



NAoPri

National Audit of
Primary Breast Cancer

NATIONAL AUDIT OF PRIMARY BREAST CANCER

Scoping Document

Summary for patients and the public



NATCAN

National Cancer Audit
Collaborating Centre



Royal College
of Surgeons
of England
ADVANCING SURGICAL CARE

LONDON
SCHOOL of
HYGIENE
& TROPICAL
MEDICINE



HQIP
Healthcare Quality
Improvement Partnership



NDRS
NATIONAL DISEASE REGISTRATION SERVICE



GIG
CYMRU
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Wales Cancer
Network

BREAST
CANCER
NOW
The research &
support charity

independent
cancer patients'
voice

força
strength against cancer



* use MY data
use MY data



MAGGIE'S
Everyone's home of cancer care

What is the NAOpri?

The [National Audit of Primary Breast Cancer \(NAOpri\)](#) is a national clinical audit which aims to find out about the quality of care provided by breast cancer services in England and Wales to all patients with primary breast cancer. This includes looking at any differences in the care provided.

The NAOpri 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 NAOpri will work closely with the other breast cancer audit, the [National Audit of Metastatic Breast Cancer \(NAoMe\)](#).

What is this document about?

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

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

How have the NAOpri 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 NAOpri and what areas of breast cancer care are most in need of improvement for patients with primary breast cancer.

How has the NAOpri engaged with patients and the public?

The NAOpri 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 and patients, to discuss priorities and thoughts on early indicators at an initial Audit Advisory Committee meeting; and

- 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 primary breast cancer. The findings from this are on the next page under Scoping Survey – Summary of findings.

What is primary 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. Male breast cancer makes up less than 1% of all breast cancer cases in the UK.

Primary breast cancer includes breast cancer which, at diagnosis, has not demonstrated spread beyond the breast or nearby lymph nodes to other parts of the body. There is also a form of breast cancer which is non-invasive where the cancer cells are restricted to the walls of the milk ducts (called ductal carcinoma in situ - DCIS). This type of breast cancer does not have the ability to spread to other parts of the body.

Most patients diagnosed with breast cancer will have primary breast cancer. Metastatic breast cancer accounts for around 5% of new invasive breast cancer cases diagnosed each year.

The management of breast cancer is increasingly complex and involves a variable sequence of treatments which are individualised to each patient. Most patients with primary breast cancer will receive surgery as their first treatment. However, patients might receive treatments before and/or after surgery based on various factors including tumour characteristics, for example, the size of the tumour and whether there is evidence of spread to the lymph nodes.

Treatment options are also influenced by tumour molecular marker expression. This includes whether the breast cancer is hormone receptor (ER/PR) positive or negative, and whether the HER2 status is positive or negative.

Which patients with primary breast cancer will be included in the NAOpri?

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

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. In doing this, priorities could be identified for primary breast cancer. The survey used open questions to avoid restricting respondents to pre-defined answers. It asked:

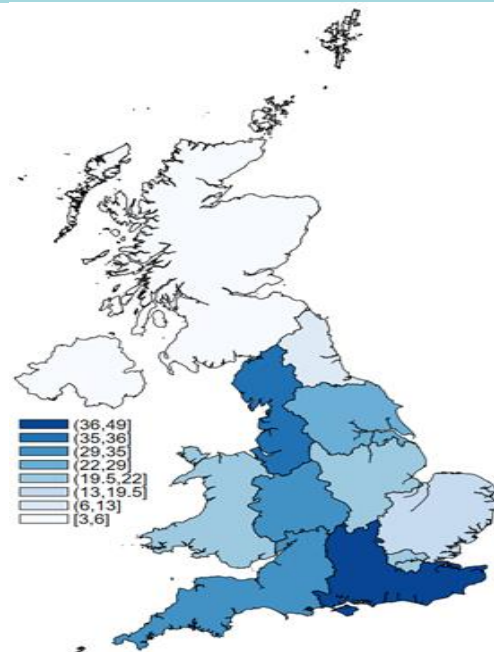
- I. What aspect of care, which affects many patients with primary breast cancer, is most in need of improvement?
- II. What aspect of care, which affects a subgroup of patients with primary breast cancer, is most in need of improvement?

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), Macmillan Cancer Support, Maggie's, and use MY data.

