionally, LFS has an association with female breast cancer (Hisada

et al., 1998). LFS is primarily caused by germline mutations in *TP53*, a tumor suppressor gene. Mutations in another tumor suppressor gene, *hCHK2*, are associated with LFS, but few families affected by this gene have been identified (Correa, 2016). All races and ethnicities are affected by LFS, but research includes predominantly Caucasian participants. Therefore, more diverse populations should be included in future LFS research (Wilsnack et al., 2021). LFS is known for being a highly penetrant syndrome that causes early-onset disease, although cancer type and age of onset can be varied among individuals. In LFS patients, the lifetime risk for cancer is greater than 70% for men and greater than 90% for women (Schneider et al., 1999). In a study following 415 *TP53* mutation carriers, 22% of participants were diagnosed with cancer by five years old, and 41% of participants were diagnosed with cancer by 18 years old. The most common tumors diagnosed among children and adolescents in this study include osteosarcoma, adrenal cortical carcinoma, brain tumors, and soft tissue sarcomas (Kratz et al, 2017).

As LFS patients face a near certainty of early-onset cancer and multiple lifetime cancer diagnoses, it is natural for affected individuals and families to experience distress and grief. With multiple cancers involved in LFS, screening regimens are intense, and patients feel overwhelmed by the frequency and potential outcomes of these screenings, such as a cancer diagnosis and insurance discrimination (Barnett et al., 2022). Furthermore, familial dynamics, roles, decision-making, and caregiving needs often evolve and present challenges to family members as they experience multiple loved ones facing cancer diagnoses across generations (Wilsnack et al., 2021). In a study conducted from 2012-2017, 120 LFS patients in 45 families participated in interviews with a family therapist about how their experiences with LFS shaped their family's identity. LFS patients often describe feeling disconnected from other family members with a less severe form of LFS or no LFS diagnosis. Also, individuals who did not have LFS but did have a partner or child

diagnosed often strongly identified as a member of the LFS community (Wilsnack et al., 2021). Due to significant family involvement in a LFS diagnosis, caregivers report feeling burdened by the unpredictability of the disease and not having enough resources to prepare for changes within the family (Werner-Lin et al., 2020). Additionally, parents with a family history of LFS are faced with a challenging decision in whether their children should undergo genetic testing for *TP53*. As children enter adolescence, the parental decision-making process for genetic testing becomes complicated, as adolescents often want to be part of the process and have a say in the decision (Barnett et al., 2022).

Peer navigation could be a viable option to ensure that LFS individuals and families experiencing these challenges have their emotional and psychosocial needs met. Social support systems have been beneficial to help LFS patients cope with their diagnosis, maintain a sense of normalcy, and have support in times of crises. Patients have also found benefit in interpersonal relationships involving the delivery of health information (Barnett et al., 2022). Peer support may also give adolescents and young adults an outlet to communicate their feelings about LFS while still maintaining family privacy (Rising et al., 2022).

3.0 Facing Our Risk of Cancer Empowered (FORCE)

FORCE is a non-profit organization whose mission is to improve the lives of those affected by hereditary cancer. Throughout its programming, FORCE employs a theme of "many mutations, many cancers, one community." FORCE was founded by Sue Friedman in 1999 after she was diagnosed with breast cancer and a *BRCA2* gene mutation at age 33. She realized that no organization existed to support people with genetic mutations that increase cancer risk (Everyday Health, n.d.).

To help achieve its mission, FORCE works with dozens of stakeholders through a partnership program. FORCE's partner organizations provide information about specific cancers and hereditary cancer syndromes, advocacy for underserved populations affected by cancer, and resources for individuals and families who need clinical services, behavioral health information, and financial support (FORCE, n.d.). One of FORCE's partners is the Tigerlily Foundation. The Tigerlily Foundation aims to provide empowerment, advocacy, and education to young women of minority backgrounds. Through the Tigerlily Foundation's Young Women's Advocate Now to Grow, Empower and Lead (ANGEL) Advocacy Training Program, women of color from urban cities in the United States with high breast cancer morbidity rates are recruited to complete a training program where they will become knowledgeable about breast cancer and related disparities that affect young African American women. Once trained, these women are able to interact with policymakers, health professionals, and other organizations in the breast cancer community to serve as an educator and advocate (Tigerlily Foundation, n.d.).

FORCE offers multiple educational resources and focuses strongly on health literacy (FORCE, n.d.). One such example is FORCE's BOAST training program. BOAST stands for

Biased, Overblown, Amateur, Sales-focused, Taken out of context, and Too early to be useful. This training was designed to help people determine how to sift through online health information and find articles that are relevant, accurate, and helpful in making medical decisions. While the BOAST program is not a peer navigation program or peer-led, its content can empower patients to learn more about their options for cancer care and treatment (FORCE, n.d.). Additionally, FORCE offers multiple supportive services, including support groups and a peer navigation program (FORCE, n.d.).

FORCE created a new peer navigation program in April 2016 that resulted in over 100 peer navigators receiving training. The trained navigators from this initial cohort are aged 21-73 and represent patients through their diverse backgrounds and experiences (Rezende et al., 2017). The peer navigation program with FORCE is open to previvors, cancer survivors, and caregivers who live in the United States and Canada. FORCE coined the term "previvor." A previvor is someone who has a genetic mutation that is associated with an increased risk of developing cancer (Friedman, 2010). The peer navigators who serve in the program are volunteers who have been personally affected by a genetic mutation or hereditary cancer syndrome. People who are interested in becoming a peer navigator will submit a volunteer application on FORCE's website. The volunteer application asks individuals about their demographics, hereditary cancer experience, and knowledge of FORCE programs. People who complete a volunteer application are interviewed. Those who are accepted to the volunteer program complete comprehensive training in peer navigation through VolunteerFORCE Academy (FORCE, n.d.). Individuals who are interested in speaking to a peer navigator will complete a survey on FORCE's website. FORCE's staff will then use the survey responses to establish a match between an individual and a trained peer navigator. Peer navigators may be matched to participants based on several criteria, including cancer

diagnosis, genetic mutation, cancer treatment underwent, geographic location, gender identity, age, and race. The peer navigators who are matched to a previvor, survivor, or caregiver are expected to provide two to three hours of support. Peer navigators will discuss topics such as hereditary cancer education, risk management, cancer treatment, quality of life, research, and supportive services (FORCE, n.d.).

4.0 Specific Aims

To identify traits of peer navigation programs that lead to good outcomes for hereditary cancer patients, a quality improvement assessment of an existing peer navigation program could further our knowledge and be beneficial for the development of future programs.

The FORCE Peer Navigation Program has been examined for this project using two data sets comprised of participant and peer navigator demographics and survey responses. The following aims will be addressed:

1. To determine what kinds of knowledge are sought from FORCE by hereditary cancer survivors and previvors.
2. To identify whether African American and male participants are interested in resources and services from FORCE's Peer Navigation Program. Male African American participants will be examined independently.
3. To determine whether patients with Hereditary Breast and Ovarian Cancer Syndrome, Lynch Syndrome, Cowden Syndrome, and Li Fraumeni Syndrome are receiving support from FORCE's Peer Navigation Program.

5.0 Materials and Methods

Two data sets were obtained from FORCE through personal correspondence with FORCE staff members. The first data set comprises survey responses from 3,722 previvors and cancer survivors located in the United States and Canada who are interested in being matched to a peer navigator. These data were collected from January 2018 through August 2022. The survey tool is available on FORCE's website (see Appendix A). Interested individuals provided the following information in the survey: demographics, genetic test results and/or cancer diagnosed, and interest in learning about quality of life, risk management, research, and treatment topics. Upon submission of the survey, the FORCE staff worked to match interested individuals to a peer navigator who is similar demographically, medically, or geographically. In this essay, the first data set will be labeled as participant data.

The second data set comprises information from 176 volunteers who serve as peer navigators. The time period during which these data were collected is unknown. The information from this data set is taken from a survey that volunteers completed upon signing up to become peer navigators. In this survey, peer navigators provided the following information: demographics, genetic mutation and/or cancer type diagnosed, and surgeries undergone (if applicable). This version of the second survey is currently not available on FORCE's website. In this essay, the second data set will be labeled as navigator data.

Descriptive analyses were performed on both data sets. Demographic information, including race/ethnicity, gender identity, sexual orientation, and genetic test results, was obtained from both data sets. In the participant data set, survey items corresponding to topics of interest to

participants were analyzed by gender and race. In the navigator data set, survey items corresponding to cancer diagnosis were analyzed.

6.0 Participant Demographics

This section will focus on survey responses from the participant data set only. From January 2018 to August 2022, 3,722 respondents completed FORCE's online survey showing interest in participating in a peer navigation program. Table 1 provides information from the participant data set about the participants' gender identity. Out of 3,722 respondents, approximately 97% identified as female, and 2.7% identified as male. Less than 1% of participants identified as non-binary, transgender, other, or preferred not to share this information.

Table 1

Self-Reported Gender Identity of Participants

Gender Identity	Count
Female	**3,595**
Male	**99**
Non-binary	**12**
Transgender	**9**
Other	**2**
Prefer Not to Share	**5**
TOTAL	**3,722**

Only 2,313 (62%) of respondents provided information about their sexual orientation (Table 2). Out of these 2,313 participants, approximately 90% identified as Straight, 4.3%

identified as Bisexual, 2.8% preferred not to share this information, 2.1% identified as Gay or Lesbian, and less than 1% identified as Transgender or Other.

Table 2

Self-Reported Sexual Orientation of Participants

Sexual Orientation	Count
Straight	**2,078**
Bisexual	**100**
Prefer Not to Share	**64**
Gay or Lesbian	**49**
Other	**21**
Transgender	**1**
TOTAL	**2,313**

3,675 participants provided information about their race and ethnicity (Table 3). Out of this total, 81.1% of respondents identified as White/Non-Hispanic, 4.4% identified as Latinx or Hispanic, 3.2% identified as Black or African American, 2.9% identified as Asian, 1.6% preferred not to share this information, 1.3% identified as Other, and 5.3% identified as two or more races.

Table 3

Self-Reported Race/Ethnicity of Participants

Race/Ethnicity	Count
White/non-Hispanic	**2,981**

Latinx or Hispanic	**163**
Black or African American	**116**
Asian	**105**
Other	**47**
Native American	**6**
Pacific Islander	**3**
Bi- or multi-racial	**196**
Prefer not to share	**58**
TOTAL	**3,675**

3,698 participants provided their genetic test results in the survey by selecting all options that apply (Table 4). Participants also had the option to free-text any response that was unavailable for selection; the free-text responses were not included in Table 4 due to their complexity. Out of 3,698 respondents, 31.5% of participants identified having a *BRCA2* mutation only, 30% identified having a *BRCA1* mutation only, 7.6% of participants have not tested yet, 4.7% identified as having an "other" mutation not listed in the survey, 3.4% identified having a *PALB2* mutation only, 2.6% identified as having negative genetic testing results, 2.4% identified as having a *CHEK2* mutation only, 2.1% identified having an *ATM* mutation only, 1.9% identified as having both *BRCA1* and *BRCA2* mutations, and 1.3% identified having a variant of uncertain significance (VUS) only. The remaining respondents disclosed having mutations related to Lynch, Li-Fraumeni, or Cowden Syndromes, less common mutations related to Hereditary Breast and Ovarian Cancer Syndrome, or two or more mutations.

Table 4

Self-Reported Genetic Information of Participants

Participant Responses	Count
APC	1
ATM	79
***ATM* VUS**	5
BARD1	8
***BRCA1* (includes response of "*BRCA1* Other")**	1,125
***BRCA1* VUS**	36
***BRCA2* (includes response of "*BRCA2* Other")**	1,179
***BRCA2* VUS**	39
BRCA1* and *BRCA2	73
***BRCA1*, *BRCA2*, VUS**	3
BRIP1	16
***BRIP1* VUS**	1
CDH1	4
CDKN2A	1
***CDKN2A* VUS**	1
***CHEK2* (includes "*CHEK2* Other"**	88
***CHEK2* VUS**	6
MLH1	9
***MLH1* VUS**	1
MSH2	7
MSH6	17
MUTYH	1
NBN	6
***PALB2* (includes "*PALB2* Other")**	128
***PALB2* VUS**	4
PMS2	11
PTEN	18
***PTEN* VUS**	1
RAD51C	7
RAD51D	6

STK11	3
TP53	17
Two or more genes indicated	117
VUS (Gene(s) Unknown)	57
Negative (Includes "Negative Other")	98
Negative, VUS	3
Negative, *BRCA1*, *BRCA2*	7
Negative, *BRCA1*	4
Negative, Multiple Genes Indicated	2
Did Not Test Yet	302
Did Not Test Yet, *BRCA1*	2
Did Not Test Yet, *BRCA2*	2
Did Not Test Yet, *BRCA1*, *BRCA2*	1
Did Not Test Yet, *MSH2*	1
Did Not Test Yet, Prefer Not to Share	1
Did Not Test Yet, Other	1
Other	175
Prefer Not to Share	25
TOTAL	3,698

6.1 Participant Topics of Interest

In the survey, participants were asked what topics they were interested in learning more about while in the peer navigation program. The topic categories and subcategories can be found in Appendix A. The survey directed participants to check all options of interest. The following subsections describe responses of participants who completed the survey.

