
National Audit of Breast Cancer in Older Patients

Part of the National Clinical Audit and Patient Outcomes Programme

2019 Annual Report

Results of the prospective audit in England and Wales for women diagnosed between January 2014 and December 2017



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

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- Marianne Dillon (Breast Cancer Audit Lead for Wales), Hywel Morgan (Deputy Director) and Julie Cowling (Information Specialist) from the Wales Cancer Network, as well as Janet Warlow (Welsh Cancer Intelligence and Surveillance Unit).
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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.

Data for this report are based on patient-level information collected by the NHS as part of the care and support of cancer patients. The data were collated, maintained and quality assured by the National Cancer Registration and Analysis Service, which is part of Public Health England. Data from the Cancer Network Information System Cymru (Canisc) and Patient Episode Database for Wales are used with permission of the NHS Wales Informatics Service bespoke analysis service.

The National Audit of Breast Cancer in Older Patients (NABCOP) continues to be an important joint project by the Association of Breast Surgery and the Clinical Effectiveness Unit of the Royal College of Surgeons of England, commissioned by the Healthcare Quality Improvement Partnership.

The audit aims to evaluate the care provided to, and subsequent outcomes for, women diagnosed with breast cancer aged 70 years or over, comparing this with a younger cohort of women diagnosed between 50 and 69 years to study any age-related treatment variations.

It is pleasing to see that the audit is now providing useful comparative data for these two age cohorts across the spectrum of breast cancer, ranging from ductal carcinoma in situ through to metastatic disease. Differences in management have been identified across the care pathway, not only between women in different age groups, but also variations between NHS organisations that need to be explored further.

There is now a clear theme emerging from the data that women aged 70+ years are not receiving the same treatment as those in the younger cohort, and that this appears to be related to their older age rather than their fitness to receive treatments. It is now important to spread the key message that chronological age alone should not be the main factor in determining treatment if we are to improve breast cancer outcomes in older people.

The data published are comprehensive, providing information for all NHS trusts in England and local health boards in Wales that provided breast cancer services from 2014–17. It is good to see that data completeness has improved overall. However, it is also disappointing that there continues to be a problem with the recording of certain data items that are essential to the interpretation of the audit data, such as performance status and estrogen receptor status. This is something that can only be addressed locally by ensuring that there are effective processes and adequate resources in place to both record and upload the required data set to the English National Cancer Registration and Analysis Service and the Cancer Network Information System Cymru in Wales.

The NABCOP project team, assisted by the Clinical Steering Group and the Project Board, are to be congratulated on having made sustained progress with the audit over the last year. It is now delivering the data we require to analyse breast cancer care, in older people, in detail and develop recommendations that will lead to improved cancer outcomes in the future.

Mark Sibbering
President, Association of Breast Surgery

The National Audit of Breast Cancer in Older Patients (NABCOP) was established to evaluate the care received by older women (aged 70+ years) diagnosed with breast cancer in NHS hospitals within England and Wales. The audit was commissioned because of the greater variation in the management of breast cancer among older women compared with women aged under 70 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. The audit works in partnership with the National Cancer Registration and Analysis Service, Public Health England and the Wales Cancer Network, and uses the routinely collected data collected by these national bodies. The audit was commissioned by the Healthcare Quality Improvement Partnership.

Third annual report

This third annual report describes the process and outcomes of care for 147,162 women, diagnosed with breast cancer between 1 January 2014 and 31 December 2017 in England and Wales. The patterns of care received by women aged 70+ years are compared with the care received by women diagnosed with breast cancer aged 50–69 years. We also distinguish between the following groups of women with breast cancer:

1. ductal carcinoma in situ (DCIS)
2. early invasive breast cancer
3. metastatic breast cancer.

The report is written primarily for clinicians, providers of breast cancer services, commissioners and healthcare regulators. A version for patients and the wider public is being produced separately and will be available in summer 2019. Supplementary material from the report, including a guide for understanding NABCOP data and tables containing individual trust results, are available on the NABCOP website (www.nabcop.org.uk).

An emerging theme in this report is that the older patients have similar clinical and pathological characteristics to 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 greater concern.

Participation and data quality

Among women aged 50 years and over diagnosed with breast cancer in 2017:

- data completeness exceeds 90% among many key items and has improved overall
- data on pretreatment performance status and molecular markers were poorly completed in some NHS organisations, particularly for older women.

Care at the time of diagnosis

The routes to diagnosis followed the expected pathways:

- 59% of women aged between 50–69 years were diagnosed after screening.
- 67% of women aged 70+ years were diagnosed after general practitioner (GP) referral.
- Overall, 1% of women were diagnosed after an emergency admission.

Among women diagnosed with early invasive breast cancer not detected at screening:

- 67% received the standard triple diagnostic assessment in a single visit, with no difference by age.

This low estimate of women having triple diagnostic assessment arose from uncertainty and incompleteness of the imaging and biopsy dates.

Where data were available, 95% of women were reported to have seen a breast clinical nurse specialist.

Treatment for women diagnosed 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.

- 93% of women aged 50–69 years had surgery, compared with 81% of women aged 70+ years.
- Rates varied across NHS organisations, particularly for women aged 70+ years.
- 63% of women aged 50–69 years received adjuvant radiotherapy after breast conserving surgery, compared with 47% of women aged 70+ years.

