NAoMe
National Audit of Metastatic Breast Cancer

NATCAN
National Cancer Audit Collaborating Centre

# National Audit of Metastatic Breast Cancer State of the Nation Report 2024

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

Version 2: October 2024

NAoMe

National Audit of Metastatic Breast Cancer

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**Version 2: October 2024**
This version of the report amends 13 numbers incorrectly reported on pages 12, 13, and 14 for key messages 5.2, 5.3, 5.4, 5.5, and 5.6.

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Royal College of Surgeons of England
ADVANCING SURGICAL CARE

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HQIP
Healthcare Quality Improvement Partnership

The National Cancer Audit Collaborating Centre (NATCAN) is commissioned by the **Healthcare Quality Improvement Partnership (HQIP)** as part of the National Clinical Audit and Patient Outcomes Programme (NCAPOP). NATCAN delivers national cancer audits in non-Hodgkin lymphoma, bowel, breast (primary and metastatic), oesophago-gastric, ovarian, kidney, lung, pancreatic and prostate cancers. HQIP is led by a consortium of the Academy of Medical Royal Colleges and the Royal College of Nursing. Its aim is to promote quality improvement in patient outcomes, and in particular, to increase the impact that clinical audit, outcome review programmes and registries have on healthcare quality in England and Wales. HQIP holds the contract to commission, manage and develop the National Clinical Audit and Patient Outcomes Programme (NCAPOP), comprising around 40 projects covering care provided to people with a wide range of medical, surgical, and mental health conditions. The programme is funded by NHS England, the Welsh Government and, with some individual projects, other devolved administrations and crown dependencies.
https://www.hqip.org.uk/national-programmes

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 undertakes key pieces of work, at times in collaboration with other bodies, with the overriding endpoint of improving patient care. The Group's objectives include advancing the education of clinical and medical oncologists in the subject of breast cancer, concerning its identification, diagnosis and treatment; promoting research for the public benefit in all aspects of breast cancer and publishing the results; and assisting in the treatment and care of persons suffering from breast cancer, or in need of rehabilitation, by the provision of education for healthcare professionals. Further information on the work of the UKBCG is communicated via this website on a regular basis https://ukbcg.org/. Registered charity no: 1177296

NDRS
NATIONAL DISEASE REGISTRATION SERVICE

This work uses data that has been provided by patients and collected by the NHS as part of their care and support. For patients diagnosed in England, the data is collated, maintained and quality assured by the National Disease Registration Service (NDRS), which is part of NHS England. Access to the data was facilitated by the NHS England Data Access Request Service.

GIG CYMRU NHS WALES
Rhwydwaith Canser Cymru
Wales Cancer Network

NHS Wales is implementing a new cancer informatics system. As a result, the quality and completeness of data from Wales is likely to have been impacted due to implementation of this new system across multiple NHS organisations (Health Boards), which has resulted in data being supplied by both old and new systems. Additionally, and reflecting the uncertainty of data quality, the data submitted to the audit may not have undergone routine clinical validation prior to submission to the Wales Cancer Network (WCN), Public Health Wales.

# Contents

# 1. Introduction

The aim of the National Audit of Metastatic Breast Cancer (NAoMe) is to evaluate the patterns of care and outcomes for people with metastatic breast cancer (MBC) in England and Wales, and to support services to improve the quality of care for these patients. This work builds on that of the National Audit of Breast Cancer in Older Patients (NABCOP[1]) but has been expanded to include younger people and men with breast cancer. This State of the Nation report publishes information on the care received by women and men diagnosed with MBC during 2019-21 in England and Wales. The care of people diagnosed with primary breast cancer (stages 0 to 3C) is reviewed in the NAoPri.

The NAoMe defines MBC as breast cancer that has spread beyond the breast and regional lymph nodes. People may be identified with metastatic disease at the time of their initial breast cancer diagnosis, referred to as a "de-novo" MBC diagnosis. Other people are diagnosed with MBC sometime after their initial diagnosis and treatment for primary breast cancer, which is called recurrent MBC. Recurrent disease may be detected not long after the initial diagnosis, or it may be decades later. See Table 1 for the NAoMe cohort definitions of de-novo and recurrent MBC used within this report.

The management of people with MBC is informed by various national and international guidelines. The NAoMe evaluates the care provided against the standards that these guidelines set for people with de-novo and recurrent metastatic disease. Clinical practice is informed by Guideline CG81[2] and Quality Standard Q12[3] from the National Institute for Health and Care Excellence (NICE), as well as guidance from the European Society of Breast Cancer Specialists (EUSOMA)[4] and the European School of Oncology (ESO) and European Society for Medical Oncology (ESMO) guidelines for advanced breast cancer (ABC 5)[5]. From these, and in consultation with its professional and patient advisory groups, the NAoMe team developed five quality improvement (QI) goals and a set of related indicators, details of which are published in the NAoMe Quality Improvement (QI) Plan. Some indicators outlined in the QI Plan remain in development and the NAoMe will report on these as the audit evolves.

The breast cancer care described for the period 2019-21 will reflect the changes introduced in the NHS during 2020 because of the COVID-19 pandemic and will be atypical to some degree. The State of the Nation Report uses National Cancer Registration Data (NDRS, "gold standard" registration data) for England, which is currently available for people diagnosed up to the end of 2021[6]. The "gold standard" data contains over 98% of all the people that will eventually be found by the registration process and has better completeness of key variables compared to more recent registration data. The gold standard data includes tumour hormone receptor status, which enables reporting of indicators for clinically distinct subgroups. "Gold standard" cancer registration data is currently available for people diagnosed up to the end of 2021, in future years we will work to provide more timely reporting. To further support QI activities, the NAoMe publishes quarterly reports of data quality metrics and patient characteristics (England only). From October 2024 these reports will include a subset of performance indicators. The quarterly reports use more timely Rapid Cancer Registration Data (time lag 4-6 months), available here: https://www.natcan.org.uk/audits/metastatic-breast/reports-2/. Whilst we have reported national figures in this report, supplementary tables provide more information about organisation and regional level variation for our key indicators. The NATCAN frequently asked questions (number 17) provides information on the NATCAN outlier policy[7] The NAoMe pages of the NATCAN website also provides access to: (1) a description of audit methods, (2) a glossary of terms, (3) resources that support local services' QI initiatives, and (4) other sources of information about breast cancer.

Healthcare professionals are encouraged to review the findings of this report, explore the results for their units, and consider whether outlying indicators require changes in practice. A patient summary will be published alongside this report to make the findings accessible to the wider public.

The NAoMe is one of ten national cancer audits commissioned within the National Clinical Audit and Patient Outcomes Programme (NCAPOP), which is funded by NHS England and the Welsh Government. These audits include the National Audit of Primary Breast Cancer (NAoPri), for which a State of the Nation report is also available. More information about the national cancer audits for England and Wales can be found at: www.natcan.org.uk.