6.1.1 Hereditary Cancer Topics

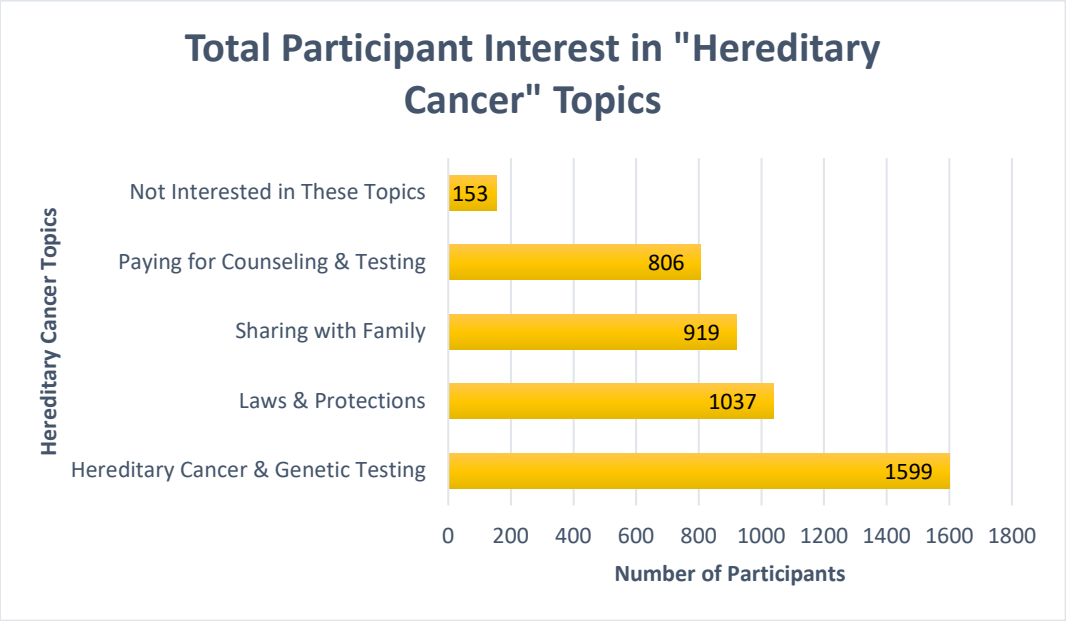


Figure 1

Out of 3,722 total participants, 2,373 participants were interested in learning more about topics relevant to hereditary cancer (Figure 1). Approximately 67.4% of respondents were interested in learning more about hereditary cancer and genetic testing. Approximately 6.4% of respondents noted they were not interested in these topics. It is unknown whether the 1,349 participants who did not respond were also uninterested in these topics, or if a response was not selected in error.

6.1.2 Cancer Risk Management Topics

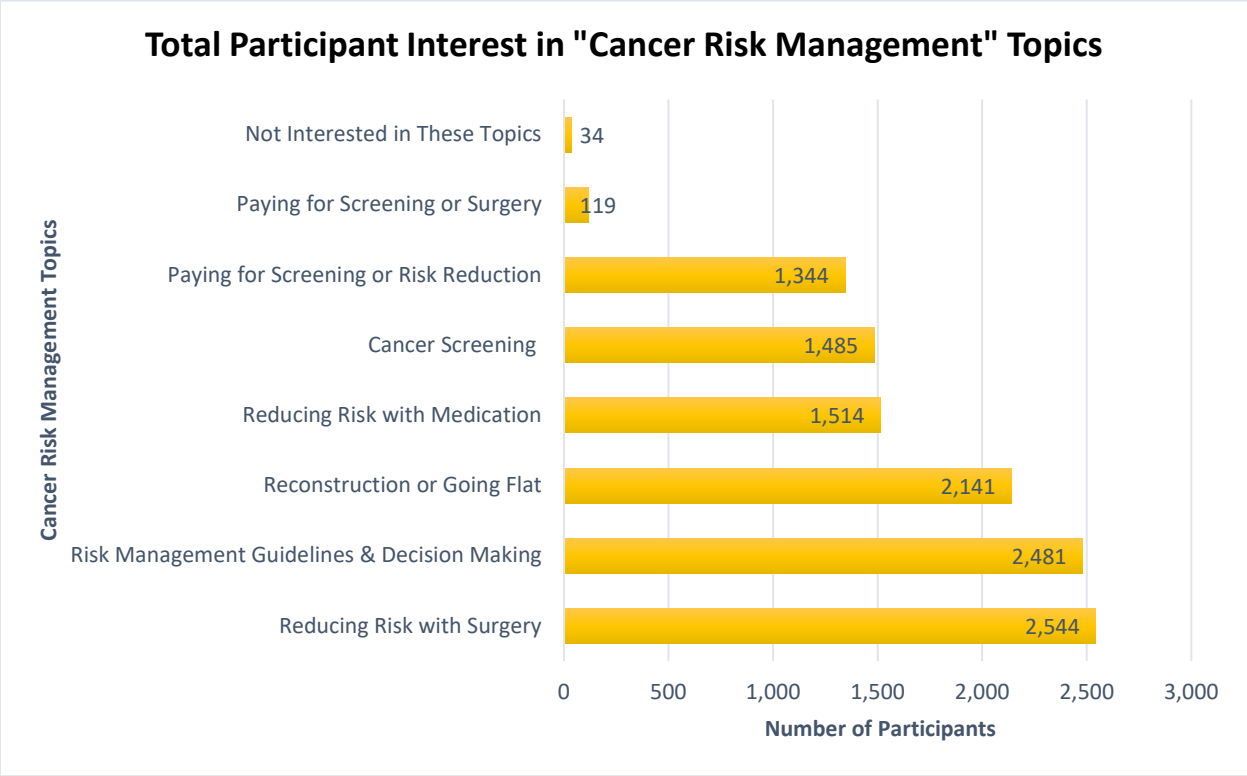


Figure 2

Out of 3,722 total participants, 3,383 participants were interested in learning more about topics relevant to cancer risk management (Figure2). Respondents were most interested in learning more about reducing risk with surgery (75.2%), risk management guidelines and decision making (73.3%), and reconstruction or going flat (63.3%).

6.1.3 Cancer Treatment Topics

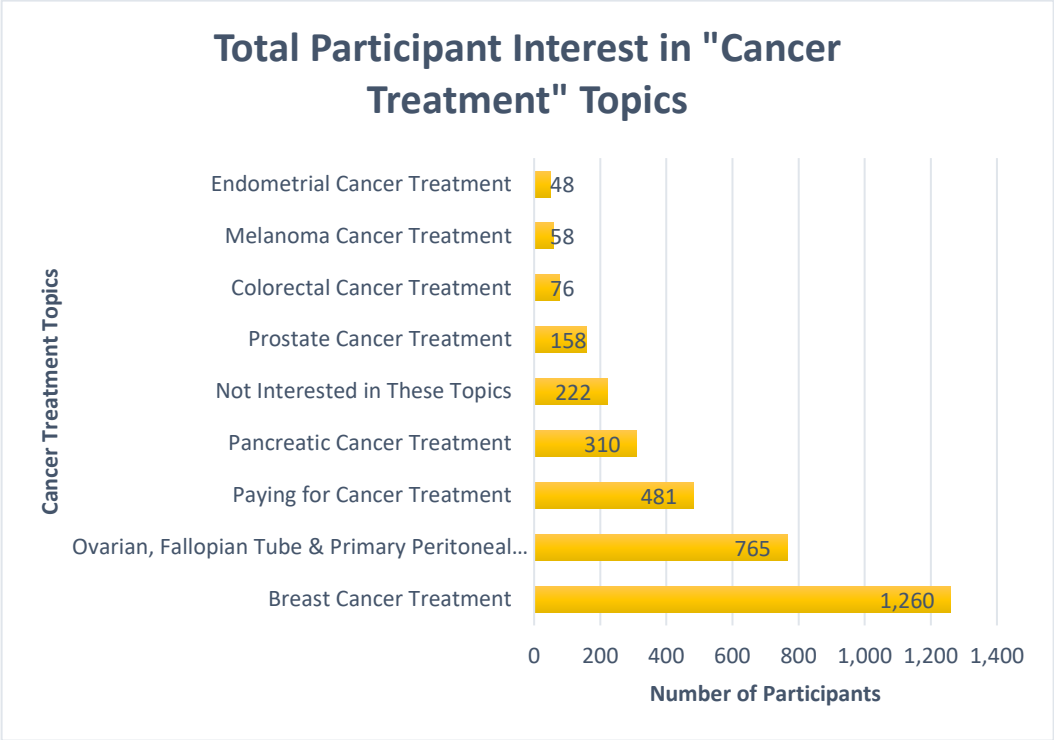


Figure 3

A total of 1,775 participants showed interest in learning more about cancer treatment topics (Figure 3). Respondents were most interested in learning about breast cancer treatment (71%), ovarian, fallopian tube, and primary peritoneal cancer treatment (43.1%), and paying for cancer treatment (27.1%).

6.1.4 Quality of Life Topics

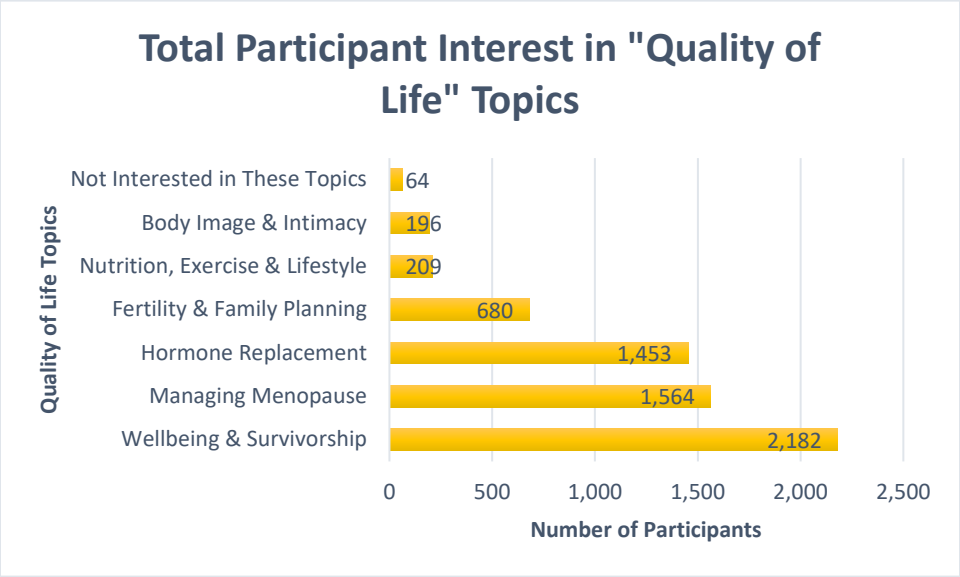


Figure 4

In the survey, 3,041 participants expressed interest in learning more about quality-of-life topics (Figure 4). Participants were most interested in wellbeing and survivorship (71.8%), managing menopause (51.4%), and hormone replacement (47.8%).

6.1.5 Support or Research Resources

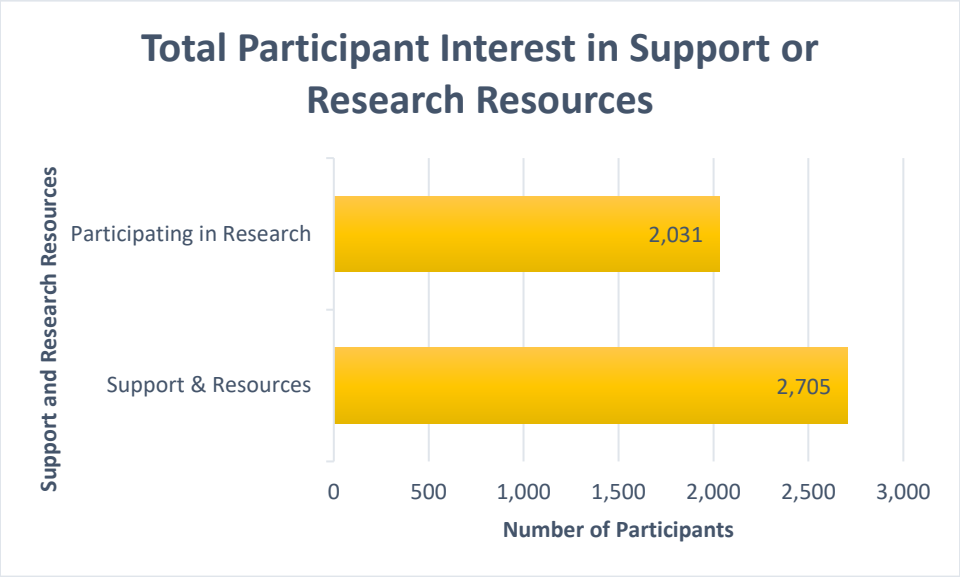


Figure 5

In the survey, 2,983 participants showed interest in learning more about support or research resources (Figure 5). Approximately 90.7% of these participants wanted to learn more about support and resources, and 68.1% of these participants were interested in learning more about participating in research.

7.0 Black or African American Participants

This section will focus on a subset of the participant data set. In this section, survey responses from Black/African American and Black mixed-race participants were analyzed. As discussed in section 1.4, Black/African American cancer patients have worse health outcomes than White/Caucasian patients. It is important to know how Black/African American patients responded to the survey to address how peer navigation can meet their needs. Black mixed-race (also referred to as Black bi- or multi-racial) participants identify as two or more races, including Black or African American. The responses from Black/African American and Black mixed-race males will be highlighted.

