National Audit of Metastatic Breast Cancer

State of the Nation Patient and Public Report 2025

A summary of findings for patients and the public

An audit of care received by people diagnosed with metastatic breast cancer
in England and Wales during 2020 to 2022

NAoMe National Audit of Metastatic Breast Cancer

NATCAN National Cancer Audit Collaborating Centre

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National Cancer Audit Collaborating Centre, Royal College of Surgeons of England, 2025.

The SotN Patient and Public report was co-produced by the members of the NAoMe project team and Patient and Public Involvement (PPI) forum.

Royal College of Surgeons of England	The Royal College of Surgeons of England is an independent professional body committed to enabling surgeons to achieve and maintain the highest standards of surgical practice and patient care. As part of this it supports audit and the evaluation of clinical effectiveness for surgery. Registered Charity no: 212808.
ABS Association of Breast Surgery	The Association of Breast Surgery is a registered charity dedicated to advancing the practice of breast surgery and the management of breast conditions for the benefit of the public. It is a multi-professional membership association, which promotes training, education, clinical trials and guideline composition and adoption. For further information, please refer to the website www.associationofbreastsurgery.org.uk. Registered charity no: 1135699
UKBCG	The UK Breast Cancer Group (UKBCG) is a forum for clinical and medical oncologists. The UKBCG acts as a stakeholder to NICE, NHS England and other organisations and carries out key pieces of work (with other organisations when necessary) with the aim of improving patient care. For more information, visit https://ukbcg.org/. Registered charity number: 1177296

Patient groups represented on the NAoMe Patient and Public Involvement (PPI) forum

Breast Cancer Now The research & support charity	Breast Cancer Now is a charity that's led by world-class research which works towards providing life-changing care. They help anyone affected by breast cancer, the whole way through their care and treatment, providing support for today and hope for the future. For more information, visit https://breastcancernow.org/. Registered charity numbers: 1160558 (England and Wales), SC045584 (Scotland) and 1200 (The Isle of Man)
independent cancer patients' voice	Independent Cancer Patients' Voice (ICPV) is a patient advocate group that is not linked to established UK cancer charities. They know how valuable medical research is to both public healthcare and the national economy. For more information, visit www.independentcancerpatientsvoice.org.uk. Registered charity number: 1138456
força strength against cancer	Força is a registered charity based in Lymington. Their aim is to promote the physical and mental health of people in Hampshire,Dorset and the Isle of Wight who are living with, or affected by, cancer. They provide financial assistance, support, education and practical advice. For more information, visit https://www.forcaagainstcancer.org.uk/. Registered charity number: 1159552
METUPUK	METUPUK are a patient advocacy group They support patients with MBC to access the best medicines to prolong and improve their quality of life. They are working towards a day when MBC can be cured. For more information, visit https://metupuk.org.uk/. Registered charity number: 1196494
Make 2nds Count	We are Make 2nds Count: a UK-wide patient and family focused charity dedicated to giving hope to women and men living with secondary (metastatic) breast cancer. For more information, visit https://make2ndscount.co.uk/ Registered charity number: SC048268

Commissioner

HQIP Healthcare Quality Improvement Partnership	The National Cancer Audit Collaborating Centre (NATCAN) is commissioned by the Healthcare Quality Improvement Partnership (HQIP) and funded by NHS England and Welsh Government as part of the National Clinical Audit and Patient Outcomes Programme (NCAPOP). NATCAN delivers national audits in bowel, breast (primary and metastatic), kidney, lung, non-Hodgkin lymphoma, oesophago-gastric, ovarian, pancreatic and prostate cancers.

Acknowledgements

This report uses information which was provided by patients and collected as part of their care and support.

NDRS National Disease Registration Service	For patients diagnosed in England, information was collected, maintained and quality assured by the National Disease Registration Service (NDRS), which is part of NHS Digital.
GIG Cymru NHS Wales Rhwydwaith Canser Cymru Wales Cancer Network	For patients diagnosed in Wales, information was collected, maintained and quality assured by the Wales Cancer Network (WCN), which is part of Public Health Wales.

