NAoMe
National Audit of Metastatic Breast Cancer

NATCAN
National Cancer Audit Collaborating Centre

National Audit of Metastatic Breast Cancer

Quality Improvement Plan – September 2024

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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.

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 have been provided by patients and collected by the NHS as part of their care and support. For patients diagnosed in England, the data are collated, 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

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.

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Executive Summary

The National Audit of Metastatic Breast Cancer (NAoMe) has been commissioned to evaluate metastatic breast cancer care delivered in NHS hospitals across England and Wales. It aims to help NHS organisations to benchmark their metastatic breast cancer care against measurable standards, to identify unwarranted variation in care, and to provide tools to help services improve quality of care for people with metastatic breast cancer. The NAoMe will build on the work of the National Audit of Breast Cancer in Older Patients (NABCOP)[1].

The NAoMe Quality Improvement Plan sets out the scope, care pathway, five improvement goals and ten performance indicators for the NAoMe. The plan expands on the 2023 Scoping Report, which described: (i) a review of pertinent guidelines and the wider relevant literature (including external quality standards), (ii) a scoping survey that collected the views of key stakeholders on the delivery of breast cancer care in the NHS, and (iii) priorities for improving metastatic breast cancer care. Further engagement with stakeholders occurred through the presence of the NAoMe at key conferences and via meetings of the NAoMe Audit Advisory Committee (AAC).

The NAoMe will include all people (women and men), aged 18 or over with breast cancer (ICD-10 diagnosis code: C50) with evidence of metastatic spread in the audit period, who are diagnosed in an NHS hospital within England and Wales. Individuals identified from death certificates only will not be included. The audit will cover the care pathway from first diagnosis of metastatic breast cancer, whether from recurrent disease or a 'de novo' diagnosis. It will evaluate the initial treatments received by these patients. Treatments may be multimodal and include any of the following: systemic anti-cancer therapy (SACT), radiotherapy, or palliative and supportive care aimed at relief of symptoms. Short- and long-term outcomes following these treatments will be evaluated.

The following quality improvement goals have been identified for the NAoMe:

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 metastatic breast cancer outcomes.

The NAoMe has identified ten indicators to monitor progress against these five improvement goals and how they map to clinical guidelines and standards. A range of improvement methods and improvement activities to help deliver the Quality Improvement Plan are also described.

[1] National Audit of Breast Cancer in Older Patients.; Available from: https://www.nabcop.org.uk/.

1. Introduction

1.1 Aim and objectives of the Quality Improvement Plan

The Quality Improvement Plan for the National Audit of Metastatic Breast Cancer (NAoMe) builds on the previous Scoping Report which set out the scope of the NAoMe and identified key areas for improvement in the care pathway. The Quality Improvement Plan defines ten key performance indicators, and how they map to the five NAoMe quality improvement goals, national guidelines, and standards. These key performance indicators will be used by the NAoMe to monitor progress towards its quality improvement goals and to stimulate improvements in metastatic breast cancer care in England and Wales.

The Quality Improvement Plan describes the approach taken to develop the NAoMe's quality improvement goals and performance indicators. In addition, it sets out the range of potential improvement methods and activities that will support implementation of the plan, including strategies for reporting and disseminating audit results.

The Quality Improvement Plan for the NAoMe was developed in consultation with key stakeholders, including people with experience of metastatic breast cancer and will be reviewed on an annual basis.

1.2 The National Cancer Audit Collaborating Centre

The NAoMe is part of the National Cancer Audit Collaborating Centre (NATCAN) a new national centre of excellence to strengthen NHS cancer services by looking at treatments and patient outcomes across the country. It was set up on 1 October 2022 to deliver six new national cancer audits, including ovarian, pancreatic, kidney, non-Hodgkin Lymphoma, primary breast cancer and metastatic breast cancer. Existing audits in prostate, lung, bowel, and oesophago-gastric cancers moved into NATCAN in 2023. The centre is commissioned by the Healthcare Quality Improvement Partnership (HQIP) on behalf of NHS England and the Welsh Government.

The aim of the ten NATCAN audits is to:

1. Provide regular and timely evidence to cancer services of where patterns of care in England and Wales may vary.
2. Support NHS services to increase the consistency of access to treatments and help guide quality improvement initiatives.
3. Stimulate improvements in cancer detection, treatment, and outcomes for patients, including survival rates.

Further information about NATCAN and key features of its approach to audit can be found in Appendix 1.

2. Background on Metastatic Breast Cancer

Breast cancer is the most common cancer diagnosed within the United Kingdom (UK), and the second most common cause of cancer death in women[2]. Metastatic breast cancer represents the presence of breast cancer beyond the breast and ipsilateral regional lymph nodes. The disease is often diagnosed due to symptoms and/or abnormalities being detected after imaging or other investigations.

People may be diagnosed with metastatic breast cancer as a 'de novo' diagnosis, where metastatic spread is present at the time of the initial breast cancer diagnosis. However, most people with metastatic breast cancer are diagnosed with the disease at some point after diagnosis and treatment for primary breast cancer. Whilst people with 'de novo' metastatic breast cancer make up approximately 5% of all people with newly diagnosed invasive breast cancer each year[3], the incidence and prevalence of metastatic breast cancer in England and Wales following an initial primary breast cancer is unknown and estimates vary considerably. This reflects the lack of data on recurrence in national cancer datasets currently. A recent study using HES data alone suggested that the number of women in England living with metastatic breast cancer is around 57,000[4].

The timing of distant recurrence is variable and largely dependent on characteristics of the primary tumour, including the stage at diagnosis and the molecular subtype as defined by estrogen receptor (ER) status and human epidermal growth factor receptor 2 (HER2) status. For people with triple negative breast cancer, a distant recurrence is often diagnosed 2-4 years after primary diagnosis; for people with ER-positive breast cancer, the time to recurrence tends to be longer.

The point at which metastatic breast cancer is diagnosed (at initial presentation compared with progression/recurrence following a diagnosis of early breast cancer) will impact the treatment options available and subsequent outcomes. Treatment options for distant recurrent disease are determined by which therapies were previously used to treat the primary tumour and their effectiveness, along with patient choice. Overall survival is, on average, longer for patients with a de novo diagnosis of metastatic disease than distant recurrence.

2.1 Main issues in metastatic breast cancer care

Various issues have been raised in relation to the diagnosis and management of metastatic breast cancer. An issue highlighted in the 2019 "The Unsurvivors" report from Breast Cancer Now was the importance of a prompt diagnosis so that treatment can begin as quickly as possible[5].

The report highlighted how timely access to treatment and care can relieve symptoms and have a dramatic impact on quality of life of patients.

The value of the multidisciplinary team (MDT) to consider the management options for people with metastatic breast cancer has also been highlighted. The MDT will help ensure patients are offered treatment options consistent with clinical guidelines as well as make judgements about non-standard management on a case- by-case basis. The contribution of breast clinical nurse specialists (CNS) to the management of people with metastatic breast cancer is also widely recognised, and ensuring patients have access to a breast CNS with knowledge of metastatic disease is a widely cited goal [6,7,8,9].

An important issue to address, related to the planning and management of care, is the current lack of information on how many people have metastatic breast cancer. Efforts are being made nationally to improve the collection of data on disease progression/recurrence (such as the date of detection and type of progression/recurrence) but planning services and evaluating the quality of care provided is hampered by the inability to follow patients along the care pathway.

