NATIONAL AUDIT OF METASTATIC BREAST CANCER

Scoping Document

Summary for patients and the public

What is the NAoMe?

The National Audit of Metastatic Breast Cancer (NAoMe) is a national clinical audit which aims to find out about the quality of care breast cancer services in England and Wales have provided to all patients with metastatic breast cancer. This includes looking at any differences in the care provided.

The NAoMe is one of six new national cancer audits to be delivered by the National Cancer Audit Collaborating Centre (NATCAN). NATCAN was established to strengthen National Health Service (NHS) cancer services across England and Wales. More information on the NATCAN can be found via www.natcan.org.uk.

The NAoMe will work closely with the other breast cancer audit, the National Audit of Primary Breast Cancer (NAoPri).

What is this document about?

This document is a summary of the activities carried out to define the scope of the NAoMe.

The NAoMe builds on the work of the National Audit of Breast Cancer in Older Patients (NABCOP; www.nabcop.org.uk), which ended in September 2022. While the NABCOP included women aged 50 years and above, the NAoMe will evaluate the care received by ***all*** patients diagnosed with metastatic breast cancer in NHS hospitals within England and Wales.

How have the NAoMe priorities been identified?

We have reviewed the work done previously by the NABCOP, clinical guidelines and other external quality standards. We have also consulted with stakeholders on priorities for the NAoMe and what areas of breast cancer care are most in need of improvement for patients with metastatic breast cancer.

How has the NAoMe engaged with patients and the public?

The NAoMe has engaged with patients and the public in a variety of ways including:

- sharing information about the new audit at professional organisation meetings, where patient charities were present;
- involving clinicians & patients, to discuss priorities and thoughts on early indicators, at an initial Audit Advisory Committee meeting;
- using an online survey (questionnaire) open from February to April 2023 to find out what areas of care are most in need of improvement for patients with metastatic breast cancer. The findings from this are on the next page under Scoping Survey – Summary of findings.

What is 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 females.

Breast cancer is considered metastatic when the cancer has spread to other areas of the body, known as metastases, commonly to bones, lungs, liver and brain. It is usually diagnosed based on the presence of symptoms and/or abnormalities found on imaging or by other investigations. It is also often called secondary or advanced breast cancer.

Which patients with metastatic breast cancer will be included in the NAoMe?

All patients (female and male), aged ≥18 years, diagnosed with metastatic breast cancer, in an NHS hospital within England and Wales, will be included in the NAoMe.

When considering metastatic (breast) cancer, there are two distinct groups of patients, defined in Box 1 below. The NAoMe will evaluate care for both patient groups.

Box 1*: Metastatic breast cancer groups*

Group	Defined as
De novo metastatic breast cancer	Those patients diagnosed with metastatic disease at first diagnosis of breast cancer. This group accounts for around 5% of all individuals newly diagnosed with invasive breast cancer each year. In England and Wales, this roughly equals 2,500 of the 50,000 new patients diagnosed each year.
Recurrent metastatic breast cancer	Those patients who were initially diagnosed with primary breast cancer and then after a period when there was no evidence of primary breast cancer it returns and spreads to (or is subsequently detected in) distant parts of the body. The incidence and prevalence of metastatic breast cancer following an initial primary breast cancer is unknown and estimates vary considerably.

Scoping Survey – Summary of findings

A survey was used to collect the views of key stakeholders on the delivery of breast cancer care in the NHS. Doing this identified priorities to be addressed for metastatic breast cancer. The survey used open questions to avoid restricting respondents to pre-defined answers. It asked:

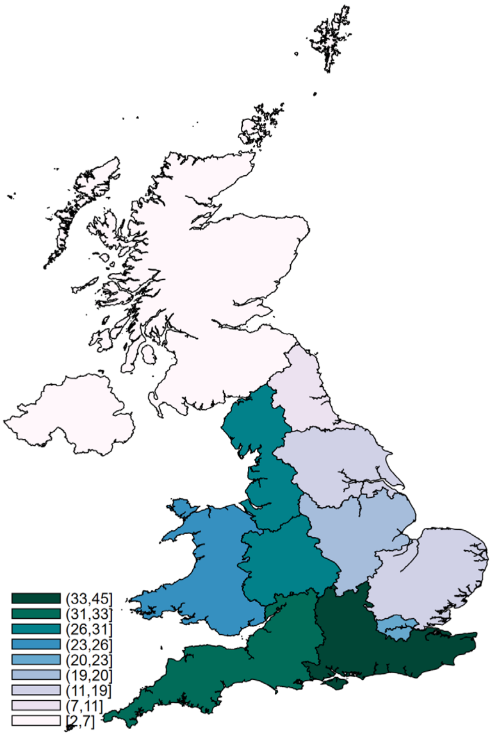
I. What aspect of care, which affects many patients with metastatic breast cancer, is most in need of improvement?
II. What aspect of care, which affects a subgroup of patients with metastatic breast cancer, is most in need of improvement?

The survey was distributed to a range of stakeholders that included patients and patient charities including individuals from Breast Cancer Now, Força - strength against cancer, Independent Cancer Patients' Voice (ICPV), METUPUK, Macmillan Cancer Support, Maggie's, and use MY data.

