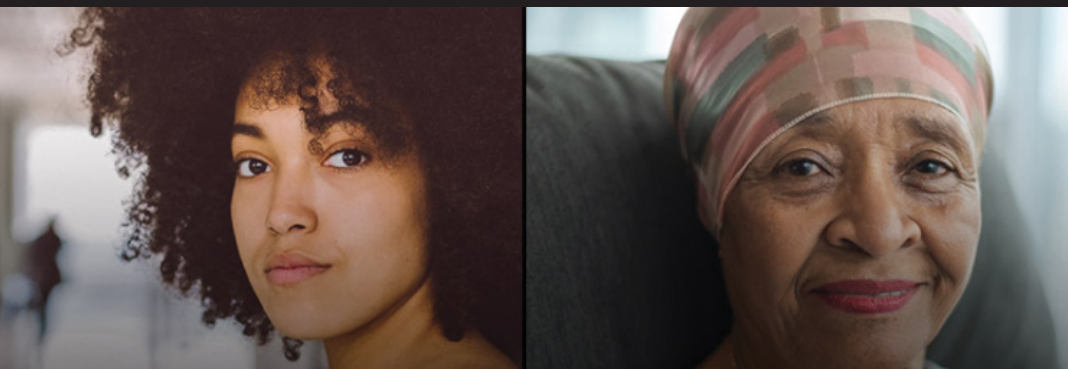




**Increasing Black Participation in
Metastatic Breast Cancer Clinical Trials:**

The **BECOME (Black Experience of
Clinical Trials and Opportunities for
Meaningful Engagement) Project**



MAY 2022

Metastatic Breast Cancer
MBCalliance➤

Driving Change through Patient-Led Research and Advocacy

The facts are starkly disturbing:

- *Among U.S. racial/ethnic groups, Black women and men have the highest death rate and shortest survival for many cancers including breast cancer.*
- *Clinical trials help improve outcomes and survival for people living with cancer, but Black women and men represent only 4% to 6% of patients in all cancer clinical trials – although about 15% of cancer patients in the U.S. are Black.*
- *Only when clinical trial participants reflect the diversity of the general population can oncologists understand how a drug works across subpopulations.*

*The Black Experience of Clinical Trials and Opportunities for Meaningful Engagement (BECOME) project aims to drive change by **better understanding barriers** to clinical trial participation for Black patients with metastatic breast cancer (MBC) and **identifying actions** to increase participation.*

How did the BECOME project get started?

The BECOME project grew out of a conversation at the 2019 San Antonio Breast Cancer Symposium between two patient advocates living with MBC – Stephanie Walker, RN, and Marina Kaplan, PhD, an epidemiologist – who connected via Living Beyond Breast Cancer’s “Hear My Voice” program. Marina had presented her study about barriers to clinical trial participation and patient-driven solutions to increasing participation. Concerned that only 8.87% of the respondents in her survey were Black, she and Stephanie discussed conducting additional research in the Black community.

Marina passed away in 2020 before the groundwork could be laid, but Stephanie was determined to pursue their shared goal. That year, she launched the BECOME project in partnership with the Metastatic Breast Cancer Alliance (MBCA), a consortium of representatives from cancer nonprofits and pharmaceutical and biotech companies, as well as individual patient advocates – many of whom are living with MBC. The mission of the MBCA is to extend life, to enhance quality of life, and to end suffering and death from MBC by advancing MBC research, improving access to quality treatments and care, and empowering people through increased education and information about the disease, and access to available resources.

How was the research conducted?

As BECOME project lead, Stephanie worked with a diverse team on the multi-phase research initiative. Researchers first conducted a literature review of selected articles on Black patient participation in cancer clinical trials. Next, they conducted virtual interviews with 31 Key Informants including Black women and men living with MBC, clinicians involved in breast cancer treatment, hospital and academic research administrators, breast cancer researchers, and administrators with insurance/payer organizations.

Based on the information learned from the literature review and interviews, researchers developed a web-based survey (with a paper-based option) of U.S. adults living with MBC. The survey explored attitudes toward and interest in clinical trials, and included some general questions about demographics and experience with the oncology care team. Survey participants were recruited through social media posts and emails—from the MBCA, MBCA members, subcommittee members, and ambassadors—to people connected with cancer communities.

Of the 424 survey respondents, 102 self-identified as Black. Respondents tended to be highly educated with high socioeconomic status, receive care through an academic medical system, and be well-insured, frequently with private insurance.