1 https://www.nabcop.org.uk/

2 National Institute for Health and Care Excellence. Advanced breast cancer: diagnosis and treatment. Clinical Guidance [CG81]. *Available from:* Recommendations | Advanced breast cancer: diagnosis and treatment | Guidance | NICE

3 National Institute for Health and Care Excellence. Breast Cancer. Quality standard [QS12]. *Available from:* https://www.nice.org.uk/guidance/qs12.

4 Biganzoli, L., et al., Updated recommendations regarding the management of older patients with breast cancer: a joint paper from the European Society of Breast Cancer Specialists (EUSOMA) and the International Society of Geriatric Oncology (SIOG). Lancet Oncol, 2021. 22(7): p. e327-e340. *Available from:* https://pubmed.ncbi.nlm.nih.gov/34000244/

5 5th ESO-ESMO international consensus guidelines for advanced breast cancer (ABC 5). *Available from:* https://pubmed.ncbi.nlm.nih.gov/32979513/

6 https://www.natcan.org.uk/resources/timeliness-of-the-national-cancer-registration-dataset-ncrd/

7 https://www.natcan.org.uk/faqs/

Throughout this report:

- the term NHS organisations is used to refer to English trusts and Welsh Health Boards collectively

- we refer to women and men as these correspond to the "sex" categories available in the data supplied. We acknowledge that some people may not identify using these binary woman-man genders.

## 1.1 Data sources and cohort definition

The audits in NATCAN including the NAoMe do not 'collect' clinical data via bespoke audit specific data collection, thereby minimising the burden of data collection on hospitals. Instead, the NAoMe uses data extracts from various national cancer datasets, which are nationally mandated flows of data from hospitals. For people treated within English NHS hospitals, the data are routinely collated, maintained and quality-assured by the National Disease Registration Service (NDRS), which is part of NHS England. For people treated in Wales, the data were provided by the Wales Cancer Network (WCN) in Public Health Wales, from the Cancer Network Information System Cymru (CaNISC) electronic patient record system. For full details of the data and methods used within this report, please see the NAoMe Methodology document, available online at https://www.natcan.org.uk/reports/naome-state-of-the-nation-report-2024/

Within the report, we distinguish between people with de-novo MBC and recurrent MBC (see Table 1). For the de-novo cohort, the NAoMe analysed data on women and men aged ≥18 years at diagnosis with breast cancer (ICD-10 diagnosis code: C50; D05) that had metastatic spread beyond the breast and regional lymph nodes (stage 4 disease) and who were diagnosed with MBC in an NHS hospital within England and Wales between January 2019 and December 2021. The de-novo cohort includes people identified with metastatic disease at the time of their initial breast cancer diagnosis or within 12 months of this date.

For the recurrent MBC cohort, we developed an approach to identify eligible people within the routine hospital datasets for England (Hospital Episodes Statistics) and Wales (Patient Episode Dataset for Wales). This was required because information about the date and type of recurrent disease is largely missing within English and Welsh cancer datasets. As described in Table 1, the approach used the hospital datasets to identify admissions (including day cases) that contained an ICD-10 diagnosis code for MBC among a cohort of people diagnosed with primary breast cancer (stage 0 to 3 or unknown) between January 2015 and December 2021. It is recognised that this approach does not identify all people who were diagnosed with recurrent MBC between January 2019 and December 2021 and who received anti-cancer therapies from NHS breast multidisciplinary teams (MDTs). This is due to:

1. Not including people whose date of diagnosis was before 2015.

2. A requirement for people to have received day case or inpatient hospital care close to the actual date when recurrent MBC was diagnosed. Not all people will have received care that required being admitted; some therapies can be delivered within the outpatient setting or as part of "hospital at home" initiatives.

3. A requirement that the ICD-10 diagnosis code for MBC was included among the conditions listed in the discharge documentation that is uploaded to the national hospital datasets.

**Table 1:** Definition of the de-novo and recurrent cohorts of patients with MBC used within this report

| |
|---|
| ***De-novo cohort*** |
| People who had an initial diagnosis of Stage 4 breast cancer (2019-2021)<br>People with an initial diagnosis of Stage 1-3 (or unknown stage) breast cancer between January 2019 and December 2021 and who had an ICD-10 diagnosis code of MBC in HES (England) or PEDW (Wales) data within 12 months of their initial date of diagnosis. The latter group corresponds to the (relatively few) individuals who were only found to have metastatic disease after treatment commenced. |
| ***Recurrent cohort*** |
| Step 1: We identified people with an initial diagnosis of stage 0-3 (or unknown stage) breast cancer between January 2015 and December 2021 and who had an ICD-10 diagnosis code of MBC in HES (England) or PEDW (Wales) admissions data at least 12 months after their initial date of diagnosis. The 12-month threshold is used by the NaoMe because metastatic disease may be identified after treatment commenced.<br>Step 2: The cohort was limited to those people identified in step 1 whose first admission containing an MBC diagnosis was between January 2019 and December 2021. |

Breast cancer recurrence is expected to precede death attributed to breast cancer for the majority of people. We combined the derived information on MBC with information on who had died to explore how this identification process performed. In brief, the analysis used the cohort of people aged <70 years diagnosed with primary breast cancer between 2015 and 2021, and used date and cause of death information from the Office for National Statistics Death Register to identify which patients had died before June 2023. Individuals stratified into the following groups: people with and without a record of MBC among (i) those who were alive at 1 June 2023, (ii) those who died from breast cancer, and (iii) those who died from other causes. The follow-up time after the date of diagnosis was consequently shorter for people diagnosed in 2021 than 2015, leading to a smaller proportion of deaths in later years.