2.2 Care pathways

Metastatic breast cancer cannot be cured but can be managed, often for long periods of time, and there is a large range of treatment options designed to control the disease. Such options include endocrine therapy (for ER-positive disease), chemotherapy, HER2-targeting drugs (for HER2-positive disease) and other inhibitors of molecular pathways within breast cancer cells including immune checkpoint inhibitors in some patients with triple negative cancer. The oncological management of metastatic breast cancer has

[2] Taylor, C., et al., Breast cancer mortality in 500 000 women with early invasive breast cancer diagnosed in England, 1993-2015: population based observational cohort study. BMJ, 2023. 381: p. e074684.
[3] Gong, Y., et al., *Incidence proportions and prognosis of breast cancer patients with bone metastases at initial diagnosis.* Cancer Med, 2018. **7**(8): p. 4156-4169.
[4] Palmieri, C., J. Owide, and K. Fryer, Estimated Prevalence of Metastatic Breast Cancer in England, 2016-2021. JAMA Netw Open, 2022. 5(12): p. e2248069.
[5] Breast Cancer Now The Unsurvivors. 2019.
[6] Cardoso, F., et al., European Society of Breast Cancer Specialists/Advanced Breast Cancer Global Alliance quality indicators for metastatic breast cancer care. Eur J Cancer, 2023. 187: p. 105-113.
[7] NICE. Breast Cancer. 2011; Available from: https://www.nice.org.uk/guidance/qs12.
[8] NICE Advanced breast cancer: diagnosis and treatment (CG81). 2009.
[9] World Health Organization Global Breast Cancer Initiative Implementation Framework: Assessing, Strengthening and Scaling-Up of Services for the Early Detection and Management of Breast Cancer. 2023

become substantially more complex over the last 10-15 years with an increasing number of evolving treatment options available.

Various factors will inform treatment options for metastatic breast cancer. These factors include tumour biology, disease distribution and burden, organ function, physical fitness, menopausal status, previous treatment, and patient choice. Although patient age at the time of diagnosis has been found to be a strong determinant of treatment received, patterns of care should be determined by "biological age" and guidelines emphasise that chronological age alone should not determine treatments.[10] Measures of patient fitness/frailty will be important to consider when evaluating performance indicators and presenting audit results.

Supportive interventions are also available including palliative radiotherapy and anti-resorptive therapies such as denosumab or bisphosphonates. Attention to symptom support, often in conjunction with community or hospital/hospice-based palliative and supportive care teams, is an important part of management.

2.3 Management of metastatic breast cancer

There are both national and international guidelines covering the management of advanced (metastatic) breast cancer (Appendix 2). These sources of information on the recommended management of patients with advanced breast cancer will provide key references for future NAoMe work and have been referred to throughout this document where relevant. There are similarities in the standards identified by the sources, including: the value of multidisciplinary teams; access to a clinical nurse specialist; assessment of oestrogen receptor and HER2 status for treatment planning; and receipt of prompt treatment.

2.4 Variation in care and outcomes

Despite clear national and international guidelines on the care of patients with metastatic breast cancer, the NABCOP Annual Reports previously highlighted variation in the patterns of use of chemotherapy treatment and outcomes, among women with de novo metastatic breast cancer aged 50 years and over (Appendix 3)[11,12].

Other studies have also reported variation in the patterns of care and treatment provided to patients with metastatic breast cancer across England and Wales[13,14].

[10] *National Institute for Health and Care Excellence. Early and locally advanced breast cancer: diagnosis and management. NICE guideline [NG101]*. Available from: https://www.nice.org.uk/guidance/ng101.
[11] National Audit of Breast Cancer in Older Patients (NABCOP). NABCOP 2020 Annual Report. 2020; Available from: www.nabcop.org.uk/reports/nabcop-2020-annual-report/.
[12] National Audit of Breast Cancer in Older Patients (NABCOP). NABCOP 2022 Annual Report. 2022; Available from: https://www.nabcop.org.uk/reports/nabcop-2022-annual-report/.
[13] Twelves, C., et al., Systemic treatment of hormone receptor positive, human epidermal growth factor 2 negative metastatic breast cancer: retrospective analysis from Leeds Cancer Centre. BMC Cancer, 2020. 20(1): p. 53.
[14] El Turabi, A., et al., Variation in reported experience of involvement in cancer treatment decision making: evidence from the National Cancer Patient Experience Survey. Br J Cancer, 2013. 109(3): p. 780-7

3. Approach to developing the Quality Improvement Plan

This NAoMe Quality Improvement Plan builds on the Scoping Report which set out the patient inclusion criteria, care pathway and priorities for quality improvement (Section 4). The Quality Improvement Plan describes five quality improvement goals and outlines ten performance indicators that have been mapped to these goals and relevant clinical guidelines (Section 5).

In Section 6 and Section 7, improvement methods and improvement activities are outlined. Finally, Section 8 sets out the approaches to evaluation of the Quality Improvement Plan. Given that this is the first national audit of metastatic breast cancer in England and Wales, the Quality Improvement Plan is expected to evolve over subsequent years.

3.1 Approach to developing the audit scope

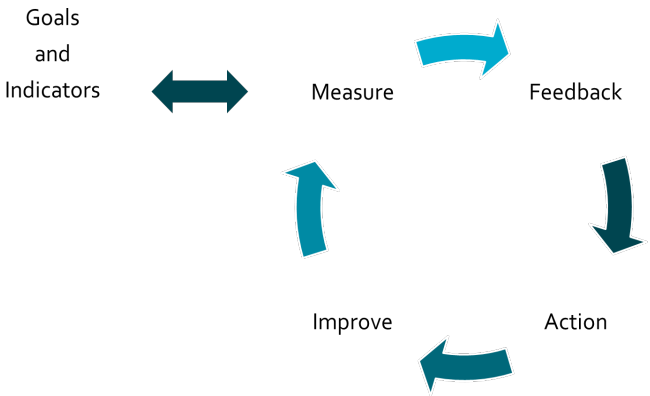
To inform the quality improvement goals and priorities of the NAoMe, the audit team conducted a review of pertinent guidelines and relevant wider literature (including external quality standards) as well as a consultation with key stakeholders. The consultation process included feedback from patient and professional representatives on the AAC and Patient and Public Involvement (PPI) Forum, along with over 250 responses from patients to the scoping survey.

The NAoMe will build on the methodological and clinical work of the NABCOP which finished in September 2022. While the NABCOP included only women aged 50 years and above, the NAoMe will evaluate the care received by all people diagnosed with metastatic breast cancer, regardless of age or gender, in NHS hospitals within England and Wales.

3.2 Approach to developing the quality improvement goals and indicators

Clinical Performance Feedback Intervention Theory (CP-FIT)[15] states that developing improvement goals and performance indicators are the first steps in the audit and feedback cycle (Figure 1).

Figure 1: The audit and feedback cycle



Using the priorities for improvement outlined in its Scoping Document, the NAoMe developed a list of 15 candidate performance indicators that mapped to five quality improvement goals. The selection of ten indicators from this list of candidates was informed by the following set of key principles.

- Measurable so that they can be the basis of credible feedback about performance. This property means that the indicators can be defined with available data in a valid, reliable, and fair manner that allows performance to be attributed to a specific unit[16].
- Actionable so that feedback translates into action to improve care. Indicators should therefore be important and address a specific pathway of care that is clear to all stakeholders. Stakeholders should understand the drivers of variation in performance within this pathway and control the levers for change. These changes should be evidence-based and address policy priorities.
- Improvable so that actions have the desired effect on patient care. There should therefore be clear scope for improvement (low baseline levels or large unwarranted variation) and a receptive context, with no unintended consequences. Some interventions may have demonstrated improvements to certain indicators in existing literature.