The analysis focused primarily on the responses from Black participants, consistent with BECOME's objectives. Black and non-Black respondents were compared, and the most meaningful differences are included in this summary.

“As a metastatic breast cancer patient, I don’t want my daughter to go through what I’ve experienced. I want to understand barriers to clinical trials for the Black community, so we can find answers on why Black men and women with MBC are dying at a faster rate.”

—Stephanie Walker, BECOME project lead & patient advocate living with MBC

What are the key learnings from the survey responses?

The survey found that *8 out of 10 Black people living with MBC would consider participating in clinical trials.*

So why are participation numbers so low? The survey revealed a broad spectrum of barriers and concerns that prevent participation by Black patients, as well as motivations that drive willingness to participate. While many of these factors have been documented in other research, the BECOME project seeks to focus on understanding the most compelling ones and identifying actions stakeholders can take to propel change.

These actions include:

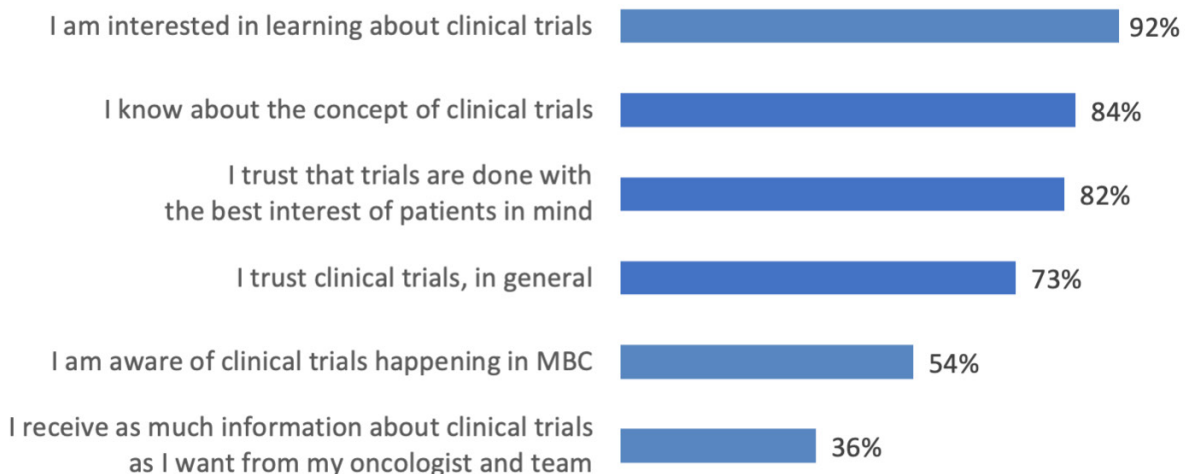


#1. Better Inform

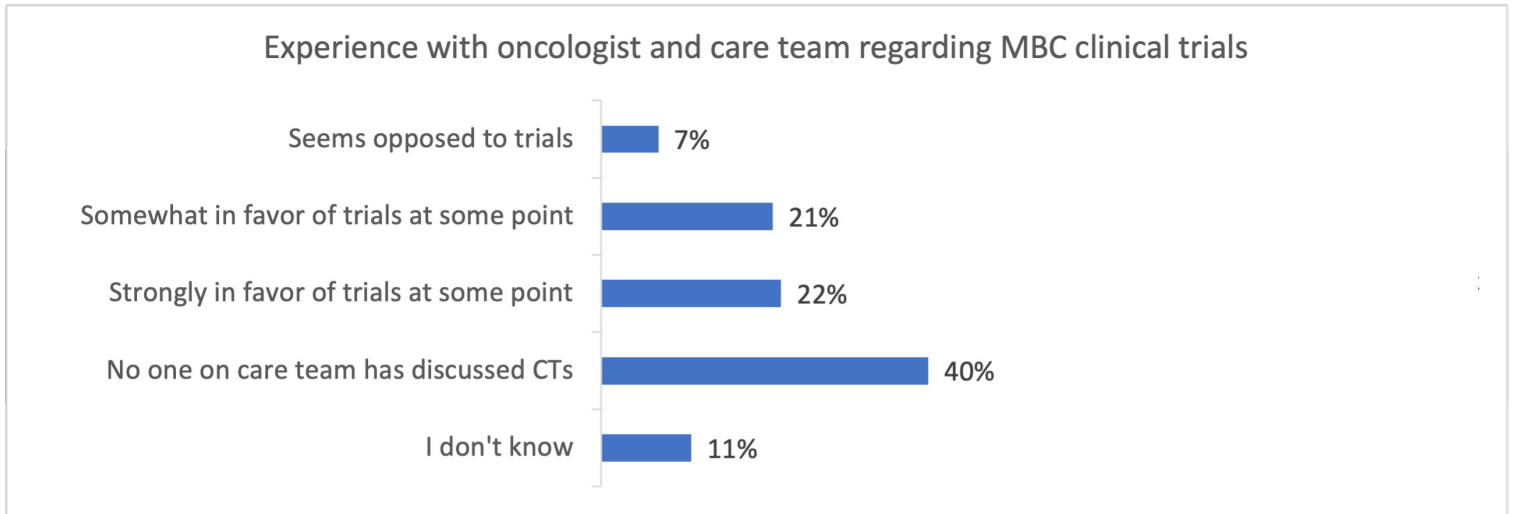
The survey responses showed that Black patients want to know about and would consider participating in clinical trials, but they lack information.

