National Audit of Breast Cancer in Older Patients

Part of the National Clinical Audit and Patient Outcomes Programme

2020 Annual Report

Results of the prospective audit in England and Wales for women diagnosed between January 2014 and December 2018

A plan for tackling variation in the presentation and treatment of breast cancer in older women in England and Wales

NA BCOP | National Audit of Breast Cancer in Older Patients

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This version (1.1) was released on 8 March 2021, and included a correction to Figure 5.3 in the patient characteristics chapter on page 16.

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We would also like to extend our thanks to the members of the Project Board and the Clinical Steering Group for their advice and contributions to the audit (see **Appendix 1**). These groups have members from patient associations, medical associations, multidisciplinary experts in the area of breast cancer and medical care of the older person, and policy makers.

This work uses patient data that has been provided by, or derived from, patients and collected by the NHS as part of their care and support. The data are collated, maintained and quality assured by the National Cancer Registration and Analysis Service, which is part of Public Health England (PHE). Access to the data was facilitated by the PHE Office for Data Release. Data from the Cancer Network Information System Cymru (Canisc) and Patient Episode Database for Wales are used with permission of the NHS Wales Informatics Service bespoke analysis service.

Foreword

Despite the fact that the incidence of breast cancer increases with age, when compared to younger patients older women have significantly poorer outcomes. This difference is thought to be due to a combination of late diagnosis and undertreatment.

NABCOP is a joint project between the Association of Breast Surgery and the Clinical Effectiveness Unit of the Royal College of Surgeons of England, commissioned by Healthcare Quality Improvement Partnership. The audit aims to evaluate the care and outcomes for women with breast cancer aged 70 and over, and compare this to a younger cohort of women aged between the ages of 50 and 69.

This audit has demonstrated surgical treatment is carried out for the majority of women in England and Wales aged over 70 with an estrogen receptor negative cancer. There is little variation across units. This differs to the treatment of older women with estrogen positive tumours who are much less likely to undergo surgical treatment of their breast cancer and receive primary endocrine treatment. Although there may be valid reasons why some women are treated with primary endocrine therapy as opposed to surgery, there were wide variations in rates of surgery across NHS organisations for women over 70 with ER+ breast cancer. This variation is even greater in women aged over 80.

As there is a survival advantage for surgery compared to primary endocrine therapy in older women with ER+ breast cancer, it is essential to ensure that patients who are fit enough for surgery are offered this option. To help clinicians, NABCOP have introduced a new fitness assessment form to be used for patients aged over 70 with breast cancer when first seen in the clinic. This comprises the Clinical Frailty Scale, the Abbreviated Mental Test Score and screening questions on significant medical problems. This form will be available at the MDT to aid decision-making.

The data items captured by the fitness assessment form are being collected in the new COSD Version 9.0 dataset from 2020. If we are to understand the reasons for the wide variations in treatment in ER+ women over 70 then it is essential that these data items are completed.

The NABCOP project team, assisted by the Clinical Steering Group and the Project Board are to be congratulated on the continued success of the audit. The data has now identified key areas where there is marked variation in treatment in units across England and Wales. The assessment of fitness will help in reducing this variation and lead to improved outcomes for older women with breast cancer.

Julie Doughty
President, Association of Breast Surgery

Executive Summary

The National Audit of Breast Cancer in Older Patients (NABCOP) was established in 2016 to evaluate age disparity in the care received by women diagnosed with breast cancer in NHS hospitals within England and Wales, specifically older women (aged 70+ years), compared with women aged 50–69 years.

The NABCOP is a collaboration between the Clinical Effectiveness Unit at the Royal College of Surgeons of England (RCS) and the Association of Breast Surgery (ABS). The audit is commissioned by the Healthcare Quality Improvement Partnership (HQIP).The audit works in partnership with the National Cancer Registration and Analysis Service (NCRAS), Public Health England (PHE) and the Wales Cancer Network, and uses the routine data collected by these national bodies. This report can therefore only describe patient and tumour characteristics and patterns of care based on the information that is available, as provided by the data partners.

The NABCOP aims to support clinicians, healthcare providers, and commissioners in order to improve breast cancer care, as well as publish comparative information on outcomes and care processes from NHS organisations. This report is written primarily for health care professionals, clinical commissioners and breast cancer service providers. A separate version is written for patients and the wider public, containing key findings and recommendations. Supplementary material from the report, including tables containing individual NHS organisation results, are available on the NABCOP website (www.nabcop.org.uk)

Fourth NABCOP Annual Report

This fourth annual report describes the process and outcomes of care for 185,648 women, aged 50 years and over, diagnosed with breast cancer between 1 January 2014 and 31 December 2018 in England and Wales. These women were treated in 122 English NHS trusts and 6 Welsh local health boards.

Key findings from the 2020 report

This annual report shows there is substantial variation in treatment patterns by patient age and between breast units across England and Wales. The nature of the variation depends upon the type of treatment. For example rates of surgery are similar among NHS organisations for women aged 50–69, and then begin to diverge. For chemotherapy, the differences between NHS organisations occur mostly regardless of age.

A key finding in the report is the greater variation in rates of surgery among women with estrogen receptor (ER) positive early invasive breast cancer compared with women with ER negative disease. Primary endocrine therapy (PET) may be more appropriate for some older women with ER positive but the results suggests there were older women who were physically fit and who did not have surgery. For these women, available evidence suggests PET alone in preference to surgery leads to worse outcomes.

The above finding emphasises the importance of older women having an appropriate fitness assessment in breast clinics prior to treatment decisions, and at a time when it could allow the patient's health to be optimised for treatment. After a successful pilot of a short assessment aid, these different aspects of patient fitness have been included as data items in the new Cancer Outcomes and Services Dataset (COSD) Version 9.0, and can be submitted to NCRAS by English NHS trusts from summer 2020.These items will support local decision-making and allow greater insight into treatment patterns across all English NHS breast units.

Another key theme is that breast cancer among older patients has similar clinical and pathological characteristics to that of younger patients, and there is no evidence that invasive breast cancer is a more benign disease in older patients. Variations in practice are therefore of concern.

Fitness assessment for older women in breast clinics

Frailty and diminished cognition are more prevalent among older patients but these characteristics are not easily discerned with current national datasets. Because of this, the NABCOP has developed a fitness assessment form for use in breast clinics when patients aged 70+ years are referred for suspected breast cancer. The form comprises the Clinical Frailty Scale (CFS), the Abbreviated Mental Test Score (AMTS), and screening questions on significant medical problems.

Participation and data completeness

Data completeness of core data items remains variable, with patterns similar to last year's report. World Health Organization (WHO) performance status completeness has improved, now at 56% overall.

The molecular markers, ER and human epidermal growth receptor 2 (HER2) status, are pivotal in breast cancer decision-making, so recording of ER status should be close to 100%. Among women diagnosed in 2018, overall completeness was 91% for ER status and 85% for HER2 status, with no improvement in recent years. Moreover, these data items were less likely to be recorded in older women. If this reflects clinical practice, this raises concern around appropriate treatment selection.

Diagnosis and supportive care

The **routes to diagnosis** for women diagnosed in 2018 followed the expected pathways, and were similar to that presented in previous reports.

Among women diagnosed with early invasive breast cancer not detected at screening, receipt of **triple diagnostic assessment (TDA) in a single visit** has shown no improvement. Variation remains both by NHS organisation and by country of diagnosis, with a number of breast units having less than 70% of patients recorded as having TDA in a single visit.

English NHS trusts can now record receipt of TDA in a single visit in a single data item in COSD Version 9.0.

Where data were available, **contact with a breast clinical nurse specialist (CNS)** has shown no change. The completeness of this data item was considerably higher for women diagnosed in England (74%) compared with Wales (52%), but still below acceptable levels.

Treatment for women with DCIS

Surgical resection is the most important treatment for DCIS, but there is lack of strong trial-based evidence to support treatment decisions in older women. Radiotherapy should be considered following breast conserving surgery (BCS) [NICE 2018].

Surgery: Use of surgery decreased with age:

- 94% for 50–69 years; 90% for 70–79 years; 60% for 80+ years.
- Women diagnosed with DCIS not detected at screening were less likely to receive surgery, compared with women diagnosed by screening.
- Rates of surgery varied across NHS organisations, particularly as age increased.

Radiotherapy: 63% of women aged 50–69 years received radiotherapy after BCS compared with 51% aged 70–79 years and 28% aged 80+ years. There was considerable variation in use by NHS organisation regardless of age.

Treatment for women with early invasive breast cancer (EIBC)

Surgical resection is the most important treatment for early invasive breast cancer [NICE 2018]. Women with estrogen receptor (ER) positive breast cancer, who are unfit or who have a reduced life expectancy can be prescribed primary endocrine therapy as an alternative to surgery. There is often no suitable alternative therapy for women with ER negative breast cancer.

Surgery: Among women diagnosed with EIBC between 2014 and 2018, use of surgery:

- Was 96% of women aged 50–69 years compared with 90% for 70–79 years and 52% for 80+ years.
- Decreased among women with ER positive EIBC as their fitness reduced; the decrease was much less among women with ER negative EIBC.
- Varied for ER positive EIBC across NHS organisations; this became evident among women aged 75+ years.

Radiotherapy should be considered following breast conserving surgery for early invasive breast cancer [NICE 2018].

Radiotherapy after mastectomy is recommended for invasive breast cancer considered to have a moderate or high risk of recurrence (N+ or T3–4 N0) [NICE 2018].

Radiotherapy: The proportion of women who had radiotherapy following surgery for EIBC varied by age, NHS organisation and surgical procedure:

- Following BCS 91% of women aged 50–69 years received radiotherapy to the breast, compared with 86% for 70–79 years and 72% for 80+ years.
- Among women who had mastectomy for node positive (N+) or tumour stage 3-4 (T3–4) node negative (N0) EIBC, 68% of women aged 50–69 years had radiotherapy compared with 64% for 70–79 years and 53% for 80+ years.

Adjuvant chemotherapy decisions should be based on an understanding of the balance between risks and benefits, particularly in women with comorbidities [NICE 2018].

Chemotherapy:

- Use of adjuvant chemotherapy was higher among women with ER negative EIBC compared with ER positive EIBC.

- Use of adjuvant chemotherapy decreased with age, with less than 10% of women aged 80+ years receiving chemotherapy.
- Among women with ER negative, HER2 negative, lymph node positive EIBC, 74% of women aged 50–69 years received adjuvant chemotherapy compared with 46% for 70–79 years; 6% for 80+ years.

Adjuvant chemotherapy and trastuzumab is recommended for HER2 positive breast cancer, regardless of ER status [Senkus 2015].

- 70% of women aged 50–69 years with HER2 positive EIBC received adjuvant chemotherapy plus trastuzumab compared with 49% for 70–79 years; 9% for 80+ years. There was considerable variation by NHS organisation, regardless of age.

Treatment for women newly diagnosed with metastatic breast cancer

- The proportion of women who were diagnosed with metastatic breast cancer was small but increased with age: 3% for 50–69 years; 7% for 70–79 years; 8% for 80+ years.

Endocrine therapy should be offered as first-line treatment for ER positive metastatic breast cancer [NICE 2009b].

Chemotherapy should be offered for ER negative, hormone refractory or rapidly progressing cancer.

- Use of endocrine therapy increased with age, but women were less likely to receive chemotherapy as age increased: 45% for 50–69 years; 27% for 70–79 years; 9% for 80+ years.
- There was large variation in the use of chemotherapy across NHS organisations, regardless of age.

Outcomes

The audit undertook preliminary analyses of various early outcomes:

- Among women receiving adjuvant chemotherapy for early invasive breast cancer, 30-day mortality after receipt of the last recorded dose was low (<2% across all age groups).
- For women with metastatic breast cancer, 30-day mortality after palliative chemotherapy was between 10 and 15%, and was not related to age at diagnosis.
- Recorded rates of any recurrence were lower than would be expected, with a high proportion of women having died from their breast cancer with no prior recurrence recorded in clinical data. Low rates of recurrence were seen for all age groups and across all geographical regions.
- Relative survival demonstrates the clear impact of stage at diagnosis on overall survival following a diagnosis of breast cancer.

Patient experience

Data from the Cancer Patient Experience Survey (CPES), for patients diagnosed with cancer in England and surveyed from 2015–2018, were linked to the NABCOP patient-level data. When it came to shared decision-making at least four in five women reported:

- their expectations were met as far as their involvement in decisions about their care and treatment, and
- their treatment options were completely explained to them.

Nevertheless, there is room for improvement as 10% fewer women with newly diagnosed metastatic breast cancer (by comparison with DCIS and early invasive) reported these levels of shared decision-making.

Of patients who had radiotherapy and chemotherapy treatments, at least four in five women agreed that they had been provided with all of the information they needed about their treatment.

Across all groupings of breast cancer (DCIS, early invasive, metastatic), at least nine in ten women had access to a clinical nurse specialist and gave high overall ratings of their care.

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www.nabcop.org.uk
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Further information

Annual Report 2020

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

185,648
women aged 50+ years diagnosed with breast cancer across England and Wales in 2014–2018.

What is the breakdown by age for women diagnosed with breast cancer between 2014–2018?

61% aged 50–69 years

39% aged 70+ years

How did women in England rate their overall care according to the Cancer Patient Experience Survey?

96% rated their overall care as 7 or higher on a scale of zero (very poor) to 10 (very good).

68% of women were estimated to have received triple diagnostic assessment in a single visit, with no difference by age at diagnosis.

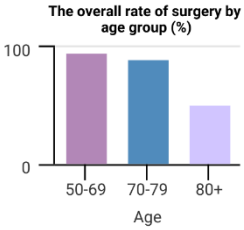
96% of women had reported contact with a clinical nurse specialist, with minimal difference by age group.

Treatment allocation by type of breast cancer across England and Wales

Early invasive breast cancer
138,099 women

62% aged 50–69 years

38% aged 70+ years



The percentage of women aged **70+** who had breast surgery varied by **NHS organisation**.

Women aged **70+** with **ER negative breast cancer** were more likely to receive surgery compared with women with **ER positive breast cancer.**

Among women who had **breast conserving surgery**:
91% of women aged **50–69** received radiotherapy
83% of women aged **70+** received radiotherapy

Among women who had **mastectomy** for high risk early invasive breast cancer:
68% of women aged **50–69** received radiotherapy
60% of women aged **70+** received radiotherapy

Use of chemotherapy was lower for older women and for women with **ER positive breast cancer**.

Ductal carcinoma in situ
19,819 women

78% aged 50–69 years

21% aged 70+ years

94% of women aged **50–69** had surgery
82% of women aged **70+** had surgery

There was greater variation across **NHS organisations** in surgery rates for women aged **70+** compared with women aged **50–69.**

63% of women aged **50–69** received radiotherapy*
47% of women aged **70+** received radiotherapy*

Rates of radiotherapy after surgery varied across **NHS organisations** for women of **all ages**.

*after breast conserving surgery

Metastatic breast cancer
8,188 women

41% aged 50–69 years

59% aged 70+ years

Older women were more likely to present with metastatic breast cancer:
3% of women aged **50–69**; **7%** of women aged **70–79**; **8%** of women aged **80+**

Fewer **older women** received **chemotherapy** compared with younger women.
Rates of chemotherapy use varied across **NHS organisations** for women of **all ages**.

GLOSSARY

Breast conserving surgery (BCS): an operation to remove a discrete lump or abnormal area of tissue from the breast without removing all breast tissue.

Chemotherapy: a drug therapy used to treat cancer, given either before or after surgery.

ER positive/negative: breast cancer cells can have receptors to estrogen on their surface. Breast cancers which have these receptors are called ER positive.

Mastectomy: an operation for breast cancer to remove all of the breast tissue.

Radiotherapy: high-energy x-ray beams to kill cancer cells.

Recommendations

		Where in report	Primary audience to action recommendation
Fitness assessment			
1.	Ensure all patients aged 70 years and over, at the initial clinic visit for suspicion of breast cancer, have the following information recorded: Clinical Frailty Scale, Abbreviated Mental Test Score, indication of whether or not the patient has an established diagnosis of dementia and severe comorbidities.	Chapter 3	Breast MDTs within NHS organisations
2.	Strive to submit the fitness assessment data items to NCRAS as part of COSD V9.0 submissions.	Chapter 3	Breast MDTs within English NHS organisations
Completeness of data items			
3.	Identify a clinician responsible for reviewing and feeding back, to staff within their breast units, on their data returns.	Chapter 4	Breast MDTs within NHS organisations
4.	Review data uploads regularly, and ensure the following are uploaded to NCRAS and Canisc: tumour size; T (tumour), N (nodal) and M (metastasis) stage; WHO performance status; ER and HER2 status for invasive breast cancer.	Chapter 4	Breast MDTs within NHS organisations, supported by IT teams
5.	Review how to improve the recording of recurrence in local medical records and ensure this information is uploaded to NCRAS and Canisc.	Chapter 10 - Section 10.2	Breast MDTs within NHS organisations supported by IT teams
Recorded molecular marker status			
6.	Carry out and record full tumour characterisation, including assessment of ER and HER2 status, for all patients with invasive breast cancer for use at multidisciplinary team meetings; in line with NICE guidance.	Chapter 5 – Section 5.2	Breast MDTs within NHS organisations supported by IT teams
Diagnosis and supportive care			
7.	Ensure women receive all components of the triple diagnostic assessment (TDA) at their initial clinic visit for suspected breast cancer.	Chapter 6 - Section 6.2	Breast MDTs within NHS organisations
8.	Submit data on triple diagnostic assessment in a single visit to NCRAS as part of COSD V9.0 submissions.	Chapter 6 - Section 6.2	Breast MDTs within English NHS organisations supported by IT teams
9.	Ensure that women are assigned a named breast clinical nurse specialist to provide information and support. Data on the assignment of a named breast clinical nurse specialist should be submitted to NCRAS and Canisc.	Chapter 6 - Section 6.3	Breast MDTs within NHS organisations supported by IT teams

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		Where in report	Primary audience
10.	Ensure patients have sufficient information about their care and treatment(s) and are engaged in a shared decision-making process by asking patients for feedback at regular intervals.	Chapter 6 to Chapter 9	Breast MDTs within NHS organisations
Treatment for Ductal Carcinoma In Situ			
11.	Consider adopting a more prescriptive policy concerning the management of DCIS that covers the use of surgery and adjuvant therapies in older women, in the context of any comorbidities and frailty.	Chapter 7	Breast MDTs within NHS organisations, commissioners and NICE
Treatment for early invasive breast cancer			
12.	Investigate and address any shortfalls in care within NHS organisations with a comparatively low rate of surgery for women aged 70+ years with ER positive breast cancer.	Chapter 8	Breast MDTs within NHS organisations supported by IT teams
13.	Counsel women with high risk early invasive breast cancer on the benefits and risks of adjuvant radiotherapy, based on tumour characteristics and objective assessment of patient fitness, rather than chronological age alone.	Chapter 8	Breast MDTs within NHS organisations
14.	Provide an objective assessment of the anticipated benefits and risks of chemotherapy, based on tumour factors and patient fitness, for all women, irrespective of age, with (1) ER negative, HER2 negative early invasive breast cancer with malignant lymph nodes or (2) HER2 positive early invasive breast cancer.	Chapter 8	Breast MDTs and oncology services within NHS organisations
Women with metastatic breast cancer			
15.	Ensure that all women with metastatic breast cancer have their tumour's ER status assessed and recorded; those with ER positive breast cancer should be offered endocrine therapy as part of their treatment package.	Chapter 9	Breast MDTs within NHS organisations supported by IT teams
16.	Ensure that, for women considered for chemotherapy, there is an objective assessment of potential benefit and predicted life expectancy. Consideration should not be based on chronological age alone.	Chapter 9	Breast MDTs and oncology services within NHS organisations

1. The National Audit of Breast Cancer in Older Patients

1.1. Introduction

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, diagnosed with breast cancer and treated in NHS hospitals within England and Wales. Breast cancer is the most common female cancer in the UK. Over 50,000 new cases of breast cancer are diagnosed in women each year in England and Wales. About one-third of such cancers are in women aged 70+ years [Office for National Statistics 2019; Welsh Cancer Intelligence and Surveillance Unit 2019].

The audit was commissioned because there was growing evidence of unexplained variation in the management of breast cancer among women aged 70+ years, compared with women aged under 70 years. The differences partly reflect the pathway to diagnosis, with breast screening offered to women between 50 and <71[1] years. Some variation in the management of patients will also reflect differences in the cancer stage and the presence of comorbidity. Nonetheless, various studies have concluded that these factors could not explain all of the observed variation between breast cancer services across England and Wales [Bates et al. 2014; Lavelle et al. 2014; Richards et al. 2016].

The audit investigates whether the care and treatment received by older women diagnosed with breast cancer is consistent with recommended practice for breast cancer management, as described by (among others) the NICE guideline [NICE2018]. It examines the care received by patients from initial diagnosis to the end of primary therapy, and contrasts how these patterns of care differ for women aged 70 years and over, compared with women aged 50–69 years. The audit adopts this approach because clinical guidelines lack specific recommendations on the management of breast cancer in older women in specific areas.

The NABCOP is a collaboration between the Association of Breast Surgery and the Clinical Effectiveness Unit of the Royal College of Surgeons of England (RCS). It is commissioned by the Healthcare Quality Improvement Partnership as part of the National Clinical Audit and Patient Outcomes Programme, which is funded by NHS England and the Welsh Government. The audit is overseen by a Project Board and supported by a Clinical Steering Group, whose role includes advising on the priorities for the audit and helping with the interpretation of its results. The Clinical Steering Group has members from patient associations, medical associations, multidisciplinary 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.

1.2. Overview of the 2020 Annual Report

This fourth NABCOP Annual Report describes information regarding diagnosis, staging and initial treatment of breast cancer, within NHS providers. We also include a preliminary look at early outcomes.

The report is aimed at those who provide, receive, commission and regulate breast cancer care. This includes clinicians and other healthcare professionals working within hospital cancer units, clinical commissioners, and regulators, as well as patients and the public who are interested in knowing how breast cancer services are delivered within the NHS. A separate report for patients and the public, aimed specifically at older patients receiving breast cancer care, their families and caregivers is published on the NABCOP website.

The report was produced using information about women aged 50 years and over who were diagnosed with breast cancer in England and Wales, during the five years between 1 January 2014 and 31 December 2018. The data were primarily collected as part of the national cancer registration process in England and Wales, but were supplemented with information from routinely collected hospital datasets, which provided additional information about the provision of breast cancer surgery. In addition, we include information from the English Cancer Patient Experience Survey (CPES), completed by patients diagnosed in England in 2015 to 2018.

[1] Up to their 71st birthday.

1.3. Management of older women with breast cancer

All women diagnosed with breast cancer follow a similar care pathway. Women will attend a breast clinic and undergo a clinical examination and some initial tests/scans. On the basis of these findings, a multidisciplinary team (MDT) meeting will discuss treatment options. Some women may only require surgery or endocrine therapy, but for women with more advanced disease, their treatment may involve a combination of surgery, radiotherapy and chemotherapy.

Differences in the patterns of care among younger and older patients do not necessarily imply deficiencies in breast cancer care for older women. The management of breast cancer should not be guided by chronological age alone: for individual women, it will reflect the characteristics of their breast cancer, as well as their general health, because of their ability to tolerate different therapies, and their personal preferences. For example:

- The short-term risks of surgery are exacerbated by the presence of cardiovascular, lung and kidney disease. Consequently, in frail women, surgery may pose a significant risk and it may be appropriate to offer primary endocrine therapy (PET) to women with estrogen receptor (ER) positive cancers instead [Morgan et al. 2014].
- The ability to tolerate adjuvant therapies 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 coexisting conditions [Lavelle et al. 2014].

It is also important to recognise that women aged 70+ years are a very heterogeneous population, and chronological age alone does not always correspond to biological age. Biological age is affected by chronic conditions (both physical and mental) as well as physical fitness and degree of frailty.

Finally, older women with breast cancer may differ from younger women in how they value quality versus quantity of life, and be willing to 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; Shrestha et al. 2019].

1.4. Other information produced by the audit

Supplementary materials for the report, including tables containing individual NHS organisation results, and further information about the audit, can be found on the website: www.nabcop.org.uk .

The NABCOP website also contains:

- Annual Reports from previous years
- Patient versions of the Annual Reports
- Links to resources that support local services' quality improvement initiatives
- Links to other sources of information about breast cancer such as Cancer Research UK

In addition, the CancerStats website produced by the National Cancer Registration and Analysis Service (NCRAS) contains information for English NHS breast units on the completeness of their Cancer Outcomes and Services Dataset (COSD) submissions, and performance indicators similar to those published in the NABCOP Annual Report (see **Appendix 2** for the NABCOP core indicators) but based on real-time data submissions.

The results from the audit are also used by various other national health care organisations. In particular, the NABCOP team has worked with HQIP and the Care Quality Commission (CQC) intelligence team to create a slide set to support the CQC hospital inspections.

2. Audit methods

2.1. Data sources

The NABCOP uses patient data routinely collected by the national cancer registration service in England and the Wales Cancer Network. This report can therefore only describe patient and tumour characteristics, along with patterns of care, based on the information that is available.

For English patients, the NCRAS provided data from its cancer analysis system, which collates patient data from a range of national data feeds across all NHS acute hospitals. This included a screening flag from the NHS Breast Screening Programme (NHSBSP) and Association of Breast Surgery (ABS) screening audit (previously provided by the Screening Histories Information Manager (SHIM) system). Data on Welsh patients were provided by the Wales Cancer Network using the Cancer Network Information System Cymru (Canisc) electronic patient record system.

The NCRAS and the Wales Cancer Network extracted details of women aged 50 years and over who were diagnosed with breast cancer in England and Wales over the five-year period between 1 January 2014 and 31 December 2018. Full details on the release of data to the NABCOP for annual reports, along with relevant timelines, can be found online at: https://www.nabcop.org.uk/resources-home/.

2.2. Patient cohort

The patients and timeframes covered in each chapter are indicated in the appropriate section. Broadly, timeframes are one year (2018) for **Chapter 6** and five years (2014–18) for **Chapters 7–10**. The full five years of data available are used for analyses considering treatments received and outcomes to enable reliable subgroup analysis by age at diagnosis and NHS organisation, as applicable. For full details of the methods used within this report, please see the NABCOP Annual Report Methodology 2020 document, available online (www.nabcop.org.uk).

Types of breast cancer

Within the report, we distinguish between the following groups of women with breast cancer:

1. ductal carcinoma in situ (DCIS; stage 0)
2. early invasive breast cancer (stages 1–3A)
3. metastatic breast cancer (stage 4).