7.1 Black/African American and Black Mixed-Race Demographics

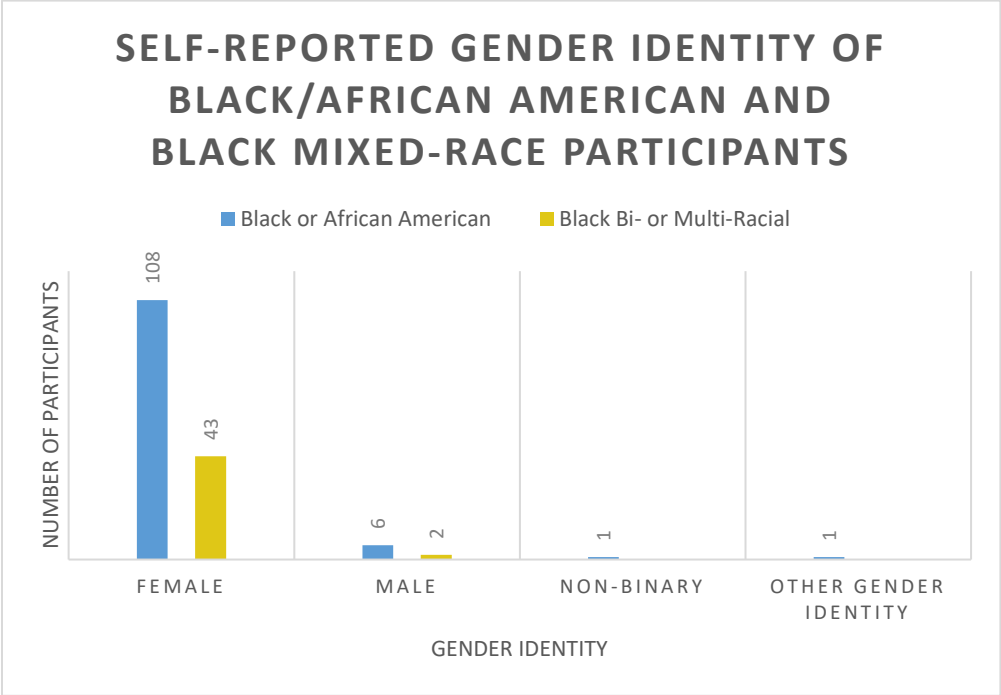


Figure 6

Out of 3,722 participants who completed the survey, 116 (3.1%) identify as Black or African American, and 45 (1.2%) identify as Black mixed-race (Figure 6). Out of 116 Black or African American participants, 108 (93.1) identify as Female, 6 (5.2%) identify as Male, and less than 2% identify as Non-Binary or "Other" gender identity. Out of 45 Black mixed-race participants, 43 (95.6%) identify as Female and 2 (4.4%) identify as Male.

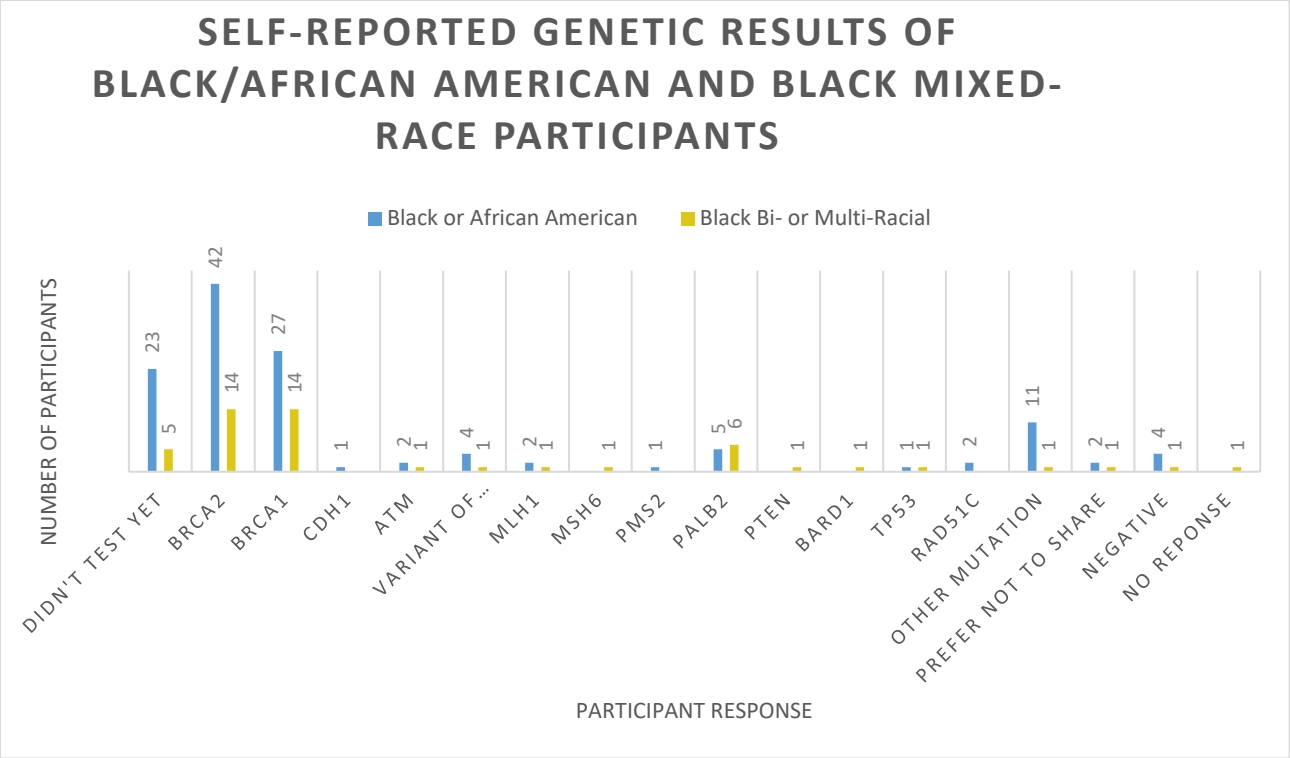


Figure 7

Out of 116 Black or African American participants, 42 (36.2%) reported having a confirmed *BRCA2* mutation, 27 (23.3%) have a *BRCA1* mutation, 23 (19.3%) have not yet tested, and 11 (9.5%) reported an "Other" mutation (Figure 7). Out of 44 Black mixed-race participants (one participant did not respond), 14 (31.8%) have a *BRCA1* mutation, 14 have a *BRCA2* (31.8%) mutation, 6 (13.6%) have a *PALB2* mutation, and 5 (11.4%) have not tested yet (Figure 7). Out of 27 Black or African American participants with a *BRCA1* mutation, 1 (3.7%) is Male. Out of 14 Black mixed-race participants, 1 (7.1%) is Male. Out of 23 Black or African American participants who have not tested, 5 (21.7%) are Male. Out of 5 Black mixed-race participants who have not tested, 1 (20%) is Male.

7.2 Black/African American and Black Mixed-Race Participant Topics of Interest

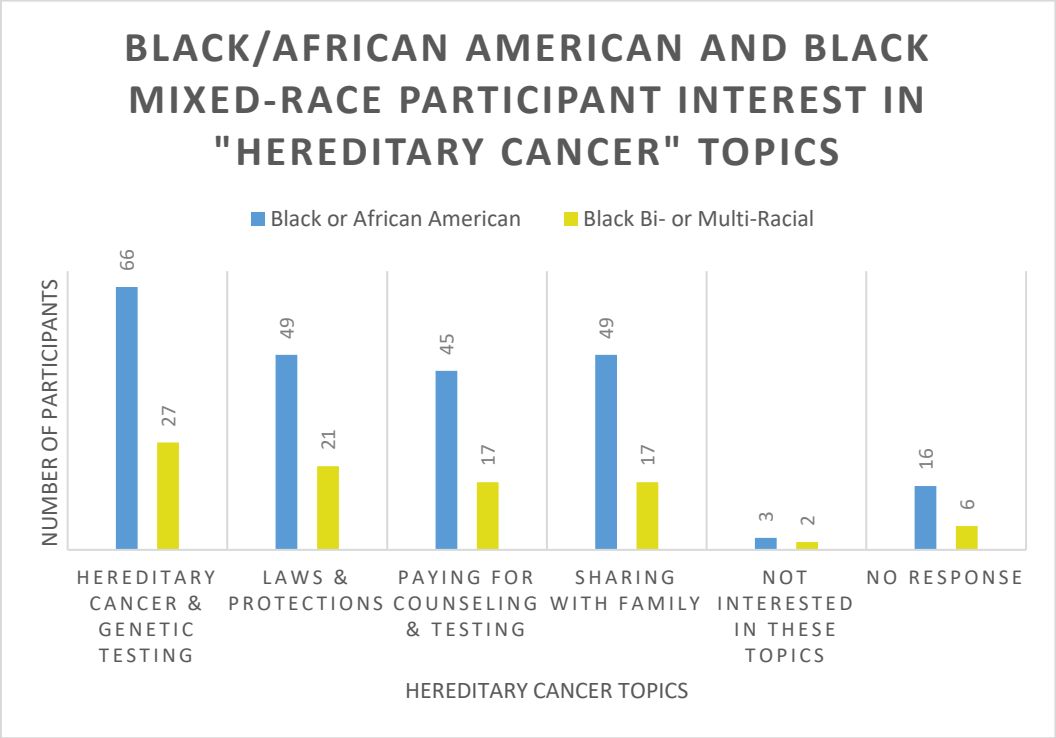


Figure 8

94 (81%) Black or African American participants and 39 (86.7%) Black mixed-race participants showed interest in learning more about Hereditary Cancer Topics (Figure 8). Black/African American (70.2%) and Black mixed-race (69.2%) both showed the most interest in hereditary cancer and genetic testing.

Black or African American Males were interested in the following “Hereditary Cancer” topics:

- Hereditary Cancer & Genetic Counseling (6, 100%)
- Paying for Counseling and Testing (5, 83.3%)

- Laws & Protections (3, 50%)
- Sharing with Family (3, 50%)

Black Mixed-Race Males were interested in the following “Hereditary Cancer” topics:

- Hereditary Cancer & Genetic Testing (1, 50%)
- Laws & Protections (1, 50%)
- Sharing with Family (1, 50%)
- No Response (1, 50%)

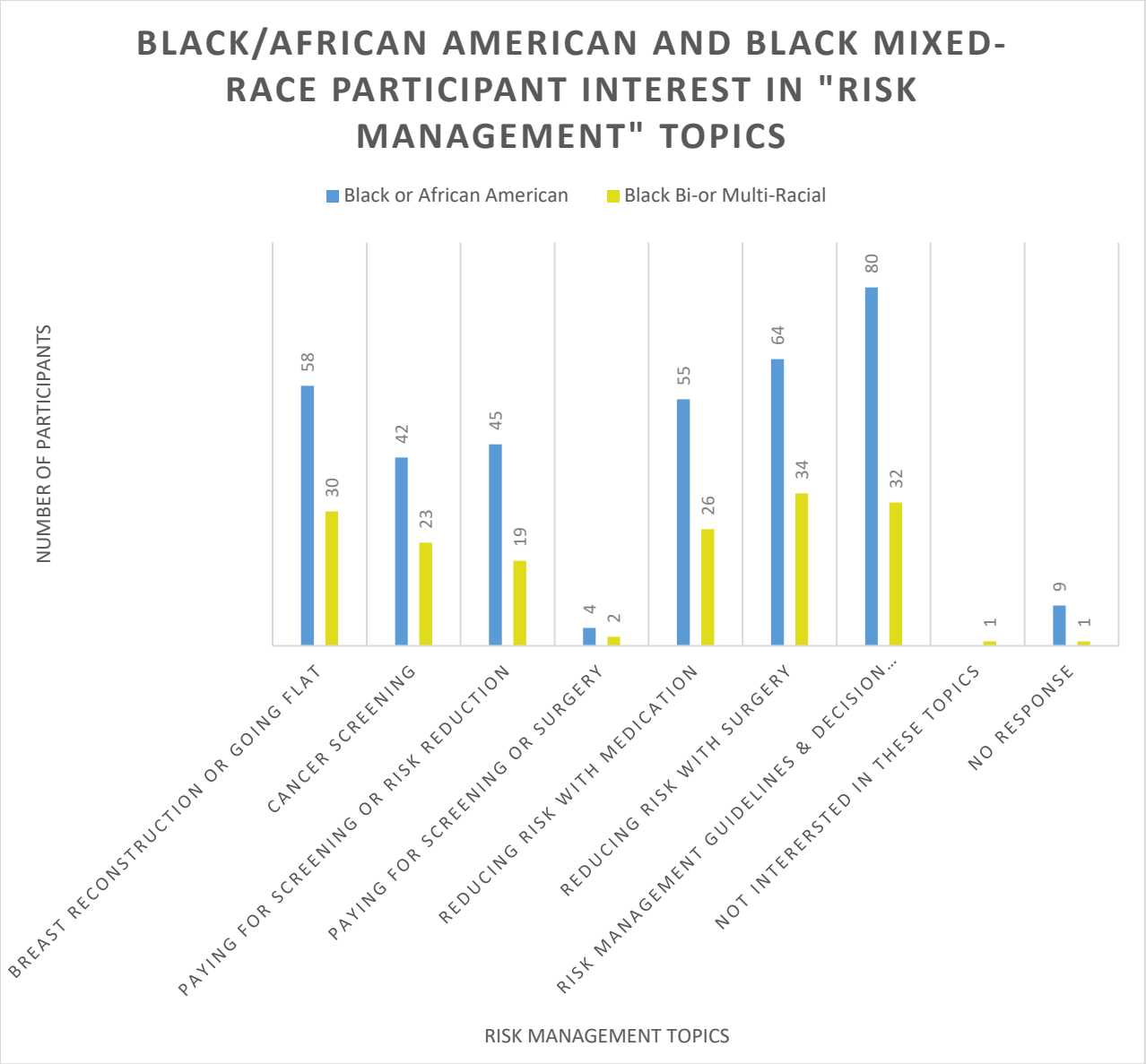


Figure 9

107 (92.2%) Black or African American participants and 44 (97.8%) Black mixed-race participants showed interest in learning more about risk management topics (Figure 9). Black/African American participants were most interested in learning about risk management guidelines and decision making (74.8%), reducing risk with surgery (59.8%), breast reconstruction or going flat (54.2%), and reducing risk with medication (51.4%).