More than 90% indicated they would be interested in learning about clinical trials, and 83% said they were somewhat or very likely to consider participating. However, only 54% were aware of clinical trials happening, and only 36% said they receive as much information as desired from their oncologist and care team.

Trust and awareness of MBC clinical trials



In addition, 40% of Black respondents reported that no one on their care team had discussed clinical trials for MBC.



“I feel trials are offered more to white people, making me feel as if I don’t matter to others. I’ve never even been given ANY info about [trials] and didn’t really know they were even an option.”

-Black respondent living with MBC



#2. Inspire Trust

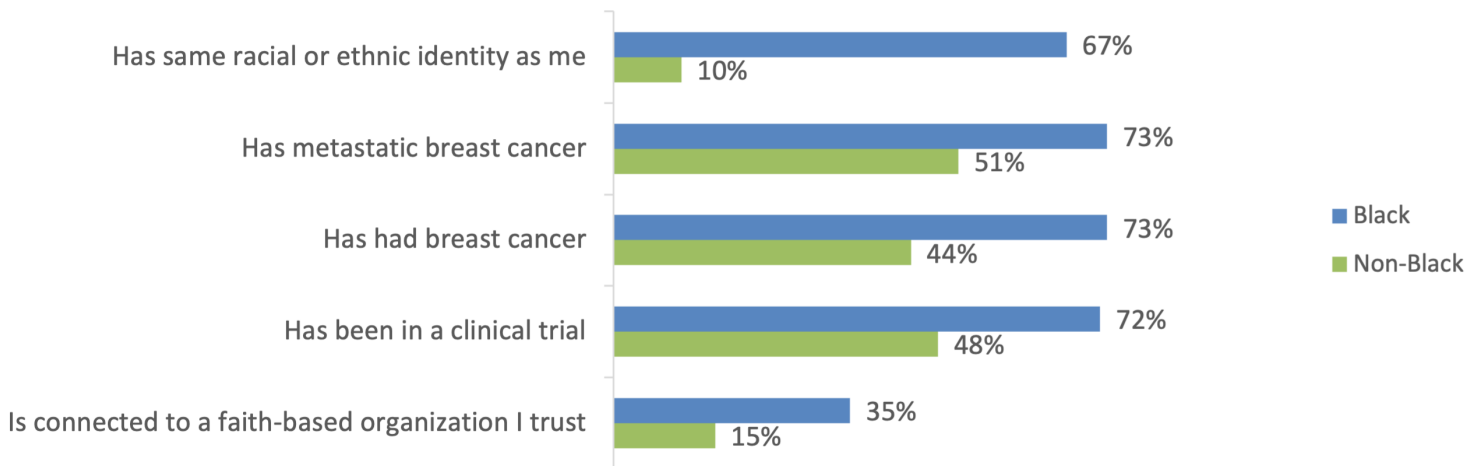
A wide variety of sources provide information about clinical trials. Some people learn about them from their doctors, while others hear from patient advocates (also known as peer support), patient or nurse navigators who work in the hospital system, an oncology nurse, or a community health worker.

Whatever the source, Black patients were more likely than non-Black patients to want to learn about clinical trials from someone with the same racial or ethnic identity and shared health experience.

Importance ratings regarding sources of information



Meaningful comparisons: Sources of information



“To increase diversity more outreach and information is needed. Go where they are. Present information by someone who looks like and understands your targeted group.”