Some of these properties are difficult to know before evaluating a performance indicator (such as existing levels of performance, the drivers of low performance, or interventions that can improve care). In addition, clinical practice may change over time so that properties of indicators also change (for instance whether they relate to a policy priority). Therefore, we expect to modify the NAoMe's improvement

[15] Brown B, Gude WT, Blakeman T, van der Veer SN, Ivers N, Francis JJ, et al. Clinical Performance Feedback Intervention Theory (CP-FIT): a new theory for designing, implementing, and evaluating feedback in health care based on a systematic review and meta-synthesis of qualitative research. Implement Sci 2019;14:40.

[16] Geary, R., et al., A step-wise approach to developing indicators to compare the performance of maternity units using hospital administrative data. BJOG: An International Journal of Obstetrics & Gynaecology, 2018. 125(7): p. 857-865.

goals and performance indicators over the duration of the audit. Recommendations will also evolve and become more focused as NAoMe learns through the audit and feedback cycle.

3.3 Data provision

The NAoMe will use information from routinely collected national healthcare datasets. These capture details on the diagnosis, management, and treatment of every person with metastatic breast cancer in England and Wales. Further details on data provision and acquisition can be found in Appendix 4 and Appendix 5.

3.4 Data limitations

For accurate and timely benchmarking, it is essential that datasets used by the NAoMe:

1. Include all the data items required to measure and risk-adjust performance indicators.
2. Are timely.
3. Have a high-level of case-ascertainment.
4. Have high levels of data completeness.
5. Are accurate.

For patients treated in England, Rapid Cancer Registration Data (RCRD) linked to other national healthcare datasets, will be used for quarterly reporting. For patients treated in Wales, no equivalent of RCRD is currently available and therefore quarterly reporting is not possible for Wales at this time.

The RCRD is compiled from Cancer Outcomes and Services Dataset (COSD) records and other sources and is made available more quickly than the gold standard National Cancer Registration Data (NCRD). The speed of production means that case ascertainment and data completeness are lower, and the range of data items in the RCRD is limited.

For example, the RCRD incorporates a small subset of COSD data items with no information on molecular markers such as endocrine receptor status or HER2 status. It includes information on diagnostic staging, but levels of completeness are lower than in the gold standard Cancer Registration records. This may prevent indicators being defined for specific patient groups and restrict the extent to which potential confounders can be included in a risk-adjustment model. This may prevent indicators being defined for specific patient groups and restrict the extent to which potential confounders can be included in a risk adjustment model. As such, the indicators used for quarterly reporting will require careful consideration and testing.

Currently, there is a lack of information regarding recurrence (both local and distant) within routinely collected national cancer data. From work done by the NABCOP evaluating the recording of recurrence information within the COSD, only 4% of patients had a record of recurrence reported with poor recording across all geographical regions. Of note only 20% of patients with a recorded breast cancer death had a recording of recurrence. As such, these data are insufficient by themselves for identifying the cohort of patients with metastatic breast cancer at progression/recurrence. It will be important for the data quality and completeness on recurrence information to improve in order to accurately define the NAoMe cohort. Rates of recurrence would be an important outcome for the NAoMe to publish and it will be particularly important to improve data quality and completeness of recurrence in the coming years.

Highlighting issues with data quality and completeness has been a common theme for all national cancer audits. It will be important for the audit team to assess this for the whole of the NAoMe cohort and focus efforts on improving data where required.

3.5 Stakeholder involvement

During the set-up phase of the audit, the NAoMe team engaged with various stakeholders including patients, clinicians, representatives of medical associations, and patient charities. This helped inform the design of a scoping survey. The findings of this survey were discussed at the first NAoMe AAC meeting in April 2023 and are described in the NAoMe Scoping Report.

In May 2023, the NAoMe team attended the UK Breast Cancer Group (UKBCG) annual meeting. The UKBCG conference attracts oncologists, surgeons, nurse specialists, and wider members of the breast care team, as well as patient representatives. The NAoMe team gave a presentation about the audit, covering what the NAoMe is aiming to achieve, how it will use the national data sources, and how people can get involved. It also provided the opportunity to encourage engagement with the audit processes.

4. Audit scope

4.1. Patient inclusion criteria

The eligibility criteria for the NAoMe are defined as all people (women and men):

- Diagnosed in the audit period with breast cancer (ICD-10 diagnosis code: C50) with evidence of metastatic spread in the audit period.
- Aged ≥18 years at diagnosis.
- Diagnosed in an NHS hospital within England and Wales.

The NAoMe will exclude individuals identified only from death certificates.

4.2. Care pathway

The audit will cover the pathway from first diagnosis of metastatic breast cancer. It will evaluate the initial treatments received by these patients.

We define initial treatments as planned treatments. Treatments may be multimodal and include any of the following: systemic anti-cancer therapy (SACT), radiotherapy, or palliative and supportive care aimed at relief of symptoms.

Short and long-term outcomes following these different treatments will be evaluated.

5. Quality Improvement Goals & Performance indicators

Details of the five NAoMe quality improvement goals and the associated ten performance indicators mapped to the improvement goals and guidelines are outlined in Table 1 below.

Further information on how the data for these performance indicators will be reported is detailed in the NAoMe metrics table (available to view on the NATCAN website).

Where appropriate, the performance indicators will be presented for specific patient groups as well as for the whole patient population. Consultation with stakeholders highlighted the value of providing information for the following patient subgroups:

- Older (≥70 years) and frail patients,
- Young people with breast cancer (<40 years),
- Men with breast cancer,
- People with triple negative breast cancer,
- According to site of metastases.

To illustrate how quality improvement activities can be stimulated by these goals and performance indicators, we have provided an example driver diagram for one of the NAoMe's quality improvement goals (Figure 2). A driver diagram is a type of structured chart which connects a goal with activities that can help organisations achieve it. It can be a useful tool for organisations who want to improve their performance by providing a way to organise, prioritise and plan the activities they will undertake to achieve the desired improvement.

