

# I count

## Triple negative breast cancer matters



Together through the *I count* campaign, MSD and the UK Charity for TNBC are raising awareness of triple negative breast cancer (TNBC) to ensure that people living with TNBC feel like they count and are being counted.

### What is TNBC?

TNBC is a type of breast cancer where the cancer cells do not have receptors for the hormones oestrogen and progesterone, or the HER2 protein, which are often targeted by existing therapies.<sup>1</sup> This means we do not have as many treatments for TNBC as other kinds of breast cancer.<sup>1</sup>

Around **8,000** people, mainly women, are believed to be diagnosed with TNBC each year in the UK,<sup>1</sup> making up around **15%** of breast cancer cases<sup>2</sup> – but the exact number is unknown



Only **77%** of people with TNBC are alive 5 years after first being diagnosed, according to international data, compared to between **85%** and **94%** for other types of breast cancer<sup>3</sup>



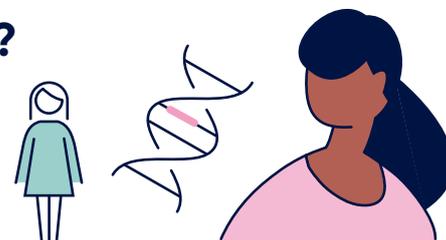
**30% to 40%** of all breast cancer deaths around the world are from TNBC<sup>3</sup>



### Who does TNBC disproportionately affect?

Global data shows that TNBC disproportionately affects:<sup>1</sup>

- Women under the age of 40
- Black women
- Women who have inherited a BRCA gene mutation



### What are the challenges in TNBC?

#### Diagnosis

A TNBC diagnosis can feel like the “*worst-case scenario*” because of its relatively poor survival rate.<sup>4</sup>

The support that people need – including for their family, finances, fertility and genetic counselling – is not always easily or equitably accessible.<sup>4</sup>

#### Treatment pathway

Treatment for TNBC can be complex<sup>1</sup> and people do not always know how to access support.<sup>4</sup>

TNBC is notable for its high rates of recurrence.<sup>5</sup> When it spreads it can be treated, but not cured, which can be very frightening.<sup>5</sup>

#### Data

There is a significant data gap around TNBC in England. TNBC-specific data is not routinely published at a national level.<sup>6</sup>

We rely on international data or incomplete national data, which cannot give us an accurate understanding of the patient population.

# Recommendations to improve the care and experiences of people living with TNBC

## Diagnosis

1. People with TNBC should be able to access the full range of information and holistic support offered by the NHS and the charity sector, as and when they need it. Healthcare professionals and patient groups should work together to signpost people in the direction of this support.
2. NHS England should ensure that every woman of reproductive age diagnosed with TNBC who wishes to access information and support around her fertility options is able to do so. Healthcare professionals should signpost women in the direction of this support.
3. NHS England should ensure that every person diagnosed with TNBC known to have the BRCA gene mutation has equitable access to information and counselling services. Healthcare professionals should signpost people in the direction of this support.

## Treatment pathway

4. People going through treatment for TNBC should have access to support tailored to their own needs. Healthcare professionals should signpost people with TNBC to information on their treatment options and potential side effects, including that offered by the UK Charity for TNBC.
5. People with TNBC should be assigned a Clinical Nurse Specialist according to their individual preferences, including in-person or virtual support, through whom they can access care that meets their needs.
6. NHS England should ensure that every person with TNBC has a designated Pathway Navigator, or equivalent role, to guide them through their treatment pathway.
7. NHS England should offer more holistic support for people living beyond TNBC to aid their physical and emotional recovery after finishing treatment.

## Data

8. NHS England should routinely collect, publish and analyse TNBC data at the national level, including but not limited to: prevalence, incidence, the existence of health inequalities, quality of care, and clinical outcomes.

## How can I support the I count campaign?

**Post your photo** on social media using the hashtag #Icount to show your support

**Raise awareness** of TNBC in Parliament by tabling a parliamentary question or a debate

**Get in touch** with Natasha Silkin at [natasha.silkin@msd.com](mailto:natasha.silkin@msd.com) to arrange a meeting to discuss the campaign and how else you can get involved



**About the I count campaign:** Together, MSD and the UK Charity for TNBC are raising awareness to ensure that people living with TNBC feel they count and are being counted. By collaborating as a community, we can bring attention to TNBC and improve people's experiences and outcomes.

**About MSD:** At MSD, we are unified around our purpose: we use the power of leading-edge science to save and improve lives around the world. For more than a century, MSD has been at the forefront of research, bringing forward medicines, vaccines, and innovative health solutions for the world's most challenging human and animal diseases.

**About UK Charity for TNBC:** The UK Charity for TNBC is dedicated to helping people with TNBC in the UK by providing them with better information and support, and by funding research into TNBC. For more information about the UK Charity for TNBC please visit <https://www.ukcharityfortnbc.org>

**REFERENCES** (All accessed November 2023 unless otherwise stated) 1 UK Charity for TNBC. What is Triple Negative Breast Cancer and What Does It Mean For Me? <https://www.ukcharityfortnbc.org/what-is-tnbc-and-what-does-it-mean-for-me> 2 Cancer Research UK. Triple negative breast cancer. <https://www.cancerresearchuk.org/about-cancer/breast-cancer/types/triple-negative-breast-cancer> 3 Manzano, A. et al. Improving the care of women with triple-negative breast cancer. The Swedish Institute for Health Economics (IHE). 2023. [https://ihe.se/wp-content/uploads/2023/03/IHE-Report-2023\\_2\\_.pdf](https://ihe.se/wp-content/uploads/2023/03/IHE-Report-2023_2_.pdf) 4 MSD. Narrative Health, commissioned on MSD behalf, conducted interviews with patients on their TNBC support needs in 2023. Data on file. 5 Stewart, Rachel L. et al. A Multigene Assay Determines Risk of Recurrence in Patients with Triple-Negative Breast Cancer. Cancer Research. Vol.79(13). pp.3466-3478. 2019. <https://doi.org/10.1158/0008-5472.CAN-18-3014> 6 DATA-CAN. UK Early Triple Negative Breast Cancer study - Collaborative working executive summary. 2020. <https://www.data-can.org.uk/wp-content/uploads/UK-Early-Triple-Negative-Breast-Cancer-study-EXECUTIVE-SUMMARY.pdf>