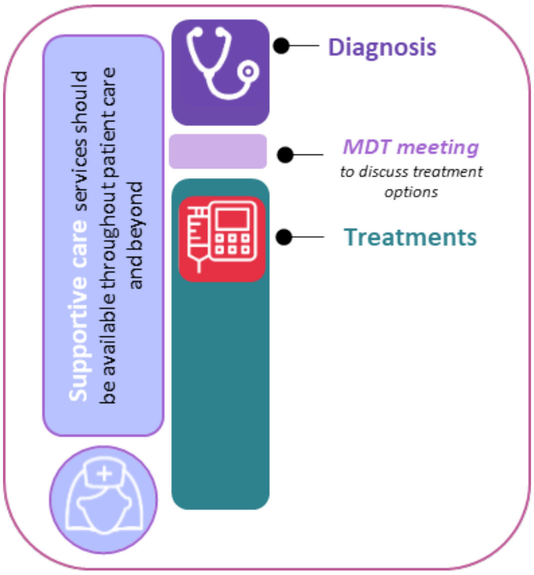
A total of **265** patients and patient advocates (professionals or members of the public advocating on patients' behalf) responded to the questions about metastatic breast cancer care, from across England and Wales (and some from Northern Ireland and Scotland).

The map to the right shows the different geographical regions where respondents lived. The increasing colour intensity indicates an increasing number of respondents in a region.

Note: The map includes 263 out of the 265 respondents. Two respondents were excluded as they did not provide their region.



Responses highlighted the following areas most in need of improvement along the care pathway



- Timely referral/diagnosis
- Timely access to appropriate imaging and results
- Timeliness of investigations & availability of pathology and scan results for treatment decisions
- Use of genetics/molecular/immune-specific testing and re-biopsy to guide treatment decisions

- Use of new drugs, immunotherapy, supportive/palliative treatment
- Timely access to treatment
- Geographical variation in treatment
- Use of surgery

- Access to a dedicated clinical nurse specialist/psychological support

Responses highlighted the following patient subgroups for whom care was most in need of improvement

- Triple negative breast cancer
- Younger patients (<40 years)
- Older patients (≥70 years)
- Site of metastases

A large percentage of responses related to the organisation of breast cancer services including:

- availability of staff (nursing and oncology) and the capacity of the cancer workforce;
- patients access to information and patient-centred communication;
- support provided for patients such as financial support;
- access to clinical trials; and
- continuity of care between different teams within hospitals or across different hospitals.

The evaluation of these aspects of the quality of care is important. However, they are not covered within the routine data that the audit has available for use and so the NAoMe will not be able to evaluate these areas.

For aspects of care relating to the experience of patients, we will look at the information collected within the national Cancer Patient Experience Survey (CPES; https://www.ncpes.co.uk/) to understand if this can be informative.

We will also provide signposting to useful resources provided by patient charities.

The findings of <u>all</u> responses to this survey are summarised in the NAoMe 2023 Scoping Document published 30 November 2023 (https://www.natcan.org.uk/audits/metastatic-breast/reports/).

How will the audit know what care patients are receiving?

The audit will use information collected within the existing national cancer datasets and other relevant health care datasets, to understand what care is provided to patients. This means that no additional data needs to be collected specifically for the audit.

These data are already collected by the:

- National Disease Registration Service (NDRS) in England
- Wales Cancer Network (WCN) in Wales

What are the priority areas identified as most in need of improvement?

- ➢ Improve recording of information on patients with recurrent metastatic breast cancer in national data.
- ➢ Improve information recorded on staging/pathology in national data sources.
- ➢ Reduce variation in timeliness & access to treatments.
- ➢ Improve access to support from a breast clinical nurse specialist.
- ➢ Improve outcomes following a diagnosis of de novo metastatic breast cancer or metastatic breast cancer at a later point.

What other things will the NAoMe need to consider when carrying out the audit?

- What sources of data are available to the audits and whether the information in them is completed for patients with metastatic breast cancer.
- What is the best way to identify patients with metastatic breast cancer who are diagnosed sometime after an initial primary breast cancer diagnosis.
- If there are enough patients to describe the care received at each NHS organisation with confidence.

How will the audit share what it finds?

The NAoMe will publish a report on an annual basis (called a ‘State of the Nation’ report). This will be used to share what the audit finds when it evaluates each of the audit performance indicators.

A summary version of the annual report will also be published for patients and the public.

As well as these, to help support NHS breast cancer services in England and Wales to check what aspects of care need improving on a more regular basis, the audit will publish quarterly dashboards on the NAoMe webpages.

The NAoMe is engaged with social media channels where it publishes weekly updates. Additionally, we publish newsletters every three months; these are hosted on the NATCAN website and emailed to the audit contacts list which includes patients, patient charities and representatives, along with clinical staff involved with breast cancer care.

How will the audit include patients in the work it does?

Patients and patient advocates are part of the Audit Advisory Committee and the NAoMe has a dedicated Patient and Public Involvement (PPI) Forum. Both of these groups provide valuable advice to the audit team on various elements of the audit including the improvement goals and related performance indicators, the design and content of the annual State of the Nation report (and associated summary version for patients and the public) and quarterly dashboards, and opportunities to disseminate audit findings and recommendations.

The PPI Forum will be drawn from patient and carer groups and set up in partnership with patient charities. Representation on the forum will aim to be broad and embrace the wide spectrum of patients affected by metastatic breast cancer within England and Wales.

Where can I find out more about the audit?

To find out more about the NAoMe please visit: https://www.natcan.org.uk/audits/metastatic-breast/

Information on what a clinical audit is can be found in FAQ #6 of:
https://www.natcan.org.uk/faqs/faqs-for-patients/

To read about why the NAoMe was commissioned and the purpose of it please visit:
https://www.hqip.org.uk/a-z-of-nca/national-audit-of-metastatic-breast-cancer-naome/