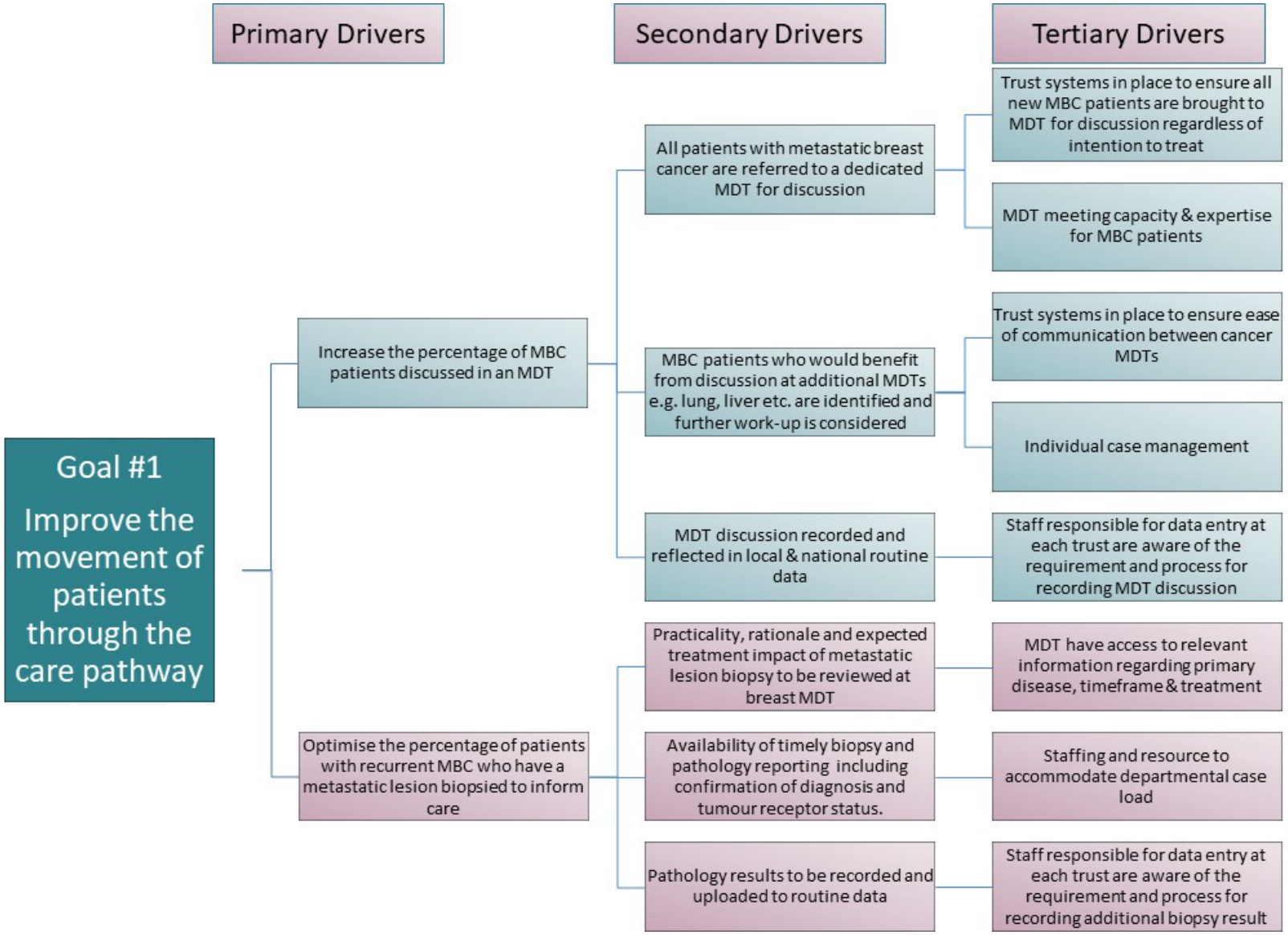
Table 1. NAoMe quality improvement goals and performance indicators

Quality improvement goal	Performance indicator/s*	National Guidance/Standards [17,18,19,20]
Goal #1 – Improve the movement of patients through the care pathway.	Percentage of patients with newly diagnosed metastatic breast cancer (MBC) discussed in a multi-disciplinary team (MDT).	*NICE Quality Standard 12 - Quality Statement 5, EUSOMA/ABC* - Breast cancer outcomes are improved when care is directed by a multi-disciplinary team. MDT discussion ensures optimal treatment is selected for each patient based on guidelines and patient related factors.
	Percentage of patients with recurrent MBC who had a metastatic lesion biopsied to inform care.	*NICE Quality Standard 12 - Quality Statement 4, NICE CG81 recommendation 1.1, EUSOMA/ABC* - Confirmation of a diagnosis of metastatic breast cancer may be required. Tumour biology is also desirable to understand all treatments and outcomes. Tumour biology in recurrent breast cancer may differ to that of the primary tumour, or the primary tumour biology may be unknown. If feasible it should be reassessed in recurrent disease where receptor status may have therapeutic indications.
Goal #2 – Reduce unwarranted variation in access and timeliness to systemic anti-cancer treatment.	Percentage of patients with ER positive MBC who received CDK 4/6 inhibitors as first line treatment.	*EUSOMA/ABC* - Endocrine therapy should be first line for ER positive/HER2-negative disease. The addition of a CDK4/6 inhibitor to endocrine therapy has been shown to substantially improve progression-free and overall survival in the first- and second-line treatment of MBC compared to endocrine therapy alone.
	Percentage of patients with HER2 positive MBC who received anti-HER2 therapy as first line treatment.	*EUSOMA/ABC* - Anti-HER2 therapy should be offered as a first line to all patients with HER2-positive MBC.
	Percentage of patients who received chemotherapy.	*EUSOMA/ABC* - Chemotherapy can be utilised for many indications in MBC dependant on tumour biology. Knowledge of patterns of chemotherapy use will be a useful comparator for other systemic treatment modalities.
Goal #3 – Reduce unwarranted variation in access and timeliness to palliative treatments.	Percentage of patients with bone metastases who received a bisphosphonate or denosumab.	*NICE CG81 recommendation 1.5, EUSOMA/ABC* - Management of bone metastases should involve a bone-modifying agent. Bone-modifying agents reduce the risk of developing skeletal-related events, delay the median time to a skeletal-related event and the onset of pain attributable to bone disease, and are cost-effective.
	Percentage of MBC patients who received radiotherapy.	*NICE CG81 recommendation 1.5, EUSOMA/ABC* - Radiotherapy can be utilised in MBC following surgical resection of a breast tumour or to target sites of distant metastases including within brain and bone. Effective control of metastatic disease via radiotherapy can improve quality of life.
Goal #4 - Improve access to nursing support.	Percentage of patients with clinical nurse specialist (CNS) contact recorded as "Yes".	*NICE Quality Standard 12 - Quality Statement 6, NICE CG81 recommendation 1.4, EUSOMA/ABC* - Assigning key workers to people with locally advanced or metastatic breast cancer leads to better health outcomes. A key worker promotes continuity of care, offering information and support for the person with breast cancer throughout their care. They can improve the patient experience and ensure patient views are taken into account.
Goal #5 - Improve and reduce variation in metastatic breast cancer outcomes.	Percentage of patients with death recorded within 30 days of a chemotherapy cycle.	*National Confidential Enquiry into Patient and Outcome Death (NCEPOD) and National Patient Safety Agency reports* have highlighted the need for improvements in the quality and safety of systemic anti-cancer therapy. Information on treatment-related death following chemotherapy can be used to inform iatrogenic risk and identify potentially futile treatment. (This is a recognised outcome measure for NHS England).
	Percentage of patients who survived at least 1, 3 or 5 years after diagnosis.	Survival is a key primary outcome in breast cancer research and can be used as an overall marker for treatment success.

* The NAoMe will publish the performance indicators (these may be fewer than ten) in the first State of the Nation Report published in September 2024. Additional indicators (up to a maximum of ten) will be reported in quarterly reports and future State of the Nation reports. The NAoMe will provide further analysis of data quality and contextual indicators (Appendix 6). The publication of indicators is aligned with data availability and completion of robust, methodological development work including appropriate risk-adjustment models.

[17] NICE. Breast Cancer. 2011; Available from: https://www.nice.org.uk/guidance/qs12.
[18] Cardoso, F., et al., European Society of Breast Cancer Specialists/Advanced Breast Cancer Global Alliance quality indicators for metastatic breast cancer care. Eur J Cancer, 2023. 187: p. 105-113.
[19] NICE Advanced breast cancer: diagnosis and treatment (CG81). 2009.
[20] World Health Organization Global Breast Cancer Initiative Implementation Framework: Assessing, Strengthening and Scaling-Up of Services for the Early Detection and Management of Breast Cancer. 2023

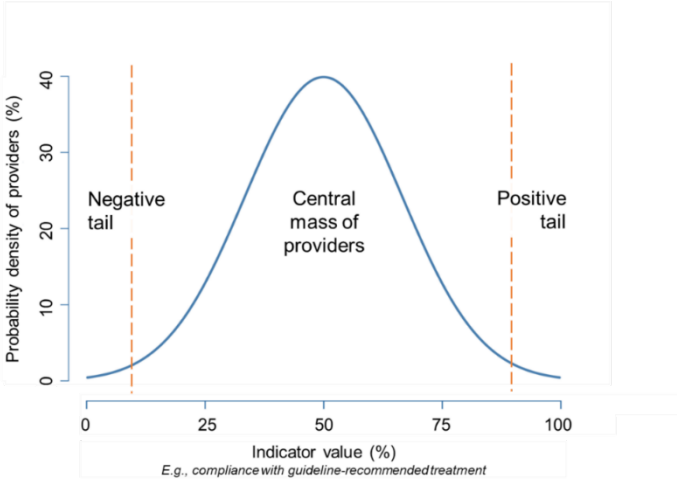
Figure 2. Example driver diagram: Goal #1 – Improving the movement of patients through the care pathway



6. Quality Improvement Framework

Figure 3 below shows a hypothetical example of how the values of a performance indicator may be distributed across NHS providers nationally at a single time point. On this indicator, a lower value indicates worse performance. The distribution can be separated into three domains: the negative tail (suggestive of worse performance), the central mass (located around the national average), and the positive tail (suggestive of better performance).