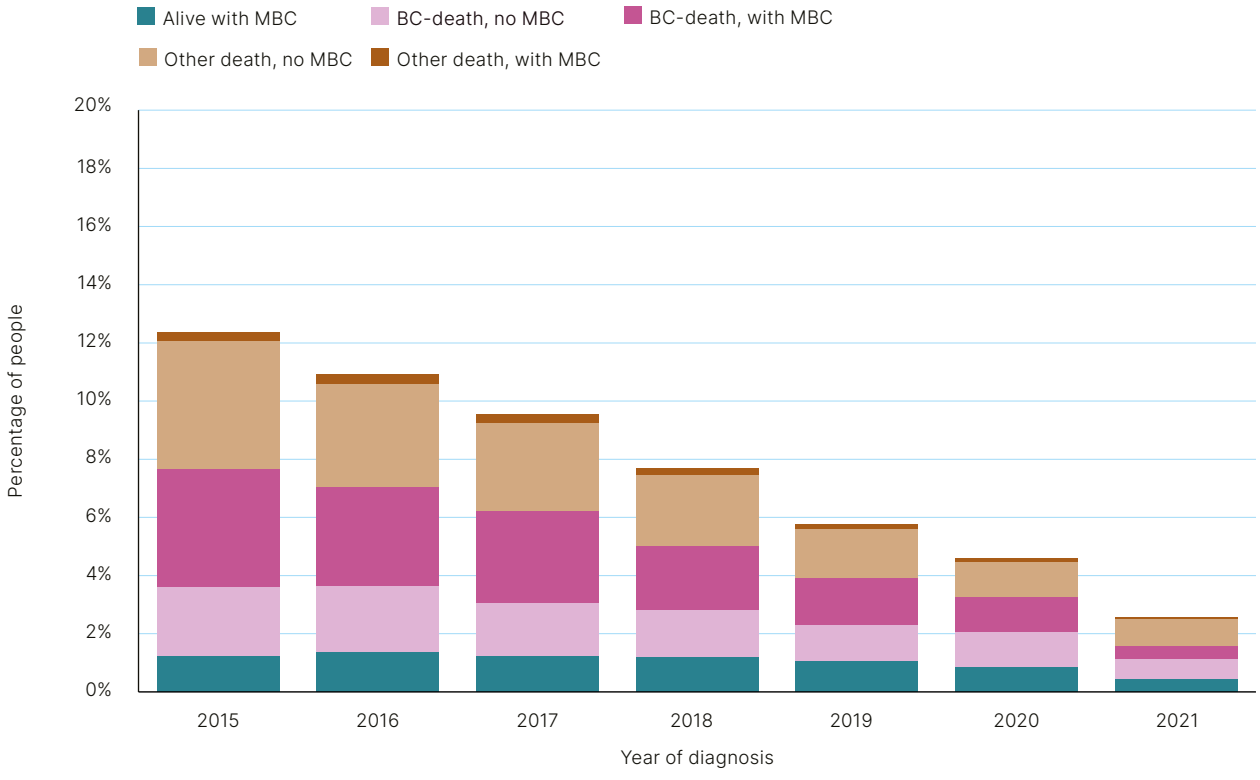
Figure 1 summarises the analysis findings, showing the pattern of recurrent MBC among people, by the year of diagnosis. In brief:

1. The proportion of people who died increased with the time from diagnosis.

2. Each year, the cause of death was recorded as from breast cancer in approximately 60% of all deaths.

3. Among individuals who died from breast cancer, 58.4% had a record of recurrent MBC in the hospital data prior to their death; the proportion was highest among the people diagnosed in 2015 (63.0%) and decreased for those diagnosed in more recent years (41.0%).

**Figure 1.** The percentage of people who had recurrent MBC recorded among those diagnosed with primary breast cancer (stage 0 to 3) in England and Wales (2015-21), stratified by the year of diagnosis, whether people had died by 1 June 2023 and by cause of death. The percentage of people who are alive without recurrent MBC are not shown.




NOTE: Data were impacted by the COVID-19 pandemic and so will be atypical to some degree during 2020-2021

The results suggest the process only identified some of the individuals eligible for inclusion in the recurrent MBC cohort. We also note that there were very few individuals who were alive and had a record of MBC, although the extent to which this represents an underestimate of the people eligible for inclusion is unclear. Individuals can live for years after diagnosis and treatment for MBC. The results confirm the approach adopted for this report is imperfect, and emphasise the need to improve the collection of data on the date and type of recurrence within the national cancer datasets.

# 2. Infographic

NAoMe
National Audit of Metastatic Breast Cancer

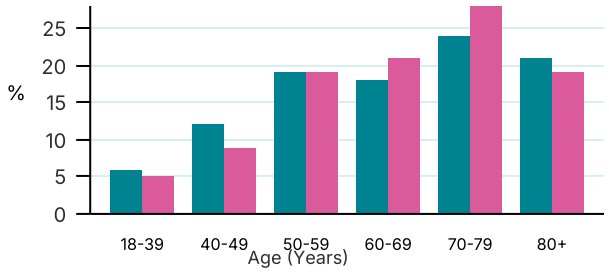
The NAoMe reports on all people (women and men) diagnosed with metastatic breast cancer (MBC) in NHS hospitals in England and Wales (also known as secondary, advanced, or stage 4 breast cancer). It includes those with MBC diagnosed at presentation (de-novo disease), as well as those with recurrent metastatic disease.

## People diagnosed 2019-2021 with metastatic breast cancer

**De-novo disease: 11,132 (11,025 women and 107 men)**

E **England: 10,661**

W **Wales: 471**




**Recurrent disease*: 5,923 (5,878 women and 45 men)**

E **England: 5,654**

W **Wales: 269**

*People with recurrent disease are not accurately recorded in the data available for this report. Information presented here uses methodology to detect people with recurrent MBC as best as we are currently able. There will be ongoing methodological work to improve and refine these methods.

## Multidisciplinary Discussion

In England 61% of women with de-novo MBC had a record of multidisciplinary team discussion of their care. In Wales this was only 6% (low data completeness).

E

W

## Biopsy

34% of people in England with recurrent MBC had a record of biopsy of a metastatic lesion. This information could not be derived for Wales.

E

## CNS Contact

Data completeness for England was low at 67% compared to 88% for Wales. Where completed, 97% of people with de-novo MBC in England and 96% in Wales had a record of Clinical Nurse Specialist (CNS) contact at diagnosis.

E

W

## Chemotherapy for recurrent disease

In England 40.4% of people with recurrent MBC received chemotherapy. Use of chemotherapy was greater among younger women with triple negative breast cancer.

E

## Systemic Therapy for de-novo disease

43% of people in England and 53% in Wales received chemotherapy for de-novo disease at some stage. Further chemotherapy details were not available for Wales.

E

W

In England, 35% of women with de-novo ER positive/HER2 negative disease received CDK 4/6 inhibitors at some stage.

In England, 75% of women with de-novo HER2 positive disease received anti-HER2 therapy at some stage.

## E Death after chemotherapy

**In England,**

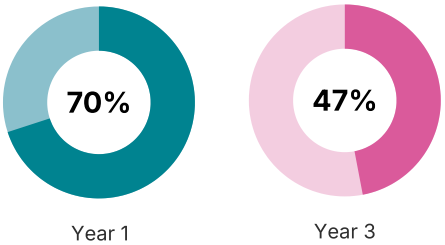
**8%** of women with de-novo MBC and

**21%** with recurrent MBC died within 30 days of chemotherapy.

This information was not available for Wales.

## Survival for de-novo disease

Percent of people who survived for 1 or 3 years after diagnosis in England and Wales (combined).




Note 1: Where we limited this information to women, this is because the number of men were too small to produce reliable statistics.

