

TIGERLILY'S TRIPLE NEGATIVE BREAST CANCER ALLIANCE

Creating Communities of Hope and Action: 10 Tiger Tips for TNBC

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

106 Survey participants were Black or African American and were diagnosed with TNBC on average within the last 7 to 8 years.

Tiger 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

Almost half of survey respondents that received a TNBC diagnosis reported not receiving information from their doctor on standard screening practices and expectations for breast cancer.

Tiger Tip #2

Ask your doctor or primary care physician to explain to you the importance of ongoing self-exams, when they would recommend a mammogram or other tests for you as well as the need for continued screening after treatment to look for recurrence. Share with your community and family.

Factoid #3

Almost half of survey respondents that received a TNBC diagnosis reported not receiving information from their provider on imaging or testing before or after the diagnostic process.

Tiger Tip #3

Ask your doctor or radiation oncologist about the process for deciding which imaging types such as a mammogram, breast ultrasound & breast MRI. Ask them to explain the level of breast density reported & the decision around potential biopsy testing. Ask for the imaging tests and results to be explained to you. Write down any questions you might have and the answers you receive from your medical team.

Factoid #4

More than half of survey respondents that received a TNBC diagnosis required multiple biopsies (2-6 times)

Tiger Tip #4

Ask your doctor to explain the reason for the type of biopsy that was ordered, what to expect during and after the procedure and to explain the findings. It is important to get the correct diagnosis and to learn about your cancer. Biopsies are sometimes needed in different areas of your breast and can help the medical team provide an accurate diagnosis that will assist in determining your specific treatment options.

Factoid #5

About half of survey respondents that received a TNBC diagnosis either did not receive or did not know if they received comprehensive biomarker testing

Tiger Tip #5

Ask your doctor for comprehensive biomarker testing at the time of your diagnosis. Comprehensive biomarker testing is an important early step towards understanding mutational patterns in cancer and the specific cancer subtype which then determines your specific and optimal treatment course. Comprehensive biomarker testing, which includes genetic testing, helps your medical team decide your best treatment options, including participating in a clinical trial.

Factoid #6

More than half of survey respondents were initially diagnosed with a breast cancer subtype other than TNBC

Tiger Tip #6

It's important that you ask your doctor about your specific breast cancer subtype and stage, and to ask them to explain to you why your cancer is determined to be a certain subtype and stage. Different breast cancer subtypes have different treatment recommendations.

Factoid #7

About a quarter of survey participants diagnosed with TNBC shared that the information they received could have been better with respect to treatment options and prognosis.

Tiger Tip #7

Become your best advocate! Ask your doctor about all your treatment options based on your biopsy results including genetic and biomarker testing. Discuss all your treatment options that may include surgery, drug therapy, radiation therapy, treatment and clinical trials.

- If you are of child-bearing years, you should discuss fertility preservation prior to drug and radiation treatment.
- If you need a mastectomy, you should have your surgeon discuss breast reconstruction pros and cons prior to surgery.
- You should ask what other services are available to you such as mental health support, financial assistance plans, a nurse navigator, and patient organization peer support.

Factoid #8

A little less than half of survey respondents diagnosed with TNBC stated that they did not feel comfortable and safe with their doctors' approach and communications.

Tiger Tip #8

Your medical care team, including their office staff, works for AND with you! You should be respected and be a lead decision maker on the medical care team. If the relationship does not meet your needs, let them know and consider getting a second opinion or transferring to a new medical care team.

Factoid #9

Survey respondents 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.

Tiger Tip #9

Disparities impact cancer care at every level, from screening and diagnosis, to access to care and treatment including an offer of a clinical trial. Everyone deserves to have access to care, to understand their diagnosis and treatment options and above all, to be treated with empathy, respect and dignity every step of the way. If you feel uncomfortable at any time, say so at the time of your visit.

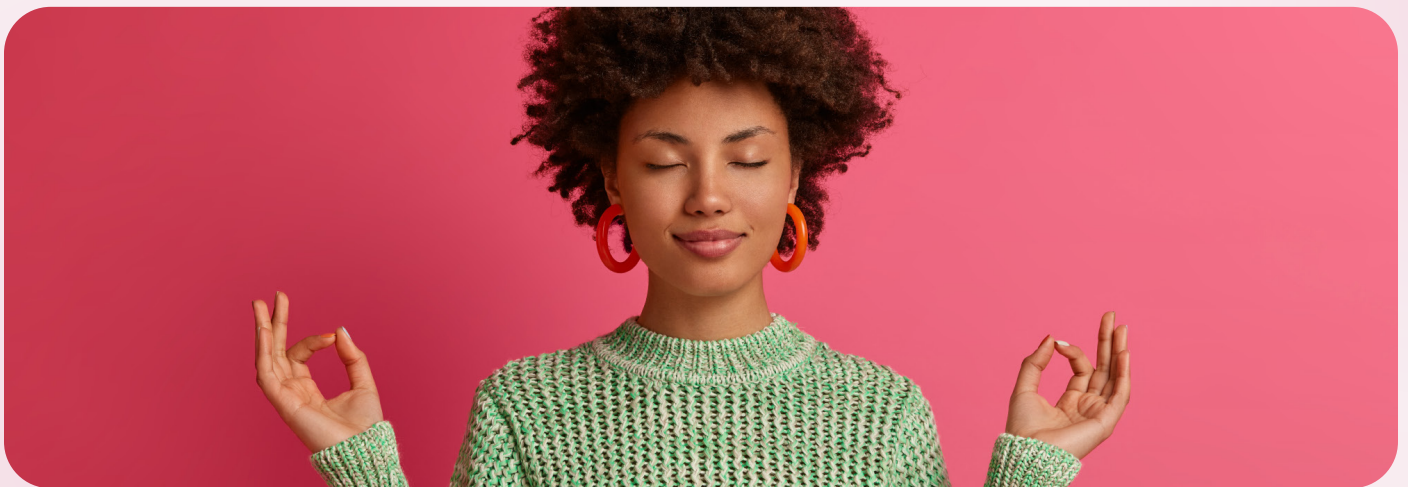
Factoid #10

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

Tiger Tip #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 often 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!



Please see our
MY LIFE TNBC issue

QR Code linked to information
provided by Tigerlily Foundation
that may matter to you