Figure 3. Hypothetical distribution of organisational values on a performance indicator



Each domain is associated with a different set of methods for improving healthcare:

Negative tail

Example methods: Regulation and public reporting of outliers with worse than expected performance

- National clinical audit has traditionally focused on the negative tail to improve healthcare. This approach implies that some NHS providers are doing something systematically worse than their peers that can be resolved through direct intervention. Such intervention may be necessary to assure minimum standards of care and to reduce the distance between the best and worst performing NHS providers. Cancer audits that pre-date NATCAN have formally reported negative outliers.

Central mass

Example methods: Statistical process control and iterative testing of interventions

- Most providers have indicator values that lie in the central mass of the distribution. Efforts focussed here may present the greatest scope for improving overall levels of care nationally. Methods in this domain suggest that all providers can improve their performance, regardless of their current levels. Local audits and evaluations can inform the iterative deployment of interventions which incrementally raise standards of care. Longitudinal monitoring by national clinical audits provides feedback about whether improvements occur or not.

Positive tail

Example methods: Positive deviance

- Some NHS providers perform exceptionally well despite similar constraints experienced by other providers, which presents opportunities to learn and share how this is achieved. 'Positive deviance' approaches assert that generalisable solutions to better performance already exist within the system. Such solutions are likely to be acceptable and transferable within existing resources. These approaches aim to identify local innovations and spread them to other settings.

The NAoMe will select which methods to implement to improve metastatic breast cancer care after investigating the distributions of its performance indicators (Section 5). This includes the distribution of performance indicator values between providers at a given time point and the values for a provider over time.

To support targeting of improvement interventions and recommendations, the audit will analyse particular patient, hospital and regional factors associated with variation in processes and outcomes of care. For example, for the utilisation of a particular evidence-based treatment, factors associated with utilisation may include advanced age, social deprivation and frailty, clinician preferences, and regional policies. Findings may be reported at an aggregated national or regional (Cancer Alliance) level and can support NHS Trusts to target interventions or evaluation at particular patient populations.

7. Improvement activities

Improvement activities and outputs of the NAoMe will be aligned to the HCIP. The NAoMe will: (1) engage in key collaborations, (2) align with other initiatives in metastatic breast cancer care, and (3) provide outputs to support quality improvement at the national, regional and local level.

The two principal strategies for reporting the NAoMe results will be producing:

- A short 'State of the Nation' (SotN) report for NHS Trusts in England and Health Boards within Wales. This annual report will publish five key recommendations and will highlight where services should focus quality improvement activities. These recommendations will be at the National and Cancer Alliance (regional) level where applicable and reflect the input of the audit teams, AAC and major national stakeholders.
- For England, a quarterly dashboard will facilitate benchmarking and the monitoring of performance at regular intervals so improvements can be tracked over time.

7.1 National and Regional

The NAoMe undertakes various activities that directly support national stakeholders and regional NHS organisations to tackle system-wide aspects related to the delivery of high-quality metastatic breast cancer services. Table 2 below details possible improvement activities by stakeholder groups.

Table 2. Potential improvement activities to be conducted by stakeholder groups

Stakeholder	NAoMe activity
NATIONAL	
NHS England and Wales	Identify issues and make recommendations, on the organisation and delivery of NAoMe cancer services, which might involve national leadership. Recommendations published in audit's State of the Nation reports.
National incentives	Provide the Care Quality Commission (CQC), Care Inspectorate Wales, and Getting It Right First Time (GIRFT) with information (from audit outputs) to support local visits to NHS organisations and options for aligning recommendations with specific incentives e.g. the Commissioning for Quality and Innovation (CQUIN) framework.
Professional organisations	Identify issues and make recommendations regarding the delivery of metastatic breast cancer care that fall within the remit of the professional organisations.
REGIONAL	
Cancer Networks / Alliances / Vanguards	Support the monitoring role of Welsh Cancer Networks and the English Cancer Alliances / Integrated Care Boards by publishing results for their region/area.

At a national level, the NAoMe team will also provide the National Cancer Registration and Analysis Service (NCRAS) Data Improvement Leads (in England), and the Wales Cancer Network with information to help them support their NHS organisations to improve the quality of their routine data submissions.

7.2 Local

Table 3 below details ways that the NAoMe supports local NHS cancer services in their care of metastatic breast cancer patients and possible associated improvement activities.

Table 3. Descriptions of potential improvement activities

NAoMe feedback activity	Description
Annual "State of the Nation" Reports	State of the Nation reports that allow NHS organisations in England and Wales to benchmark themselves against clinical guideline recommendations and the performance of their peers.
Web-based dashboard	Results presented for individual NHS organisations that allow the user to compare the results of a selected provider against a peer organisation.
Local Action Plan template	Allows NHS organisations to document how they will respond to the State of the Nation Report recommendations.
Outlier reporting	In the future, the NAoMe will report NHS provider values that are more than three standard deviations from the expected level of performance (i.e. deemed a potential outlier). NAoMe will support potential negative outliers to identify areas for improvement.
Data case studies	Examples of different approaches used by NHS trusts in England to ensure their Cancer Outcomes and Services Dataset (COSD) submissions to NCRAS are as complete and accurate as possible.
Improvement Case Studies	Examples of different approaches used by NHS trusts to improve care quality or recommendations identified from review of processes within positive or negative outlying providers, with a specific focus on the pathway of care.
Interventions	This will include possible interventions that have been identified in the literature linked to the performance indicators assessed by the audit or include interventions developed by Trusts/Alliances in the NHS.
Targets	Recommendations may include targets or thresholds for performance indicators e.g. XX % expected to receive treatment.
Materials supplementary to the State of the Nation Report	Including tools for improving data completeness.

7.3 Improvement tools

The NATCAN website includes a Quality Improvement Resources page with links to the RCSEng website and other web-based materials that direct healthcare providers to various quality improvement tools including:

- How to' guides including quality improvement methodology.
- Links to existing resources.
- Links to training courses for quality improvement.
- Good practice repository with available contact information.

7.4 Improvement workshops

The NAoMe will support a range of improvement activities that are aligned to national meetings and quality improvement initiatives of relevant professional bodies. For example, members of the audit team presented at the 2023 Royal College of Radiologists Clinical Oncology Quality Improvement Audit Forum.

As the audit matures the NAoMe will explore how workshops could be utilised to aid the implementation of quality improvement strategies. The NAoMe project team will consult with the AAC regarding workshop content and target audience.

7.5 Designing a National Quality Improvement Initiative

Using the rapid cancer registry data, the NAoMe will design a national Quality Improvement initiative aiming "to close the audit cycle" following an approach commonly referred to as the "plan-do-study-act" method[21].