Contents

Acronyms

CDK 4/6 – Cyclin Dependant Kinase 4/6

CNS – Clinical Nurse Specialist

COSD – Cancer Outcomes and Services Dataset

ER – Oestrogen receptor

HER2 - Human Epidermal growth factor Receptor-2

MBC – Metastatic Breast Cancer

MDT – Multidisciplinary Team

NAoMe – National Audit of Metastatic Breast Cancer

NHS – National Health Service

NICE – National Institute of Health and Care Excellence

SACT – Systemic Anti-Cancer Therapy

SotN – State of the Nation

1. What is the NAoMe?

The National Audit of Metastatic Breast Cancer (NAoMe) is a national clinical audit. It aims to find out about the health and healthcare of people with metastatic breast cancer (MBC) in England and Wales, and to promote changes in patient care by highlighting areas where improvements could be made.

2. What is metastatic breast cancer (MBC)?

MBC is breast cancer that has spread beyond the breast and nearby lymph nodes to other parts of the body. People with MBC can be categorised into two groups:

- *De novo* – breast cancer where the spread of disease to other parts of the body can be seen at the time of the initial breast cancer diagnosis
- Recurrent – breast cancer where the spread of disease to other parts of the body is found after the initial diagnosis and treatment of a primary breast cancer

See below for how people were categorised as having either '*de novo*' or 'recurrent' MBC for this report

***De novo* MBC**

People who:

- had an initial diagnosis of MBC between 2020 and 2022 and had not previously had a primary breast cancer diagnosis; or
- had an initial diagnosis of primary breast cancer between 2020 and 2022, and whose cancer was found to have spread within 6 months of being diagnosed

Recurrent MBC

- People with an initial diagnosis of primary breast cancer between 2015 and 2022, and whose cancer was found to have spread 6 months or more after being diagnosed
- This group was then limited to those people whose metastatic cancer was first recorded between 2020 and 2022

3. What is this report about?

This is a summary of the main findings and recommendations in the second NAoMe State of the Nation report (SotN report).

You can download the full report, as well as additional information including information about individual NHS organisations, here. This also allows you to see the results for your own hospital.

The purpose of the clinical audit is to assess the patterns of care and outcomes for people with MBC in England and Wales. The audit aims to help NHS services improve the quality of their data and the care they provide to patients with MBC. The results of this audit are based on data about people in England and Wales diagnosed and treated for MBC between January 2020 and December 2022. The breast cancer care described for this period includes changes introduced in the NHS during the COVID-19 pandemic. As a result, findings in 2020 to 2021 may be different to 2022.

You can find an explanation of key terms used in the full report in the glossary on page 2.

We produced this report with the NAoMe Patient and Public Involvement forum, who represent and support the rights and interests of patients.

SotN report page

In this summary, speech bubbles (like this one) tell you which pages in the annual report give further information.

4. What data does the NAoMe use?

SotN report page 2

The NAoMe uses information from electronic medical records that is routinely recorded as part of patient care in English and Welsh hospitals.

5. Where can I find more information about the NAoMe?

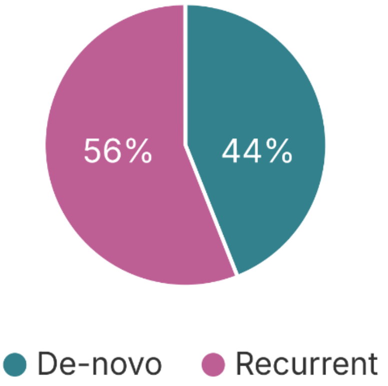
- Find full details on the NAoMe improvement goals and performance indicators here
- Follow us on X @NAoMe_News, Bluesky @NAoMe-news and LinkedIn
- Read our newsletters on the National Cancer Audit Collaborating Centre (NATCAN) website here.
- Email us at breastcanceraudits@rcseng.ac.uk

6. Who is the SotN report about?

The audit had information on 22,762 people who were diagnosed with MBC between 2020 and 2022 in England and Wales, of which 99% were women. There were 10,012 people with a *de novo* MBC diagnosis and 12,750 people with a recurrent MBC diagnosis.