Age groups

In this 2020 Annual Report, we investigate age disparity further by presenting three main subgroups of age: 50–69 years; 70–79 years; 80+ years. Specifically, within the chapters of this report, percentages for all three age groups are shown, with the addition of a percentage for the 70+ age group provided to enable comparison with previous annual reports. These are presented in bullet point lists with all percentages being for the age-specific subgroup identified.

Within figures showing individual NHS organisations, where the older age groups are combined and reported on as 70+ years this is due to the number of patients within the eldest subgroup being insufficient to draw valid conclusions.

2.3. Measurement of patient fitness

As noted in **Chapter 1**, as women age health differences often emerge. The datasets available for this annual report contain a limited number of data items to record this information, notably the World Health Organization (WHO) performance status instrument, which measures the functional status of patients on a scale from 0 to 4. Unfortunately, this data item remains poorly completed for breast cancer patients in the cancer datasets (**Table 4.1**). The report therefore uses two other approaches to measure patient fitness. These are:

- the RCS Charlson Comorbidity Index [Armitage et al. 2010]
- the Secondary Care Administrative Records Frailty (SCARF) Index [Jauhari at al. 2020].

Both of these measures use information from the hospital admissions data (Hospital Episode Statistics and the Patient Episodes Database for Wales). The RCS Charlson Comorbidity Index is based on 14 conditions that are typically associated with survival after breast cancer diagnosis, such as myocardial infarction, congestive heart failure, chronic pulmonary disease, renal disease and diabetes. The score counts the number of conditions recorded in hospital admissions around the time of diagnosis, as well as in the previous two years.

The measure of frailty used in this report is based on the 'cumulative deficit' model [Clegg et al. 2016], and describes frailty in relation to 32 different symptoms, signs, diseases and disabilities (referred to as deficits).

The index counts the number of deficits recorded in hospital admissions around the time of diagnosis, as well as in the previous two years.

For both measures conditions/deficits are identified using the International Statistical Classification of Diseases and Related Health Problems (ICD-10) codes, captured within the diagnosis fields of the hospital admissions data.

2.4. Patient experience

The English Cancer Patient Experience Survey (CPES) comprises a series of questions with multiple response options, aimed at providing insight into the care experienced by cancer patients across England. The survey samples all adults with a confirmed primary diagnosis of cancer, discharged from an NHS trust after an inpatient episode or day case attendance for cancer related treatment in the months of April, May and June of the corresponding year [Quality Health 2015–18].

The English CPES collected in 2015 is the first year of the survey that could be linked to the NABCOP English patient-level dataset. For this annual report, surveys collected from 2015 to 2018, were linked to the NABCOP English dataset. Across these years, and all cancer sites, the overall response rate was 65% of all patients invited.

The responses of the patients in the NABCOP cohort are summarised in **Chapters 6–9** and enable us to provide English NHS trusts with the following information on the experience of their patients' care:

- engagement in decisions about care and treatment
- clarity around treatment options
- involvement of a clinical nurse specialist and ease of contacting them
- overall rating of patients' care.

The NABCOP will request and report on the 2019 CPES dataset when it becomes available; as well as continue to investigate the possibility of receiving Welsh CPES data.

2.5. Outcomes following a diagnosis of breast cancer

In this report, we have a chapter specifically looking at early outcomes following a diagnosis of breast cancer (**Chapter 10**). This is the second NABCOP annual report where overall survival following a diagnosis of breast cancer is presented; this time we also present relative survival to show the impact of the breast cancer on survival. In addition, we present short-term mortality following (adjuvant/palliative) chemotherapy along with investigating the reporting of recurrence within the routinely collected data used by the NABCOP.

3. Fitness assessment for older women in breast clinics

3.1. NABCOP fitness assessment form

Deciding among the various treatment options for breast cancer may be challenging for clinicians, and requires balancing different patient and clinical characteristics alongside individual patient preference. Ageing is a highly individual process and chronological age often fails to fully depict the complexity of older adults. It is therefore important for the clinical assessment process to identify patients who are robustly fit and others who may require additional support or who may have more complicated health needs, to ensure that the appropriate provision of care can be implemented.

With this in mind, the NABCOP has investigated the practicality of introducing an assessment form to help physicians screen for frailty and cognitive deficit in older patients attending a breast clinic, with a suspected diagnosis of cancer. The audit team reviewed the literature on the measurement of frailty among breast cancer patients, and organised a multidisciplinary group to consider what might be required from a screening process. The team then piloted a short 'Fitness Assessment Form' (**Figure 3.1**) that was based on the evidence found from the review and advice from the group.

The form was designed to be suitable for use in a busy diagnostic clinic. Eligible patients include patients aged 70 years and over who are attending breast clinic for the first time for suspicion of breast cancer. It contained the Clinical Frailty Scale, Abbreviated Mental Test Score (AMTS) and two screening questions on significant medical problems. Together, this information would help:

- to identify a (pre-) frail patient as well as a fit patient, and
- to improve understanding of, and future support for, clinical decision-making and allow insight into potential reasons for those decisions.

Performing the assessment at the first diagnostic clinic visit allows the results to be considered during the initial multidisciplinary meeting where pivotal treatment decisions are often made. The Clinical Frailty Scale [Rockwood et al. 2005] and Abbreviated Mental Test Score [Hodkinson 1972] are validated tools and have not been adapted.

The form was piloted across 11 NHS organisations in 2018 with feedback from participants published in the NABCOP 2019 Annual Report (https://www.nabcop.org.uk/reports/nabcop-2019-annual-report/).

A revised version of the fitness assessment form was produced in 2019. This contains a further screening question about whether a patient has an established diagnosis of dementia, to reflect the importance of recognising cognitive impairment in the decision-making process.

What does the guidance say?

It is important that all women are assessed for treatment not just on the basis of their chronological age (see the European Society of Medical Oncology (ESMO) 2015 guidelines [Senkus et al. 2015] on primary breast cancer):

> *'Age should be taken into consideration in conjunction with other factors and should not be the sole determinant for withholding or recommending a treatment… Overall, we strongly recommend that 'younger' patients should not be over-treated because they are 'young', just as 'older' patients should not be under-treated, because they are deemed to be old.'*

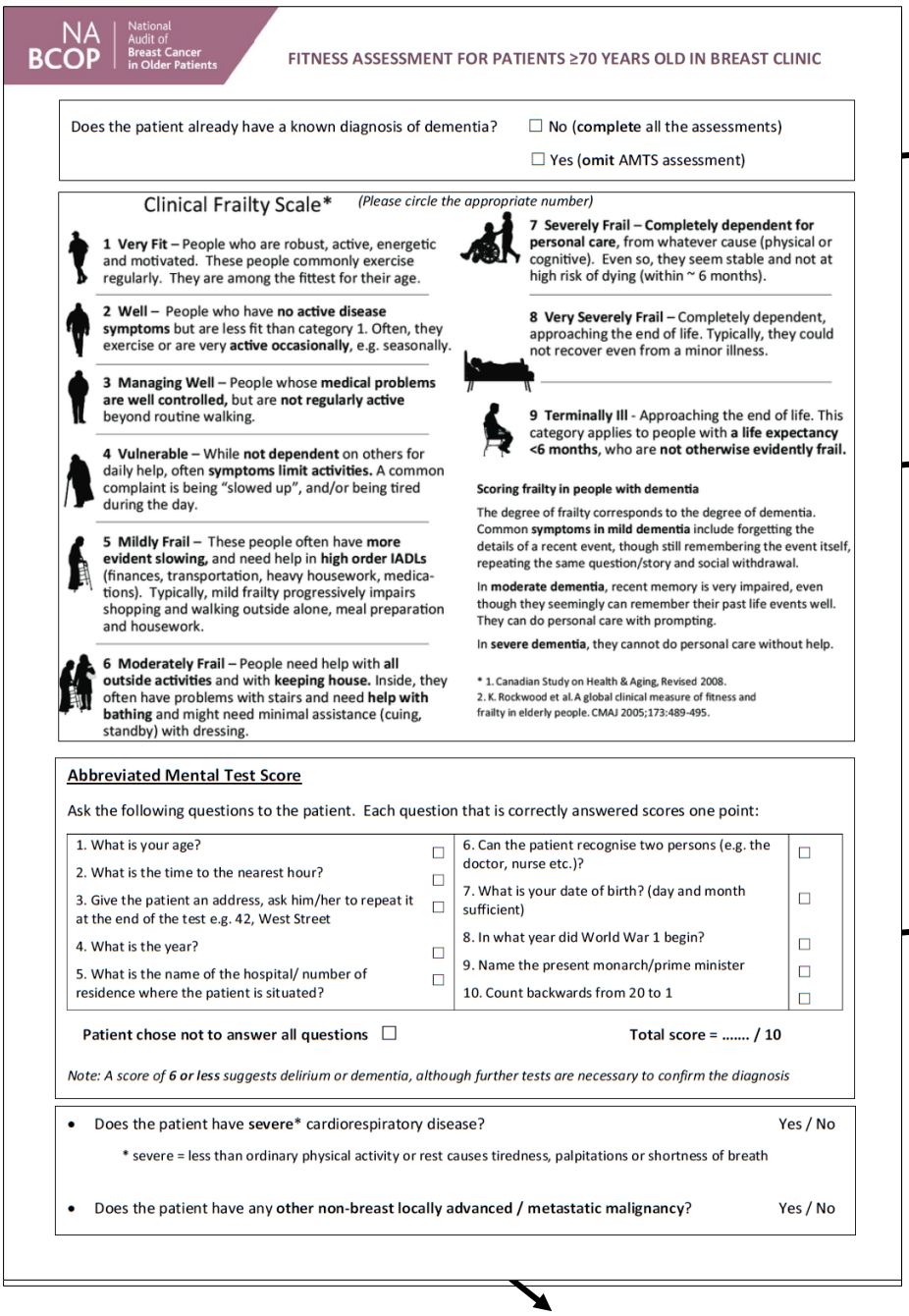
The International Society of Geriatric Oncology (SIOG) expanded their guidelines in 2012 on the management of elderly patients with breast cancer [Biganzoli et al. 2012] to include recommendations on geriatric assessment:

> *'Estimation of life expectancy and ability to undergo treatment might be improved by collaborative geriatric and oncology management, and a multi-domain geriatric assessment.'*

The Comprehensive Geriatric Assessment (CGA) is a detailed process of care for an individual, comprising physical, functional, psychological and pharmacological assessments. The SIOG guidelines present some evidence that CGA can have an impact on management decisions, but conclude, '*In breast cancer, robust evidence is lacking on the effect of using CGA results to guide treatment.'*

Figure 3.1. The NABCOP fitness assessment form for women aged 70 years and over in breast clinic

If you would like further information, or to download a PDF copy of the NABCOP Fitness Assessment Form, please visit the NABCOP website via the link: https://www.nabcop.org.uk/resources/fitness-assessment-tool/



NABCOP National Audit of Breast Cancer in Older Patients

FITNESS ASSESSMENT FOR PATIENTS ≥70 YEARS OLD IN BREAST CLINIC

Does the patient already have a known diagnosis of dementia? ☐ No (**complete** all the assessments) ☐ Yes (**omit** AMTS assessment)

Clinical Frailty Scale* *(Please circle the appropriate number)*

1 Very Fit – People who are robust, active, energetic and motivated. These people commonly exercise regularly. They are among the fittest for their age.

2 Well – People who have **no active disease symptoms** but are less fit than category 1. Often, they exercise or are very **active occasionally**, e.g. seasonally.

3 Managing Well – People whose **medical problems are well controlled,** but are **not regularly active** beyond routine walking.

4 Vulnerable – While **not dependent** on others for daily help, often **symptoms limit activities.** A common complaint is being "slowed up", and/or being tired during the day.

5 Mildly Frail – These people often have **more evident slowing,** and need help in **high order IADLs** (finances, transportation, heavy housework, medications). Typically, mild frailty progressively impairs shopping and walking outside alone, meal preparation and housework.

6 Moderately Frail – People need help with **all outside activities** and with **keeping house.** Inside, they often have problems with stairs and need **help with bathing** and might need minimal assistance (cuing, standby) with dressing.

7 Severely Frail – Completely dependent for personal care, from whatever cause (physical or cognitive). Even so, they seem stable and not at high risk of dying (within ~ 6 months).

8 Very Severely Frail – Completely dependent, approaching the end of life. Typically, they could not recover even from a minor illness.

9 Terminally Ill - Approaching the end of life. This category applies to people with **a life expectancy <6 months**, who are **not otherwise evidently frail.**

Scoring frailty in people with dementia

The degree of frailty corresponds to the degree of dementia. Common **symptoms in mild dementia** include forgetting the details of a recent event, though still remembering the event itself, repeating the same question/story and social withdrawal.

In **moderate dementia**, recent memory is very impaired, even though they seemingly can remember their past life events well. They can do personal care with prompting.

In **severe dementia**, they cannot do personal care without help.

* 1. Canadian Study on Health & Aging, Revised 2008.
2. K. Rockwood et al. A global clinical measure of fitness and frailty in elderly people. CMAJ 2005;173:489-495.

Abbreviated Mental Test Score

Ask the following questions to the patient. Each question that is correctly answered scores one point:

1. What is your age?	☐	6. Can the patient recognise two persons (e.g. the doctor, nurse etc.)?	☐
2. What is the time to the nearest hour?	☐	7. What is your date of birth? (day and month sufficient)	☐
3. Give the patient an address, ask him/her to repeat it at the end of the test e.g. 42, West Street	☐	8. In what year did World War 1 begin?	☐
4. What is the year?	☐	9. Name the present monarch/prime minister	☐
5. What is the name of the hospital/ number of residence where the patient is situated?	☐	10. Count backwards from 20 to 1	☐

Patient chose not to answer all questions ☐ **Total score = ... / 10**

*Note: A score of **6 or less** suggests delirium or dementia, although further tests are necessary to confirm the diagnosis*

- Does the patient have **severe*** cardiorespiratory disease? Yes / No

  * severe = less than ordinary physical activity or rest causes tiredness, palpitations or shortness of breath

- Does the patient have any **other non-breast locally advanced / metastatic malignancy**? Yes / No

An initial screening question to identify those patients with a known diagnosis of dementia.

The Clinical Frailty Scale is an assessment of a patient's frailty status. The judgement may be informed by one or more tests and routine clinical assessment.

The AMTS is a series of questions designed to assess a patient's cognitive ability, scored out of 10. It is a validated instrument that has been used in various clinical settings.

Two further screening questions capture whether the patient has (a background of severe cardiorespiratory symptoms or has advanced/metastatic cancer (excluding breast cancer).

3.2. Changes to COSD to reflect items in the NABCOP fitness assessment form

Having data on national patterns of patient fitness at the point of diagnosis is important to understand how overall health influences the management of women with breast cancer.

From summer 2020[2], the components on the fitness assessment form are able to be routinely recorded as part of the updated Cancer Outcomes and Services Dataset (COSD, Version 9.0). COSD is one of the main national datasets used by NABCOP. Table 3.1 contains a description of the data items.

What next?

At present, the fitness assessment form data items will only be collected for breast cancer patients diagnosed and treated in England. However, with new plans announced in September 2019 to develop digital health services in Wales, we hope that the collection of these data items will be extended to patients diagnosed and treated in Wales in the near future.

Recommendations

- Ensure all patients aged 70 years and over, at the initial clinic visit for suspicion of breast cancer, have the following information recorded: Clinical Frailty Scale, Abbreviated Mental Test Score, indication of whether or not the patient has an established diagnosis of dementia and severe comorbidities (Rec #1).
- Strive to submit the fitness assessment data items to NCRAS as part of COSD V9.0 submissions (Rec #2).

Table 3.1. New data items on fitness assessment in the breast cancer section of the updated COSD Version 9.0

Data item No.	Data Item Name	Description	National code definition
BR4500	FITNESS ASSESSMENT INDICATOR	Indicate if there was a Fitness Assessment carried out on the patient. **If yes please complete the following five data items. (These assessments and questions are for patients aged 70 and over at diagnosis)**	Yes
			No
BR4510	FITNESS ASSESSMENT DATE	The date the fitness assessment was completed	Date
BR4520	CLINICAL FRAILTY SCALE	Record the point on the Clinical Frailty Scale, as assigned by the appropriate clinician after discussion with the patient	1 (Very fit) to 9 (Terminally ill)
BR4530	ABBREVIATED MENTAL TEST SCORE	Record the total Abbreviated Mental Test Score, this should be a score from 0 to 10	(0-10)
BR4540	CARDIORESPIRATORY DISEASE	Does the patient have severe cardiorespiratory disease? Severe = less than ordinary physical activity or rest causes tiredness, palpitations or shortness of breath	Yes
			No
BR4550	OTHER NON BREAST LOCALLY ADVANCED/METASTATIC MALIGNANCY	Does the patient have any other Non-Breast Locally Advanced/Metastatic Malignancy?	Yes
			No

Note: The above table is a summarised version of the COSD Version 9.0 final dataset table published online. For a full list of breast specific data items, and further details on reporting these fitness assessment data items, please consult the online COSD Version 9.0 user guide: http://www.ncin.org.uk/collecting_and_using_data/data_collection/cosd_downloads_v9.

For women diagnosed in Wales it is anticipated that this information will be collected as specific data items within the revised Canisc.

[2] Implementation date deferred until 1 July 2020. This may be subject to further change. For further information visit - https://www.datadictionary.nhs.uk/data_dictionary/messages/clinical_data_sets/data_sets/cancer_outcomes_and_services_data_set/cancer_outcomes_and_services_data_set_-_core_fr.asp?shownav=1

4. Participation and data completeness

4.1. Participating NHS organisations across England and Wales

Information from 122 English NHS trusts and 6 Welsh local health boards are included in this 2020 Annual Report. There are fewer English NHS trusts in this report than in the 2019 Annual Report due to trust mergers, and a higher number of organisations diagnosing fewer than 150 patients over the five years (or fewer than 30 patients in 2018). **Appendix 3** contains a full list of the English NHS trusts and Welsh local health boards for whom data are provided for analysis in this annual report.

4.2. Overview of data completeness

The course of treatment offered to a patient with breast cancer is influenced by patient characteristics (general health and fitness), patient preference and the characteristics of the tumour (molecular markers, grade and stage at diagnosis). The recording of this information in the cancer datasets is therefore vital to understand patterns of care across NHS organisations. **Table 4.1** shows data completeness for a selection of core data items for women diagnosed in 2018, by age and country of diagnosis. It highlights a mixed picture of data completeness, both between countries and for the different age bands. For invasive tumours:

- Tumour grade: almost 100% completeness across age ranges and country of diagnosis.
- T stage: 94% complete overall with a reduction in completeness by age; lower completion in Wales.
- N stage: 94% complete overall with a reduction in completeness as age increased for women in England; 100% in Wales for all ages.
- Overall stage: women aged 80+ years were less likely to have overall stage recorded compared with those women aged 50–79 years**.**
- Tumour size was less well reported than tumour stage, particularly for older women.

Table 4.1 highlights that completion of WHO performance status remains poor, particularly for women diagnosed in Wales. There has however been some improvement in this over time.

Data concerning clinical nurse specialist (CNS) contact has shown no improvement in completeness for women diagnosed in 2018, compared with previous years, and is variably reported across NHS organisations.

For women with invasive breast cancer, data on ER and HER2 status continues to be less complete for older women, and overall there has been no improvement since the last report.

On the whole, data completeness has shown no improvement compared with that shown in the 2019 Annual Report[3]. The cause of poor data completion of some key data items within NCRAS and Canisc remains uncertain. More complete information would allow the NABCOP analyses to more accurately report on patterns of care for women with breast cancer.

The NABCOP website provides a selection of resources for NHS organisations across England and Wales to use to review their levels of data completeness (https://www.nabcop.org.uk/resources), including:

- the NHS organisation data viewer, which presents individual NHS organisation completeness of key NABCOP data items, by age; and
- a guide to improving data completeness, which contains information on how trusts in England can access CancerStats to interrogate their COSD returns in real time, as well as containing information on the national processes across Wales to aid local health boards to improve their data returns.

Recommendations

- Identify a clinician responsible for reviewing and feeding back, to staff within their breast units, on their data returns (Rec #3).
- Review data uploads regularly, and ensure the following are uploaded to NCRAS and Canisc: tumour size; T (tumour), N (nodal) and M (metastasis) stage; WHO performance status; ER and HER2 status for invasive breast cancer (Rec #4).

[3] https://www.nabcop.org.uk/reports/nabcop-2019-annual-report/

Table 4.1. Availability of core data items for women diagnosed in 2018; total availability and breakdown by country of diagnosis

Data item	Total % available	% availability of data items by country and age at diagnosis								
		All			England (n = 36,645)			Wales (n = 2,251)		
		50–69 years	70–79 years	80+ years	50–69 years	70–79 years	80+ years	50–69 years	70–79 years	80+ years
All tumours										
Total women	**38,896**	**22,851**	**9,511**	**6,534**	**21,513**	**8,979**	**6,153**	**1,338**	**532**	**381**
Laterality	100%	100%	100%	99%	100%	100%	99%	100%	99%	99%
Clinical nurse specialist contact	72%	73%	74%	70%	74%	75%	70%	46%	56%	64%
WHO performance status[a]	56%	58%	57%	51%	61%	60%	54%	5%	7%	7%
Non-invasive tumours										
Total women	**4,417**	**3,273**	**883**	**261**	**3,078**	**835**	**250**	**195**	**48**	**11**
Grade	97%	97%	96%	87%	97%	96%	87%	99%	98%	100%
ER status	31%	29%	34%	45%	29%	34%	43%	31%	23%	82%
Non-invasive tumour size	12%	12%	12%	9%	8%	8%	6%	75%	77%	82%
HER2 status	7%	6%	6%	10%	6%	6%	8%	17%	13%	45%
Invasive tumours										
Total women	**34,479**	**19,578**	**8,628**	**6,273**	**18,435**	**8,144**	**5,903**	**1,143**	**484**	**379**
Grade	100%	100%	99%	99%	100%	99%	100%	100%	99%	99%
Tumour stage	94%	96%	95%	87%	97%	95%	88%	89%	85%	61%
Nodal stage	94%	97%	95%	86%	96%	95%	85%	100%	100%	100%
Metastasis stage[b]	93%	95%	95%	85%	96%	95%	87%	89%	85%	61%
Overall stage	92%	94%	94%	84%	95%	95%	86%	82%	77%	55%
ER status	91%	92%	91%	86%	92%	91%	85%	97%	94%	93%
HER2 status	85%	89%	86%	74%	89%	86%	73%	94%	91%	83%
Whole tumour size	79%	83%	81%	65%	83%	82%	67%	77%	69%	35%
PR status	59%	61%	59%	56%	61%	59%	55%	60%	66%	62%

Note: Data items are ordered within sections based on total % available (highest % to lowest %).

Items are shaded according to level of data completeness according to quintiles: 0–20% 20–40%, 40–60%, 60–80%, 80–100%.

[a] WHO performance status reported within two months of diagnosis and prior to primary treatment starting.

[b] A recording of 'MX' within the data received is interpreted as intentionally unmeasured and not counted as missing.

It should be noted that with the emerging relevance of ER for decisions concerning endocrine therapy in DCIS, the NABCOP project team feel that HER2 status may also, in the future, come to be used as a possible, prognostic factor and would be needed for clinical research involving HER2-targeting therapies, it is therefore useful to collect. It is because of this that we report on the completion of ER and HER2 status (in the above table) in relation to non-invasive tumours. We are however aware that current guidance does not mandate this assessment in patients with DCIS and we would therefore not mandate the assessment and recording of HER2 status.

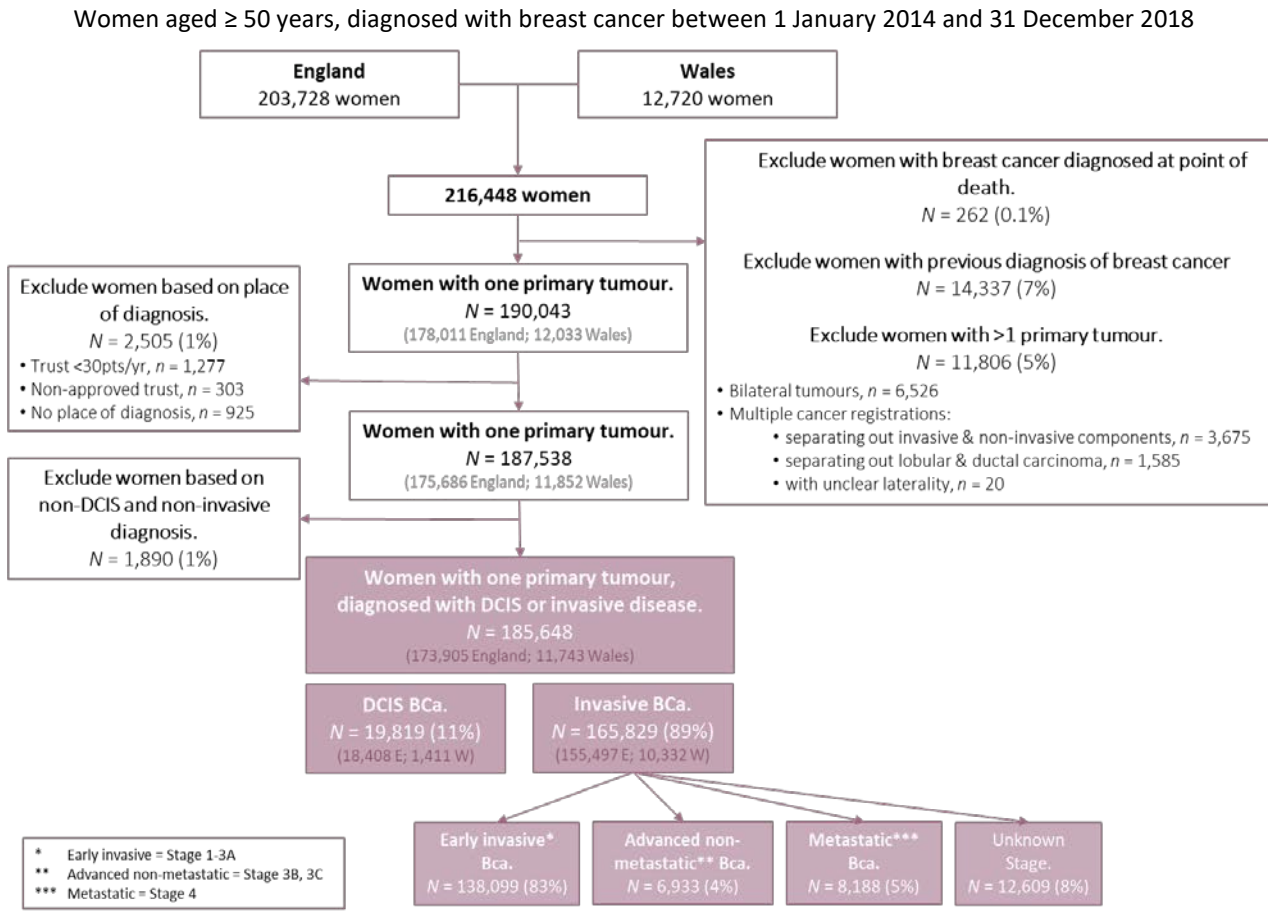
5. Patient characteristics

5.1. The NABCOP population

Figure 5.1 describes how the cohort of patients in the datasets provided by the English and Welsh cancer registries was prepared for analysis. The cohort includes the patient group for the five years from 2014 to 2018, and captures the care received by patients who were diagnosed with a single primary breast cancer.