# 3. Recommendations

| Recommendation | Audience | Audit Findings | Quality Improvement Goal | National guidance / standards / resources |
|---|---|---|---|---|
| 1. Ensure the care for people newly diagnosed with MBC (either de-novo or recurrent) is discussed within a breast multidisciplinary team (MDT) meeting. | England:<br>Breast care teams and clinical management in English NHS trusts<br><br>Wales:<br>Breast care teams and clinical management in Welsh NHS Health Boards. | Widespread variation (6% for Wales and 61% for England) in the recording of MDT discussions for those with de-novo MBC. | Goal #1 – Improve the movement of patients through the care pathway. | *NICE Quality Standard 12 - Quality Statement 5.*<br><br>Breast cancer outcomes are improved when care is directed by a MDT. |
| 2. Examine biopsy rates for MBC and aim to increase this where feasible if the results may have therapeutic implications. | England:<br>Cancer Alliances working with breast care teams and clinical management (incl. oncology teams) in English NHS trusts<br><br>Wales:<br>Breast care teams and clinical management (incl. oncology teams) in Welsh NHS Health Boards. | In England 34% of people with recurrent MBC had a record of a biopsy for a metastatic lesion. This indicator could not be derived for Welsh patients from the data items available. | Goal #1 – Improve the movement of patients through the care pathway. | *NICE Quality Standard 12 - Quality Statement 4, NICE CG81 recommendation 1.1*<br><br>Confirmation of a diagnosis of MBC may be required. If feasible, it should be reassessed in recurrent MBC if receptor status has therapeutic indications. |
| 3. Confirm breast multidisciplinary teams (MDT) have a data lead responsible for ensuring the quality of national data submissions. Reviews of data completeness within breast MDTs should include full tumour characterisation, ER[8] and HER2[12] status, performance status, the NABCOP fitness assessment data items (for people aged 70+ years) and contact with clinical nurse specialists (CNS).<br><br>*(Recommendation aligned with the report for the National Audit of Primary Breast Cancer[8].)* | England:<br>Integrated Care Boards (ICB) working with breast care teams and clinical management in English NHS trusts<br><br>Wales:<br>Breast care teams and clinical management in Welsh NHS Health Boards. | Completeness for individual COSD data item "patient seen by a CNS at diagnosis" was low (67% overall) across all English NHS organisations. Completeness of data on ER, HER2 status and performance status was low (<75%) and requires improvement. Although these items were better reported in Welsh data, both nations would benefit from improved data completeness. | Applies to all QI goals as will facilitate the identification of the correct cohort for each performance indicator, as well as aiding interpretation of wider results. | The Cancer Outcome and Services Data set (COSD)[9] has been the national standard for reporting cancer in the NHS in England since January 2013. Feedback reports for the data submitted are available through the *CancerStats*[10] website. COSD is the main source for the rapid cancer registration dataset. Improved completeness of this dataset is required to ensure quarterly reporting.<br><br>The *Welsh Cancer Intelligence and Surveillance Unit*[11] collects, analyses and releases information about cancer in Wales. The Welsh Health Circular mandates high quality data submissions[12]. |

8 ER status = oestrogen receptor status, HER2 status = human epidermal growth factor receptor 2 status
9 https://digital.nhs.uk/ndrs/data/data-sets/cosd#:~:text=The%20COSD%20specifies%20the%20data,NDRS%20on%20a%20monthly%20basis.
10 https://digital.nhs.uk/ndrs/data/cancerstats2-platform-user-guide#the-cancerstats2-platform
11 https://phw.nhs.wales/services-and-teams/welsh-cancer-intelligence-and-surveillance-unit-wcisu/
12 https://www.gov.wales/nhs-wales-national-clinical-audit-and-outcome-review-plan-2024-2025-whc02524

| Recommendation | Audience | Audit Findings | Quality Improvement Goal | National guidance / standards / resources |
|---|---|---|---|---|
| 4. Ensure the recording of date and type of breast cancer recurrence in cancer datasets by:<br><br>(a) Education on the recording of recurrence, sharing the NAoMe Guide to collecting COSD data for breast cancer recurrence[13] with NHS organisation.<br><br>(b) reviewing the process of capturing these data within a breast multidisciplinary team (MDT), and ensuring these data are uploaded to cancer datasets.<br><br>*(Recommendation aligned with the report for the National Audit of Primary Breast Cancer[14].)* | England:<br>Breast care teams and clinical management in English NHS trusts<br><br>Wales:<br>Breast care teams and clinical management in Welsh NHS Health Boards. | The NAoMe recurrent Metastatic Breast Cancer (MBC) cohort is considerably smaller than expected. Expert advice suggests the recurrent MBC cohort should be significantly larger than the de-novo MBC cohort. Additionally, a high proportion of individuals diagnosed with primary breast cancer whose death certificates recorded them to have died from their cancer did not have a record of recurrent MBC. | Applies to all Quality Improvement (QI) goals as will facilitate identification of the correct cohort of patients for NAoMe. | The Cancer Outcome and Services Data set (COSD)[15] has been the national standard for reporting cancer in the NHS in England since January 2013. Feedback reports for the data submitted are available through the *CancerStats*[16] website. COSD is the main source for the rapid cancer registration dataset. Improved completeness of this dataset is required to ensure quarterly reporting.<br><br>The *Welsh Cancer Intelligence and Surveillance Unit*[17] collects, analyses and releases information about cancer in Wales. The Welsh Health Circular mandates high quality data submissions[18]. |

13 ER status = oestrogen receptor status, HER2 status = human epidermal growth factor receptor 2 status
14 https://www.natcan.org.uk/audits/primary-breast/reports-2/
15 https://digital.nhs.uk/ndrs/data/data-sets/cosd#:~:text=The%20COSD%20specifies%20the%20data,NDRS%20on%20a%20monthly%20basis.
16 https://digital.nhs.uk/ndrs/data/cancerstats2-platform-user-guide#the-cancerstats2-platform
17 https://phw.nhs.wales/services-and-teams/welsh-cancer-intelligence-and-surveillance-unit-wcisu/
18 https://www.gov.wales/nhs-wales-national-clinical-audit-and-outcome-review-plan-2024-2025-whc02524

# 4. Description of people with metastatic breast cancer (MBC)

## 4.1 Data completeness

**Key Messages:** NHS organisations should prioritise improving the recording of data on recurrent MBC and ensure information on key aspects of an individual's breast cancer is complete when data are submitted to NDRS and CaNISC. Particular attention should be given to data on the date and type of cancer recurrence. Improvements are required in the completeness of hormone receptor and human epidermal growth factor receptor 2 (HER2) status, and performance status at the time of diagnosis. The reasons for poor data completeness are likely to vary across organisations and data items – recording of information at MDT, data entry/audit resource.

