Black wo(men) speak about clinical trials: are you listening?

Authors
Stephanie Walker, Metastatic Breast Cancer Alliance
Jasmine Souers, The Missing Pink Breast Cancer Alliance
Martha Carlson, Metastatic Breast Cancer Alliance
Monique Gary, DO, FACS, FSSO, Dartmouth Geisel School of Medicine
Medha Deoras-Sutliff, MS, Metastatic Breast Cancer Alliance
Tisha M. Felder, PhD, MSW, University of South Carolina

What
A symposium that convened 236 people
Patients/advocates (85), nonprofit (65), pharma (52), health care providers (13), researchers (11), other (10)

Purpose
• Create urgency to diversify participation in metastatic breast cancer (MBC) clinical trials (CTs)
• Share patient-led research related to clinical trials

Two surveys, each with over 100 Black people living with MBC
One survey with broad sample of women of color, almost 100 of whom had breast cancer

Symposium Partners
Carrie’s TOUCH
For the Breast of Us
Metastatic Breast Cancer Alliance
The Missing Pink Breast Cancer Alliance
Touch, The Black Breast Cancer Alliance

It matters who talks with me about clinical trials – and how

Research Findings
Patients value support and communication from a source who...
Shares their experience
• Has had breast cancer ~ 73% rate highly
• Has same racial/ethnic identity ~ 67% rate highly
Provides info clearly and understandably
87% rate highly
Spends ample time with them
76% rate highly

Actions
Provide access to relatable sources through intentional staffing practices
Share clinical trial information in a non-hurried, patient-friendly, culturally sensitive manner

Help me overcome my hurdles to clinical trial participation

Research Findings
Experience/Fears/Myths
Medical racism – Only 32% trust fair/equal treatment in clinical trials
Experimentation – 69% believe CTs involve experimenting on patients
Treatment – 59% believe treatment may not “be real”

Barriers
Finding trials ~ 54%
Extra expenses ~ 46%
Travel time ~ 47%
Insurance ~ 73% feel centers that run CTs don’t take their insurance

Concerns
Side effects ~ 73%
Harm ~ 57%
Lack of effectiveness ~ 63%

Actions
Build relationships and inspire trust
Directly and sensitively address concerns, misunderstandings and fears about CTs
Reduce or eliminate logistical & financial barriers
• Help find trials
• Provide personalized assistance navigating logistics and expenses

Research Findings
What
Patient interest is high...
• 8 out of 10 Black people living with MBC would consider participating in CTs
• 72% highly trust their HCP as a CT information source
...but HCP-initiated discussion is low
40% of patients were not told about CTs

Actions
Educate, empower, equip and encourage health care teams to talk with Black patients about clinical trials

Health care provider communication is key to diversifying clinical trial participation.