

Advocacy for Community Hope and Action

TRIPLE NEGATIVE BREAST CANCER

Tigerlily Foundation completed a 2023 survey focused on the care experienced across the continuum of care with 106 Black women diagnosed with TNBC.

The median age of survey participants was 48 and most reported being diagnosed with TNBC between 1-8 years ago. The survey results revealed several actionable findings represented as factoids. This is the first survey conducted of its kind and it both confirmed and provided additional insights into the disparities and gaps in TNBC care experienced by Black women.

Tigerlily Foundation continues to actively engage, listen to and empower Black Women at risk or who have been diagnosed with TNBC to advocate for their care. We are actively engaging multiple stakeholders as part of Tigerlily's *TNBC Alliance* in two major metro areas (District of Columbia, Dallas /Fort Worth) to continue to learn and act on these findings together across Multiple health care stakeholder types at different health care settings (e.g., oncology health care specialists, primary care providers, health educators, community based organization, community navigators including Tigerlily ANGEL Advocates).



Our TNBC survey findings are accepted for presentation at the AACR Science of Cancer Care Health Disparities Meeting in Orlando, Fla, on Oct 1, 2023.



FACTOID
#1

Survey participants were all Black or African American and were diagnosed with TNBC on average in the last 7-8 years.

Tip #1: By getting involved in advocacy, participating in surveys, research, policy or clinical trials we can work to improve health outcomes and the patient experience. Tigerlily uses real- world survey results to empower women for improvement in health outcomes and to improve the patient experience. We also use patient-informed survey results to justify a research project, advocate for policy change and inform additional surveys to learn more so that we never stop listening to you so we can advocate for you on issues that matter the most. Thank you for considering participation in our patient experience surveys.

FACTOID
#2

38% of respondents that received a TNBC diagnosis reported not receiving information from their provider on screening, imaging, or testing before or after the diagnostic process.

Tip #2: Ask your doctor or radiation oncologist about the process for screening, imaging types and testing which includes mammogram, ultrasound, and MRI as well as interpretation of breast density results and decisions around potential biopsy testing. Ask how specific imaging types and testing are decided and ask to have your results explained to you. Be sure to take notes on any questions and answers you receive from your medical team.

FACTOID
#3

63% of survey participants that received a TNBC diagnosis required multiple biopsies (2- 6 times).

Tip #3: Ask your care team what kind of biopsy you will be receiving (and why that one was chosen) what to expect during the procedure, what you will receive with respect to the findings and what to expect for recovery. It is important to get the correct diagnosis and to learn as much as possible about your cancer. Biopsies are sometimes needed in different areas of your breast and can help your medical team provide conclusive and accurate diagnosis and determine treatment options based off these findings.

FACTOID #4 52% of survey participants that received a TNBC diagnosis either did not receive or did not know if they received biomarker testing.

Tip #4: Did you know you should ask your doctor for biomarker testing at the time of your diagnosis? Biomarker testing, which includes genetic testing, can help your medical team decide on the best treatment options including possible clinical trials. Biomarker testing results can take up to 4 weeks to get back; but the information may help you and your doctor to decide on the best treatment or a clinical trial that is right for you.

FACTOID #5 57% of survey participants were initially diagnosed with a cancer sub-type other than TNBC.

Tip #5: Comprehensive Biomarker testing is an important early step towards understanding mutational patterns in cancer and the specific cancer subtype which then determines the appropriate and optimal treatment course. It's important to understand that mutational patterns may change over time so repeated biomarker testing may be recommended by your doctor. It's important to ask your doctor about biomarker testing and genetic testing before your treatment is determined.

FACTOID #6 40% of survey participants diagnosed with TNBC stated they did not feel comfortable/ safe with their doctor's approach and communications.

Tip#7: Your medical team works for you, the patient! You should feel respected, a part of

the medical team and lead decision maker. It is important you feel comfortable, informed and supported by all individuals involved in your care including the office staff. You have the right to high comfort with the relationship between you, your provider and the office staff. If the relationship doesn't meet your needs, let them know and consider getting a second opinion and transferring to a new medical team.

FACTOID #7 26% of survey participants diagnosed with TNBC shared that the information they received could have been better with respect to treatment options and prognosis.

Tip# 6: Become your best advocate. Ask your doctor about all your treatment options including genetic and biomarker testing, treatment options, clinical trials, types of surgery, options for doing or not doing reconstruction surgery, questions you may have on fertility preservation, mental health support and what additional services and support such as a nurse navigator, social worker or financial assistance and patient organization peer support is available to you.

FACTOID #8 Survey participants diagnosed with TNBC reported that the most common areas where they felt bias on the part of their provider and/or staff were type and level of insurance coverage, disability, age, body type and language.

Tip 8. Disparities impact cancer care at every level, from screening and diagnosis, to access to care and treatment. Everyone deserves to have access to quality care, understand their diagnosis and treatment options and be treated

with dignity, care and respect without bias every step of the way. If you ever feel uncomfortable, even on the next visit, say something.

FACTOID #9 57% of survey participants diagnosed with TNBC reported that clinical trials were not discussed with them.

Tip #9: Every person diagnosed with cancer should have the opportunity to be offered to participate in clinical trials as an integral component of high-quality cancer care and as a human right to life. Clinical trials are often available and absolutely a good treatment option for patients diagnosed with TNBC because of the opportunity to act on results of your biomarker testing for targeted treatment. Most major treatment breakthroughs have come about through clinical trials. There is a need for BIPOC communities to participate in clinical trials so that the researchers understand what therapies are safe and effective for you. Discuss clinical trials as a treatment option with your medical team and keep asking questions as new trials, medical advancements and opportunities frequently come up. Be Un-stoppable. Discuss clinical trials as a treatment option with your medical team and keep asking questions as new trials, medical advancements and opportunities frequently come up.

FACTOID #10 More than half of survey respondents diagnosed with TNBC reported that clinical trials were not discussed with them.

TigerTip #10: Every person diagnosed with cancer should have the opportunity to be offered to participate in clinical trials as an integral component of high-quality cancer care and as a human right to life. Clinical trials are now available and are a good treatment option for patients diagnosed with TNBC because of the opportunity to act on results of your biomarker testing for targeted treatment. Novel targeted treatment is available through clinical trials. There is a need for BIPOC communities to participate in clinical trials so that the researchers understand what drug treatment therapies are safe and effective for you and your community. Discuss clinical trials as a treatment option with your medical care team and keep asking questions since new trials and medical advancements frequently come up. ●

You are your best advocate! Keep pushing for options for healthy results!

"I had to put in the work to educate myself on my illness but also be a voice for the voiceless. I did intense research on my cancer subtype, Triple Negative Breast Cancer (TNBC) and learned how it affects Women of Color more than any other ethnic group."

Michelle Anderson-Benjamin



Tigerlily ANGEL Advocate