

National Audit of Metastatic Breast Cancer

State of the Nation Patient and Public Report 2024

A summary of findings for the patients and public

An audit of care received by people diagnosed with metastatic breast cancer
in England and Wales during 2019 to 2021



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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 in England and Wales. The NAOme aims 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. MBC can be split 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 2019 and 2021 and had not previously had a primary breast cancer diagnosis; or
- had an initial diagnosis of primary breast cancer between 2019 and 2021 and whose cancer spread within 12 months of being diagnosed.

Recurrent MBC

People with an initial diagnosis of primary breast cancer between 2015 and 2021 and whose cancer spread 12 months or more after being diagnosed.

This group was then limited to those people whose metastatic cancer was first recorded between 2019 and 2021.

3. What is this report about?

This is a summary of the main findings and recommendations in the first NAOme State of the Nation report (SotN report). You can download the full report from our website at <https://www.natcan.org.uk/reports/naome-state-of-the-nation-report-2024/>. You can also use this link to get more information. This includes data from individual NHS organisations, so you can see results from 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, and help NHS services to improve the quality of their data and the care they provide. The results of this audit are based on people in England and Wales diagnosed and treated for MBC between 2019 and 2021. The breast cancer care described for this period of time includes changes introduced in the NHS during the Covid-19 pandemic. As a result, data for 2020 to 2021 may be different.

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 5

The NAOme uses information from electronic medical records routinely recorded as part of patient care in English and Welsh hospitals. For more information, see page 5 of the SotN report.

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

- Follow us on X using our handle [@NAOme_News](https://twitter.com/NAOme_News)
- Read our newsletters on the National Cancer Audit Collaborating Centre (NATCAN) website at <https://www.natcan.org.uk/news/>
- Email us at breastcancer audits@rcseng.ac.uk

6. Glossary

Term	Definition
Biopsy	A procedure to remove a small portion of the cancer or tumour. It is important for making a diagnosis.
Cancer Outcomes and Services Data set (COSD)	The COSD sets out the data that the NHS in 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 treatment used to treat 'hormone positive' breast cancer. It is a form of systemic anti-cancer therapy.
First-line treatment	The initial treatment or set of treatments given to a person with breast cancer.
Human epidermal growth factor receptor-2 (HER2)	A protein found on the surface of cancer cells which helps them to grow.
Human epidermal growth factor receptor-2 (HER2) status	This helps determine whether a breast cancer has a higher-than-normal level of HER-2. If the status is HER2-positive, specific systemic anti-cancer therapies can be used.
Metastatic breast cancer	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 team made up of different professionals.
Multidisciplinary team	The team of specialists who deliver breast cancer care are known as a multidisciplinary team (MDT).

Term	Definition
Oestrogen receptor	A protein found on the surface of cancer cells that binds (sticks) to the hormone oestrogen.
Oestrogen receptor (ER) status	This helps determine whether or not there are oestrogen receptors within a breast cancer. Breast cancers which are ER-positive can be treated with endocrine therapy.
Primary breast cancer	Breast cancer which, when diagnosed, was found only in the breast or nearby lymph nodes.
Radiotherapy	High energy X-rays used to kill cancer cells.
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.
Second-line treatment	The treatments given after the initial (first-line) treatment.
Systemic anti-cancer therapy (SACT)	Drug treatment for cancer.
Systemic treatments	Cancer treatments which aim to treat the whole body (for example, chemotherapy and endocrine therapy).

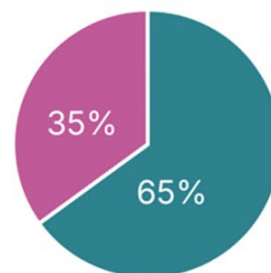
7. Who is the SotN report about?

SotN report page 10

17,055
people were diagnosed
with MBC between
2019 and 2021 in
England and Wales. Of
these, **99%** were
women.



This chart shows the split between people with de-novo MBC and recurrent MBC whose data was used in this SotN report.



● De-novo ● Recurrent

Note: People with recurrent MBC are not accurately recorded in the data that was available for the SotN report.

8. How complete is metastatic breast cancer data?

SotN report page 10

Complete data

This chart shows the percentage of people in England and Wales with de-novo MBC who had complete data for each tumour characteristic shown. Complete data means information about the person's cancer was recorded in their electronic medical records.