Treatment for women diagnosed with early invasive breast cancer

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.

- 87% of women received surgery (95% for 50–69 years; 74% for 70+ years).
- Among women aged 70+ years those with ER-negative breast cancer were more likely to have surgery (90%) than those with ER-positive breast cancer (73%).
- Among women aged 70+ years with no comorbidity (Charlson Comorbidity Index 0), 94% with ER-negative breast cancer had surgery compared with 84% with ER-positive breast cancer.

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

- 89% had radiotherapy to the breast after breast conserving surgery (91% for 50–69 years; 84% for 70+ years).

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].

- Among women who had mastectomy for high-risk early invasive breast cancer, 64% had radiotherapy (67% for 50–69 years; 60% for 70+ years).
- Rates of adjuvant radiotherapy following breast conserving surgery or mastectomy varied across NHS organisations.

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

- Use of adjuvant chemotherapy was more common among women aged 50–69 years (74%) with ER-negative, human epidermal growth receptor 2 (HER2) negative early invasive breast cancer and

malignant nodes, than women aged 70+ years with the same tumour profile (30%).

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

- 59% of women with HER2-positive breast cancer had adjuvant chemotherapy plus trastuzumab (69% for 50–69 years; 36% for 70+ years).
- Variation in the rate of adjuvant chemotherapy plus trastuzumab was observed across NHS organisations, regardless of age.

Treatment for women diagnosed with metastatic breast cancer:

- The percentage of women diagnosed with metastatic breast cancer at presentation increased with age (3% for 50–69 years; 7% for 70+ years).

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

- 57% of women aged 50–69 years with ER-positive metastatic breast cancer were recorded to have received endocrine treatment compared with 76% of women aged 70+ years.

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

- Women aged 70+ years were less likely to receive chemotherapy (24%), compared with women aged 50–69 years (59%), irrespective of ER status and patient fitness.

Patient experience

This is the first report using data linked from the English Cancer Patient Experience Survey (CPES) to the NABCOP patient-level data. Currently, CPES is only available for NABCOP patients diagnosed with cancer in England in 2015. At least three in four of these women reported experiencing high levels of involvement in decisions about care and treatment and access to a clinical nurse specialist. Nevertheless, there is room for improvement, with only 65% of women aged 70+ years newly diagnosed with metastatic breast cancer reporting that their treatment options were completely explained to them. Across all groupings of breast cancer (DCIS, early invasive, metastatic), over 90% of women gave a high rating for their care.

For breast cancer units within NHS organisations

Completeness of data items

1. NHS organisations must ensure that the following information is uploaded to the national cancer registration services:
 - tumour size consistent with the entered T (tumour) stage
 - N (nodal) stage, M (metastasis) stage
 - ER and HER2 status for invasive breast cancer
 - World Health Organization performance status.
2. NHS organisations should identify a clinician responsible for reviewing and checking their units' data returns.

Triple diagnostic assessment

3. NHS organisations must ensure that:
 - women are able to receive triple assessment at their initial clinic visit after referral for suspected breast cancer, in line with National Institute for Health and Care Excellence (NICE) recommendations
 - dates of assessment for all investigations performed at a triple assessment clinic are submitted to the national cancer registration services.

Involvement of a breast clinical nurse specialist

4. NHS organisations must 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 are submitted to the national cancer registration services.

Treatment for DCIS

5. NHS organisations must ensure that:
 - women are counselled appropriately about the gap in knowledge and guidelines
 - emphasis is placed on treating women with DCIS using a risk-based, rather than age-stratified, approach (clinical research in this area should be prioritised)
 - older women who undergo breast conserving surgery for high-risk DCIS, and who have few comorbidities and frailty, should be for radiotherapy.

Treatment for early invasive breast cancer

6. NHS organisations must ensure that:
 - there is consistent assessment and recording of comorbidity and frailty in breast clinics
 - medical optimisation of women with ER-positive early invasive breast cancer is instituted to maximise potential for their suitability for surgery
 - women with high-risk early invasive breast cancer are counselled on the benefit and risk of adjuvant radiotherapy based on tumour characteristics and objective assessment of patient fitness, rather than chronological age alone
 - 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 have an objective assessment of likelihood of benefit and risk of chemotherapy based on tumour factors and patient fitness
 - they evaluate their services for medical optimisation for older women, who would benefit from receiving chemotherapy.

Treatment for metastatic breast cancer

7. NHS organisations must ensure that:
 - ER status is assessed and recorded for women with metastatic breast cancer; all women who are ER-positive should be offered endocrine therapy
 - consideration of chemotherapy is based on an objective assessment of the likelihood of benefit, health and predicted life expectancy rather than chronological age alone.

Patient experience of breast cancer

8. NHS organisations must ensure that women are given enough information about their radiotherapy or chemotherapy treatments. Clinical teams should ask for feedback from their patients, at regular intervals, to ensure that they have sufficient information and are engaged in a shared decision-making process.

For professional organisations involved in breast cancer care

9. Royal colleges and specialist associations involved in breast cancer care should collaborate with the NABCOP around the need for using a reliable, consistent description of patient fitness.

