



SYMPOSIUM  
**BLACK  
WO(MEN)  
SPEAK**

**Research Presentations**



S P E A K E R

# Stephanie Walker

---

The BECOME Project

[black-women-speak.org](https://black-women-speak.org)

---

BLACK  
WO(MEN)  
SPEAK



# BECOME

Black Experience of Clinical Trials  
& Opportunities for Meaningful  
Engagement

**Hear our voice: Patient driven solutions to improve clinical trials**  
 Marina Kaplan  
 Living Beyond Breast Cancer

**BACKGROUND**

- The rate of participation in clinical trials is dismally low, slowing the process of drug development and increasing cost.
- A critical gap exists in identifying actionable system level barriers.
- Patient-driven solutions ensure that our clinical trials become more equitable, attractive and accessible to a diverse pool of potential participants.

**MEASUREMENT**

- A mixed-methods sequential explanatory design was used to explore patient and caregiver experiences with clinical trials.
- Interviews:** Purposeful stratified sampling was used to recruit administrators and payers.
  - 52 interviews conducted (28 MBC social media groups, 6 researchers/research administrators, 6 researchers/research administrators)
  - Data informed survey development
- Surveys:** Online survey (based on Key Informant Interviews) reaching approximately 496 survey respondents.
  - Demographics (race, gender, age, education, income)
  - Trial participation (past, current, future)
  - Relative importance of barriers
  - System level barriers
  - Solutions
  - 496 survey respondents
  - Mean age: 52
  - Mean years since diagnosis: 4.5

**SURVEY RESULTS**

**Reasons for and against trial participation**

**Reasons for participating**

- Innovative treatments
- Close monitoring
- May be more effective
- Helps others with MBC
- Contribution to research
- Trial drugs usually free

**Reasons for not participating**

- Data may be misused
- May be harmful
- A lot of travel
- A lot of paperwork
- Medical expenses
- Too many tests
- Side effects
- Financial burden
- May not be effective
- Guinea pig label

**System level barriers**

Percentage of respondents

Difficulty finding trials, Lack of trials near me, Washout period too long, Eligibility of too few people

Minor barrier, Moderate barrier, Significant barrier

**become**  
 Black Experience of Clinical Trials and Opportunities for Meaningful Engagement

**take the survey**

**become** Black Experience of Clinical Trials and Opportunities for Meaningful Engagement

Metastatic Breast Cancer  
**MBCalliance**



**Thelma Brown**  
Patient Advocate &  
Early-stage Survivor



**Beth Burnett**  
Patient Advocate



**Martha Carlson**  
Patient Advocate  
Living with MBC



**Sheila Fuhs**  
Patient Advocate  
Living with MBC



**Lesley Kailani Glenn**  
Patient Advocate  
Living with MBC



**Carla Harvey**  
Patient Advocate  
Living with MBC



**Janine Guglielmino**  
Nonprofit Representative  
LBBC



**Reginald Hogans**  
Patient Advocate &  
Early-stage Survivor

**become**  
Black Experience of Clinical Trials &  
Opportunities for Meaningful Engagement



**Subcommittee**

**Stephanie Walker**, Project Lead  
Patient Advocate Living with MBC



**Felicia Johnson**  
Patient Advocate  
Living with MBC



**Katrina Johnson**  
Industry Representative  
Pfizer



**Caroline Johnson**  
Nonprofit Representative  
Twisted Pink



**Jeanette Meibach**  
Industry Representative  
Immunomedics



**Joanna Morales**  
Nonprofit Representative  
Triage Cancer



**Sheila Pettiford**  
Patient Advocate  
Living with MBC



**Nunny Reece**  
2/10/78 – 2/1/2021



**Claire Saxton**  
Nonprofit Representative  
CSC

# Primary purpose

Quantify views of people living with MBC to inform decisions, priorities, and actions

# Key inputs

- Literature review
- Key informant interviews
- Extensive involvement of BECOME leadership team and subcommittee
- Expertise of consulting team

# Topics

- Demographics and descriptors
- Experience with oncology care team
- Perceptions of clinical trials
- Motivations
- Barriers
- Support needs
- Information needs