The design and methodology underpinning this Quality Improvement initiative will be available in the next iteration of the HCIP further to consultation with NAoMe stakeholders.

[21] Taylor, M.J., et al., Systematic review of the application of the plan-do-study-act method to improve quality in healthcare. BMJ Qual Saf, 2014. 23(4): p. 290-8.

7.6 Patient and Public Involvement

The NAoMe will strive to involve people with lived experience of metastatic breast cancer in improvement plans. This includes establishing a standalone NAoMe PPI Forum, a key advisory stakeholder group developed in consultation with patient charities including Breast Cancer Now, METUPUK, Independent Cancer Patients' Voice (ICPV), Força - strength against cancer, Macmillan Cancer Support, use MY data and Maggie's.

Members of the NAoMe PPI Forum will be regularly consulted on the design of the audit and the communication of its results including:

1. The development and review of patient information materials and summaries of the State of the nation reports.
2. Co-development and/or co-authorship of scientific papers that explore NAoMe results.
3. Developing the design and function of the website to ensure that patients and the public can easily find relevant results together with appropriate explanatory information.
4. Shaping the development of the NAoMe's quality improvement goals, activities and outputs by ensuring this work is relevant from a patient perspective.

7.7 Communication & dissemination activities

The NAoMe will communicate regularly with stakeholders, including patients and the public in the following ways:

- Newsletters – The NAoMe Newsletter is distributed to key stakeholders on a quarterly basis, highlighting quality improvement methods and tools (where appropriate). These are also all published on the NAoMe website.
- Website and Social Media – The NAoMe website will be kept up to date. The @NAoMe_news X account (previously Twitter) will post weekly (and re-post) about key resources, publications or topics of interest to our stakeholders, including tools to aid quality improvement.
- Conferences and Peer Reviewed Papers – The NAoMe will present audit progress at national conferences including at the UK Breast Cancer Group and Association of Breast Surgeons annual conferences. Following the example of the NABCOP, the NAoMe will publish articles in peer reviewed journals such as British Journal of Surgery, British Journal of Cancer, BMJ Oncology, Clinical Oncology and Cancer Epidemiology.

8. Evaluation

The NAoMe will report year-on-year progress against improvement goals to the AAC and in the SotN reports on an annual basis. This will focus on describing how values of performance indicators have changed over time at a national level.

To evaluate the impact of specific NAoMe or other national interventions on the performance of NHS providers, quasi-experimental methods (when allocation of providers to certain groups cannot be controlled) or trial-based methods (when group allocation can be controlled) will be used.

The NAoMe will examine the opportunities for, and strengths and limitations of quasi-experimental and trial-based evaluation methods once it is more fully established.

Appendices

Appendix 1. National Cancer Audit Collaborating Centre (NATCAN)

The National Audit of Metastatic Breast Cancer (NAoMe) is part of the National Cancer Audit Collaborating Centre (NATCAN), a national centre of excellence launched on 1st October 2022 to strengthen NHS cancer services by looking at treatments and patient outcomes in multiple cancer types. The centre was commissioned by the Healthcare Quality Improvement Partnership (HQIP) on behalf of NHS England and the Welsh Government with funding in place for an initial period of three years.

NATCAN is based within the Clinical Effectiveness Unit (CEU), the academic partnership between the Royal College of Surgeons of England (RCS Eng) and the London School of Hygiene & Tropical Medicine. The CEU is recognised as a national centre of expertise in analytic methodology and the development of administrative and logistic infrastructure for collating and handling large-scale data for assessment of healthcare performance.

NATCAN was set up on 1 October 2022 to deliver six new national cancer audits, including ovarian, pancreatic, breast (two separate audits in primary and metastatic disease) and non-Hodgkin Lymphoma. Existing audits in prostate, lung, bowel, and oesophago-gastric cancers moved into NATCAN in 2023. This critical mass of knowledge and expertise enable it to respond to the requirements of the funders and stakeholders.

The aim of the ten NATCAN audits is to:

1. Provide regular and timely evidence to cancer services with a focus on where patterns of care in England and Wales vary.
2. Support NHS services to increase the consistency of access to treatments and help guide quality improvement initiatives.
3. Stimulate improvements in cancer detection, treatment, and outcomes for patients, including survival rates.

Key features of NATCAN's audit approach

The design and delivery of the audits in NATCAN has been informed by the CEU's experience delivering national audits, built up since its inception in 1998. Key features of all audit projects within the CEU include:

- Close clinical-methodological collaboration
- Use of national existing linked datasets as much as possible
- Close collaboration with data providers in England (National Disease Registration Service [NDRS, NHSE] and Wales (Wales Cancer Network [WCN], Public Health Wales [PHW])
- A clinical epidemiological approach, informing quality improvement activities.
- "Audit" informed by "research".

All these features will support NATCAN's focus on the three "Rs", ensuring that all its activities are clinically relevant, methodologically **r**obust, and technically **r**igorous.

Organisational structure of NATCAN

Centre Board

NATCAN has a multi-layered organisational structure. NATCAN's Board provides top-level governance and oversees all aspects of the delivery of the contract, ensuring that all audit deliverables are produced on time and within budget and meet the required quality criteria. The Board also provides the escalation route for key risks and issues. It will also consider NATCAN's strategic direction. The Board will meet at 6-monthly intervals and will receive regular strategic updates, programme plans, and progress reports for sign-off. Risks and issues will be reported to the NATCAN Board for discussion and advice.

Executive Team

NATCAN's Executive Team is chaired by the Director of Operations (Dr Julie Nossiter) and includes the Clinical Director (Prof Ajay Aggarwal), the Director of the CEU (Prof David Cromwell), the Senior Statistician (Prof Kate Walker), and the Senior Clinical Epidemiologist (Prof Jan van der Meulen) with support provided by NATCAN's project manager (Ms Verity Walker). This Executive Team is responsible for developing and implementing NATCAN's strategic direction, overseeing its day-to-day running, and coordinating all activities within each of cancer audits. This group meets monthly. The Executive Team will provide 6-monthly updates to NATCAN's Board.

Advisory groups

The Executive Team will be supported by two external groups. First, the Technical Advisory Group including external senior data scientists, statisticians, and epidemiologists as well as representatives of the data providers (NDRS, NHSD and WCN, PHW), co-chaired by NATCAN's Senior Statistician and Senior Epidemiologist, will advise on national cancer data collection, statistical methodology, development of relevant and robust performance indicators to stimulate QI, and communication to practitioners and lay audiences.

Second, the Quality Improvement Team includes national and international experts who have extensive experience in QI and implementation research. This team will provide guidance on the optimal approaches to change professional

and organisational behaviour. It will be chaired by NATCAN's Clinical Director and managed by the Director of Operations.

This set up will provide a transparent and responsive management structure allowing each audit to cater for the individual attributes of the different cancer types, while also providing an integrated and consistent approach across the NATCAN audits. The integrated approach will result in efficient production of results through sharing of skills and methods, a common "family" feel for users of audit outputs, and a shared framework for policy decisions and, project management.

Audit Project Teams

Audit development and delivery is the responsibility of each Project Team. The Project Team works in partnership to deliver the objectives of the audit and is responsible for the day-to-day running of the audit and producing the deliverables. It will lead on the audit design, data collection, data quality monitoring, data analysis and reporting.

Each cancer audit Project Team is jointly led by two Clinical Leads representing the most relevant professional organisations, and senior academics with a track record in health services research, statistics, data science and clinical epidemiology, affiliated to the London School of Hygiene and Tropical Medicine. In addition, each audit will have a clinical fellow, who contributes to all aspects of the audits, reinforcing the audits' clinical orientation and contributing to capacity building.

