
National Audit of Breast Cancer in Older Patients

Part of the National Clinical Audit and Patient Outcomes Programme

2018 Annual Report

Results of the Prospective Audit in England and Wales for women diagnosed between January 2014 and December 2016



NA
BCOP

National
Audit of
Breast Cancer
in Older Patients

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This version (1.1) was released on 13 July 2018, and included corrections to Table 7.1 in the Surgery chapter on page 42

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This national clinical audit is commissioned by the Healthcare Quality Improvement Partnership (HQIP) as part of the National Clinical Audit (NCA) Programme. HQIP is led by a consortium of the Academy of Medical Royal Colleges, the Royal College of Nursing and National Voices. Its aim is to promote quality improvement, and in particular to increase the impact that clinical audit has on healthcare quality in England and Wales. HQIP holds the contract to manage and develop the NCA Programme, which comprises more than 30 clinical audits that cover 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, in the case of some individual audits, by the Health Department of the Scottish Government, the Department of Health, Social Services and Public Safety (DHSSPS) Northern Ireland and the Channel Islands.

We would like to acknowledge the support of the breast cancer specialists and staff at English NHS trusts and Welsh local health boards who have participated in the National Audit of Breast Cancer in Older Patients (NABCOP).

We would like to thank:

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- Marianne Dillon (Breast Cancer Audit Lead for Wales), Hywel Morgan (Deputy Director) and Julie Cowling (Information Specialist) from the Wales Cancer Network, as well as Janet Warlow (Welsh Cancer Intelligence & Surveillance Unit).
- Lucy Davies (Association Manager) from the Association of Breast Surgery, for help establishing contacts across the country and publicising the existence of NABCOP and its publications.

We would also like to extend our thanks to the members of the Project Board and the Clinical Steering Group (CSG) for their advice and contributions to the audit (see Appendix 1). We are also grateful for the members of the CSG and other colleagues for participating in a series of subgroups to advise on the method of analysis, presentation of results and the potential measurement of frailty, cognition and comorbidity (see Appendix 1).

Data for this report are based on patient-level information collected by the NHS as part of the care and support of cancer patients. The data were collated, maintained and quality assured by the National Cancer Registration and Analysis Service, which is part of Public Health England.

Data from the Cancer Network Information System Cymru (Canisc) and Patient Episode Database for Wales (PEDW) were used with permission of the NHS Wales Informatics Service bespoke analysis service.

It is a pleasure to write the foreword to the second annual report from the National Audit of Breast Cancer in Older Patients (NABCOP). This is an important joint project by the Association of Breast Surgery and the Clinical Effectiveness Unit of the Royal College of Surgeons of England, commissioned by Healthcare Quality Improvement Partnership.

Its stated aim is to evaluate the care provided to and subsequent outcomes for women diagnosed with breast cancer aged 70 years or over. This is increasingly relevant given our ageing population with an ever-rising incidence of breast cancer. It is also important that the project compares their care provision with a younger cohort of women diagnosed between 50 and 69 years to establish any age-related treatment variations and then explore the reasons for these.

This report publishes information for all NHS trusts in England and local health boards in Wales that provided breast cancer services, over the three year period 2014–16. It allows us for the first time to take a detailed look at variations in the care of older patients with breast cancer according to their locality.

Reported completeness for some data items is variable and for performance status in particular it is consistently poor. I hope that reading this report will stimulate responsible clinicians to ensure that all required data items are collected within their institution and to check that there are effective processes and adequate resources in place to upload the required data set to the English National Cancer Registration and Analysis Service (NCRAS) and Canisc in Wales.

The NABCOP project team assisted by the clinical steering group, and project board, are to be congratulated on the great progress made with the audit over the last year. It is starting to deliver the required data to allow us to explore in detail breast cancer care in older people. It is important that we now build on these strong foundations to enable us to optimise cancer outcomes for our older breast cancer patients in the future.

Mark Sibbering
President, Association of Breast Surgery

Executive Summary

The National Audit of Breast Cancer in Older Patients (NABCOP) was commissioned to evaluate the quality of care provided to women aged 70 years or older by breast cancer services in England and Wales. The aim of the audit is to evaluate the care delivered to women from the point of initial diagnosis to the end of primary treatment, and to provide information on the comparative performance of NHS breast cancer units. The patterns of care observed for older women will be compared with those among women diagnosed with breast cancer aged 50–69 years.

In this annual report, we present information on the care received by women diagnosed between 1 January 2014 and 31 December 2016 in England and Wales. As well as describing how these patterns of care differ between women in the younger and older age groups, we also distinguish between three main groups of breast cancer – women with ductal carcinoma *in situ* (DCIS), with early invasive disease (stage 1 to 3A), and with advanced disease (stage 3B, 3C and 4).

The report is primarily written for clinicians, providers of breast cancer services, commissioners and health care regulators. A version for patients and the wider public is being produced separately and will be available on the NABCOP website (www.nabcop.org.uk) in summer 2018.

NHS provider participation and data quality

All NHS trusts and local health boards in England and Wales providing breast cancer services during the 2014–16 period participated in the audit. The information presented in this report was derived from data from the national cancer registration services in England and Wales.

To understand patterns of care, it is important to have data on key features of an individual’s cancer. The data completeness for key data items for English NHS trusts and Welsh health boards was of variable quality.

- In England: Tumour (T) stage was 91% complete; Nodal (N) stage was 86% complete, and its completeness improved annually.
- In Wales: Tumour (T) stage was 80% complete; while Nodal (N) stage was available for all women.

Disappointingly, the World Health Organization (WHO) performance status at diagnosis was not well reported in any year in either England or Wales, and only eight English NHS trusts submitted this information for more than 80% of women.

The NICE quality standard (QS12) statement #4 recommends that “People with newly diagnosed invasive breast cancer... have the oestrogen receptor (ER) and human epidermal growth factor receptor 2 (HER2) status of the tumour assessed”. Overall, these data were available for most women, but there was a decrease in their completeness among older age groups (see below). The proportions of women with ER and HER2 status tested and recorded were also variable across NHS trusts and local health boards.

Table ES1: Completeness of molecular marker status, by country of diagnosis and age at diagnosis

	English data		Welsh data	
	50–59 years	90+ years	50–59 years	90+ years
ER status complete	87%	57%	94%	91%
HER2 status complete	86%	59%	89%	81%

Characteristics of women diagnosed with breast cancer

In England and Wales 12,729 women aged 50 years and over were diagnosed with DCIS and 106,975 were diagnosed with invasive breast cancer between 2014 and 2016. Among women aged 50–69 years at diagnosis, 14% were diagnosed with DCIS. This decreased to less than 5% among women aged 85 years or older at diagnosis. This difference likely reflects the use of breast screening in women aged less than 70 years.

Among those women diagnosed with invasive tumours, the key features of the disease in women aged 70 years and over compared with women aged 50–69 years were:

- A greater proportion had larger breast tumours
- Slightly more women were diagnosed with metastatic axillary lymph nodes, although older women were less likely to have lymph nodes reported as being examined
- Similar proportions of women were diagnosed with high grade disease and tumours that were ER and HER2 positive.

Route to diagnosis

Women can be diagnosed with breast cancer through a number of different care pathways. Between 2014 and 2016:

- Among women aged 50–69 years one-third were diagnosed after referral from their GP, while more than half were diagnosed after screening
- Among women aged 70+ years, two-thirds were GP referrals while only one-sixth were from screening
- Among all women, the proportion diagnosed after an emergency presentation was very low, at around 1% (0.3% 50–69 years; 1.3% 70+ years).

The proportion of women who were diagnosed after screening or GP referral was observed to vary by NHS trust and local health board. Furthermore, a handful of NHS trusts had a high proportion of women with an unknown route to diagnosis. Such units should examine how to improve the completeness of their data.

Triple assessment at a single visit

Patients with suspected breast cancer are recommended to undergo a “triple assessment” (clinical assessment, imaging and tissue biopsy) in a single hospital visit [NICE 2002; NICE 2009a]. This applies particularly to women with symptomatic disease.

Determining whether a woman had received “triple assessment” was not straightforward. Adopting a strict set of criteria for the analysis of English data suggested that among women diagnosed with early invasive breast cancer, and who were not referred from screening, 28% received triple assessment in a single visit, with no difference by age (27% for 50–69 years; 29% for 70+ years). This low figure arose from uncertainty and incompleteness of the imaging and biopsy dates:

- 6% of women had an ultrasound and biopsy date but no mammogram date reported
- 43% of women were missing a mammogram and/or biopsy date

Among women with early invasive breast cancer diagnosed within Wales who were not referred from screening, applying the same criteria suggested 56% of women received triple diagnostic assessment in a single visit, again with little variation across the age groups.

If the criteria are relaxed (eg assuming missing mammogram/biopsy dates were the same as the date of biopsy/mammogram respectively; incorporating the use of ultrasound instead of mammogram; allowing biopsy and mammogram dates to differ by one day), the estimated proportion of women having triple assessment on the same day increased to 82% (81% for 50–69 years; 82% for 70+ years). There was considerable variation in the estimated proportions of women who received a triple diagnostic assessment in a single visit among NHS trusts and local health boards.

Involvement of a breast clinical nurse specialist

It is recommended that a woman with breast cancer is assigned a named breast clinical nurse specialist (CNS) to provide information and support during their diagnosis and treatment. The Cancer Patient Experience Survey (CPES) in England suggests that, overall, NHS breast cancer units are performing well on this indicator. In 2013, 90% of women that completed the CPES questionnaire reported being ‘given the name of a CNS who would be in charge of their care’.

Data on each individual’s contact with a breast CNS are reported within the English Cancer Outcomes and Services Dataset (COSD) dataset and were complete for 68% of women aged 50 years and over diagnosed between 2014 and 2016 (69% for 50–69 years; 66% for 70+ years). Within the completed data, 85% of women were reported to have seen a breast CNS (14% had contact reported as unknown) and access to a breast CNS did not differ strongly according to age (85% for 50–69 years; 84% for 70+ years).

Time from diagnosis to treatment with surgery or chemotherapy

Over the past decade, NHS cancer services have focused on reducing the time to initial treatment. We examined whether the time to surgery or chemotherapy from the date of diagnosis varied between NHS breast cancer units for women who received surgery or chemotherapy as their primary treatment (women receiving another treatment prior to this were not included).

Overall, the typical (median) time from diagnosis to this primary treatment with surgery or chemotherapy was comparable across women of different ages:

- Age 50–69 years = 4.7 weeks (IQR¹ 3.4–6.0 weeks)
- Age 70+ years = 4.6 weeks (IQR 3.3–5.7 weeks).

Approximately 22% of women waited more than 6 weeks to start treatment with surgery or chemotherapy (23% for 50–69 years; 20% for 70+ years), but waits tended not to extend far beyond this.

The time from diagnosis to treatment was not related to age at any of the NHS trusts or local health boards, and there was limited variation across the organisations. All but one NHS trust reported that 75% or more of their patients start treatment within eight weeks of diagnosis.

Surgical treatment

The proportion of women who had surgery for early invasive breast cancer decreased with increasing age, falling from 96% for women aged 50–59 years to 19% for women aged 90+ years. As expected, the likelihood of surgery among women fell as levels of fitness decreased, although the size of the change was much larger for women aged 70+ years compared with women aged 50–69 years. For example, the proportions of women aged 70+ years having surgery fell from 88% for women with performance status 0 to 17% for women with performance status 3–4.

There was some variation in the unadjusted proportions of women who received primary surgical treatment across NHS trusts in England and local health boards in Wales, particularly among women 70+ years. This variation reduced to levels that would be expected from random variation alone after adjustment for patient case-mix².

Women with early invasive breast cancer are recommended to have a 'sentinel node biopsy' (SNB) at the time of primary surgery if an ultrasound examination (+/- biopsy) did not find evidence of cancer spread to the axillary lymph nodes. Within English NHS trusts and Welsh local health boards during 2014–16, we found:

- The overall rate of SNB was 83% for women aged 50–69 and 78% for women aged 70+ years
- There were a few NHS trusts where the proportion of women who had SNB was lower than the typical rate across the other NHS trusts and local health boards. The variation across organisations was slightly greater among women aged 70+ years.

Duration of hospital stay following primary breast surgery

For many women who underwent breast cancer surgery, the time spent in hospital was short, with women typically admitted and discharged as day cases or within two days. Of women who had breast conserving surgery (BCS), only 4% stayed beyond two days.

For women who had a mastectomy and SNB (without breast reconstruction), the proportion of women staying more than two days was more varied across NHS trusts in England and local health boards in Wales.

- 25% of women aged 70+ years stayed in hospital for more than two nights compared with only 16% of women aged 50–69
- There was variation in length of stay between NHS trusts and local health boards across all age groups. This variation was greatest among women aged 70+ years, which might be expected due to reduced levels of overall fitness.
- However, the proportion exceeded 20% in women aged 70+ years in 71 organisations. These longer stays might reflect appropriate management of patients at risk of ongoing problems but it might also be indicative of local barriers to discharge.

¹ Interquartile Range (IQR) is a measure of variability. It is based on dividing a data set into quartiles. The IQR is the difference between the first and third quartiles.

² As described in the statistical analysis section of the audit methods (Chapter 2).

Radiotherapy after breast surgery

Guidelines recommend that radiotherapy after BCS should be considered for all patients who receive BCS for DCIS or early invasive breast cancer. Among NHS organisations in England and Wales during the audit period:

- 54% of women diagnosed with DCIS had postoperative radiotherapy after BCS (57% for 50–69 years; 41% for 70+ years).
- Among women with early invasive disease, 85% of those aged 50–69 years had radiotherapy to the breast after BCS. Use of radiotherapy postoperatively was observed to decrease slightly with increasing age: 80% for women aged 70+ years (72% of women aged 80–89 years) received radiotherapy.

The use of radiotherapy after mastectomy is recommended only for patients with invasive disease who are considered to have a moderate or high risk of recurrence (eg four or more positive nodes) and is not recommended after mastectomy for women with DCIS.

- Among women with early invasive disease treated with mastectomy, the proportion of women who had radiotherapy to the chest wall decreased with age (37% 50–69 years; 31% 70+ years).

Examining the pattern of adjuvant³ radiotherapy after BCS across NHS trusts / local health boards highlighted that there was limited variation across NHS organisations among women aged 50–69 years, but that the proportion of women who received radiotherapy after breast conserving surgery among women aged 70+ years varied markedly. There was also variation across NHS organisations in the use of radiotherapy after mastectomy among women regardless of age.

Use of chemotherapy

Adjuvant chemotherapy improves disease-free survival and overall survival in patients with early invasive breast cancer, although the benefit appears to be greater in younger patients and the evidence for benefit in the over-80s is almost non-existent. Examining the overall pattern of chemotherapy use for women with early invasive breast cancer highlights patterns of treatment that were broadly consistent with clinical recommendations:

- There was greater use of both adjuvant and neo-adjuvant⁴ chemotherapy among women with higher stage early invasive disease
- The use of chemotherapy was more common among women with ER-negative disease (61% 50–69 years; 23% 70+ years) and among those with HER2- positive disease (60% 50–69 years; 28% 70+ years).

The results also highlight a decreased use of chemotherapy (both neo-adjuvant and adjuvant) with increasing age at diagnosis regardless of tumour characteristics. This is consistent with previous studies and might be expected given the increasing levels of poor health among older women and the relative lack of trial-based evidence for older patients. In the next annual report, we will provide greater insight into chemotherapy treatment patterns.

Key themes and pathways to improvement

The motivation for this national clinical audit was a concern that NHS breast cancer services had a variable approach to the management of breast cancer among older women compared with women aged under 70 years. It was recognised that some of this variation reflected differences in the severity of the breast cancer that older patients were diagnosed with, as well as the greater impact of comorbid conditions on treatment options. Nonetheless, a series of studies over the last decade had concluded that these factors could not explain all the observed variation between breast cancer services [Bates *et al* 2014; Lavelle *et al* 2014; Richards *et al* 2016].

What the NHS is doing well

In relation to our assessment of the care pathway in this report, the audit has found a high degree of consistency in some areas of care among women of all ages. The audit found similar levels of performance among NHS organisations in:

- the proportion of women having triple assessment at a single visit;
- access to a breast clinical nurse specialist;
- the distribution of times between the date of diagnosis and the start of primary treatment where this was surgery or chemotherapy; and
- access to sentinel node biopsy

³ Treatments given in addition to the primary, or initial, treatment.

⁴ Treatments given before the primary, or initial, treatment.

Room for improvement

However, NHS breast cancer units should not interpret these findings as an indication that breast cancer care in the NHS cannot be improved. Indeed, there are various reasons to recommend that units start to monitor their performance in this area using the audit indicators.

First, NHS organisations could look to improve performance generally in some areas of the care pathway, such as in reducing the extreme times between the date of diagnosis and the start of treatment. Second, breast cancer units have the potential to monitor their activity using local data in a timelier manner than is currently possible at a national level.

Third, this report highlights various areas of poor quality in the data submitted to NCRAS and the Wales Cancer Network during the years 2014–16. Starting to reproduce the indicators locally should help NHS organisations to determine why these specific data items are not always being submitted and to take remedial action to remove the identified barriers. Improving the quality of data sent to the cancer registration services is a key priority for the coming year. Particular attention should be given to the following data items as they are fundamental to understanding the nature of the disease and the treatment options available to patients:

1. Tumour size and its consistency with the entered T stage
2. N stage, M stage
3. ER status and HER2 status
4. Performance status.

There are other aspects of the care pathway in which the audit found differences in the primary treatment among women in different age groups as well as variation among NHS organisations. In particular, among women with early invasive breast cancer, the audit found:

- the proportion of women having surgery as their primary treatment fell with age, although the variation among NHS organisations was within expected levels once differences in patient case-mix were taken into account; and
- variation among NHS organisations in the proportion of women having radiotherapy after primary surgery (BCS or mastectomy).

All NHS trusts and local health boards should ensure that older women are offered treatments in line with guidelines and that chronological age alone should not be a dominant factor in the decision to offer particular treatments.

Recommendations

For breast cancer units within NHS trusts and local health boards

Data completeness of data items describing types of breast cancer

1. NHS trusts and local health boards must ensure that the following information is uploaded to the national cancer registration services:

- Tumour size and its consistency with the entered T stage
- N stage, M stage
- ER status and HER2 status
- WHO performance status.

Triple diagnostic assessment

2. All NHS trusts and local health boards must

- ensure that women are able to receive triple assessment at their initial clinic visit after referral for suspected breast cancer, in line with NICE recommendations; and
- review and, where necessary, improve the process of submitting, to the national cancer registration services, the dates of assessment for all investigations performed at a triple assessment clinic.

Involvement of a breast clinical nurse specialist (CNS)

3. All NHS trusts must

- ensure that women are assigned a named breast clinical nurse specialist (CNS) to provide information and support; and
- review how data on the assignment of a named breast CNS is submitted to NCRAS and ensure their figures agree with those reported by the patient experience survey.

Time from the date of diagnosis to first treatment

4. All NHS trusts and local health boards must ensure that

- the time from diagnosis to the start of first treatment is within specified limits.

Surgery for DCIS or invasive breast cancer

5. NICE [2009a] recommends treating patients with early breast cancer, irrespective of age, with surgery and appropriate systemic therapy, rather than endocrine

therapy alone, unless significant comorbidity precludes it. All NHS trusts and local health boards must ensure that

- WHO performance status and, for women having surgery, American Society of Anaesthesiologists classification (ASA) score are complete. This will enable better understanding of the reasons behind the variation in the patterns of primary surgery between women of different ages and across NHS organisations.

Radiotherapy after breast cancer surgery

6. NHS trusts and local health boards must ensure that

- radiotherapy be considered for all women who receive BCS for DCIS or early invasive breast cancer after breast conserving surgery, in line with guidelines, regardless of age; and
- all women at higher risk of local recurrence with early invasive breast cancer who undergo mastectomy should be considered for adjuvant radiotherapy.

Chemotherapy for early invasive breast cancer

7. All NHS trusts and local health boards must ensure that

- chronological age alone should not be a dominant factor in the decision to offer chemotherapy for women at high risk of recurrence especially if their breast cancer is ER-negative or HER2-positive, in line with guidelines.

For commissioners / regional networks

8. Commissioners (in England) and Welsh health boards should review the results for the organisations within their regions to assure themselves of the quality of care provided to their patients. They should work with NHS providers to

- develop strategies for addressing areas of variation; and
- ensure local providers are able to submit complete and accurate data to the national cancer registration services.

For professional stakeholder organisations

9. Professional stakeholder organisations should collaborate and define the need for a reliable, consistent and recordable description of patient fitness. This will improve the accuracy in reporting on treatments and outcomes in older patients.

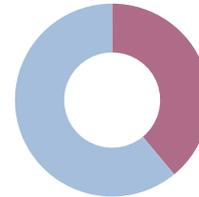
The aim of NABCOP is to evaluate process of care and outcomes for women, aged 70 years or over, diagnosed with breast cancer in England and Wales.

2014–2016

119,704 new diagnoses of unilateral breast cancer among women aged 50 years and older

61%

aged 50–69 years



39%

aged 70+ years

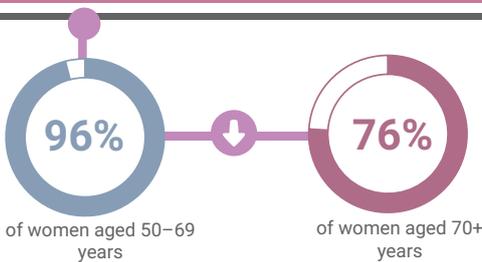
How does breast cancer differ by age in England and Wales?

in women aged 50–69 years

in women aged 70+ years

Presentation through screening	57%	👤👤👤👤👤👤👤👤	18%	👤👤👤👤👤👤👤
Invasive breast cancer	86%	👤👤👤👤👤👤👤👤👤	94%	👤👤👤👤👤👤👤👤👤
Early stage invasive breast cancer	76%	👤👤👤👤👤👤👤👤	70%	👤👤👤👤👤👤👤

Key findings



had surgery for early invasive breast cancer

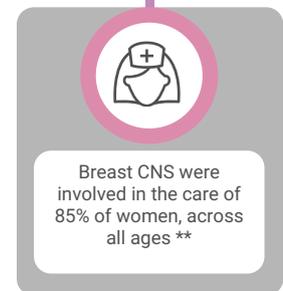
98% of women aged 50–69 years

87% of women aged 70+ years

without medical problems received surgery for early invasive breast cancer

Regional variation in treatment patterns for older women

- in rate of surgery
 - in rate of radiotherapy
- for early invasive breast cancer



** where reported

Chemotherapy



low use in older women, regardless of tumour characteristics

Recommendations

- For breast cancer units within NHS trusts/health boards:** To ensure accurate reporting of local practices, there must be improvement in the completeness and quality of data returns to national cancer registration services.
- For commissioners/ local networks:** To review results of their local organisations, commissioners/local networks must hold providers to account to address areas of variation, including the process for data submission to cancer registration services.
- For professional stakeholder organisations:** To collaborate and define the need for a reliable, consistent and recordable description of patient fitness. This will improve the accuracy in reporting on treatments and outcomes in older patients.

Further information

www.nabcop.org.uk

@NABCOP_news

1. The National Audit for Breast Cancer in Older Patients (NABCOP)

1.1 Background

Various studies have examined the delivery of breast cancer care by NHS services in the UK, and have found that in many cases hospital services have a non-standard and variable approach to the management of older patients [NCIN 2011]. The diversity in the patterns of care among younger and older patients may arise for various reasons, and is not in itself evidence of deficiencies in breast cancer care among older women. Possible reasons for the variation include:

- differences in the nature and extent of disease;
- differences in the prevalence and severity of comorbidities and frailty that may contraindicate surgery, chemotherapy or radiotherapy; and
- patient preference, cultural attitudes and social circumstances.

Nonetheless, the variation may also arise because of idiosyncrasies linked with clinical practice. Although clinical guidelines emphasise that breast cancer treatment should be based on clinical need and fitness for treatment rather than age [NICE 2009b; Biganzoli *et al* 2012], there is currently a lack of advice in these guidelines about the best way to tailor treatments to the individual needs of older women. This can result in different treatment preferences among clinicians.

There is also evidence that older women are less involved in the decision-making process than younger women, and that clinicians have a different approach to communication and management in response to a patient's age [WMCIU 2011; Lavelle *et al* 2014; Morgan *et al* 2015].

1.2 Aim of the audit

The **National Audit of Breast Cancer in Older Patients (NABCOP)** was established in April 2016 to evaluate the process of care and outcomes for women, aged 70 years or over, diagnosed with breast cancer and treated in NHS hospitals within England and Wales. Breast cancer is the most common female cancer in the UK. About 45,000 new cases of breast cancer are diagnosed in women each year in England and Wales, about one-third of which are in women aged over 70 years [ONS 2015].

The audit will examine the care pathway from initial diagnosis to the end of the primary therapy, and provide information on the comparative performance of NHS trusts and local health boards. The audit will investigate whether the care received by older women with breast cancer is consistent with recommended practice for breast cancer management, as described by (among others) the NICE guidelines [NICE 2009a; NICE 2009b], and will identify areas of care where improvements can be made. Because current clinical guidelines lack specific recommendations on the management of older women, the audit follows a comparative approach in which the patterns of breast cancer care observed for women diagnosed aged 70+ years are compared with those among women diagnosed aged 50–69 years. This will identify whether older women with breast cancer receive equitable care compared to younger women.

NABCOP is a collaboration between the Association of Breast Surgery (ABS) and the Clinical Effectiveness Unit (CEU) of the Royal College of Surgeons of England (RCS), and is commissioned by the Healthcare Quality Improvement Partnership (HQIP) as part of the National Clinical Audit Patient Outcomes Programme. The audit is overseen by a project board and supported by a clinical steering group (CSG), whose role includes advising on the priorities for the audit and helping with the interpretation of its results. The CSG has members from patient associations, medical associations, multi-disciplinary experts in the area of breast cancer and medical care of the older person, and policy makers (see Appendix 1).

More information about the audit can be found on the website: www.nabcop.org.uk.

1.3 Overview of the 2018 NABCOP annual report

In this second annual report, we present information on the care received by women diagnosed between 1 January 2014 and 31 December 2016 in England and Wales. This period reflected the most recent data available from the English National Cancer Registration and Analysis Service and the Wales Cancer Network, which was partly determined by the need to allow at least six months of follow-up after diagnosis to capture the treatments received by women⁵.