Black or African American Males were interested in the following “Risk Management” topics:

- Risk Management Guidelines & Decision-Making (5, 83.3%)
- Reducing Risk with Medication (4, 66.7%)
- Paying for Screening or Risk Reduction (4, 66.7%)
- Cancer Screening (4, 66.7%)
- Reducing Risk with Surgery (3, 50%)
- Breast Reconstruction or Going Flat (3, 50%)

Black mixed-race Males were interested in the following “Risk Management” topics:

- Reducing Risk with Medication (2,100%)
- Cancer Screening (2,100%)
- Reducing Risk with Surgery (1,50%)
- Breast Reconstruction or Going Flat (1, 50%)
- Risk Management Guidelines or Decision Making (1, 50%)
- Paying for Screening or Risk Reduction (1, 50%)

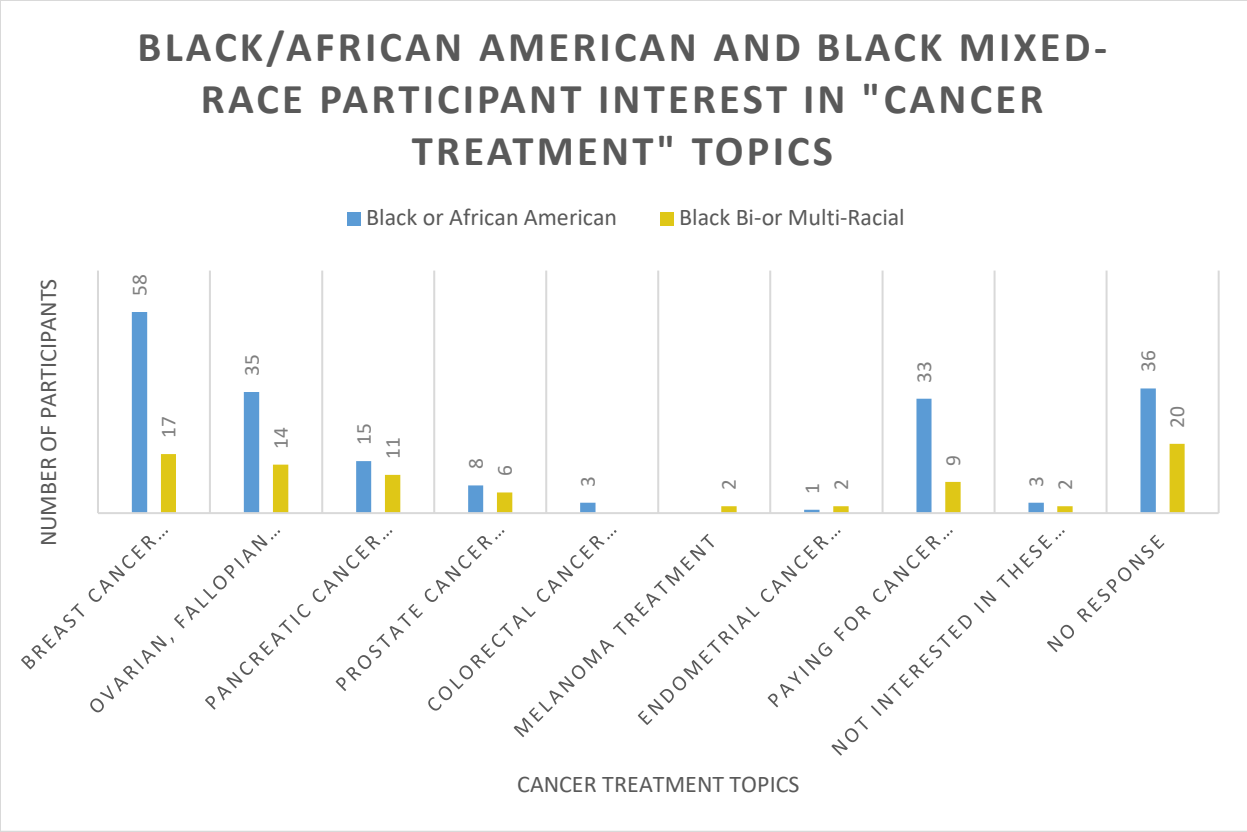


Figure 10

80 (69%) Black or African American Participants and 25 (55.6%) of Black mixed-race participants showed interest in learning more about cancer treatment topics (Figure 10). Black or African American participants were most interested in learning about breast cancer treatment (72.5%) and ovarian, fallopian tube, and primary peritoneal cancer treatment (43.8%), and 45% did not provide a response. Black mixed-race participants were most interested in learning about breast cancer treatment (68%), ovarian, fallopian tube, and primary peritoneal cancer treatment (56%) and pancreatic cancer treatment (44%).

Black or African American Males were interested in learning more about the following "Cancer Treatment" topics:

- Breast Cancer Treatment (3, 50%)
- Ovarian, Fallopian Tube, and Primary Peritoneal Cancer Treatment (3, 50%)
- Pancreatic Cancer Treatment (3, 50%)
- Prostate Cancer Treatment (3, 50%)
- Paying for Cancer Treatment 3, 50%)
- No Response (3, 50%)

Black mixed-race Males were interested in learning more about the following "Cancer Treatment" topics:

- Breast Cancer Treatment (1, 50%)
- Ovarian, Fallopian Tube, and Primary Peritoneal Cancer Treatment (1, 50%)
- Paying for Cancer Treatment (1,50%)
- No Response (1,50%)

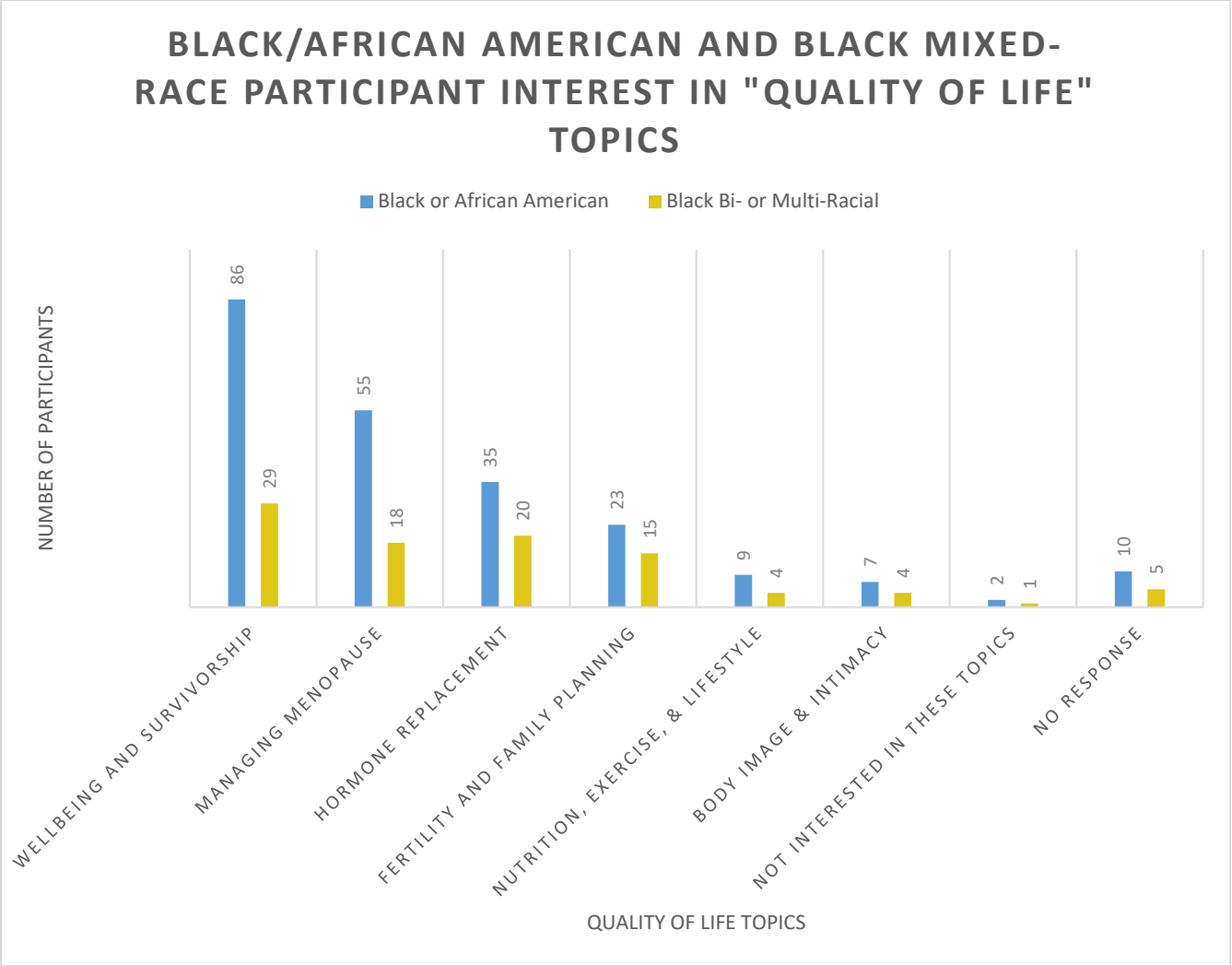


Figure 11

106 (91.4%) of Black or African American participants and 40 (88.9%) of Black mixed-race participants were interested in learning more about quality-of-life topics (Figure 11). Black or African American participants were most interested in learning about wellbeing and survivorship (81.1%) and managing menopause (51.9%). Black mixed-race participants were most interested in learning about wellbeing and survivorship (72.5%), hormone replacement (50%), and managing menopause (45%).

Black or African American Males were interested in learning more about the following "Quality of Life Topics":

- Wellbeing and Survivorship (5, 83.3%)
- Fertility and Family Planning (2, 33.3%)
- Hormone Replacement (2, 33%)
- Managing Menopause (2, 33%)
- No Response (1, 16.7%)

Black mixed-race Males were interested in learning more about the following "Quality of Life Topics":

- Fertility and Family Planning (2, 100%)
- Hormone Replacement (2, 100%)
- Managing Menopause (2, 100%)
- Wellbeing and Survivorship (2, 100%)

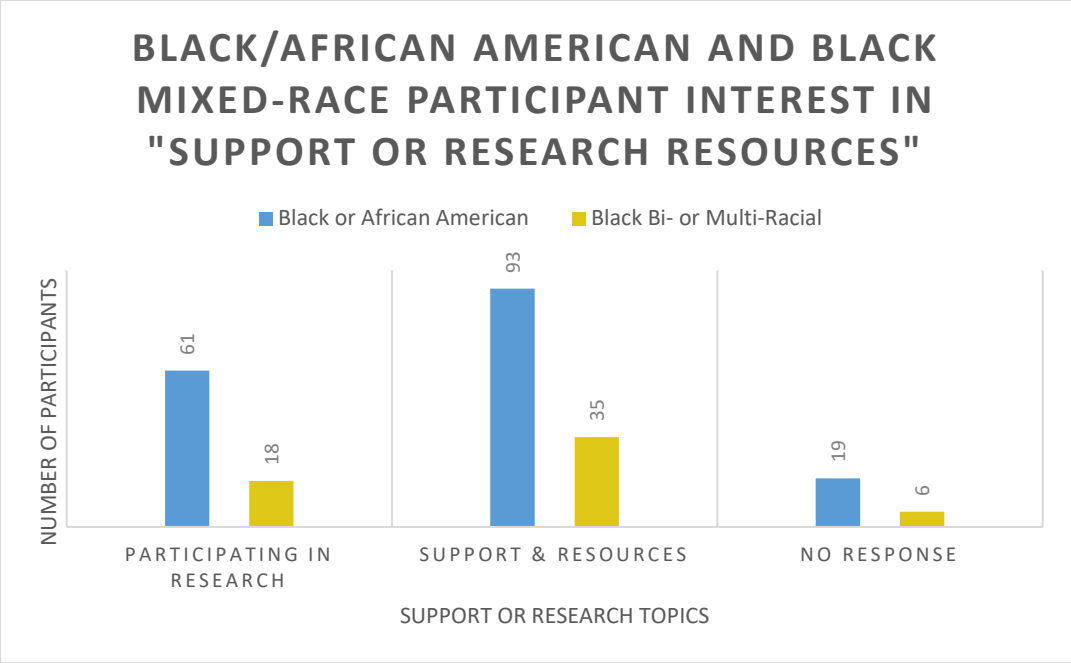


Figure 12

97 (83.6%) Black or African American participants and 39 (86.7%) of Black mixed-race participants were interested in learning more about support or research resources (Figure 12). Both Black/African American and Black mixed-race participants were most interested in learning about support and resources (95.6% and 89.7% respectively) followed by research opportunities (62.9% and 46.1% respectively).