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

2014–2017

147,162 new diagnoses of unilateral breast cancer among women aged 50 years and older, in England and Wales

61%
aged 50–69 years

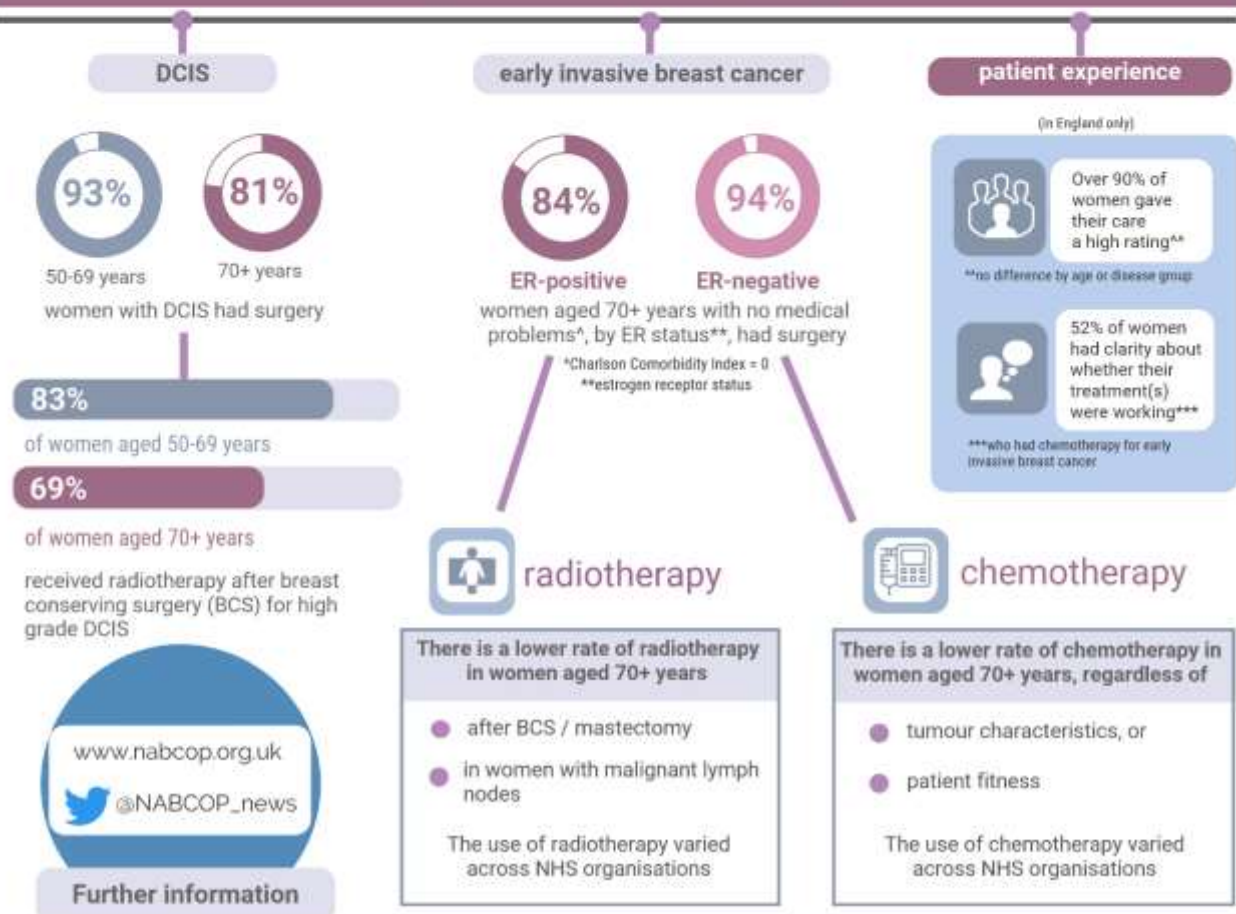


39%
aged 70+ years

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



Treatment allocation



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. The audit was commissioned because of the greater variation in the management of breast cancer among women aged 70+ years compared with women aged under 70 years. It examines the care received by patients from initial diagnosis to the end of primary therapy and provides information on the comparative performance of NHS trusts and local health boards.

While some variation in the management of patients will reflect differences in stage and the presence of comorbidity, various studies over the past decade concluded that these factors could not explain all the observed variation in breast cancer services in England and Wales [Bates *et al* 2014; Lavelle *et al* 2014; Richards *et al* 2016]. Specifically, the audit investigates whether the care received by older women with breast cancer is consistent with recommended practice for breast cancer management, as described by (among others) the NICE guideline [NICE 2018]. Currently, clinical guidelines lack specific recommendations on the management of breast cancer in older women in some areas and, consequently, the audit adopts a comparative approach of evaluation for these parts of the care process.

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 2018; Welsh Cancer Intelligence and Surveillance Unit 2019]. There is no agreed definition of an 'older woman with breast cancer', but the phrase is often used to refer to women aged 70 years or older when diagnosed [Biganzoli *et al* 2004]. This partly reflects the pathway to diagnosis, with breast screening offered to women aged 50–70 years. We follow this definition of an older woman in this report.