Various clinical factors will inform treatment options for people with MBC alongside patient preferences. These factors include tumour biology, disease distribution and burden, organ function, physical fitness, menopausal status, and previous treatments. The recording of this clinical information in national cancer datasets is vital to understand patterns of care within the NHS.

As noted in section 1.1, complete information about the date and type of recurrent disease is fundamental for the effective running of the NAoMe. These data have often been missing within English and Welsh cancer registration datasets. Efforts are underway to improve this situation, but a sustained effort is required to remove the various barriers that prevent the flow of data from NHS breast multidisciplinary teams (MDT) to the National Disease Registration Service in England and the Welsh Cancer Network. This includes identifying a data lead responsible for checking the accuracy and completeness of data being entered from their MDT, as well as efforts to improve the understanding of how to enter recurrence information correctly to ensure the data are recorded.

In relation to the de-novo cohort, the completeness of clinical factors collected at the time of diagnosis was excellent for age at diagnosis and sex (100%) but was lower for other items (see Table 2), particularly performance status (both countries) and oestrogen / progesterone receptor (ER / PR) status and human epidermal growth factor receptor 2 (HER2) status. Data completeness for ER status for England is lower than in previous NABCOP annual reports due to a new method of analysis.

The percentage reported here reflects the data quality as received by the NAoMe without augmentation using data for endocrine therapy prescription to highlight the need for improved data quality.

**Table 2.** Percentage of records with complete data for selected items collected at the time of diagnosis for people diagnosed with de-novo MBC in England and Wales (2019-21)

| Data item | England (n=10,661) | Wales (n=471) |
|---|---|---|
| Tumour grade | 88.3% | 93.6% |
| Overall stage | 86.7% | 74.9% |
| ER* status | 58.8% | 86.0% |
| HER2** status | 73.3% | 76.6% |
| PR*** status | 46.1% | 76.9% |
| Performance status¥ | 61.3% | 27.2% |

**Notes:** *ER status = oestrogen receptor status, **HER2 status = human epidermal growth factor receptor 2 status, ***PR status = progesterone receptor status, ¥Performance Status (scores: 0-4) is a fitness assessment tool used in oncology to stratify people based on their ability to carry out activities of daily living. NOTE: Data were impacted by the COVID-19 pandemic and so will be atypical to some degree during 2020-2021

## 4.2 Patient characteristics

There were 11,132 people with a de-novo MBC diagnosis (England: n=10,661; Wales: n=471), of whom 11,025 were women and 107 were men. There were data on 5,923 people with a date of diagnosis for recurrent MBC between 2019 and 2021 (England: n= 5,654; Wales: n=269). Of these 5,878 were women and 45 were men.

That the NAoMe recurrent MBC cohort is smaller than the de-novo MBC cohort suggests a significant under-recording of recurrent disease, and we therefore caution against interpreting these figures as an accurate representation of the incidence of MBC in England and Wales.

Table 3 summarises the characteristics of people diagnosed with de-novo MBC between 2019 and 2021. We focus on the de-novo cohort because it is uncertain how representative the NAoMe cohort of people with recurrent MBC is of this population. Among people with de-novo MBC, the age at diagnosis was lower for women than men, with the mean age for de-novo diagnoses being 65.1 years for women (IQR: 53-77) and 71.9 years for men (IQR: 64-81). The percentage with metastases at different anatomical sites was: bone=40.3%, lung=20.1%, liver=20.0%, and brain=3.9%. (NB: Individuals could have metastases at more than one site.)

Among people with recurrent MBC, the distributions of age and sex were similar to that observed for the de-novo cohort. The percentage of people with metastases at different anatomical sites was: bone=47.3%, liver=29.7%, lung=28.2%, and brain=11.1%. (NB: Individuals could have metastases at more than one site.)

**Table 3.** Characteristics of people diagnosed with de-novo MBC in England and Wales (2019-21).

| | England | Wales | | England | Wales |
|---|---|---|---|---|---|
| **No. of patients** | | | **Grade* (E=9,415, W=441)** | | |
| 2019 | 3,494 | 144 | G1 | 4.3% | 5.0% |
| 2020 | 3,387 | 139 | G2 | 51.0% | 42.4% |
| 2021 | 3,780 | 188 | G3 | 44.7% | 52.8% |
| **Age (years)** | | | **Performance status* (E=6,530, W=128)** | | |
| Under 40 | 5.8% | 4.7% | 0 - fully active | 64.2% | 48.4% |
| 40-49 | 12.5% | 9.1% | 1 - restricted in strenuous activity | 20.2% | 22.7% |
| 50-59 | 19.0% | 18.9% | 2 - active 50% or more of the day | 8.7% | 11.7% |
| 60-69 | 18.3% | 20.8% | 3+ - active 50% or less of the day | 7.0% | 17.2% |
| 70-79 | 23.7% | 27.6% | **ER status* (E=6,268, W=405)** | | |
| 80+ | 20.7% | 18.9% | Positive | 72.5% | 68.9% |
| **Gender** | | | **HER2 status* (E=7,813, W=361)** | | |
| Female | 99.0% | >99.0% | Positive | 21.0% | 24.9% |
| Male | 1.0% | <1.0% | | | |

**Notes:** ER status = oestrogen receptor status, HER2 status = human epidermal growth factor receptor 2 status, Performance Status (scores: 0-4) is a fitness assessment tool used in oncology to stratify people based on their ability to carry out activities of daily living. NOTE: Data were impacted by the COVID-19 pandemic and so will be atypical to some degree during 2020-2021

* Values are calculated where a person's data has been recorded. The sample sizes are in brackets. Refer to Table 2 for information on data completeness.

# 5. Patterns of care in England and Wales

## 5.1 Care options discussed by a multidisciplinary team (MDT) for people with de-novo MBC

**Key messages:** Among 10,555 women with de-novo MBC in England, 61.2% had a record that their care was discussed at a multidisciplinary team (MDT) meeting. The percentage fell from 68.1% for women aged 18-49 years to 55.6% for women aged 80 years & over. 63.2% of the 106 men identified in England had a record of an MDT meeting.

For people with de-novo MBC treated in Wales (471), 5.7% were reported as having their care discussed at an MDT meeting. Unfortunately, the data did not allow for us to distinguish if an MDT discussion did not occur or whether the date was not recorded. Improvement is required for both rates of MDT discussion and accurate recording of this activity.

**Denominator:** Women and men diagnosed with de-novo MBC between 2019 and 2021. (Patients analysed: England = 10,661, Wales = 471).

One of the five QI goals adopted by the NAoMe was to "improve the movement of patients through the care pathway" (Goal 1). Various national and international guidelines recommend that an MDT considers the management options for people with MBC (including the NICE Quality Standard 12[18]) so that patients are offered treatment options consistent with clinical guidelines, NICE guidance on NHS commissioned treatments, as well as individualised options when required by a person's circumstances. Evidence suggests that patient outcomes are improved when care is directed by an MDT. As such, the audit reports on those people with de-novo MBC who have their care discussed by an MDT. Due to low data completeness, it has not been possible to meaningfully report on MDT discussions for those with recurrent MBC.

