

Abstract Title: Black Wo(Men) Speak about clinical trials: Are you listening?

## ABSTRACT PREVIEW: BLACK WO(MEN) SPEAK ABOUT CLINICAL TRIALS: ARE YOU LISTENING?

### [Black Wo\(Men\) Speak about clinical trials: Are you listening?](#)

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## Abstract: Patient Posters

### Abstract

#### Background

Among U.S. racial/ethnic groups, Black people with breast cancer have the highest death rate and shortest survival. Although ~15% of U.S. cancer patients are Black, only 4-6% of clinical trial participants are Black. This discrepancy in clinical trial participation reflects the inequity in breast cancer outcomes and is addressable by multiple stakeholders.

#### Methods

The Metastatic Breast Cancer Alliance (MBCA) is a consortium of representatives of nonprofits, pharmaceutical/biotech companies, and patient advocates. Black Experience of Clinical Trials and Opportunities for Meaningful Engagement (BECOME), a patient-led initiative of MBCA, surveyed U.S. adults living with metastatic breast cancer (MBC) to understand barriers and solutions to trial participation. Inspired by the results of BECOME and three other partner organizations' studies, MBCA hosted the Black Wo(Men) Speak Symposium (BWSS). The goals of BWSS were to: 1) educate the community-at-large (e.g., healthcare providers, MBC patients) about the urgent need to diversify clinical trials; and 2) empower the Black patient community to speak up regarding clinical trial options.

#### Findings

BWSS created a unique environment for exchanging information and ideas across stakeholder groups. Research themes inspired conversations and connections between 236 attendees (79 Black, 157 non-Black): 85 Patient advocates, 65 nonprofit representatives, 52 pharma/biotech representatives, 13 health care providers (HCPs), 11 researchers, and 10 others. People attended in-person (116) or virtually (120).

BECOME and the additional aligned projects overlapped in seeking change related to clinical trial participation of Black people diagnosed with breast cancer. A synthesis revealed themes and recommendations.

Theme One: **Disconnect** between patient interest (high) and oncology-team-initiated discussion (low) of clinical trials. Recommendations focused on educating HCPs to talk about trials.

Theme Two: Need improvement on **what is said and provided**. Patient communication needs to address: concerns about side effects and harm; worries about effectiveness; misunderstandings about trials; medical mistrust; privacy fears; financial concerns; trial logistics; motivations to participate. Recommendations focused on building trust through clear communication; addressing concerns about side effects, effectiveness, harm, and fair treatment; tailoring messages about benefits; help finding trials; and logistical and "total cost" financial assistance.

Theme Three: **Who** communicates matters - HCPs are a key source to share clear, culturally-appropriate information, covering the trial's "why/what/how." Access to sources with shared experience (e.g., been in a trial, similar health condition, shares racial or ethnic identity) is valuable. Recommendations focused on encouraging HCPs to deliver patient-friendly information in an unbiased manner, and staffing practices to provide access to a relatable source.

After review of research, program modules focused on how HCP communication can impact trial enrollment, pharma and patient advocacy collaboration, and role of patients and caregivers in trial decisions.

### Implications

Black people living with MBC are willing to consider and independently seek out clinical trials. Studies revealed needs, desires, and opportunities. Increased stakeholder collaboration can lead to meaningful change. Allied health professionals may be uniquely positioned to communicate with patients about clinical trials, equipped with culturally-sensitive messages revealed via research and convenings.

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Stephanie Walker is an individual patient advocate for the Metastatic Breast Cancer Alliance (MBCA) and will be the Lead Author listed on the abstract and poster. Medha Deoras-Sutliff is the patient advocacy organization representative for the MBCA and will be the submitting author assisting with all administrative duties but will be listed as Co-Author on the abstract/poster.

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