The report describes information regarding diagnosis and staging, and initial treatments within NHS providers. The report investigates how these patterns of care differ between women in the younger and older age groups, and distinguishes between three main groups of breast cancer:

- Ductal carcinoma *in situ* (DCIS), the most common type of non-invasive tumour
- Early invasive disease (defined as stage 1 to 3A)
- Advanced disease (stage 3B, 3C and 4).

The information presented in this 2018 annual report was derived primarily from data collected as part of the national cancer registration process in England and Wales. This was supplemented with information from routinely collected hospital data, specifically in relation to the provision of breast cancer surgery.

1.4 Management of older women with breast cancer

There is considerable variation among women aged over 70 years in terms of their general health, and chronological age alone does not correspond well to the notion of biological age. Biological age takes into account how someone's health is affected by chronic conditions (both physical and mental) as well as physical fitness and degree of frailty. The management of breast cancer for individual women will reflect the characteristics of their disease, as well as their general health because of their ability to tolerate different therapies, and their personal preferences (see Figure 1.1 for a general overview of typical care pathway). For example:

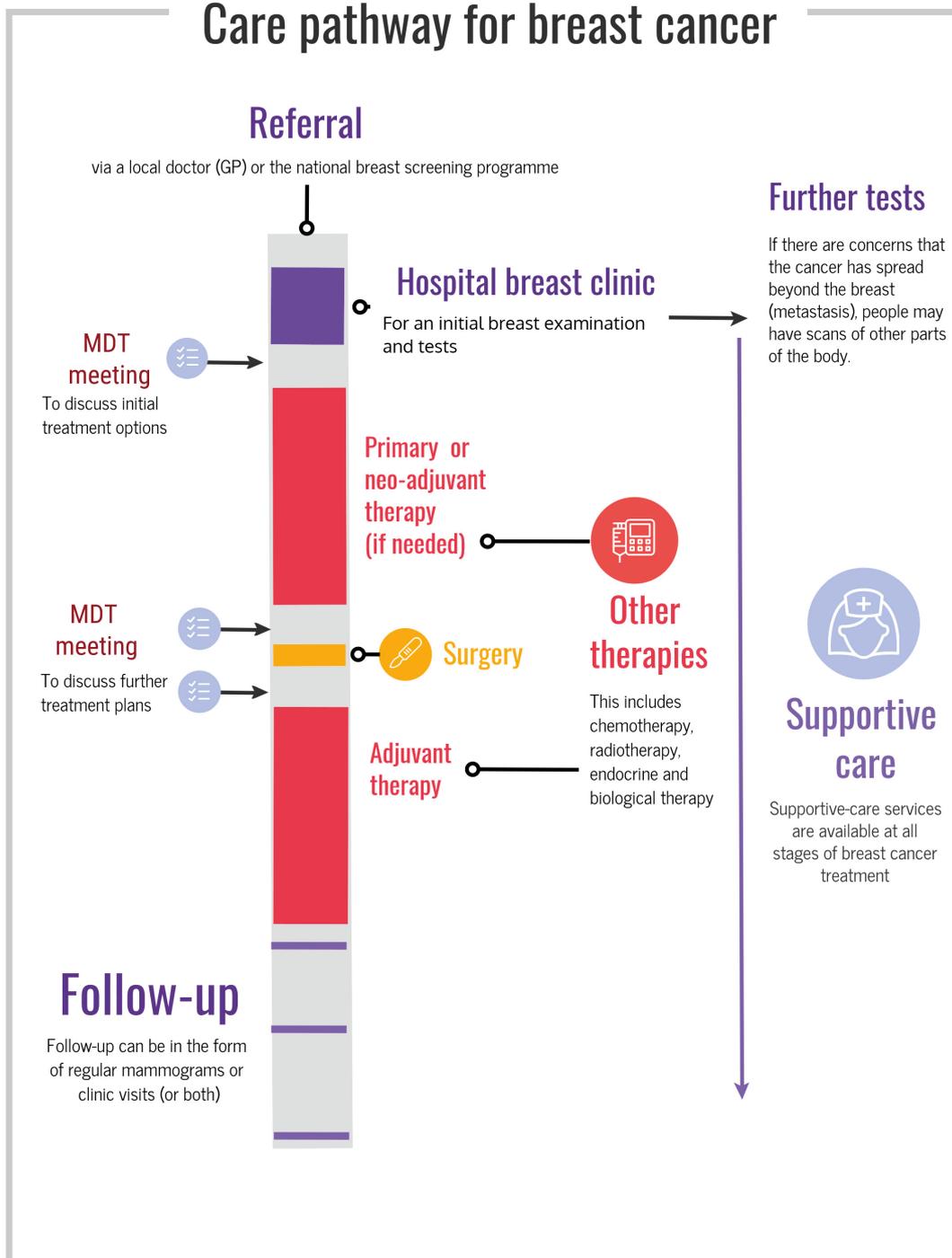
- The short-term risks of surgery and anaesthesia are exacerbated by the presence of cardiovascular, lung and kidney disease. Consequently, in frail women for whom surgery may pose a significant risk, it may be appropriate to offer primary endocrine therapy instead [Hind *et al* 2015]
- The ability to tolerate chemotherapy and radiotherapy may also be reduced by poor physical function and frailty [Biganzoli *et al* 2012]
- The benefits of different therapies may be influenced by whether or not a woman's life expectancy is more likely to be affected by the breast cancer or other co-existing conditions [Lavelle *et al* 2014].

Finally, it is worth noting that older women with breast cancer may differ from younger women in how they balance a desire to extend their life by undergoing treatments that potentially have unpleasant side effects against a desire to maintain their current quality of life [Wedding *et al* 2007].

There is no agreed definition of an "older woman with breast cancer", but the phrase is often used to refer to women aged 70 years or older when diagnosed [Biganzoli *et al* 2004]. This partly reflects how the characteristics of the disease vary across age groups, with the majority of women aged 70 or over diagnosed with invasive breast cancer. It also partly reflects the pathway to diagnosis, with breast screening offered to women aged 50–70 years. We will follow this definition of an older woman in this report.

⁵ It takes a minimum of nine months for data on a breast cancer patient to be available for inclusion in a NABCOP report. Patients diagnosed in December 2016 will have data on investigations, initial treatments and follow-up treatments uploaded via the Cancer Outcomes and Services Dataset (COSD) between February and July 2017. Therefore, their final registration will not be completed until August 2017. NCRAS must then quality assure this dataset before making it available for statistical analysis.

Figure 1.1: An example of a typical breast cancer care pathway in English NHS hospitals and Welsh local health boards



2. Audit methods

2.1 Introduction

The NABCOP uses patient data collected by the national cancer registration services in England and the Wales Cancer Network in Wales. For English patients, the National Cancer Registration and Analysis Service (NCRAS), provided data from its Encore system, which collates patient data from a range of national data-feeds across all NHS acute hospitals. These data feeds include:

- National cancer registrations, which include information from hospital pathology systems
- Cancer Outcomes and Services Dataset (COSD) data items, which are submitted routinely by service providers via multi-disciplinary team (MDT) electronic data collection systems to the National Cancer Data Repository (NCDR) on a monthly basis
- Chemotherapy and radiotherapy data stored in the systemic anti-cancer therapeutic (SACT) database and radiotherapy dataset (RTDS)
- Hospital Episode Statistics (HES), the administrative database of all NHS hospital admissions in England. Records were supplied by NHS Digital to NCRAS.

Data on Welsh patients were provided by the Wales Cancer Network (WCN) using the Canisc electronic patient record system. In Wales, the Cancer Network runs quarterly reports of cancers diagnosed which are distributed to designated clinicians within the health boards for validation of accuracy and completeness. The validated reports are then signed off by the network audit lead for data submission. The records of these patients from the Patient Episode Database for Wales (PEDW), the Welsh equivalent of HES, are also linked to the cancer records.

NCRAS and the Wales Cancer Network extracted the details of women, aged 50 years and over, diagnosed with unilateral breast cancer in England and Wales over the three-year period between 1 January 2014 and 31 December 2016.

The NABCOP project team based at the Clinical Effectiveness Unit (CEU)⁶ process and analyse the complex and large datasets received from NCRAS and the Wales Cancer Network, prior to reporting on the performance of providers of breast cancer services in England and Wales.

Specifically, using specialised statistical software⁷, the project team:

- **Clean the datasets received:** This includes checking the datasets for discrepancies, and undertaking processes such as de-duplication of records and data augmentation (adding of extra information). For example, if a patient's oestrogen receptor (ER) status is missing in the English Cancer Registry dataset, this may be present in the English Cancer Outcomes and Services Dataset (COSD) dataset. This additional information results in a more complete set of information on ER status.
- **Merge the relevant datasets:** This involves ensuring that the English and Welsh datasets are re-structured to fit together, in order for them to be analysed simultaneously.
- **Where necessary, derive new information (data items) to enable final analyses:** For example, calculation of the Charlson comorbidity score using patient diagnosis information in HES and PEDW.
- **Conduct analyses and present audit results:** In aggregated tables and graphs for annual reports and other outputs (such as peer reviewed articles and papers).

Types of breast cancer patients

In this report, we distinguish between three main groups of breast cancer:

- Ductal carcinoma *in situ* (DCIS), the most common type of non-invasive tumour;
- Early invasive disease (defined stage 1 to 3A);
- Advanced disease (stage 3B, 3C and 4).

The allocation of patients to these groups was based on the overall stage, as determined using the UICC TNM staging classification, which was being used by the cancer registration services in England (7th edition) and Wales (6th edition) during 2014–16. The overall stage is derived from the individual T (tumour size), N (lymph node status) and M (metastatic disease) components, the process of which is described overleaf.

⁶ The CEU is an academic collaboration between The Royal College of Surgeons of England and the London School of Hygiene and Tropical Medicine, and undertakes national clinical audits and research. Since its inception in 1998, the CEU has become a national centre of expertise in methods, organisation, and logistics of large-scale studies of the quality of surgical care.

⁷ Stata® is a statistical package for data analysis, data management, and graphics (<https://www.stata.com/>)

Table 2.1: TNM stage groupings

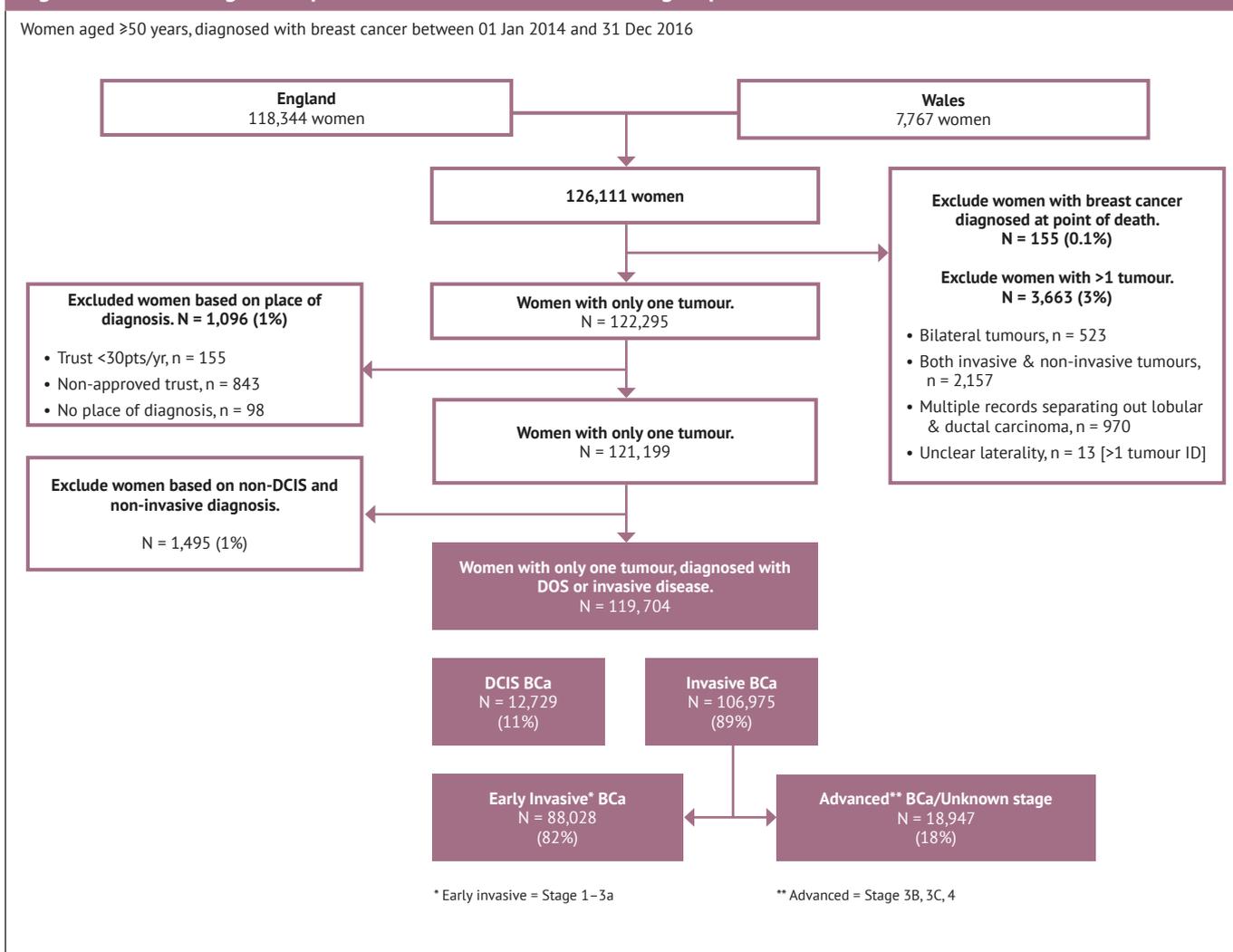
Stage grouping	T stage	N stage	M stage	Key
DCIS / Stage 0	Tis	N0	M0	Tumour size T1 = 1–20mm T2 = 21–50mm T3 = 51+ mm T4 = tumour spread to skin or chest wall Nodal status N0 = no cancer cells in lymph nodes N1, N2, N3 increasing spread of cancer within the lymphatic system mi = micrometastases
Early breast cancer				
IA	T1	N0	M0	
IB	T0 / T1	N1(mi)	M0	
IIA	T0 / T1 T2	N1 N0	M0	
IIB	T2 T3	N1 N0	M0	
IIIA	T0, T1, T2 T3	N2 N1, N2	M0	
Locally advanced disease				
IIIB	T4	N0, N1, N2	M0	
IIIC	Any T	N3	M0	
Metastatic disease / Stage IV	Any T	Any N	M1	

Note: More information about staging and other terms used in this report can be found in the glossary at the end of this report.

Preparation of patient cohort

The figure below describes how the audit group was defined from the datasets provided by the English and Welsh cancer registries, over the three years of 2014, 2015 and 2016.

Figure 2.1: Flow diagram of patients included within NABCOP group



Key patient characteristics

Information on tumour characteristics are captured within the cancer registry datasets, typically being measured around the time of diagnosis or after surgery. The English and Welsh datasets contain data items (or allow these to be derived) for:

- tumour size and laterality;
- tumour grade;
- the disease stage using the UICC TNM classification system; and
- molecular markers: oestrogen receptor (ER) status, progesterone receptor (PR) status, and HER2 (human epidermal growth factor receptor 2) status.

Other patient characteristics such as age and performance status were also primarily sourced from the NCRAS and Canisc datasets. Performance status is a measure of how disease(s) impact(s) a patient's ability to manage on a daily basis, which can become more limited as an individual ages [Oken *et al* 1982]. The measure collected in the datasets was developed to standardise the reporting of chemotherapy toxicity and response in clinical trials in cancer patients.

The presence of comorbidities was derived from information on secondary diagnoses in the hospital admission data (HES / PEDW) measured using the Royal College of Surgeons of England (RCS) modified Charlson score [Armitage *et al* 2010]. The RCS Charlson score is derived from the commonly used Charlson Comorbidity system, which was adapted to suit surgical patients. A patient is scored based on the presence or absence of 14 specified medical conditions (see glossary for further details).

Translation of a frailty index into a version derivable from hospital data

Among older patients, frailty plays an important role in the selection of breast cancer treatments. This is because, in frail women, surgery may pose a significant risk, and the ability to tolerate chemotherapy and radiotherapy may be reduced (see section 1.4 on the management of older women with breast cancer).

NHS trusts and local health boards are recommended to assess patients for frailty using a formal assessment tool, although services are hampered by the lack of an agreed instrument and the inaccuracy of simple tools.

A common way of describing frailty is to use the "cumulative deficit model". This defines frailty in relation to a range of variables that include symptoms, signs, diseases, disabilities and abnormal laboratory values. These are collectively referred to as deficits [Mitnitski 2001]. The original model was based on 92 deficits but recent work has shown that this can be reduced to a more manageable number. Recently, Clegg *et al* 2016 has proposed a method of deriving a frailty index from primary care electronic health records using Read codes to capture 36 individual variables that are biologically plausibly associated with frailty, which was named the electronic Frailty Index (eFI) (see Box 1 for list of deficits).

Box 1. List of 36 deficits contained in the eFI

Activity limitation	Ischaemic heart disease
Anaemia and haematinic deficiency	Memory and cognitive problems
Arthritis	Mobility and transfer problems
Atrial fibrillation	Osteoporosis
Cerebrovascular disease	Parkinsonism and tremor
Chronic kidney disease	Peptic ulcer
Diabetes	Peripheral vascular disease
Dizziness	Polypharmacy
Dyspnoea	Requirement for care
Falls	Respiratory disease
Foot problems	Skin ulcer
Fragility fracture	Sleep disturbance
Hearing impairment	Social vulnerability
Heart failure	Thyroid disease
Heart valve disease	Urinary incontinence
Housebound	Urinary system disease
Hypertension	Visual impairment
Hypotension/ syncope	Weight loss and anorexia

We used this approach and translated these deficits into ICD-10 codes that could be identified within the diagnosis fields within the hospital admissions data (note that it was not possible to find a translation for the deficit of poly-pharmacy). We propose that this is equivalent to the primary care based eFI. It produced the type of pattern that would be expected from a measure of frailty (Table 4.1) and was incorporated into the risk-adjustment algorithms.

Table 2.2: Distribution of frailty among women in the audit group by age at diagnosis calculated using the hospital version of the electronic Frailty Index (eFI)

	Age at diagnosis	
	50–69 years	70+ years
Total number of patients	72, 540	47, 304
Frailty category (based on score*)		
Fit (0–0.12)	98.6%	87.7%
Mild frailty (>0.12–0.24)	1.2%	9.5%
Moderate to severe frailty (>0.24)	0.2%	2.8%
Missing	2, 879	3,981

* The Frailty score is derived by counting the number of deficits a patient has and dividing by the total number of deficits (n=35).

Information on treatment patterns

The information on patterns of surgery was derived using the data extracted from the routine hospital datasets (HES for English patients and PEDW for Welsh patients) as well as the cancer registration treatment datasets. We identified when a patient underwent different types of surgery by searching for admissions in which the following OPCS procedure codes appear in the list of procedure codes

- breast conserving surgery (B28.1-3, B28.5-9)
- mastectomy (B27)
- sentinel lymph node biopsy (T86.2, T87.3, T91.1)
- axillary nodal dissection (T85.2).

Statistical analysis

For the majority of the core indicators reported here, the results are reported as percentages (%). Results are typically provided as an overall figure and broken down by age at diagnosis, and by diagnosing NHS organisation. Note: within tables, the total percentage may not equal 100% owing to rounding errors.

In descriptive analyses of continuous variables, the distribution of values is described using appropriate statistics (eg mean and standard deviation or median and interquartile range). We follow the Office for National Statistics policy on the publication of small numbers to minimise the risk of patient identification from these aggregate results.

Comparisons across the two pre-defined age groups (50–69 years; 70+ years) are made for all core indicators. To show this graphically across NHS trusts and local health boards, we have used a “pyramid” plot: the left side of the pyramid shows the 50–69 years population and the right side displays the 70+ years population. Along the vertical axis, the pyramid plots display the organisations. Along the horizontal axis, the plots display the value of the indicator (eg percentage of women who had triple assessment). The centre of the pyramid starts at the value of zero and extends out with increasing size to the left for the 50–69 years group and right for the 70+ years group. Note there are two exceptions to this where type of molecular marker and type of primary surgery are instead on the horizontal axis and the two age groups overlaid.

Furthermore, the pyramid plots are formatted by country, with Wales at the top followed by England below. These plots are ordered by proportions in the group of women aged 50–69 years, as this is the reference group for comparison with women aged 70+ years.

For analyses looking at the sequencing of treatments, the following time frames were used in order to more accurately conclude that two treatments were given in sequence. This applied to the following indicators:

- Radiotherapy after surgery: radiotherapy is reported as starting within six months of surgical procedure (BCS or mastectomy) OR radiotherapy is reported as starting over six months after surgery, but chemotherapy is given in the interim.

For several indicators, such as the proportion of women having surgery, the values for each NHS trust / local health board were adjusted to take into account the differences in the case-mix of patients treated at each organisation. The risk adjustment process was performed using a multivariable logistic regression model.

This model was used to estimate the probability of the patient experiencing the event (eg the likelihood of having surgery) for each individual, and these were then summed to calculate the predicted number of events for each NHS organisation. The regression models were developed from the following:

- Patient characteristics: age at diagnosis, comorbidities, performance status, frailty status and the Indices of Multiple Deprivation for England (IMD) and Wales (WIMD).
- Tumour characteristics: invasive grade, tumour stage group, ER and HER2 status and nodal disease burden.
- Type of breast surgery (where applicable).

The date of diagnosis⁸ used to define the audit group, and subsequently used within relevant analyses, was provided within the NCRAS Registry dataset for English patients and within the Canisc dataset for Welsh patients. This is calculated using a methodology in accordance with the European Network of Cancer Registries.

The analysis was undertaken by the audit team at the Clinical Effectiveness Unit.

⁸ Based on the data available this was the date of biopsy for most cases.

3. Participation and data completeness

3.1 Participating NHS organisations across England and Wales

All NHS trusts submitting data to NCRAS (for England) and local health boards submitting data to Canisc (for Wales) were considered for inclusion within this report. A full list of English NHS trusts and Welsh local health boards can be found in Appendix 2.

In total, 131 English NHS trusts and 6 Welsh local health boards were included in the audit. In most cases, the analyses describe the patterns of care at organisations by allocating women to the hospital at which they were diagnosed. This means that some indicators are not derived for particular specialist cancer treatment centres.

3.2 Overview of data completeness

Patterns of treatment are influenced by various features of a woman's breast cancer and general health. The tumour characteristics that play a major role in determining what treatments are most appropriate are:

- Tumour grade
- Tumour size (T stage)
- The number of metastatic lymph nodes for invasive disease (N stage)
- Metastatic spread (M stage)
- Molecular markers: oestrogen receptor (ER) status and HER2 status
- Measures of general health that influence treatment patterns and outcomes include:
 - WHO performance status, a measure of physical function
- The presence of comorbidities

Tables 3.1 and 3.2 show the data completeness for a selection of core data items for English NHS trusts and Welsh local health boards, respectively. These highlight a mixed picture of data completeness across the core data items and illustrate how completeness has changed over the time period covered by this report. In summary:

- Laterality and invasive grade were well completed in both English and Welsh datasets. Tumour size was less well reported than the T stage despite the fact that T stage is derived from tumour size.
- In England: Tumour (T) stage was 91% complete; Nodal (N) stage was 86% complete, and its completeness improved annually
- In Wales: Tumour (T) stage was 80% complete; whilst Nodal (N) stage was complete for all women⁹

The following data items are necessary for clinical decision making within breast cancer units. Where completeness was poor, it is unclear why items were not being uploaded to NCRAS and Canisc. Disappointingly, the WHO performance status was not well reported in any year in either England or Wales, and only eight English NHS trusts submitted this information for more than 80% of women.

⁹ Nodal stage completeness based on reported N stage, augmented with details from reported number of nodes positive and determined to be N0 where nodal stage still missing but reported diagnosis code is DCIS.

Table 3.1: Availability of core data items for women diagnosed in England; total availability and breakdown by year of diagnosis

Data Item	Source	Availability of data item by year of diagnosis						
		Total% available	2014		2015		2016	
			% available (all trusts)	No. trusts >80%*	% available (all trusts)	No. trusts >80%	% available (all trusts)	No. trusts >80%
Invasive grade	Cancer Registry; COSD	99%	99%	131	100%	131	100%	131
Laterality	Cancer Registry; COSD	99%	99%	131	99%	131	99%	131
Ethnicity	Cancer Registry	94%	95%	130	93%	127	94%	130
Tumour stage	Cancer Registry	94%	92%	123	94%	127	95%	129
Metastases stage**	Cancer Registry; COSD	94%	91%	119	94%	129	95%	127
Stage	Cancer Registry; COSD	93%	91%	118	94%	129	95%	127
Non-invasive grade	COSD	92%	85%	95	95%	121	96%	120
Nodal stage	Cancer Registry; COSD	86%	84%	102	87%	120	88%	115
ER status	Cancer Registry; COSD	86%	78%	81	88%	109	90%	116
HER2 status	Cancer Registry; COSD	82%	79%	78	81%	90	85%	93
Tumour size	Cancer Registry; COSD	71%	71%	33	69%	35	72%	39
PR status	Cancer Registry; COSD	49%	46%	25	49%	37	52%	43
WHO performance status	Cancer Registry & SACT	30%	23%	12	31%	17	38%	22

KEY: * No. of trusts with more than 80% of women having this data

** Mx is interpreted as unmeasured and not counted as missing

Note: ER, PR and HER2 status data completeness for invasive breast cancer only

Tumour size completeness was higher in those women receiving surgery, although all women should have their tumour sized and this reported.