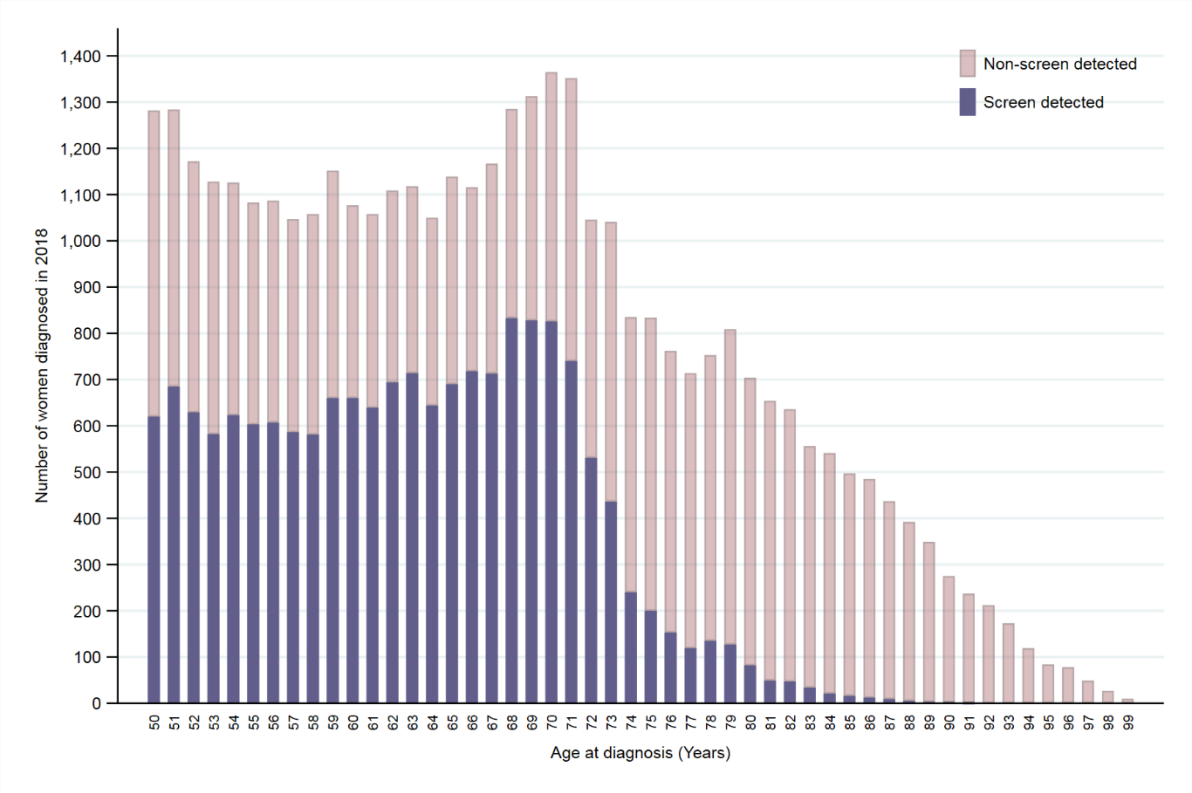
Figure 5.2 shows the breakdown of women diagnosed in 2018 by age at diagnosis and by method of presentation. From 2014 to 2018, there has been a slight change in the age distribution of women diagnosed with breast cancer. With each year, there has been an increase in the number of women diagnosed between the ages of 50–71, and we have seen a shift in the peak age for older women to be diagnosed from 68 to 71 years old. Of those women diagnosed at age 71, around half were diagnosed via breast screening services. For women diagnosed in England in 2018, there was an increase in the percentage of women screened in the 71–74 years age group which may reflect the failure of breast screening services to offer women a final screening before their 71st birthday, as reported within the most recent breast screening programme [Screening and Immunisations Team 2020].

Figure 5.1. Flow diagram of patients included within the NABCOP group



Note: See Appendix 3 for full list of NHS organisations included in this report as well as the names of NHS organisations with <30 patients/year. The number of women with a 'Non-approved trust' refers to those where their registered trust of diagnosis has no active breast unit. 'Multiple registrations' may not be registrations with the same date; the NABCOP will investigate inclusion of such women in future reports.

Figure 5.2. (Absolute) number of women diagnosed with breast cancer in England and Wales in 2018, by age at diagnosis and method of presentation



Note: The peak among women aged 68–71 years reflects the age structure of the general population. The incidence of breast cancer continues to increase among older women.

An overview of the patient and tumour characteristics of women diagnosed across the five-year period is provided in Table 5.1 and Table 5.2, broken down by age and type of tumour or disease stage. In total, there were 185,648 women diagnosed with breast cancer between 2014 and 2018:

- 61% were aged 50–69 years;
- 39% were aged 70+ years (the sum of 22% 70–79 years and 17% 80+ years).

Among women aged 50–69 years, 14% were diagnosed with DCIS. This decreased to 6% in women aged 70–79 years and was less than 3% among women aged 80 years or older. Differences in DCIS tumour characteristics, by age at diagnosis, included higher tumour grade as age decreased, and smaller tumour size among women aged 80+ years at diagnosis. Overall 1 in 5 women (22%) with DCIS were reported to have had surgery to examine their lymph nodes. Of these women, 79% received a mastectomy and 20% had breast conserving surgery (the remaining 1% had no surgery reported).

Considering key features of invasive breast cancer (Table 5.1), we see the breast cancer diagnosed in women between 50–79 years old tends to share similar tumour features. The key features of invasive breast cancer were as follows:

- The percentage of women with T1 tumours, where reported, tended to decrease with increased age at diagnosis, particularly in early invasive breast cancer.
- Tumours tended to be predominantly grade 2, regardless of age.
- Similar percentages of women had ER positive tumours, regardless of age.
- HER2 positive breast cancer rates were lower among older women, but data completeness was worse among this age group.

Among all breast cancer groups, as age at diagnosis increased, women were more likely to have poorer levels of fitness (measured by WHO performance status, Charlson Comorbidity Index and SCARF index).

Table 5.1. Patient and tumour characteristics for women aged 50 years and over diagnosed with breast cancer between January 2014 and December 2018, split by breast cancer group and age at diagnosis

Characteristic at diagnosis	DCIS (n = 19,819)			Early invasive (n = 138,099)			Metastatic (n = 8,188)		
	50–69 years	70–79 years	80+ years	50–69 years	70–79 years	80+ years	50–69 years	70–79 years	80+ years
Number of women	15542 (78%)	3207 (16%)	1070 (5%)	85854 (62%)	31097 (23%)	21148 (15%)	3379 (41%)	2349 (29%)	2460 (30%)
% screen detected cancer[a]	13208 (85%)	2085 (65%)	159 (15%)	50158 (58%)	10174 (33%)	890 (4%)	426 (13%)	80 (3%)	8 (0.3%)
Year of diagnosis – number of women diagnosed									
2014	3071	552	201	16577	5832	4109	650	473	495
2015	2943	585	221	17146	5890	4259	704	468	491
2016	3141	554	174	17509	5852	4152	672	448	499
2017	3114	633	213	17333	6224	4211	672	490	524
2018	3273	883	261	17289	7299	4417	681	470	451
Grade of disease – DCIS | Invasive									
% with grade reported	*96%*	*94%*	*84%*	*100%*	*100%*	*100%*	*100%*	*100%*	*100%*
Low | 1	10%	12%	17%	19%	15%	13%	4%	5%	5%
Intermediate | 2	30%	34%	40%	53%	57%	59%	46%	47%	46%
High | 3	60%	54%	43%	27%	27%	24%	39%	33%	26%
Not assessable	0%	0%	0%	1%	1%	4%	12%	14%	23%
Tumour size (cm)									
% with tumour size reported	*22%*	*20%*	*15%*	*87%*	*86%*	*73%*	*34%*	*34%*	*30%*
> 0.1 to 2	54%	53%	42%	65%	56%	40%	20%	16%	16%
> 2 to 5	34%	36%	41%	31%	40%	55%	54%	62%	59%
> 5	12%	11%	16%	4%	4%	5%	26%	22%	24%
Lymph node examination									
% with nodes examined	22%	23%	19%	83%	80%	43%	19%	14%	8%
Number of malignant lymph nodes (if examined)									
% with malignant nodes reported	*N/A*	*N/A*	*N/A*	*100%*	*100%*	*100%*	*98%*	*96%*	*97%*
0 malignant nodes	N/A	N/A	N/A	75%	74%	68%	12%	11%	14%
1–3 malignant nodes	N/A	N/A	N/A	21%	21%	25%	48%	49%	52%
4–9 malignant nodes	N/A	N/A	N/A	4%	5%	7%	23%	21%	17%
10+ malignant nodes	N/A	N/A	N/A	0%	0%	0%	17%	19%	17%

Note:

[a] screen detected status provided from the NHS breast screening audit; previously data provided from the Screening Histories Information Manager (SHIM).

Table 5.1. *…continued from previous page*									
	DCIS (n = 19,819)			Early invasive (n = 138,099)			Metastatic (n = 8,188)		
Characteristic at diagnosis	50–69 years	70–79 years	80+ years	50–69 years	70–79 years	80+ years	50–69 years	70–79 years	80+ years
ER status									
% with ER status reported	*27%*	*30%*	*44%*	*91%*	*91%*	*88%*	*78%*	*77%*	*69%*
Positive	81%	82%	85%	87%	87%	87%	78%	78%	80%
Negative	19%	18%	15%	13%	13%	13%	22%	22%	20%
HER2 status									
% with HER2 status reported	*4%*	*4%*	*7%*	*89%*	*87%*	*75%*	*75%*	*72%*	*57%*
Positive	33%	19%	15%	12%	10%	10%	24%	18%	16%
Negative	58%	72%	76%	80%	82%	81%	67%	73%	74%
Borderline	9%	9%	9%	8%	8%	10%	9%	9%	10%
WHO performance status[b]									
% with WHO PS reported	*33%*	*35%*	*32%*	*44%*	*43%*	*40%*	*51%*	*42%*	*32%*
0	92%	79%	46%	89%	70%	39%	59%	39%	24%
1	7%	15%	29%	9%	21%	28%	23%	31%	24%
2+	1%	6%	26%	2%	9%	33%	18%	30%	51%
Charlson Comorbidity Index (CCI)									
% with CCI calculated	*96%*	*97%*	*94%*	*97%*	*98%*	*93%*	*95%*	*95%*	*94%*
0	90%	80%	64%	91%	81%	64%	82%	65%	53%
1	8%	14%	22%	7%	12%	18%	13%	20%	23%
2+	2%	6%	14%	2%	7%	17%	6%	15%	24%
Secondary Care Administrative Records Frailty (SCARF) Index									
% with SCARF index calculated	*96%*	*97%*	*94%*	*97%*	*98%*	*93%*	*95%*	*95%*	*94%*
Fit	85%	70%	47%	86%	71%	51%	71%	51%	34%
Mild-moderate frailty	14%	27%	39%	13%	24%	33%	26%	39%	41%
Severe frailty	1%	3%	14%	1%	4%	16%	3%	10%	24%

Note:

[b] WHO performance status reported within two months of diagnosis and prior to primary treatment starting.

Table 5.2. Patient and tumour characteristics for women aged 50 years and over diagnosed with breast cancer between January 2014 and December 2018, split by breast cancer group and age at diagnosis

Characteristic at diagnosis	Advanced non-metastatic (n = 6,933)			Unknown stage [a] (n = 12,609)		
	50–69 years	70–79 years	80+ years	50–69 years	70–79 years	80+ years
Number of women	2897 (42%)	1683 (24%)	2353 (34%)	4985 (40%)	2525 (20%)	5099 (40%)
% screen detected cancer [b]	580 (20%)	118 (7%)	10 (0.4%)	2308 (46%)	462 (18%)	103 (2%)
Year of diagnosis – number of women diagnosed						
2014	597	360	470	1294	685	1414
2015	573	322	476	958	499	1039
2016	586	343	492	870	441	851
2017	578	318	468	818	381	837
2018	563	340	447	1045	519	958
Grade of disease						
% with grade reported	*100%*	*100%*	*100%*	*96%*	*95%*	*98%*
1	3%	3%	6%	14%	12%	11%
2	48%	48%	50%	47%	50%	50%
3	47%	46%	35%	28%	24%	17%
Not assessable	2%	3%	9%	11%	15%	22%
Tumour size (cm)						
% with tumour size reported	*65%*	*63%*	*45%*	*42%*	*38%*	*24%*
> 0.1 to 2	17%	13%	10%	45%	36%	27%
> 2 to 5	52%	54%	58%	40%	50%	57%
> 5	32%	34%	32%	15%	14%	16%
Lymph node examination						
% with nodes examined	59%	55%	27%	40%	31%	7%
Number of malignant lymph nodes (if examined)						
% with malignant nodes reported	*88%*	*92%*	*92%*	*99%*	*99%*	*99%*
0 malignant nodes	6%	8%	11%	33%	34%	32%
1–3 malignant nodes	11%	14%	20%	54%	48%	51%
4–9 malignant nodes	8%	9%	14%	12%	17%	17%
10+ malignant nodes	75%	69%	55%	1%	1%	0%

Note:

[a] Unknown stage includes those patients for whom no overall stage is reported and for whom no stage could be derived from reported TNM stage or ICD-10 code being D05 (i.e. DCIS).

[b] screen detected status provided from the NHS breast screening audit; previously data provided from the Screening Histories Information Manager (SHIM).

Table 5.2. *…continued from previous page*						
	Advanced non-metastatic (n = 6,933)			Unknown stage (n = 12,609)		
Characteristic at diagnosis	**50–69 years**	**70–79 years**	**80+ years**	**50–69 years**	**70–79 years**	**80+ years**
ER status						
% with ER status reported	*89%*	*89%*	*83%*	*74%*	*72%*	*68%*
Positive	76%	74%	78%	83%	86%	90%
Negative	24%	26%	22%	17%	14%	10%
HER2 status						
% with HER2 status reported	*88%*	*84%*	*71%*	*69%*	*65%*	*55%*
Positive	23%	19%	16%	19%	14%	10%
Negative	70%	72%	73%	75%	81%	82%
Borderline	7%	8%	11%	6%	5%	8%
WHO performance status[c]						
% with WHO PS reported	*52%*	*45%*	*41%*	*23%*	*20%*	*22%*
0	80%	53%	29%	83%	49%	24%
1	15%	30%	27%	11%	23%	21%
2+	5%	17%	44%	6%	28%	55%
Charlson Comorbidity Index (CCI)						
% with CCI calculated	*97%*	*95%*	*89%*	*86%*	*89%*	*86%*
0	89%	78%	66%	88%	67%	48%
1	8%	14%	16%	9%	16%	23%
2+	3%	8%	18%	4%	17%	29%
Secondary Care Administrative Records Frailty (SCARF) Index						
% with SCARF index calculated	*97%*	*95%*	*89%*	*86%*	*89%*	*86%*
Fit	85%	68%	50%	83%	57%	33%
Mild-moderate frailty	13%	25%	33%	15%	31%	37%
Severe frailty	2%	6%	18%	2%	12%	30%

Note:

[c] WHO performance status reported within two months of diagnosis and prior to primary treatment starting.

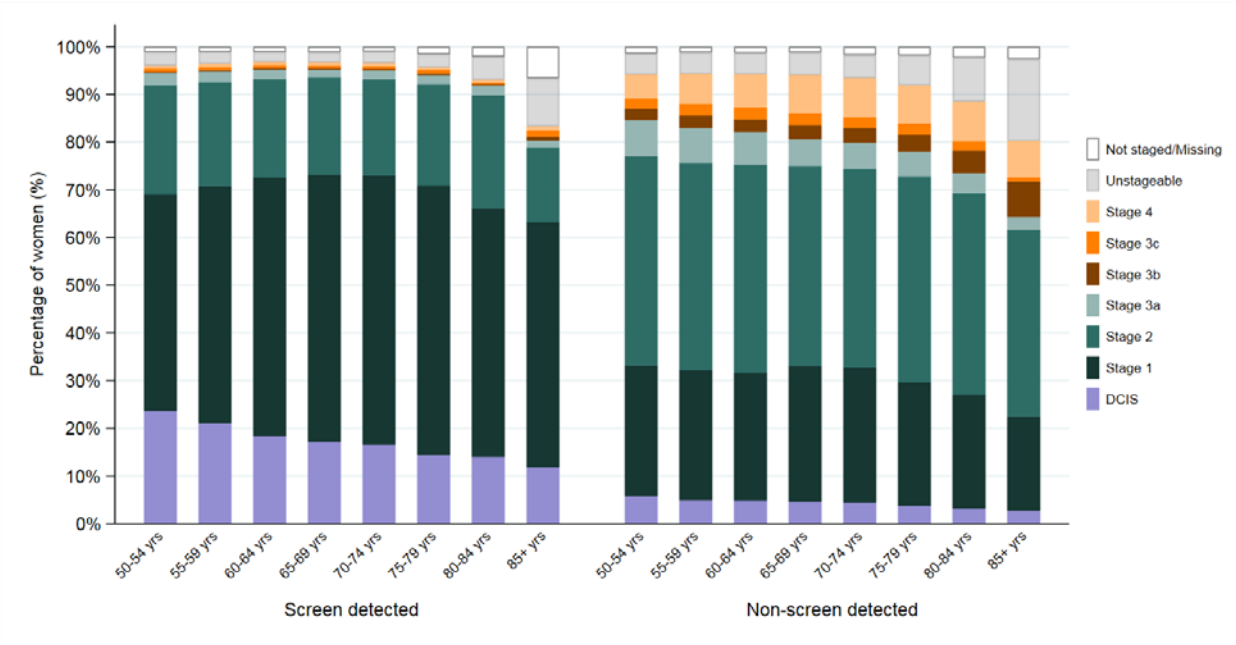
Figure 5.3 provides more detail on the change in breast cancer stage by age and method of presentation. Among women aged 50–69 years, the majority of women had stage 1 or 2 breast cancer, which is likely to reflect the influence of screening. Among women aged 75 years and over at diagnosis, the percentage of patients with stage 1 cancers decreased with age. There was a small increase in the percentage of women with metastatic breast cancer (stage 4); this was most marked within the non-screen detected group.

The other noticeable feature in Figure 5.3 is the percentage of women with breast cancer reported as 'unstageable', which increases with age. This rose from 4% among women aged 50–69 years to 21% among women aged 85 years and over. 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 may 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 percentage of women with staging information did not substantially differ for women whose pathway to diagnosis was screening (97%) compared with those diagnosed with non-screen detected breast cancer (94%).

Figure 5.3. Distribution of breast cancer stage by method of presentation and age at diagnosis (5-year age bands)



5.2. Recorded molecular marker status

Determining treatment plans for patients, including the need for primary systemic or adjuvant treatment, requires information on various characteristics of the breast tumour. In particular, for women with invasive breast cancer, it is recommended that the results of ER, PR and HER2 assessments are available and recorded at the multidisciplinary team meetings [NICE 2018]:

1. Women with tumours that are ER positive are suitable for consideration of endocrine therapy. In early invasive breast cancer, this treatment modality is usually given as adjuvant therapy, but 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 HER2 positive tumours are suitable for HER2-targeting systemic therapy e.g. trastuzumab [NICE 2018].

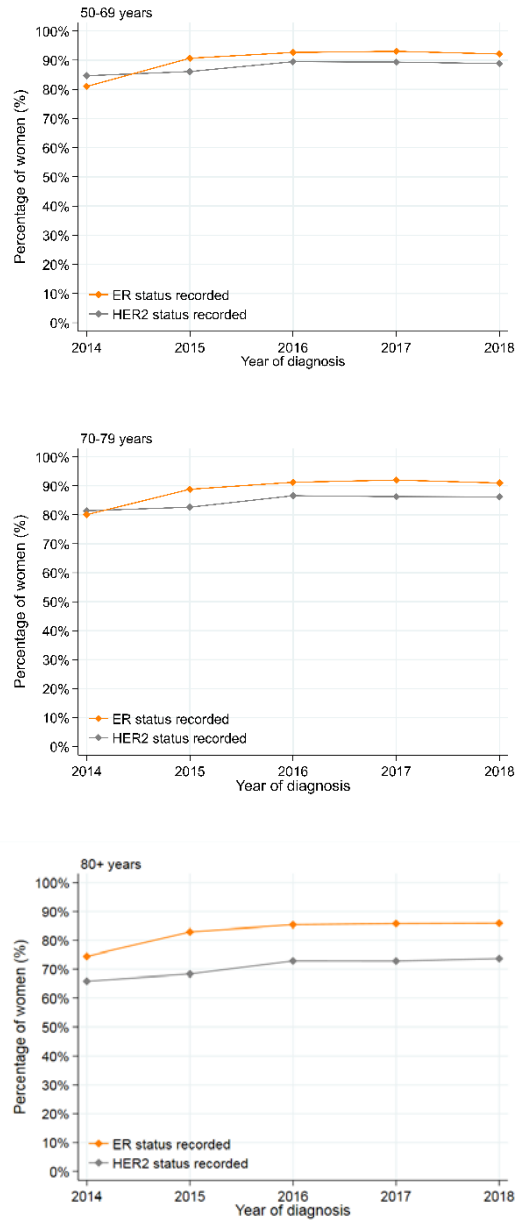
What does the guidance say?

The importance of receptor testing is recognised in NICE guideline (NG101) [NICE 2018]:

> *'Request the oestrogen receptor (ER), progesterone receptor (PR) and human epidermal growth receptor 2 (HER2) status of all invasive breast cancers simultaneously at the time of initial histopathological diagnosis.'*

Note: This guidance was in place in the 2009 NICE guideline, CG80 [NICE 2009a], with the exception that PR status was not a recommended part of routine assessment.

Figure 5.4. Data completeness of ER/HER2 status by year and age at diagnosis



Numerator *(Core Ind #3)*	1. Women with ER status recorded 2. Women with HER2 status recorded
Denominator	Women diagnosed with invasive breast cancer
Country	England & Wales
Timeframe	*Women diagnosed in 2018*

Why do we look at this in the NABCOP?

- We investigate variation by age to understand if older women are not having a completed tumour profile compared to younger women, as this could influence and restrict treatment options in the older age group.

What do we see within this audit group?

For women diagnosed with invasive breast cancer in 2018, overall 91% had information on ER status:

- 92% among women aged 50–69 years;
- 89% among women aged 70+ years;
  - 91% for women aged 70–79 years;
  - 86% for women aged 80+ years.

Completion of HER2 status was lower for the same women, with overall only 85% having information:

- 89% among women aged 50–69 years;
- 81% among women aged 70+ years;
  - 86% for women aged 70–79 years;
  - 74% for women aged 80+ years.

Data completeness was higher overall in Wales, compared with England (see **Chapter 4**). Additionally, completeness was higher among those women presenting via screening.

These patterns are similar to those presented in the NABCOP 2019 Annual Report. Specifically, although data completeness of ER and HER2 status has shown improvements over time, this has largely remained unimproved for women diagnosed in more recent years in both England and Wales (**Figure 5.4**). Additionally, reporting continues to be lower in older women, particularly for HER2 status.

Recommendation

- Carry out and record full tumour characterisation, including assessment of ER and HER2 status, for all patients with invasive breast cancer for use at multidisciplinary team meetings; in line with NICE guidance (Rec #6).

6. Diagnosis and supportive care

This chapter focuses on those elements of diagnosis that illustrate the care pathway and support received for women diagnosed with breast cancer. It covers the route by which a woman presents to a breast clinic, is diagnosed, and contact with a breast clinical nurse specialist.

6.1. Route to diagnosis

Numerator *(Core Ind #1)*	Number diagnosed after: 1. referral from GP 2. referral from screening 3. referral from other specialties 4. an emergency presentation
Denominator	All women
Country	England & Wales
Timeframe	*Women diagnosed in 2018*

Why do we look at this in the NABCOP?

- To make sure rates of women referred after emergency presentation are not unduly high.
- To investigate variation by age and by NHS organisation.

What is the evidence base for this process?

Survival rates among patients diagnosed following emergency presentation are considerably lower than those presenting through managed routes such as GP referral or screening programmes [Elliss-Brookes et al. 2012].

Patients typically present to an NHS breast clinic, with suspected breast cancer, via one of three main routes:

1. referral by a GP, after experiencing symptoms associated with the cancer
2. referral from the national breast screening programmes (NHS Breast Screening Programme in England and Breast Test Wales in Wales), which invite women aged 50 to <71 years to undergo mammography every three years (women aged 47–73 years are eligible in some regions of England as part of the AgeX trial[4])
3. referral after a clinical assessment and/or investigation performed for another disease (e.g. a CT scan) has identified a potential breast cancer.

Less commonly, diagnosis may be after an emergency presentation.

What do we see within this audit group?

Table 6.1 shows the route to diagnosis for all women diagnosed in 2018:

- 45% presented via GP
- 44% presented from screening
- 5% presented from other specialties
- <1% were diagnosed after emergency presentation

Emergency presentation rates for 2018 were low, although rates among women aged 80+ years were slightly higher (2%) than those among women aged 50–69 years and 70–79 (0.4% and 0.7% respectively).

The route to diagnosis was strongly influenced by age (Figure 6.1) and was also related to disease stage at diagnosis (Figure 6.2). The patterns of route to diagnosis by NHS organisation were similar to those for women diagnosed in 2017 [NABCOP 2019 Annual Report].

It should be noted that, in England in 2018, there was an increase in the percentage of women screened in the 71–74 years age group which may be partially attributable to activity relating to the national breast screening incident [Screening and Immunisations Team 2020]. This may explain the increased rates of women aged 70–79 years presenting via the NHS screening programme; this high rate (37%) was predominantly influenced by those women aged 70–73 years.

Table 6.1. Route to diagnosis by age at diagnosis

Reported route to diagnosis	50–69 years	70–79 years	80+ years	Overall
GP presentation	34%	50%	74%	45%
NHS screening programme	58%	37%	4%	44%
Referral from other specialties	3%	6%	10%	5%
After emergency presentation	0.4%	0.7%	2%	0.7%
Other	0.4%	0.6%	0.7%	0.5%
Unreported	*4%*	*5%*	*9%*	*5%*

Note: 407 women had >1 referral source reported for the same date of whom 52% were had screen detected cancer and so are included within 'NHS screening programme' in the table above; the remaining 48% were not included in the table above.