SotN report page 7

Pie chart to show the proportion of patients with MBC with *de novo* and recurrent disease in this report

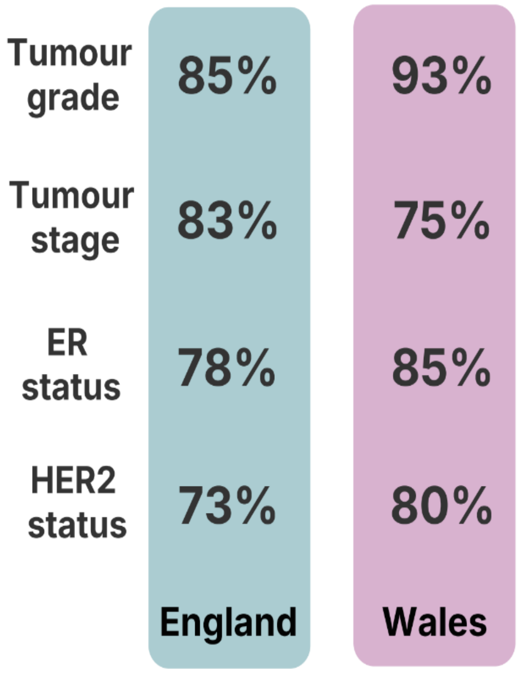


7. How complete is data on people with metastatic breast cancer?

SotN report page 7

The chart (right) shows the percentage of people in England and Wales with *de novo* MBC who had complete data for each tumour characteristic. Complete data means the information required by the audit about the person's cancer was recorded in their electronic medical records.

Data completeness for England and Wales for important data items among patients with *de novo* MBC



	England	Wales
Tumour grade	85%	93%
Tumour stage	83%	75%
ER status	78%	85%
HER2 status	73%	80%

Recurrence data

The number of people with MBC whose data we have was lower than expected. This is due to information on metastatic recurrence not being submitted from a patient's electronic medical records to the national cancer information systems in England and Wales.

Working with the National Disease Registration Service, we have produced a guide to collecting data for breast cancer recurrence in the Cancer Outcomes and Services Dataset (COSD) for English NHS hospitals.

You can read this guide at: https://www.natcan.org.uk/library/guide-to-collecting-cosd-data-for-breast-cancer-recurrence/.

Why does this matter?

Treatment options depend on the specific type of breast cancer a person has and their fitness for treatment. It is important that this information is recorded accurately in national cancer databases to allow the NAoMe to better understand patterns of breast cancer care within the NHS.

The NAoMe recurrent metastatic breast cancer (MBC) cohort is smaller than expected due to the incomplete collection of key data items in the national cancer databases used in England and Wales.

Key findings from NAoMe 2025

Breast care teams should make sure the date and type of breast cancer recurrence are recorded accurately by:
(a) Using the NAoMe guide on how to record this information in England

(b) Reviewing and improving how this information is collected and uploaded to national cancer data systems in England and Wales.

NAoMe 2025 SotN Recommendation

Breast care teams should nominate someone responsible for checking the quality of the data entered in a patient's electronic medical records. This should include checking that important details—like the date when metastatic recurrence was diagnosed, the cancer type, hormone receptor status, fitness (especially for people aged 70 and over), and whether a clinical nurse specialist (CNS) was involved—are fully recorded.