Table 3.2: Availability of core data items for women diagnosed in Wales; total availability and breakdown by year of diagnosis

Data Item	Source	Availability of data item by year of diagnosis						
		Total% available	2014		2015		2016	
			% available (all LHBs)	No. LHBs >80%*	% available (all LHBs)	No. LHBs >80%	% available (all LHBs)	No. LHBs >80%
Nodal stage	Canisc	100%	100%	6	100%	6	100%	6
Laterality	Canisc	100%	100%	6	100%	6	100%	6
Non-invasive grade	Canisc	99%	99%	6	99%	6	99%	6
Invasive grade	Canisc	99%	99%	6	99%	6	99%	6
ER status	Canisc	94%	92%	6	92%	6	97%	6
HER2 status	Canisc	91%	89%	5	89%	5	94%	6
Metastases stage**	Canisc	83%	85%	5	79%	5	84%	5
Tumour stage	Canisc	80%	82%	4	77%	5	82%	5
Tumour size	Canisc	64%	62%	3	63%	0	67%	1
PR status	Canisc	54%	52%	1	53%	2	58%	2
WHO performance status	Canisc	1%	1%	0	1%	0	3%	0

KEY: * No. of Local health boards (LHB) with more than 80% of women having this data

** Mx is interpreted as unmeasured and not counted as missing

Note: ER, PR and HER2 status data completeness for invasive breast cancer only

Tumour size completeness was higher in those women receiving surgery, although all women should have their tumour sized and this reported

3.3 Recorded molecular marker status

Numerator	1. Women with ER status recorded 2. Women with HER2 status recorded
Denominator	Women diagnosed with invasive breast cancer

This section focuses on two of the core data items highlighted in the previous tables, which form part of the core indicators that NABCOP aims to evaluate.

Determining planning and receipt of primary systemic or adjuvant treatment requires tumour characterisation. As well as information on disease stage, it is recommended that the results of ER and HER2 assessments for invasive breast cancer are available and recorded at the multi-disciplinary team meetings:

1. Women with tumours which are ER-positive are suitable for consideration of primary endocrine therapy. This treatment modality can be used as the primary treatment for patients who have a short life expectancy or are unsuitable for surgery [Biganzoli *et al* 2012].
2. Women with tumours which are HER2-positive are suitable for trastuzumab (biological therapy) as a systemic treatment [NICE 2009a].

The importance of these two molecular markers is recognised in NICE quality standard (QS12) statement 4 [NICE 2011]:

“People with newly diagnosed invasive breast cancer... have the oestrogen receptor (ER) and human epidermal growth factor receptor 2 (HER2) status of the tumour assessed.”

What do we see within this audit group?

Data on ER status and HER2 status was reported for 86% and 82%, respectively, of women diagnosed with invasive breast cancer of all stages (n=106,975). Completion varied by age for both markers (Figure 3.1)

For the English data:

- ER status completeness decreased with increasing age from 87% to 75%
- HER2 status also decreased from 86% to 59%.

For the Welsh data:

- ER status completeness fell marginally with increasing age from 94% to 90%
- HER2 status also changed marginally from 89% to 81%.

The completeness of these two molecular marker data items was found to be higher among English women with screen-detected cancer (90% vs 84% for ER status; 88% vs 80% for HER2 status); completeness was comparable, if slightly higher among those with screen detected cancer, for Welsh women.

There was seen to be variation in completeness of both molecular markers, but particularly HER2 status, by NHS trust regardless of age (Figure 3.2).

Recommendations for NHS organisations submitting data to NCRAS and Canisc

For each of the following data items that describe a woman’s breast cancer and general fitness, NHS trusts and local health boards must identify why this information was not available for upload to NCRAS and Canisc and introduce procedures to ensure that it is submitted whenever available:

- Tumour size and its consistency with the entered T stage
- N stage and M stage
- ER status and HER2 status
- WHO performance status.

Figure 3.1: Proportion of women with invasive breast cancer that had complete data on ER status and HER2 status, by age at diagnosis

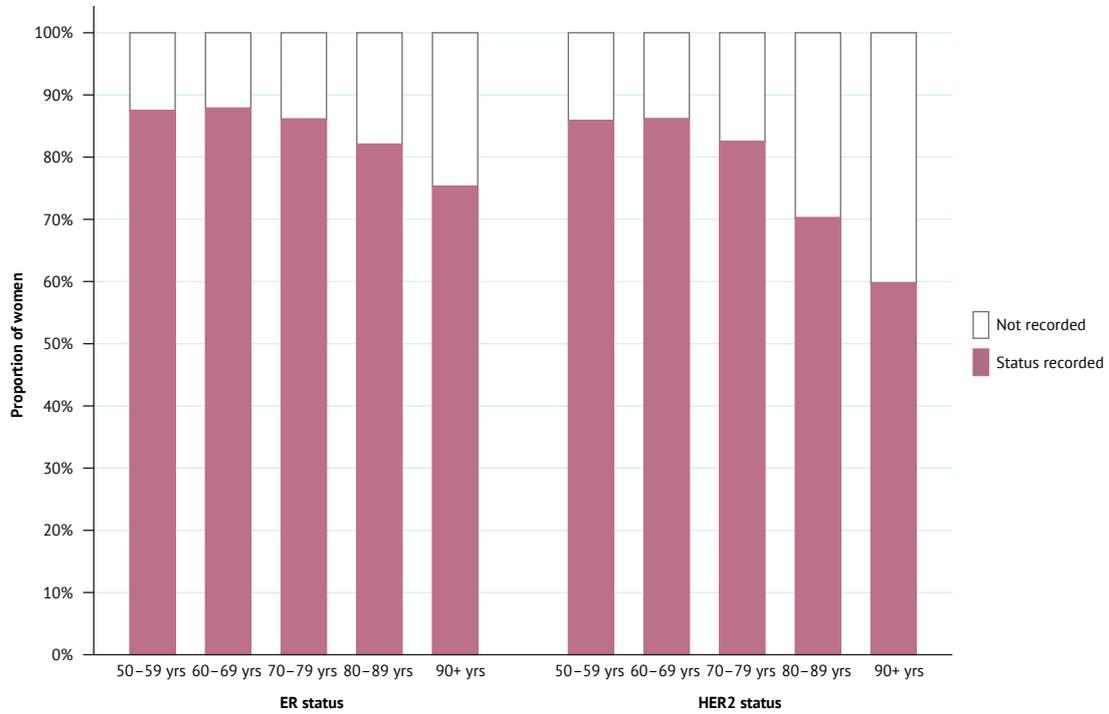
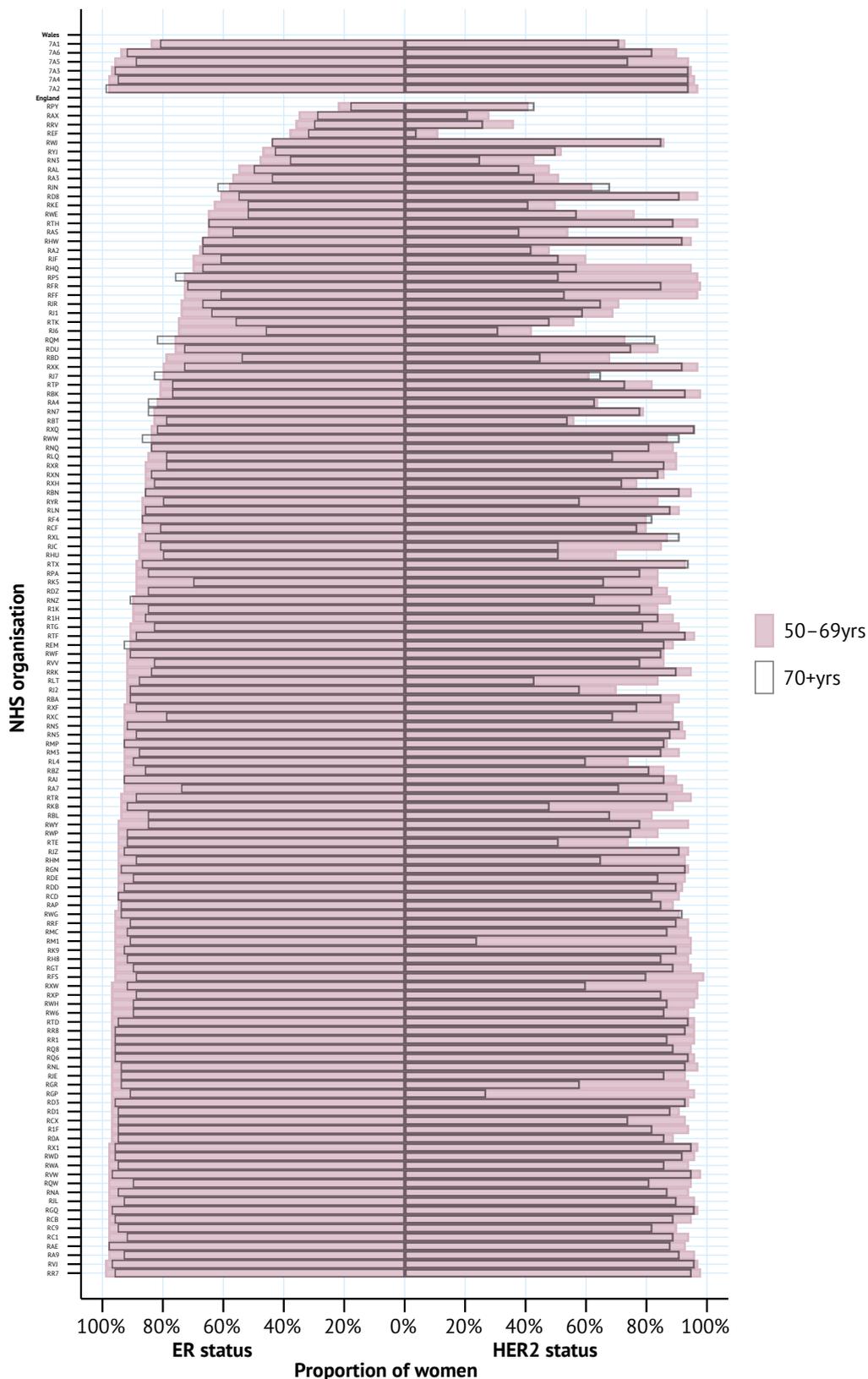


Figure 3.2: Proportion of women with invasive breast cancer with ER status (on left) and HER2 status (on right) reported by diagnosing LHB/trust and age at diagnosis



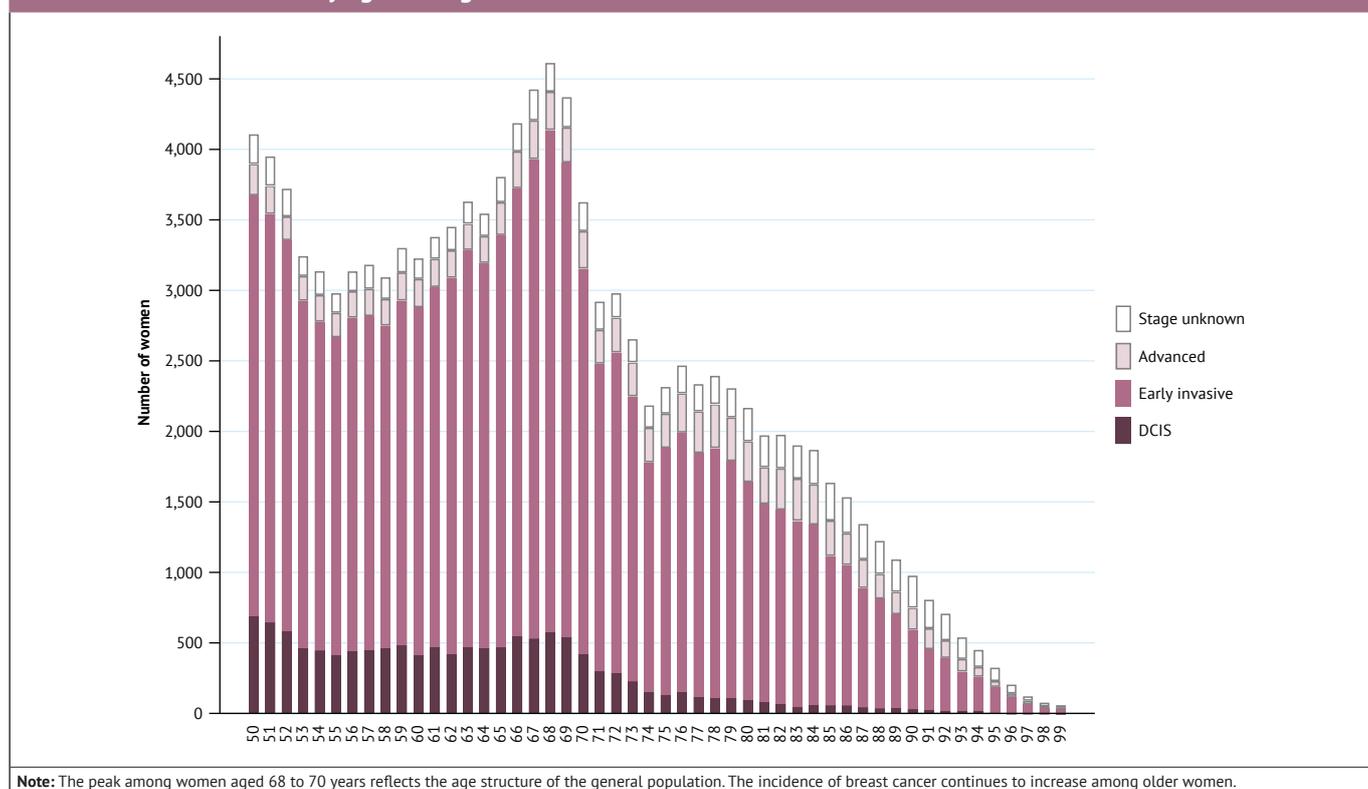
Note: Figure ordered by country of diagnosis and then organisation-specific proportions with ER status (left side) reported in women aged 50-69 years at diagnosis as the reference group for comparison with women aged 70+ years (proportions for 70+ years shown in the clear bars overlaying the pink bars).

4. Patient Characteristics

The NABCOP is focused on the care of women with breast cancer aged 70 years and over, in comparison to those aged 50–69 years, at diagnosis. The number of women who were diagnosed in England and Wales by age is shown in Figure 4.1. The number of diagnosed women was highest among women aged 65–69 years, and lower in older women. This reflects the age structure of the general population. The incidence of breast cancer within the 65–69 age band is roughly 400 per 100,000 and the incidence continues to rise to around 470 per 100,000 for women aged 80–84 years [ONS 2017].

Among women aged 50–69 years, 14% were diagnosed with DCIS. This decreased to less than 5% among women aged 85 years or older. Older women were also more likely to be diagnosed with advanced disease (Stage 3B-4); this accounted for 12% of women aged 70+ years compared with 6% of women aged 50–69 years. This difference is likely to reflect the use of breast screening in women under 70 years of age.

Figure 4.1: (Absolute) number of women diagnosed with breast cancer in England and Wales between 2014 and 2016 by age at diagnosis



Note: The peak among women aged 68 to 70 years reflects the age structure of the general population. The incidence of breast cancer continues to increase among older women.

Table 4.1 gives an overview of the patient and tumour characteristics of women within the audit, broken down by DCIS or invasive disease groupings. Among women diagnosed with DCIS, there was little difference between the characteristics of tumours for women aged 50–69 years compared with those aged 70 years and over.

Among those women diagnosed with invasive tumours, the key features of the disease among those aged 70+ years compared with aged 50–69 years are:

- A greater proportion had larger breast tumours
- Slightly more women had positive lymph nodes, although a lower proportion of the older women had lymph nodes sampled
- Similar proportions of women with invasive disease had high grade disease
- Similar proportions of women were ER-positive and/or HER2-positive. This is slightly unexpected given the large proportion of screen detected cancers in women aged 50–69 years.

Not surprisingly, more women aged 70 years and over at diagnosis were recorded as having one or more comorbid conditions.

Table 4.1: Patient and tumour characteristics for women aged 50 years and over diagnosed with DCIS or invasive breast cancer between January 2014 and December 2016

Characteristic at diagnosis	DCIS Group (n=12,729)		Invasive Group (n=106,975)	
	50–69 years	70+ years	50–69 years	70+ years
Number of women	10,002 (79%)	2,727 (21%)	62,477 (58%)	44,498 (42%)
Grade of disease - DCIS Invasive				
Low 1	9%	13%	18%	13%
Intermediate 2	27%	33%	52%	55%
High 3	64%	54%	28%	26%
Not assessable	0%	0%	2%	6%
<i>missing</i>	626	319	320	267
Tumour size (cm)				
>0.1–2	49%	47%	59%	42%
>2–5	38%	38%	35%	50%
>5	13%	15%	5%	8%
<i>missing</i>	7,439	2,079	11,936	14,341
Lymph node involvement where sampled				
Nodes examined	N/A	N/A	75%	51%
Number of nodes positive (if examined)				
0	N/A	N/A	71%	67%
1–3	N/A	N/A	22%	23%
4–9	N/A	N/A	4%	6%
10+	N/A	N/A	2%	3%
<i>missing</i>	N/A	N/A	234	145
Metastatic disease (M stage)				
M0	N/A	N/A	93%	89%
M1	N/A	N/A	4%	8%
Mx	N/A	N/A	3%	3%
<i>missing</i>	N/A	N/A	3,123	5,363
ER status				
Positive	N/A	N/A	86%	86%
Negative	N/A	N/A	14%	14%
<i>missing</i>	N/A	N/A	5,598	5,810
HER2 status				
Positive	N/A	N/A	13%	11%
Negative	N/A	N/A	81%	82%
Borderline	N/A	N/A	5%	6%
<i>missing</i>	N/A	N/A	8,242	10,124
Charlson comorbidity score				
0	90%	78%	91%	72%
1	8%	15%	7%	16%
2–3	2%	7%	2%	12%
<i>missing</i>	422	144	2,390	3,790
WHO performance status*				
0	92%	72%	88%	54%
1	6%	17%	9%	24%
2–4	1%	10%	3%	22%
<i>missing</i>	7,634	2,109	43,481	32,133

*Note: WHO performance status reported within two months of diagnosis and prior to primary treatment

Figure 4.2 highlights the change in disease severity by age in more detail. Among women aged 50–69 years, the majority of women had stage 1 or 2 disease, which is likely to reflect the influence of breast cancer screening. Among women aged 70–89 years at diagnosis, the proportion of stage 1 cancers decreased with age, with the proportion of stage 2 cancers increasing the most among the other known stage categories. There was a small increase in the proportion of women with metastatic disease (stage 4).

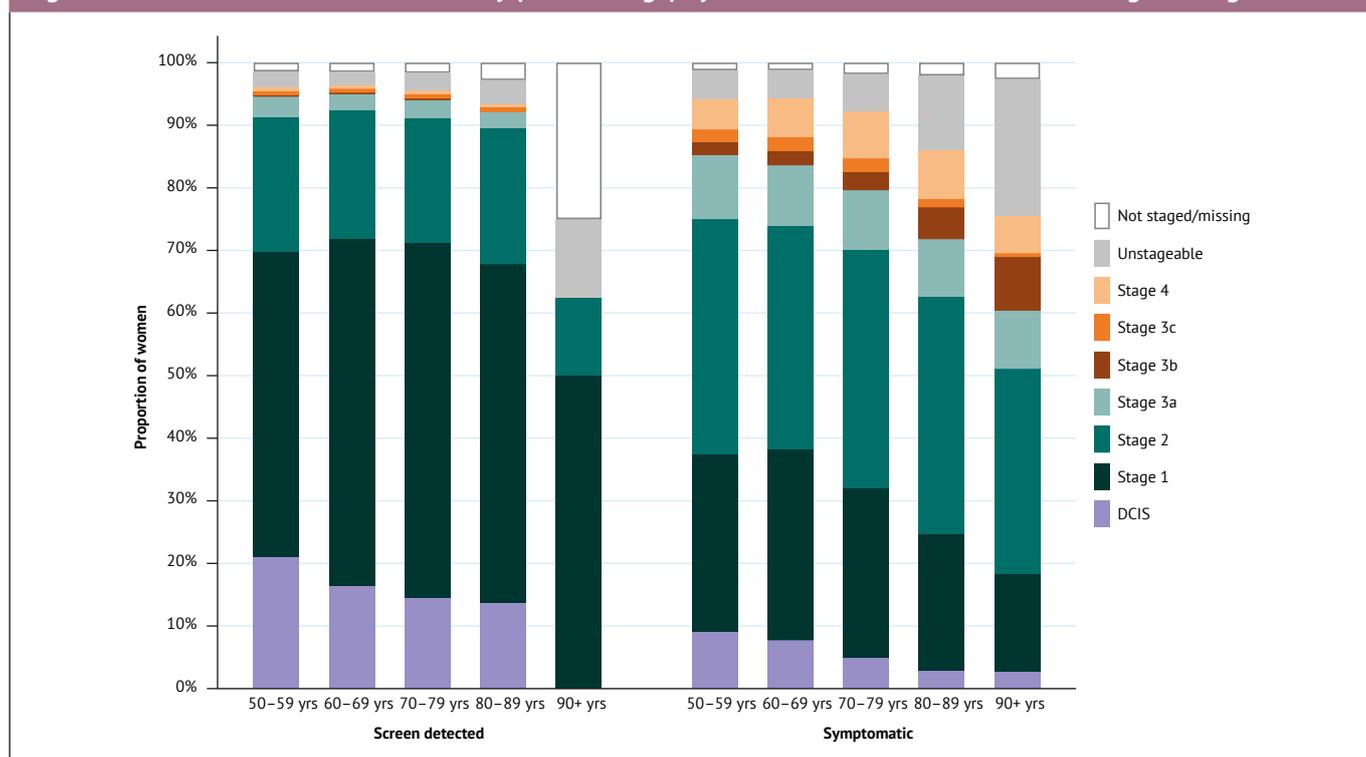
The other noticeable feature in Figure 4.2 is the increasing proportion of women with disease reported as “unstageable”, rising from 5% among women aged 50–69 years to more than 20% among women over 95 years. There are various possible reasons for this:

1. There may be unwillingness among women to undergo staging investigations or these may be judged clinically unnecessary given the general poor health of an individual.
2. There might be aspects of the care pathway that make the collection of the data more difficult.

In relation to the second point, we observed that, among women aged 50–69 years:

- The proportion of women with staging information did not substantially differ for women whose pathway to diagnosis was screening (96%) compared with those diagnosed with symptomatic disease (94%).

Figure 4.2: Distribution of disease severity (overall stage) by screen-detected cancer status and age at diagnosis



5. Diagnosis

This chapter focuses on those elements of diagnosis which illustrate the care pathway for women diagnosed with breast cancer, in particular the route through which a woman presents with breast cancer and how it is then diagnosed.

5.1 Route to diagnosis

Numerator	Number of women diagnosed after: 1. referral from GP 2. referral from screening 3. referral from other specialities 4. an emergency presentation
Denominator	Women with DCIS or invasive breast cancer (ie all women in the NABCOP)

In NHS trusts within England and local health boards in Wales, patients typically present with suspected breast cancer to a breast clinic through one of three main routes:

1. they may be referred by a general practitioner (GP) after experiencing symptoms associated with the cancer;
2. they may be referred from the national breast screening programmes (NHS Breast Screening Programme (NHSBSP) in England and Breast Test Wales (BTW) in Wales) which invite women aged 50–70 years to undergo a mammogram assessment every three years (women aged 47–73 years are eligible in some regions of England as part of the AgeX trial¹⁰); or
3. they may be referred after a clinical assessment and/or investigation performed for another disease (eg CT scan) has identified a potential breast cancer. This group of women are often elderly as they are more likely to have other chronic conditions.

Less commonly, diagnosis may be after an emergency presentation. Women diagnosed in this way have been reported to have lower survival than women diagnosed via other routes, and studies suggest older women are more frequently being diagnosed in this way.

What do we see within this audit group?

Routes to diagnosis were seen to vary by age (Table 5.1), specifically:

- Among women aged 50–69 years one-third were diagnosed after referral from their GP, while more than half were diagnosed after screening
- Among women aged 70+ years, two-thirds were GP referrals while only 17% were from screening (4% for 50–69 years; 8% for 70+ years)
- Among all women, proportions diagnosed after referral from other specialities were low, at around 5%
- Among all women, the proportion diagnosed after an emergency presentation was very low, at around 1% (0.3% for 50–69 years; 1.3% for 70+ years). This is a much lower percentage than observed in other types of cancer, such as gastric cancer.

There was observed variation by NHS trust and local health board (Figure 5.1).

Recommendations

- All NHS trusts and local health boards must endeavour to examine the quality of their data to ensure the route to diagnosis is captured correctly
- The handful of NHS trusts with a high proportion of women with an unknown route to diagnosis should examine how the completeness of their data could be improved.

¹⁰ <http://www.agex.uk>

Table 5.1: Route to diagnosis by age group at diagnosis

Reported route to diagnosis	50–69 years	70+ years	Overall
NHS screening programme	57.3%	17.6%	41.6%
GP presentation	33.2%	64.0%	45.4%
Referral from other specialities	3.7%	7.7%	5.3%
After emergency presentation	0.3%	1.3%	0.7%
Other	0.6%	0.9%	0.7%
<i>Unreported</i>	4.9%	8.5%	6.3%

Note: Among 599 women with multiple referral sources reported for the same date: 526 were reported to have screen detected cancer and so are included within "NHS screening programme" in the table above; the remaining 73 were not included in the table above.

Routes to diagnosis by NHS breast cancer unit, broken down by age group, are shown in Figure 5.1. Three distinct areas can be seen within this figure, particularly for England:

1. The top section reflects the fact that not all hospitals receive referrals from breast screening services.
2. In the middle section, there was some variation in the proportion of women aged 50–60 years who were diagnosed through breast cancer screening. This might reflect the different levels of screening uptake around the country or the geographical closeness of some units to each other.
3. At the bottom of the figure, the proportion of women diagnosed through breast screening is surprisingly high for both age groups. These NHS trusts should examine the quality of their data to ensure the route to diagnosis is captured correctly.

5.2 Triple diagnostic assessment in a single visit

Numerator	Women receiving triple diagnostic assessment in a single visit
Denominator	Women with non-screen detected early invasive breast cancer

Since 2002, it has been regarded as best practice for patients with suspected breast cancer to undergo a “triple assessment” in most cases. This comprises the following three elements, all of which should be performed at the time of initial consultation [NICE 2002]:

- Clinical assessment – the breast clinician / specialist nurse will take a full history and perform a physical examination
- Imaging – ultrasound of the symptomatic breast area or mammography abnormality. A mammogram to assess the presence of a breast tumour (for patients aged over 40 years and not referred through the NHSBSP; screened patients will have already had imaging). The axilla may also be imaged.
- Histopathology assessment – tissue biopsies are obtained from areas in the breast (+/- axilla) that are suspicious of cancer.