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 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 2019 Annual Report

This third NABCOP Annual Report describes information regarding diagnosis, staging and initial treatment of breast cancer within NHS providers. The report describes how these patterns of care differ between women in the younger (50–69 years) and older (70+ years) age groups, and distinguishes these patterns in women with:

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

The report describes the care received by women aged 50 years and over who were diagnosed with breast cancer in England and Wales between 1 January 2014 and 31 December 2017. The data analysed for this report were primarily collected as part of the national cancer registration process in England and Wales. These data were supplemented with information from routinely collected hospital data, specifically in relation to the provision of breast cancer surgery. The report uses the most recent data available from the English and Welsh cancer registration services, and reflects the need to allow at least six months of follow-up after diagnosis to capture all the primary treatments received by women. In addition, for the first time, we report on information from the English Cancer Patient Experience Survey (CPES), completed by patients diagnosed in England in 2015.

1.3 Management considerations for older women with breast cancer

Patterns of care

All women diagnosed with breast cancer follow a similar care pathway (see **Figure 1.1** for a general overview). However, various studies have examined the delivery of breast cancer care by NHS services in the UK and have identified varied approaches to the management of older patients within NHS breast cancer units [National Cancer Intelligence Network 2011]. The diversity in the patterns of care among younger and older patients may arise for various reasons and is not in itself evidence of deficiencies in breast cancer care among older women.

Comorbidity and frailty

It is also important to recognise that there is considerable variation among women aged 70+ years in terms of their general health, and chronological age alone does not correspond well to the notion of biological age. Biological age takes into account how someone's health is affected by chronic conditions (both physical and mental) as well as physical fitness and degree of frailty. The management of breast cancer for individual women will reflect the characteristics of their 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 and anaesthesia are exacerbated by the presence of cardiovascular, lung and kidney disease. Consequently, in frail women for whom surgery may pose a significant risk, it may be appropriate to offer primary endocrine therapy to women with estrogen receptor (ER)-positive cancers instead [Hind *et al* 2006].
- 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 worth noting that older women with breast cancer may differ from younger women in how they balance a desire to extend their life by undergoing treatments that potentially have unpleasant side effects against a desire to maintain their current quality of life [Wedding *et al* 2007].