[4] NHS Breast Screening Programme. AgeX Trial: http://www.agex.uk

Figure 6.1. Referral route to diagnosis among women diagnosed in 2018, by country and age at diagnosis (5-year age bands)

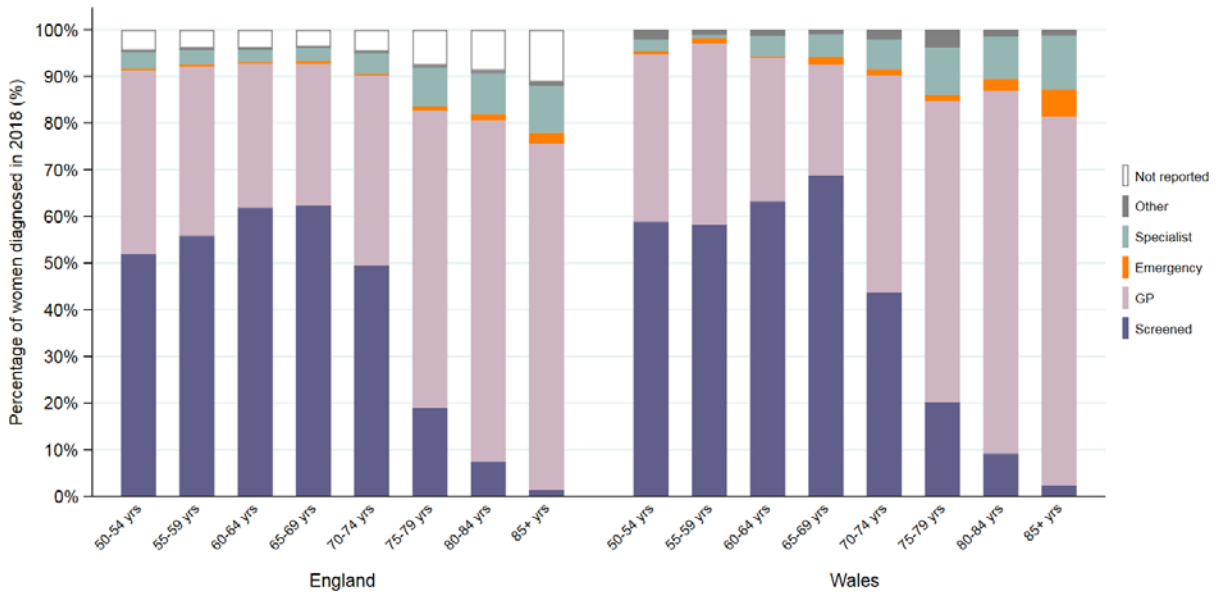
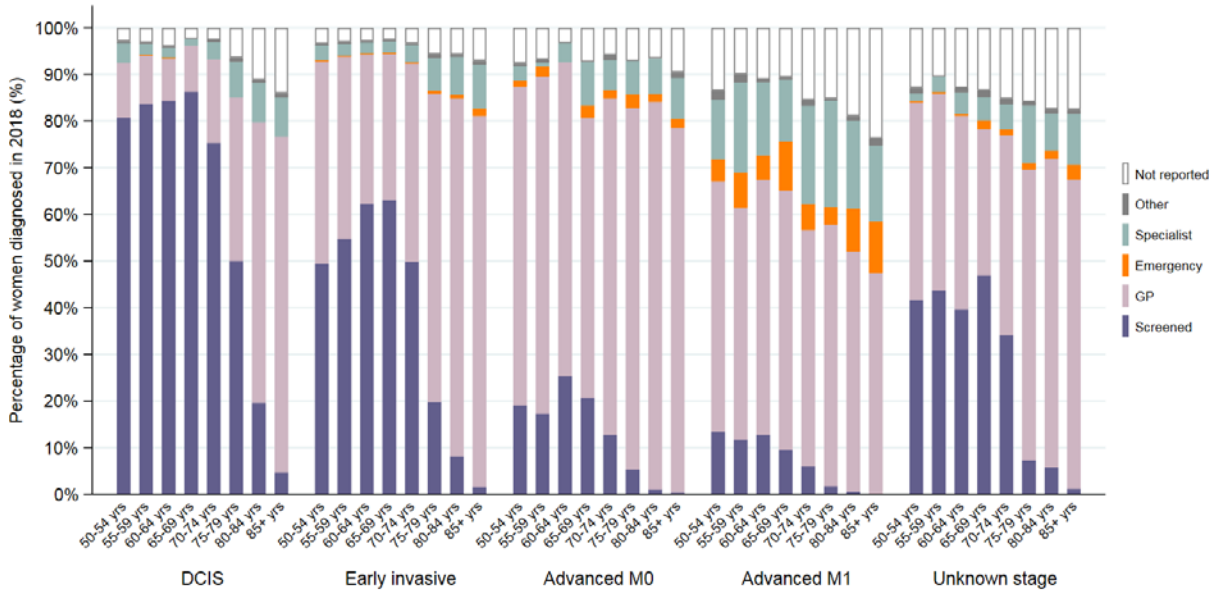


Figure 6.2. Referral route to diagnosis among women diagnosed in 2018, by stage and age at diagnosis (5-year age bands)



6.2. Triple diagnostic assessment in a single visit

This indicator describes the percentage of patients who were calculated to have received the standard triple diagnostic assessment in a single visit; defined as when the mammogram imaging date (or date first seen) and the biopsy or cytology date were reported and were the same.

Women diagnosed at screening will have the imaging and biopsy components of the triple diagnostic assessment performed according to screening protocols, where those with initial mammographic abnormalities are recalled to have assessment with further imaging and biopsies. Such women are therefore not included within this assessment of performance.

What is the evidence base for this process?

Triple diagnostic assessment in a single visit is associated with higher diagnostic accuracy and high levels of patient satisfaction, as well as being cost effective [NICE 2002].

What does the guidance say?

Since 2002, it has been regarded as best practice for patients with suspected breast cancer to undergo a 'triple diagnostic assessment' at their first clinic visit. This comprises the following three elements, as required:

- Clinical assessment – the breast clinician/specialist nurse will take a full history and will perform a physical examination.
- Imaging – imaging assessment may consist of an ultrasound or mammography, depending on certain patient characteristics and symptoms of presentation. The axilla may also be imaged.
- Histopathology assessment – tissue biopsies are obtained from areas in the breast (± axilla) that are suspicious of cancer.

'*Giving people with suspected breast cancer the triple diagnostic assessment at a single hospital visit will help to ensure rapid diagnosis. It will also help to reduce the anxiety and stress associated with multiple visits for different parts of the triple diagnostic assessment.'* [NICE 2016]

Numerator *(Core Ind #2)*	Women receiving triple diagnostic assessment in a single visit
Denominator	Women with non-screen detected early invasive breast cancer
Country	England & Wales
Timeframe	*Women diagnosed in 2018*

Why do we look at this in the NABCOP?

- We investigate variation by age and NHS organisation to ensure all women received the same standard of care through the initial process of a breast cancer diagnosis.

What do we see within this audit group?

68% of women were estimated to have received triple diagnostic assessment (TDA) in a single visit, with no difference by age at diagnosis:

- 67% among women aged 50–69 years;
- 69% among women aged 70+ years;
  - 69% for women aged 70–79 years;
  - 69% for women aged 80+ years.

There has been little improvement in performance over time (**Figure 6.3**).

Of these women receiving TDA in a single visit:

- 35% were based on matching mammogram and biopsy dates.
- 65% were based on matching first seen and biopsy dates.

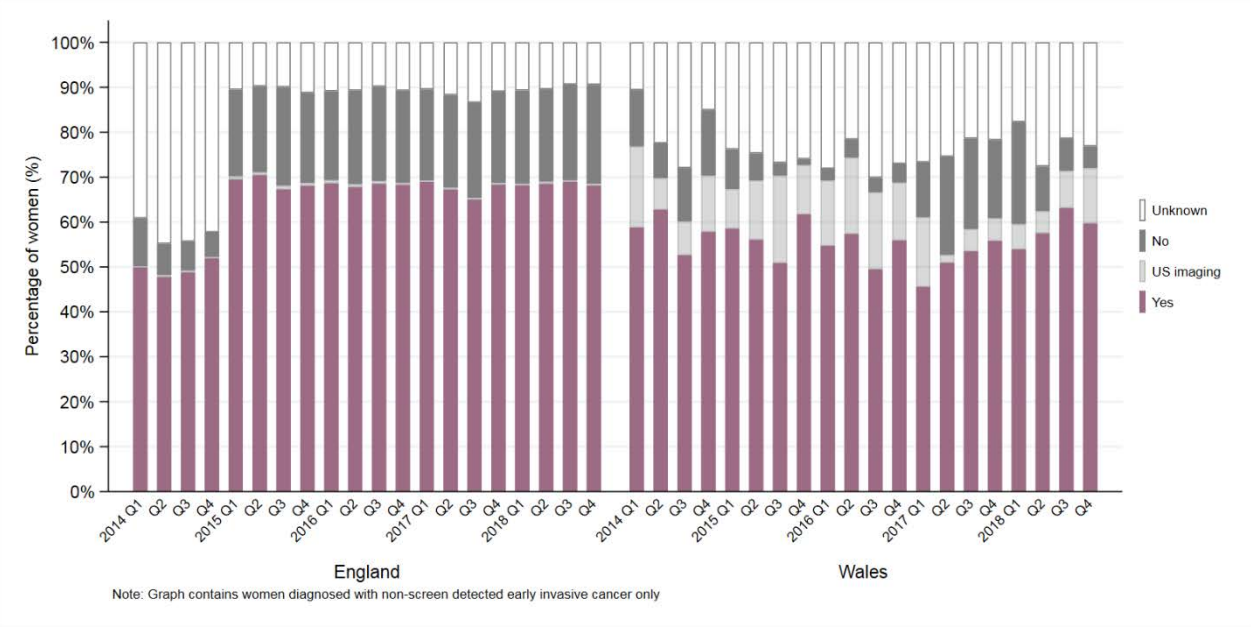
There was a difference according to country of diagnosis (**Figure 6.4**):

- 59% for women diagnosed in Wales;
- 68% for women diagnosed in England.

There was variation by NHS organisation (**Figure 6.5**) with 35% of NHS organisations having <70% of patients recorded as receiving TDA in a single visit based on our criteria.

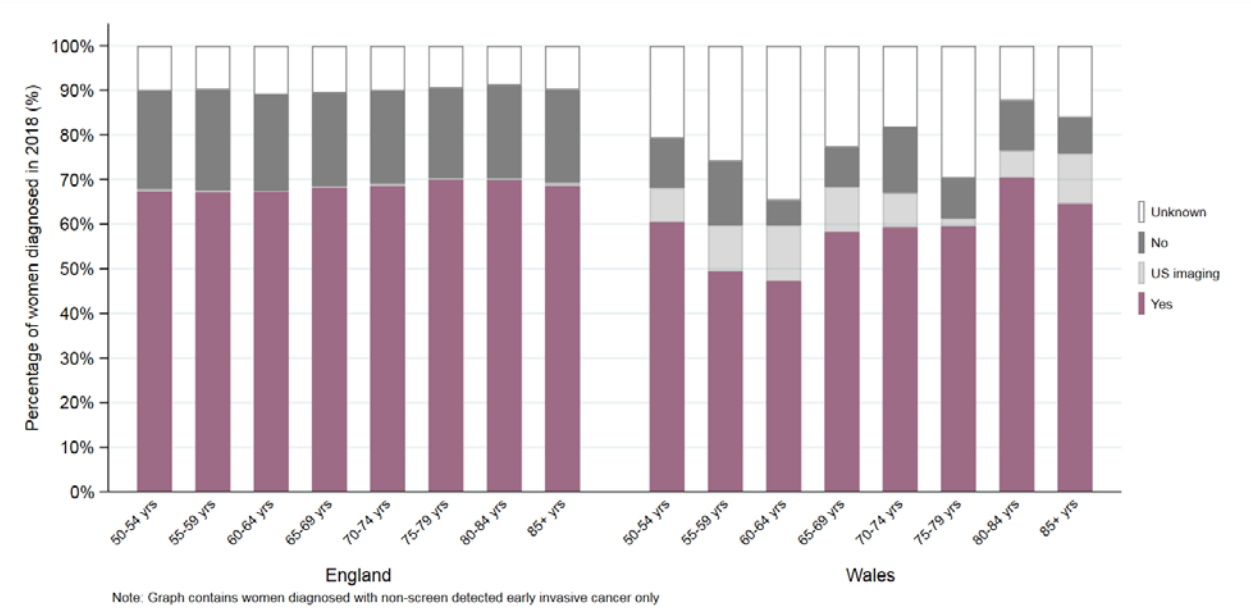
For 11% of women a mammogram and/or biopsy date were missing; in 74% of such cases the biopsy date was missing.

Figure 6.3. Receipt of triple diagnostic assessment in a single visit among women with non-screen detected early invasive breast cancer, by country of diagnosis and year of diagnosis (3-monthly intervals)



Note: US imaging = Ultrasound imaging. The percentage of women for whom no mammogram was reported but they had an ultrasound reported as performed on the same date as their diagnostic biopsy.

Figure 6.4. Receipt of triple diagnostic assessment in a single visit among women with non-screen detected early invasive breast cancer diagnosed in 2018, by country and age at diagnosis (5-year age bands)



Note: US imaging = Ultrasound imaging. The percentage of women for whom no mammogram was reported but they had an ultrasound reported as performed on the same date as their diagnostic biopsy.

If the criteria are relaxed (assuming missing mammogram/first seen dates and biopsy dates were the same; using ultrasound date where this matched biopsy date; allowing mammogram/first seen dates and biopsy 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 triple diagnostic assessment in a single visit increased to 81%, with no difference by age at diagnosis. There remains variation by NHS organisation with 1 in 5 having <70% of patients receiving TDA in a single visit.

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 (e.g. patient on anticoagulant medication) the diagnostic biopsy is not carried out on the same date. It is likely that management is appropriate, but we cannot label these women as receiving triple diagnostic assessment in a single visit. To date, there is no other national source of information on how well breast units are providing triple assessment, against which our results can be compared. Additionally, there was no data item within the national datasets for the NABCOP to directly assess this. The provision of timely triple assessment is a basic tenet of modern breast cancer care and compliance should be accurately recorded. Confirmation as to whether triple diagnostic assessment happened in a single visit has therefore been added to COSD Version 9.0, and will be collected from summer[5] 2020 (**Table 6.2**) for women diagnosed in an NHS organisation in England. This data item should be available for all women diagnosed with breast cancer from 2020 onwards.

Recommendations

- Ensure women receive all components of the triple diagnostic assessment (TDA) at their initial clinic visit for suspected breast cancer (Rec #7).
- Submit data on triple diagnostic assessment in a single visit to NCRAS as part of COSD V9.0 submissions (Rec #8).

Table 6.2. New data item on triple diagnostic assessment in a single visit in the breast cancer section of the updated COSD Version 9.0

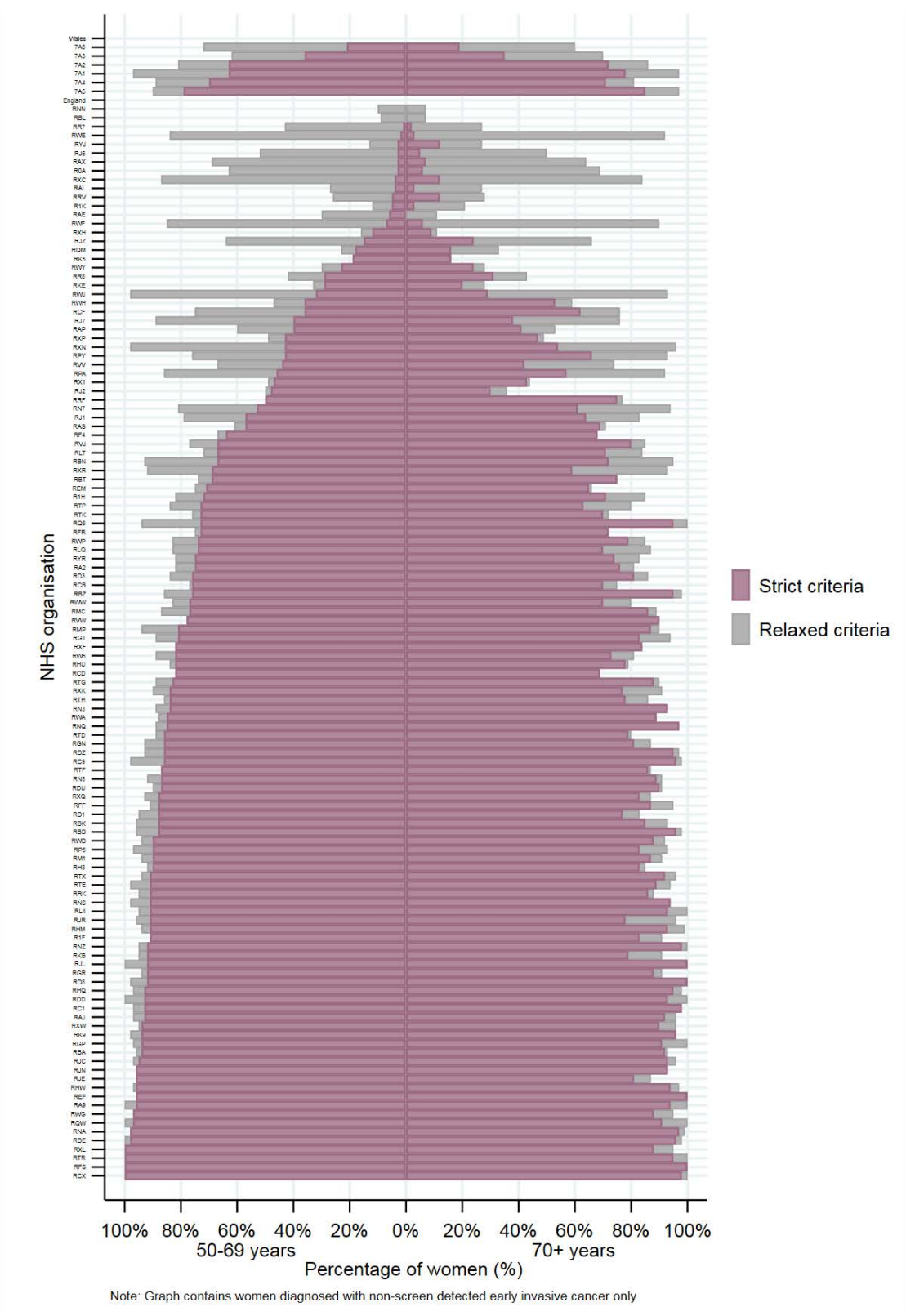
Data item No.	Data Item Section	Data Item Name	Description	National code definition	Data Dictionary Element
BR4400	BREAST - TRIPLE DIAGNOSTIC ASSESSMENT	**TRIPLE DIAGNOSTIC ASSESSMENT**	Was a triple diagnostic assessment completed for the patient in a single visit, following initial referral?	Yes No Not Known	BREAST TRIPLE DIAGNOSTIC ASSESSMENT INDICATOR

Note: The above table is a summarised version of the COSD Version 9.0 final dataset table published online. For a full list of breast specific data items please consult the online COSD Version 9.0 user guide: http://www.ncin.org.uk/collecting_and_using_data/data_collection/cosd_downloads_v9.

For women diagnosed in Wales it is anticipated that this information will be collected as a specific data item within the revised Canisc.

[5] Implementation date deferred until 1 July 2020. This may be subject to further change. For further information visit - https://www.datadictionary.nhs.uk/data_dictionary/messages/clinical_data_sets/data_sets/cancer_outcomes_and_services_data_set/cancer_outcomes_and_services_data_set_-_core_fr.asp?shownav=1

Figure 6.5. Receipt of triple diagnostic assessment in a single visit among women with non-screen detected early invasive breast cancer diagnosed in 2018, by diagnosing NHS organisation and age at diagnosis



Note: Graph contains women diagnosed with non-screen detected early invasive cancer only

6.3. Involvement of a breast clinical nurse specialist or key worker

What does the guidance say?

All people with breast cancer should have a named clinical nurse specialist or other specialist key worker with equivalent skills, who will support them throughout diagnosis, treatment and follow-up [NICE 2009a, 2018].

Numerator *(Core Ind #5)*	Women seen by a breast clinical nurse specialist/named key worker
Denominator	All women
Country	England & Wales
Timeframe	*Women diagnosed in 2018*

Why do we look at this in the NABCOP?

- To investigate any variation in CNS contact by age and by NHS organisation to ensure all women receive support throughout diagnosis and treatment.

What do we see within this audit group?

- Data on clinical nurse specialist contact (CNS) were reported for 72% of women aged 50 years and over who were diagnosed in 2018.
- Data completeness, among women diagnosed in 2018, differed by country of diagnosis:
  - 52% of women diagnosed in Wales;
  - 74% of women diagnosed in England.

Completeness did not vary by age at diagnosis in England, but completeness increased with age among women diagnosed in Wales (46%; 56% and 64% for age groups 50–69; 70–79 and 80+ years respectively).

Among women for whom data existed, 96% had contact with a CNS. Rates of contact were similar by age and by country of diagnosis (**Figure 6.6**):

- 99% of women diagnosed in Wales;
- 96% of women diagnosed in England.

There was variation across NHS organisations in the completeness of these data. Variation in CNS contact by NHS organisation, where data were available, was similar to those for women diagnosed in 2017 (as presented in the NABCOP 2019 Annual Report).

Data completeness has changed over time (**Figure 6.7**) There was an improvement over time among trusts in England, but a reduction in completeness among Welsh local health boards. This pattern was seen regardless of age at diagnosis. Missing data continues to limit the audit's ability to evaluate conclusively how well NHS organisations are performing against this measure.

Table 6.3 shows the data item on involvement of a breast CNS within the core dataset of COSD for those NHS organisations in England.

What do NABCOP patients tell us in the English 2015-18 CPES?

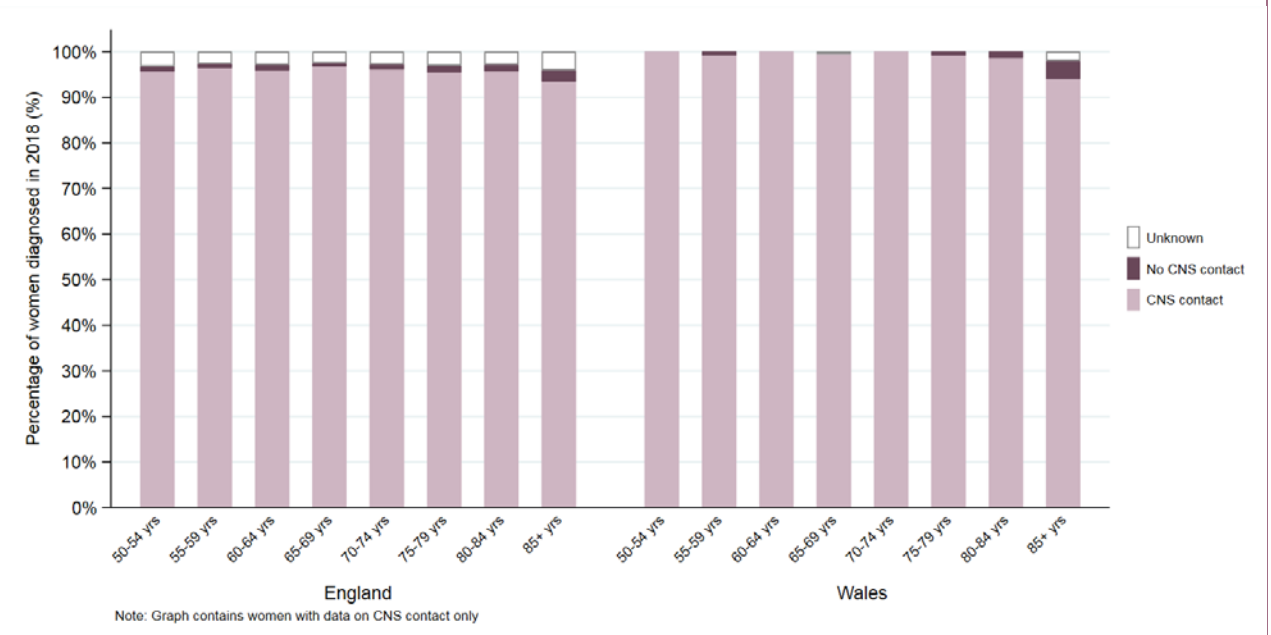
- 96% of respondents reported being given the name of a clinical nurse specialist who would support them through their treatment. This was comparable across the age groups.
- When asked how easy or difficult it had been to contact their clinical nurse specialist, 87% of respondents said that it had been 'quite easy' or 'very easy'. This was slightly higher for women aged 70+ years (89%), compared with women aged 50–69 years (86%).

The information from women diagnosed in 2018 and the results of the English CPES suggest that, overall, NHS breast units are performing well on this indicator.

Recommendations

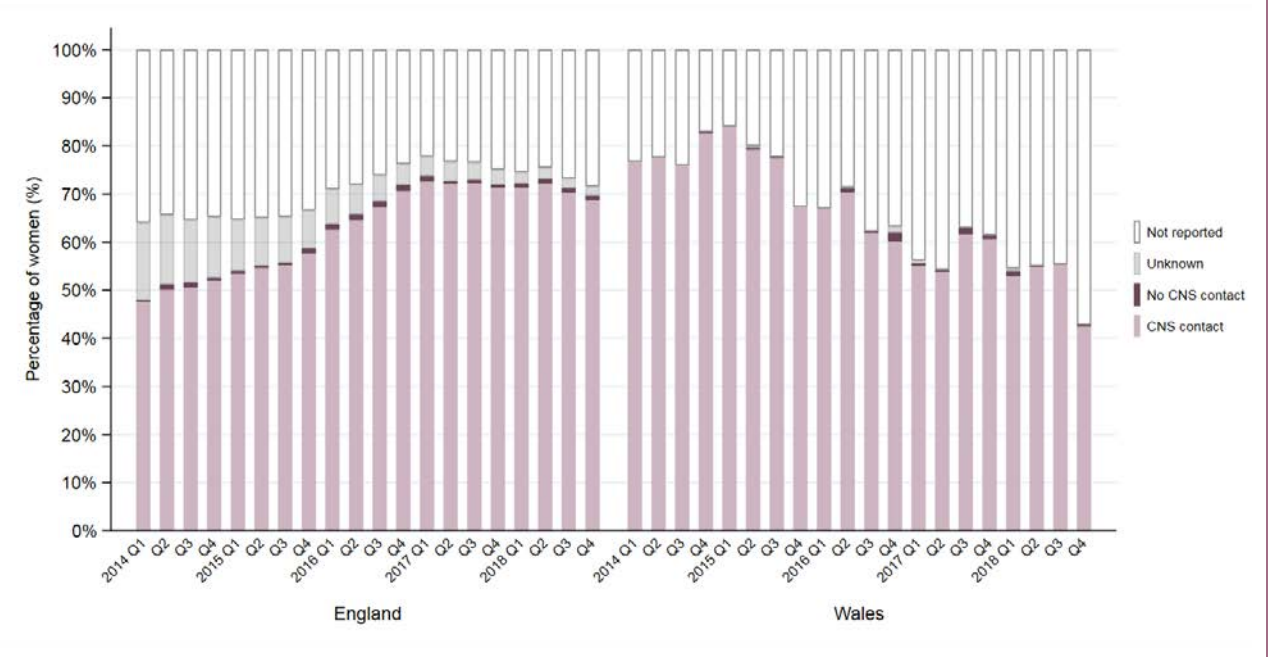
- Ensure that women are assigned a named breast clinical nurse specialist to provide information and support. Data on the assignment of a named breast clinical nurse specialist should be submitted to NCRAS and Canisc (Rec #9).
- Ensure patients have sufficient information about their care and treatment and are engaged in a shared decision-making process by asking patients for feedback at regular intervals (Rec #10).