Women diagnosed via the screening programme will have the imaging component of the triple diagnostic assessment performed at the time of second stage screening, reducing the need to have all three elements performed within a single visit. Such women are therefore not included within the denominator of this indicator.

This indicator describes the proportions who were calculated to have received the standard triple diagnostic assessment (TDA) in a single visit. A woman was defined as having TDA when both the mammogram imaging date and biopsy or cytology date were reported and were the same. The date of clinical evaluation is not formally reported in the cancer registration datasets and so this was assumed to have been on the same day as imaging.

What do we see within this audit group?

Among women with non-screen detected cancer, adopting a strict set of criteria for dealing with data issues, 29% were estimated as having received TDA in a single visit. The proportion was consistent across ages (28% for 50–69 years; 30% for 70+ years).

This low figure arose from various vagaries of the imaging and biopsy dates

- 6% of women had an ultrasound and biopsy date but no mammogram date
- 43% of women were missing a mammogram and/or biopsy date

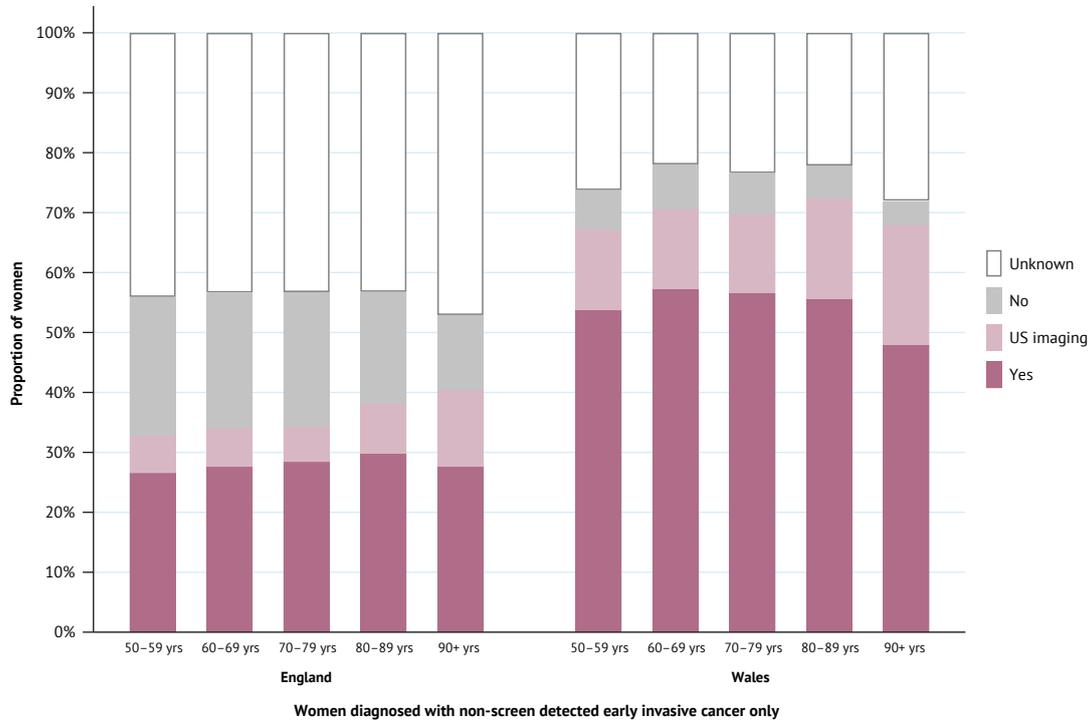
It should be noted that there was a difference according to country of diagnosis, with 56% of women with non-screen detected cancer diagnosed within Wales estimated as receiving TDA in a single visit (Figure 5.2) compared with 28% in England.

There was variation across diagnosing NHS trusts and local health boards regardless of age at diagnosis (Figure 5.3).

Recommendations

- NHS trusts and local health boards must ensure that women are able to receive triple assessment at their initial clinic visit after referral for suspected breast cancer, in line with NICE recommendations
- NHS trusts and local health boards must review and, where necessary, improve the process of submitting, to the national cancer registration services, the dates of assessment for all investigations performed at a triple assessment clinic.

Figure 5.2: Receipt of TDA in a single visit, among women with non-screen detected early invasive breast cancer, by country of diagnosis and age at diagnosis



Key: US imaging = Ultrasound imaging; the proportion of women for whom ultrasound imaging rather than a mammogram was reported as performed on the same date as their diagnostic biopsy.

If the criteria are relaxed (assuming missing mammogram/ biopsy dates were the same as the date of biopsy/ mammogram respectively; using ultrasound data where this matched biopsy date; allowing biopsy and mammogram dates to differ by one day in case the record date corresponds to the date of reporting rather than the date of assessment), the estimate of women having TDA increases to 82% (81% for 50–69 years; 82% for 70+ years).

Figure 5.3 shows the proportion of women calculated as receiving triple diagnostic assessment across all LHBS/ NHS trusts using these two criteria definitions.

Deciding which of the two criteria definitions is likely to most accurately reflect practice within NHS trusts and local health boards is not straightforward. At a triple assessment clinic, there will be women who have a clinical examination and imaging with mammogram and/ or ultrasound but due to specific circumstances (eg patient on anti-coagulant medication) the diagnostic biopsy is not carried out on the same date.

It is likely that this group are being managed correctly, but we cannot label these women as receiving triple assessment when adopting a strict definition that requires all dates to be known and the reason for absence of dates is not available.

In the relaxed definition, a one-day difference in dates was allowed because the date may refer to the reporting of results rather than assessment. This approach can also be criticised because it does not take into account that many breast cancer units offer women “rapid access clinics”. These aim to provide women with this triple assessment in a single visit and to provide the results of the imaging tests performed at that clinic visit rather than at a later date.

Unfortunately, there is no other national source of information on how well breast cancer units are providing triple assessment against which our results can be compared. The provision of timely triple assessment is a basic tenet of breast cancer care and compliance should be accurately recorded.

Figure 5.3: Proportion of women receiving triple diagnostic assessment in a single visit by LHB/trust and age at diagnosis



Note: Figure ordered by country of diagnosis and then organisation-specific proportion in receipt of triple diagnostic assessment in a single visit in women aged 50–69 years at diagnosis (under strict criterion), as the reference group for comparison with women aged 70+ years.

5.3 Metastatic disease at initial presentation

Numerator	Women with metastatic disease at initial presentation
Denominator	Women diagnosed with invasive breast cancer

Patients with metastatic cancer are rarely cured of their disease, but survival has improved over time as treatment options have expanded and therapies have become more effective. It has previously been reported that the risk of being diagnosed with metastatic disease increases with age.

What do we see within this audit group?

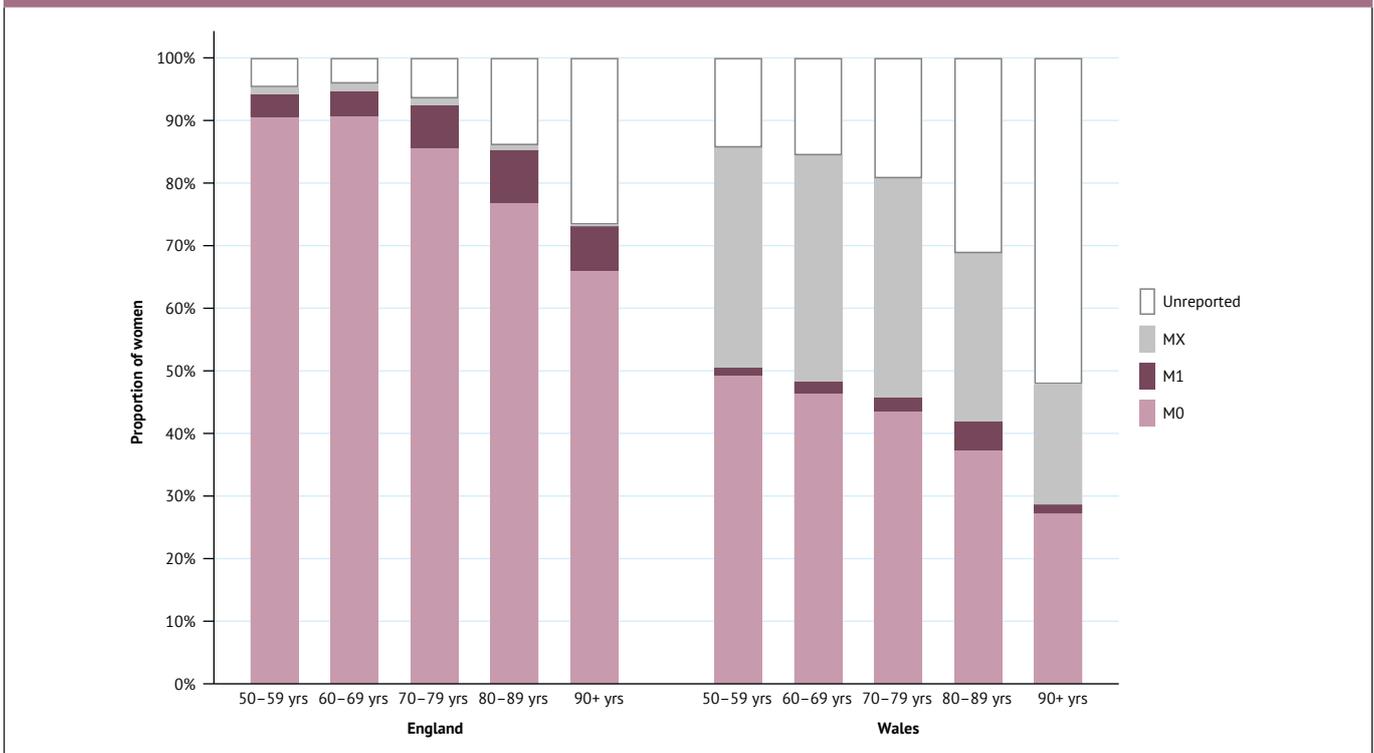
Among those women diagnosed with invasive breast cancer, 5% were reported to have metastatic disease at the time of diagnosis.

As expected the proportions of women diagnosed with metastatic disease increased with increasing age (Figure 5.4) from around 4% among women aged 50–69 years to 8% among women aged 80 years and over at diagnosis.

There was a slight variation in the proportion of women diagnosed with metastatic disease across the NHS breast cancer units, with 17 units having over 10% of older women diagnosed with metastatic disease (ranging from 11–21%).

Figure 5.4 below also highlights a noticeable increase in the proportion of unreported M stage values among women aged 80 and above. This may reflect the fact that some women are not considered as candidates for surgery or adjuvant chemotherapy and so may not undergo full staging investigations.

Figure 5.4: Proportion of women with metastatic disease (M1) at initial presentation, by country of diagnosis and age at diagnosis



6. Treatment planning

This chapter focuses on two important aspects of treatment planning:

1. Whether there was contact with a breast clinical nurse specialist (CNS)
2. How long women were waiting from diagnosis to primary treatment with surgery or chemotherapy.

6.1 Involvement of a breast clinical nurse specialist or key worker

Numerator	Women seen by a breast CNS/named key worker
Denominator	Women diagnosed with DCIS or invasive breast cancer (ie all women)

It is recommended that each patient is assigned a named breast CNS to provide relevant information, and psychological support, and help guide the patient and her family through their diagnosis, treatment and follow-up [NICE 2009a; 2009b].

The organisational audit results published in the 2017 NABCOP annual report reported that all except one of the responding English NHS trusts and Welsh local health boards had at least follow-up whole time equivalents (WTE) breast CNS on-site, and on average, there were 90 new breast cancer patients (per annum) under the care of one breast CNS in each NHS trust / local health board. However, this figure ranged across units from 25 to 200 patients per breast CNS.

Data on each individual patient's contact with a breast CNS are collected within the COSD core dataset. Information on this aspect of patient care is not available within the cancer datasets collected for Wales and so this section includes data on women diagnosed in England.

The information shown within this section can be placed in wider context by considering the results of the Cancer Patient Experience Survey (CPES). CPES suggests that, overall, NHS breast cancer units are performing well on this indicator. In 2013, 90% of women that completed the CPES questionnaire reported being 'given the name of a breast CNS who would be in charge of their care'. The proportion for women aged 70+ years was similar for women aged 50–69 years.

What do we see within this audit group?

1. Data on CNS contact was only reported for 68% of women aged 50 years and over diagnosed in England (69% for 50–69 years vs 66% for 70+ years); this and changes in completion over time limit our ability to evaluate conclusively how well NHS trusts are performing against this measure.
2. The completeness of this data has however improved over the audit period (Figure 6.1), in terms of both availability and a decreasing proportion of patients for whom CNS contact was reported as "unknown" (14% overall).
3. Among all women, "no CNS contact" was typically reported for around 1% (0.7% for 50–69 years vs 1.0% for 70+ years); this did not change as the proportion of unknown values decreased over time giving some confidence that the unknown values are missing at random and the figures are representative. (Figure 6.2)
4. Among women with data 85% had contact with a CNS (85% 50–69yrs vs 84% 70+yrs)
5. There was variation across NHS trusts in the completeness of this data (Figure 6.3).

Recommendations

- NHS trusts must ensure that women are assigned a named breast clinical nurse specialist (CNS) to provide information and support
- NHS trusts must review how data on the assignment of a named breast CNS are submitted to NCRAS and ensure their figures agree with those reported by the patient experience survey.

Figure 6.1: Proportion of women seen by a breast CNS by year of diagnosis (quarters)

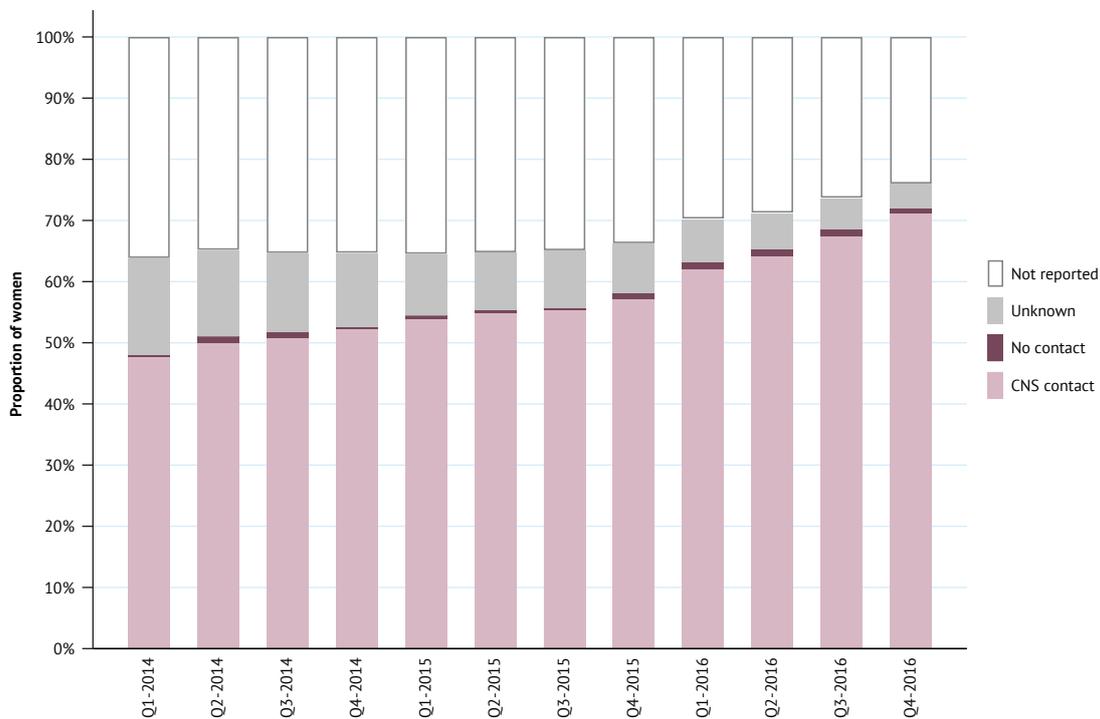
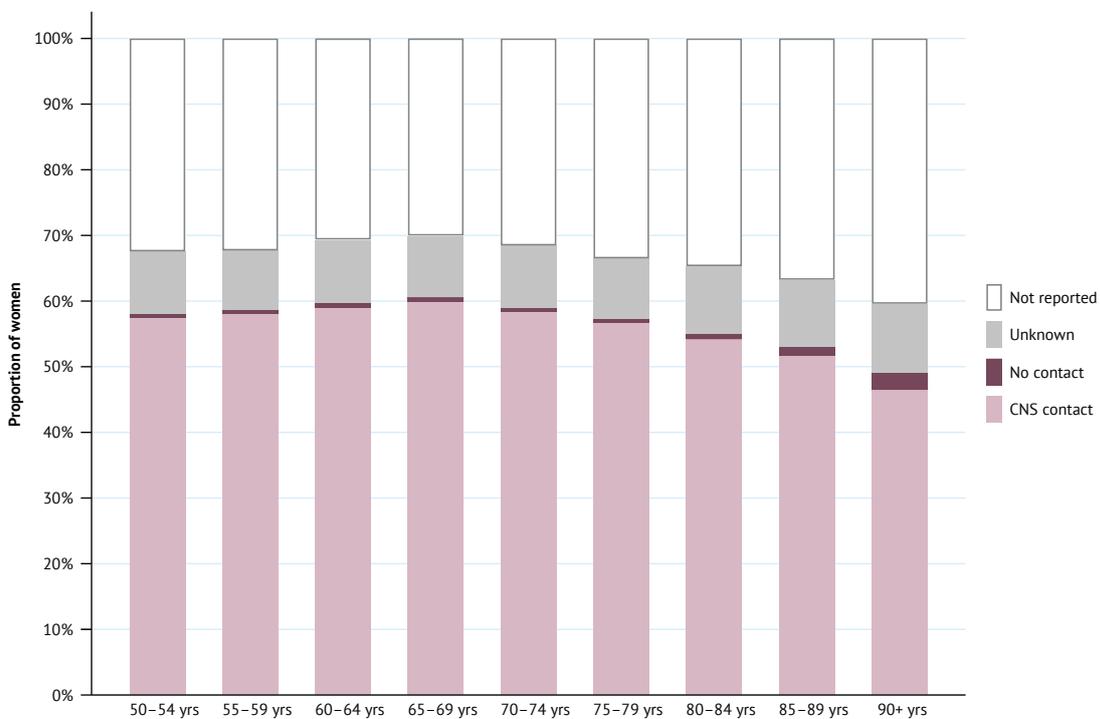
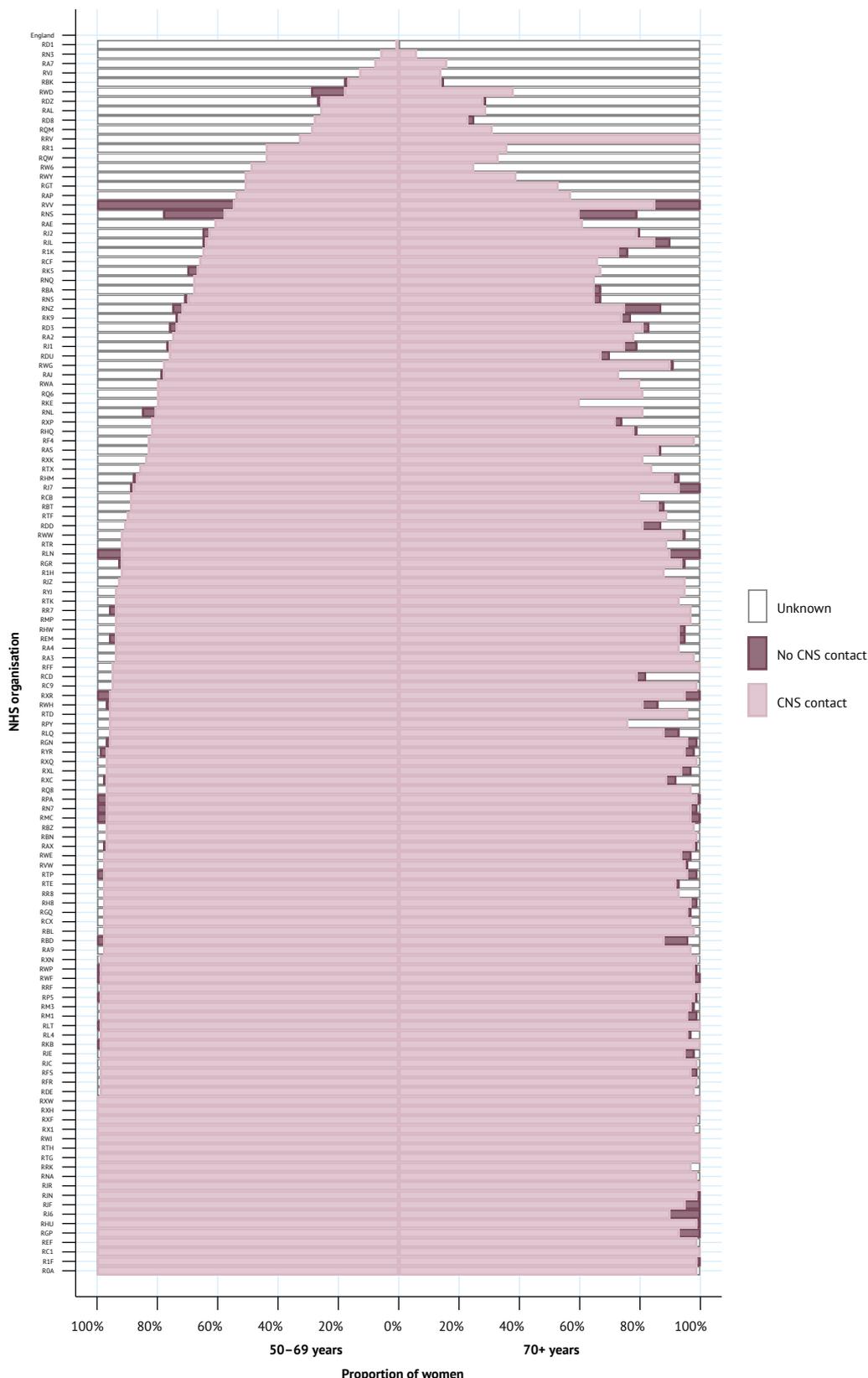


Figure 6.2: Proportion of women seen by a breast CNS by age at diagnosis



Note: Women with an 'unknown' status have had information recorded in the COSD dataset indicating that it is not known (or not recorded) whether the patient has been seen by a breast CNS. Women with 'not reported' status have no CNS information recorded.

Figure 6.3: Proportion of women in contact with a breast CNS recorded by diagnosing LHB/trust and age at diagnosis. Only women with data are included.



Note: Figure ordered by trust-specific rates of CNS contact in women aged 50-69 years at diagnosis, as the reference group for comparison with women aged 70+ years.

6.2 Time from diagnosis to first treatment with surgery or chemotherapy

Numerator	Time from date of diagnosis to date of primary treatment with surgery or chemotherapy
Denominator	Women diagnosed with DCIS or invasive breast cancer who received surgery or chemotherapy as primary treatment

Over the past decade, NHS cancer services have focused on reducing the time between a patient experiencing symptoms and initial treatment. In particular, the cancer waiting times (CWT) initiative recommends that all cancer patients should be treated within 31 days of the decision to treat (DTT). The DTT is usually defined as the date the patient agrees to a treatment plan for his or her cancer, and NHS cancer services are expected to treat 96% of patients within this 31-day period (operational standard). However, this standard only captures a portion of the time that elapses after a patient has received their diagnosis.

The NABCOP did not have CWT data, nor was the aim of this section to consider how well NHS trusts and local health boards are meeting this target. Rather we aimed to examine the waiting experience of women, and consider whether the time to primary treatment from the date of diagnosis varied between NHS trusts and local health boards for women diagnosed with DCIS or invasive breast cancer who received surgery or chemotherapy as primary treatment, as well as whether there was any difference across the two age groups.

We focused on time to treatment with chemotherapy or surgery but did not include women whose first reported treatment was a treatment other than surgery or chemotherapy. It should be noted that times may appear longer than in practice where a woman was started on another initial treatment but this was not recorded.

What do we see within this audit group?