Black or African American Males were most interested in learning about the following "Support or Research" Resources:

- Participating in Research (4, 66.7%)
- Support & Resources (4, 66.7%)
- No Response (1, 16.7%)

Black mixed-race Males were most interested in learning about the following "Support or Research" Resources:

- Support & Resources (2, 100%)
- Participating in Research (1, 50%)

8.0 Male Participants

This section will focus on a subset of the participant data set. In this section, survey responses from male participants are analyzed. As discussed in section 1.3, male participants are affected by hereditary cancer but are underserved, as several resources are targeted toward women with a *BRCA* mutation. Male patients affected by hereditary cancer syndromes have unique needs from women, as they can develop male breast cancer and prostate cancer. Therefore, it is important to know how male participants respond to survey questions about peer navigation so FORCE can ensure these participants are receiving support from navigators who have similar experiences. Black or African American males will be included in these statistics. Out of 3,722 total participants, 99 (2.7%) are Male.

8.1 Self-Reported Race/Ethnicity of Male Participants

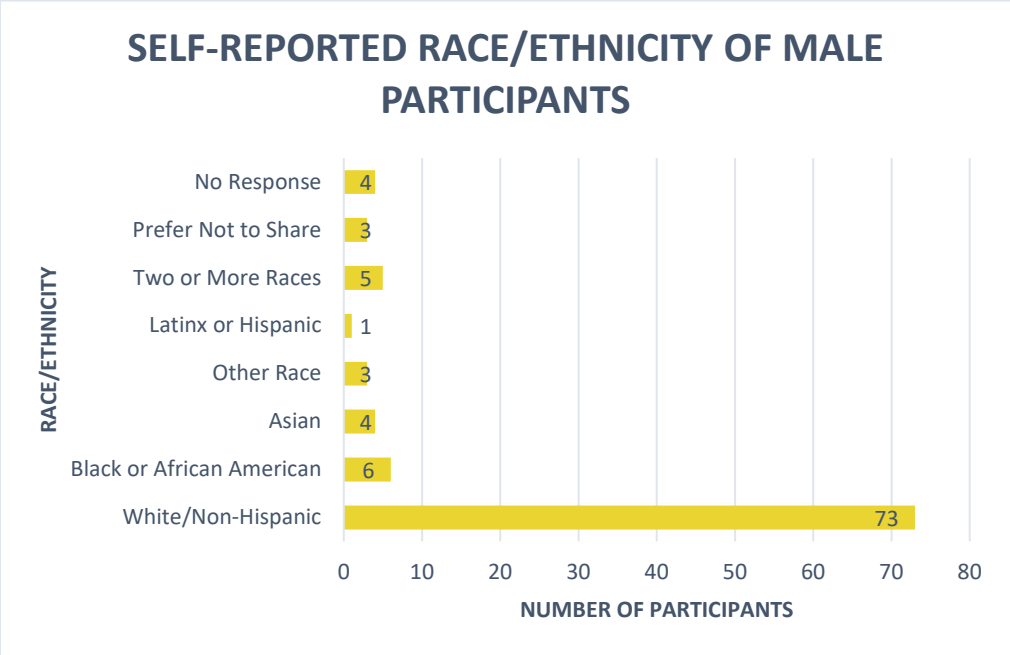


Figure 13

96% of males provided information about their race/ethnicity in the survey (Figure 13). Most male participants are White/Non-Hispanic (73.7%), and approximately 6% of male participants are Black or African American. The other categories each make up approximately 5% or less of male participants.

8.2 Genetic Test Results of Male Participants

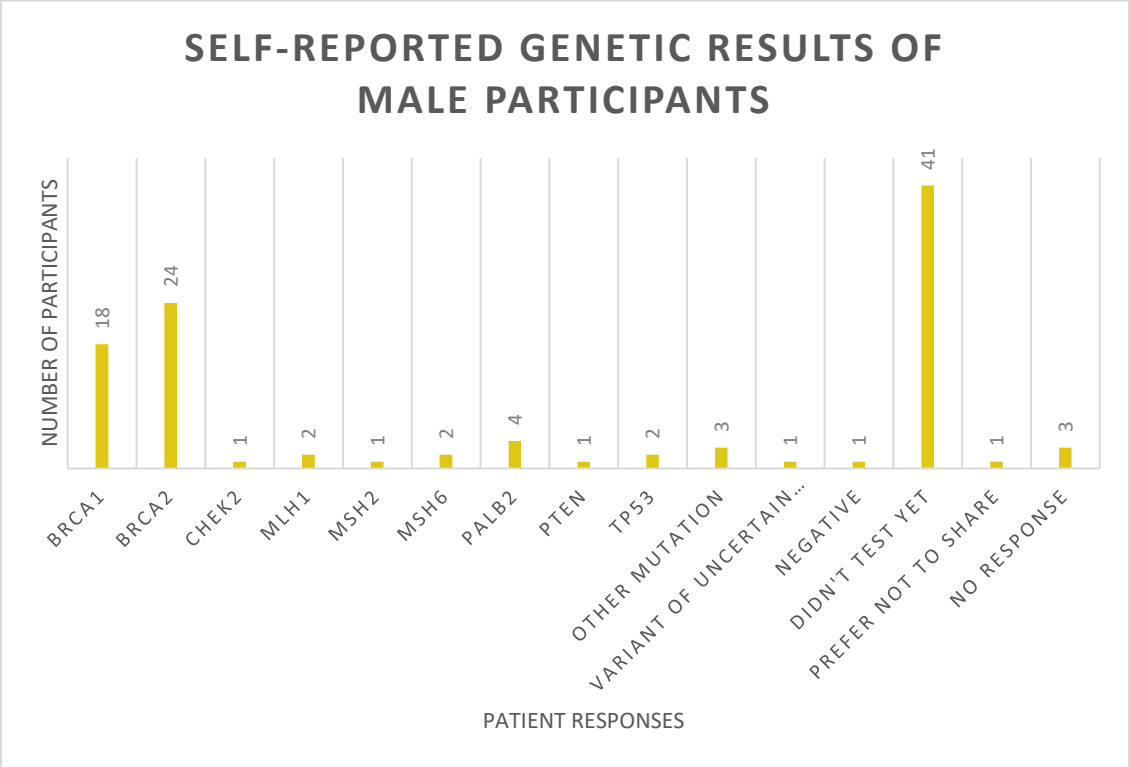


Figure 14

97% of male participants provided their genetic test results in the survey (Figure 14). The most common mutations in this group are in *BRCA2* (24.2%) and *BRCA1* (18.2%). Approximately 41.4% of male participants reported not having yet been tested.

8.3 Male Participant Topics of Interest

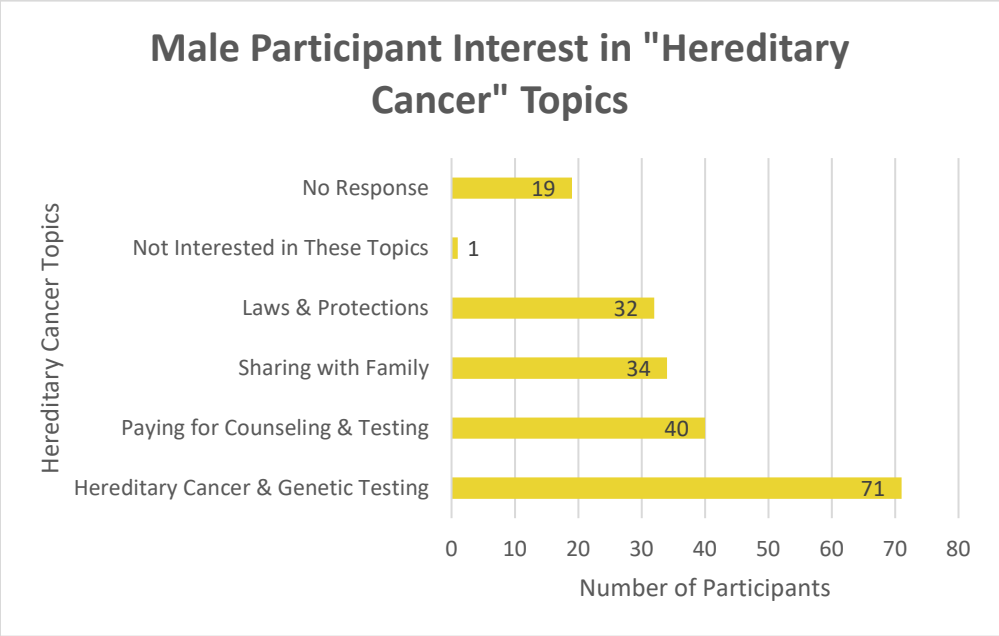


Figure 15

80.8% of male participants reported being interested in learning more about hereditary cancer topics (Figure 15). These participants are most interested in learning about hereditary cancer and genetic testing (88.8%) and paying for counseling and testing (50%).

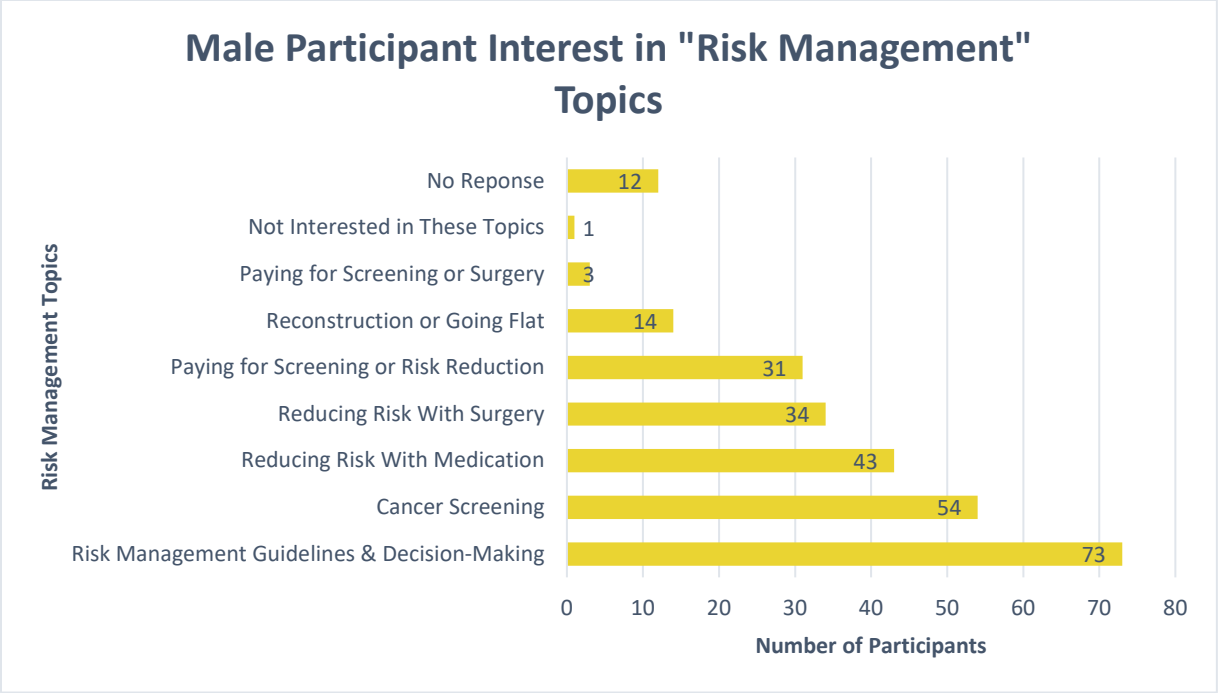


Figure 16

87.9% of participants are interested in learning more about risk management topics (Figure 16). These participants are most interested in learning about risk management guidelines and decision-making (83.9%), cancer screening (62.1%), and reducing risk with medication (49.4%).