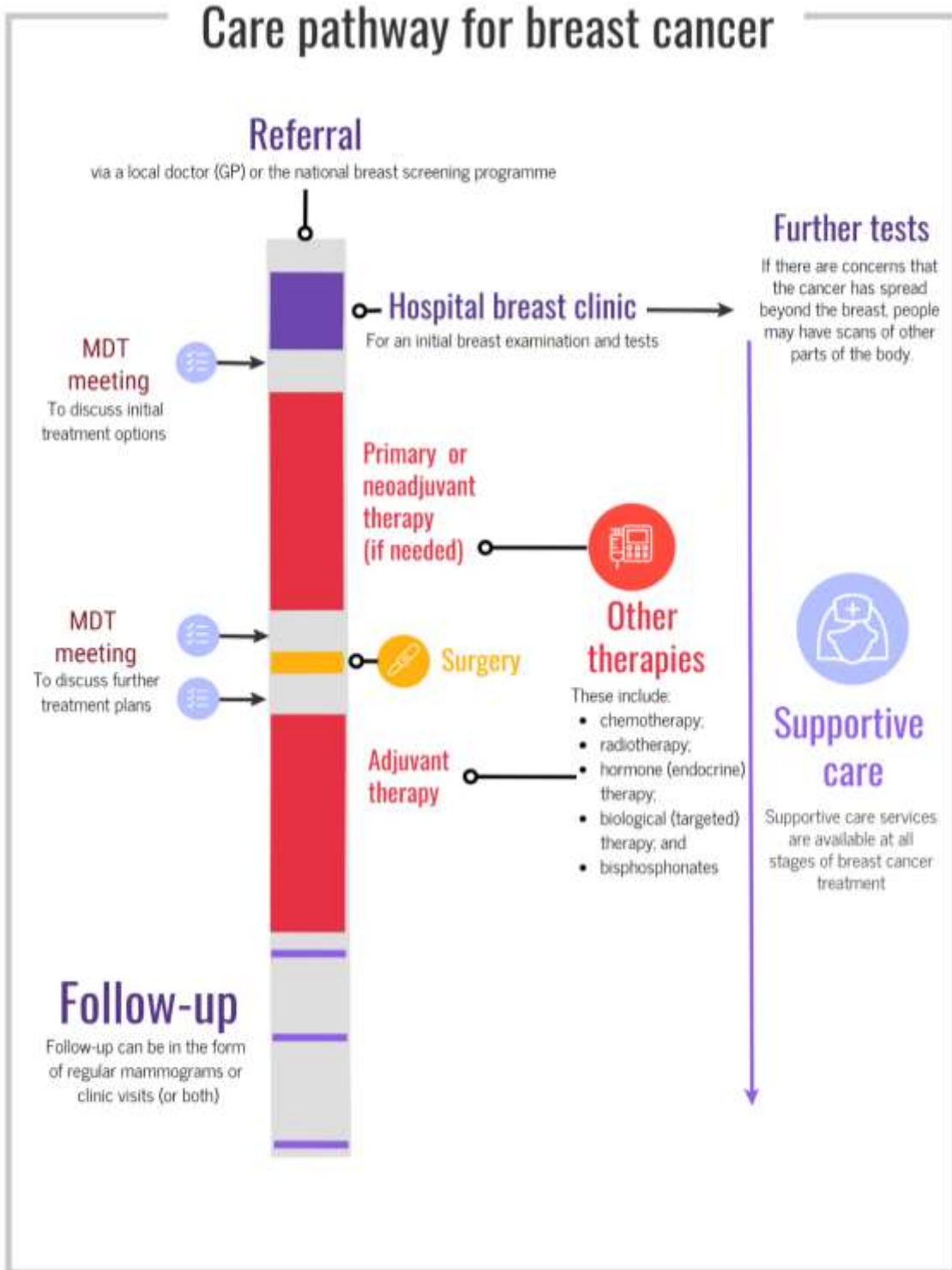
Variation in management

Despite these differences, evidence suggests that variation in treatment patterns may arise from idiosyncrasies within clinical practice. First, although clinical guidelines emphasise that breast cancer treatment should be based on clinical need and fitness for treatment rather than age [NICE 2018; Biganzoli *et al* 2012], there is a lack of advice in these guidelines about the best way to tailor treatments to the individual needs of older women. This can result in different treatment preferences among clinicians.

Patient involvement in decision making

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

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



MDT = multidisciplinary team.

2. Audit methods

The NABCOP uses patient data collected by the national cancer registration services in England and the Wales Cancer Network.

For English patients, the National Cancer Registration and Analysis Service (NCRAS), provided data from its cancer analysis system, which collates patient data from a range of national data feeds across all NHS acute hospitals. 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 those details of women aged 50 years and over who were diagnosed with breast cancer in England and Wales over the four-year period between 1 January 2014 and 31 December 2017. As noted in **Chapter 1**, these were the most recent data available for this annual report. Patients diagnosed in England in December 2017 had data on investigations, initial and follow-up treatments uploaded via the Cancer Outcomes and Services Dataset between February and July 2018. Consequently, their final registration was not completed until August 2018. The cancer registration services then quality assure the datasets before making them available to the audit for statistical analysis.

The timeframes covered in each chapter are indicated in the appropriate section. Broadly, they are one year (2017) for **Chapter 5** and four years (2014–17) for **Chapters 6–8**. For full details of the methods used within this report, please see the NABCOP Annual Report Methodology 2019 document, available online (www.nabcop.org.uk).

2.1 Types of breast cancer

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

1. DCIS (stage 0)
2. early invasive breast cancer (stages 1–3A)
3. metastatic breast cancer (stage 4).

2.2 Measurement of patient fitness

As noted in **Chapter 1**, older women can differ markedly in relation to their health. The cancer registration datasets contain a limited number of data items to record this information, notably the World Health Organization (WHO) performance status instrument, which measures the functional ability of patients on a scale from 0 to 4. Unfortunately, this data item is poorly completed in the registration datasets (**Table 3.1**). The report therefore uses two other approaches to measure patient fitness. These are:

- the RCS Charlson Comorbidity Index
- a hospital version of the electronic Frailty Index.

Both these measures use information from the 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 times that each condition is recorded in hospital admissions around the time of diagnosis, as well as the previous 12 months.

The measure of frailty used in this report is based on the electronic Frailty Index proposed by Clegg *et al* [2016]. This describes frailty using the ‘cumulative deficit’ model, in which frailty is measured in relation to 36 different symptoms, signs, diseases and disabilities (referred to as deficits). We translated 35 of these deficits (excluding polypharmacy) into 10th revision of the International Statistical Classification of Diseases and Related Health Problems (ICD-10) codes, which are captured within the diagnosis fields of the hospital admissions data.

2.3 Patient experience

The English CPES in 2015 is the first year of the survey that can be linked to the NABCOP English patient-level dataset.¹ It comprises a series of questions with multiple response options, in line with other patient surveys.

The 2015 CPES was completed by 66% of patients with a confirmed primary diagnosis of cancer, discharged from an English NHS trust after an inpatient episode or day case attendance for cancer-related treatment in the months of April, May and June 2015 [Quality Health 2015].

The responses of the patients in the NABCOP cohort are summarised in **Chapters 5–8** 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 and treatment effectiveness
- involvement of a clinical nurse specialist and ease of contacting them
- overall rating of patients' care.

The NABCOP will request and report on the 2016 and 2017 CPES datasets when these become available; as well as investigate the possibility of requesting the Wales CPES 2016 dataset.

2.4 Survival following a diagnosis of breast cancer

This is the first NABCOP annual report where overall survival following a diagnosis of breast cancer is described. There are various factors which affect survival including age, tumour characteristics, patient fitness and cancer treatments. In this report, we have focused on reporting the baseline (observed) survival for women with DCIS (**Chapter 6**), early invasive (**Chapter 7**) and metastatic breast cancer (**Chapter 8**). In the coming years, NABCOP will aim to provide more detailed information on the influence of patient and tumour characteristics on survival.

¹ The 2015 CPES survey was on patients discharged between 1 April 2015 and 30 June 2015. NABCOP will request and report on the 2016 and 2017 CPES datasets when these become available. NCRAS is in the process of signing the data sharing agreement to access the 2016 data.

3. Participation and data completeness

3.1 Participating NHS organisations across England and Wales

The audit received information from all NHS trusts that submitted data to the NCRAS (for England) and all local health boards submitting data to the Canisc (for Wales). **Appendix 2** contains a full list of English NHS trusts and Welsh local health boards with data provided for analysis in this annual report.