Overall, among women receiving surgery or chemotherapy as primary treatment, the typical (median) time from diagnosis to (the first of) these treatments was comparable across the two age groups:

1. Age 50–69 years = 4.7 weeks (IQR 3.4–6.0 weeks)
2. Age 70+ years = 4.6 weeks (IQR 3.3–5.7 weeks).

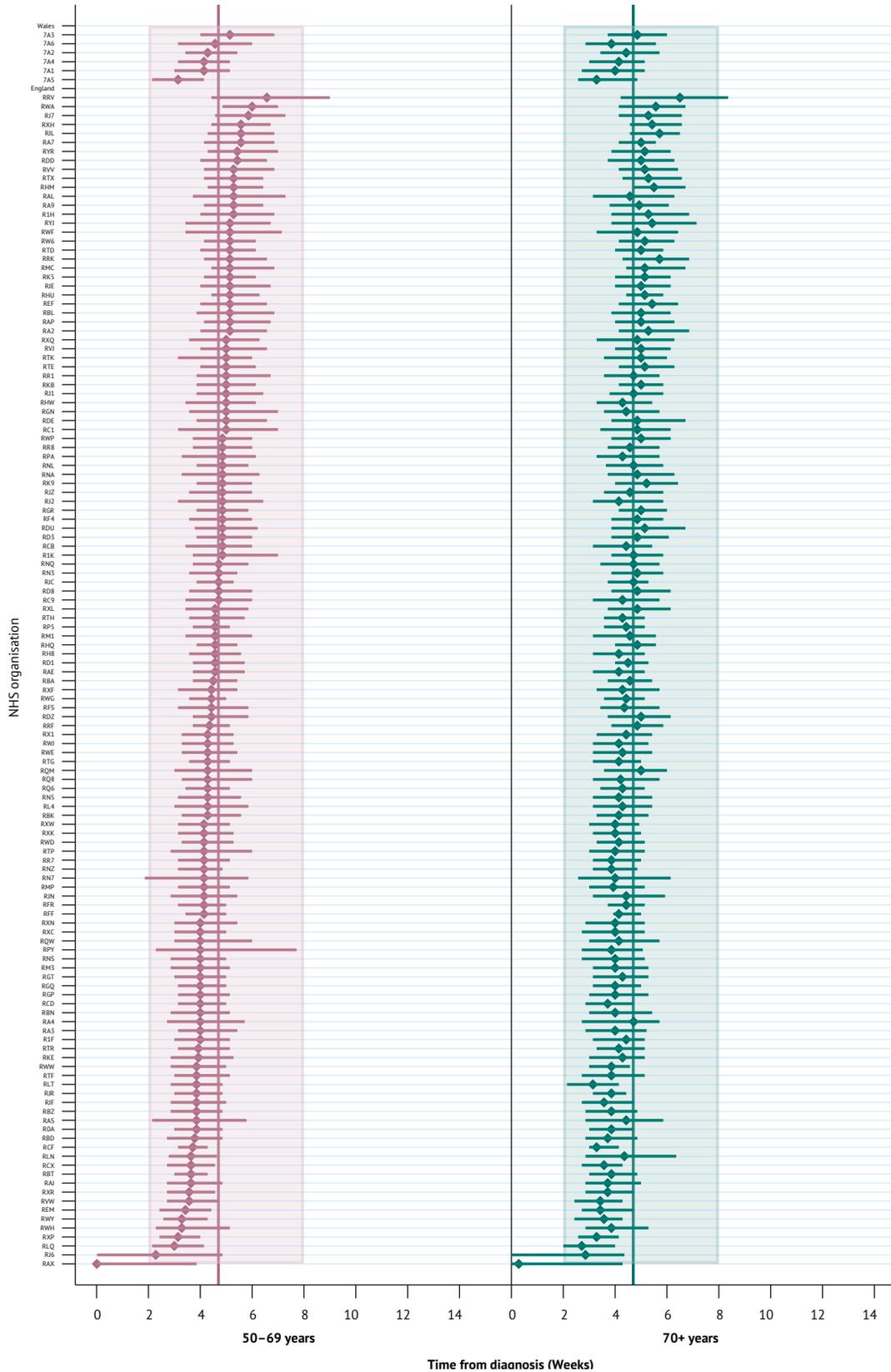
92% of women started surgery or chemotherapy within eight weeks of diagnosis; 78% within six weeks. Both timings were comparable across age groups (92%/77% for 50–69 years vs 94%/80% for 70+ years).

Figure 6.4 illustrates the distribution of waiting times from date of diagnosis, within NHS trusts and local health boards, for patients whose primary treatment was surgery or chemotherapy. There is limited variation across organisations, with all but eight NHS trusts reported that 75% of patients underwent surgery or chemotherapy within eight weeks of their diagnosis date. The waiting experience did not look to be related to age at any of the NHS trusts or local health boards.

Recommendations

- NHS trusts and local health boards must ensure the time from diagnosis to the start of first treatment remains within acceptable limits.

Figure 6.4: Time from diagnosis to first treatment with surgery or chemotherapy, by diagnosing LHB/trust and age at diagnosis



Note: Lines at 4.7 weeks are the median for the 50-69 years age group. Figure ordered by country of diagnosis and then organisation-specific median time from diagnosis in women aged 50-69 years at diagnosis, as the reference group for comparison with women aged 70+ years.

Table 6.1: Proportion of women whose treatment started within a fixed number of weeks after diagnosis among women having surgery or chemotherapy as their primary treatment

Time from diagnosis to treatment	50–69 years		70+ years	
	Surgery	Chemotherapy*	Surgery	Chemotherapy*
Total women	60,445	4,452	26,839	740
Up to 6 weeks	78%	61%	80%	51%
Up to 7 weeks	10%	13%	9%	15%
Up to 8 weeks	5%	8%	4%	8%
Up to 9 weeks	2%	4%	2%	5%
Up to 10 weeks	1%	3%	1%	4%
Up to 12 weeks	1%	4%	1%	4%
Beyond 12 weeks	3%	8%	2%	12%

* women with invasive disease only

7. Surgery

This chapter focuses on patterns of breast cancer surgery. Specifically, we report on:

- which women with early invasive breast cancer had surgery to remove the tumour, and who had surgery to the axillary lymph nodes;
- patterns of surgery for women with ductal carcinoma *in situ* (DCIS); and
- the duration of overnight hospital stay for these women.

For the purposes of reporting, women are described as having ‘no surgery’ if there was no surgical information reported in the audit datasets. In many cases, this will be because women had another course of treatment, such as primary endocrine therapy (PET). However, in some cases, it will be because the surgery was performed in independent healthcare providers in England and Wales and private hospitals do not generally contribute treatment information to the national cancer registration services datasets.

7.1 Surgical treatment for early invasive breast cancer

Numerator	Women who had mastectomy or breast conserving surgery (BCS)
Denominator	Women diagnosed with early invasive breast cancer

Surgical resection is a central treatment for both invasive breast cancer and DCIS, with NICE guidance (CG80) recommending:

“1.12.1 Treat patients with early invasive breast cancer, irrespective of age, with surgery and appropriate systemic therapy, rather than endocrine therapy alone, unless significant comorbidity precludes surgery [NICE 2009a].”

Surgery to the breast involves either a mastectomy or breast conserving surgery (BCS). The type of procedure will depend upon patient preferences and tumour characteristics. A small tumour in relation to the size of the breast is optimal for BCS. For patients having a mastectomy, some may also have breast reconstruction at the same time (immediate reconstruction, [IR]) or as a subsequent separate planned procedure (delayed reconstruction). Breast reconstruction procedures are more common among women aged under 70 years [HQIP NMBRA, 2010].

What do we see within this audit group?

There is an age variation in the proportion of women who receive surgery for early invasive breast cancer. Specifically:

- Among women aged 70+ years 76% had primary surgical treatment, compared with 96% of women aged 50–69 years (Figure 7.1)
- The likelihood of surgery fell as levels of fitness decreased, although the size of the change was much larger for older women (Table 7.1).

There was also variation across NHS organisations in the proportions of women aged 70+ years who received breast surgery for early invasive breast cancer (Figure 7.2).

Rates of surgery also varied by country with 88% of women in England receiving primary surgery (73,870 / 83,830) and 92% of women in Wales (3,868 / 4,198).

During the three-year audit period, the proportion of women undergoing primary surgery decreased with increasing age (Figure 7.1). In addition, among women aged over 70 years:

- The proportion not reported as receiving surgery increased from 22.9% in 2014 to 26.2% in 2016.
- The increased rate of women not having surgery was reflected by a fall in the proportion having BCS; there was little change in the proportion having mastectomy.

Patterns of surgery did not change over time for women aged 50–69 years.

Women aged 70+ years were less likely to receive BCS for tumours less than 5cm (T-stage ≤2). As anticipated, immediate breast reconstruction (IR) following mastectomy was more common among younger women, with 26.4% of women aged 50–69 years undergoing IR compared with only 3.3% of women aged 70+ years.

Recommendations

- NHS trusts and local health boards must ensure that WHO performance status and ASA score are complete, as this will enable better understanding of the reasons behind the variation in the patterns of primary surgery between women of different ages and across NHS organisations.

Clinicians take a patient’s overall health into consideration when reviewing primary treatment options and suitability for surgery and adjuvant therapies. A challenge for the audit when analysing patterns of surgery is to capture the overall fitness of a patient. The WHO performance status is the only recorded measure of a patient’s functional ability in the cancer registration datasets, and this was generally poorly completed (see Table 4.1). We therefore augmented the dataset with two measures derived from hospital administrative data:

- **The Charlson comorbidity score**, a measure of comorbidity that is based on the presence or absence of specific medical problems.
- A hospital-version of the **electronic Frailty Index (eFI)**. The eFI is calculated based on the presence or absence of 36 ‘deficits’ in a patient, which includes psychosocial and functional problems. Our version is derived from hospital administrative data and captures 35 of the 36 deficits.

Table 7.1 demonstrates how the likelihood of surgery among women varied with different levels of fitness, as described by the three available measures: WHO performance status, Charlson comorbidity score and the hospital version of the eFI. For each variable, the proportion of women who had surgery fell as levels of fitness decreased, although the size of the change was much larger for women aged 70+ years

Figure 7.2 shows the risk-adjusted proportion of women with early invasive breast cancer who received primary surgical treatment for each age group, within NHS trust/ local health boards. There was some variation in the proportion of women aged 70+ years who received primary surgery.

Some women who did not receive primary surgery might have been prescribed primary endocrine therapy if their cancers were ER positive. Guidelines on the management of older patients with breast cancer issued by the International Society of Geriatric Oncology (SIOG) and the European Society of Breast Cancer Specialists (EUSOMA) advise that primary endocrine therapy should only be offered to women with “*a short estimated life expectancy (<2–3 years), who are considered unfit for surgery after optimisation of medical conditions*”. [Biganzoli et al 2012].

In the audit group, ER status was not reported in 18% of women aged 70+ years, who did not undergo surgery. Of those with a recorded ER status, 96.3% were ER positive of whom 92.1% had primary endocrine therapy.

Improving the data completion on patient characteristics and the WHO performance status will enable better understanding of the reasons behind the variation in the patterns of primary surgery.

Figure 7.1 Type of primary treatment for early invasive breast cancer, by age at diagnosis

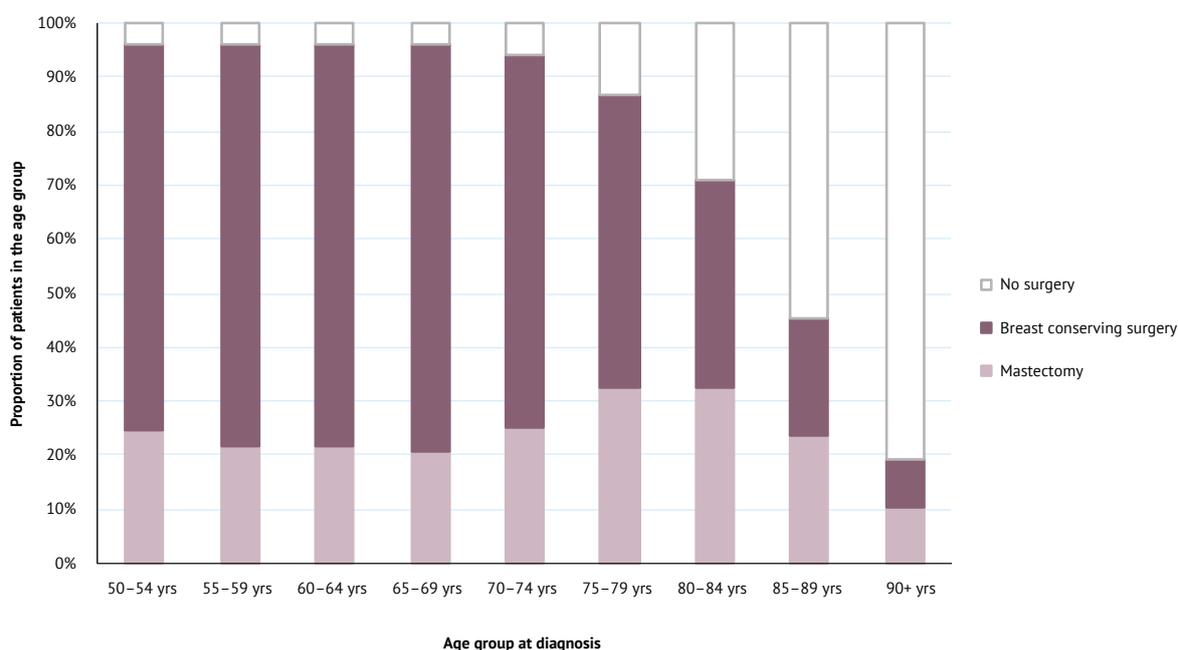
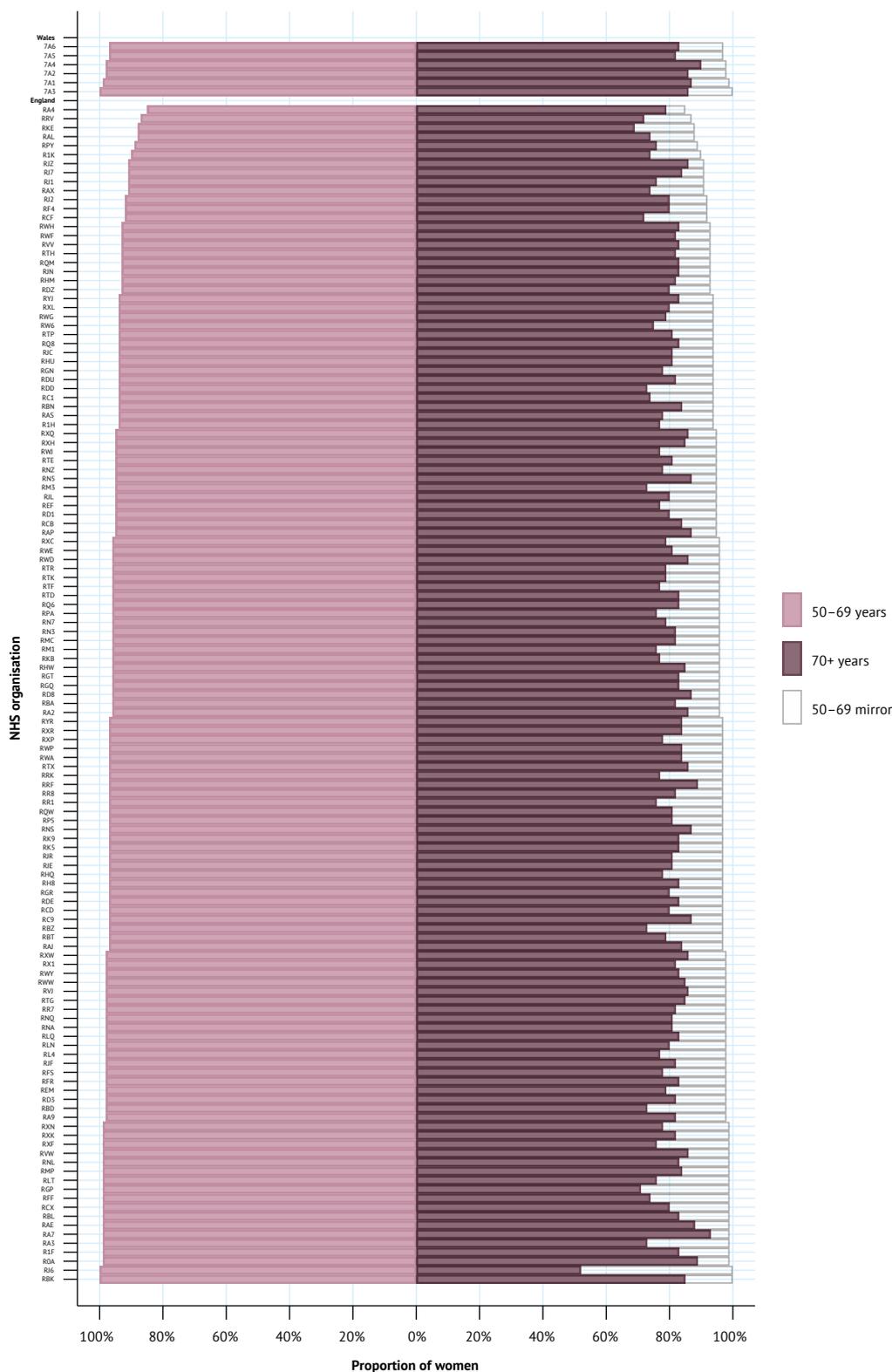


Table 7.1 Impact of patient fitness on the likelihood of a woman receiving surgery for early invasive breast cancer, as measured by three different factors, by age at diagnosis

Measure of fitness	50–69 years		70+ years	
	No. of patients	Proportion having surgery	No. of patients	Proportion having surgery
Number of women	54,817	96%	33,211	75.6%
Charlson comorbidity score:				
0	48,616	97.5%	23,436	87.2%
1	3,454	95.2%	4,390	66.8%
>1	1,063	88.5%	3,096	44.9%
unknown	1,684	61.6%	2,289	14.2%
Hospital version of eFI				
Fit	52,506	97.3%	27,884	84.4%
Mild frailty	564	88.8%	2,369	46.3%
Moderate to severe frailty	63	61.9%	669	20.5%
unknown	1,684	61.6%	2,289	14.2%
WHO/ECOG performance status				
0	15,073	96.9%	5,707	87.8%
1	1,372	93.1%	2,264	73.7%
2	198	84.8%	911	45.6%
3 or 4	116	51.7%	795	16.5%
unknown	38,058	96%	23,534	75.9%

Figure 7.2: Risk adjusted proportion of women receiving primary surgical treatment for early invasive breast cancer by diagnosing LHB/trust and age at diagnosis



Note: Figure ordered by country of diagnosis and then organisation-specific proportions receiving primary surgical treatment in women aged 50-69 years at diagnosis, as the reference group for comparison with women aged 70+ years. The '50-69 mirror' bars are the reflection of the proportions for the 50-69 age group over the proportions for the 70+ age group, to aid comparison.

7.2 Axillary surgery for women with early invasive breast cancer who had breast surgery

This section reports on surgical procedures to the axilla for the purposes of breast cancer staging and management. Initial surgery to the axilla is usually performed at the same time as the breast surgery procedure. The type of axillary surgery a patient receives is directed by axillary ultrasound (+/- axillary biopsy) findings at the time of diagnosis.

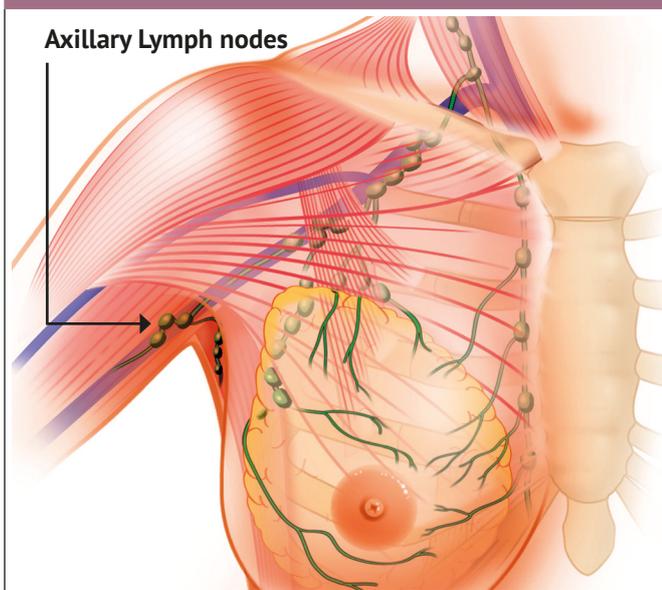
If the ultrasound assessment and histological assessment of the axilla shows that the cancer has spread to the axillary lymph nodes, a patient will tend to have one of two types of treatment: (1) a surgical procedure called axillary node dissection (AND), whereby all the axillary lymph nodes are removed, or (2) axillary radiotherapy. If the ultrasound shows no evidence of cancer spread, patients having primary surgery will usually undergo a less invasive procedure called 'sentinel node biopsy' (SNB), which involves the examination of the first few lymph nodes (sentinel node) to which a tumour is likely to spread. If the sentinel node contains macrometastases (>2mm in size), a patient may go on to have an AND or axillary radiotherapy [NICE, 2009a].

If cancer has spread to the axillary lymph nodes, there is a higher risk of the disease also occurring in the lymph nodes on the chest wall and/or in the neck (see Figure 7.3¹¹). Radiotherapy to these nearby lymph nodes may be offered to women with a high risk of recurrence following an AND or axillary radiotherapy [RCR, 2016].

What do we see in this audit group?

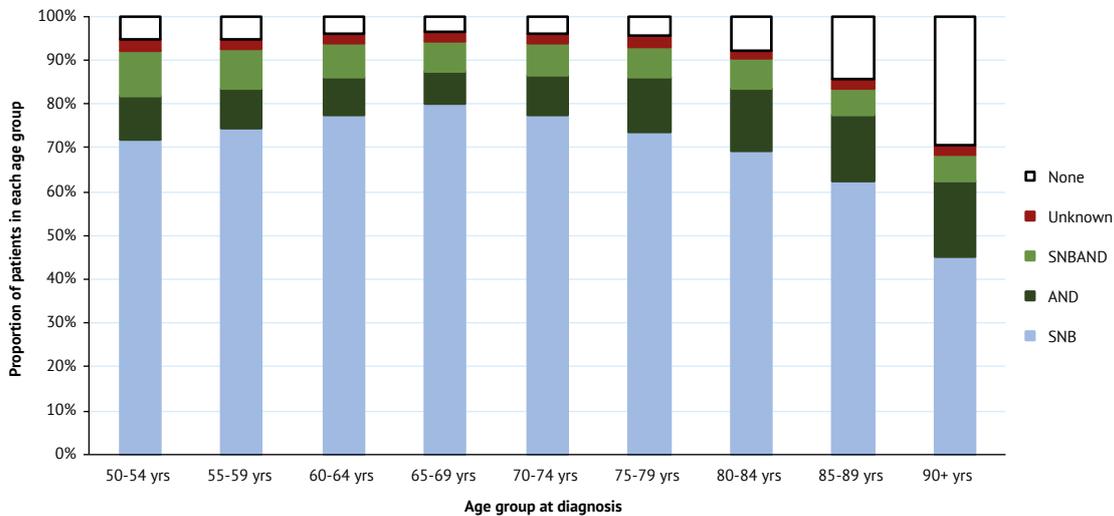
- The overall rate of SNB was: 83% for women aged 50–69 and 78% for women aged 70+ years (Table 7.2)
- The SNB rate was >90% for all women with clinical node negative breast cancer. The variation across NHS organisations in the proportion of women who underwent SNB for clinically node negative breast cancer was slightly greater among women aged 70+ years (Figure 7.5 and 7.6).
- AND was a common treatment for women with a higher burden of nodal involvement, regardless of age (Table 7.3).

Figure 7.3: Illustration of the regional lymph nodes that drain the breast



¹¹ Figure 7.3 Image courtesy of Medical Images. 'Lymph nodes in the breast'. Credit: BSIP / KERMOAL <https://www.medicalimages.com/stock-photo-lymph-node-drawing-image11895377.html>

Figure 7.4: Types of axillary procedures in women who had surgical resection for early invasive breast cancer, by age at diagnosis



Note: Unknown (procedure) refers to women with early invasive disease and who were stated to have a recorded nodal status but for whom an axillary procedure could not be located. SNBAND refers to patients that have both SNB and AND.

In this section, women with early invasive disease who were stated to have a pathologically recorded nodal status but for whom an axillary procedure could not be located were reported as an unknown (procedure).

Overall, 97.1% of women aged 50–69 years and 94.8% of women aged 70+ years had axillary surgery as part of their primary surgical treatment for early invasive breast cancer.

Older women were less likely to undergo axillary surgery (Figure 7.4). There was a steady decline in the proportion of women who underwent a SNB, from around 80% (50–54 years) to 45% (90+ years). This was only due in part to a small increase in the proportion of women who had an AND directly (without a prior SNB).

Women aged 80+ years, who had mastectomy were found to be more likely to undergo an axillary procedure compared with those undergoing BCS. This may reflect that, among older patients undergoing breast conserving surgery, an increased proportion of procedures are performed under local anaesthesia which may be difficult to combine with an axillary operation.

7.2.1 Sentinel node biopsy in women with early invasive breast cancer

Numerator	Women with early invasive breast cancer who had a sentinel node biopsy (SNB)
Denominator	Women diagnosed with early invasive breast cancer

Over 90% of women who have early invasive breast cancer with no pathological lymph node involvement had a SNB (Figure 7.5–7.6). The majority of women across all age groups underwent SNB. However, there was a higher proportion of women aged 70+ years who presented with metastatic lymph nodes and proceeded directly to an AND (Table 7.2).

This section reports on the use of sentinel node biopsy (SNB) in women with early invasive breast cancer. According to NICE (CG80) guidance [NICE 2009a]:

“1.4.1 Minimal surgery, rather than lymph node clearance, should be performed to stage the axilla for patients with early invasive breast cancer and no evidence of lymph node involvement on ultrasound or negative ultrasound-guided needle biopsy. SNB is the preferred technique.”

Figures 7.5 and 7.6 show the variation in the adjusted rate of SNB in women with pathologically negative nodes in early invasive breast cancer between age groups, across NHS trusts and local health boards in England and Wales. The number of NHS trusts/local health boards whose reported practices differed from the majority was slightly higher for women aged 70+. This variation may arise for a number of reasons including: differences in the completeness of data submitted; differences in the clinical protocols adopted by hospitals; or factors not picked up in the current risk adjustment.

All NHS trusts and local health boards must endeavour to examine the quality of their data to ensure information on SNB is captured correctly.