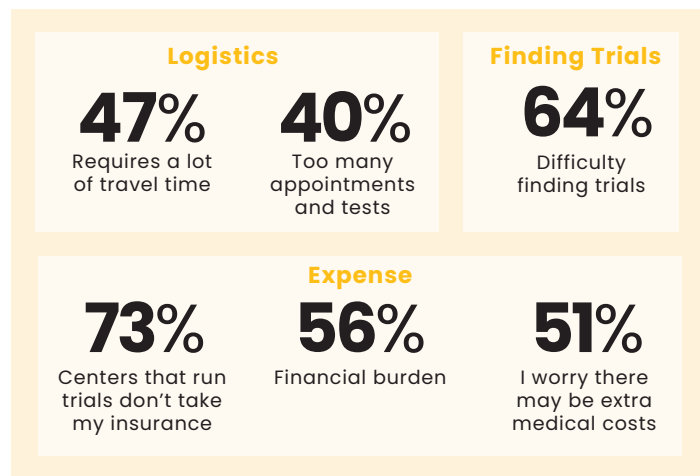
-Black respondent living with MBC



#3. Ensure Access

Gaining a deeper understanding of the barriers to Black patient participation in clinical trials was one of the key goals of the BECOME project. It is notable these barriers persist even in this group of respondents with a high level of resources, access (i.e., care at academic medical institutions), education, and insurance.

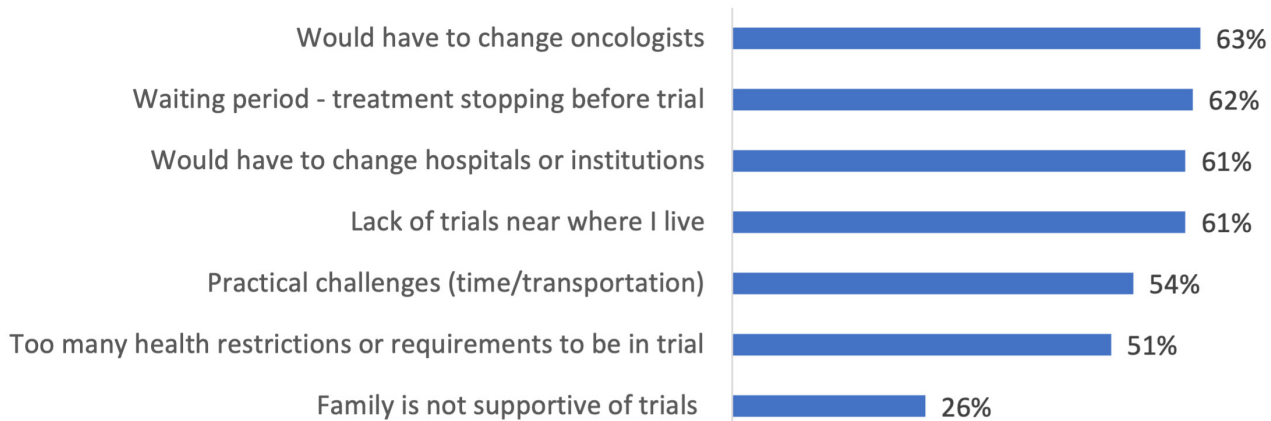
The survey found that Black respondents considered the following to be important barriers to clinical trial participation:



"I do feel like the African American community are the last ones to know about these trials or may never know due to the color of our skin. I only found about clinical trials through a nonprofit organization. Even though I found out through them I didn't understand how to go about getting one and proceed forward."

-Black respondent living with MBC

Factors that prevent people from participating in MBC clinical trials



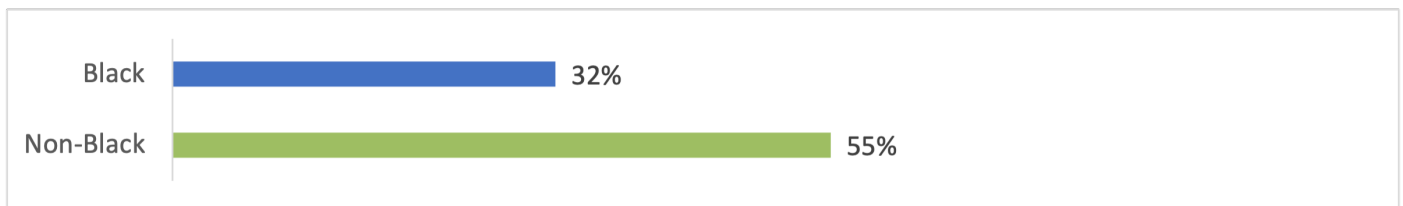


#4. Address Concerns and Reinforce Motivations

The survey identified numerous concerns about participation in clinical trials. Common worries, which were shared by Black and non-Black respondents, included side effects (73% Black, 66% non-Black) and effectiveness of trial drugs (63% Black, 62% non-Black).