The delivery of the audit is coordinated by an audit manager who is supported by NATCAN's wider infrastructure. Data scientists with experience in data management and statistics and methodologists with experience in performance assessment and QI work across audits.

Audit Advisory Committee / Clinical Reference Groups

Each audit has an Audit Advisory Committee / Clinical Reference Group (https://www.natcan.org.uk/resources/naome-aac/) representing a wide range of stakeholders. This group will act as a consultative group to the Project Team on clinical issues related to setting audit priorities, study methodology, interpretation of audit results, reporting, QI, and implementation of recommendations.

Effective collaboration within the centre and across audits facilitates the sharing of expertise and skills in all aspects of the delivery process, notably: designing the audits, meeting information governance requirements, managing and analysing complex national cancer data to produce web-based performance indicator dashboards / state of the nation reports, and supporting quality improvement.

This organisation creates "critical mass" and audit capacity that is able to respond to the requirements of the funders (NHS England and Welsh Government) and the wider stakeholder "family".

Audit PPI Forums

Patients and patient charities are involved in all aspects of the delivery of the cancer audits. Each audit has a standalone Patient and Public Involvement (PPI) Forum to provide insight from a patient perspective on strategic aims and specific audit priorities. This will include shaping the development of each audit's quality improvement initiatives by ensuring this work is relevant from a patient perspective. A key activity of the PPI Forums will be to actively participate in the production of patient-focussed audit outputs (including patient and public information, patient summaries of reports, infographics and design and function of the NATCAN website), guiding on how to make this information accessible.

Appendix 2. Relevant international and national guidelines and resources

Reviewed external standards which include reference to metastatic breast cancer.

International and national guidelines

NICE Quality Standard 12 (2011; updated 2016)[22]

Statement 4 - People with newly diagnosed invasive breast cancer and those with recurrent breast cancer (if clinically appropriate) have the oestrogen receptor (ER) and human epidermal growth factor receptor 2 (HER2) status of the tumour assessed.

Statement 5 - People with breast cancer who develop metastatic disease have their treatment and care managed by a multidisciplinary team.

Statement 6 - People with locally advanced, metastatic or distant recurrent breast cancer are assigned a key worker.

WHO Global Breast Cancer Initiative Implementation Framework, 2023[23]

- It is crucial that patients with metastatic breast cancer are discussed by a multidisciplinary tumour board and that a common strategy is defined.
- No treatment should be initiated without the histological confirmation of malignant disease. For de novo metastatic breast cancer, a biopsy of the primary tumour is needed; for recurrent metastatic breast cancer, a biopsy of one of the metastatic lesions is recommended.
- Starting as early as possible, supportive oncology (including palliative care) and psychological support are also fundamental.
- A fundamental indicator for tracking the timeliness of access to cancer treatments is the interval between metastatic breast cancer diagnosis and start of treatment.
- It is important to monitor the proportion of patients still on treatment 12 months after its start to track treatment abandonment. Since metastatic breast cancer is an incurable disease, some form of treatment is almost always necessary.

EUSOMA/ABC quality indicators for metastatic breast cancer care. 2023[24]

- Ensure patients with MBC have appropriate and equitable access to multidisciplinary opinions and care teams, too select optimal treatment based on guidelines, to appropriately select patients for nonstandard management on a case-by-case basis and disease characteristics, and to select patients for clinical trials.
- Appropriate pathological characterisation of disease.
- Appropriate treatment (endocrine therapy; chemotherapy, targeted therapy; immunotherapy)
- Bone modifying agents.
- Brain radiotherapy.
- Appropriate use of tumour markers.

NICE. Advanced breast cancer: diagnosis and treatment (CG81). Key priorities. 2009 updated 2017[25]

- Assess oestrogen receptor (ER) and human epidermal growth factor receptor 2 (HER2) status at the time of disease recurrence if receptor status was not assessed at the time of initial diagnosis. In the absence of any tumour tissue from the primary tumour, and if feasible, obtain a biopsy of a metastasis to assess ER and HER2 status.
- Offer endocrine therapy as first-line treatment for the majority of patients with ER-positive advanced breast cancer.
- Healthcare professionals involved in the care of patients with advanced breast cancer should ensure that the organisation and provision of supportive care services comply with the recommendations made in 'Improving outcomes in breast cancer: manual update' (NICE cancer service guidance [2002]) and 'Improving supportive and palliative care for adults with cancer' (NICE cancer service guidance [2004]), in particular the following two recommendations:
    - 'Assessment and discussion of patients' needs for physical, psychological, social, spiritual and financial support should be undertaken at key points (such as diagnosis at commencement, during, and at the end of treatment; at relapse; and when death is approaching).'
    - 'Mechanisms should be developed to promote continuity of care, which might include the nomination of a person to take on the role of "key worker" for individual patients.'
- A breast cancer multidisciplinary team should assess all patients presenting with uncontrolled local disease and discuss the therapeutic options for controlling the disease and relieving symptoms.

[22] NICE. Breast Cancer. 2011; Available from: https://www.nice.org.uk/guidance/qs12.
[23] World Health Organization Global Breast Cancer Initiative Implementation Framework: Assessing, Strengthening and Scaling-Up of Services for the Early Detection and Management of Breast Cancer. 2023.
[24] Cardoso, F., et al., European Society of Breast Cancer Specialists/Advanced Breast Cancer Global Alliance quality indicators for metastatic breast cancer care. Eur J Cancer, 2023. 187: p. 105-113.
[25] NICE Advanced breast cancer: diagnosis and treatment (CG81). 2009.

- Consider offering bisphosphonates to patients newly diagnosed with bone metastases to prevent skeletal-related events and reduce pain.

Other relevant resources

Breast Cancer Now. The Unsurvivors. 2019[26]

We believe a crucial element of follow-up support is that information on the signs and symptoms of secondary breast cancer must be given to all patients treated for primary breast cancer, at a time and in a manner that suits them.

It is crucial that people with secondary breast cancer are diagnosed promptly so they can begin treatment and access supportive care as quickly as possible.

Timely access to treatment and care can relieve symptoms and have a dramatic impact on quality of life.

Access to a CNS is particularly important for people with secondary breast cancer who will be on lifelong treatment and often have very complex emotional and supportive care needs.

Appendix 3. Variation in care and outcomes highlighted by NABCOP

The NABCOP highlighted various areas in which patterns of care differed between NHS breast cancer units across England and Wales[27].

At the beginning of the breast cancer care pathway, variation was shown in the proportion of women who received triple diagnostic assessment in a single visit. Although there was no difference in the use of triple diagnostic assessment according to age, there was marked variation identified across different NHS organisations.

For women diagnosed with ductal carcinoma in-situ (DCIS), variation was identified in the use of surgery, particularly in those aged 70 years and above. In addition, there was significant variation in the proportion of women with DCIS who received radiotherapy. For example, 60% of those aged 50 to 69 years received adjuvant radiotherapy compared to 27% aged 80 years and above. There was considerable variation in radiotherapy use across NHS organisations, regardless of age.

For women with early invasive breast cancer, variation was identified across several treatment modalities including surgery, radiotherapy, and chemotherapy. There was considerable variation in the use of post-mastectomy radiotherapy across different NHS organisations, regardless of age. Similarly, there was considerable variation in the use of adjuvant chemotherapy and trastuzumab for women with HER2-positive disease. Another example of this was the large differences across organisations in the proportion of older women who received surgery for hormone-sensitive breast cancer compared to women diagnosed with hormone-negative breast cancer, regardless of patient fitness. Breast cancer guidelines recommend treatment options should be determined by “biological age” and not chronological age[28].

