

Research Presentations

SPEAKER

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#BlackDataMatters



Why Are We Here?

Black Breast Cancer Our Definition

Black Breast Cancer is the constellation of exposures, experiences, and lack of science for Black women diagnosed with breast cancer that causes Black women to face disproportionately worse breast cancer outcomes.





Methodology



• Qualitative focus groups (2h) and individual in-depth interviews (1h) among Black women diagnosed with, or at risk for, breast cancer, and their family members

o Women ages 25-70

- o Never participated in clinical trials
- Sample
 - n=48 Total
 - o Stage II or III breast cancer, in Remission (n=8)
 - o Stage II or III breast cancer (n=11)
 - o Stage IV breast cancer (n=10)
 - o Family members of Stages II or III breast cancer patients (n=6)
 - o Family members of Stage IV breast cancer patients (n=4)



At risk for breast cancer (n=9)



Fear of the Unknown



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

SUGAR

Lack of Awareness of Black Breast Cancer



Insufficient Information

WE DON'T Know what We don't Know.

NOT

Health Illiteracy Breeds Health Inequity



"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

Source: BlackData Matters Proprietary TOUCHBBCA Research

The Breastie Voice is the Voice of Trust







"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











5000 Black Women In Clinical Trial Portals

Challenging the Ecosystem



- Patient voices and stories RULE!
- Accept that "Your Baby Could Be Ugly"
- Cultural humility builds trust (words and visuals)
- Leverage the power of advocacy
- What you do is louder than what you say
- The answers are out of your comfort zone
- The Golden Rule will always WIN!





THANK YOU!