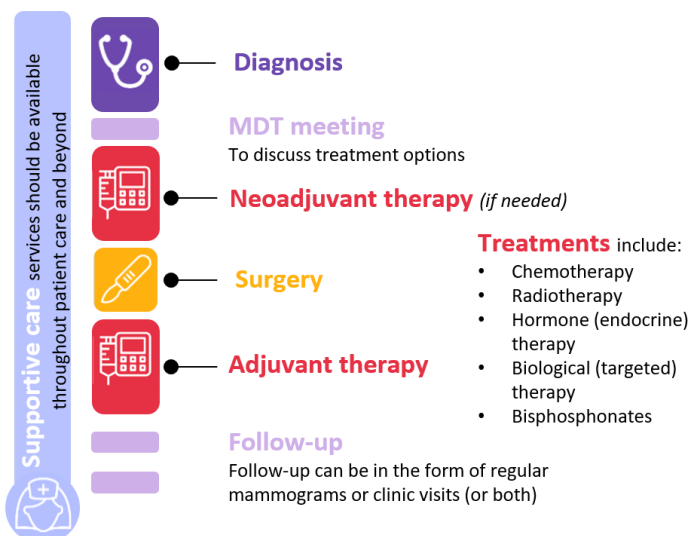
A total of **288** patients and patient advocates (professionals or members of the public advocating on patients' behalf) responded to the questions about primary breast cancer care from across England and Wales (and some from Northern Ireland and Scotland).

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 285 out of the 288 respondents. Three respondents were excluded as they did not provide their region.



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

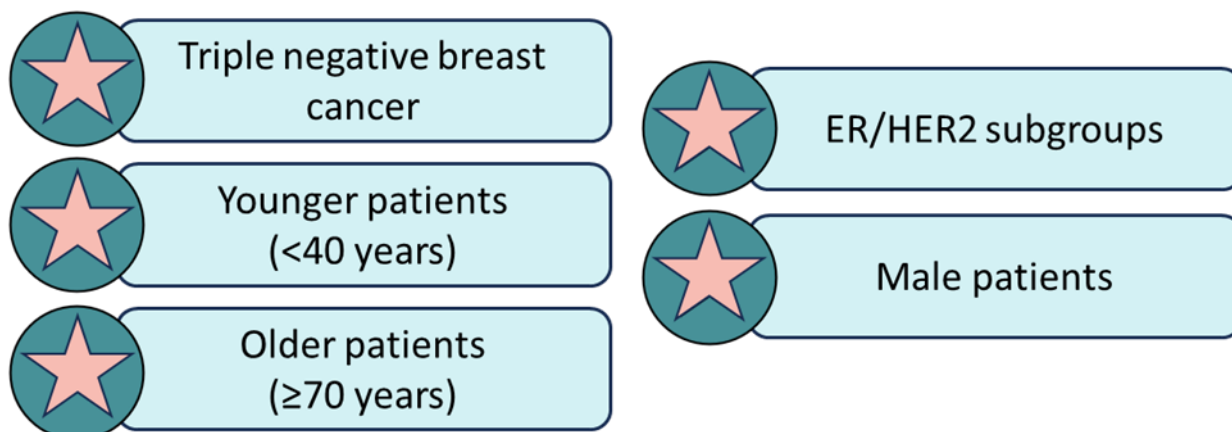


- Timely referral & diagnosis
- Timely access to appropriate imaging & results
- Timeliness of investigations & availability of pathology and scan results for treatment decisions
- Use of genetics/molecular/immune-specific testing to guide treatment decisions

- Timely access to treatments
- Geographical variation in treatment (e.g. reconstructive surgery)
- Issues with treatments (e.g. re-operations, adherence to hormone therapy)

- Access to a dedicated clinical nurse specialist
- Psychosocial support
- Short and long-term treatment side effects
- Long-term follow-up & support

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



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;
- patient 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 NAOpri 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 all responses to this survey are summarised in the NAOpri 2023 Scoping Document published 30 November 2023 (<https://www.natcan.org.uk/audits/primary-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 key information about patients and their primary breast cancer in national cancer datasets.
- Reduce variation in the care of patients undergoing surgery.
- Reduce variation for patients who receive oncological treatments such as chemotherapy, radiotherapy, and hormone therapy.
- Improve care as patients move through the primary breast cancer care pathway.
- Improve and reduce variation in primary breast cancer outcomes.

The above will also be explored for specific patient groups including older and frail patients, younger patients with breast cancer, male breast cancer patients, and patients with triple negative breast cancer.

What other things will the NAOpri 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 primary breast cancer.
- 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 NAOpri 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 NAOpri webpages.

The NAOpri 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 NAOpri 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 primary breast cancer within England and Wales.

Where can I find out more about the audit?

To find out more about the NAOpri please visit: <https://www.natcan.org.uk/audits/primary-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 NAOpri was commissioned and the purpose of it please visit:
<https://www.hqip.org.uk/a-z-of-nca/national-audit-of-primary-breast-cancer-naopri/>