



SYMPOSIUM  
**BLACK  
WO(MEN)  
SPEAK**

**Research Presentations**



SPEAKER

# Dr. Tisha Felder

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Putting it All Together

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

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BLACK  
WOMEN  
SPEAK



## Putting it all together

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# four key initiatives with similar goals

1

## Black Data Matters

(Touch, The Black Breast Cancer Alliance)

“...determine strategies to increase the participation of Black women diagnosed with breast cancer in clinical trial research.”



2

## BECOME (MBC Alliance)

“...drive change by better understanding barriers to clinical trial participation for Black patients with metastatic breast cancer (MBC) and identifying actions to increase participation.”



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## four key initiatives with similar goals

### 3 Increasing Representation of Women of Color in Breast Cancer Clinical Trials

(For the Breast of Us)

“... understand how key players in the clinical trial space... can ...help mobilize the breast cancer community, assist women of color in overcoming these barriers, and increase clinical trial diversity.”



### 4 Project SOAR (Carrie's TOUCH)

“... to explore in the breast cancer context the potential relevance and influence of the Strong Black Woman schema.”





## purpose of synthesis

- Identify common themes
  - Multiple studies point towards similar actions
  - Consider amplifying these themes
- Identify complementary results
  - Studies examined complementary questions
  - Consider actions based on synthesis

Share findings with symposium attendees to drive a collaborative set of actions.





## approach

- Reviewed reports on results in broad strokes
- What this is and is not
  - Thematic exploration, focused on the symposium
  - NOT: academic meta-analysis; new data analysis; statistically tested
  - NOT intended for publication
- For the Symposium, focuses on results (as available) particular to:
  - Respondents: People who are Black and are living with MBC
  - Questions: Clinical trials for MBC



# overall methods

- Studies 1, 2, and 3:
  - Qualitative work informed survey development
  - Online surveys
  - Analyzed data for subgroups of interest
- Study 4: Unique approach that may provide a model for patient empowerment





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## compare, contrast, & complement

- **Studies 1 and 2** are the most similar in terms of survey questions, approaches, and comparable data

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## compare, contrast, & complement

- **Study 3** takes a broader approach
  - Sample includes general population
  - Questions examine broad healthcare experience

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## compare, contrast, & complement

- **Study 4** brings in a different set of information and approach, serving as an important complement to the other studies
  - Collected information *and* employed a unique approach that demonstrated a method to interact with patients
  - Gatherings with African American women (AAW) who have had breast cancer to explore SBW schema in breast cancer context
  - In addition, Study 4 is expected to produce an additional set of data (not available at the time of writing this synthesis)



## themes

Looking across Studies 1, 2, and 3, the following themes are supported:

- Compared to general population, appears that all three studies tended to reach a **more connected sample (by nature of the outreach)**
- Disconnect between patient interest and HCP-initiated discussion
  - Awareness of CTs, in general, seems relatively high
  - Interest and willingness to participate appears high
  - **Discussion of CTs by HCPs is low** (Study 1's MBC respondents have higher rate of discussion but often initiated by patient)



# themes

## Important issues to address when communicating with patients about CTs

- **Barriers, concerns, and challenges**
  - Concerns and fears about side effects, harm, risks, or unintended consequences
  - Worries about effectiveness or unknown outcomes
  - Misunderstandings and myths (e.g., placebo or “sugar pill”)
- **Issues of mistrust**
  - Medical racism, unequal or unethical treatment
  - Being a guinea pig, part of an experiment
  - Privacy and confidentiality
- **Financial and logistical concerns**
  - Finding trials
  - Financial burden, many kinds of expenses, time off work
  - Insurance worries
  - Distance from trial locations



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# themes

## Motivations

- Treatment may be better; Access newest treatment
- Treatment may be free
- Close monitoring and evaluation
- Help future patients, specifically in a relatable way (own family, “others like me,” or “people with my racial or ethnic identity”)



# themes

## Communication sources and responsibilities

- **HCPs** are a key source, with people seeking clear information that is easy to understand, culturally-appropriate, and covers **WHY, WHAT, and HOW**
- Further, someone **with a shared experience** is very valuable
  - Been in a trial
  - Has a similar health condition
  - With the same racial or ethnic identity
- **Family or faith-based support** can also be important
- **Study 3:** CROs, HCPs, government, pharmaceutical companies, and nonprofit organizations are all responsible for equal representation in CTs



## themes

The road to a trial can be made easier by providing:

- **Clear communication** with patients that explains how the science works and addresses barriers, myths, mistrust, and fears
- Easy-to-use, accessible **tools** to find clinical trials
- **Financial assistance** for total cost of participation
- **Logistical help**: Transportation, household, and childcare assistance
- **Emotional support** and access to counseling



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# Complementary data

- **Study 1 addresses:**

- Emotions and experience when CTs are discussed with doctors
- Impact of race on care
- Sources of satisfaction with care team
- What equitable care means
- Message testing

- **Study 3 addresses:**

- Building trust with HCPs
- Early experiences with the health care system
- Highlighted differences in care, healthcare experience, and perceptions of clinical trials between white people and minorities



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# Complementary data




- **Study 4: Project SOAR provides a model for patient empowerment**

Gatherings were conducted with African American women (AAW) who have had breast cancer

- Culturally curated four-hour gatherings to explore the Strong Black Woman (SBW) schema in the breast cancer context
- Follow-up surveys with participants in gatherings showed benefits:
  - Self-care
  - Feeling empowered in relationship with doctor, saying “no” to things they would prefer not to do
  - Feeling empowered to have more conversations with their doctors (*Note: Initiating conversations with doctors helps in accessing CTs*)

Additional survey data not yet available



The content for this synthesis came from the generous sharing of data and wisdom of the people who led each study.

In addition to the people who shared their experiences and opinions in all survey and focus group work, MBCA and the BECOME team are grateful to the following individuals and organizations for their time and energy:

- **Touch, The Black Breast Cancer Alliance; Ricki Fairley**
- **For the Breast of Us; Marissa Thomas; Jasmine Souers; Sommer Consulting**
- **Rev. Dr. Tammie Denyse**

**Thank you.**