In total, 124 English NHS trusts and 6 Welsh local health boards were included in this 2019 Annual Report. There are fewer English NHS trusts in this report than in the 2018 Annual Report for several reasons. First, there were several trust mergers. Second, the number of trusts diagnosing fewer than 120 patients over the four years (or fewer than 30 patients in 2017) differed from last year.

3.2 Overview of data completeness

Patterns of treatment are influenced by various features such as tumour characteristics and the general health and preferences of patients. Those tumour characteristics that play a major role in determining the most appropriate course of treatment, particularly for invasive breast cancer, include:

- tumour grade
- tumour size (T stage)
- the number of malignant lymph nodes (N stage)
- metastatic spread (M stage)
- molecular markers: ER status, progesterone receptor (PR) status and human epidermal growth receptor 2 (HER2) status

Table 3.1 shows data completeness for a selection of core data items in women diagnosed in 2017 by English NHS trusts and Welsh local health boards. It highlights a mixed picture of data completeness:

- Tumour grade was captured for nearly all patients in both English and Welsh datasets.
- In England, data completeness have continued to improve annually: T stage was 95% complete; N stage was 89% complete.
- In Wales: T stage was 84% complete; while N stage was complete for all women.²

- Tumour size was less well reported than tumour stage despite the fact that T stage is derived from tumour size. Completeness was higher in women that had surgery, but all women should have their tumour size reported. Completeness was lowest among women with DCIS or metastatic cancer.

Where data completeness was poor, it remains unclear why items were not uploaded to the NCRAS and Canisc.

Table 3.1 also shows that the WHO performance status remains poorly reported, particularly in Wales. This limits the degree to which physical fitness (which is particularly important for understanding patterns of care among older patients) can be described. Fortunately, information on comorbidities and frailty were available for over 90% of patients.

Suggestions on how NHS organisations can improve data completeness and quality can be found on the website: www.nabcop.org.uk.

Recommendations for NHS organisations submitting data to the NCRAS and Canisc

NHS organisations must ensure that the following information is uploaded to the national cancer registration services:

- tumour size consistent with the entered T stage
- N stage, M stage
- ER and HER2 status for invasive breast cancer
- WHO performance status.

NHS organisations should identify a clinician responsible for reviewing and checking their units' data returns.

² N stage completeness based on reported N stage, augmented with details from reported number of malignant nodes and determined to be N0 where nodal stage still missing but the reported diagnosis code is DCIS.

Table 3.1: Availability of core data items for women diagnosed in 2017; total availability and breakdown by country of diagnosis

Data item	Total % available	Availability of data item by country of diagnosis			
		England (trusts)		Wales (local health boards)	
		% available (all)	No. > 80% ^a	% available (all)	No. > 80% ^a
All tumours					
Laterality	100%	100%	124	100%	6
Clinical nurse specialist contact	74%	76%	83	56%	0
WHO performance status ^b	50%	53%	38	1%	0
Non-invasive tumours					
Grade	97%	97%	118	99%	6
ER status	32%	30%	24	63%	1
Non-invasive tumour size	14%	10%	6	75%	3
HER2 status	9%	6%	5	51%	1
Invasive tumours					
Grade	100%	100%	124	99%	6
Tumour stage	94%	95%	124	82%	5
Nodal stage	94%	94%	124	100%	6
Metastasis stage ^c	94%	95%	123	82%	5
Overall stage	93%	94%	123	74%	2
ER status	91%	91%	107	94%	6
HER2 status	85%	85%	92	89%	6
Whole tumour size	79%	80%	62	63%	1
PR status	58%	58%	54	57%	2
<p>Note: Data items are ordered within sections based on total % available (highest % to lowest %).</p> <p>^a No. of organisations with more than 80% of women having these data.</p> <p>^b WHO performance status reported within two months of diagnosis and prior to primary treatment starting.</p> <p>^c A recording of Mx is interpreted as intentionally unmeasured and not counted as missing.</p>					

4. Patient characteristics

4.1 The NABCOP population

Figure 4.1 describes how the cohort of patients in the datasets provided by the English and Welsh cancer registries were prepared for analysis. The cohort describes the patient group for the four years from 2014 to 2017. The report describes the care received by patients with unilateral breast cancer who were diagnosed and treated within active NHS organisations. We therefore excluded a minority of records that related to women who died without receiving treatment for their cancer, had bilateral breast cancer or could not be allocated to an NHS hospital with an active breast cancer unit.

Figure 4.2 shows numbers of women aged 50 years and over who were diagnosed in England and Wales in 2017. The pattern across the ages is similar to that presented in the 2018 Annual Report which included women diagnosed from 2014–2016.

Numbers of women diagnosed were highest among women aged 65–69 years, after which they fall among women of increasing age (reflecting the age structure of the general population). The peak at 65–69 years is related to the age range covered by the breast cancer screening programme during these years, the number of women in the general population in that age group and the increased incidence of breast cancer with age.