## 5.2 People with recurrent MBC who had a biopsy of a metastatic lesion

**Key messages:** Among 5,654 people with recurrent MBC in England, 34.0% had a record of a biopsy around the time of their MBC diagnosis. The percentage fell from 48.0% for women aged 18-49 years to 15.8% for women aged 80 years & over.

This indicator could not be derived for Welsh patients from the data items available.

**Denominator:** Women and men who had recurrent MBC diagnosed between 2019 and 2021. (Patients analysed: England = 5,654; Wales = 269).

It is beneficial to confirm a diagnosis of metastatic cancer with a biopsy where feasible. It also establishes the recurrent tumour biology which may differ from the primary tumour.

In calculating this indicator, we assumed that the biopsy was of the metastatic lesion given the timing of the procedure. The anatomical site of the biopsy could not be determined from the data available. This indicator also contributes to the NAoMe QI Goal 1, to "improve the movement of patients through the care pathway". As the audit evolves, it is an aspiration of the NAoMe that this analysis informs a target for biopsy of a metastatic lesion.

19 National Institute for Health and Care Excellence. *Breast Cancer. Quality Standard [QS12].* 2011 (updated 2016). *Available from: https://www.nice.org.uk/Guidance/QS12*

## 5.3 People with reported contact with a clinical nurse specialist (CNS)

**Key messages:** For England, whether or not the patient saw a clinical nurse specialist (CNS) was recorded for 67.0% of people with de-novo MBC diagnosed between 2019 and 2021. Of these, 97.0% were recorded as having seen a CNS at diagnosis. In Wales, whether or not the patient saw a clinical nurse specialist (CNS) was recorded for 87.5% of people with de-novo MBC diagnosed between 2019 and 2021. Of these, 95.6% were recorded as having seen a CNS at diagnosis. The estimates were similar for women and men.

**Denominator:** Women and men with a de-novo diagnosis of MBC between 2019 and 2021. (Patients analysed: England = 10,661; Wales = 471).

The contribution of breast CNS support to the management of people with MBC is widely recognised. Ensuring patients have access to a breast CNS with knowledge of metastatic disease is a recommended standard of care in clinical guidelines[20,21]. In line with this, Goal 4 from the NAoMe QI Plan is to "improve access to nursing support".

In cases where CNS information was recorded, there were high rates of CNS contact at diagnosis with MBC (97.0% England and 95.6% Wales). It is possible that this data item is more likely to be completed after a person diagnosed with de-novo MBC had contact with a CNS. The rates of CNS contact in those for whom data is missing may be significantly lower.

We were unable to produce this indicator for people with recurrent MBC. However, we note that the MBC pilot data collection project reported in 2012 that only 53% of patients were recorded as being referred to a CNS at the time of recurrent/metastatic diagnosis[22]. A similar percentage was reported in a survey of women living with MBC published in 2023.[23]

## 5.4 People with ER positive MBC who had cyclin dependent kinase (CDK) 4/6 inhibitors as first-line treatment

**Key messages:** Among 3,732 women with a de-novo diagnosis of ER positive/HER2 negative MBC in England, 34.9% had a cyclin dependent kinase (CDK)4/6 inhibitor prescribed. The percentage varied greatly with age, with CDK 4/6 inhibitors prescribed in just under 40% of women aged 18-79 years, compared to 17.1% for women aged 80 years and over. 26.8% of the 41 men with ER positive/HER2 negative MBC had a CDK 4/6 inhibitor. This indicator could not be derived for Welsh patients from the data items available.

**Denominator:** Women and men with a de-novo diagnosis of ER positive/HER2 negative MBC between 2019 and 2021. (Patients analysed: England = 3,773; Wales = 216). Indicator includes people with unknown HER2 status and excludes people who died within 30 days of diagnosis.

For people with ER positive/HER2 negative disease, endocrine therapy is recommended as first-line therapy. The addition of a CDK 4/6 inhibitor to endocrine therapy was shown to substantially improve progression free survival and overall survival in the first- and second-line treatment of MBC compared to endocrine therapy alone. The relatively low usage of CDK 4/6 inhibitors in this patient group may reflect the increased toxicity compared to use of endocrine therapy alone, as well as the increased monitoring requirements for these drugs. The inclusion of these results creates a baseline for monitoring current treatment patterns and begins to address Goal 2 of the NAoMe QI Plan to "reduce unwarranted variation in access and timeliness to systemic anti-cancer treatment". We will expand and refine this analysis in subsequent NAoMe outputs.

20 NICE. Breast Cancer. Quality Standard 12, 2011; *Available from:* https://www.nice.org.uk/Guidance/QS12

21 NICE Advanced breast cancer: diagnosis and treatment (CG81). 200; *Available from:* https://www.nice.org.uk/guidance/cg81.

22 National Cancer Intelligence Network. Recurrent and Metastatic Breast Cancer Data Collection Project. London: NCIN; 2012. *Available from:* https://data.parliament.uk/DepositedPapers/Files/DEP2012-1127/PQ115046-47-48-2.pdf

23 Fallowfield L, Starkings R, Palmieri C, Tait A, et al Living with metastatic breast cancer (LIMBER): experiences, quality of life, gaps in information, care and support of patients in the UK. Support Care Cancer. 2023; 31(8):459. doi: 10.1007/s00520-023-07928-8. *Available from:* https://pubmed.ncbi.nlm.nih.gov/37432501/

## 5.5 People with HER2 positive MBC who had anti-HER2 therapy as first-line treatment

**Key messages:** Among 1,560 women with a de-novo diagnosis of HER2 positive MBC in England, 75.0% had anti-HER2 therapy prescribed. The percentage exceeded 85% for women aged 18-69 years, and was 60.1% and 28.4% for women aged 70-79 and 80 years and over, respectively, which is likely to reflect the increasing burden of comorbid disease and frailty among older women. Only 10 men were identified with HER2 positive MBC, of whom 4 had anti-HER2 therapy.

This indicator could not be derived for Welsh patients from the data items available.

**Denominator:** Women and men with a de-novo diagnosis of HER2 positive MBC between 2019 and 2021. (Patients analysed: England = 1,570; Wales = 86). Excludes people who died within 30 days of diagnosis.

For people with HER2 positive MBC, anti-HER2 therapy in combination with chemotherapy is recommended as first line therapy except in the presence of medical contraindications (such as cardiac dysfunction), physical frailty, or a strong patient preference against chemotherapy. The optimal sequence of anti-HER2 therapies has evolved over time. It is also unclear whether anti-HER2 therapies can be discontinued in patients with controlled disease without impacting on survival. The decreasing use of anti-HER2 therapies with increasing age may reflect an increasing incidence of frailty that prohibits chemotherapy treatment and consequently anti-HER2 therapies.