**Methodology:**  
Research Phases  
/Development/  
Participant Recruitment

# Key Informant Interviews

- In-depth qualitative interviews with a range of vantage points
- 13 Black people living with MBC

## Participants

- 8 clinicians
- 4 hospital/academic research administrators
- 4 breast cancer researchers
- 2 payers (insurance)

## Topics

- Considerations and Barriers
- Support and Information
- Recruitment



# Survey Development

- Drafted by CBWhite using inputs – lit review, 2019 survey, key informant interviews, and BECOME and MBCA experiences and objectives
- Reviewed by six beta testers and principal investigator identified by MBCA
- Revised based on feedback and input

# Next Steps

- MBCA submitted to North Star Review Board
- Programmed for online administration
- Paper version created by MBCA for those requesting it



*"By faith I have lived with Metastatic Breast Cancer, terminal stage 4, for almost 7 years. I support clinical trials. I support the **BECOME** project. We need your support too."*

Sheila Pettiford  
**MBC Patient and Advocate**





# Final Report

Patient-led research found **8 out of 10 Black women and men living with metastatic breast cancer would consider participating in clinical trials.**



## Better Inform >

**ONLY 36%** of Black women and men living with MBC receive as much information as desired about clinical trials



## Inspire Trust >

**67%** of Black women and men living with MBC want information about clinical trials from a person with same racial or ethnic identity



## Ensure Access >

**64%** of Black women and men living with MBC have difficulty finding clinical trials



## Address Concerns >

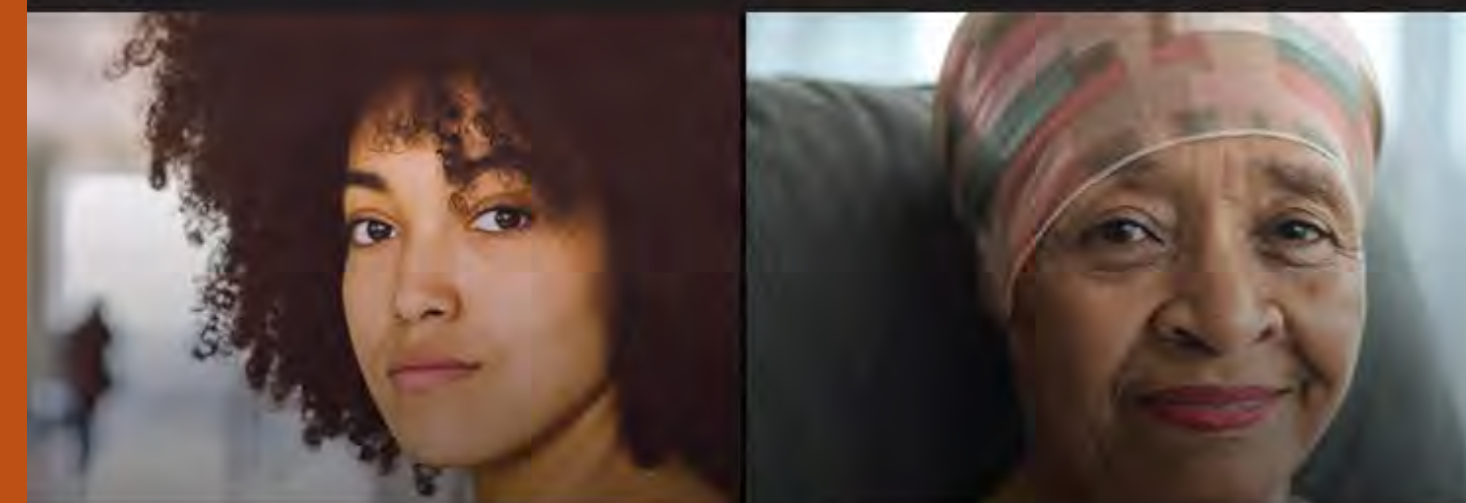
**ONLY 32%** of Black women and men living with MBC believe treatment during clinical trials will be fair and equal



# BECOME

(Black Experience of Clinical Trials and Opportunities for Meaningful Engagement)

# RESEARCH REPORT



AUGUST 2022

Metastatic Breast Cancer  
**MBCalliance** >

Thank you.

