

# Engaging Young African American Women Breast Cancer Survivors: A Novel Storytelling Approach to Identify Patient Centred Research Priorities

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## For which topic were research priorities identified?

breast cancer survivors

## In which location was the research priority setting conducted?

North America - USA

## Why was it conducted at all?

Young women with breast cancer may face unique challenges related to relationships, parenting, finances and employment compared to their older counterparts. Evidence suggests that young African American female breast cancer survivors (YAABCS) face even greater challenges. The breast cancer mortality rates are three times higher in young African American women than in young Caucasian women. few efforts have sought to bring YAABCS, healthcare providers and researchers together to inform research priorities that will lead to improved breast cancer outcomes and care.

## What was the objective?

to engage patients, healthcare providers and stakeholders in identifying recommendations to address research and practice gaps that impact young African American breast cancer survivors

## What was the outcome?

a ranking list of 18 research topics

## How long did the research prioritization take?

January 2018 - September 2018

## Which methods were used to identify research priorities?

group discussion; meeting; workshop

## How were the priorities for research identified exactly?

Step 1: 2 group discussions: one group discussion with patient advisory group and one group discussion with other stakeholders to generate and refine research priorities, participants were asked to discuss the question: "What are the most relevant and important questions/issues across the cancer control continuum (from prevention to survivorship) that you believe would improve breast cancer outcomes among young African American women?". Step 3: 6 workshops: to identify the top five concerns and challenges of African American breast cancer survivors and to help survivors identify, structure, practice and share their personal stories effectively, storytelling approach was used in workshop. Step 4: meeting/conference: consisting of keynote speakers and storytelling and discussion groups, participants were asked to rank by order of importance eight research areas, five areas were ranked most important, participants were then encouraged to join one of five discussion groups targeting one of the five areas and asked to develop specific research topics, participants at each table were then asked to vote on their top 3 topics they believed would have the most impact, final voting round in plenary using dot to vote

## Which stakeholders took part?

YAABC survivors, healthcare providers, academic researchers and representatives from patient advocate groups. Meeting/conference: 100 participants: 43 patients/family members, 20 providers/researchers and 37 community members.

## How were stakeholders recruited?

Three approaches were used to recruit participants and conference attendees: (a) physicians and nurses recruited patients during their clinical visits (patients only); (b) existing community-based partnerships were leveraged to recruit through breast cancer support groups, local African American beauty salons, churches, neighborhood health centres and social service agencies; and (c) advertisements and programming on V100.7, a popular radio station in the African American community.

## Were stakeholders actively involved or did they just participate?

Stakeholders were mere participants of the research prioritization process; they were not actively involved in the process.