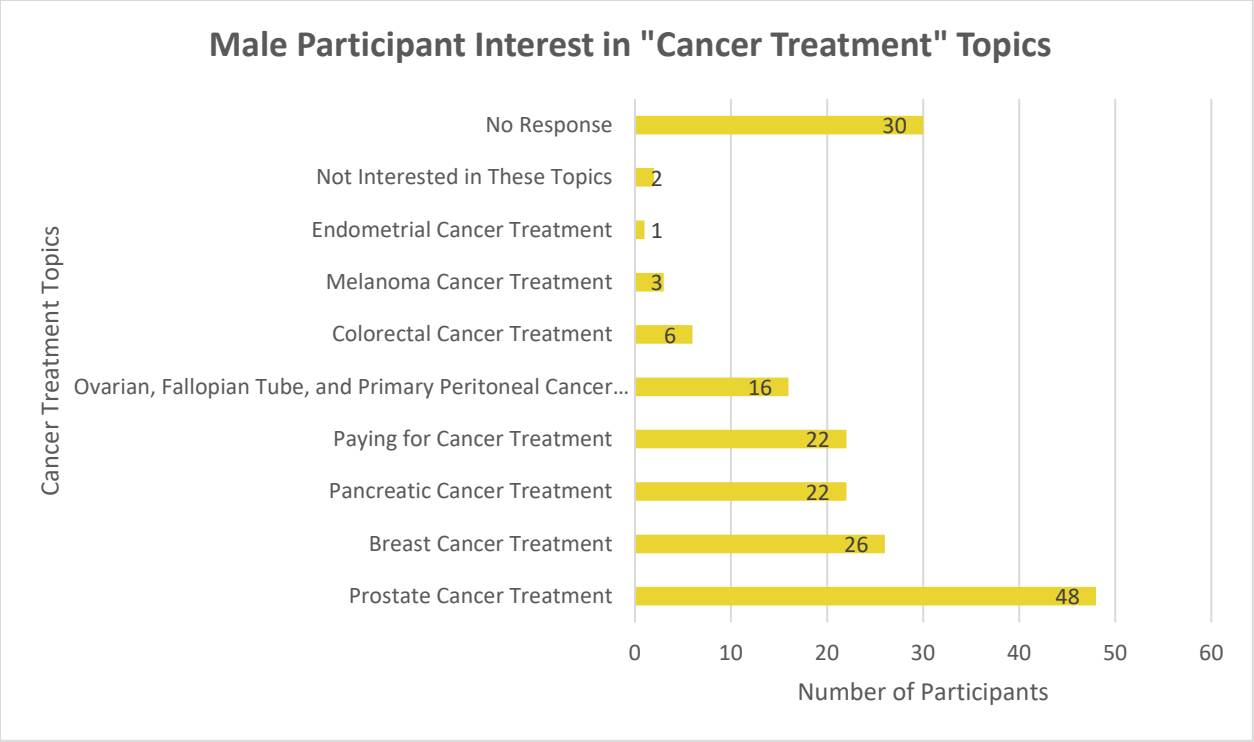


Figure 17

69.7% of male participants were interesting in learning more about "Cancer Treatment" topics (Figure 17). These participants were most interested in learning about prostate cancer treatment (69.6%).

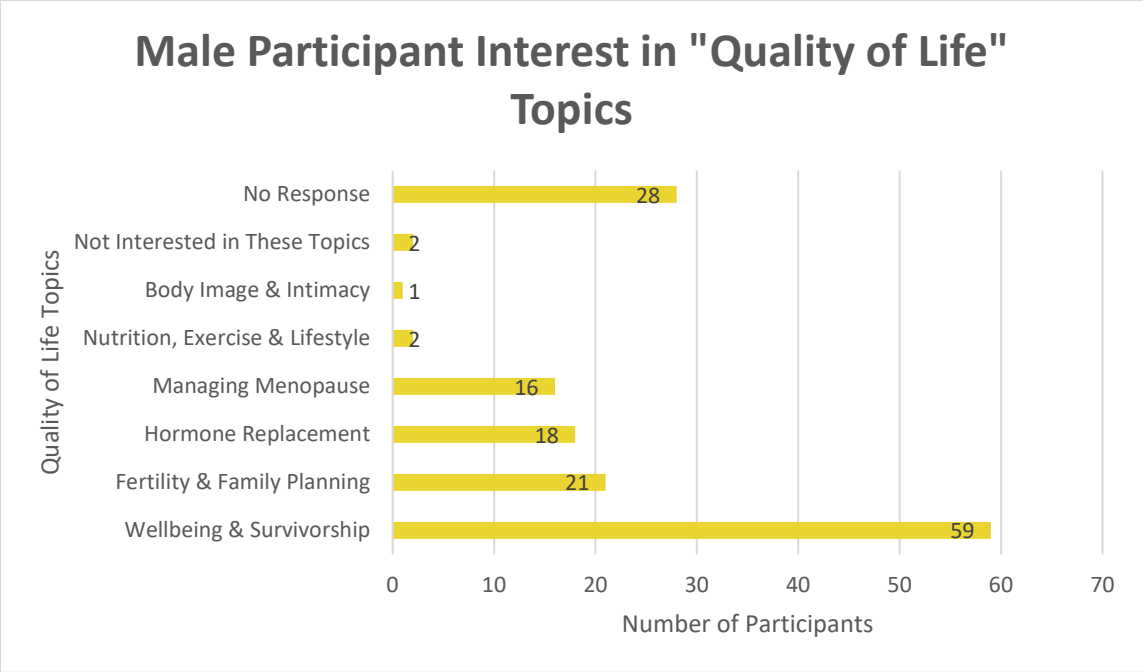


Figure 18

71.7% of male participants were interested in learning more about quality-of-life topics (Figure 18). These participants were most interested in learning about wellbeing and survivorship (83.1%).

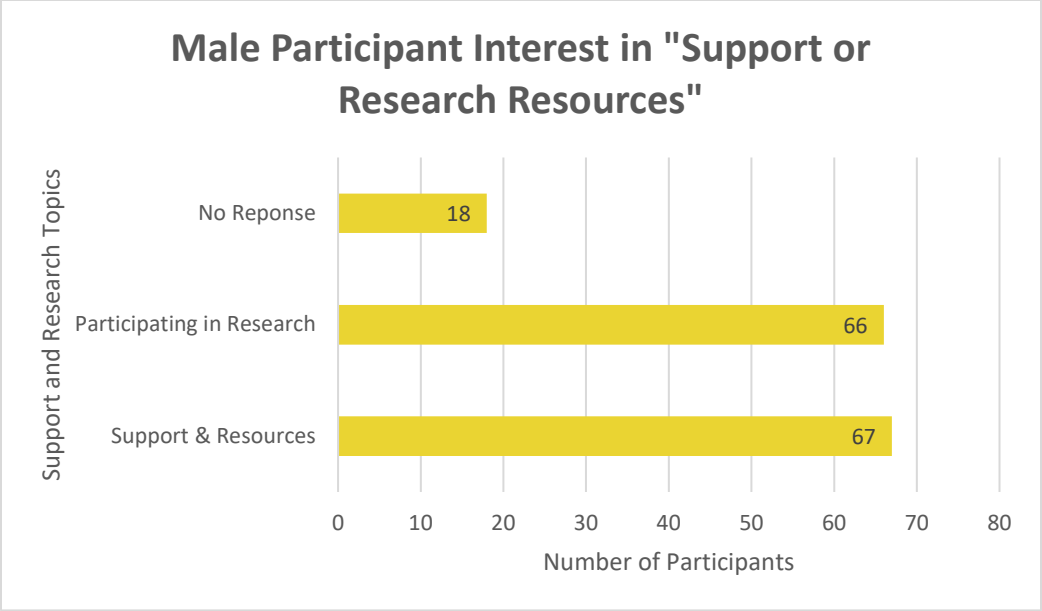


Figure 19

81.8% of male participants were interested in learning about support and resources (82.7%) and participating in research (81.5%) (Figure 19).

9.0 Comparison of Black and Male Participant Responses to All Participants

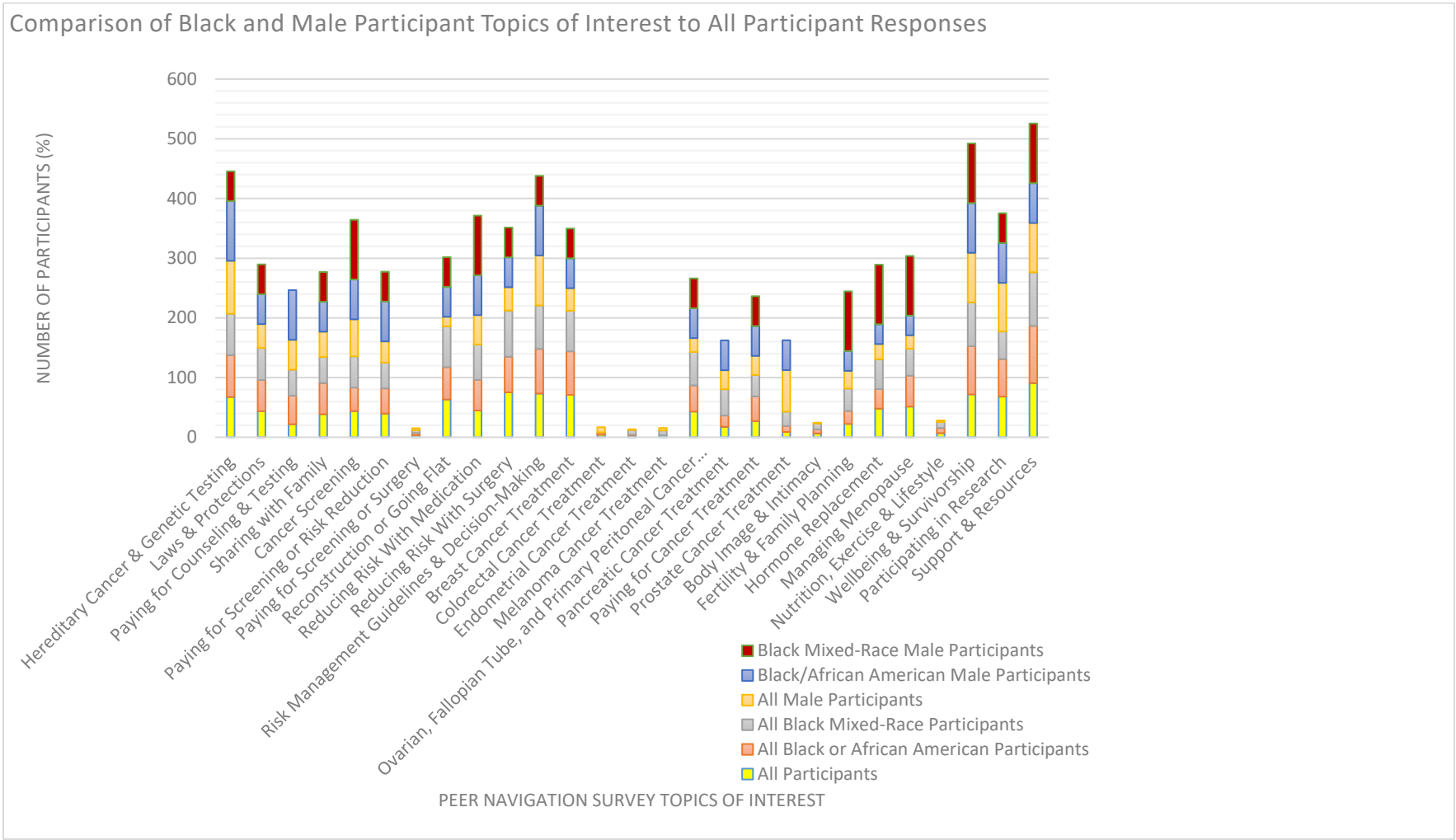


Figure 20

Of note, the amount of interest in "Wellbeing and Survivorship," "Participating in Research," "Support and Resources," "Hereditary Cancer and Genetic Testing," "Laws and Protections," and "Risk Management Guidelines and Decision-Making" appears to be similar across all groups (Figure 20). *All Black/African American Participants* showed less interest in "Cancer Screening" and "Pancreatic Cancer Treatment" than other groups. *Black/African American Male Participants* showed more interest in "Paying for Counseling and Testing" than other groups. *All Male Participants* were less interested in "Reconstruction and Going Flat," "Reducing Risk with Surgery," "Breast Cancer Treatment," and "Ovarian, Fallopian Tube, and Primary Peritoneal Cancer Treatment" than other groups. Additionally, *All Male Participants* showed more interest in "Prostate Cancer Treatment" than other groups.

10.0 Peer Navigator Demographics

This section will focus on survey responses from the navigator data set. Most of the individuals in the navigator data set have personal experience in dealing with a cancer diagnosis and treatment. Demographics from the navigator data set can provide information on which participants would likely benefit from a one-on-one match with a navigator.

Table 5

Self-Reported Navigator Gender Identity

Navigator Self-Reported Gender Identity	Count
Female	**169**
Male	**6**
Non-Binary	**1**
TOTAL	**176**

Out of 176 Navigators, 96% are Female and 3.4% are Male (Table 5).

Table 6

Self-Reported Navigator Sexual Orientation

Navigator Sexual Orientation	Count
Straight	**162**
Bisexual	**4**
Gay or Lesbian	**1**
Other	**1**
Prefer not to share	**4**

TOTAL	**172**

Out of 176 Navigators, 172 (97.7%) provided information to FORCE about their sexual orientation (Table 6). Approximately 94.2% of respondents are Straight and 2.3% are Bisexual.

Table 7

Navigator Genetic Information

Navigator Gene Mutation	Count
APC	**1**
ATM	**4**
BRCA1	**66**
BRCA1 VUS	**1**
BRCA2	**65**
BRCA2 VUS	**1**
BRCA1 and *BRCA2*	**2**
BRIP1	**2**
CHEK2	**4**
MSH2	**5**
MSH6	**2**
PALB2	**6**
PMS2	**1**
TP53	**1**
Two or More Mutations	**12**
Negative	**2**

Didn't Test Yet	**1**
TOTAL	**176**

176 Navigators provided their genetic test results (Table 7). Most Navigators have *BRCA1* and *BRCA2* mutations (37.5% and 36.9% respectively).

