

# How we learn from Black TNBC patients to act for equitable and unbiased care

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## Background

- ❑ Black women are at higher risk for early onset and increased breast cancer mortality, especially from the sub-type, Triple-Negative Breast Cancer (TNBC), than their white peers.
- ❑ In TNBC, there is a higher rate of recurrence and metastasis to other organs.
- ❑ Black women have the lowest survival rate at each stage of TNBC diagnosis compared to other demographic groups.
- ❑ 80% of cancer patients are treated in a community setting.
- ❑ A patient experience survey has not been implemented or published with Black women diagnosed with TNBC.
- ❑ Tigerlily Foundation (TLF), a national, trusted patient organization conducted a TNBC survey with Black women to understand the patient experience throughout the cancer continuum of care.

**The question: What is the care experience of Black women diagnosed with TNBC across the continuum of care for multi-stakeholder action?**

## Methods:

- ❑ The survey instrument received an IRB exception and included 40 questions organized by the following 8 themes: Demographics, Self-Detection/Early Assessment, Screening to Diagnosis, Diagnosis to Treatment, Post Treatment and Palliative Care/Survivorship, Emotional Trauma and Mental Health, and Trust/Bias.
- ❑ Survey launched December 2022 and successfully fielded for 5 weeks. Two approaches influenced this innovative study design: 1) a health literate and culturally sensitive approach with glossary and 2) a Trusted community outreach approach. E-Bank cards (\$100) were provided based on validated responses.
- ❑ Survey link was sent to 30+ leaders of partner patient-based organizations, HCP leaders and community-based organizations in 20+ high risk geo locations who shared the TLF survey with their constituents. This survey was not launched on social media channels.

## Conclusions:

Tigerlily successfully reached Black TNBC patients to share their authentic experiences and provided a framework for other research and patient organizations to do the same. It is critical to address the disproportionate impact of TNBC in partnership with Black women. To achieve equitable health outcomes with high impact, we advise public and private sector leaders especially in community-based settings to listen to patients and act deliberately on disparities across the TNBC continuum of care.



***Health Equity is achieved when the patients say so...***

## Selected Results:

**(N=106, Age Range, 25-71, Black women DX with TNBC)**

- ❑ **38%** did not receive “what to expect” information from providers before or after the screening process.
- ❑ **57%** were initially diagnosed with a different breast cancer subtype other than TNBC.
- ❑ **62%** DX with TNBC reported requiring a biopsy 2-6 times.
- ❑ **52%** were not offered biomarker driven care.
- ❑ **57%** reported not knowing about clinical trials as an option.
- ❑ **41%** said that they did not think their Dr. was comfortable with caring for them based on their race, age, body image or type of insurance.

## Future Directions:

- 1 Partner with Tigerlily Foundation to help to gain trusted, authentic perspectives in the community from young BIPOC women and ANGEL advocates to better understand and act on their care experience for cancer or chronic conditions.
- 2 Build capacity for prospective implementation science in the community to drive best case care interventions.
- 3 Employ coordinated community-based education and empowerment programs in TNBC that include multiple stakeholders (including PCPs) focused on standards for all care continuum domains including the gaps between domains.
- 4 Increase public awareness of health issues in Black women and address education, bias, resistance, access to biomarker testing and eligibility for participation in clinical research for access to novel targeted therapies.