## 5.6 People who received chemotherapy

**Key messages:** Among people with a de-novo MBC diagnosis (2019-2021) in 42.7% (England) and 53.1% (Wales) received chemotherapy. The rate for men was lower than for women. The use of chemotherapy was greatest among women with HER2 positive disease; over 80% of those aged 18-59 received chemotherapy, but the proportion reduced as the age at diagnosis rose above 70 years. 65.8% of women with triple negative disease received chemotherapy.

Among people with recurrent MBC in England (2019-2021), 40.4% received chemotherapy. This indicator could not be derived for Welsh patients from the data items available.

The proportion of men who had chemotherapy was similar to women. The use of chemotherapy was greatest among younger women with triple negative disease, with just over 70% of those aged 18-49 receiving this therapy. The proportion of women who had chemotherapy decreased as the age of recurrent MBC diagnosis rose.

**Denominators:** (1) Women and men with a de-novo diagnosis of MBC between 2019 and 2021. (Patients analysed: England = 10,661; Wales = 471).

(2) Women and men diagnosed with recurrent MBC between 2019 and 2021. (Patients analysed: England = 5,654; Wales = 269).

Different chemotherapy regimens are offered to patients with MBC according to tumour biology, organ function, disease distribution, performance status, previous treatment, and patient preference. Chemotherapy is indicated for people with MBC in the following situations:

1. Triple negative MBC with/without immune checkpoint inhibitor
2. HER2 positive disease (ER +ve and -ve) in combination with anti-HER2 therapies
3. ER positive disease when there is evidence of endocrine resistance, when hormonal therapies are exhausted or in selected patients with severe organ dysfunction resulting from visceral metastases.[24]

24 See NAoMe glossary of terms. *Available from:* https://www.natcan.org.uk/reports/naome-state-of-the-nation-report-2024/

Box 1 and 2 describe chemotherapy use for the de-novo and recurrent cohorts. They demonstrate reducing rates of chemotherapy use with advancing age with the lowest rates in those with HER2-ve, ER+ve disease across all age groups.

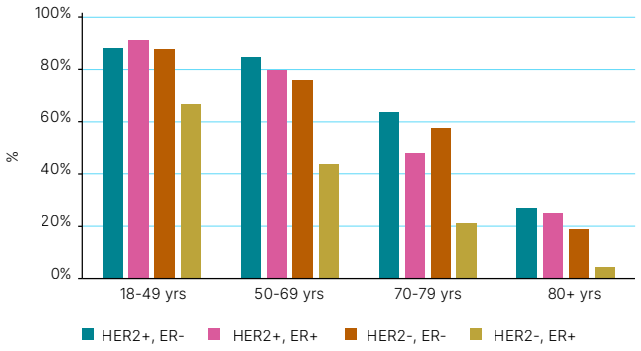
There are further complexities to understanding patterns of chemotherapy use in the NAoMe recurrent cohort, where treatment decisions will be influenced by treatment received for an individual's primary cancer. We will expand and refine this analysis in subsequent NAoMe outputs.

**Box 1.** Summary statistics about the percentage of people with de-novo MBC who had chemotherapy

**Table 4.** Chemotherapy among people with de-novo MBC

| | E+W | England | Wales |
|---|---|---|---|
| **All patients** | **43.2%** | **42.7%** | **53.1%** |
| Women | 43.3% | 42.9% | 53.2% |
| Men | 23.4% | - | - |
| *Subgroups for England and Wales in women* | | | |
| **HER2*+ve ER** -ve** | **HER2+ve ER+ve** | **HER2 -ve ER -ve** | **HER2 -ve ER +ve** |
| 73.3% | 73.1% | 65.8% | 35.4% |

**Figure 2.** Use of chemotherapy in women with de-novo MBC (2019-21)



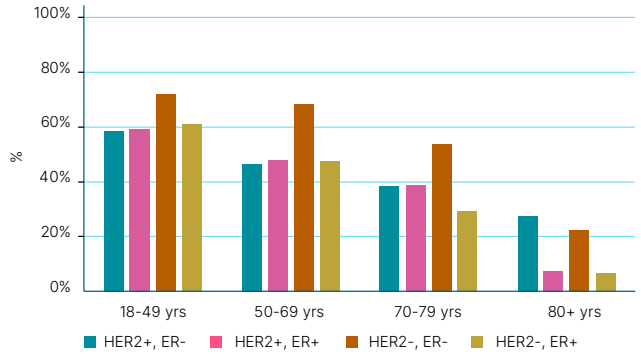

**Notes:** *HER2 status = human epidermal growth factor receptor 2 status, **ER status = oestrogen receptor status. We limit reporting hormone receptor subgroups to women only because the number of men involved were too small to produce reliable statistics. NOTE: Data were impacted by the COVID-19 pandemic and so will be atypical to some degree during 2020-2021.

**Box 2.** Summary statistics about the percentage of people with recurrent MBC who had chemotherapy

**Table 5.** Chemotherapy among people with recurrent MBC in England

| | E+W | England | Wales |
|---|---|---|---|
| **All patients** | **N/A** | **40.4%** | **N/A** |
| Women | N/A | 40.4% | N/A |
| Men | N/A | 40.9% | N/A |
| *Subgroups for England and Wales in women* | | | |
| **HER2*+ve ER** -ve** | **HER2+ve ER+ve** | **HER2 -ve ER -ve** | **HER2 -ve ER +ve** |
| 45.4% | 41.1% | 61.4% | 37.7% |

**Figure 3.** Use of chemotherapy in women with recurrent MBC (2019-21)




**Notes:** *HER2 status = human epidermal growth factor receptor 2 status, **ER status = oestrogen receptor status. We limit reporting hormone receptor subgroups to women only because the number of men involved were too small to produce reliable statistics. NOTE: Data were impacted by the COVID-19 pandemic and so will be atypical to some degree during 2020-2021.

# 6. Patient outcomes

## 6.1 Death recorded within 30 days of the start of a chemotherapy cycle

**Key messages:** Among women diagnosed with metastatic breast cancer in England (2019-21), 30-day mortality rates following the start of a cycle of chemotherapy were 8.3% for women with a de-novo diagnosis and 20.7% for women with recurrent disease. There was little difference by age.

This indicator could not be derived for Welsh patients from the data items available.

**Denominators:** (1) Women with a de-novo diagnosis of MBC between 2019 and 2021 who received chemotherapy. (Patients analysed: England = 4,529; Wales = 250).

(2) Women diagnosed with recurrent MBC between 2019 and 2021 who received chemotherapy. (Patients analysed: England = 2,268; Wales = N/A).