11.0 Comparing Participants to Navigators

In the volunteer survey, Navigators were asked if they were diagnosed with the following cancers: breast, ovarian, prostate, pancreatic, and colorectal. Since these are cancers that Participants are most interested in learning more about (Figure 3), a Patient to Navigator ratio can determine if there are enough Navigators to support Participants. With the exception of colorectal cancer, these cancer types are all associated with *BRCA1* and *BRCA2* mutations, which are the most common mutations in this cohort of Participants and Navigators (Tables 4 and 7). Similarly, the prevalence of Participants and Navigators with Hereditary Breast and Ovarian Cancer, Lynch, Cowden, and Li-Fraumeni Syndromes can determine if there are enough Navigators to support Participants with cancer predisposition syndromes.

11.1 Comparing Participant Interest in Cancer Treatment Topics to the Number of Navigators Diagnosed with Cancer

Table 8

Comparison of Participants' Interest and Navigators' Experience in Cancer Treatment

Cancer Treatment Type	Number of Participants Interested in "Cancer Treatment" Topics	Number of Navigators Diagnosed
Breast Cancer Treatment	1,260	59
Ovarian Cancer Treatment	765	13

Colorectal Cancer Treatment	76	5
Pancreatic Cancer Treatment	310	1
Prostate Cancer Treatment	158	1

Of note, there is only 1 (0.57%) Navigator each to support patients interested in pancreatic or prostate cancer (Table 8).

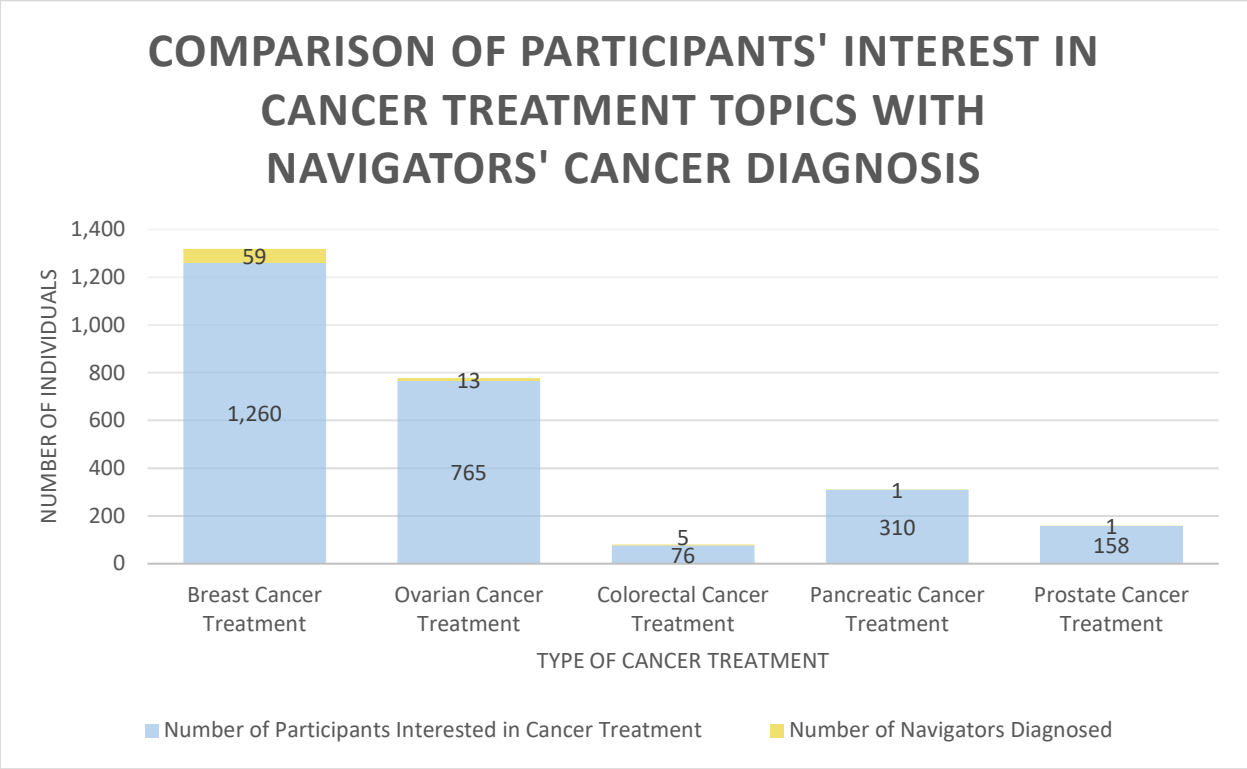


Figure 21

The Participant to Navigator ratios for breast cancer, ovarian cancer, colorectal cancer, pancreatic cancer, and prostate cancer are 1:22, 1:59, 1:16, 1:310, 1:158 respectively (Figure 21). It is unreasonable that one Navigator can meet the needs of hundreds of Participants, as each match is estimated to have at least two to three hours of communication between Navigator and

Participant. Therefore, Participants with pancreatic and prostate cancer may not be well supported by the peer navigation program if Participants are matched to Navigators based on cancer type.

11.2 Assessing Prevalence of Hereditary Cancer Syndromes Among Participants and Navigators

Table 9

Prevalence of HBOC, Lynch, Cowden, and Li-Fraumeni Syndromes Among Participants

Syndrome	Count	Prevalence (%)
HBOC (*BRCA1, BRCA2*)	2,543	**68.32**
Lynch (*MLH1, MSH2, MSH6, PMS2, EPCAM*)	58	**1.56**
Cowden (*PTEN*)	25	**0.67**
Li-Fraumeni (*TP53*)	24	**0.64**

Table 10

Prevalence of HBOC, Lynch, Cowden, and Li-Fraumeni Syndromes Among Navigators

Syndrome	Count	Prevalence (%)
HBOC (*BRCA1, BRCA2*)	140	**79.55**
Lynch (*MLH1, MSH2, MSH6, PMS2, EPCAM*)	11	**6.25**
Cowden (*PTEN*)	2	**1.14**

Li-Fraumeni (*TP53*)	3	**1.70**

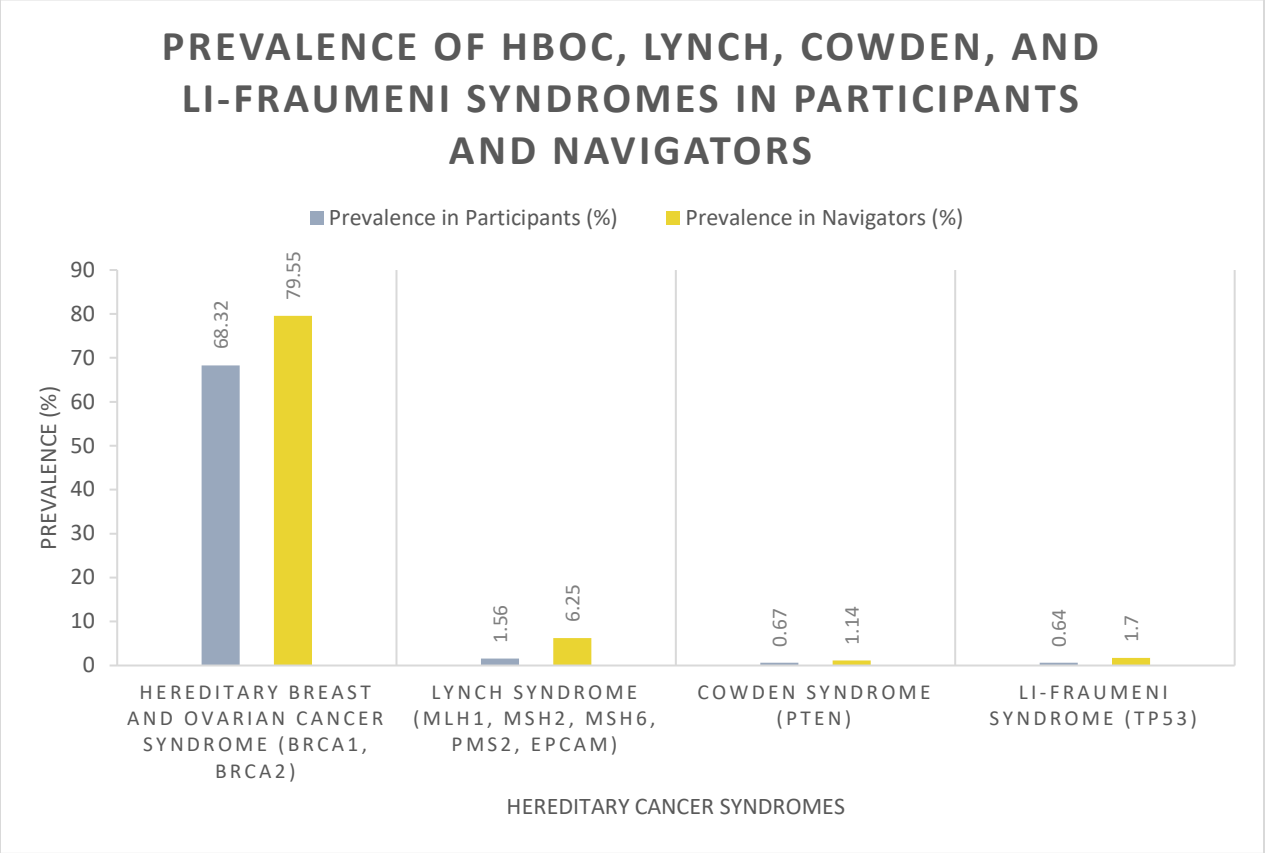


Figure 22

The prevalence of these hereditary cancer syndromes is higher in navigators than participants, suggesting that there should be enough navigators to support participants with these syndromes if participants wish to be matched with a navigator who has the same genetic mutation (Figure 22). Based on the data from Tables 9 and 10, the approximate navigator to participant ratios for HBOC, Lynch, Cowden, and Li-Fraumeni syndromes are 1:19, 1:6, 1:13, and 1:8 respectively. FORCE estimates that navigators spend two to three hours per participant match. Therefore, it is estimated that navigators with a *BRCA* mutation spend 38-57 hours supporting

participants with a *BRCA* mutation. Since the ratios for Lynch, Cowden, and Li-Fraumeni syndromes have less participants per navigator, it is reasonable that participants can be supported if they are matched to a navigator with a mutation in the same gene. It is important to consider genetic status in a match between navigator and participant, as participants would likely want information on cancer prevention, detection, risk management, and treatment from navigators who have personal experience in these areas.

12.0 Discussion

The demographics from the data set consisting of participant survey responses show that most individuals who wish to participate in the navigation program are white, straight females who are affected by a *BRCA1* or *BRCA2* mutation or related cancer diagnosis. This is consistent with previous research, which found that most participants in a *BRCA* study were white, non-Hispanic women (Guo et al., 2022).

Despite the small percentage of Black or African American participants in this cohort, nearly 20% of them have not yet had genetic testing. Findings from the literature suggest that racial health disparities, such as systemic racism and socioeconomic differences, prevent Black patients from receiving access to genetic services. Researchers from Arizona State University have previously mishandled genetic information belonging to members of the Havasupai tribe by using their DNA for other studies without consent, leading to minority groups becoming wary of genetic testing (Matalon et al., 2023). Additionally, genetic services are underutilized in Black individuals, who often have low socioeconomic status due to a lack of formal education, low health literacy, and low household income (Dusic et al., 2022). Genetic services are an integral part of preventing, detecting, and treating hereditary cancer conditions; without access to genetic testing, Black patients are at high risk of mortality and morbidity related to hereditary cancers (Reid et al., 2021). Therefore, it is important for FORCE to address these disparities that prevent Black and African American patients from obtaining genetic services.

Additionally, Black/African American participants were more interested in learning about ways to pay for genetic counseling and testing compared to other participants. These findings suggest that Black and other racially underserved patients may benefit from a more thorough

education on obtaining health insurance, finding nearby genetic services, and the benefits and drawbacks of genetic testing. More information is needed to know what topics covered in the peer navigation program are most beneficial for participants and where gaps in knowledge and care still exist. Since data analyzed in this essay were collected before any peer navigation services were received, it would be helpful for FORCE to implement a post-experience survey for participants to provide feedback on their experience in the peer navigation program and suggest additional education that the program could provide to participants in the future. Per FORCE staff members, in the time since these two data sets were created, surveys have been implemented for participants and navigators to complete following their match to share their feedback.

The results of this analysis show that while many participants with common cancers, like breast cancer, wished to be part of the navigation program, there were also several participants with rare cancer syndromes. Only two navigators were diagnosed with prostate or pancreatic cancer. It is important for participants to be matched to navigators based on cancer type, as participants can gain valuable insights from their navigator on the clinical management and treatment of their cancer. For instance, patients who have a *BRCA* mutation and breast cancer often have a mastectomy. These breast cancer patients would not be able to share their surgical experiences with prostate or pancreatic cancer patients who have a *BRCA* mutation, as they would need different surgeries. Participants matched based on mutation alone can have vastly different cancers and experiences from each other. Therefore, it is important for FORCE to increase their recruitment efforts to include more peer navigators with less common genetic mutations and hereditary cancer diagnoses if they want to match a growing volume of requests. In 2020, FORCE expanded their community to include people with less common mutations and Lynch syndrome

(FORCE, n.d.). More information needs to be obtained from FORCE about their current processes for recruiting peer navigators to determine where improvements could be made.