Table 7.2: Surgical assessment of axillary lymph nodes for women with early invasive breast cancer, by age at diagnosis

Investigation method	Age group at diagnosis			
	50–69 years		70+ years	
	Total	%	Total	%
Clinical assessment / imaging to SNB	45,943	83.4%	20,802	78.3%
Clinical assessment / imaging to AND	7,672	13.9%	5,017	18.9%
Clinical assessment / imaging to an unknown axillary procedure	1,295	2.4%	578	2.2%
No reported surgery after imaging	166	0.3%	165	0.6%
Total number of women	55,076		26,562	

Figure 7.5: Funnel plot of adjusted rate of sentinel node biopsy in women aged 50–69 who had surgery for pathologically negative nodes in early invasive breast cancer, by diagnosing NHS trust and local health board

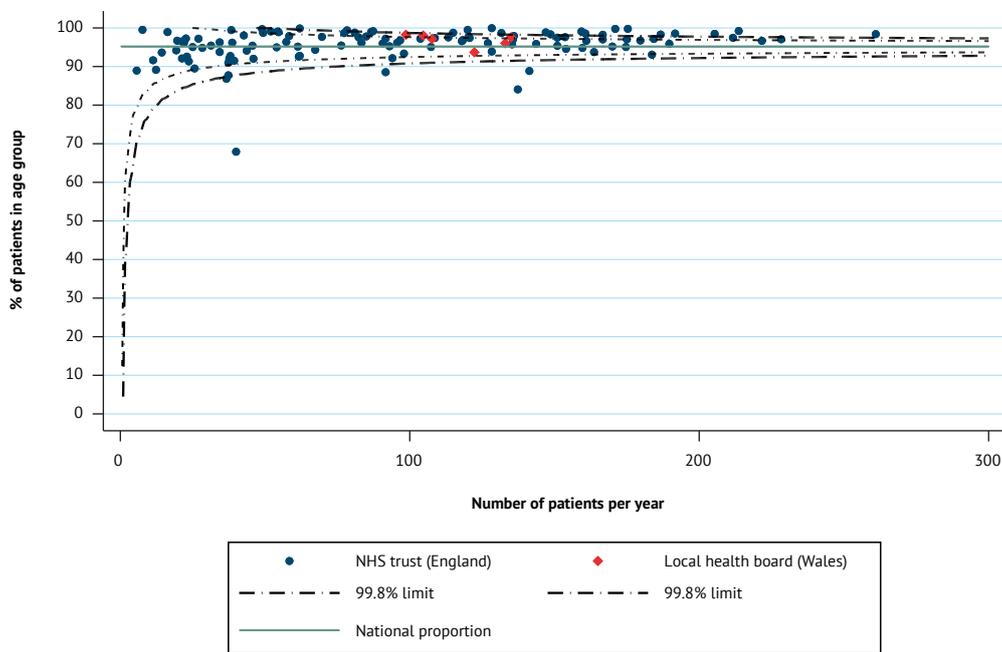
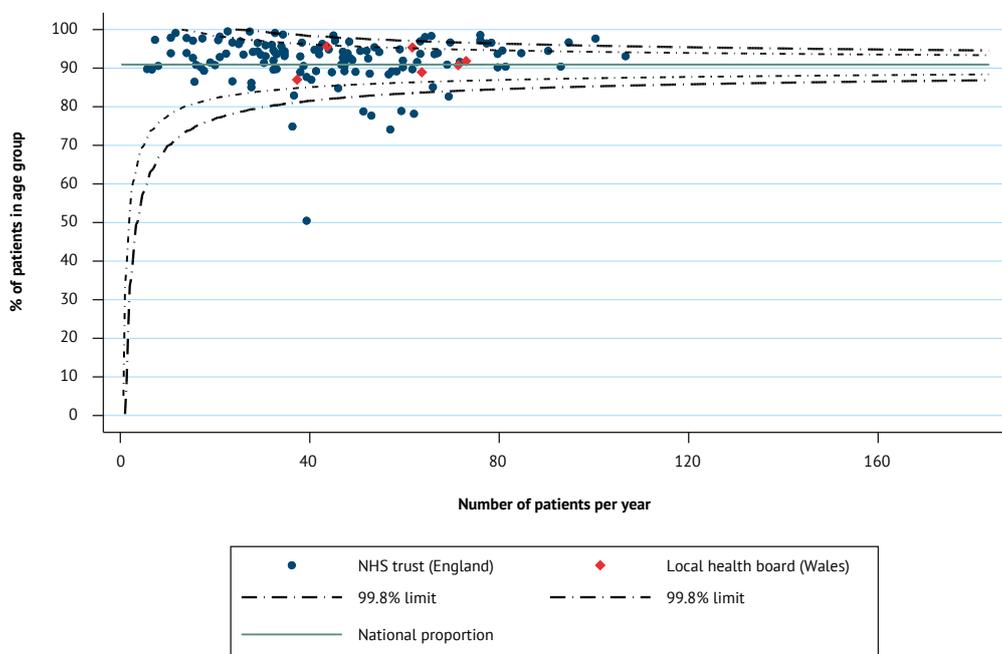


Figure 7.6: Funnel plot of adjusted rate of sentinel node biopsy in women aged 70+ who had surgery for pathologically negative nodes in early invasive breast cancer, by diagnosing NHS trust and local health board



7.2.2 Treatment to regional lymph nodes in women with early invasive breast cancer

Numerator	Women who undergo axillary node dissection (AND)
Denominator	Women with early invasive breast cancer and metastatic regional lymph nodes who had primary breast surgery

This section reports on the treatment of patients with metastatic axillary lymph nodes (nodal stage: N1–2) in women with early invasive breast cancer. As discussed earlier, treatment to the axilla can include either AND or axillary radiotherapy (RT). RT may also be delivered to other regional lymph nodes in the neck and/or to the internal mammary region and also to the chest wall (Figure 7.3). Unfortunately, it is not possible to distinguish which specific areas received radiotherapy in the RTDS records – these aforementioned areas are all labelled ‘regional nodes’. The details on regional radiotherapy prescription in women diagnosed in Welsh local health boards was also not consistently reported within Canisc.

Owing to the imprecise nature of the data on radiotherapy treatments, this section only reports on the surgical treatment of metastatic axillary lymph nodes.

Over 50% of women with early invasive cancer across all age groups had an AND for disease spread to the axillary lymph nodes (Figure 7.7).

As shown in Table 7.3, women were more likely to have an AND for axillary nodal metastasis following a mastectomy compared to BCS, irrespective of age. There is strong evidence to support the use of external beam radiotherapy to the breast after BCS for patients with early invasive breast cancer [EBCTCG 2011]. Therefore, it is possible that these women who undergo BCS are also more likely to be considered for regional nodal radiotherapy for metastatic disease.

AND was a common treatment for women with a higher burden of nodal involvement, regardless of age.

Figure 7.7 Regional treatment in women with node positive early invasive breast cancer who received primary breast surgery in England, by age at diagnosis

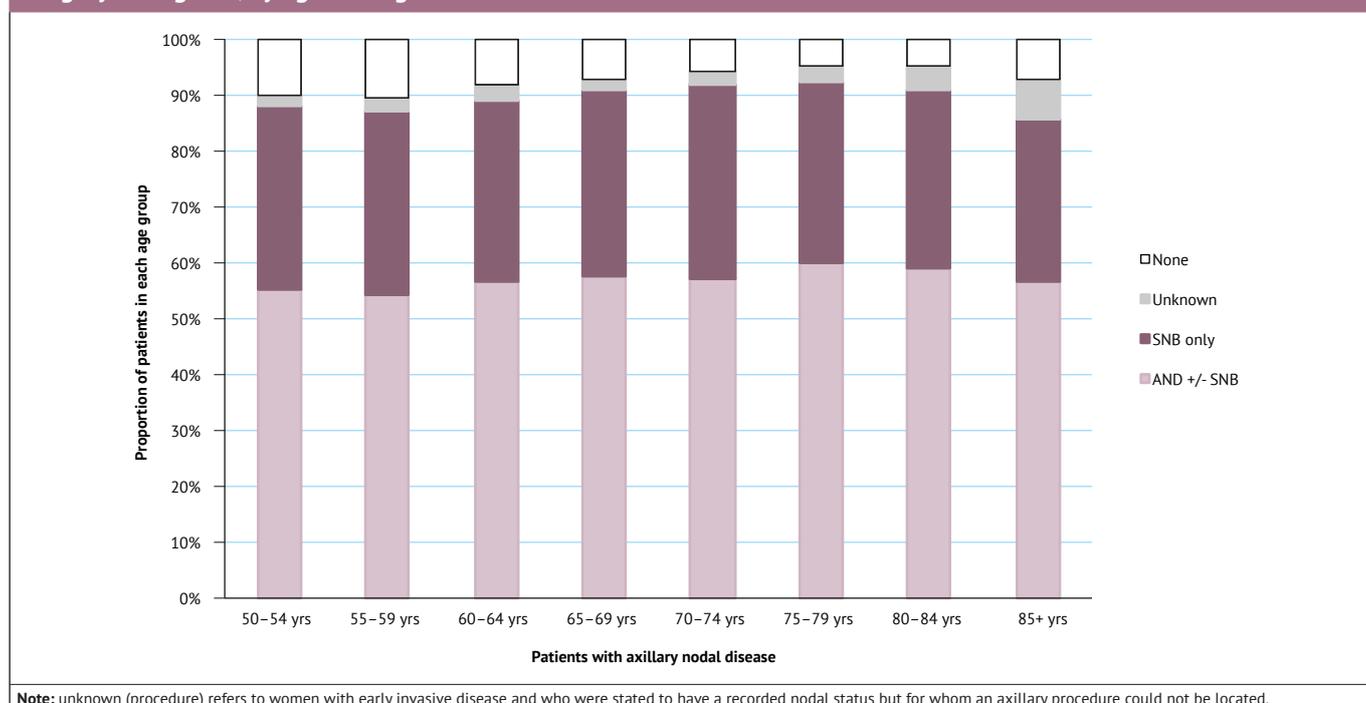


Table 7.3: Surgical treatment of axillary nodal disease in women with early invasive breast cancer by age at diagnosis, nodal status and primary breast surgery procedure

Treatment received	Age at diagnosis					
	50–69 years			70+ years		
	N-stage					
	N0	N1	≥N2	N0	N1	≥N2
Breast Conserving Surgery (BCS)						
AND +/- SNB	1.6%	48.6%	85.2%	1.9%	45.0%	84.9%
SNB only	93.2%	42.4%	9.4%	88.9%	48.6%	11.7%
Unknown	2.4%	2.5%	0.3%	2.3%	2.4%	0.5%
None reported	2.8%	6.5%	5.1%	7.0%	4.0%	3.0%
Total women	32,198	8,318	965	12,899	3,027	436
Mastectomy						
AND +/- SNB	7.3%	59.0%	86.6%	10.3%	55.6%	87.3%
SNB	84.2%	27.1%	7.2%	80.7%	36.6%	8.6%
Unknown	3.1%	2.1%	0.5%	2.5%	2.3%	0.2%
None reported	5.4%	11.7%	5.7%	6.5%	5.5%	3.9%
Total women	6,961	4,676	1,157	5,592	3,093	954

There is increasing debate about the use of AND and regional radiotherapy to manage axillary nodal disease. Unfortunately, the inability to clearly distinguish between the nodal areas irradiated in RTDS limits the ability to report on the management of axillary metastasis on a national level.

7.3 Primary surgical treatment for ductal carcinoma *in situ* (DCIS)

Numerator	Women who had mastectomy or breast conserving surgery for DCIS
Denominator	Women diagnosed with DCIS

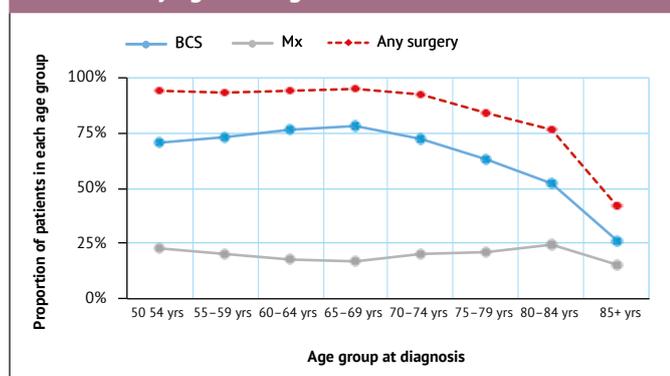
Overall, 11,809/112,433 (11%) women in England and 920/6,351 (13%) in Wales had DCIS. Older women were less likely to present with screen-detected disease and women aged 70+ years accounted for 21% of the total DCIS cohort (Table 7.4).

Table 7.4: Screen detected status for women with DCIS by age at diagnosis

Age group at diagnosis (years)	Screen detected status (% in age group)			Total number of women
	symptomatic	screen detected	unknown	
50–54	13.7%	65.8%	20.5%	2,832
55–59	13.7%	68.4%	18.0%	2,256
60–64	11.7%	71.7%	16.6%	2,248
65–69	13.2%	70.9%	15.9%	2,670
70–74	27.3%	57.8%	14.9%	1,386
75–80	57.2%	30.2%	12.6%	626
80–85	63.2%	20.9%	15.9%	360
85+	34.6%	3.7%	61.8%	356

Older women were less likely to receive surgical treatment for DCIS, which mainly reflects the decreasing proportion of older women undergoing BCS. This may be due to fewer mammographic-detected presentations among older women. The proportion of women undergoing mastectomy did not differ with age or by method of DCIS detection (Figure 7.8).

Figure 7.8 Use of BCS or mastectomy (Mx) for women with DCIS by age at diagnosis



There were too few women treated at each NHS organisation to compare the patterns of care for DCIS among women aged 50–69 and women aged 70+ years.

7.4 Duration of hospital stay following primary breast surgery

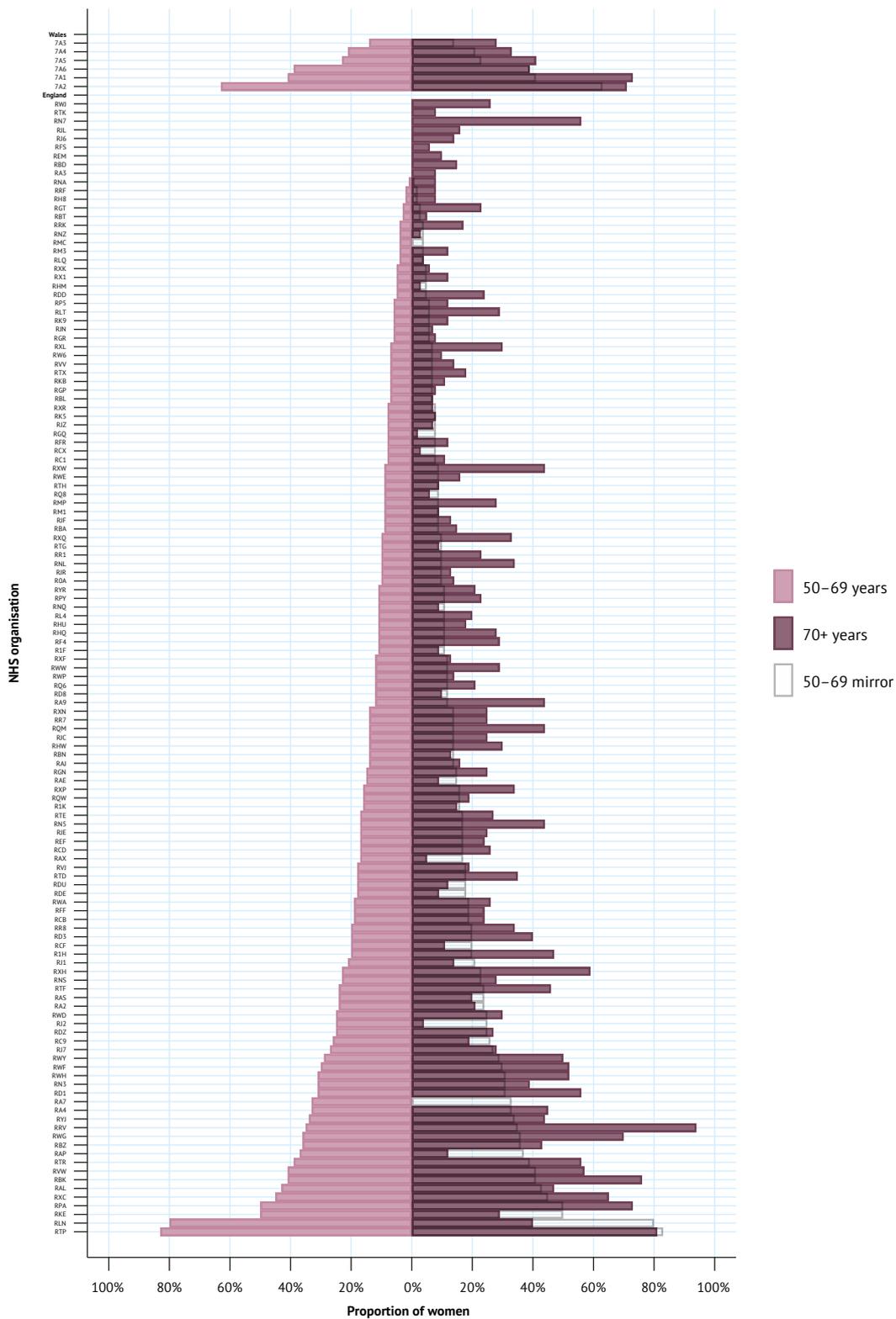
Numerator	Women who stayed in hospital for more than two nights
Denominator	Women diagnosed with DCIS or invasive breast cancer who had surgery

In this section, we report the proportion of women who had an inpatient stay lasting more than two nights after having primary surgical treatment (irrespective of the type of breast cancer).

What do we see in the audit group?

- Irrespective of age, the majority of women had breast surgery as a day case procedure.
 - ♦ Only 4% of women who had BCS had inpatient stays lasting longer than two nights.
- Among women who had a mastectomy and SNB (without reconstruction):
 - ♦ 25% of women aged 70+ years stayed in hospital for more than two nights, compared with only 16% of women aged 50–69
 - ♦ There was variation in length of stay between NHS trusts and local health boards across all age groups. This variation was greatest among women aged 70+ years, which might be expected owing to the reduced levels of overall fitness (Figure 7.10).
 - ♦ In women aged 70+ years, length of stay exceeded two nights for more than 20% of women at 71 NHS trusts and local health boards, which might be indicative of local barriers to discharge.

Figure 7.9 Proportion of women staying more than two nights as an inpatient after undergoing mastectomy and SNB (without reconstruction) by diagnosing LHB/NHS trust and age at diagnosis



Note: Figure ordered by country of diagnosis and then organisation-specific proportions with more-than-two-nights' inpatient stay in women aged 50-69 years at diagnosis, as the reference group for comparison with women aged 70+ years.

8. Radiotherapy

Numerator	Women who receive RT to the: 1. Breast after BCS 2. Chest wall after mastectomy
Denominator	Women diagnosed with DCIS or early invasive breast cancer who had surgery

This chapter focuses on use of radiotherapy (RT) after surgery for Ductal Carcinoma *In Situ* (DCIS) or early invasive breast cancer. We evaluated the use of radiotherapy after BCS and mastectomy separately.

There is strong evidence to support the use of external beam radiotherapy after BCS for patients with early invasive breast cancer. Compared with surgery alone, the combination of radiotherapy and surgery has been shown to reduce the risk of cancer recurrence within the affected breast at 10 years from 35% to 19.3%. Studies have also reported a slight decrease in the risk of breast cancer death at 15 years from 25.2% to 21.4%. Similarly, for patients with DCIS, studies have reported that radiotherapy after BCS reduces the relative risk of recurrent disease (DCIS or invasive cancer) at 10 years by around 50% [EBCTCG 2011].

Guidelines recommend that external beam radiotherapy after BCS should be considered for all patients undergoing BCS for DCIS or early invasive breast cancer. The use of radiotherapy after mastectomy is recommended only for patients with invasive disease who are considered to have a moderate or high risk of recurrence, and is not recommended after mastectomy for patients with DCIS [NICE, 2009a].

What do we see within this audit group?

DCIS (Figure 8.1):

1. Among women who had BCS, 54% had postoperative radiotherapy to the breast. Rates varied by age: 57% of women aged 50–69 years had postoperative RT, compared with 41% of women aged 70+ years, and 24% among women aged 80–89 years.
2. Among women who had mastectomy, there was very little use of adjuvant radiotherapy, as would be expected.

Early invasive breast cancer:

- Among women who had BCS, 84% had postoperative radiotherapy to the breast. Rates varied modestly by age (Figure 8.2): 85% of women aged 50–69 years had postoperative RT, compared with 80% of women aged 70+ years and 72% of women aged 80–89 years. Use was not uncommon among women aged 90+ years at 36%.
- Among women who had mastectomy, 35% had postoperative radiotherapy to the chest wall. Rates decreased by age, from 41% for women aged 50–59 years to 15% for women aged 90+ years (37% for 50–69 years vs 31% for 70+ years).
- In England there was variation across NHS trusts in the use of radiotherapy after BCS among women aged 70+ years at diagnosis. Within-trust rates did not necessarily follow the rates observed in the 50–69 years age group.
- Variation in use of radiotherapy after mastectomy was observed regardless of age.

Recommendations

- All NHS trusts and local health boards must ensure that radiotherapy be considered for all women who receive BCS for DCIS or early invasive breast cancer, in line with guidelines, regardless of age. Clinical trials in this area should be strongly supported.
- All NHS trusts and local health boards must ensure that all women with early invasive breast cancer who undergo mastectomy are appropriately considered for adjuvant radiotherapy.

Figure 8.1: Receipt of radiotherapy after surgery for women with DCIS, by type of primary surgery and age at diagnosis

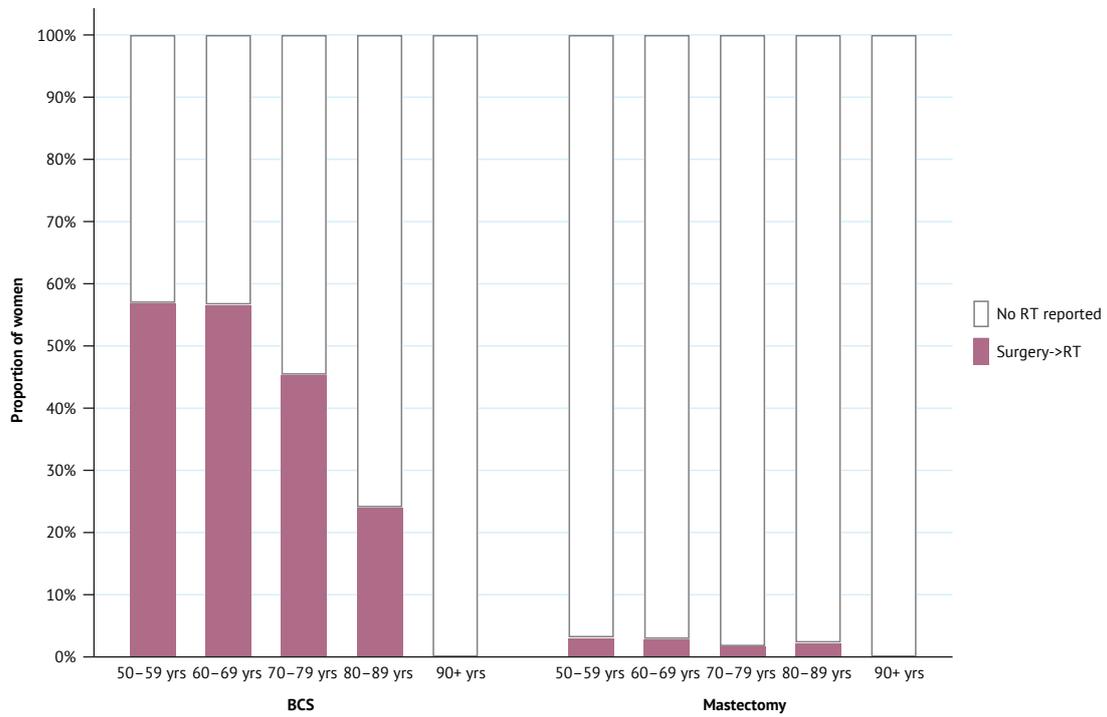


Figure 8.2: Receipt of radiotherapy after surgery for early invasive breast cancer, by type of primary surgery and age at diagnosis

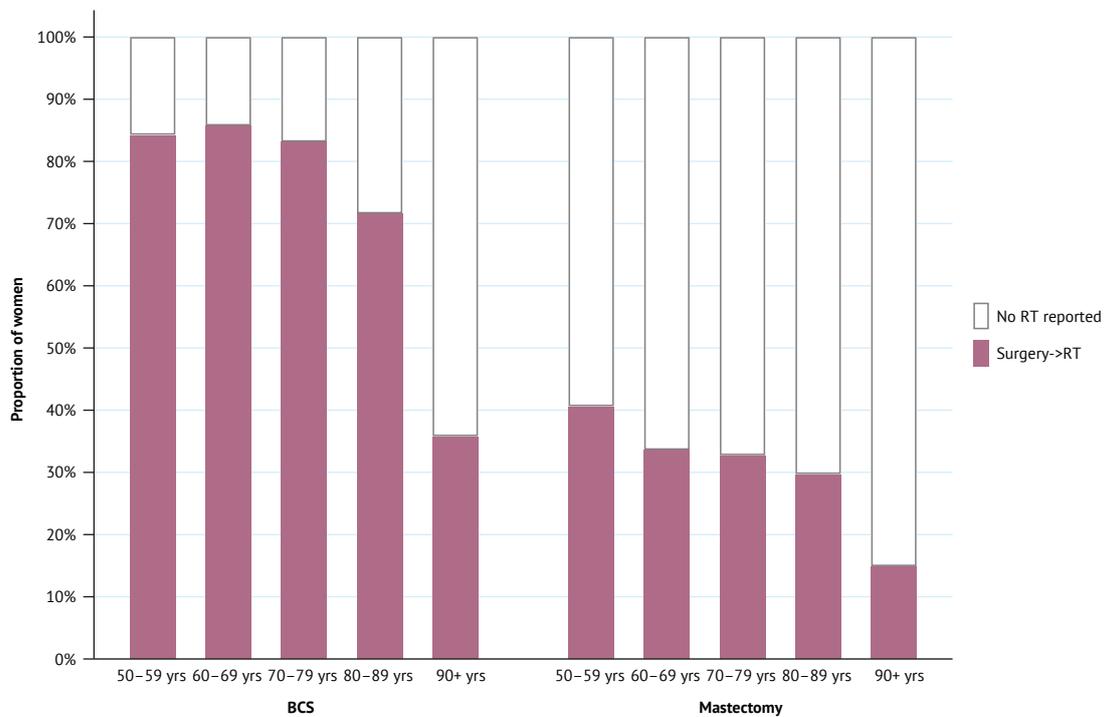
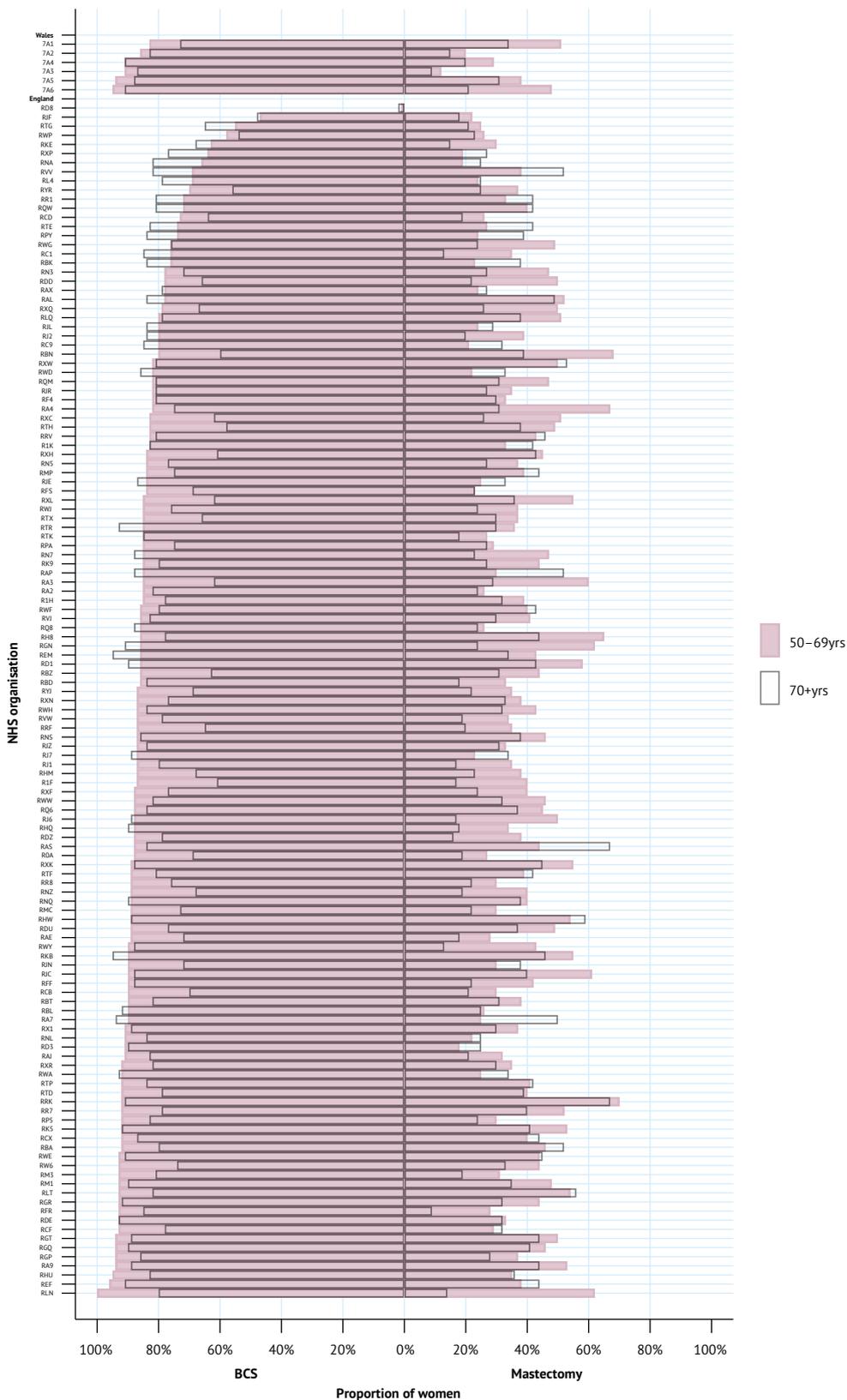


Figure 8.3: Receipt of radiotherapy after breast conserving surgery (LHS) or mastectomy (RHS) for early invasive breast cancer by diagnosing LHB/trust and age at diagnosis



Note: Figure ordered by country of diagnosis and then organisation-specific rates of radiotherapy after BCS (LHS) in women aged 50–69 years at diagnosis, as the reference group for comparison with women aged 70+ years.