Figure 6.6. Reported contact with a breast clinical nurse specialist among women diagnosed in 2018, by country of diagnosis and age at diagnosis (5-year age bands)



Note: CNS = Clinical nurse specialist. "Unknown" is where contact is specifically reported as such.

Figure 6.7. Percentage of women with data on breast clinical nurse specialist contact, by country of diagnosis and year of diagnosis (3-monthly intervals)



Note: CNS = Clinical nurse specialist. "Unknown" is where contact is specifically reported as such.

Table 6.3. The data item on whether a patient saw a Clinical Nurse Specialist – collected, for women diagnosed in England, within the core section of COSD

Data item No.	Data Item Section	Data Item Name	Description	National Code	National Code Definition	Data Dictionary Element
CR2050	CORE - CLINICAL NURSE SPECIALIST + RISK FACTOR ASSESSMENT	CLINICAL NURSE SPECIALIST INDICATION CODE	Record if and when the patient saw an appropriate site specific clinical nurse specialist.	Y1	Yes - Clinical Nurse Specialist present when PATIENT given diagnosis	CLINICAL NURSE SPECIALIST INDICATION CODE
				Y3	Yes - Clinical Nurse Specialist not present when PATIENT given diagnosis but saw PATIENT during same Consultant Clinic Session	
				Y4	Yes - Clinical Nurse Specialist not present during Consultant Clinic Session when PATIENT given diagnosis but saw PATIENT at other time	
				Y5	Yes - Clinical Nurse Specialist not present when PATIENT given diagnosis but the patient was seen by a trained member of the Clinical Nurse Specialist team	
				NI	No - PATIENT not seen at all by Clinical Nurse Specialist but Clinical Nurse Specialist informed of diagnosis	
				NN	No - PATIENT not seen at all by Clinical Nurse Specialist and Clinical Nurse Specialist not informed of diagnosis	
				99	Not Known (Not recorded)	

Note: The above table is a summarised version of the COSD Version 9.0 final dataset table published online. For a full list of core data items, please consult the online COSD Version 9.0 user guide: http://www.ncin.org.uk/collecting_and_using_data/data_collection/cosd_downloads_v9.

For women diagnosed in Wales it is anticipated that information on CNS contact will be collected as a specific data item within the revised Canisc.

7. Ductal carcinoma in situ

This chapter describes the use of primary surgery and adjuvant radiotherapy for those women diagnosed with ductal carcinoma in situ (DCIS), defined as stage 0. These women form around 10% of the patients included within the NABCOP.

DCIS is typically diagnosed among women aged between 50 and <71 years as a consequence of their participation in population-level breast screening programmes and the use of digital mammography [Kerlikowske 2010]. The AgeX trial in England aims to evaluate the benefit of extending the screening age beyond 70 years and is currently recruiting.

What does the guidance say?

Surgical resection is the most important treatment for DCIS. Women may have either a mastectomy or breast conserving surgery. For women who have surgery, NICE guidance (NG101) recommends:

> *'Consider adjuvant radiotherapy for women with DCIS following breast-conserving surgery with clear margins, and discuss with them the possible benefits and risks of radiotherapy.'* [NICE 2018]

Recommendations on the management of older patients with DCIS issued by the International Society of Geriatric Oncology and European Society of Breast Cancer Specialists support this statement, and note that there is a lack of strong clinical trial-based evidence to support DCIS treatment decisions in older women [Biganzoli et al. 2012].

There were 19,819 women newly diagnosed with DCIS between January 2014 and December 2018 (18,408 in England; 1,411 in Wales).

Older women newly diagnosed with DCIS were less likely to be screen detected:

- 83% for women aged 50–69 years;
- 53% for women aged 70+ years;
  - 65% for women aged 70–79 years;
  - 15% for women aged 80+ years.

7.1. Surgical treatment for DCIS

Numerator *(Core Ind #7)*	Women who had mastectomy or breast conserving surgery within 12m of diagnosis
Denominator	Women diagnosed with DCIS
Country	England & Wales
Timeframe	*Women diagnosed from 2014–18*

Why do we look at this in the NABCOP?

- To provide contemporary national figures on the rates of surgery for women diagnosed with DCIS.
- To look at the impact of method of presentation and grade on receipt of surgery.
- To investigate variation by age and by NHS organisation.

What do we see within this audit group?

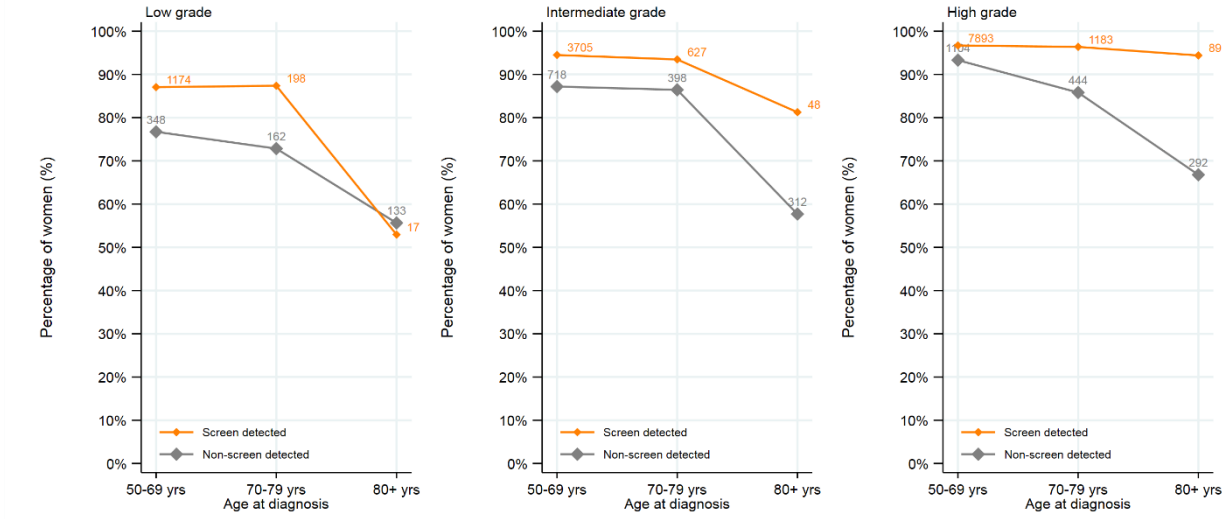
Figure 7.1 shows the percentage of women receiving surgery for DCIS decreased with a woman's age at diagnosis. Specifically, rates of surgery within 12 months of diagnosis were:

- 94% among women aged 50–69 years;
- 82% among women aged 70+ years;
  - 90% for women aged 70–79 years;
  - 60% for women aged 80+ years.

Women with non-screen detected DCIS had lower rates of surgery compared with those with screen detected DCIS, regardless of tumour grade. Surgery rates also differed by age, with a marked difference in those women aged 80+ years, compared with younger women. It should be noted that completeness of tumour grade was lower among those women with non-screen detected breast cancer.

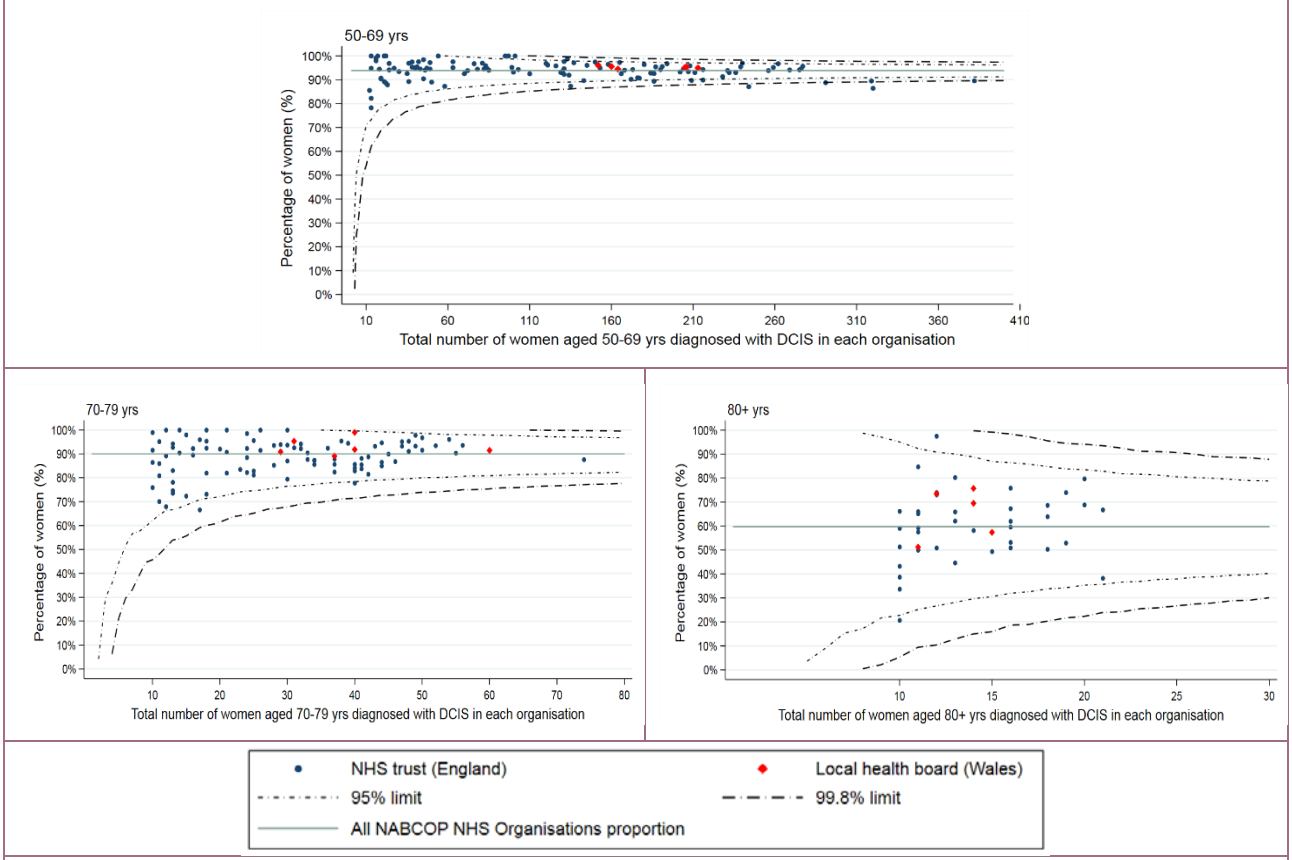
There was wider variation in the rate of surgery among women aged 70+ years between NHS organisations in England and Wales in comparison with women aged 50–69 years (Figure 7.2). There has been minimal change in the rates of surgery for all age groups, across the audit period (2014–2018). As shown in Figure 7.2, the rate of surgery was not associated with the number of women diagnosed with DCIS in each NHS organisation (unit volume).

Figure 7.1. Impact of non-invasive grade on observed receipt of surgery for DCIS, by method of presentation and age at diagnosis



Note: Numbers reported within the figures are the total number of patients in that group.

Figure 7.2. Risk-adjusted rates of surgery for DCIS across NHS organisations, by age at diagnosis



Note: Risk-adjusted percentages are from logistic regression models, adjusted for influential patient and tumour characteristics.

What do NABCOP patients, diagnosed with DCIS, tell us in the English 2015-18 CPES?

- 90% of respondents with more than one treatment option reported that, before their cancer treatment started, their options were explained to them completely. This was lower for women aged 50–69 years (89%) compared with women aged 70+ years (95%). [96% for 70–79 years; 90% for 80+ years.]
- 88% of respondents reported that they were definitely involved as much as they wanted to be in decisions about their care and treatment. This was lower for women aged 50–69 years (87%) compared with women aged 70+ years (93%). [94% for 70–79 years; 90% for 80+ years.]
- On a scale of 0 (very poor) to 10 (very good), 96% of respondents gave their overall care a rating of 7 or higher. This was comparable across the age groups.

7.2. Radiotherapy treatment for DCIS

Numerator *(Core Ind #11)*	Women who received adjuvant radiotherapy
Denominator	Women who had breast conserving surgery for DCIS
Country	England & Wales
Timeframe	*Women diagnosed from 2014–18*

Why do we look at this in the NABCOP?

- To provide national figures for the rates of adjuvant radiotherapy after breast conserving surgery for women diagnosed with DCIS.
- To investigate variation by age and by NHS organisation.

What do we see within this audit group?

Among women undergoing breast conserving surgery the percentage going on to receive radiotherapy decreased with age at diagnosis:

- 63% among women aged 50–69 years;
- 47% among women aged 70+ years;
  - 51% of women aged 70–79 years;
  - 28% of women aged 80+ years.

Use of radiotherapy was greater among women with high-grade DCIS, but a similar pattern with age at diagnosis was seen:

- 84% among women aged 50–69 years;
- 71% among women aged 70+ years;
  - 75% of women aged 70–79 years;
  - 43% of women aged 80+ years.

There is marked practice variation between NHS organisations in the use of radiotherapy after breast conserving surgery for DCIS, as seen in Figure 7.3. This may reflect the uncertainty concerning which patient subgroups derive the most benefit from radiotherapy and differing perceptions of the value of this treatment.

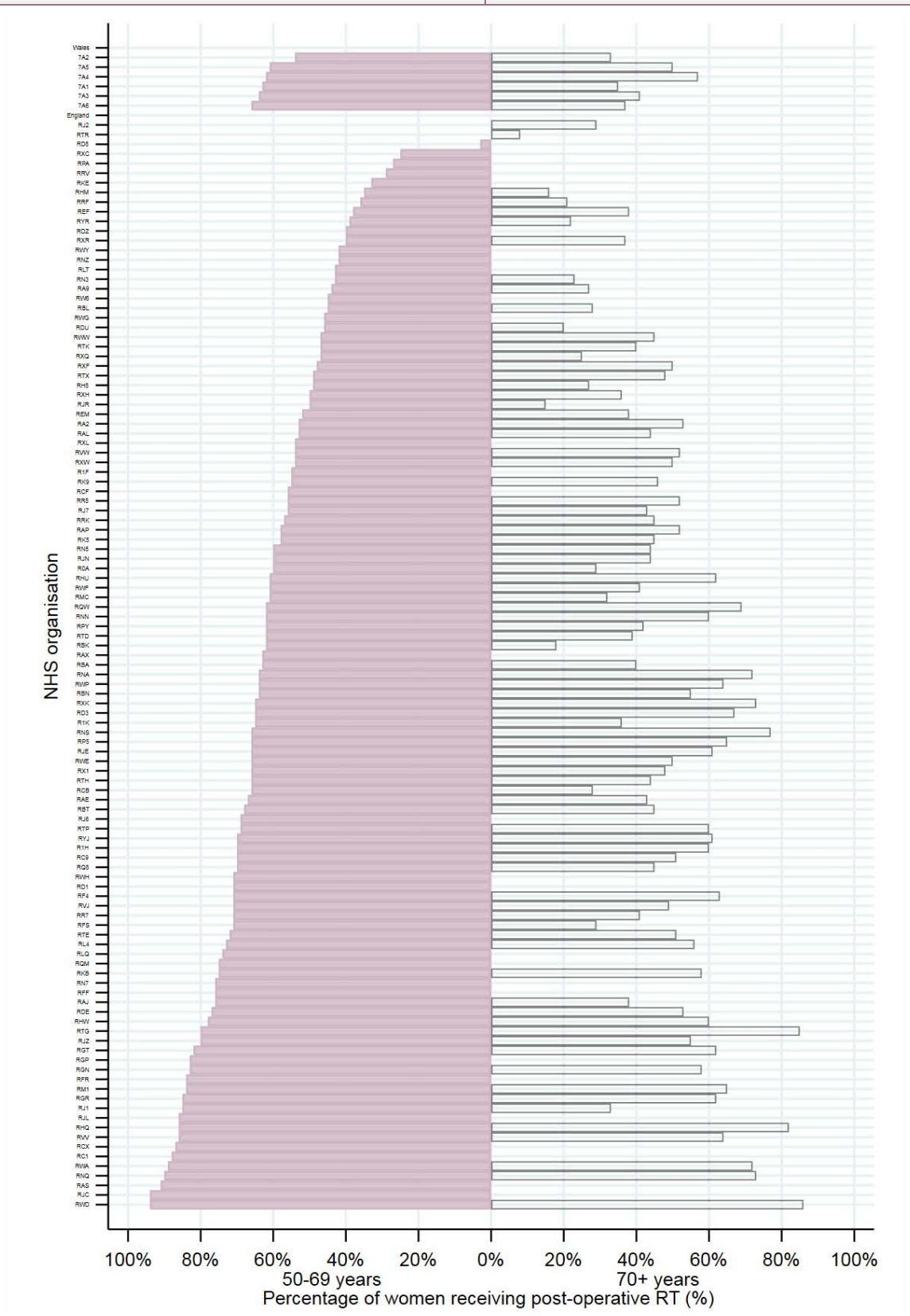
What do NABCOP patients, diagnosed with DCIS who received radiotherapy, tell us in the English 2015-18 CPES?

- Among respondents who received radiotherapy, 89% agreed completely that they had all the information they needed about their radiotherapy treatment before it started. This was slightly higher for women aged 70+ years (92%) compared with women aged 50–69 years (89%).

Recommendations

- Consider adopting a more prescriptive policy concerning the management of DCIS that covers the use of surgery and adjuvant therapies in older women, in the context of any comorbidities and frailty (Rec #11).
- Ensure patients have sufficient information about their care and treatment and are engaged in a shared decision-making process by asking patients for feedback at regular intervals (Rec #10).

Figure 7.3. Observed percentage of women with DCIS receiving radiotherapy after breast conserving surgery, by diagnosing NHS organisation and age at diagnosis



Note: Within each age group, NHS organisations with <10 patients are not shown.

8. Early invasive breast cancer

This chapter focusses on those women diagnosed with early invasive breast cancer, defined as stage 1–3A. Such women form three-quarters of the patient group within the NABCOP. This chapter describes the use of primary surgery, adjuvant radiotherapy and chemotherapy.

What is the evidence base for treatment decisions?

Surgical excision, along with adjuvant therapies, is standard of care for women diagnosed with early invasive breast cancer. Although women with ER positive breast cancer are suitable for primary endocrine therapy, surgical excision in combination with systemic endocrine therapy is superior in breast cancer disease control and survival, compared with primary endocrine therapy alone [Ward et al. 2018].

Compared with breast conserving surgery alone, the combination of radiotherapy and breast conserving surgery has been shown to significantly reduce the risk of cancer recurrence within the affected breast and also decrease the risk of breast cancer death [Early Breast Cancer Trialists' Collaborative Group 2011].

Adjuvant chemotherapy is a well-established treatment for early breast cancer, with evidence of its effectiveness from multiple randomised trials and meta-analyses [Early Breast Cancer Trialists' Collaborative Group 2012]. Adjuvant chemotherapy improves disease-free survival and overall survival in patients with early invasive breast cancer, although the absolute benefits tend to be greater in younger patients. It is effective for patients regardless of ER status. The absolute benefit may be less among patients with ER positive breast cancer who also receive endocrine therapy. Among older patients, adjuvant chemotherapy is likely to be most beneficial for patients with ER negative and/or node positive disease and is most commonly used in those with ER negative breast cancer [Biganzoli et al. 2012].

8.1. Surgical treatment for early invasive breast cancer

What does the guidance say?

Surgical resection is a central treatment for early invasive breast cancer, with NICE guidance (NG101) recommending:

> *'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 2018]

Guidelines on the management of older patients with breast cancer issued by the International Society of Geriatric Oncology and European Society of Breast Cancer Specialists 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].

Numerator *(Core Ind #7)*	Women who had mastectomy or breast conserving surgery within 12m of diagnosis
Denominator	Women diagnosed with early invasive breast cancer
Country	England & Wales
Timeframe	*Women diagnosed from 2014–18*

Why do we look at this in the NABCOP?

- To provide contemporary national figures for the rates of surgery for women diagnosed with early invasive breast cancer and type of primary surgery received.
- To investigate whether rate of surgery is similar among women with the same level of fitness, regardless of chronological age.
- To investigate whether rate and type of surgery varies based on ER status.
- To investigate variation by age and by NHS organisation.

What do we see within this audit group?

The percentage of women receiving surgery for early invasive breast cancer decreased with age at diagnosis. Specifically, rates of surgery within 12 months of diagnosis were:

- 96% among women aged 50–69 years;
- 75% among women aged 70+ years;
  - **90% for women aged 70–79 years;**
  - **52% for women aged 80+ years.**

The decrease in rates of surgery with age at diagnosis was observed to be more marked for women with ER positive breast cancer aged 75 years and over (**Figure 8.1**).

In women with no comorbidities (Charlson Comorbidity Index = 0) and ER positive breast cancer, age continued to be associated with substantially lower use of surgery:

- 97% among women aged 50–69 years;
- 85% among women aged 70+ years;
  - **94% for women aged 70–79 years;**
  - **65% for women aged 80+ years.**

Considering use of surgery in the presence of comorbidity there is a noticeable decrease in rates for older women, whereas the presence of comorbidity does not appear to have the same impact in younger women (**Figure 8.2**).

There was variation across NHS organisations in the percentage of older women who received breast surgery for early invasive breast cancer, according to ER status (**Figure 8.3**).

The receipt of primary surgery among women varied with different levels of fitness and ER status as shown in **Table 8.1** and **Figure 8.2**. As age at diagnosis increased, those with ER negative cancer were more likely to receive surgery compared with those with ER positive cancer, regardless of fitness. However:

- Rates of surgery diminished as levels of fitness decreased;
- Overall, the reduction in the rate of surgery was much larger for older women with ER positive breast cancer.

This may be because women who did not undergo surgery for ER positive breast cancer had the option of receiving primary endocrine therapy. Among women who did not undergo surgery for ER positive tumours recorded use of primary endocrine therapy increased with age:

- 51% (n = 1257) of women aged 50–69 years;
- 93% (n = 9736) of women aged 70+ years;
  - 86% (n = 2061) of women aged 70–79 years;
  - 95% (n = 7675) of women aged 80+ years.