12.1 Limitations

This analysis contains several limitations. First, some of the conclusions reached may not be generalizable to the entire population. The results on Black/African American or Black multi-race males are based on responses from eight people. This could skew the data and likely led to inflated percentages in Figure 20. Despite the small sample size, previous research corroborates this essay's finding that Black/African American males are most interested in learning about genetic testing and paying for testing. This study found that disparities among Black men can both influence and prevent them from pursuing genetic testing. However, increased education and health literacy may make Black men more interested in pursuing testing in the future (Rogers et al, 2018).

Additionally, reporting bias might have occurred because the survey data collected was self-reported. Several participants left questions blank, even when there was an option for "Not Interested in These Topics" or "Prefer Not to Share". It is unclear if these questions were left blank knowingly or in error, but it does impact the results. The free-text responses given by participants were omitted in the analysis of data, as many of these responses contained contradictory information, especially for genetic test results. Several responses found in Table 3 demonstrate that participants may not understand what their genetic test results mean. For example, several participants reported having negative test results but also selected a gene. This finding suggests

that there may be low health literacy levels among participants. To address this, FORCE could rewrite the surveys to improve clarity and readability.

Future research could focus on the outcomes of patients after participating in the peer navigation program, as patients who participate may be empowered to take medically actionable steps to prevent and manage hereditary cancer.

12.2 Summary of Recommendations for FORCE

In summary, the results from this essay suggest several recommendations that FORCE can employ to improve the peer navigation program. First, FORCE should collect information from participants after they have gone through the peer navigation program. This can create an opportunity for male and Black/African American participants to share their opinion about the program and give FORCE insight into the information participants would have liked to receive. Per FORCE staff members, this has been implemented and is currently underway. Secondly, FORCE should recruit more navigators with rare mutations and less common cancer diagnoses as demand grows. FORCE can perform outreach within its partner organizations to cast a wider net and reach potential navigators from more diverse backgrounds. Lastly, FORCE should consider rewriting the participant sign-up survey to address low genetic literacy among this population. Specifically, analysis of the participant data set indicates that the survey item about genetic test results may be confusing in the way it is currently written. This survey item could potentially be separated into two different questions to gain clarity about whether patients have a positive test result or VUS.

12.3 Conclusion

This essay aims to identify what topics potential peer navigation program participants are most interested in learning about and specifically examines the interests of male and Black/African American participants. Additionally, this essay examines if there are enough peer navigators to serve participants with HBOC, Lynch, Cowden, and Li-Fraumeni syndromes.

Findings from this essay can address disparities that exist among underserved patients in the hereditary cancer and genetics communities. Furthermore, the analyses performed in this essay can inform FORCE of ways to improve its peer navigation program to make it more inclusive of underrepresented groups.

This essay includes analyses of two data sets from the FORCE peer navigation program. The first data set comprises survey responses from previvors, survivors, and caregivers interested in receiving support from peer navigators. The second data set comprises survey responses from individuals who have personal experiences with hereditary cancer and are interested in volunteering with FORCE as a peer navigator.

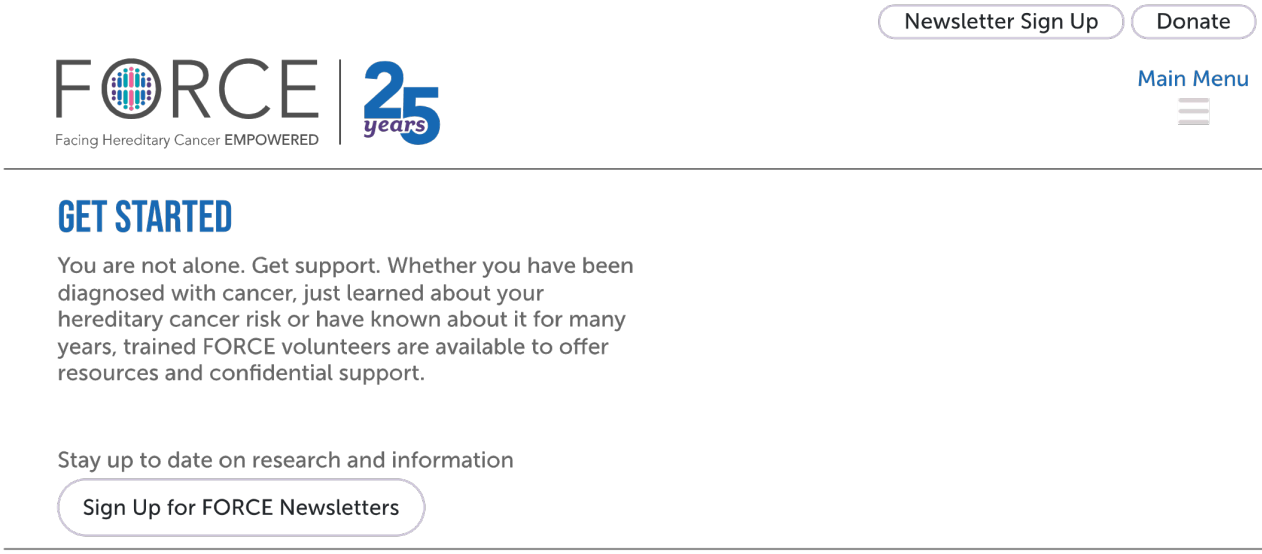
Descriptive analyses of the participant data set examined what information patients and caregivers would be most interested in receiving through the peer navigation program. The survey responses from Black/African American and male participants were independently examined. These analyses found that several Black/African have not yet had genetic testing, and Black/African American participants are more interested in receiving information about paying for genetic counseling and testing than other groups of participants. Only eight males of Black/African American descent are part of this data set; results from these analyses may not be generalizable to all Black/African American men.

Descriptive analyses of the navigator data set examined navigator to patient ratios for breast, ovarian, pancreatic, prostate, and colorectal cancers, as well as navigator to patient ratios for HBOC, Lynch, Cowden, and Li-Fraumeni syndromes. These analyses found that only two navigators in this data set have prostate or pancreatic cancer. It is hypothesized that participants with other cancer types and hereditary cancer syndromes would be well supported by peer navigators in the FORCE program.

This essay has limitations in addition to the small sample size of Black/African American participants previously mentioned. The analyses in this essay are based on survey responses from individuals before they have gone through the peer navigation program. Survey responses from the participant data set are limited to what potential participants hope to learn from the program and do not reflect what information they actually learned. Additionally, the survey responses found in both data sets are self-reported. Low health and genetic literacy levels among respondents may lead to bias if survey items were not clearly understood.

In conclusion, findings from this essay indicate that FORCE's peer navigation program has the capacity to support many cancer patients and caregivers. However, disparities may exist for underrepresented groups, such as male and Black/African American patients, participating in the peer navigation program. FORCE can improve the peer navigation program by surveying participants who have completed the program to identify where gaps in care still exist. Finally, FORCE can strengthen their current recruitment efforts of peer navigators so participants with rare cancers or gene mutations can receive support from a navigator who shares the same experiences.

Appendix A FORCE Peer Navigation Participant Survey



FORCE Peer Navigation Program

Welcome to the FORCE Peer Navigation Program. This program is only available for people from the United States and Canada. Please fill out this confidential survey so that we can try to match you to someone as much like yourself as possible. Once you submit your information, a FORCE Peer Navigator Volunteer will follow up with you within one week by email. Our goal is to provide you with resources that will empower you to make informed medical decisions with your healthcare providers. Thank you for reaching out to FORCE.

Acknowledgement

I understand that FORCE, its officers, directors, employees, and those volunteers in this program do not provide medical advice and that nothing provided by FORCE or the volunteers in this program either through the program or through the other materials or website of FORCE, are to be considered as medical advice and any information I receive from this program or from other FORCE materials should not be considered as such. I acknowledge I am providing information about myself and my medical condition voluntarily and understand that such information is collected in FORCE's secure database. This information is accessible by FORCE employees only. I understand that FORCE shares the basic information I provide only to my selected peer navigator so that they may provide the appropriate information to me. If you would like your information to be removed from our database, please contact privacy@facingourrisk.org. In the event of a life threatening situation we reserve the right to contact emergency services. This program is only available for people from the United States and Canada. Please read our full disclaimer and privacy policy. *

☐ Yes

Contact Information

First Name *

Last Name *

Street Address

City

State *

Please select...

Zip Code

Phone Number *

Email *

Email - enter again for verification *

What is your time zone?

○ Pacific
○ Mountain
○ Central
○ Eastern
○ Hawaii
○ Alaska

What time of day is best to reach you? (morning, afternoon, evening or share specific times)

Does FORCE have your permission to leave a voice mail if we cannot reach you by email?

- ○ Yes
- ○ No

Have you communicated with a Peer Navigator before?

- ○ No
- ○ Yes, I would like to communicate with the same peer navigator.
- ○ Yes, I would like to communicate with a different peer navigator.

Demographics: If you are a caregiver, please complete this survey for the person you are supporting.

Birthdate (MM/DD/YYYY) *

Gender *

Please select...

What are your pronouns?

Please select...

Do you think of yourself as:

Please select...

Check all that apply *

- ☐ Asian
- ☐ Black or African American
- ☐ Latinx or Hispanic
- ☐ Prefer not to share
- ☐ Native American
- ☐ Pacific Islander
- ☐ White/Non-Hispanic
- ☐ Other, specify below

Other

Have YOU, yourself, ever been diagnosed with cancer? Or if you are a caregiver, answer for the person you are supporting.

☐ Colorectal
☐ Endometrial
☐ Ovarian/Fallopian Tube/Primary Peritoneal
☐ Pancreatic
☐ Prostate
☐ No, I'm at high risk/Previvor

Are you a caregiver seeking information? ☐ Yes

Have you ever been diagnosed with any other cancer? ☐ Yes

Have you had genetic counseling?

○ Yes
○ No

Do you have a family history of cancer?

○ Yes
○ No
○ Not sure

Genetic test results:

Check all that apply *

☐ Haven't tested
☐ Negative
☐ APC variant I1307K
☐ APC (FAP or AFAP)
☐ ATM
☐ BARD1
☐ BRCA 1
☐ BRCA 2
☐ BRIP1
☐ CDH1
☐ CDK4
☐ CDKN2A
☐ CHEK2
☐ Variant of uncertain significance
☐ Other, please specify below
☐ EPCAM
☐ MLH1
☐ MSH2
☐ MSH6
☐ MUTYH
☐ NBN
☐ PALB2
☐ PMS2
☐ PTEN
☐ RAD51C
☐ RAD51D
☐ STK11
☐ TP53
☐ Prefer not to share

Other genetic mutation

Are you interested in learning about any of the following HEREDITARY CANCER topics? Check all that interest you.

- ☐ Hereditary Cancer & Genetic Testing
- ☐ Paying for Counseling & Testing
- ☐ Laws & Protections
- ☐ Sharing with Family

Are you interested in learning about any of the following CANCER RISK MANAGEMENT topics? Check all that interest you.

- ☐ Risk Management Guidelines & Decision-Making
- ☐ Cancer Screening
- ☐ Reducing Risk with Medication
- ☐ Reducing Risk with Surgery
- ☐ Breast Reconstruction or Going Flat
- ☐ Paying for Screening or Risk Reduction

Are you interested in learning about any of the following CANCER TREATMENT topics? Check all that interest you.

- ☐ Breast Cancer Treatment
- ☐ Colorectal Cancer Treatment
- ☐ Endometrial Cancer Treatment
- ☐ Melanoma Treatment
- ☐ Ovarian, Fallopian Tube & Primary Peritoneal Cancer Treatment
- ☐ Pancreatic Cancer Treatment
- ☐ Prostate Cancer Treatment
- ☐ Paying for Cancer Treatment

Are you interested in learning about any of the following QUALITY OF LIFE topics? Check all that interest you.

- ☐ Wellbeing & Survivorship
- ☐ Managing Menopause
- ☐ Hormone Replacement
- ☐ Fertility & Family Planning

Are you interested in learning about SUPPORT or RESEARCH resources? Check all that interest you.

- ☐ Participating in Research
- ☐ Support & Resources

SIGN UP TO RECEIVE:

Personalized and Confidential Support. Based on the information you submit through a secure survey, you'll be matched with a trained Peer Navigator who shares a similar experience and "gets" your situation for a phone call or email exchange.

Resource Guide. When you sign up, you will receive a guide filled with expert-reviewed resources. This information will help you navigate your decision-making process with your family and healthcare providers.

Do you want to request an American Sign Language Interpreter for your call?

○ Yes

FORCE Information

☑ Sign up for FORCE newsletters to stay up-to-date on hereditary cancer news, research, support, advocacy and clinical trial information.

How did you learn about the Peer Navigation Program?

○ Genetic Counselor	○ Healthcare Provider
○ Internet Search	○ FORCE Meeting or Event
○ FORCE Helpline	○ Facebook
○ FORCE E-Newsletter	○ Other, specify below

Other

If you click Submit, and it stays on this screen, scroll up to make sure that you answered all questions that say "This field is required." and that there are no other error messages in red.

Submit

KNOWLEDGE CAN SAVE LIVES

Receive FORCE Newsletters

Stay up to date on hereditary cancer information.

First Name

Last Name

Email Address

What is your primary connection to hereditary cancer? *

-choose-

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