	England	Wales
Tumour grade	88%	94%
Tumour stage	87%	75%
ER status	59%	86%
HER2 status	73%	77%

Recurrence data

The number of people with recurrent MBC whose data we have is much lower than we expected. Experts suggested we should have more data for people with recurrent MBC than for people with de-novo MBC. A large number of people diagnosed with primary breast cancer who died from their cancer did not have a record of recurrent MBC. Working with the Cancer Outcomes and Services Data set (COSD), we have produced a guide to collecting COSD data for the recurrence of breast cancer. You can read this guide at:

<https://www.natcan.org.uk/resources/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. It is important that this information is recorded accurately on national cancer databases to allow the NAOme to better understand patterns of breast cancer care in the NHS.



Call for action

The NAOme calls for **improvements in recording complete data for important tumour characteristics and recurrence.**

9. Who is involved in patient care?

SotN report pages 12 to 13

Multidisciplinary team discussion

6 in 10 people



In England and Wales, six in 10 people with de-novo MBC had their care discussed by a multidisciplinary team.

Why does this matter?

The National Institute of Health and Care Excellence (NICE) include multidisciplinary team discussion in their quality standards of breast cancer care.

A multidisciplinary team will assess each person and discuss the possible treatments for a person's cancer and symptom relief.

When a multidisciplinary team manages the treatment and care of people with advanced breast cancer who develop metastatic disease, health outcomes are improved.



Call for action

The NAoMe calls for **all MBC patients** to have their care **discussed in an multidisciplinary team meeting** and for this to be recorded in routine data.

Clinical nurse specialist

7 in 10 people



In England and Wales, seven in 10 people with de-novo MBC were supported by a clinical nurse specialist.

Why does this matter?

The National Institute of Health and Care Excellence (NICE) include this in their quality standards of breast cancer care.

Assigning a clinical nurse specialist to a person with MBC leads to better health outcomes.

A clinical nurse specialist 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 make sure patient views are taken into account.



Call for action

The NAoMe calls for information about whether the **clinical nurse specialist assigned to a patient specialises in metastatic disease** to be recorded and accessible.

10. How is metastatic breast cancer treated?

SotN report pages 12 to 15

Biopsies

3 in 10 people



In England, three in 10 people with recurrent MBC had a biopsy to determine their care.

Why does this matter?

A biopsy is the removal of a small portion of a tumour. In cases of MBC, a biopsy can remove part of a metastasis (a tumour that has spread away from the breast). This is looked at under a microscope and tested to see tumour characteristics.

Taking a biopsy can be an important part of making a diagnosis. It can be used to check whether a tumour is ER-positive or HER2-positive.

The multidisciplinary team may suggest different treatments based on a person's biopsy results.



Call for action

The NAOme calls for **more biopsies** for people with MBC when the results may affect treatment plans.

Chemotherapy

4 in 10 people



In England and Wales, four in 10 people with MBC received treatment with chemotherapy.

Why does this matter?

Chemotherapy can be used as part of the treatment for MBC for many different reasons. How it is used depends on a person's tumour type.

Understanding patterns of how chemotherapy is used, and how this varies with age and location, helps us compare chemotherapy with other systemic treatment options.

For people with **de-novo MBC**, chemotherapy was most often used when the cancer was **HER2-positive**.

For people with **recurrent MBC**, chemotherapy was most often given to **younger women whose cancer was ER-negative and HER2-negative**.

CDK4/6 inhibitors

4 in 10 people



In England, four in 10 people with ER-positive de-novo MBC received treatment with CDK4/6 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 increase survival for people with MBC.

Anti-HER2 therapy should be offered as a first-line treatment to all patients with MBC whose tumours are HER2-positive.