Figure 8.1. Observed receipt of surgery for women with early invasive breast cancer, by ER status, age at diagnosis (5-year age bands) and type of surgery

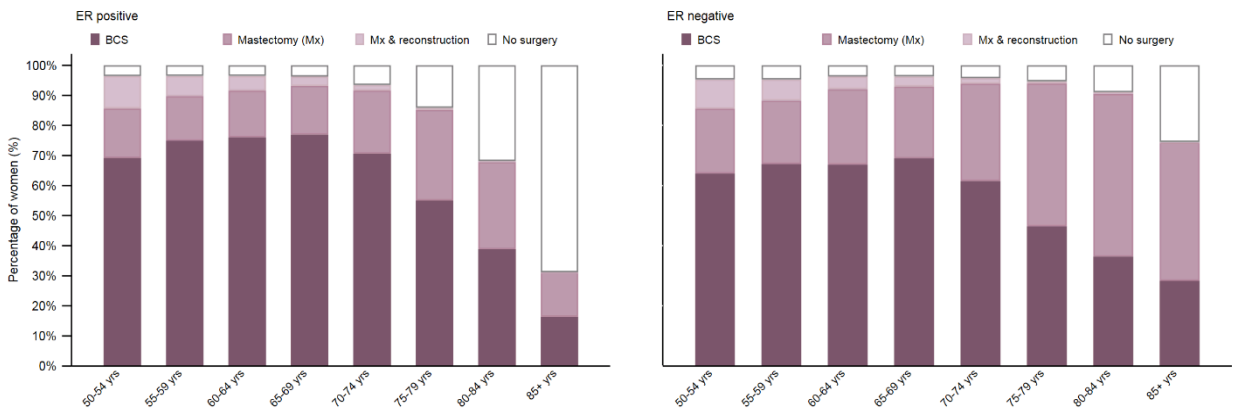


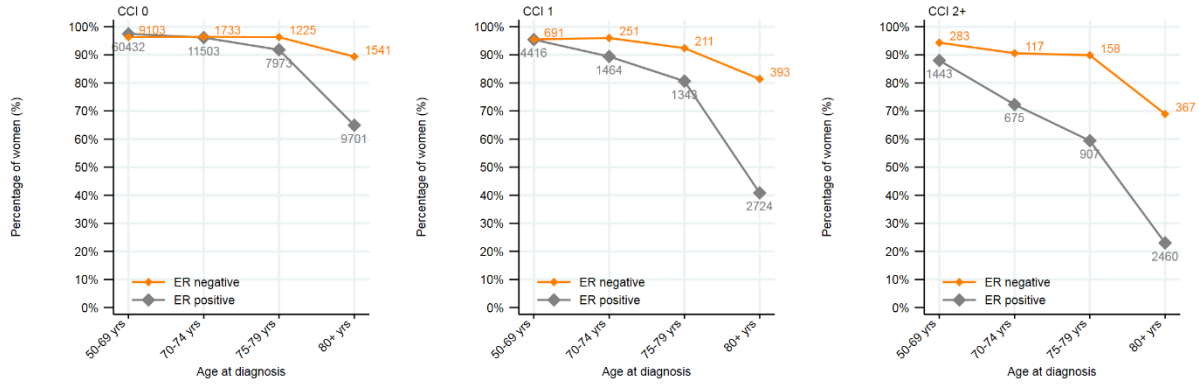
Table 8.1. Impact of patient fitness on the likelihood of receiving surgery for early invasive breast cancer, as measured by three different factors, by ER status and age at diagnosis

	ER positive						ER negative					
	50–69 years		70–79 years		80+ years		50–69 years		70–79 years		80+ years	
Measure of fitness	Total no. of women	% receiving surgery	Total no. of women	% receiving surgery	Total no. of women	% receiving surgery	Total no. of women	% receiving surgery	Total no. of women	% receiving surgery	Total no. of women	% receiving surgery
All women	68062	96%	24464	90%	16103	50%	10274	96%	3754	95%	2361	83%
Charlson Comorbidity Index												
0	60468	97%	19482	94%	9704	65%	9103	96%	2958	96%	1541	89%
1	4419	95%	2809	85%	2726	41%	691	96%	462	94%	393	81%
2+	1443	88%	1582	65%	2462	23%	283	94%	275	90%	367	69%
Unknown	*1732*	*68%*	*591*	*43%*	*1211*	*5%*	*197*	*73%*	*59*	*68%*	*60*	*25%*
WHO performance status												
0	26080	97%	7416	95%	2590	70%	4461	96%	1160	97%	387	91%
1	2517	94%	2187	88%	1909	55%	569	94%	406	96%	287	91%
2+	615	78%	872	57%	2110	21%	114	90%	168	86%	314	69%
Unknown	*38850*	*96%*	*13989*	*90%*	*9494*	*50%*	*5130*	*96%*	*2020*	*95%*	*1373*	*83%*
SCARF Index												
Fit	57382	98%	17178	95%	7664	68%	8612	96%	2624	97%	1227	91%
Mild–moderate frailty	8326	96%	5742	87%	4932	47%	1336	96%	904	95%	727	84%
Severe frailty	622	80%	953	54%	2296	18%	129	93%	167	87%	347	65%
Unknown	*1732*	*68%*	*591*	*43%*	*1211*	*5%*	*197*	*73%*	*59*	*68%*	*60*	*25%*

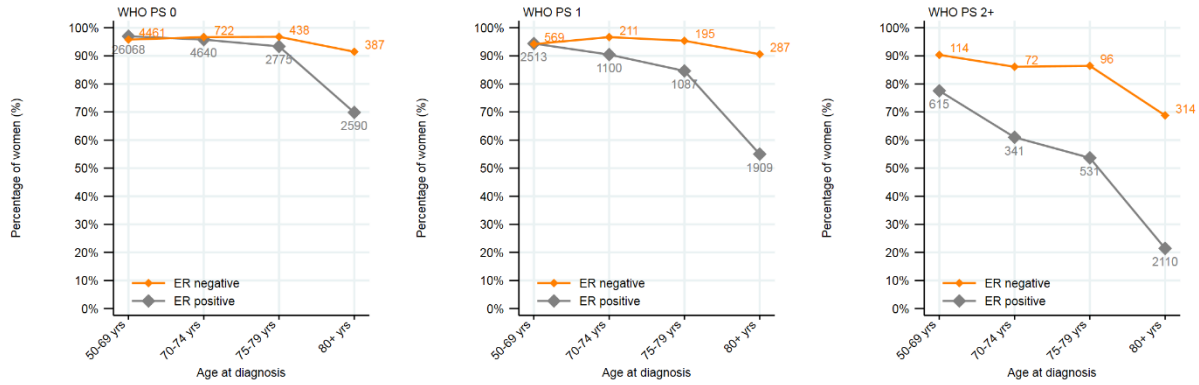
Note: This table does not include the 12,888 women with no recorded/unknown ER status.

Figure 8.2. Impact of patient fitness on the likelihood of receiving surgery for early invasive breast cancer, as measured by three different factors, by age at diagnosis and ER status

Charlson Comorbidity Index



WHO performance status



SCARF Index

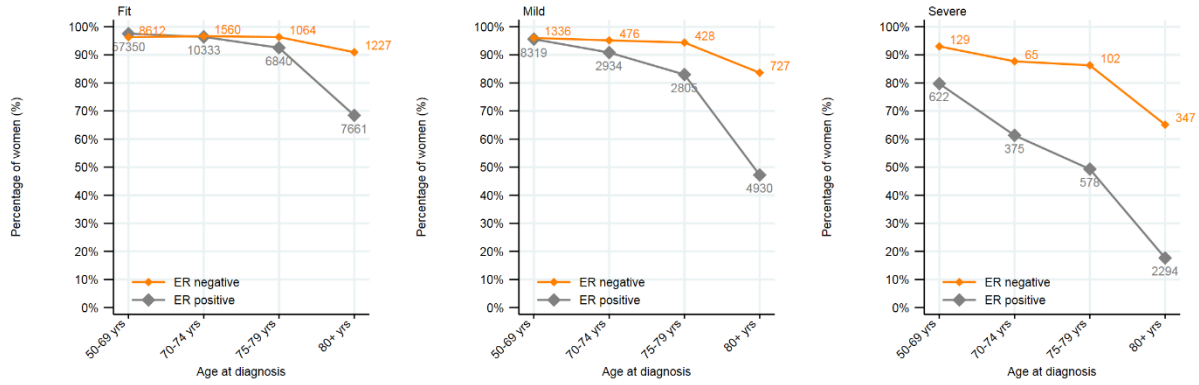
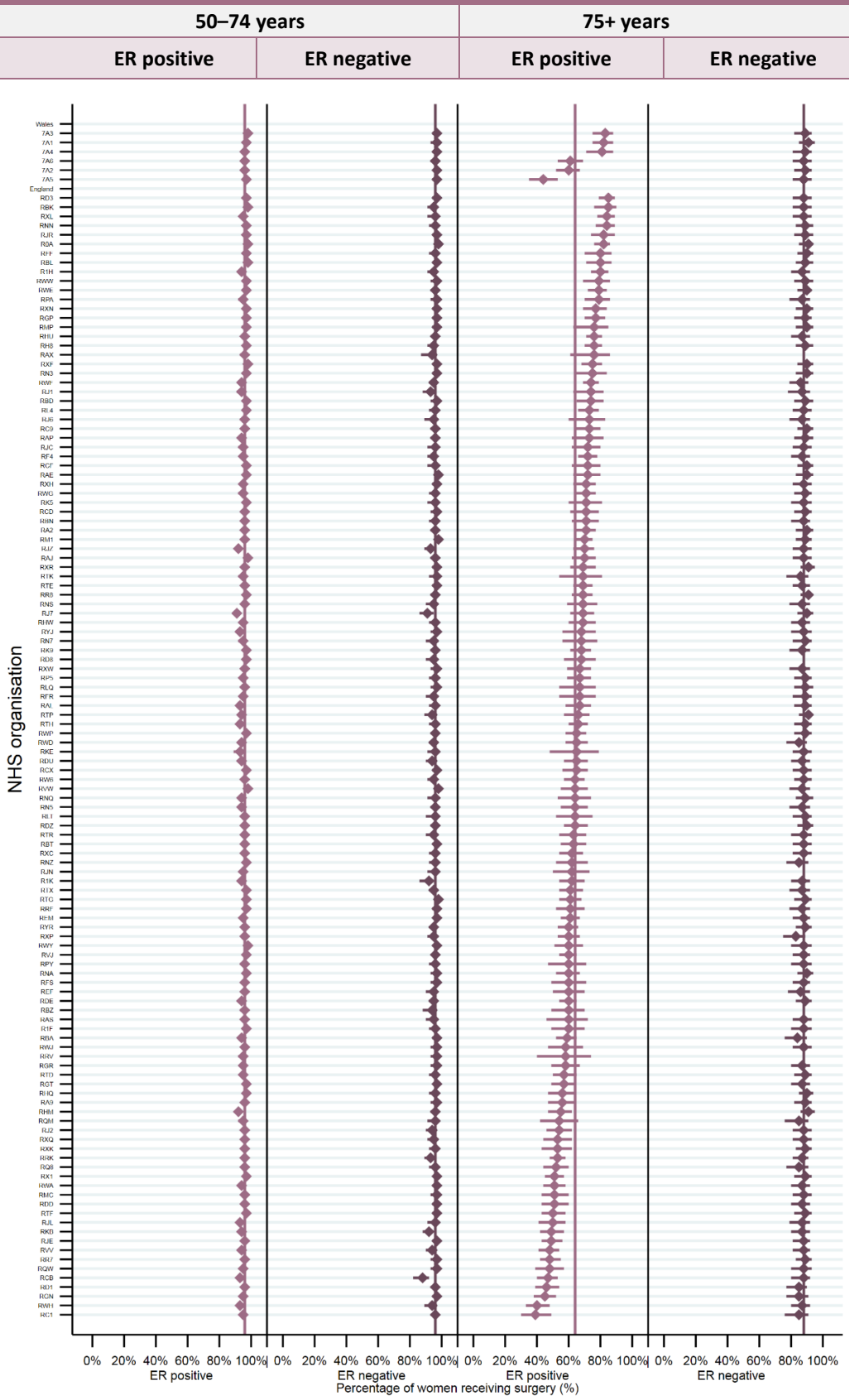


Figure 8.3. Risk-adjusted percentage (95% confidence interval) of women receiving primary surgical treatment for early invasive breast cancer, by diagnosing NHS organisation, age at diagnosis and ER status



Note: Solid vertical lines are the observed percentage of women in that age and ER status group receiving surgery for early invasive breast cancer, respectively. Risk-adjusted percentages and 95% confidence intervals are from random effects logistic regression model, adjusted for influential patient and tumour characteristics; NHS organisation included as a level.

Within each age group and ER status, NHS organisations with <10 patients are not shown.

What do NABCOP patients, diagnosed with early invasive breast cancer, tell us in the English 2015-18 CPES?

87% of respondents with more than one treatment option reported that, before their cancer treatment started, their options were explained to them completely. This was lower for women aged 50–69 years (86%) compared with women aged 70+ years (90%).

- Among women who did not have surgery, 83% of women aged 50–69 and 70–79 years reported that their options were explained to them completely, compared with 76% of women aged 80+ years. [82% for all respondents]
- Among those women who had surgery, 86% of women aged 50–69 years reported that their options were explained to them completely, compared with 90% of women aged 70+ years. [87% for all respondents]
- There was no overall difference in response by ER status. [87% for ER positive (86% for 50–69 years; 90% for 70+ years), and 87% for ER negative (85% for 50–69 years; 90% for 70+ years)]

82% of respondents reported that they were definitely involved as much as they wanted to be in decisions about their care and treatment (81% for 50–69 years; 86% for 70+ years).

On a scale of 0 (very poor) to 10 (very good), 96% of respondents gave their overall care a rating of 7 or higher. This was comparable across the age groups.

- Among women who did not have surgery, almost all women aged 50–79 years gave their overall care a rating of 7 or higher (99% in 50–69 years, 100% in 70–79 years), compared with 87% of women aged 80+ years. [99% for all respondents]
- Among those women who had surgery, there was no difference in response by age group. [96% for all respondents]
- There was no overall difference in response by ER status. [96% for ER positive, and 97% for ER negative]

Recommendation

- Investigate and address any shortfalls in care within NHS organisations with a comparatively low rate of surgery for women aged 70+ years with ER positive breast cancer (Rec #12).

8.2. Radiotherapy treatment for early invasive breast cancer

The use of radiotherapy after surgery depends on the type of operation performed. Postoperative radiotherapy is recommended for the majority of women with early invasive breast cancer who receive breast conserving surgery, whilst post-mastectomy radiotherapy is only recommended for women considered to be at moderate or high risk of recurrence.

What does the guidance say?

NICE guidance (NG101) recommends:

> *'Consider adjuvant therapy after surgery for people with invasive breast cancer, and ensure that recommendations are recorded at the multidisciplinary team (MDT) meeting. Base recommendations about adjuvant therapy on MDT assessment of the prognostic and predictive factors, and the possible risks and benefits of the treatment. Make decisions with the person after discussing these factors.'* [NICE 2018]

Guidelines recommend that external beam radiotherapy should be considered for all patients undergoing breast conserving surgery for early invasive breast cancer. Trials have suggested that omission of radiotherapy after breast conserving surgery in low risk (e.g.N0, ER+, G1/2) patients and 65+ years is reasonable [Kunkler et al. 2015]. This is reflected in the Royal College of Radiologists [2017] Consensus Statements on Breast Radiotherapy.

The use of radiotherapy after mastectomy is recommended for patients with invasive breast cancer who are considered to have a moderate or high risk of recurrence (N+ or T3–4 N0) [NICE 2018].

Numerator *(Core Ind #11)*	Women receiving radiotherapy to the: 1. breast after breast conserving surgery 2. chest wall after mastectomy
Denominator	Women diagnosed with early invasive breast cancer who had surgery
Country	England & Wales
Timeframe	*Women diagnosed from 2014–18*

Why do we look at this in the NABCOP?

- To provide contemporary national figures for the rates of adjuvant radiotherapy, according to type of primary surgery received.
- To investigate whether radiotherapy rates are similar among women with the same level of comorbidity, regardless of chronological age.
- To investigate variation by age and by NHS organisation.

What do we see within this audit group?

Among women who had breast conserving surgery, 89% received postoperative radiotherapy.

Rates of radiotherapy varied by age (**Figure 8.4**), with lower reported use as age increased:

- 91% among women aged 50–69 years;
- 83% among women aged 70+ years;
  - 86% for women aged 70–79 years;
  - 72% for women aged 80+ years.

Among women with high risk (N+ or T3–4 N0) early invasive breast cancer receiving mastectomy, 64% received post-mastectomy radiotherapy.

Rates of radiotherapy varied by age (**Figure 8.4**), with lower reported use as age increased:

- 68% among women aged 50–69 years;
- 60% among women aged 70+ years;
  - 64% for women aged 70–79 years;
  - 53% for women aged 80+ years.

Patterns of radiotherapy have not changed over the audit period (2014–2018).

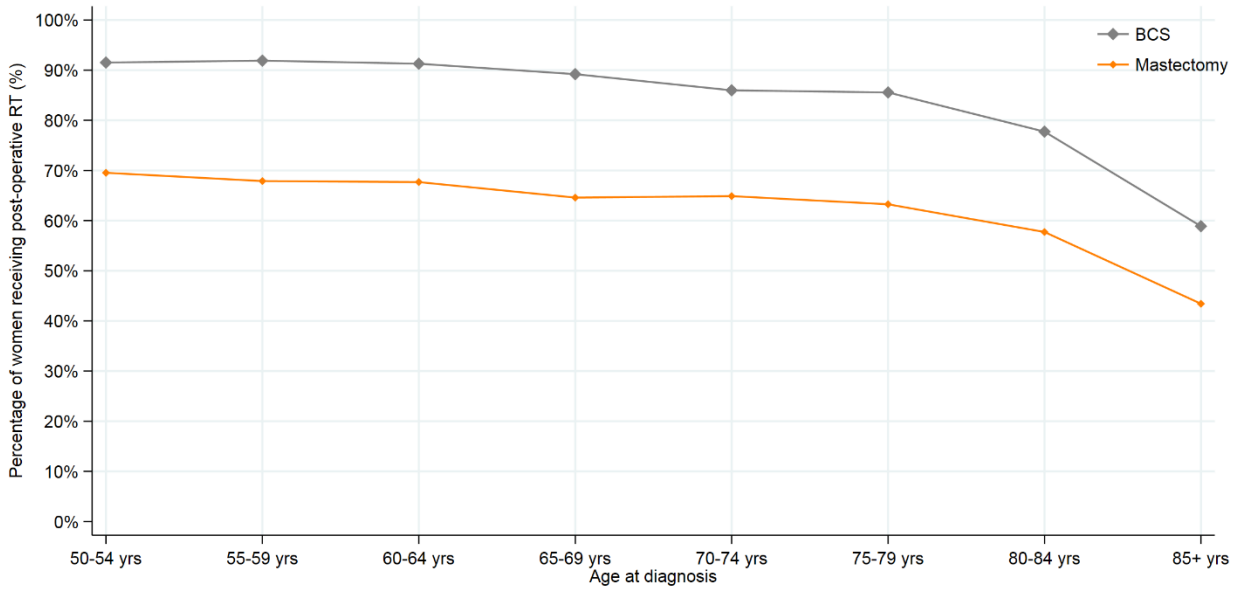
Rates of radiotherapy reduced with age, regardless of patient fitness (**Figure 8.5**)

There was variation by NHS organisation (**Figure 8.6**). This was most marked for women whose primary surgery was mastectomy, regardless of age. Additionally, rates of radiotherapy after BCS were high for women aged 50–69 years, whereas there was large variation across NHS organisations for older women.

What do NABCOP patients, diagnosed with early invasive breast cancer who received radiotherapy, tell us in the English 2015-18 CPES?

- Among respondents who received radiotherapy, 88% agreed completely that they had all the information they needed about their radiotherapy treatment before it started. There was no difference in responses by age group.

Figure 8.4. Observed percentage of women with early invasive breast cancer receiving radiotherapy, by type of primary surgery and age at diagnosis (5-year age bands)

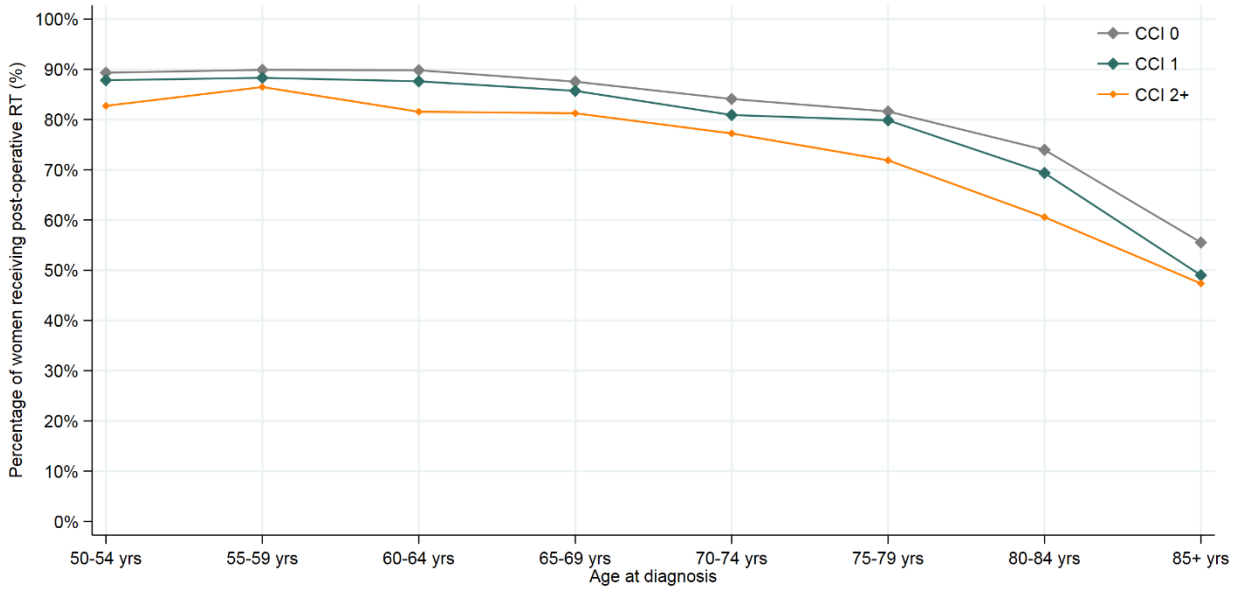


Note:

Post-mastectomy radiotherapy in women with node positive early invasive breast cancer or node-negative T3/4 early invasive breast cancer.

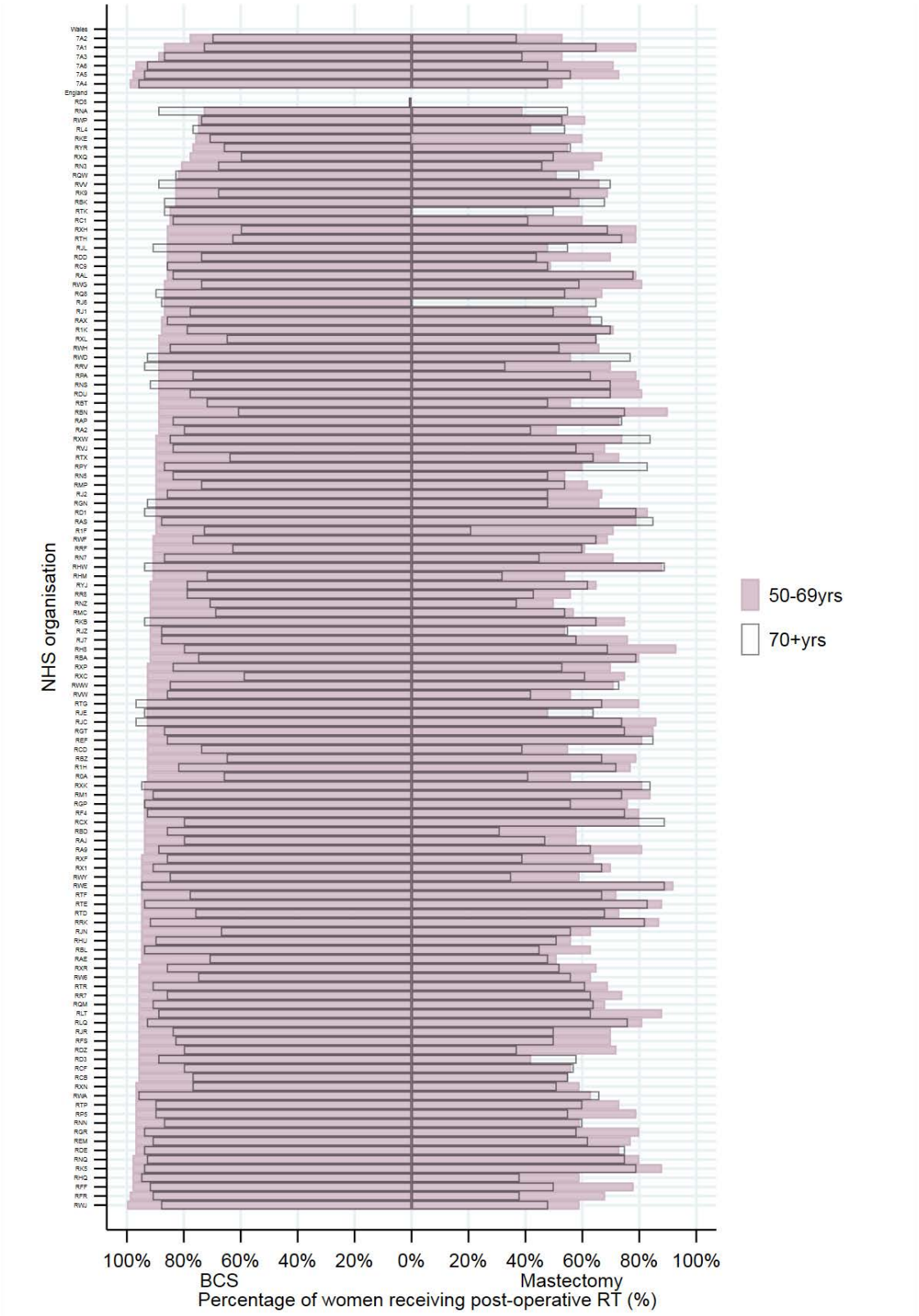
BCS = breast conserving surgery; RT = radiotherapy.

Figure 8.5. Observed percentage of women with early invasive breast cancer receiving radiotherapy, by Charlson Comorbidity Index and age at diagnosis (5-year age bands)



Note: CCI = Charlson Comorbidity Index; RT = radiotherapy.

Figure 8.6. Observed percentage of women with early invasive breast cancer receiving radiotherapy after breast conserving surgery or mastectomy, by diagnosing NHS organisation and age at diagnosis



Note:

Post-mastectomy radiotherapy in women with node positive early invasive breast cancer or node-negative T3/4 early invasive breast cancer.

BCS = Breast conserving surgery.

Within each age group and type of surgery, NHS organisations with <10 patients are not shown.

Recommendation

- Counsel women with high-risk early invasive breast cancer on the benefit and risk of adjuvant radiotherapy based on tumour characteristics and objective assessment of patient fitness, rather than chronological age alone (Rec #13).

8.3. Chemotherapy treatment for early invasive breast cancer

This section examined the use of adjuvant chemotherapy (CT) for those women with early invasive breast cancer:

1. all women;
2. women with ER negative, HER2 negative breast cancer and malignant lymph nodes (N+);
3. women with HER2 positive breast cancer for whom the guidelines recommend use of adjuvant chemotherapy plus trastuzumab.

What does the guidance say?

Adjuvant chemotherapy decisions should be based on an understanding of the balance between the risks and benefits particularly in people with comorbidities [NICE 2018]. European Society for Medical Oncology guidelines recommend treating all patients with HER2 positive cancer with chemotherapy and anti-HER2 treatment such as trastuzumab [Cardoso 2019].

NICE guidance recommends that ER and HER2 status be obtained for all patients with invasive breast cancer [NICE 2018].

Numerator *(Core Ind #12)*	Women who receive adjuvant CT
Denominator	Women diagnosed with early invasive breast cancer who had surgery (with no neoadjuvant CT)
Country	England & Wales (England only in HER2 positive analysis)
Timeframe	*Women diagnosed from 2014–18*

Why do we look at this in the NABCOP?

- To provide contemporary national figures on rates of adjuvant chemotherapy, according to ER status and type of primary surgery received.
- To assess the use of anti-HER2 therapy in women diagnosed with HER2 positive early invasive breast cancer.
- To investigate whether chemotherapy rates are similar among women with the same level of comorbidity, regardless of age.
- To investigate variation by age and by NHS organisation.

What do we see within this audit group?

(1) Among all women with early invasive breast cancer (Figure 8.7), rates of adjuvant chemotherapy were considerably higher among younger women with ER negative compared with ER positive breast cancer.

(2) Among women with ER negative, HER2 negative, N+ early invasive breast cancer who received primary surgery, 53% were identified as having received adjuvant chemotherapy. Numbers were too low to look at variation by NHS organisation, but we do see that rates of treatment varied by age, with lower reported use as age increased:

- 74% among women aged 50–69 years
- 30% among women aged 70+ years
  - 46% for women aged 70–79 years;
  - 6% for women aged 80+ years.

(3) Among women with HER2 positive early invasive breast cancer, who received primary surgery, 59% were identified as having received adjuvant chemotherapy plus trastuzumab.

Rates of treatment varied by age, with lower reported use as age increased:

- 70% among women aged 50–69 years
- 37% among women aged 70+ years
  - 49% for women aged 70–79 years;
  - 9% for women aged 80+ years.