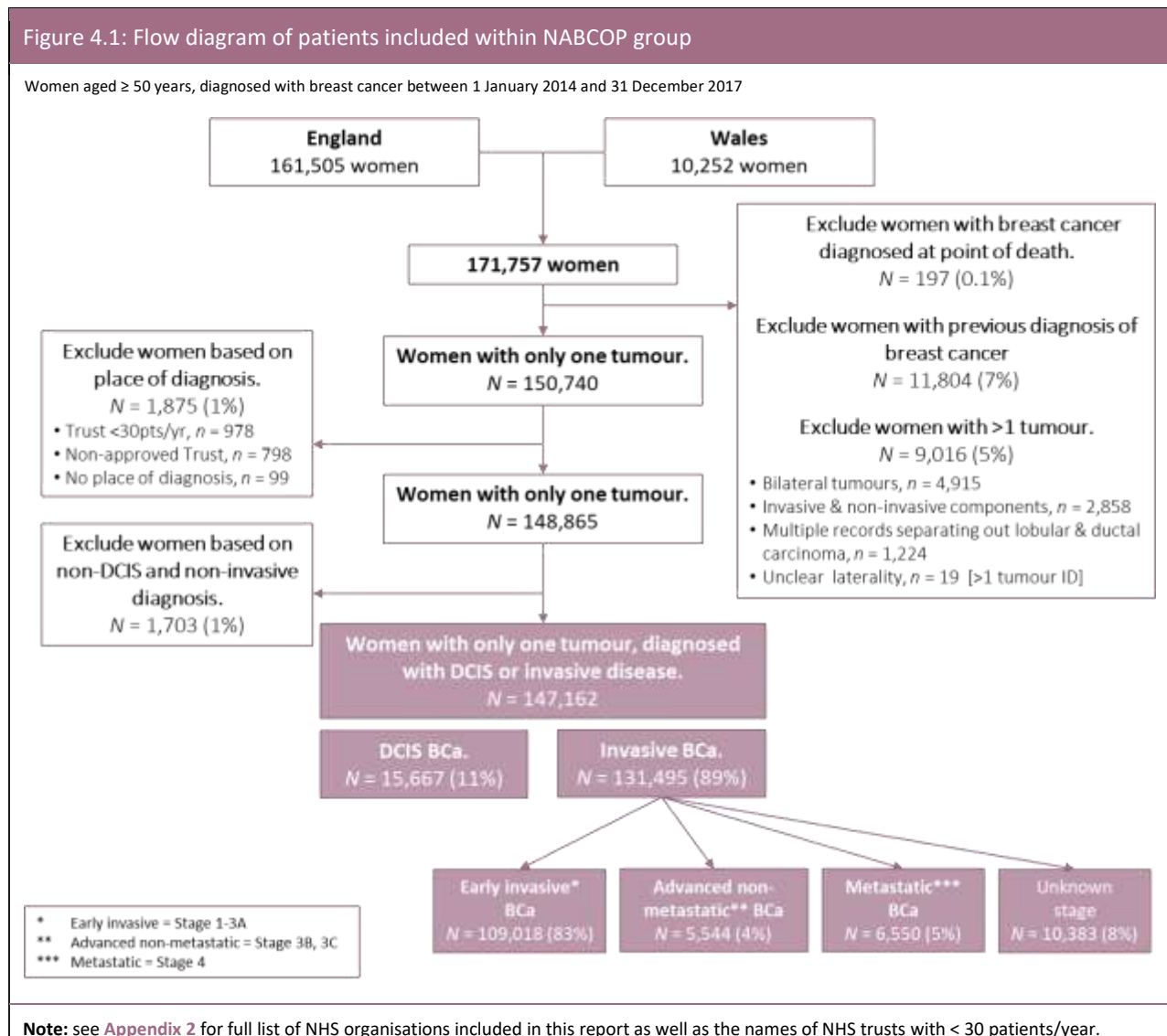
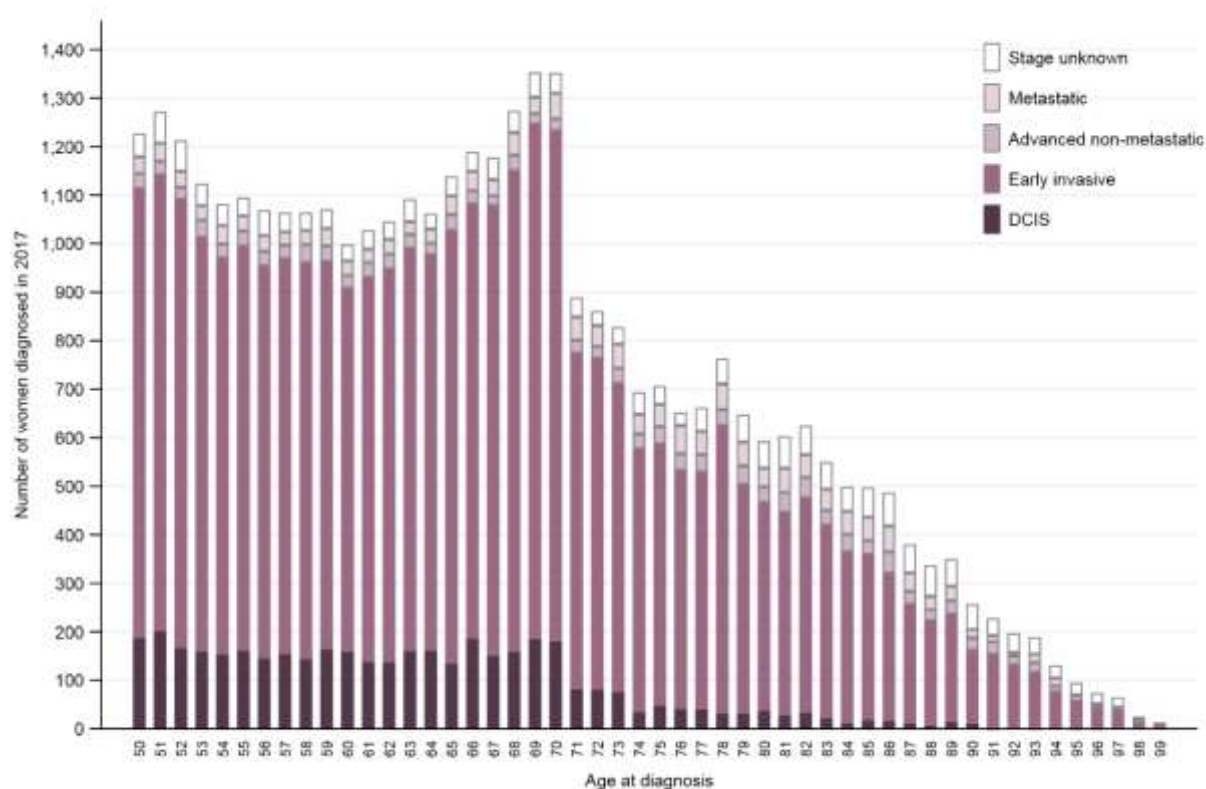


