

A group of four Black women are gathered around a device, possibly a smartphone or tablet. They are looking at the screen with varying degrees of focus and concern. The woman on the far left has her eyes closed and a somber expression. The woman next to her is resting her chin on her hand, looking down. The woman in the center is wearing glasses and looking intently at the device. The woman on the far right has her eyes closed and a pensive expression. The background is slightly blurred, suggesting an indoor setting.

#BLACKDATAMATTERS

**Black Breast Cancer and Barriers to
Clinical Research**



**The mission of
Black Data Matters
is to empower Black
patients to directly
change a research
and medical system
that often fails
them.**



Center for
Healthcare
Innovation



BREASTCANCER.ORG



Black Data Matters Goals:

- Increase Black women's participation in clinical trials to advance science and save lives
- Disrupt how the breast cancer ecosystem engages Black women in clinical trial research
- Strive towards health equity for Black women diagnosed with or at risk for breast cancer
- Help Black women get the best breast cancer care





Our research aims to:

- Confirm & validate tactical barriers to clinical trial participation
- Measure the impact of placebo myth
- Unpack the ramifications of medical mistrust
- Uncover & understand emotional barriers to clinical trial participation
- Understand the disconnect between current recruiting tactics/messaging and trial participation
- Prioritize barriers to participation to develop relevant and effective messaging

What was different about our qualitative approach?

Designed to explore the deeply rooted emotional barriers and cultural drivers around Black women's resistance to clinical trials

Held intimate conversations moderated by a Black breast cancer survivor who is a patient advocate and respected member of the Black breast cancer community





Qualitative Methodology

- All digital
- 6 hour-long individual interviews
- 14 two-hour focus groups
- Participants (n=48) included:
 - Black women with breast cancer who had never participated in a clinical trial, (n=29)
 - Family members of Black women with breast cancer (n=10)
 - Black women at risk for breast cancer (n=9)
- Participants ranged in age from 27-63 (mean age 42)
- Patient population was n=19 patients with Stage II or III, and n=10 with Stage IV




*"Don't do a clinical trial! You
will get the sugar pill and die."*
Metastatic Patient





“Whenever I would hear clinical trial, I would always think experiment because it was never really broken down to me, I never considered it, and I've never been approached personally to participate. But I know with my former oncologist, I wouldn't say that I trusted him too much... he didn't really answer a lot of my questions...”

-Patient Stage II/III



“I feel like a lot of the research is not with Black women. So if I had someone who went through it already, I trust their pain and their feedback.”

Patient in Stage II



But there's hope!

Culturally relevant, educational messaging stimuli delivered by a trusted member of the community is effective in driving a perception shift, with many respondents willing to reconsider their hesitation or skepticism.





Messages that changed perceptions:

A clear, simple explanation of standard of care and how cancer trials work

Even current treatments are actually a trial for their body & their cancer

Every drug they take (Advil, Benadryl) was once in a trial

Think about community & family: Do it for your daughter!

You get high quality of care & surveillance in a trial



What we hope to learn from our quantitative research:

- Validation of the qualitative insights
- Severity of the “Sugar Pill” impact on patient decision-making
- Clarity around the effectiveness of the messaging concepts
- Hierarchy and ordering of educational messaging
- Audience segmentation



Quantitative Study Design



- Questionnaire developed over 2 months of intense collaboration with partners, luminaries in the medical research field, and leading Black HCPs
- 25 minutes in length
- Participants split into Gen Pop (n=150) and those providing clinical data (n=100)
- Currently 80% recruited



**Rigorous
research**



**Changing
the game**



Surround Sound Educational Movement

Through our rigorous research, we are learning how best to develop culturally competent strategies and messaging that educates, encourages, and effectively motivates Black women to participate in clinical trials.



Campaign Evolution

A collaborative, community-based education campaign led by our Breastie Choir

The right information from the right voice delivered where our audience lives, works, prays and plays



**black
herstory**