However, some concerns were much more significant to Black patients:

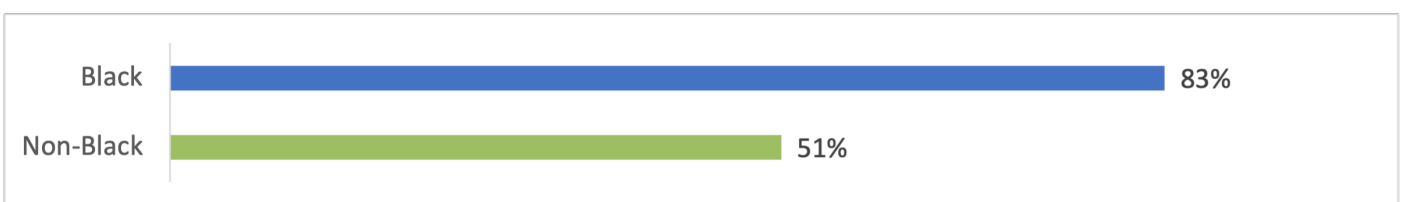
- Black patients were *less likely* than non-Black patients to trust that people of all races and ethnicities get fair and equal treatment in trials.



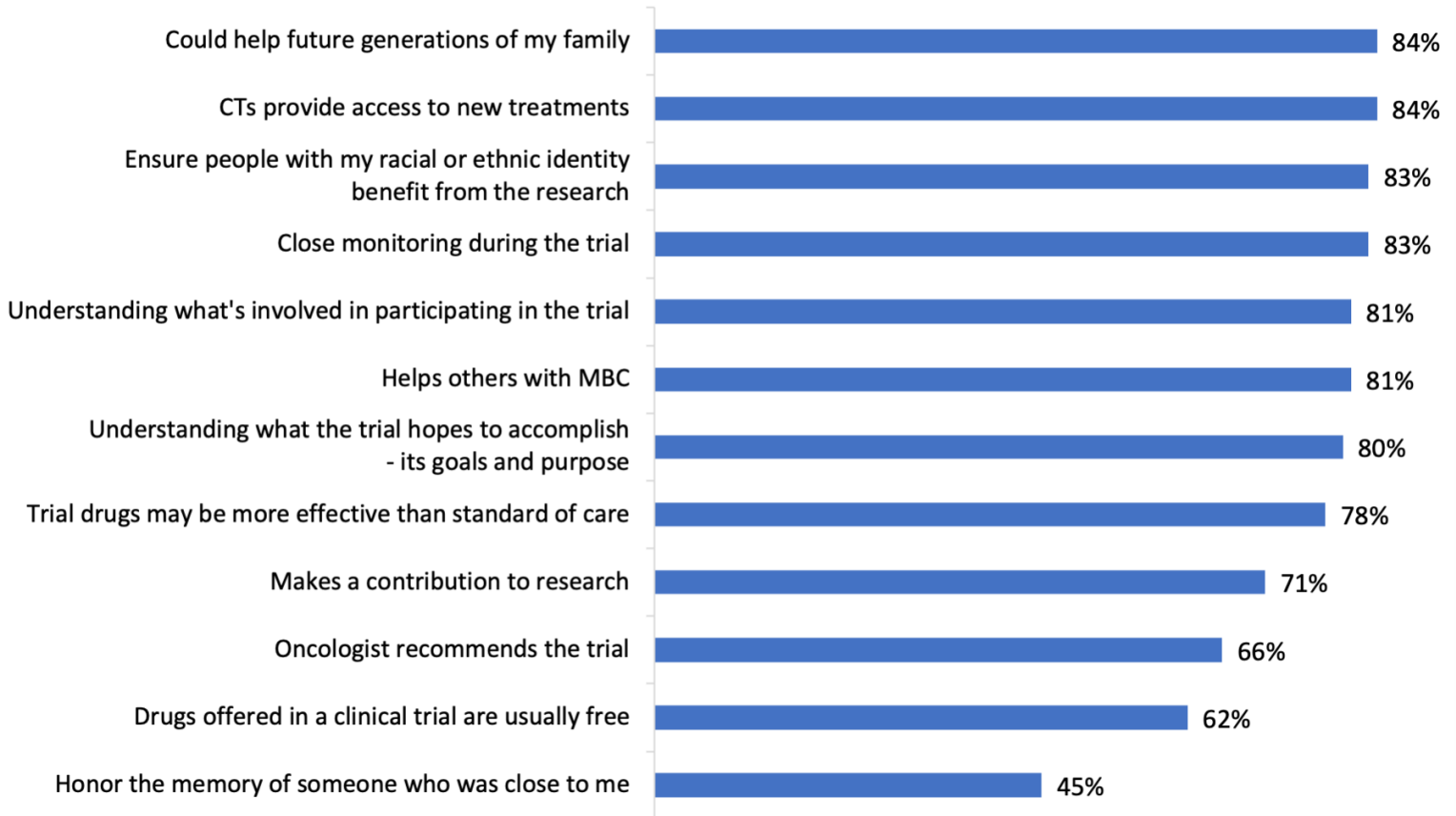
- Black patients were *more likely* than non-Black patients to believe unstudied treatments may be harmful.