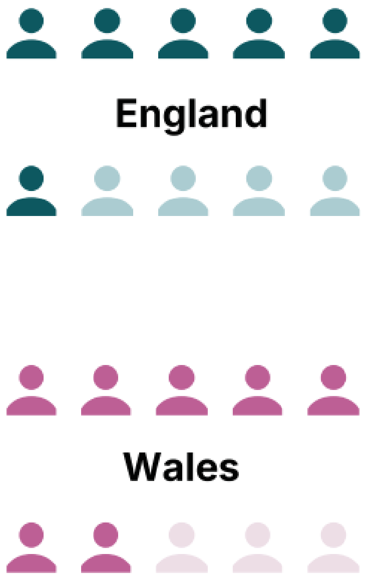
NAoMe 2025 SotN Recommendation

8. Who is involved in patient care?

Multidisciplinary team discussion

SotN report page 10

Overall, 6 in 10 people in England and 7 in 10 people in Wales with *de novo* MBC had their care discussed by a multidisciplinary team (MDT). We cannot report this statistic for people with recurrent MBC because, for most of these people, the information isn't recorded in a way that shows whether they were discussed in an MDT meeting. There were differences between NHS Breast Units in how many patients were discussed at an MDT meeting. About 1 in 4 units discussed most of their patients (80% or more), while about 1 in 8 discussed fewer than 30% of patients.



Proportion of patients in England and Wales discussed at a breast cancer MDT

Why does this matter?

The National Institute of Health and Care Excellence (NICE) include MDT discussion in their quality standards of breast cancer care. An MDT will assess each person and discuss the possible treatments for a person's cancer and symptom relief. When an MDT manages the treatment and care of people with advanced breast cancer who develop metastatic disease, health outcomes are improved.

In England, 6 in 10 people with newly diagnosed *de novo* MBC were recorded as having their care discussed at a multidisciplinary team (MDT) meeting. In Wales, 7 in 10 people with newly diagnosed *de novo* MBC were recorded as having been discussed at an MDT.

Key findings from NAoMe 2025

Breast care teams should make sure that everyone who is newly diagnosed with MBC (either *de novo* or recurrent) is discussed within a breast multidisciplinary team (MDT) meeting.

NAoMe 2025 SotN Recommendation

Clinical Nurse Specialist

SotN report page 8

Among people with Clinical Nurse Specialist (CNS) data recorded, 9 in 10 people in England and 8 in 10 people in Wales had recorded contact with a CNS.

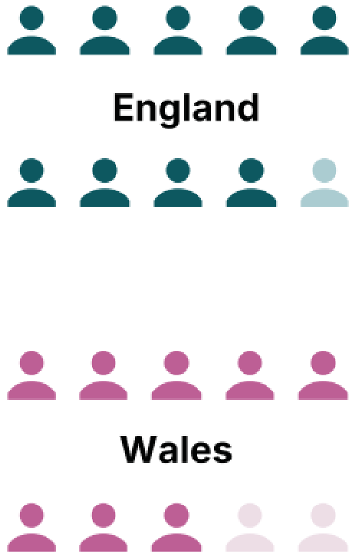
Information about CNS contact was available for 6 in 10 people in England and 9 in 10 people in Wales. This means that true levels of performance are uncertain, particularly in England, and data completeness needs to be improved.

Currently, data is not available on whether the contact was with a clinical nurse specialist whose role is focused on metastatic breast cancer.

Why does this matter?

The National Institute of Health and Care Excellence (NICE) includes this in their quality standards of breast cancer care. Assigning a CNS to a person with MBC leads to better health outcomes.

A CNS promotes continuity of care as they can give information and support for the person with breast cancer throughout their treatment. They can improve the patient experience and help ensure patient views are heard.



Proportion of patients with MBC in England and Wales with recorded contact with a CNS

In England, 6 in 10 people had complete data for CNS support. Data completeness for CNS contact in England requires improvement. In Wales, 9 in 10 people had complete data for CNS support.

Key findings from NAoMe 2025

9. How is metastatic breast cancer treated?

CDK4/6 inhibitors

SotN report page 10

In England, 4 in 10 people with ER positive, HER2 negative *de novo* MBC received treatment with CDK4/6 inhibitors. This information was not available for Wales. The use of CDK4/6 inhibitors varied a lot by age. The drugs were given to 5 in 10 people aged 18–79, but less than 2 in 10 of those aged 80 and over. Even after taking differences in patients' health into account, some Breast Units gave these drugs to more than half of their patients, while others gave them to fewer than 1 in 10.