Rates of chemotherapy (and trastuzumab) for both groups were observed to have increased over the five-year period this section covers, regardless of age. Overall use of chemotherapy has shown some increase among older women over time.

As expected, rates also varied by:

- tumour grade (higher use among higher grade tumours)
- nodal status (higher use among node positive)
- Charlson Comorbidity Index (lower use with higher score i.e. presence of more comorbid conditions; Figure 8.8).

Variation by NHS organisation was observed regardless of age (Figure 8.9).

Note: HER2 status completion was lower among women aged 70+ years, compared with women aged 50–69 years (Chapter 5, Table 5.1).

Additionally, the reason for this variation involves a combination of factors, which may include patient and clinician preferences.

What do NABCOP patients, diagnosed with early invasive breast cancer who received chemotherapy, tell us in the English 2015-18 CPES?

- Among respondents who received chemotherapy, 83% agreed completely that they had all the information they needed about their chemotherapy treatment before it started. This 83% agreement, reported by women aged 50–69 and 70–79 years, was higher than the 77% reported by women aged 80+ years.

Recommendations

- Provide an objective assessment of the anticipated benefits and risks of chemotherapy based on tumour factors and patient fitness, for all women, irrespective of age, with (1) ER negative, HER2 negative early invasive breast cancer with malignant lymph nodes or (2) HER2 positive early invasive breast cancer (Rec #14).
- Ensure patients have sufficient information about their care and treatment and are engaged in a shared decision-making process by asking patients for feedback at regular intervals (Rec #10).

Figure 8.7. Observed percentage of women with early invasive breast cancer receiving adjuvant chemotherapy, by ER status and age at diagnosis (5-year age bands)

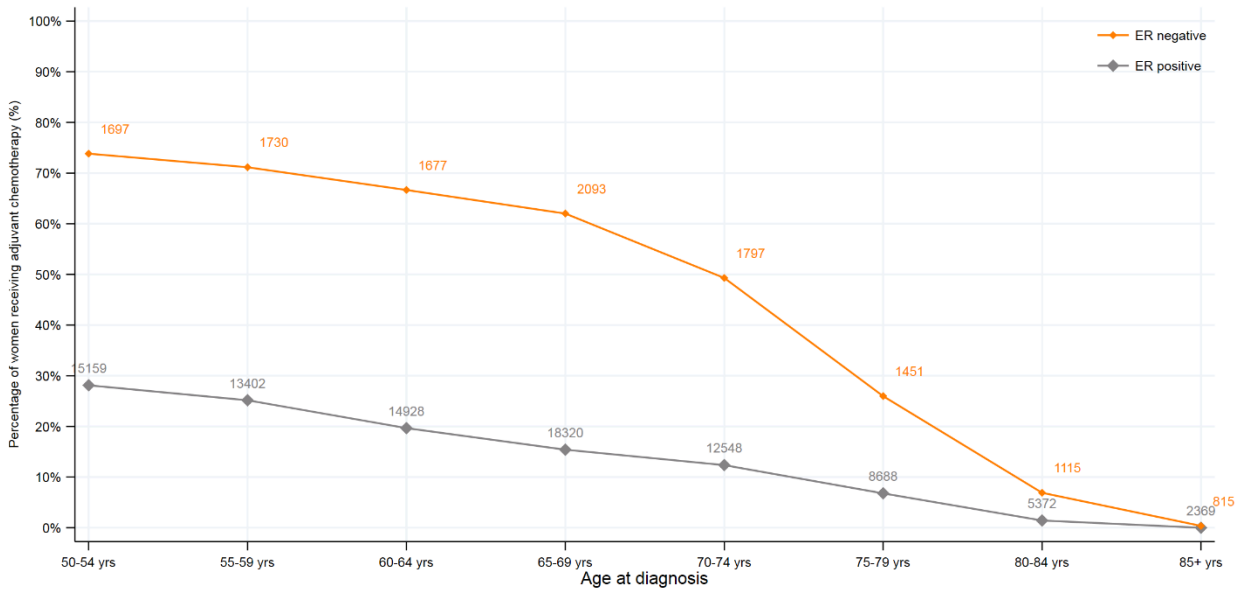
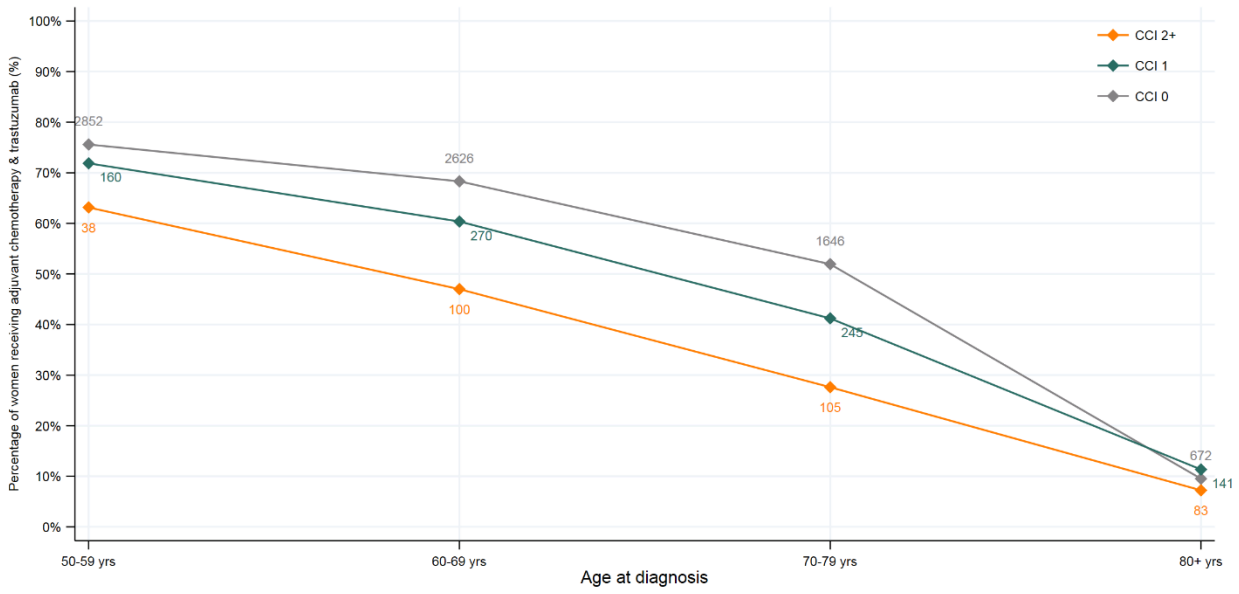
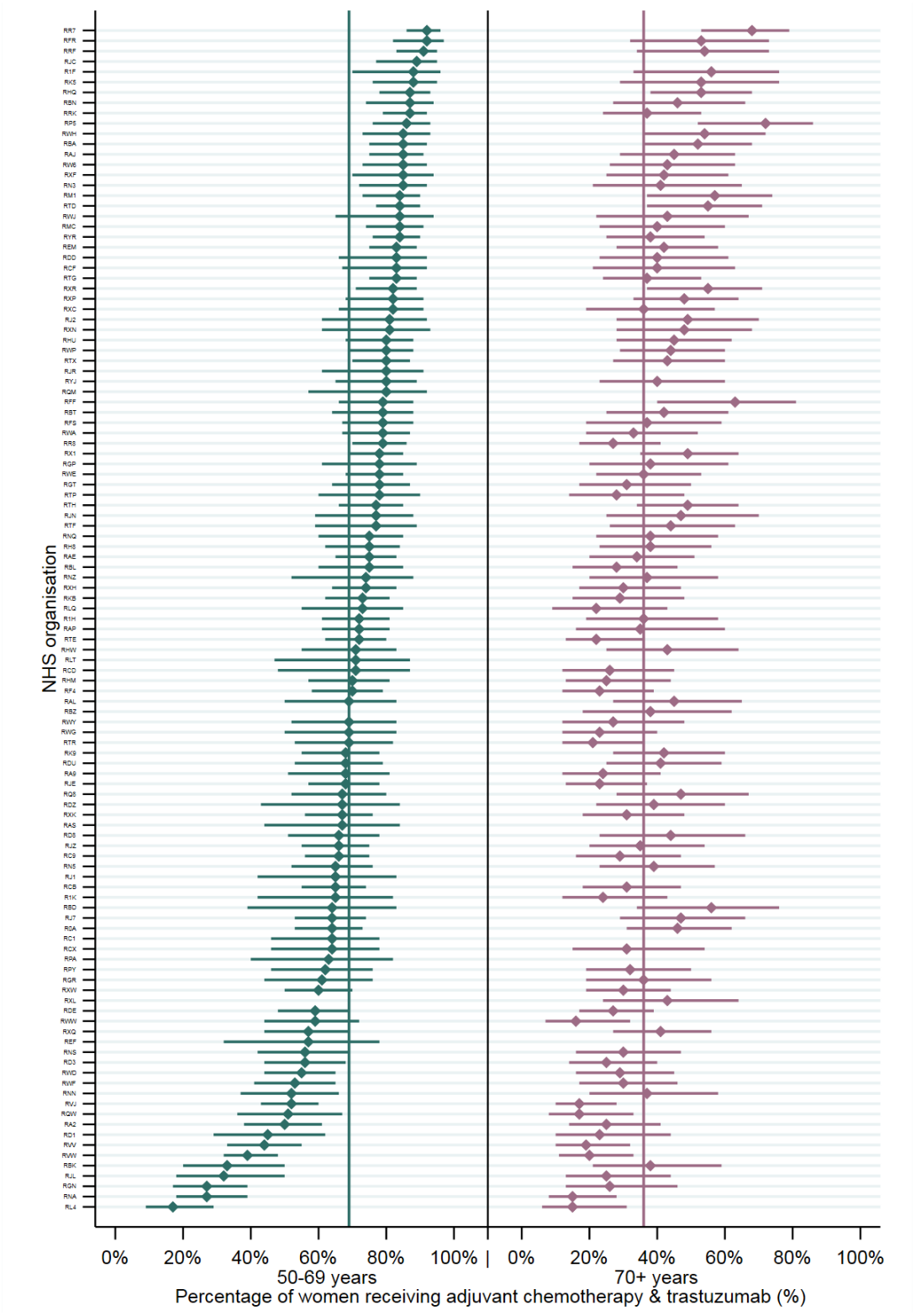


Figure 8.8. Observed percentage of women with HER2 positive early invasive breast cancer receiving adjuvant chemotherapy plus trastuzumab, by Charlson Comorbidity Index and age at diagnosis (10–year age bands)



Note: CCI = Charlson Comorbidity Index.

Figure 8.9. Risk-adjusted percentage (95% confidence interval) of women with HER2 positive early invasive breast cancer receiving adjuvant chemotherapy plus trastuzumab, by diagnosing NHS organisation and age at diagnosis



Note: Lines at 70% and 37% are the observed percentage of women, aged 50–69 years and 70+ years, respectively, receiving adjuvant chemotherapy plus trastuzumab for HER2 positive early invasive breast cancer. Risk-adjusted percentages and 95% confidence intervals are from random effects logistic regression model, adjusted for influential patient and tumour factors; NHS organisation included as a level.

Within each age group, NHS organisations with <10 patients are not shown.

9. Metastatic breast cancer

Patients with metastatic breast cancer are not curable, but survival has improved substantially over time as systemic treatment options have expanded and therapies have become more effective. It was previously reported that the risk of being newly diagnosed with metastatic breast cancer increases with age [Cancer Research UK].

What does the guidance say?

NICE guideline (CG81) recommendations on systemic disease modifying therapy include [NICE 2009b]:

'1.3.1. Offer endocrine therapy as first-line treatment for the majority of patients with ER-positive advanced breast cancer.

1.3.2. Offer chemotherapy as first-line treatment for patients with ER-positive advanced breast cancer whose disease is imminently life-threatening or requires early relief of symptoms because of significant visceral organ involvement, providing they understand and are prepared to accept the toxicity.

1.3.3. For patients with ER-positive advanced breast cancer who have been treated with chemotherapy as their first-line treatment, offer endocrine therapy following the completion of chemotherapy.'

The International Society of Geriatric Oncology and the European Society of Breast Cancer Specialists also specifically recommend chemotherapy for 'ER-negative, hormone refractory or rapidly progressing disease. Single agent chemotherapy or combination oral chemotherapy are feasible options in elderly patients' [Biganzoli et al. 2012].

Numerator *(Core Ind #4)*	Women with metastatic breast cancer at initial presentation
Denominator	Women diagnosed with invasive breast cancer
Country	England & Wales
Timeframe	*Women diagnosed from 2014–18*

Why do we look at this in the NABCOP?

- To provide contemporary national figures for the percentage of women diagnosed with invasive breast cancer who present with metastases, and their referral route to the breast service.
- To investigate use of initial chemotherapy (within 3 months of diagnosis) and whether this varies by chronological age, among women with the same level of fitness, as well as looking by ER status.
- To investigate variation by age and by NHS organisation.

What do we see within this audit group?

Among women diagnosed with invasive breast cancer, 5% were reported to have metastatic breast cancer at initial presentation (without a previous registration of early invasive breast cancer). Most women presented via referral from the GP or another (non-breast) specialty (**Table 9.1**).

Presentation with metastatic breast cancer increased with age:

- 3% among women aged 50–69 years;
- 7% among women aged 70+ years;
  - 7% for women aged 70–79 years;
  - 8% for women aged 80+ years.

Among women with a known ER status, 79% were ER positive with similar percentages between the age groups (see **Chapter 5, Table 5.1**).

Rates of recorded endocrine treatment for ER positive metastatic breast cancer, differed by age:

- 57% among women aged 50–69 years;
- 79% among women aged 70+ years;
  - 75% for women aged 70–79 years;
  - 83% for women aged 80+ years.

Older women with metastatic breast cancer were less likely to receive chemotherapy:

- 45% among women aged 50–69 years
- 18% among women aged 70+ years;
  - 27% for women aged 70–79 years;
  - 9% for women aged 80+ years.

This pattern was observed irrespective of ER status and patient fitness (**Figure 9.1**). There was an increased use of chemotherapy over the five-year audit period.

There was variation by NHS organisation regardless of age (**Figure 9.2**)

Table 9.1. Route to diagnosis, for women with newly diagnosed metastatic breast cancer, by age at diagnosis

Reported route to diagnosis	50–69 years	70–79 years	80+ years	Overall
GP presentation	54%	58%	54%	55%
Referral from other specialties	16%	19%	21%	18%
NHS screening programme	13%	4%	0%	7%
After emergency presentation	5%	6%	9%	6%
Other	1.5%	2.5%	1.6%	1.8%
Unreported	*9%*	*10%*	*15%*	*11%*

Figure 9.1. Predicted use of chemotherapy for metastatic breast cancer, from a multilevel mixed-effects logistic regression model, across four patient and tumour characteristics

Charlson Comorbidity Index

Age at diagnosis	ER positive			ER negative		
	0	1	2+	0	1	2+
55 years	46%	36%	31%	66%	56%	51%
65 years	39%	29%	25%	59%	49%	43%
75 years	24%	17%	14%	42%	32%	27%
85 years	9%	6%	5%	18%	13%	10%

SCARF Index

Age at diagnosis	ER positive			ER negative		
	0	1	2+	0	1	2+
55 years	48%	38%	32%	67%	58%	51%
65 years	41%	32%	26%	60%	51%	44%
75 years	25%	19%	15%	43%	34%	28%
85 years	10%	7%	5%	20%	14%	11%

Note: Higher percentages are shown in dark blue with a gradient down to light blue for lowest percentages. Other influential patient and tumour characteristics are included at overall means.

What do NABCOP patients, with newly diagnosed metastatic breast cancer, tell us in the English 2015-18 CPES?

- 77% of respondents with more than one treatment option reported that, before their cancer treatment started, their options were explained to them completely. This was comparable across the age groups. [76% for 50–69 years; 77% for 69-70 years; 80% for 80+ years.]
- 73% of respondents reported that they were definitely involved as much as they wanted to be in decisions about their care and treatment. This was lower for women aged 50–69 years (71%) compared with women aged 70+ years (75%). [73% for 70–79 years; 80% for 80+ years.]
- Among all respondents who received chemotherapy, 79% agreed completely that they had all the information they needed about their chemotherapy treatment before it started. This agreement was higher for women aged 80+ years (84%), compared with women aged 50–79 years (79%). [80% for 50–69 years; 77% for 70–79 years.]
- On a scale of 0 (very poor) to 10 (very good), 93% of respondents gave their overall care a rating of 7 or higher. This was comparable across the age groups.

Recommendations

- Ensure that all women with metastatic breast cancer have ER status assessed and recorded; those with ER positive breast cancer should be offered endocrine therapy as part of their treatment package (Rec #15).
- Ensure that, for women considered for chemotherapy, there is an objective assessment of potential benefit and predicted life expectancy. Consideration should not be based on chronological age alone (Rec #16).
- Ensure patients have sufficient information about their care and treatment and are engaged in a shared decision-making process by asking patients for feedback at regular intervals (Rec #10).

Figure 9.2. Risk-adjusted percentage (95% confidence interval) of women with newly diagnosed metastatic breast cancer receiving chemotherapy, by age at diagnosis

Note: Lines at 46% and 19% are the observed percentage of women, aged 50–69 years and 70+ years respectively, receiving chemotherapy for newly diagnosed metastatic breast cancer. Risk-adjusted percentages and 95% confidence intervals are from random effects logistic regression model, adjusted for influential patient and tumour characteristics; NHS organisation included as a level.

Within each age group, NHS organisations with <10 patients are not shown.

10. Outcomes

This chapter provides some preliminary analyses of early outcomes for women with breast cancer diagnosed over the five year audit period (2014–2018). More detailed analyses of outcomes will be provided in subsequent years. We used the full five years of data to ensure sufficient numbers of patients were included in the analyses.

10.1. Short-term mortality following adjuvant chemotherapy for invasive breast cancer

The use of chemotherapy in early invasive breast cancer, as adjuvant or neo-adjuvant therapy to improve survival, or as palliative treatment for advanced metastatic breast cancer, has increased in recent decades. The use of chemotherapy in older women tends to be reserved for those with higher levels of fitness. For this section, only those women diagnosed and treated within England are included as date of last cycle was required, and this information is not available for those women diagnosed and treated in Wales.

Numerator	Women who died within 30 days of their last reported cycle of chemotherapy
Denominator	Women receiving adjuvant chemotherapy for invasive breast cancer
Country	England
Timeframe	*Women diagnosed from 2014–18*

Why do we look at this in the NABCOP?

30-day mortality following chemotherapy is considered to be a useful indicator for avoidable harm and treatment futility. Monitoring this outcome provides valuable information to clinicians making treatment decisions and can contribute to efforts to improve patient outcomes.

What do we see within this audit group?

Overall, 30-day mortality following adjuvant chemotherapy for early invasive breast cancer was observed to be low (Table 10.1), including subgroups of those women defined as 'fit' by three different measures. There was a slight increase in 30-day mortality with older age at diagnosis. Altogether, rates were in line with 30-day mortality rates previously reported by Wallington et al. [2016].

Among women with metastatic breast cancer 30-day mortality rates, following palliative chemotherapy, were around 15%, with little difference by age. Rates among women defined as 'fit' were comparable regardless of measure of fitness.

Table 10.1. Percentage (%) of women with invasive breast cancer who died within 30 days of their last recorded cycle of (adjuvant/palliative) chemotherapy, by stage of breast cancer and age at diagnosis

	50–59 years		60–69 years		70–79 years		80+ years	
	Total no. of women receiving chemo	% dying within 30 days of chemo	Total no. of women receiving chemo	% dying within 30 days of chemo	Total no. of women receiving chemo	% dying within 30 days of chemo	Total no. of women receiving chemo	% dying within 30 days of chemo
Early invasive								
All women	**10658**	**0.6%**	**8524**	**0.8%**	**3545**	**1.2%**	**165**	**1.2%**
Frailty = Fit	9562	0.6%	7206	0.7%	2766	0.9%	111	0.0%
CCI = 0	9937	0.6%	7702	0.8%	3090	1.0%	124	0.0%
WHO PS = 0	4620	0.7%	3420	0.9%	1296	0.5%	44	2.3%
Metastatic								
All women	**748**	**14.6%**	**724**	**16.0%**	**660**	**13.3%**	**247**	**15.4%**
Frailty = Fit	590	12.5%	545	16.0%	409	13.2%	131	17.6%
CCI = 0	635	12.8%	613	15.8%	485	12.8%	173	15.6%
WHO PS = 0	300	10.3%	228	11.8%	160	8.8%	41	14.6%

Note: Frailty measure calculated using the SCARF Index.

10.2. Recorded rates of recurrence

Data relating to any breast cancer recurrence, for women diagnosed and treated in England, is collected within the Cancer Outcomes and Services Dataset (COSD) and forms part of the datasets that the NABCOP receives. Specifically, there are fields which provide us with detail of the date and type of recurrence. Similar data fields are collected within the data for those women diagnosed and treated in Wales.

Numerator	Women with a reported breast cancer recurrence
Denominator	All women
Country	England & Wales
Timeframe	*Women diagnosed from 2014–18*

Why do we look at this in the NABCOP?

Accurate data on recurrence would allow benchmarking of outcomes in the context of provision of care at breast unit level, contributing to efforts to improve patient care.

We would expect there to have been a recurrence for the majority of women who subsequently died from their breast cancer. We therefore compared the number of women who were recorded to have died from their breast cancer, with the number who had recurrence reported, to investigate whether reported recurrence rates are complete. We also looked at variation in recurrence rates by age, year of diagnosis and geography.

What do we see within this audit group?

Considering all women diagnosed between 2014–2018, recorded rates of any recurrence ever reported were low among all disease groups and only varied slightly by age at diagnosis.

A high percentage of women are reported to have died from their breast cancer, with no prior recurrence recorded (**Table 10.2**).

The recorded rates did not differ by year of diagnosis (**Figure 10.1**), although we would expect rates to be higher among women diagnosed a longer time ago. The recorded rates of recurrence we report in this section are likely to be considerably lower than rates of recurrence in practice. Additionally, there was no variation by geographical region (**Figure 10.2**), suggesting that all NHS organisations are poor at recording this information.

Recommendation

- Review how to improve the recording of recurrence in local medical records and ensure this information is submitted to NCRAS and Canisc (Rec #5).

Table 10.2. Percentage (%) of women with any reported recurrence, by stage of breast cancer and age at diagnosis, for all patients diagnosed from 2014–2018

	50–59 years		60–69 years		70–79 years		80+ years	
	Total no. of women	% with reported recurrence	Total no. of women	% with reported recurrence	Total no. of women	% with reported recurrence	Total no. of women	% with reported recurrence
All women	**54582**	**3.0%**	**58075**	**2.7%**	**40861**	**3.9%**	**32130**	**4.0%**
DCIS	8065	0.4%	7477	0.4%	3207	0.4%	1070	0.7%
Early Invasive	40992	2.1%	44862	1.7%	31097	2.0%	21148	2.1%
Advanced M0	1435	9.6%	1462	8.8%	1683	8.3%	2353	5.2%
Unknown Stage	*2544*	*2.6%*	*2441*	*2.4%*	*2525*	*2.9%*	*5099*	*1.9%*

Figure 10.1 Recorded rates of any recurrence by year of diagnosis (2014–2018) and age at diagnosis

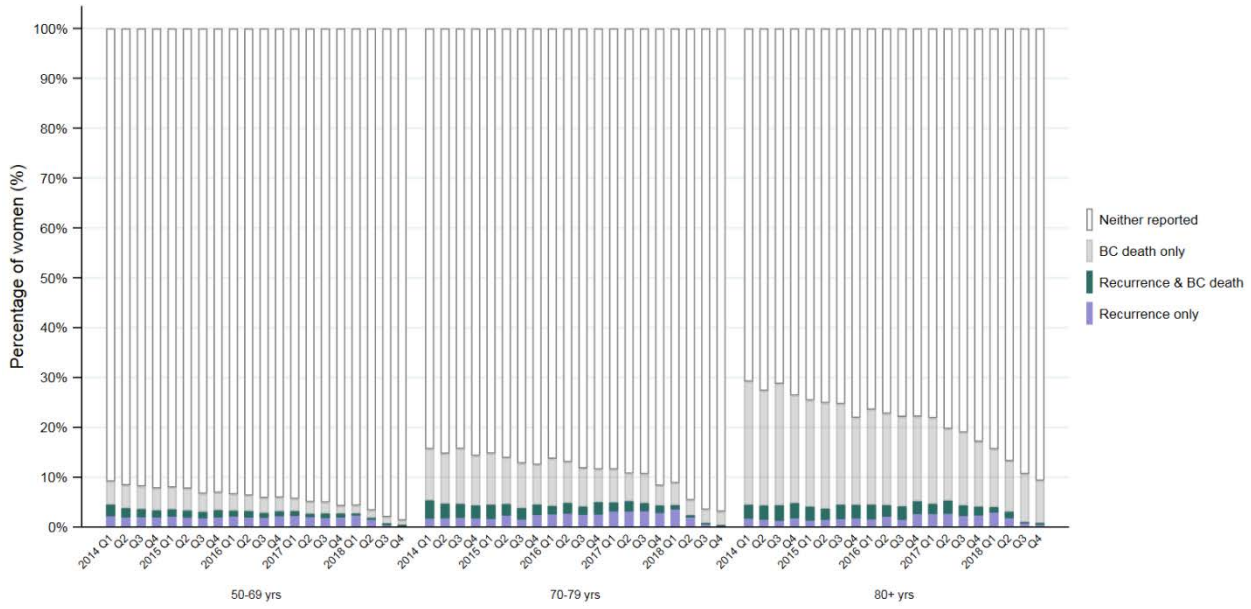
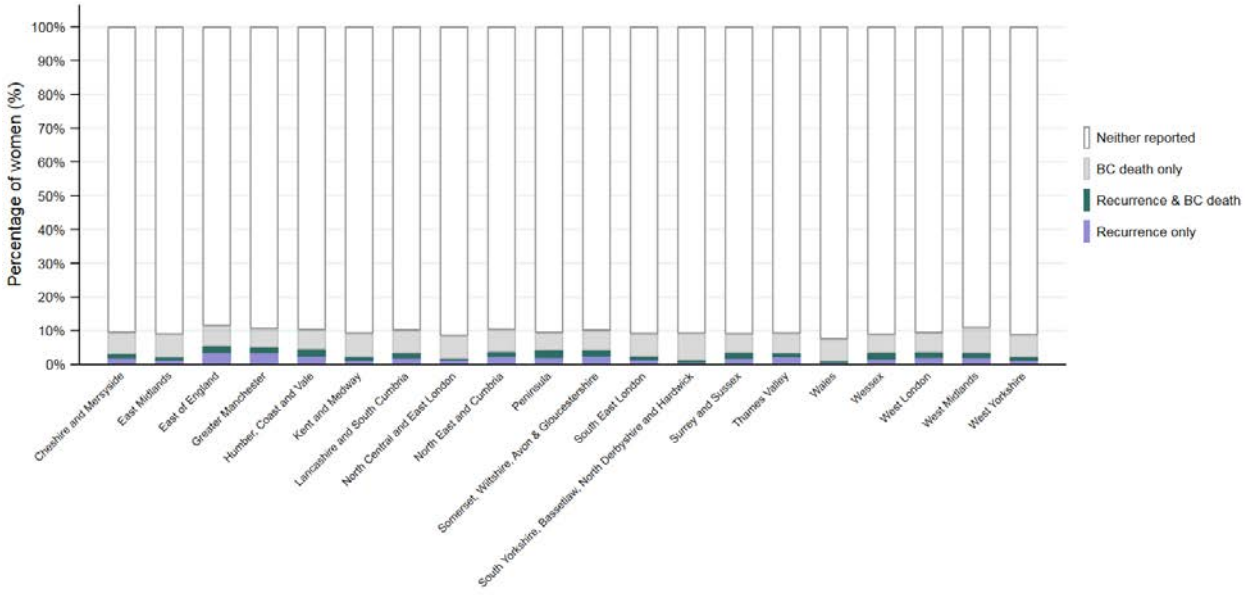


Figure 10.2 Recorded rates of any recurrence by geographical region at diagnosis, for all patients diagnosed from 2014–2018



10.3. Relative survival

Numerator *(Core Ind #13)*	Women reported as having died
Denominator	All women
Country	England & Wales
Timeframe	*Women diagnosed from 2014–18*

Why do we look at this in the NABCOP?