The survey also identified reasons Black patients would be willing to participate in a clinical trial, many of which are shared by non-Black patients. A motivation that stood out in terms of being compelling to Black respondents was to “ensure people with my racial or ethnic identity will benefit.”



Reasons to participate in an MBC clinical trial



“The distrust from incidents like the Tuskegee Experiment is still an issue that resonates within our community. Trust has to be rebuilt. Seeing people of color participating in clinical trials will help bridge this gap to get much needed data.”

-Black respondent living with MBC

These findings reinforce the need to understand and acknowledge the issues that worry Black patients as well as the reasons that drive their desire to participate in clinical trials. They also underscore the critical importance of communicating clearly, concisely, and truthfully so that Black patients understand the why, what, and how of clinical trial participation.

What are the next steps?

All stakeholders – including oncology care teams, insurers, hospital systems, researchers and contract research organizations, pharmaceutical and biotech companies, government agencies, cancer and community organizations, and patients/advocates – have a responsibility and a role to play in increasing Black participation in MBC clinical trials.

Next steps include:

- **Expand survey respondent base.** In future studies of clinical trial participation, investigators hope to reach a broader group to more fully represent the Black patient experience.
- **Share results and develop strategies.** Members of the BECOME initiative will meet with other groups who have recently performed surveys focused on Black women and men with breast cancer to share results and identify strategies to improve care.
- **Increase Black patient enrollment in clinical trials.** Activities could include training healthcare providers to deliver patient-friendly information in an unbiased manner, improved patient education, and helping patients find and access clinical trials.

Acknowledgments

The Metastatic Breast Cancer Alliance (MBCA) is grateful to the many MBCA member organizations and individuals who participated in the BECOME project and to the people who participated in the interviews and survey.

The project would not have happened without Stephanie Walker, who brought the issue to MBCA and led the subcommittee with passion and dedication. She was joined on the BECOME subcommittee by Thelma Brown, Beth Burnett, Martha Carlson, Sheila Fuhs, Carla Harvey, Janine Guglielmino (LBBC), Reginald Hogans, Caroline Johnson (Twisted Pink), Felicia Johnson, Katrina Johnson (Pfizer), Jeannette Meibach (Gilead), Joanna Morales (Triage Cancer),

Sheila Pettiford, Claire Saxton (CSC), and MBCA staff members Laurie Campbell and Dana Mooney. Our committee would also like to acknowledge MBCA committee member Nunny Reece (2/10/78 – 2/1/21), who died of MBC during our work together. Her memory and the memory of all those we have lost to MBC motivate our continued advocacy.

The consulting firm of CBWhite assembled a team of qualitative and quantitative researchers who worked with the subcommittee throughout the process, conducted the interviews, wrote the survey, analyzed and synthesized data (creating much of the material included in this report), facilitated the formation of recommendations, and delivered a webinar for MBCA members.

Tisha Felder, PhD, MSW, served as Principal Investigator and provided insights and guidance throughout the effort. Monique Gary, DO, FACS, FSSO, served as a Sponsor for the ASCO submission and provided thoughtful input.

Kristine De La Torre, PhD, conducted the literature review and prepared the comprehensive report.

Deborah Render provided copy editing.

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Learn more about the BECOME Project results and recommended actions here:

Comprehensive report (to come)

[ASCO poster](#)

<https://www.mbcalliance.org/projects/become/>