9. Chemotherapy

Numerator	Women who receive chemotherapy 1. Neo-adjuvant chemotherapy 2. Adjuvant chemotherapy
Denominator	Women diagnosed with early invasive breast cancer <i>Subgroups</i> 1. ER-negative 2. HER2-positive

This chapter focuses on use of chemotherapy for women with early invasive breast cancer. We evaluated use of chemotherapy in the neo-adjuvant and adjuvant setting, for women with tumour characteristics where guidelines suggest chemotherapy should be offered.

Adjuvant chemotherapy improves disease-free survival and overall survival in patients with early invasive breast cancer, although the benefit tends to be greater in younger patients. It is effective for patients with both ER-positive and negative breast cancer, although the absolute benefit may be less among patients with ER-positive disease treated by endocrine therapy, particularly for those with low risk of recurrence. Among older patients, adjuvant chemotherapy is most commonly used in those with ER negative disease [Biganzoli *et al* 2012].

Neo-adjuvant chemotherapy may be recommended where the findings at diagnosis confirm that adjuvant chemotherapy would be advocated and there may be specific advantages to commencing with chemotherapy because this can shrink the tumour and facilitate subsequent BCS instead of mastectomy.

These initial findings provide a simple descriptive picture of the use of chemotherapy across women of different ages. The observations are broadly in line with previous studies given the increasing levels of poor health among older women, however for those younger women with HER2-positive early invasive breast cancer they are considerably lower than might be expected in practice.

In the next annual report, we will provide greater insight into chemotherapy treatment patterns by women's age at diagnosis.

What do we see within this audit group?

The pattern of chemotherapy use for women diagnosed with early invasive breast cancer is summarised in Figures 9.1–9.3. The patterns are broadly consistent with clinical recommendations; in particular:

1. There was greater use of both adjuvant and neo-adjuvant chemotherapy among women with higher stage early invasive disease (Figure 9.1).
2. Use of chemotherapy was more common among women with
 - ♦ ER-negative disease (Figure 9.2: 61% for 50–69 years; 23% for 70+ years)
 - ♦ HER2-positive disease (Figure 9.3: 60% for 50–69 years; 28% for 70+ years).

However, all three figures highlight the reduced use of chemotherapy (both neo-adjuvant and adjuvant) with increasing age at diagnosis regardless of tumour characteristic.

Recommendations

- All NHS trusts and local health boards must ensure that in line with guidelines, chronological age alone should not be a dominant factor in the decision to offer chemotherapy for women at high risk of recurrence especially if their breast cancer is ER-negative or HER2-positive.

Figure 9.1: Use of chemotherapy for women with early invasive breast cancer, by overall stage and age at diagnosis

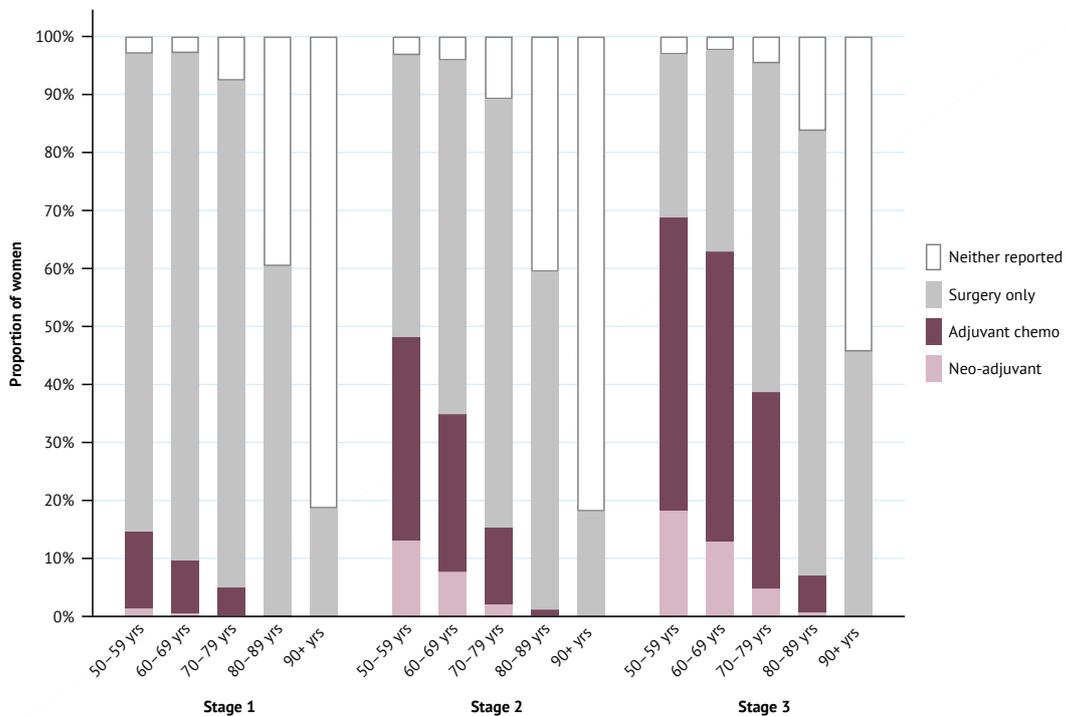


Figure 9.2: Use of chemotherapy for women with early invasive breast cancer, by ER status and age at diagnosis

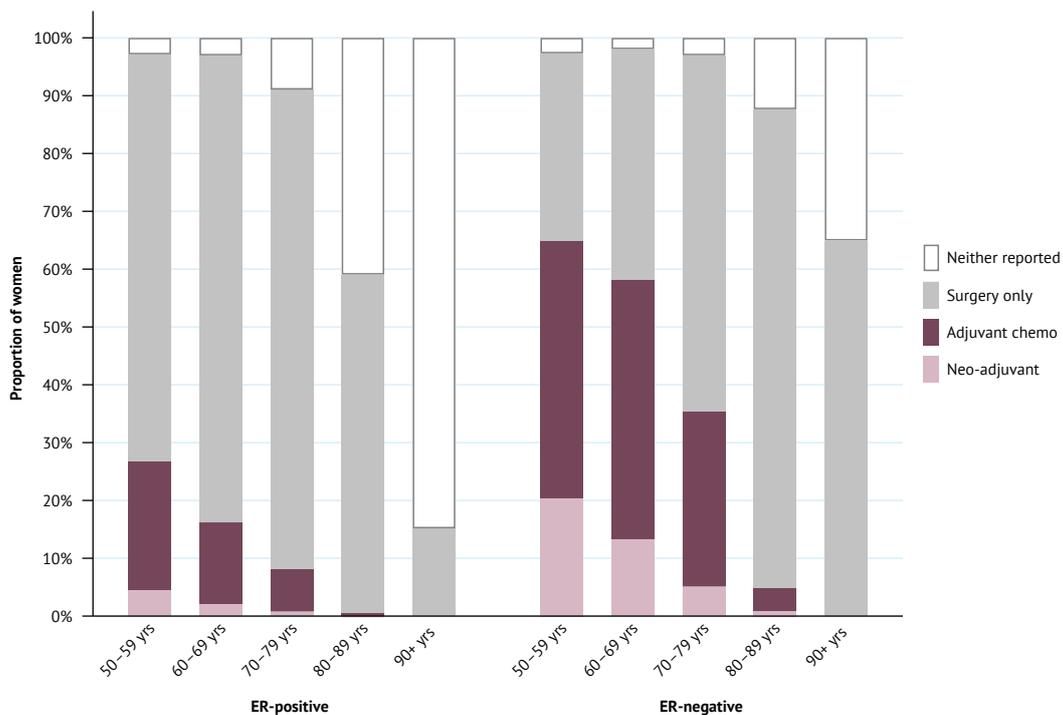
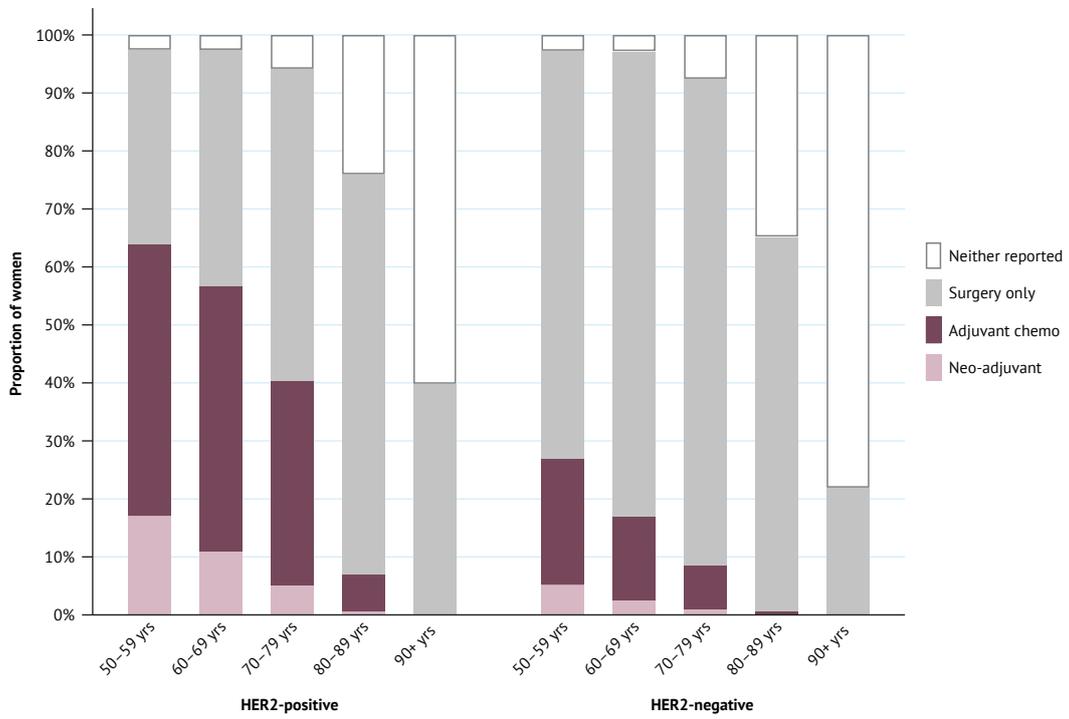


Figure 9.3: Use of chemotherapy for women with early invasive breast cancer, by HER2 status and age at diagnosis



10. Feasibility studies

10.1 Extending the audit to include private hospitals

The aim of this feasibility study was to examine the possibility of including data on patients treated in private sector hospitals in the prospective audit. This would be valuable because it would ensure that the audit has data on all treatments received by patients and not only those provided by NHS trusts and local health boards and this would improve oversight and governance within the private sector.

Currently, private hospitals in England are encouraged to submit data to the National Cancer Registration and Analysis Service (NCRAS) but they are not mandated to do so. In particular, there is no legal gateway for NCRAS to collect data on all patients managed and treated in the private sector data without patients giving individual consent for their data to be submitted to the cancer registry. Section 251 approval¹² does allow NCRAS to collect the Cancer Outcomes and Services Dataset (COSD)¹³ on patients with cancer without individual patient consent, but it cannot specifically mandate organisations outside the NHS to submit these data.

Although COSD data collection is not mandatory for private hospitals, some information on treatment provided in the private sector is captured by NCRAS:

- Some private hospitals provide pathology data routinely via an automatic route that helps and supports cancer registration.
- It is mandatory for an NHS trust to collect (and report on) information about cancer treatments provided by private hospitals but paid for by the NHS trust
- When patients have gone to a private provider for part of their cancer management and treatment, cancer registration officers write to the treating consultant requesting more information. Although this is not always responded to, NCRAS does receive some data to support registration this way.

NCRAS and the Welsh cancer registration services are both aiming to improve the completeness of data from the independent sector.

There are various initiatives in this area that are expected to lead to greater engagement with the private sector. These include: the response to the Paterson Enquiry¹⁴, and reviews involving the Royal College of Surgeons (RCS) and the Care Quality Commission (CQC) to ensure safety standards. Participation in national clinical audit is also under consideration by some private hospitals.

In summary, it is not currently feasible for NABCOP to extend the audit to include private sector hospitals. The NABCOP project team will keep a watching brief on this matter and respond to developments in this area that could make it possible.

10.2 Extending the audit to cover patients with recurrent disease

As we noted in the 2017 annual report, NCRAS is developing an algorithm in collaboration with a team from the Nuffield Department of Population Health, University of Oxford, to identify recurrence in patients with invasive breast cancer. The algorithm will use data from the English Cancer Registration system, Hospital Episode Statistics (HES), Cancer Waiting Times (CWT) and the Radiotherapy Dataset (RTDS). Annual updates of these recurrences as well as the incorporation of the Systemic Anti-Cancer Therapy (SACT) and PHE primary care prescription data are planned.

The performance of the algorithm is currently being evaluated and is expected to be available for use later in 2018, after testing and publication. This may make it possible for NABCOP to receive information on recurrence for English cases. The NABCOP project team will aim to report on these patients when the data becomes available.

¹² Section 251 of NHS Act 2006 and Health Service (Control of Patient Information) Regulations 2002, <https://www.hra.nhs.uk/approvals-amendments/what-approvals-do-i-need/confidentiality-advisory-group/>

¹³ http://www.ncin.org.uk/collecting_and_using_data/data_collection/cosd

¹⁴ <https://www.gov.uk/government/news/government-launches-independent-national-inquiry-into-convicted-surgeon-ian-paterson>

10.3 The feasibility of extending the audit along the patient pathway to include (a) routes to diagnosis, (b) bone health management, (c) planning of palliative care.

This feasibility study explored the potential of the NABCOP team to access data sources on primary/ community care and thereby extend its ability to examine more aspects of the care pathway.

- a. *Routes to diagnosis:* A data item on routes to diagnosis (based on an algorithm that combines information from more datasets than those received by NABCOP) is available from NCRAS for 2014 and 2015 diagnoses¹⁵. The delays caused by the linkage of these datasets means that it is not available within the NABCOP reporting period.
- b. *Bone health management:* The experience of other national clinical audits (such as the Falls and Fragility Fracture Audit Programme) suggests that access to data on bone health management remains difficult. First, there are considerable and unresolved information governance issues regarding the access to primary care data at a patient level. Nevertheless, NCRAS is exploring the use of primary care prescriptions data (which will likely be available by the time we enter year four of NABCOP¹⁶), which should allow – for example – the identification of prescriptions for drugs for bone health management.
- c. *Planning of palliative care:* The National End of Life Care Intelligence Network (NEoLCIN)¹⁷ collates existing data and information on end of life care for adults in England and supports the implementation of the government's End of Life Care Strategy. Discussion is ongoing between NEoLCIN and NCRAS to understand how the work may be able to benefit NABCOP going forward.

In summary, progress on extending the audit to report on routes to diagnosis, on bone health management, and on the planning of palliative care is currently limited. The NABCOP project team will work in collaboration with NCRAS colleagues, and will seek to make use of new data sources as they become available.

10.4 The value of linking data from the National Cancer Patient Experience Survey with the patient-level prospective audit data

The Cancer Patient Experience Survey (CPES) has been running in England since 2010, with the most recent report published by NHS England / Quality Health for patients diagnosed in 2016.¹⁸

The 2014 CPES dataset¹¹ has been provided by NCRAS to the NABCOP project team, as the next step following the feasibility study reported on in the 2017 annual report. This dataset contains the responses from cancer patients discharged in 2013, which precedes the current NABCOP 2014–2016 data reporting period. It has, however, enabled us to explore the data available and confirm that (as described in the NABCOP 2017 annual report), the CPES survey will enable us to provide NHS trusts with the following information:

- Whether delayed diagnosis is more common in older women
- Side-effects of treatment
- Involvement in decisions about care
- Ease of contacting the clinical nurse specialist
- Providing information for families to help care for patients at home.

The 2014 CPES dataset¹⁹ indicates that, for example: 90% of female patients who completed the CPES questionnaire in autumn 2013, were given the name of a breast CNS who would be in charge of their care (accounting for 91% of patients under the age of 70, and 89% of patients 70+ years of age).

The 2015 CPES dataset²⁰ is the first year of CPES that can be linked to the NABCOP patient-level dataset. It was not possible to use this dataset in this report, and findings using this dataset will be published in the next annual report.

We will request and report on the 2016 and 2017 CPES datasets when these become available.²¹

¹⁵ This data comes in the form of a look-up table with 1 code for eg GP, Emergency presentation, etc.

¹⁶ NCRAS currently have a four month snapshot of prescription data from April to July 2015. They then expect to get another four month snapshot. Again we can work closely with the NCRAS team to establish when it would be likely to have a workable set of prescription data.

¹⁷ <http://www.endoflifecare-intelligence.org.uk/home>

¹⁸ The 2016 survey on patients discharged between 01/04/2016 and 30/06/2016 achieved a response rate of 66.4% from an overall sample of 109,663 patients across the breadth of all cancers.

¹⁹ The 2014 CPES dataset is on patients discharged between 01/09/2013 and 30/11/2013.

²⁰ The 2015 survey is on patients discharged between 01/04/2015 and 30/06/2015. NOTE: A 2014 survey was not conducted, and the survey reporting period changed to April–June in 2015 – for reporting to coincide with the year of the survey.

²¹ NCRAS are in the process of signing the data sharing agreement to access the 2016 data. The fieldwork for the 2017 dataset is still being undertaken.

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Appendix 1. Project Board and Clinical Steering Group members

Project Board members (excluding project team)		
Name	Organisation	Role
Mr Nick Markham*	Royal College of Surgeons of England	*Project Board Chair, Invited Review Mechanism Chair
Dr Jacinta Abraham	Velindre NHS Trust	Breast Clinical Oncologist & Medical Director
Ms Karen Clements	National Cancer Registration and Analysis Service, Public Health England	NABCOP / NCRAS Project Manager
Miss Marianne Dillon	Abertawe Bro Morgannwg University Health Board Wales Cancer Network	Breast Surgeon Breast Cancer Audit Lead for Wales
Mr Mark Sibbering	Association of Breast Surgery	President
Mr Mirek Skrypak	Healthcare Quality Improvement Partnership	Associate Director for Quality and Development
Ms Sophia Turner	Independent Cancer Patients' Voice	Patient Representative
Ms Sarah Walker	Healthcare Quality Improvement Partnership	Project Manager
Ms Maggie Wilcox	Independent Cancer Patients' Voice	Patient Representative
Clinical Steering Group (CSG) members (excluding project team)		
Name	Organisation	Role
Ms Karen Clements ^{2,3}	National Cancer Registration and Analysis Service, Public Health England	NABCOP / NCRAS Project Manager
Miss Marianne Dillon ^{2,3}	Abertawe Bro Morgannwg University Health Board Wales Cancer Network	Breast Surgeon Breast Cancer Audit Lead for Wales
Prof. Deborah Fenton	Swansea University	Professor of Nursing
Mr Ashu Gandhi ²	Association of Breast Surgery University Hospital of South Manchester NHS Foundation Trust NHS Breast Screening Programme	Chair of Professional Standards, ABS Oncoplastic Breast and Endocrine Surgeon Surgical Chair
Prof. Margot Gosney ¹	British Geriatrics Society University of Reading Royal Berkshire NHS Foundation Trust	Deputy Chair of the Academic & Research Committee Director of Clinical Health Sciences Honorary Consultant in Elderly Care Medicine
Ms Lis Grimsey	Association of Breast Surgery	Macmillan Nurse Consultant
Prof. Chris Holcombe	Royal Liverpool and Broadgreen University Hospitals NHS Trust National Breast Clinical Reference Group	Oncoplastic Breast Surgeon Deputy Chair
Ms Eluned Hughes ⁵	Breast Cancer Now	Head of Public Health and Information
Ms Jacquie Jenkins	Public Health England, Screening Quality Assurance Service	Deputy Director of Quality Assurance
Prof. Ian Kunkler	University of Edinburgh NHS Lothian	Professor of Clinical Oncology Clinical Oncologist
Miss Fiona MacNeill	Getting It Right First Time (GIRFT) The Royal Marsden NHS Foundation Trust	Clinical Lead for Breast Surgery Consultant Breast Surgeon
Mr Andrew Murphy	National Cancer Registration and Analysis Service, Public Health England	Head of Cancer Datasets
Dr Emma Pennery	Breast Cancer Care	Clinical Director
Dr Stanley Ralph ¹	Age Anaesthesia Association Royal Derby Hospitals NHS Trust	Honorary Secretary Anaesthetist
Dr Alistair Ring ^{2,3}	Royal Marsden NHS Foundation Trust	Medical Oncologist
Prof. Tom Robinson ¹	University of Leicester University Hospitals of Leicester NHS Trust	Head of Department and Professor of Stroke Medicine Honorary Consultant Physician

Clinical Steering Group (CSG) members (excluding project team)

Name	Organisation	Role
Dr Nisha Sharma	Leeds Teaching Hospitals NHS Trust British Society of Breast Radiology	Director of Breast Screening (Leeds-Wakefield and Clinical Lead for Breast Imaging) Secretary
Dr Richard Simcock ¹	Macmillan Cancer Support	Chair of the Expert Reference Group (ERG) for Cancer Care in Older People convened by Macmillan
Ms Sophia Turner ³	Independent Cancer Patients' Voice	Patient Representative
Ms Maggie Wilcox ³	Independent Cancer Patients' Voice	Patient Representative
Prof. Lynda Wyld ^{1,2}	University of Sheffield Jasmine Breast Centre, Doncaster Bridging the Age Gap Study	Professor of Surgical Oncology Honorary Consultant Breast Surgeon Principal Investigator

CSG Subgroup guests attendees (excluding project team)

Name	Organisation	Role
Dr Michael Fertleman ¹	Charing Cross and St Mary's Hospitals	Lead clinician for the medical care of elderly orthopaedic patients (at both)
Dr Tania Kalsi ¹	Guy's & St Thomas' NHS Foundation Trust	Consultant Geriatrician
Dr Martin Vernon ¹	Manchester Royal Infirmary	Consultant Geriatrician Clinical Director, Community Adults and Specialist Services Directorate

Project Team

Name	Organisation	Role
Prof. Kieran Horgan	Leeds Teaching Hospitals NHS Trust	Consultant breast surgeon, Chair Breast SSCRG (NCRAS)
Prof. David Dodwell	Leeds Teaching Hospitals NHS Trust	Consultant clinical oncologist, Chair SACT
Miss Yasmin Jauhari	Clinical Effectiveness Unit, RCS	Clinical research fellow
Mrs Melissa Gannon	Clinical Effectiveness Unit, RCS	Research fellow / methodologist
Ms Jibby Medina	Clinical Effectiveness Unit, RCS	Project manager
Prof. David Cromwell	Clinical Effectiveness Unit, RCS	Director CEU

We are grateful to the members of the following subgroups for their expert input over the last year, to help shape key aspects of the audit's work:

¹ Assessing frailty, comorbidities and cognition (held 13 December 2017)

² Data analyses inclusion and exclusion criteria (2 February 2018)

³ Presentation of audit results (22 February 2018).

Note: Members/attendees of each group are highlighted by group numbers 1 to 3.