Proportion of people with ER positive HER 2 negative *de novo* MBC receiving CDK 4/6 inhibitors

Why does this matter?

If a tumour is ER positive or HER2 positive, these can be targeted by specific treatments. Endocrine therapy should be given as first-line treatment to people whose tumours are ER positive but HER2 negative. Adding CDK4/6 inhibitors to endocrine therapy has been shown to improve the results of treatment for people with MBC.

There is significant variation in the use of CDK4/6 inhibitors for people with ER positive, HER2 negative *de novo* MBC in England.

Key findings from NAoMe 2025

Breast care teams should look at how often people with ER positive, HER2 negative MBC are treated with CDK4/6 inhibitors in the first year after diagnosis. Where use is low, teams should explore why this might be and how care could be improved.

NAoMe 2025 SotN Recommendation

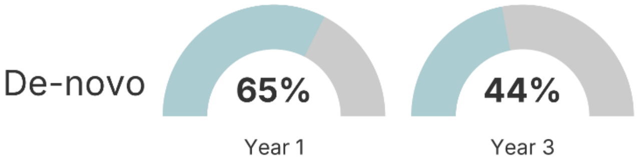
10. What are the outcomes for patients with metastatic breast cancer?

Survival

SotN report page 12

In England and Wales:

- 65% of people with *de novo* MBC survive for **one year** after diagnosis.
- 44% of people with *de novo* MBC survive for **three years** after diagnosis.



Survival among patients with recurrent metastatic breast cancer could not be reported as the audit does not have a complete cohort for this group of people. Work is underway to enable the accurate reporting of survival among these patients.

Why does this matter?

Many patients with MBC ask healthcare professionals about their chance of survival during their cancer journey. This information can help patients and healthcare professionals plan future care needs.

Early Death after Chemotherapy

SotN report page 11

Among people who had chemotherapy, their death within 30 days of receiving a dose of chemotherapy was recorded in:

- 10% of people with *de novo* MBC in England
- 19% of people with recurrent MBC in England

Note: This information was not available for people in Wales.

Among people with *de novo* and recurrent MBC, there were differences in the number of people who died within 30 days of receiving chemotherapy across regions in England. Comparatively high death rates after chemotherapy could suggest issues with treatment choice or monitoring. On the other hand, very low death rates might mean doctors were being overly cautious, which could also affect patient care. For people with newly *de novo* MBC, age made little difference to death rates within 30 days of starting chemotherapy. However, for those with recurrent MBC, younger people (under 70) had higher death rates, which may be due to more aggressive treatment (eg, being given a greater dose of chemotherapy).

Why does this matter?

Differences in the number of people who died within 30 days of receiving chemotherapy may reflect how the clinical team decide who is well enough for treatment. This could mean that some people are given treatment that may not help them, or others may miss out on treatment that could – both scenarios need to be looked at.

There is significant variation in deaths within 30-days of chemotherapy for people with *de novo* and recurrent MBC across regions in England.

Key findings from NAoMe 2025

Breast care teams should look at how many people die within 30 days of having chemotherapy. If a hospital has a much higher or lower rate than the national average, they should review the outcomes and check how chemotherapy is being prescribed, to make sure the risks and benefits are being properly considered.

NAoMe 2025 SotN Recommendation

11. What you can do

Accurate information is needed to understand the care and outcomes for all people living with metastatic breast cancer. Lots of information about patients with metastatic breast cancer is known. However, which patients have recurrent (rather than *de novo*) disease is less clear in the data. This limits our ability to report outcomes for patients with recurrent disease and work is underway to address this.

If you have recurrent MBC, you can ask your breast cancer team if the date when this was diagnosed has been recorded on national cancer databases. You can find data for the NHS organisation where you are receiving care at NAoMe. The NAoMe guide to collecting this information can be found here: https://www.natcan.org.uk/library/guide-to-collecting-cosd-data-for-breast-cancer-recurrence/.