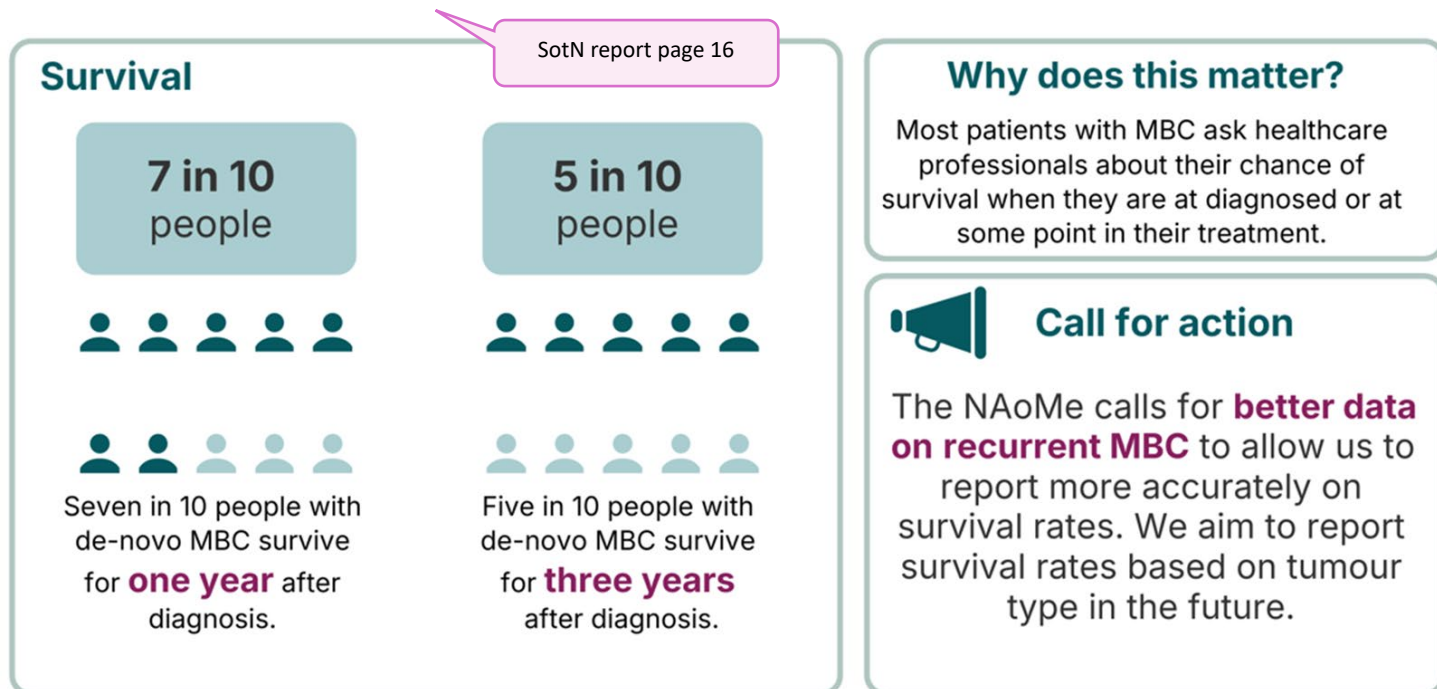
Anti-HER2 treatment

8 in 10 people



In England, eight in 10 people with HER2-positive de-novo MBC received treatment with anti-HER2 medications.

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



12. What you can do

Accurate information is important for achieving healthcare equality for all patients and across regions. If your MBC is recurrent, ask your breast cancer team if this has been recorded on national cancer databases. You can find data for the NHS organisation where you are receiving care at <https://www.natcan.org.uk/reports/naome-state-of-the-nation-report-2024/>

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
Independent Cancer Patients' Voice (ICPV)	www.independentcancerpatientsvoice.org.uk
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
Men's Virtual Meet-Up (VMU)	https://www.themensvmu.org/
Where to find information on how patient information is securely collected and shared	
use MY data	www.usemydata.org

13. Information and support about breast cancer



Find out more

You can find more information about the NAOme at

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

For general information about breast cancer, and how patient information is used to improve outcomes, you can visit the following websites.



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

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The National Cancer Audit Collaborating Centre (NATCAN) is a national centre of excellence set up to evaluate cancer care in England and Wales. It is part of the National Clinical Audit and Patient Outcomes Programme (NCAPOP) and is funded by NHS England and the Welsh Government.



The Royal College of Surgeons of England is an independent professional body committed to supporting surgeons to help them achieve and maintain the highest standards of surgical practice and patient care. As part of this, it helps with carrying out audits and evaluating clinical effectiveness for surgery. Registered charity number: 212808



The Association of Breast Surgery is a registered charity that is dedicated to improving breast surgery and how breast conditions are managed for the benefit of the public. For more information, visit www.associationofbreastsurgery.org.uk. Registered charity number: 1135699



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 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 (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 is a registered charity based in Lymington. Their aim is to promote the physical and mental health of people in Hampshire and Dorset 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 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

Commissioner



The Healthcare Quality Improvement Partnership (HQIP) is led by a group from the Academy of Medical Royal Colleges, the Royal College of Nursing and National Voices. It aims to promote quality improvement in patient outcomes and increase the effect that clinical audits, outcome review programmes and registries have on the quality of healthcare in England and Wales. For more information, visit <https://www.hqip.org.uk/national-programmes>.

Acknowledgements



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.



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.

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