We wanted to conduct some preliminary analyses of overall survival outcomes among women not receiving primary surgery for DCIS or early invasive breast cancer, or women diagnosed with metastatic disease, by age at diagnosis. Specifically, here we have presented relative survival to show the impact of a patient's breast cancer on survival following their diagnosis.

This section provides estimated overall and relative survival up to 4 years from diagnosis, by grouped age at diagnosis, for the following groupings:

- women who do not receive surgery for DCIS;
- women who do not receive surgery for early invasive breast cancer;
- women with newly-diagnosed metastatic breast cancer regardless of treatment provision.

What do we see within this audit group?

For all disease groups shown, estimated 12 month overall survival decreased with age. Specifically for ages 50–69 years, 70–79 years and 80+ years:

- Among women not receiving surgery for DCIS 98%, 92%, 86% respectively were alive at 12 months;
- Among women not receiving surgery for ER positive EIBC 95%, 88%, 84% respectively were alive at 12 months;
- Among women not receiving surgery for ER negative EIBC 87%, 68%, 59% respectively were alive at 12 months;
- Among women with metastatic breast cancer 74%, 61%, 45% respectively were alive at 12 months.

Care is required in interpreting these data and analyses of cause specific survival invariably provide a better picture of the effect of breast cancer on patients' survival. To this effect **Figures 10.3–10.6** below show the relationship between age at diagnosis and relative survival, enabling us to see the effect of age at diagnosis on the prognosis of breast cancer, among those women not receiving primary surgery (DCIS and early invasive breast cancer) or diagnosed with metastatic disease.

Relative survival, as described by the National Cancer Institute, is "*a way of comparing the survival of people who have a specific disease with those who don't, over a certain period of time…It is calculated by dividing the percentage of patients with the disease who are still alive at the end of the period of time by the percentage of people in the general population of the same sex and age who are alive at the end of the same time period. The relative survival rate shows whether the disease shortens life.*"

Figure 10.3. Relative survival of women with DCIS who did not receive surgery, by age at diagnosis

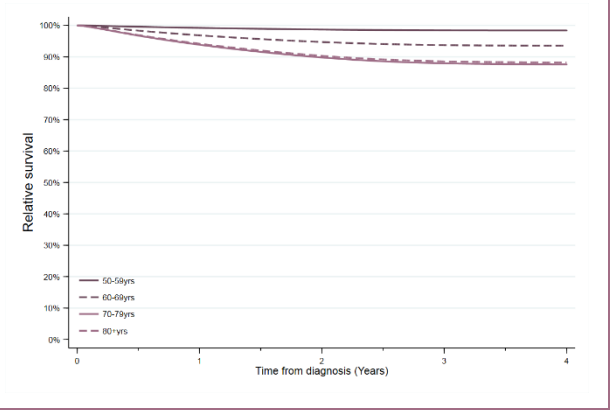


Figure 10.4. Relative survival of women with early invasive breast cancer who did not receive surgery, by ER status and age at diagnosis

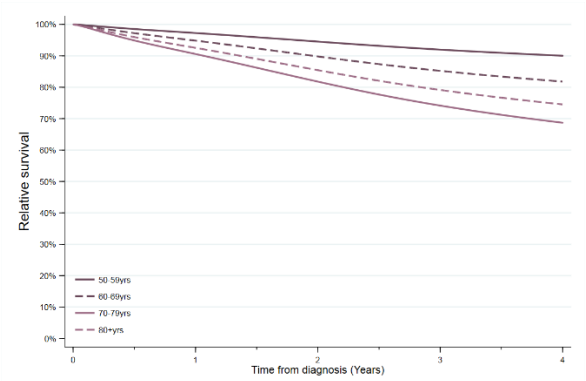
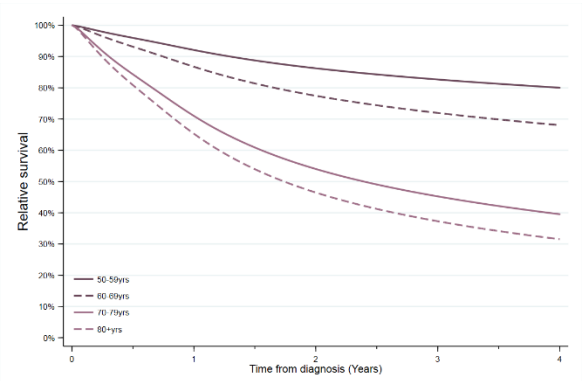
ER positive	ER negative
	

Figure 10.5. Relative survival of women with early invasive breast cancer who did not receive surgery, by ER status and Charlson Comorbidity Index (CCI))

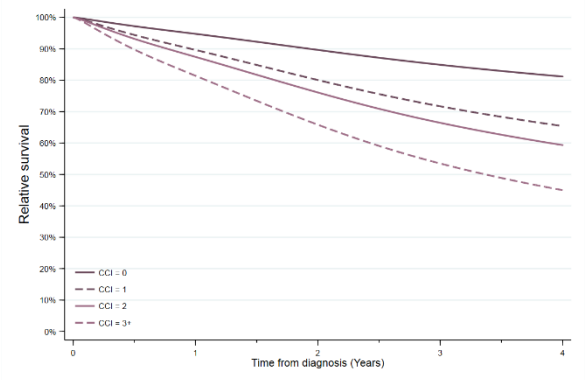
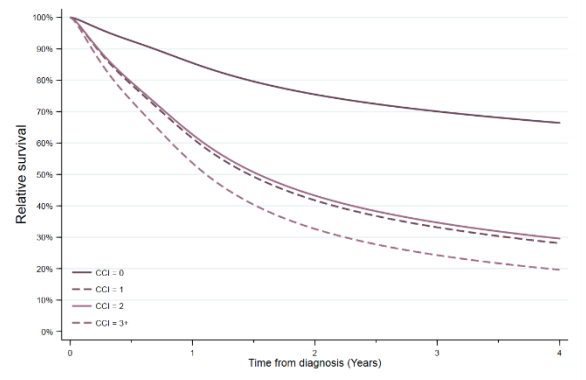
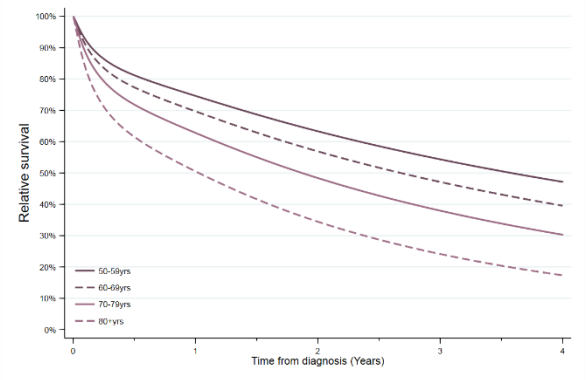
ER positive	ER negative
	

Figure 10.6. Relative survival of women with metastatic breast cancer, by age at diagnosis



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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
Dr Jacinta Abraham	Velindre NHS Trust	Breast Clinical Oncologist and Medical Director
Ms Karen Clements	National Cancer Registration and Analysis Service, Public Health England	NCRAS Project Manager
Miss Marianne Dillon	Swansea Bay University Health Board Wales Cancer Network	Consultant Breast Surgeon Breast Cancer Site Group Lead
Dr Julie Doughty	Association of Breast Surgery	President
Ms Patricia Fairbrother	Independent Cancer Patients' Voice	Patient Representative [Member until Dec 2019]
Ms Janice Rose	Independent Cancer Patients' Voice	Patient Representative
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	HQIP Project Manager
Ms Carla Whitbread	força - strength against cancer	Patient Representative [Member from Dec 2019]

Clinical Steering Group members (excluding project team)		
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Clinical Steering Group members continues on the next page.

Clinical Steering Group members continued from previous page.

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Dr Alistair Ring	The Royal Marsden NHS Foundation Trust	Medical Oncologist
Prof. Tom Robinson	University of Leicester University Hospitals of Leicester NHS Trust NIHR Senior Investigator	Deputy Head of the College of Life Sciences and Professor of Stroke Medicine Honorary Consultant Stroke Physician
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Project team		
Name	**Organisation**	**Role**
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[1]We are grateful to the members of the Public and Patients publications subgroup for their expert input, to help shape this aspect of the audit's work.

Appendix 2: Description of the NABCOP core set of indicators

Pathway	Indicator	Denominator	Numerator	Standard/ guideline
Diagnosis and staging	1. Referral route to diagnosis	All women	Women diagnosed after: 1. referral from screening 2. referral from GP 3. referral from other specialities 4. an emergency presentation	NICE CG80, 2009a NICE QS12, 2011
Diagnosis and staging	2. Triple diagnostic assessment in a single visit	Women with non-screen detected early invasive breast cancer	Women who receive triple diagnostic assessment in a single visit	NICE CG80, 2009a NICE QS12, 2011
Diagnosis and staging	3. Recorded molecular marker status	Women with invasive breast cancer	Women with molecular marker status recorded: 1. ER status 2. HER2 status	NICE CG80, 2009a
Diagnosis and staging	4. Metastatic disease at initial presentation	Women diagnosed with invasive breast cancer	Women with metastatic disease at initial presentation	NICE CG81, 2009b
Diagnosis and staging	5. Seen by a breast CNS/named key worker	All women	Women seen by a breast CNS/named key worker	NICE CG80, 2009a NICE CG81, 2009b
Treatment	6. Time to primary treatment	Women who receive surgery or chemotherapy as primary treatment	Time from date of diagnosis to chemotherapy or surgical treatment	DoH 2007 DoH 2011
Surgery	7. Surgery for DCIS or early stage invasive breast cancer	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	NICE CG80, 2009a Biganzoli *et al* 2012

Pathway	Indicator	Denominator	Numerator	Standard/ guideline
Surgery	8. Mastectomy for early invasive breast cancer	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	NICE CG80, 2009a Biganzoli *et al* 2012
Diagnosis and staging	9. Any axillary nodal surgery	Women with early invasive breast cancer	Women who received SNB, axillary node sampling or dissection; with recorded lymph node status	NICE QS12, 2011 NICE CG80, 2009a Biganzoli *et al* 2012 NICE DG8, 2013 SIGN 134, 2013
Acute care	10. 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. 1. Proportion who have a prolonged stay after surgery.	NICE QP case study, 2012 SCT, 2016
Radiotherapy	11. Radiotherapy after breast cancer surgery	Women with DICS or early invasive breast cancer who received surgery	Women who receive radiotherapy after surgery: 1. BCS 2. Mastectomy	NICE CG80, 2009a Biganzoli *et al* 2012 SIGN 134, 2013
Chemotherapy	12. Chemotherapy for invasive breast cancer	Women with early invasive breast cancer. Subgroups = 1. ER negative 2. HER2 positive	Women who receive chemotherapy: 1. Neoadjuvant 2. Adjuvant	NICE CG80, 2009a NICE CG81, 2009b Biganzoli *et al* 2012 SIGN 134, 2013
Outcomes	13. Mortality at one, three and five years	All women	Women who die within: 1. One year 2. Three years 3. Five years	DoH Public Health Outcomes Framework 2013-2016 DoH NHS Outcomes Framework 2015–16

Appendix 3: NHS organisations and geographical regions

Organisation code	Organisation name	Patients ≥50 years diagnosed 2014–18	Patients ≥50 years diagnosed in 2018
Cheshire and Merseyside			
RBL	Wirral University Teaching Hospital NHS Foundation Trust	1410	285
RBN	St Helens & Knowsley Teaching Hospitals NHS Trust	997	234
RBT	Mid Cheshire Hospitals NHS Foundation Trust	1295	233
REM	Liverpool University Hospitals NHS Foundation Trust	2752	586
RJN	East Cheshire NHS Trust	974	250
RJR	Countess Of Chester Hospital NHS Foundation Trust	799	167
RWW	Warrington & Halton Hospitals NHS Foundation Trust	1001	210
East Midlands			
RK5	Sherwood Forest Hospitals NHS Foundation Trust	877	177
RNQ	Kettering General Hospital NHS Foundation Trust	1010	186
RNS	Northampton General Hospital NHS Trust	1185	252
RTG	University Hospitals Of Derby & Burton NHS Foundation Trust	2806	604
RWD	United Lincolnshire Hospitals NHS Trust	2271	437
RWE	University Hospitals Of Leicester NHS Trust	2931	572
RX1	Nottingham University Hospitals NHS Trust	2479	537
East of England			
RAJ	Southend University Hospital NHS Foundation Trust	1645	367
RC1	Bedford Hospital NHS Trust	603	172
RC9	Luton & Dunstable University Hospital NHS Foundation Trust	2085	379
RCX	The Queen Elizabeth Hospital, Kings Lynn, NHS Foundation Trust	871	181
RD8	Milton Keynes University Hospital NHS Foundation Trust	920	199
RDD	Basildon & Thurrock University Hospitals NHS Foundation Trust	695	131
RDE	East Suffolk & North Essex NHS Foundation Trust	2643	527
RGN	North West Anglia NHS Foundation Trust	1547	352
RGP	James Paget University Hospitals NHS Foundation Trust	810	180
RGR	West Suffolk NHS Foundation Trust	986	198
RGT	Cambridge University Hospitals NHS Foundation Trust	1604	359
RM1	Norfolk & Norwich University Hospitals NHS Foundation Trust	2204	475
RQ8	Mid Essex Hospital Services NHS Trust	1312	289
RQW	The Princess Alexandra Hospital NHS Trust	1039	219
RWG	West Hertfordshire Hospitals NHS Trust	861	207
RWH	East & North Hertfordshire NHS Trust	899	212
Greater Manchester			
R0A	Manchester University NHS Foundation Trust	2991	605
RMC	Bolton NHS Foundation Trust	1614	366
RMP	Tameside & Glossop Integrated Care NHS Foundation Trust	307	79
RRF	Wrightington, Wigan & Leigh NHS Foundation Trust	1354	308
RW6	Pennine Acute Hospitals NHS Trust	1168	257
RWJ	Stockport NHS Foundation Trust	597	122

Organisation code	Organisation name	Patients ≥50 years diagnosed 2014–18	Patients ≥50 years diagnosed in 2018
Humber, Coast and Vale			
RCB	York Teaching Hospital NHS Foundation Trust	2177	453
RJL	Northern Lincolnshire & Goole NHS Foundation Trust	892	202
RWA	Hull University Teaching Hospitals NHS Trust	1971	457
Kent and Medway			
RN7	Dartford & Gravesham NHS Trust	350	121
RPA	Medway NHS Foundation Trust	658	302
RVV	East Kent Hospitals University NHS Foundation Trust	2478	484
RWF	Maidstone & Tunbridge Wells NHS Trust	2851	405
Lancashire and South Cumbria			
RTX	University Hospitals Of Morecambe Bay NHS Foundation Trust	1976	411
RXL	Blackpool Teaching Hospitals NHS Foundation Trust	685	134
RXN	Lancashire Teaching Hospitals NHS Foundation Trust	787	157
RXR	East Lancashire Hospitals NHS Trust	1539	318
North Central and North East London			
R1H	Barts Health NHS Trust	2120	348
RAL	Royal Free London NHS Foundation Trust	1595	380
RAP	North Middlesex University Hospital NHS Trust	1827	270
RF4	Barking, Havering & Redbridge University Hospitals NHS Trust	1950	405
RKE	Whittington Health NHS Trust	279	60
RRV	University College London Hospitals NHS Foundation Trust	446	99
North East and Cumbria			
RNN	North Cumbria Integrated Care NHS Ft	1149	247
RR7	Gateshead Health NHS Foundation Trust	2199	494
RTD	The Newcastle Upon Tyne Hospitals NHS Foundation Trust	2239	473
RTF	Northumbria Healthcare NHS Foundation Trust	882	178
RTR	South Tees Hospitals NHS Foundation Trust	811	151
RVW	North Tees & Hartlepool NHS Foundation Trust	1945	399
RXP	County Durham & Darlington NHS Foundation Trust	982	186
Peninsula			
RA9	Torbay & South Devon NHS Foundation Trust	1097	170
RBZ	Northern Devon Healthcare NHS Trust	350	77
REF	Royal Cornwall Hospitals NHS Trust	1680	386
RH8	Royal Devon & Exeter NHS Foundation Trust	1845	415
RK9	University Hospitals Plymouth NHS Trust	1716	398
Somerset, Wiltshire, Avon and Gloucestershire			
RBA	Taunton & Somerset NHS Foundation Trust	1829	428
RD1	Royal United Hospitals Bath NHS Foundation Trust	966	190
RNZ	Salisbury NHS Foundation Trust	542	104
RTE	Gloucestershire Hospitals NHS Foundation Trust	2357	488

Organisation code	Organisation name	Patients ≥50 years diagnosed 2014–18	Patients ≥50 years diagnosed in 2018
RVJ	North Bristol NHS Trust	3128	770
South East London			
RJ1	Guys & St Thomas NHS Foundation Trust	734	195
RJ2	Lewisham & Greenwich NHS Trust	851	148
RJZ	Kings College Hospital NHS Foundation Trust	2625	532
South Yorkshire, Bassetlaw and North Derbyshire			
RFF	Barnsley Hospital NHS Foundation Trust	793	177
RFR	The Rotherham NHS Foundation Trust	818	169
RFS	Chesterfield Royal Hospital NHS Foundation Trust	1193	275
RHQ	Sheffield Teaching Hospitals NHS Foundation Trust	1758	375
RP5	Doncaster & Bassetlaw Teaching Hospitals NHS Foundation Trust	1507	284
Surrey and Sussex			
RA2	Royal Surrey County Hospital NHS Foundation Trust	3255	584
RDU	Frimley Health NHS Foundation Trust	1806	412
RTK	Ashford & St Peters Hospitals NHS Foundation Trust	317	139
RTP	Surrey & Sussex Healthcare NHS Trust	916	220
RXC	East Sussex Healthcare NHS Trust	997	215
RXH	Brighton & Sussex University Hospitals NHS Trust	2052	437
RYR	Western Sussex Hospitals NHS Foundation Trust	2520	540
Thames Valley			
RHW	Royal Berkshire NHS Foundation Trust	1493	310
RN3	Great Western Hospitals NHS Foundation Trust	1465	325
RTH	Oxford University Hospitals NHS Foundation Trust	2149	482
RXQ	Buckinghamshire Healthcare NHS Trust	1665	332
Wessex			
R1F	Isle Of Wight NHS Trust	568	107
RBD	Dorset County Hospital NHS Foundation Trust	478	99
RD3	Poole Hospital NHS Foundation Trust	1986	399
RDZ	The Royal Bournemouth & Christchurch Hospitals NHS Foundation Trust	782	155
RHM	University Hospital Southampton NHS Foundation Trust	1976	412
RHU	Portsmouth Hospitals NHS Trust	2146	416
RN5	Hampshire Hospitals NHS Foundation Trust	1728	393
West London			
R1K	London North West Healthcare NHS Trust	1068	246
RAS	The Hillingdon Hospitals NHS Foundation Trust	446	87
RAX	Kingston Hospital NHS Foundation Trust	563	116
RJ6	Croydon Health Services NHS Trust	229	102
RJ7	St Georges University Hospitals NHS Foundation Trust	2464	472
RPY	The Royal Marsden NHS Foundation Trust	1512	266
RQM	Chelsea & Westminster Hospital NHS Foundation Trust	537	174
RYJ	Imperial College Healthcare NHS Trust	1967	373

Organisation code	Organisation name	Patients ≥50 years diagnosed 2014–18	Patients ≥50 years diagnosed in 2018
West Midlands			
RBK	Walsall Healthcare NHS Trust	791	174
RJC	South Warwickshire NHS Foundation Trust	715	127
RJE	University Hospitals Of North Midlands NHS Trust	2357	430
RKB	University Hospitals Coventry & Warwickshire NHS Trust	1777	407
RL4	The Royal Wolverhampton NHS Trust	1202	279
RLQ	Wye Valley NHS Trust	709	148
RLT	George Eliot Hospital NHS Trust	393	74
RNA	The Dudley Group NHS Foundation Trust	1268	263
RRK	University Hospitals Birmingham NHS Foundation Trust	2885	603
RWP	Worcestershire Acute Hospitals NHS Trust	2182	484
RXK	Sandwell & West Birmingham Hospitals NHS Trust	1568	342
RXW	Shrewsbury & Telford Hospital NHS Trust	1784	367
West Yorkshire			
RAE	Bradford Teaching Hospitals NHS Foundation Trust	1873	351
RCD	Harrogate & District NHS Foundation Trust	412	98
RCF	Airedale NHS Foundation Trust	456	123
RR8	Leeds Teaching Hospitals NHS Trust	2565	515
RWY	Calderdale & Huddersfield NHS Foundation Trust	748	182
RXF	Mid Yorkshire Hospitals NHS Trust	1016	236
Wales			
7A1	Betsi Cadwaladr University Health Board	2969	598
7A2	Hywel Dda University Health Board	1840	353
7A3	Abertawe Bro Morgannwg University Health Board	2132	410
7A4	Cardiff and Vale University Local Health Board	1188	238
7A5	Cwm Taf University Health Board	1534	283
7A6	Aneurin Bevan University Health Board	1807	369

Notes:

1. The registration dataset for 2014–18 included several NHS trusts at which fewer than 150 patients were diagnosed over the five-year period. These NHS trusts were not included in this report. They are: Lancashire & South Cumbria NHS Foundation Trust, Queen Victoria Hospital NHS Foundation Trust, Epsom & St Helier University Hospitals NHS Trust, Southport & Ormskirk Hospital NHS Trust, Yeovil District Hospital NHS Foundation Trust, and Homerton University Hospital NHS Foundation Trust.
2. A further four NHS trusts had fewer than 30 patients diagnosed in the most recent year this report presents data on (i.e. 2018) and as such are not included; these are: South Tyneside NHS Foundation Trust, University Hospitals Bristol NHS Foundation Trust, Weston Area Health NHS Trust, Salford Royal NHS Foundation Trust.
3. 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.

For all three scenarios above, where possible, any women reported as being diagnosed at one of these centres have been reassigned to the trust where the primary diagnostic multidisciplinary team took place or where surgery took place.

Glossary and abbreviations

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

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.

AMTS – Abbreviated Mental Test Score (see **Chapter 3**).

Axilla – the area under the arm, known as the arm-pit. Some women may need to have surgery to the axilla to remove some, or all lymph nodes (glands) in this region.

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 Screening – Breast screening involves women being invited to a breast X-ray (mammogram). It aims to diagnose women early because it can allow 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.

Breast Test Wales – The national breast screening programme for Wales, which offers a mammogram every three years for the detection of early breast cancer for women aged over 50.

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

Canisc – Cancer Network Information System Cymru. An all-Wales electronic patient record used for clinical management of cancer patients.

Charlson Comorbidity Index – 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.

Chemotherapy – Drug therapy used to treat cancer.

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

Comorbidity – A medical condition that coexists alongside primary breast cancer.

CPES – The Cancer Patient Experience Survey has been running in England since 2010. CPES is not specific to breast cancer. It is completed during a three-month window in each survey year, by patients with (any) cancer who were discharged from an English NHS trust after an admission for cancer related treatments. Further details on the CPES questions can be found at http://www.ncpes.co.uk/reports/2015-reports/guidance/2486-2015-national-cancer-patient-experience-survey-questionnaire/file.

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).

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

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

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

HER2 – HER2 (human epidermal growth receptor 2) protein, a receptor that is present on normal breast cells. It is involved in the signalling and promotion of cell growth. 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.

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.

ICD-10 – International Classification of Diseases, 10th 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 Patient Episode Database for Wales.

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. The Welsh IMD is the official measure of relative deprivation for small areas in Wales.

Invasive breast cancer – There is invasion of cancerous cells in the breast beyond the original lining of breast ducts/glands. In this report, early invasive breast cancer is defined as stages 1–3A.

Lymph nodes (glands) – These 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.

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

Multidisciplinary team – A team of specialist healthcare professionals from various backgrounds (e.g. doctors, nurses, administrative staff) who collaborate to organise and deliver care for patients with a specific condition (e.g. breast cancer).

Metastatic breast cancer – Often denoted as M1. This is when cancer has spread from the place in which it started to other parts of the body. It is also referred to as stage 4 cancer.

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

Neoadjuvant treatments – These are treatments given before the primary treatment. The term usually refers to treatments given before surgery to shrink the cancer, making it easier to remove.

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

NICE – The National Institute for 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). 96% of non-invasive breast cancer are ductal carcinoma in situ (DCIS).

Non-screen detected breast cancer – The term used to refer to women who are diagnosed with breast cancer after presenting with symptoms to their GP, by referral from another medical specialty or as an emergency presentation, as opposed to women diagnosed after being screened.

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.

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 treatments.

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

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

(breast) Reconstruction surgery – The surgical recreation of the breast mound (or shape) after some or all of this has been removed (e.g. after breast cancer surgery).

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.

Systemic anti-cancer therapy – An additional therapy (e.g. chemotherapy, endocrine therapy, HER2 targeting therapy) provided to improve the effectiveness of the primary treatment (e.g. 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 (brand name 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 – 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.

WHO performance status – The World Health Organization (WHO) 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.