This section includes only those women diagnosed and treated within England because the date of last chemotherapy cycle was required, and this information was not available in the Welsh dataset.

Monitoring 30-day mortality following chemotherapy is considered a useful process for assessing treatment safety and can contribute to efforts to improve patient outcomes, linking with Goal 5 of the NAoMe QI Plan to "improve and reduce variation in MBC outcomes". The indicator provides information on how patients tolerate chemotherapy regimens and the related toxicities and complications as well as treatment decisions. Some patients are at higher risk of adverse outcomes following chemotherapy and monitoring outcomes can identify areas for improvement in chemotherapy delivery and supportive care. For people who have been offered chemotherapy as a treatment option, knowledge of short-term mortality rates can help inform shared decision-making about treatment options and enable the potential benefits of treatment to be balanced against its risks.

In the future, it will be important for this performance indicator to provide greater granularity. For example, for those with recurrent disease, it will be important to differentiate between patients depending on where they are in their treatment pathway (e.g., first-line[25] or second-line[11] treatment). This will help to describe the appropriate use of treatments.

We limit reporting this indicator to women only because the number of men involved were too small to produce reliable statistics.

## 6.2 Survival

**Key messages:** The 1-year and 3-year survival figures were 70% and 47% for people with a de-novo diagnosis of MBC between 2019 and 2021 in England and Wales. Within these figures, there are differences in survival between individuals; for example, people diagnosed with triple negative disease (ER-ve, HER2 -ve) had poorer survival compared to people with ER positive and HER2 positive tumours. We will undertake work to develop meaningful indicators on survival and will provide more detailed figures in subsequent reports.

One of the five QI goals adopted by the NAoMe was to "improve and reduce variation in MBC outcomes" (Goal 5). To achieve this, the audit will develop a risk-adjusted indicator to monitor the percentage of patients who survived at least 1, 3 or 5 years from the date of breast cancer diagnosis. Survival is a key outcome of treatment for patients and is used in research that evaluates the comparative effectiveness of treatments. Many factors can influence patient survival and we will undertake work to ensure the indicator provides a fair reflection of outcomes at an organisational level.

This report focuses on survival for people with de-novo diagnoses of MBC. Case ascertainment for recurrent MBC must be improved for survival statistics to be meaningful for this cohort. Moreover, it will be important to have accurate information about the date of metastatic recurrence; currently, the date of recurrence is based on the date of a hospital admission.

25 Defined in Glossary of terms; available from: https://www.natcan.org.uk/reports/naome-state-of-the-nation-report-2024/

# 7. Commentary

This first State of the Nation (SOTN) report for the NAoMe has focused on the care delivered in NHS hospitals across England and Wales to people diagnosed with MBC between 2019 and 2021. The analysis allocated patients based on their place of diagnosis, either an English NHS trust or Welsh health board (see methodology document) and provided some baseline information on performance indicators that were selected to monitor progress against the five NAoMe QI goals:

1. Improve the movement of patients through the care pathway.
2. Reduce unwarranted variation in access and timeliness to systemic anti-cancer treatment.
3. Reduce unwarranted variation in access and timeliness to palliative treatments.
4. Improve access to nursing support.
5. Improve and reduce variation in MBC outcomes.

This report provided information at a national level, and for specific groups of patients. Information at the level of NHS organisations can be found in the associated report data tables and dashboard. It is essential that NHS trusts and cancer alliances in England and NHS hospitals and health boards in Wales use these materials to review their performance and, where indicated, initiate local QI activities (https://www.natcan.org.uk/reports/naome-state-of-the-nation-report-2024/).

In this report, we have highlighted that the poor data on recurrence within national cancer datasets is the greatest challenge faced by the NAoMe. We urge NHS organisations to prioritise recording of the date of recurrence to enable accurate analysis of this population. Due to poor completeness of the data, the cohort of recurrent MBC analysed for this report was constructed using diagnostic information in routine hospital data (HES and PEDW) for patients with a diagnosis of primary breast cancer from 2015. People diagnosed before 2015 or who did not have an admission around the time the recurrent MBC was detected were therefore not included. That the recurrent MBC cohort was smaller than the de-novo MBC cohort demonstrates that the cohort is incomplete, and the report should not be used for activities such as resource planning that require estimates of demand. A priority for the NAoMe is working with the relevant parties to improve the capture of data on recurrence, so the case-ascertainment of people with diagnosed recurrent MBC increases. This work has already begun. The NAoMe, in collaboration with NDRS has designed a guide about how to collect COSD data on breast cancer recurrence, and we will be publicising this guide and other resources[26]. Similar work to improve recording of recurrence in Wales is in development.

The findings in this report provide an initial view on care delivered to people with MBC. The results establish an important baseline on which NAoMe can build, particularly in relation to the use of various systemic anti-cancer treatments. Complete information on the tumour characteristics at the time of initial diagnosis is fundamental to interpreting these treatment patterns, and current levels of completeness on data items such as performance status, ER / PR status and HER2 status impair our ability to draw conclusions. Improvements in the quality of these key data items should be a priority.

Despite these reservations, the SOTN results highlight several areas where attention is required. Discussion of the care of people with MBC by an MDT is a recognised standard which is reported to improve patient outcomes. During 2019-21, 61.2% (England) and 5.7% (Wales) of patients with de-novo MBC had a record that their care was discussed within an MDT. There were no data available to report the rate of MDT discussion within the recurrent MBC cohort. The very low rate of MDT discussion in Wales will probably reflect low levels of data completeness rather than represent an accurate reflection of practice. However, ensuring patients are discussed at MDT meetings should be an important focus for NHS breast MDTs across England and Wales.

Access to a CNS for patients with MBC is also reported to improve care. The high rates of CNS contact (97.0% in England and 95.6% in Wales) estimated are reassuring but they may be artificially high because the completeness of data on CNS contact in England was low at 67%. Data completeness for Wales was higher at 87.4%. It is possible that this data item is completed more often if a patient saw a CNS. This data item records CNS contact at a single point in time which further limits any insight gained into CNS access. Discussions with stakeholders have highlighted the value of being able to report whether patients have contact with a metastatic-specific CNS. This information is not currently available from routine data. The NAoMe Feasibility Document describes work to assess the feasibility of assessing symptomatic, supportive, social & psychological care in metastatic breast cancer within the audit.

Developmental work by a number of national bodies, including the UK Breast Cancer Group (UKBCG) and Breast Cancer Now is underway to agree the definition of a metastatic CNS. Once agreed a data item could be introduced to the appropriate national cancer datasets in England and Wales.

26 https://digital.nhs.uk/ndrs/data/data-sets/cosd/cosd-user-guide/introduction---how-to-record-recurrence-progression-and-transformations