Appendix 2. NHS providers and geographical regions

Provider Code	Provider Name	Patients ≥50 years diagnosed 2014–16
Cheshire and Merseyside		
RBL	Wirral University Teaching Hospitals NHS Foundation Trust	960
RBN	St Helens and Knowsley Teaching Hospitals NHS Trust	594
RBT	Mid Cheshire Hospitals NHS Foundation Trust	716
REM	Aintree University Hospital NHS Foundation Trust	412
RJN	East Cheshire NHS Trust	696
RJR	Countess Of Chester Hospital NHS Foundation Trust	492
RQ6	Royal Liverpool and Broadgreen University Hospitals NHS Trust	1,359
RWW	Warrington and Halton Hospitals NHS Foundation Trust	639
East Midlands		
RK5	Sherwood Forest Hospitals NHS Foundation Trust	577
RNQ	Kettering General Hospital NHS Foundation Trust	688
RNS	Northampton General Hospital NHS Trust	757
RTG	Derby Teaching Hospitals NHS Foundation Trust	1,286
RWD	United Lincolnshire Hospitals NHS Trust	1,519
RWE	University Hospitals Of Leicester NHS Trust	1,932
RX1	Nottingham University Hospitals NHS Trust	1,574
East of England		
RAJ	Southend University Hospital NHS Foundation Trust	1,053
RC1	Bedford Hospital NHS Trust	354
RC9	Luton & Dunstable University Hospital NHS Foundation Trust	1,381
RCX	Queen Elizabeth Hospital Kings Lynn NHS Foundation Trust	568
RD8	Milton Keynes University Hospital NHS Foundation Trust	559
RDD	Basilston & Thurrock University Hospitals NHS Foundation Trust	456
RDE	Colchester Hospital University NHS Foundation Trust	875
RGN	North West Anglia NHS Foundation Trust	994
RGP	James Paget University Hospitals NHS Foundation Trust	559
RGQ	Ipswich Hospital NHS Trust	842
RGR	West Suffolk NHS Foundation Trust	690
RGT	Cambridge University Hospitals NHS Foundation Trust	984
RM1	Norfolk & Norwich University Hospitals NHS Foundation Trust	1,407
RQ8	Mid Essex Hospital Services NHS Trust	812
RQW	Princess Alexandra Hospital NHS Trust	692
RWG	West Hertfordshire Hospitals NHS Trust	546
RWH	East & North Hertfordshire NHS Trust	550
Greater Manchester		
R0A	Manchester University NHS Foundation Trust	1,885
RM3	Salford Royal NHS Foundation Trust	375
RMC	Bolton NHS Foundation Trust	1,027
RMP	Tameside Hospital NHS Foundation Trust	239
RRF	Wrightington, Wigan & Leigh NHS Foundation Trust	840
RW6	Pennine Acute Hospitals NHS Trust	739
RWJ	Stockport NHS Foundation Trust	394
Humber, Coast and Vale		
RCB	York Teaching Hospital NHS Foundation Trust	1,394
RJL	Northern Lincolnshire and Goole NHS Foundation Trust	528
RWA	Hull and East Yorkshire Hospitals NHS Trust	1,216

Provider Code	Provider Name	Patients ≥50 years diagnosed 2014–16
Kent and Medway		
RN7	Dartford and Gravesham NHS Trust	232
RPA	Medway NHS Foundation Trust	318
RVV	East Kent Hospitals University NHS Foundation Trust	1,593
RWF	Maidstone and Tunbridge Wells NHS Trust	1,919
Lancashire and South Cumbria		
RTX	University Hospitals Of Morecambe Bay NHS Foundation Trust	1,196
RXL	Blackpool Teaching Hospitals NHS Foundation Trust	439
RXN	Lancashire Teaching Hospitals NHS Foundation Trust	537
RXR	East Lancashire Hospitals NHS Trust	965
North Central and North East London		
R1H	Barts Health NHS Trust	1,400
RAL	Royal Free London NHS Foundation Trust	908
RAP	North Middlesex University Hospital NHS Trust	1,303
RF4	Barking, Havering and Redbridge University Hospitals NHS Trust	1,283
RKE	Whittington Hospital NHS Trust	185
RRV	University College London Hospitals NHS Foundation Trust	289
North East and Cumbria		
RLN	City Hospitals Sunderland NHS Foundation Trust	137
RNL	North Cumbria University Hospitals NHS Trust	712
RR7	Gateshead Health NHS Foundation Trust	1,324
RTD	Newcastle Upon Tyne Hospitals NHS Foundation Trust	1,419
RTF	Northumbria Healthcare NHS Foundation Trust	579
RTR	South Tees Hospitals NHS Foundation Trust	543
RVW	North Tees and Hartlepool NHS Foundation Trust	1,239
RXP	County Durham and Darlington NHS Foundation Trust	648
Peninsula		
RA9	Torbay & South Devon NHS Foundation Trust	764
RBZ	Northern Devon Healthcare NHS Trust	232
REF	Royal Cornwall Hospitals NHS Trust	1,088
RH8	Royal Devon and Exeter NHS Foundation Trust	1,154
RK9	Plymouth Hospitals NHS Trust	1,043
Somerset, Wiltshire, Avon & Gloucestershire		
RA3	Weston Area Health NHS Trust	210
RA4	Yeovil District Hospital NHS Foundation Trust	92
RA7	University Hospitals Bristol NHS Foundation Trust	158
RBA	Taunton & Somerset NHS Foundation Trust	1,165
RD1	Royal United Hospitals Bath NHS Foundation Trust	661
RNZ	Salisbury NHS Foundation Trust	365
RTE	Gloucestershire Hospitals NHS Foundation Trust	1,550
RVJ	North Bristol NHS Trust	1,832
South East London		
RJ1	Guy's and St Thomas' NHS Foundation Trust	423
RJ2	Lewisham and Greenwich NHS Trust	589
RJZ	Kings College Hospital NHS Foundation Trust	1,593

Provider Code	Provider Name	Patients ≥50 years diagnosed 2014–16
South Yorkshire, Bassetlaw and North Derbyshire		
RFF	Barnsley Hospital NHS Foundation Trust	511
RFR	The Rotherham NHS Foundation Trust	518
RFS	Chesterfield Royal Hospital NHS Foundation Trust	749
RHQ	Sheffield Teaching Hospitals NHS Foundation Trust	1,109
RP5	Doncaster and Bassetlaw Hospitals NHS Foundation Trust	986
Surrey & Sussex		
RA2	Royal Surrey County Hospital NHS Foundation Trust	1,920
RDU	Frimley Health NHS Foundation Trust	1,262
RTK	Ashford and St. Peters Hospitals NHS Foundation Trust	260
RTP	Surrey and Sussex Healthcare NHS Trust	564
RXC	East Sussex Healthcare NHS Trust	679
RXH	Brighton and Sussex University Hospitals NHS Trust	1,340
RYR	Western Sussex Hospitals NHS Foundation Trust	1,574
Thames Valley		
RHW	Royal Berkshire NHS Foundation Trust	1,003
RN3	Great Western Hospitals NHS Foundation Trust	932
RTH	Oxford University Hospitals NHS Foundation Trust	1,353
RXQ	Buckinghamshire Healthcare NHS Trust	1,099
Wessex		
R1F	Isle Of Wight NHS Trust	387
RBD	Dorset County Hospital NHS Foundation Trust	320
RD3	Poole Hospital NHS Foundation Trust	1,245
RDZ	Royal Bournemouth and Christchurch Hospitals NHS Foundation Trust	544
RHM	University Hospital Southampton NHS Foundation Trust	1,275
RHU	Portsmouth Hospitals NHS Trust	1,437
RN5	Hampshire Hospitals NHS Foundation Trust	1,110
West London		
R1K	London North West Healthcare NHS Trust	667
RAS	Hillingdon Hospitals NHS Foundation Trust	302
RAX	Kingston Hospital NHS Foundation Trust	360
RJ6	Croydon Health Services NHS Trust	94
RJ7	St Georges University Hospitals NHS Foundation Trust	1,526
RPY	Royal Marsden NHS Foundation Trust	1,107
RQM	Chelsea and Westminster Hospital NHS Foundation Trust	277
RYJ	Imperial College Healthcare NHS Trust	1,263

Provider Code	Provider Name	Patients ≥50 years diagnosed 2014–16
West Midlands		
RBK	Walsall Healthcare NHS Trust	505
RJC	South Warwickshire NHS Foundation Trust	431
RJE	University Hospitals Of North Midlands NHS Trust	1,629
RJF	Burton Hospitals NHS Foundation Trust	498
RKB	University Hospitals Coventry & Warwickshire NHS Trust	1,155
RL4	Royal Wolverhampton NHS Trust	708
RLQ	Wye Valley NHS Trust	457
RLT	George Eliot Hospital NHS Trust	252
RNA	Dudley Group NHS Foundation Trust	822
RR1	Heart Of England NHS Foundation Trust	1,110
RRK	University Hospitals Birmingham NHS Foundation Trust	774
RWP	Worcestershire Acute Hospitals NHS Trust	1,351
RXK	Sandwell and West Birmingham Hospitals NHS Trust	1,013
RXW	Shrewsbury and Telford Hospital NHS Trust	1,150
West Yorkshire		
RAE	Bradford Teaching Hospitals NHS Foundation Trust	1,257
RCD	Harrogate & District NHS Foundation Trust	276
RCF	Airedale NHS Foundation Trust	251
RR8	Leeds Teaching Hospitals NHS Trust	1,661
RWY	Calderdale & Huddersfield NHS Foundation Trust	475
RXF	Mid Yorkshire Hospitals NHS Trust	638
Wales		
7A1	Betsi Cadwaladr University Local Health Board	1,872
7A2	Hywel Dda University Local Health Board	1,159
7A3	Abertawe Bro Morgannwg University Local Health Board	1,333
7A4	Cardiff and Vale University Local Health Board	912
7A5	Cwm Taf University Local Health Board	915
7A6	Aneurin Bevan University Local Health Board	1,080
Notes:		
<ol style="list-style-type: none"> 1. The registration dataset for 2014–16 included several NHS trusts at which fewer than 90 patients were diagnosed over the 3 year period. These NHS trusts were not included in this report; they are: South Tyneside NHS Foundation Trust, Epsom & St Helier University Hospitals NHS Trust, Homerton University Hospital NHS Foundation Trust, Southport & Ormskirk Hospital NHS Trust, and South Tyneside NHS Foundation Trust. 2. The Christie NHS Foundation Trust, Clatterbridge Cancer Centre NHS Foundation Trust and Velindre NHS Trust are tertiary centres that mainly provide oncological treatment for breast cancer patients, they have therefore not been included directly within the NABCOP report; any women reported as being diagnosed at one of these centres have been reassigned to the trust where the MDT took place or where surgery took place. 		

Appendix 3: Description of the NABCOP core set of indicators

Pathway	Type*	Indicator	Denominator	Numerator	Data Source	Standard/ guideline	Report Section
Diagnosis and staging	P	Referral route to diagnosis ²	All women	Women diagnosed after: 1. referral from screening 2. referral from GP 3. referral from other specialities 4. an emergency presentation	COSD Cancer Registry Canisc	NICE CG80, 2009a NICE QS12, 2011	5.1
Diagnosis and staging	P	Triple diagnostic assessment in a single visit ^{1,2}	Women with non-screen detected early invasive breast cancer	Women who receive triple diagnostic assessment in a single visit	COSD Cancer Registry Canisc	NICE CG80, 2009a NICE QS12, 2011	5.2
Diagnosis and staging	P	Recorded molecular marker status ^{1,2}	Women with invasive breast cancer	Women with molecular marker status recorded: 1. ER status 2. HER2 status	COSD Cancer Registry Canisc	NICE CG80, 2009a	3.3
Diagnosis and staging	P	Metastatic disease at initial presentation	Women diagnosed with invasive breast cancer	Women with metastatic disease at initial presentation	Cancer Registry COSD Canisc	NICE CG81, 2009b	5.3
Diagnosis and staging	P	Seen by a breast CNS/named key worker ³	All women	Women seen by a breast CNS/named key worker	COSD	NICE CG80, 2009a NICE CG81, 2009b	6.1
Treatment	P	Time to primary treatment	Women who receive surgery or chemotherapy as primary treatment	Time from date of diagnosis to chemotherapy or surgical treatment	HES SACT COSD Cancer Registry PEDW Canisc	DoH 2007 DoH 2011	6.2
Surgery	P	Surgery for DCIS or early stage invasive breast cancer ^{3,7}	Women with DCIS or early stage invasive breast cancer	Women who receive surgery Two indicators based on denominator: 1. DCIS 2. Early stage invasive breast cancer	HES PEDW COSD Cancer Registry Canisc	NICE CG80, 2009a Biganzoli <i>et al</i> 2012	7.1 and 7.3
Surgery	P	Mastectomy for early invasive breast cancer ^{3,7}	Women with early stage invasive breast cancer	Women who receive mastectomy: 1. Proportion of mastectomies by age group 2. Proportion of mastectomies for given total tumour size <15mm	HES PEDW COSD Cancer Registry Canisc	NICE CG80, 2009a Biganzoli <i>et al</i> 2012	7.1
Diagnosis and staging	P	Any axillary nodal surgery ²	Women with early invasive breast cancer	Women who received SNB, axillary node sampling or dissection; with recorded lymph node status	HES PEDW COSD Cancer Registry Canisc	NICE QS12, 2011 NICE CG80, 2009a Biganzoli <i>et al</i> 2012 NICE DG8, 2013 SIGN 134, 2013	7.2

Pathway	Type*	Indicator	Denominator	Numerator	Data Source	Standard/ guideline	Report Section
Acute care	P	Length of hospital stay after surgery	Women with DCIS or invasive breast cancer who receive surgery	Length of hospital stay from date of surgery to date of discharge from hospital: 1. Proportion by type of surgery 2. Proportion who have a prolonged stay after surgery	HES PEDW	NICE QP case study, 2012 SCT, 2016	7.4
Radiotherapy	P	Radiotherapy after breast cancer surgery ^{3,10,11}	Women with DCIS or early invasive breast cancer who received surgery	Women who receive radiotherapy after surgery: 1. BCS 2. Mastectomy	HES RTDS Cancer Registry COSD PEDW Canisc	NICE CG80, 2009a Biganzoli <i>et al</i> 2012 SIGN 134, 2013	8
Chemotherapy	P	Chemotherapy for invasive breast cancer ⁵	Women with early invasive breast cancer. Subgroups = 1. ER-negative 2. HER2-positive	Women who receive chemotherapy: 1. Neo-adjuvant 2. Adjuvant	HES SACT Cancer Registry COSD PEDW Canisc	NICE CG80, 2009a NICE CG81, 2009b Biganzoli <i>et al</i> 2012 SIGN 134, 2013	9
Outcomes	O	Mortality at one, three and five years ²	All women	Women who die within: 1. One year 2. Three years 3. Five years	ONS	DoH Public Health Outcomes Framework 2013–2016 DoH NHS Outcomes Framework 2015–16	Not analysed for this annual report
Key: O – outcome indicator P – process indicator							

ABS – The Association of Breast Surgery. The association that represents healthcare professionals treating malignant and benign breast disease in the UK, Ireland and worldwide. It focuses on education, audit and guidelines to enhance the treatment of patients with breast disease. Registered charity no: 1135699

Adjuvant (treatments) – These are treatments given after primary treatment, which in the case of breast cancer is surgery, to lower the risk of the cancer coming back. Adjuvant cancer treatments usually refer to chemotherapy or radiotherapy.

AND – Axillary node dissection. A procedure to remove the majority of the glands (lymph nodes) under the armpit (axilla). This is performed in patients with evidence of cancer in the axillary lymph nodes.

ASA score – The American Society of Anaesthesiologists classification. A scoring system based on perioperative health and comorbidities of a surgical patient. A high ASA score denotes a higher risk of perioperative complications in the short and long term.

ASA classification	Definition	Examples
I	A normal healthy patient	Healthy, non-smoking, minimal alcohol use
II	A patient with mild systemic disease	Disease with minimal functional limitations eg current smoker, well controlled diabetes mellitus
III	A patient with severe systemic disease	Diseases with substantive functional limitations eg poorly controlled diabetes mellitus, end stage renal failure (ESRF) with regular dialysis, history (>3 months) of myocardial infarction
IV	A patient with severe systemic disease that is a constant threat to life	eg recent (<3 months) myocardial infarction, ESRF without regular dialysis

ASA classification	Definition	Examples
V	A moribund patient who is not expected to survive without the operation	eg ruptured abdominal/thoracic aneurysm
VI	A declared brain-dead patient whose organs are being removed for donor purposes	

BCS – Breast conserving surgery. A procedure to remove a discrete lump or abnormal area of tissue from the breast, without the removal of all breast tissue.

Breast reconstruction surgery – The surgical recreation of the breast mound (or shape) after some or all of this has been removed (eg after breast cancer surgery).

BTW – Breast Test Wales is the national breast-screening programme for Wales which offers three yearly mammograms for the detection of early breast cancer for women aged over 50.

CaNISC – An all-Wales electronic patient record used for clinical management of cancer patients.

Charlson comorbidity score – This is a commonly used scoring system for medical comorbidities. The score is calculated based on the absence (0) and presence (≥ 1) of specific medical problems. The conditions covered by the index include: myocardial infarction, congestive cardiac failure, cerebrovascular disease, dementia, chronic pulmonary disease, rheumatological disease, liver disease, hemiplegia or paraplegia, renal disease, any malignancy, metastatic solid tumour and AIDS/HIV infection.

Chemotherapy – Drug therapy used to treat cancer.

CNS – Clinical nurse specialists. Specially trained nurses who provide an essential role in supporting the various aspects of care for a cancer patient.

Comorbidity – A coexisting medical condition that is unrelated to the primary breast cancer.

COSD – The Cancer Outcomes and Services Dataset. The national standard dataset for recording details of cancer patients in England. NHS providers submit COSD data items to NCRAS who compile the dataset by combining it with information from other NHS systems.

DCIS – Ductal carcinoma *in situ*. The most common type of non-invasive breast cancer whereby the abnormal cells are restricted to the walls of the milk ducts (*in situ*).

Delayed breast reconstruction – The reconstruction of the breast mound (or shape) after a mastectomy has already been performed. This is undertaken as a separate operative procedure.

Endocrine therapy – Anti-oestrogen drug therapy used to treat 'hormone positive' breast cancer. This treatment reduces the levels of oestrogen and progesterone in the body or blocks its action.

ER status – Oestrogen receptor status. Breast cancers can grow in response to the sex hormone oestrogen. Approximately 70% of invasive breast cancers are 'ER positive' as they have receptors for oestrogen. These receptors (often termed molecular markers) are targets for endocrine therapy. Cancers without oestrogen or progesterone receptors will not benefit from antioestrogenic treatment.

Funnel plot²² – A graph which identifies organisations which are outliers, where the local situation might require closer inspection – either because an area is doing well or because there is some indication that it is performing poorly. In this report:

- Each point on the funnel plot represents an NHS organisation.
- Each funnel plot is for one measure, with its values shown on the vertical/Y axis.
- The size of the organisations' cohort is shown on the horizontal or X axis.
- The benchmark value is shown as a horizontal line through the centre of the graph.

The graph shows two funnels (one within the other) that lie on either side of the benchmark and are called the control limits – similar to confidence intervals.

- The inner lines show two standard deviations or 95% control limits. The outer lines represent three standard deviations or 99.8% control limits.
- The funnel shape is formed because the control limits get narrower as the population size increases.

The outer funnel is used to decide if an area is significantly different to the benchmark with 99.8% confidence. If a point lies within the funnel then we conclude that it is not significantly different to the benchmark. If it falls outside the funnel then we can say the value is significantly 'better' or significantly 'worse' than the benchmark, depending on the direction of the indicator/outcome.

GP – General Practitioners. Doctors in the community who manage common medical conditions.

HER2 – HER2 (human epidermal growth factor) protein. A receptor that is present on normal breast cells. It is involved in the signalling and promotion of cell growth, and may be described as HER2/neu gene as this gene is responsible for the overproduction of HER2 protein in each cell. Breast cancer cells with higher levels of HER2 receptors (HER2 positive) are more aggressive and may grow more quickly. These receptors (often termed molecular markers) are the target of anti-HER2 therapies such as trastuzumab.

HES – Hospital Episode Statistics. A database that contains data on all inpatients treated in NHS trusts in England. This includes details of admissions, diagnoses and treatments.

HQIP – Healthcare Quality Improvement Partnership. Aims to promote quality improvement in healthcare, and in particular to increase the impact of clinical audit on the services provided by the NHS and independent healthcare organisations.

ICD10 – International Classification of Diseases, Tenth Revision. This is the World Health Organization international standard diagnostic classification, which is used to code diagnoses and complications in the Hospital Episode Statistics database of the English NHS and in PEDW in Wales.

Immediate breast reconstruction – The reconstruction of the breast mound (or shape) at the same time as the mastectomy, undertaken as part of the same operative procedure.

IMD – Index of Multiple Deprivation. This is the official measure of relative deprivation for small areas in England. IMD is often described as a rank within a category of five (quintile), in the order of the most to least deprived.

²² Funnel Plot Source: David Spiegelhalter, Medical Research Council Biostatistics Unit - <http://www.erpho.org.uk/Download/Public/6990/1/INPHO%204%20Quantifying%20performance.pdf>

Invasive breast cancer – There is invasion of cancerous cells in the breast beyond the original lining of breast ducts/glands.

IQR – The Interquartile Range (IQR) is a measure of variability. It is based on dividing a data set into quartiles. The IQR is the difference between the first and third quartiles.

Lymph nodes – These glands are part of the lymphatic network in the body, which plays an important role in the immune system. Cancer can spread from its area of origin to other parts of the body via the lymphatic network.

LOS – Length of stay. The amount of time a patient stays overnight in a hospital bed following a hospital admission.

Mastectomy – A type of surgical procedure for breast cancer treatment, which involves removing all breast tissue.

MDT – The multi-disciplinary team is a team of specialist health care professionals from various backgrounds (eg doctors, nurses, administrative staff) who collaborate to organise and deliver care for patients with a specific condition (eg breast cancer).

Metastatic disease – Often denoted as M1. When cancer has spread from the place in which it started to other parts of the body.

NCRAS – The National Cancer Registration and Analysis Service. Collects, analyses and reports on cancer data for the NHS population in England.

Neo-adjuvant (treatments) – These are treatments given before the primary treatment. Neo-adjuvant treatments for cancer usually refer to treatments given before surgery to shrink the cancer, making it easier to remove.

NHS – The National Health Service. The public health service in the United Kingdom.

NHSBSP – The NHS breast screening programme. In this programme asymptomatic women aged 47–70 (or 50–73 in some areas) are invited for three yearly mammograms for the detection of early breast cancer.

NICE – The National Institute of Health and Care Excellence. An organisation responsible for providing national guidance on the promotion of good health and the prevention and treatment of ill health.

Non-invasive breast cancer – Cancerous cells are restricted to the walls of the breast duct/gland of origin (*in situ*).

ONS – The Office for National Statistics. The government department responsible for collecting and publishing official statistics about the UK’s society and economy. This includes cancer registration data, and the national death register.

PEDW – The Patient Episode Database for Wales. A database that contains data on all inpatient and day case activity in NHS Wales hospitals. This includes details of admissions, diagnoses and those treatments undergone.

(WHO/ECOG) Performance Status – The World Health Organization (WHO)/ Eastern Cooperative Oncology Group (ECOG) performance status indicator is a measure of how disease(s) impact(s) a patient’s ability to manage on a daily basis. It was initially developed in the research setting to standardise the reporting of chemotherapy toxicity and response in clinical trials in cancer patients. However, it is now in the public domain and is routinely used in other research and clinical settings.

Performance status	Definition
0	Fully active, able to carry on all pre-disease performance without restriction
1	Restricted in physically strenuous activity but ambulatory and able to carry out work of a light or sedentary nature
2	Ambulatory and capable of all self-care but unable to carry out any work activities. Up and about more than 50% of waking hours
3	Capable of only limited self-care, confined to bed or chair more than 50% of waking hours
4	Completely disabled. Cannot carry on any self-care. Totally confined to bed or chair
5	Dead

PET – Primary endocrine therapy. Patients are treated with endocrine therapy rather than surgery as their main treatment for breast cancer.

Radiotherapy – The use of high-energy x-ray beams to kills cancer cells.

RCS – 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.

RTDS – The Radiotherapy Data Set. Contains information about radiotherapy treatment received by cancer patients in England, and includes details on treatment intent, doses and fractions, treatment region and number of attendances.

SACT – Systemic Anti-Cancer Therapy dataset. Contains information predominantly about chemotherapy treatment, along with some information on other drugs, received by patients in England. Details include drug regimen, number of cycles, treatment intent, performance status and reasons for any change in treatment.

Screening – Breast screening involves women being invited to have an x-ray examination called a mammogram. It aims to diagnose women early because it can enable clinicians to identify cancers when they are too small to feel. Typically, all women aged between 50 and 70 are invited for breast cancer screening every three years.

Sentinel lymph nodes – The first few lymph nodes into which a tumour is likely to spread.

SLNB – Sentinel lymph node biopsy. Allows identification of spread of cancer cells outside the area of origin.

Symptomatic breast cancer – The term used to refer to women who are diagnosed with breast cancer after presenting with symptoms to their GP, as opposed to women diagnosed after being screened.

Systemic anti-cancer therapy – An additional therapy (eg chemotherapy, endocrine therapy HER2 targeting therapy) provided to improve the effectiveness of the primary treatment (eg breast cancer surgery). This aims to reduce the chance of recurrence of the cancer and to improve the patient's overall chance of survival. These treatments may be provided before (neo-adjuvant) or after (adjuvant) surgery.

Trastuzumab – A drug therapy (whose brand name is Herceptin) used to treat breast cancer in women who have tumours that are HER2 -positive. It may be used on its own or in combination with other chemotherapy drugs.

Wales Cancer Network (WCN) – The WCN supports health boards and trusts in Wales to meet the requirements of the Welsh Government's Cancer Delivery Plan, and other national strategic plans and frameworks for cancer.

They are responsible for the collection, analysis and reporting of data to support the clinical management of cancer patients in Wales.

Welsh Index of Multiple Deprivation (WIMD) – The WIMD is the official measure of relative deprivation for small areas in Wales.