The NABCOP also highlighted variation in outcomes. For example, re-operation rates were higher in younger patients and in women with DCIS. In relation to the choice of re-operation procedure, older women had higher rates of mastectomy rather than having further breast-conserving surgery, compared to younger patients. Geographical variation in re-operation rates was seen.

For patients who received adjuvant chemotherapy for early invasive breast cancer, 28% were found to have had at least one treatment-related overnight hospital admission within 30 days of a chemotherapy cycle. Geographical variation in short-term morbidity following adjuvant chemotherapy was also demonstrated across different NHS organisations.

[26] Breast Cancer Now The Unsurvivors. 2019.
[27] National Audit of Breast Cancer in Older Patients.; Available from: https://www.nabcop.org.uk/
[28] National Institute for Health and Care Excellence. Early and locally advanced breast cancer: diagnosis and management. NICE guideline [NG101]. Available from: https://www.nice.org.uk/guidance/ng101.

Appendix 4. Data provision

The NATCAN Executive Team has worked closely with data providers in England (NDRS, NHSE) and in Wales (WCN, PHW) to establish efficient “common data channels” for timely and frequent access to datasets, combining data needs across all cancer types into a single request in each Nation and only using routinely collected data, thereby minimising the burden of data collection on provider teams.

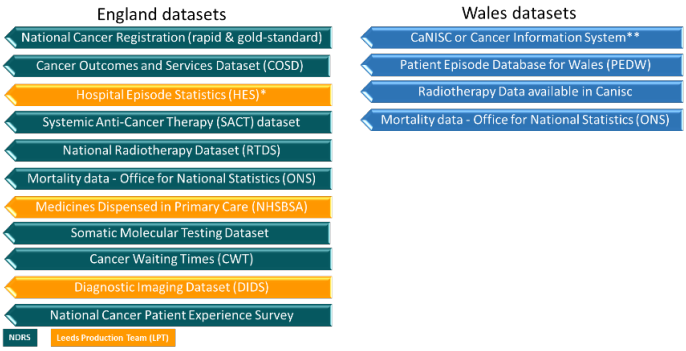
Annual and quarterly data

NATCAN will utilise two types of routinely collected data in England. First, an annual "gold-standard” cancer registration dataset, released on an annual basis with a considerable delay between the last recorded episode and the data being available for analysis, and second, a “rapid” cancer registration dataset (RCRD), released at least quarterly with much shorter delays (3 months following diagnosis). The CEU’s recent experience with English rapid cancer registration data, in response to the COVID pandemic has demonstrated the latter’s huge potential, despite a lower case ascertainment and less complete staging information[29].

NATCAN will utilise these data across all cancers linked to administrative hospital data (Hospital Episode Statistics/Systemic Anti-Cancer Therapy/Radiotherapy Data Set/Office for National Statistics among other routinely collected datasets, see Figure 4) for describing diagnostic pathway patterns, treatments received and clinical outcomes.

An equivalent data request will be made to the Wales Cancer Network (WCN)/Public Health Wales (PHW).

Figure 4. National datasets available to NATCAN



* Includes inpatient and outpatient data and Emergency care Dataset (ECDS).

** NHS Wales will use Welsh registry information for the initial years data for the audit. From 2022 data submissions will be from either CaNISC or the new cancer dataset forms.

Appendix 5: Data acquisition

Patient-level data on many aspects of breast cancer care are routinely collected in hospitals and mandatorily submitted to national organisations (Appendix 4). These existing electronic data flows will be used by the NAoMe to reduce the burden of data collection on staff and patients. This patient data, collected by the National Disease Registration Service (NDRS) for England and the Wales Cancer Network (WCN) for Wales, will be used to report on breast cancer care for the NAoMe. Over time, these national cancer datasets have improved in their completeness, quality, and the richness of information on tumour characteristics, and consequently their ability to be used to describe patterns of care.

The NATCAN’s data partners are the National Disease Registration Service (NDRS) and the Wales Cancer Network (WCN). The NDRS will provide data on patients with a registered diagnosis of breast cancer in England NHS trusts whilst the WCN will provide data on patients with a registered diagnosis of breast cancer in Welsh local health boards.

For England, data on patients with metastatic breast cancer will be provided by the NDRS on a quarterly cycle (based on data from the Rapid Cancer Registration Dataset; RCRD) and on an annual cycle (based on standard Cancer Registration). All data will be provided linked at patient/tumour-level to other national datasets including the COSD, Hospital Episode Statistics (HES) data, the National Radiotherapy Dataset (RTDS), Systemic Anti-Cancer Therapy (SACT) data, Cancer Waiting Times (CWT) data, the Primary Care Prescription Database (PCPD), the Diagnostic Imaging Dataset (DIDS), Somatic Molecular Testing data, and Civil Registration (death) records.

Data from the WCN will be provided on an annual cycle in the first instance. Wales has a different data collection process to England. Data will be provided linked to Patient Episode Data Wales (PEDW) data, Lower Layer Super Output Area (LSOA) data, and Office for National Statistics (ONS) death records. Data on patients in Wales with a diagnosis of metastatic breast cancer will be provided on an annual cycle in the first instance. Wales has a different data collection process to England.

A key requirement for the NAoMe will be having data items that allow the characteristics of a patient’s metastatic breast cancer to be described sufficiently accurately at the point of diagnosis to apply the desired inclusion criteria and define important patient subgroups. The information available for describing metastatic breast cancer in the national cancer datasets differs according to whether it is de novo or progressive/recurrent MBC.

[29] Nossiter, J., et al., Impact of the COVID-19 pandemic on the diagnosis and treatment of men with prostate cancer. BJU Int, 2022. 130(2): p. 262-270.

Appendix 6: Data Quality and Contextual Indicators for the NAoMe

QI Goal	Data quality Indicator	Contextual Indicator
General - improving data quality and completeness	Percentage of patients with M stage recorded as M1 or distant recurrence recorded	None
	Percentage of patients with site of metastases at first metastatic diagnosis recorded	
	Percentage of patients with primary tumour molecular status (ER/PR/HER2) recorded	
	Percentage of patients with Fitness Assessment Form information recorded	
Goal #1 – Improve the movement of patients through the care pathway.	Percentage of patients with an MDT discussion date recorded	Percentage of patients discussed at a Breast MDT
		Percentage of patients discussed at other non-breast MDT e.g. lung, CUP
		Percentage of patients with the ER and HER2 status of the primary tumour determined through a biopsy
Goal #2 – Reduce unwarranted variation in access and timeliness to systemic anti-cancer treatment.	None	Percentage of patients with ER positive breast cancer who received endocrine based therapy as first line treatment
		Percentage of patients with HER2 positive breast cancer who received a single anti-HER2 agent as first line treatment
		Percentage of patients with HER2 positive breast cancer who received dual anti-HER2 agents as first line treatment
		Percentage of patients with triple negative PD-L1 positive MBC who received immune check point inhibitors as first line treatment
Goal #3 – Reduce unwarranted variation in access and timeliness to palliative treatments.	None	Percentage of patients with bone metastases who received bone radiotherapy
		Percentage of patients with brain metastases who received brain radiotherapy
		Percentage of patients with MBC who develop malignant spinal cord compression who receive either radiotherapy or surgical intervention within 24 hours of diagnosis
Goal #4 - Improve access to nursing support.	Percentage of patients with information recorded on CNS contact	Percentage of patients with metastatic breast CNS contact recorded
Goal #5 - Improve and reduce variation in metastatic breast cancer outcomes.	None	None