12. Information and support about breast cancer

You can find more information about the NAoMe at

https://www.natcan.org.uk/audits/metastatic-breast/

Where to find information and support about breast cancer	
Breast Cancer Now	https://breastcancernow.org/ Helpline - 0808 800 6000
Cancer Research UK	www.cancerresearchuk.org
Macmillan Cancer Support	https://www.macmillan.org.uk/cancer-information-and-support/breast-cancer
Make 2nds Count	https://make2ndscount.co.uk/
NHS choices	www.nhs.uk/conditions/breast-cancer/
Lobular Breast Cancer UK	https://lobularbreastcancer.org.uk/
Inflammatory Breast Cancer Network UK	www.ibcnetworkuk.org
Maggie's	https://www.maggies.org/
Men's Virtual Meet-Up (VMU)	https://www.themensvmu.org/

Where to find information on how patient information is securely collected and shared, and opportunities for you to participate in research	
use MY data	www.usemydata.org
Independent Cancer Patients' Voice (ICPV)	www.independentcancerpatientsvoice.org.uk

13. Glossary

Term	Definition
Cancer Outcomes and Services Data set (COSD)	The COSD sets out the data that NHS England must record for all cancer patients. For more information, visit https://digital.nhs.uk/ndrs/data/data-sets/cosd
Chemotherapy	Treatment with drugs that kill cancer cells. This is a type of systemic anti-cancer therapy.
Clinical nurse specialist (CNS)	A highly experienced nurse who plays a crucial role in supporting patients throughout their diagnosis, treatment and follow-up care for breast cancer.
Cyclin dependant kinase 4/6 inhibitors (CDK4/6 inhibitors)	Drugs that work to prevent the growth of cancer cells. They are used in combination with endocrine therapy to treat oestrogen receptor positive MBC.
De novo metastatic breast cancer	Breast cancer where the spread of disease to other parts of the body can be seen at the time of the initial breast cancer diagnosis.
Endocrine therapy	Drug therapy used to treat oestrogen and or progesterone receptor positive breast cancer. It is a type of systemic anti-cancer therapy (SACT). Also known as 'hormone therapy'. This stops oestrogen from helping the cancer to grow.
First-line treatment	The initial treatment or set of treatments given to a person with metastatic breast cancer.
Human epidermal growth factor receptor-2 (HER2)	A protein found on the surface of some breast cancer cells which helps them to grow.
Human epidermal growth factor receptor-2 (HER2) status	A description of the level of HER2 seen in a breast cancer. A breast cancer that has a higher-than normal level of HER2 is described as HER2 positive. HER2 status helps determine whether specific systemic anti-cancer therapies known as anti-HER2 drug treatments can be used.
Metastatic Breast Cancer (MBC)	Breast cancer that has spread beyond the breast and nearby lymph nodes to other parts of the body such as the bones, lungs, liver or brain. Also called advanced breast cancer, secondary breast cancer or stage 4 breast cancer.
Metastatic breast clinical nurse specialist	A person whose main role is to provide direct support and care to patients with MBC. They work within a multiprofessional team.
Multidisciplinary team (MDT)	The team of specialists who deliver breast cancer care are known as a multidisciplinary team.
Oestrogen receptor (ER)	A protein found on the surface of cancer cells that the hormone oestrogen binds (sticks) to.
Oestrogen receptor (ER) status	A description of the level of oestrogen receptors seen in a breast cancer. Breast cancers which are ER positive are sensitive to oestrogen and can be treated with endocrine therapy.
Primary breast cancer	Breast cancer which, when diagnosed, was found only in the breast or nearby lymph nodes.
Recurrent metastatic breast cancer	Breast cancer where the spread of disease to other parts of the body is found at some point after the initial diagnosis and treatment of a primary breast cancer.
Systemic anti-cancer therapy (SACT)	These are drug treatments for cancer which aim to treat the whole body. For example, chemotherapy and endocrine therapy.