Figure 4.2: (Absolute) number of women diagnosed with breast cancer in England and Wales, by age at diagnosis – women diagnosed in 2017 only



Note: The peak among women aged 68–70 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 four-year period is provided in **Table 4.1**, broken down by age and breast cancer group. In total, there were 147,162 women newly diagnosed with unilateral breast cancer between 2014 and 2017; of these, 61% were aged 50–69 years, while 39% were aged 70+ years.

Among women aged 50–69 years, 14% were diagnosed with DCIS. This decreased to less than 5% among women aged 85 years or older (6% aged 70+ years). Older women were more likely to be diagnosed with advanced stage (stages 3B–4), accounting for 12% of women aged 70+ years compared with 6% of women aged 50–69 years. This difference may be related to the reduced influence of breast screening on stage at diagnosis in women under 70 years of age.

Among women diagnosed with DCIS, there was little difference in the tumour characteristics of women aged 50–69 years compared with those aged 70+ years.

Of all women aged 50–69 years, 76% were diagnosed with early invasive breast cancer, compared with 71% of women aged 70+ years. 3% of women aged 50–69 years presented with metastatic breast cancer compared with 7% of women aged 70+ years.

The key features of invasive breast cancer among women aged 70+ years compared with those aged 50–69 years are as follows:

- A lower percentage of older women had breast tumours less than 2cm in size and more had tumours 2–5cm in size.
- As the stage increased from early invasive (stages 1–3A) to metastatic (stage 4), higher percentages of younger women had grade 3 breast cancer compared with older women.
- Similar percentages of women had ER-positive and/or HER2-positive breast cancer.
- More women aged 70+ years at diagnosis were recorded as having one or more comorbid conditions or as being frail, regardless of breast cancer group.

Table 4.1: Patient and tumour characteristics for women aged 50 years and over diagnosed with breast cancer between January 2014 and December 2017, split by breast cancer group and age at diagnosis

Characteristic at diagnosis	DCIS (n = 15,667)		Early invasive (n = 109,018)		Advanced non-metastatic (n = 5544)		Metastatic (n = 6550)		Unknown stage ^a (n = 10,383)	
	50–69 years	70+ years	50–69 years	70+ years	50–69 years	70+ years	50–69 years	70+ years	50–69 years	70+ years
Number of women	12482 (80%)	3185 (20%)	68613 (63%)	40405 (37%)	2333 (42%)	3211 (58%)	2683 (41%)	3867 (59%)	4087 (39%)	6296 (61%)
% screen detected cancer	10449 (84%)	1598 (50%)	40017 (58%)	8017 (20%)	459 (20%)	93 (3%)	337 (13%)	66 (2%)	1851 (45%)	442 (7%)
Year of diagnosis – number of women diagnosed										
2014	3107	771	16633	9930	600	817	646	966	1327	2135
2015	2982	817	17162	10127	570	793	696	958	979	1555
2016	3190	734	17508	9990	586	830	677	946	894	1312
2017	3203	863	17310	10358	577	771	664	997	887	1294
Grade of disease – DCIS Invasive										
% with grade reported	95%	89%	100%	100%	100%	100%	100%	100%	96%	97%
Low 1	9%	13%	19%	14%	3%	5%	4%	5%	14%	11%
Intermediate 2	27%	33%	53%	58%	48%	49%	47%	46%	46%	50%
High 3	64%	54%	27%	26%	47%	40%	38%	30%	28%	19%
Not assessable	0%	0%	1%	2%	3%	7%	11%	19%	11%	20%
Tumour size (cm)										
% with tumour size reported	24%	22%	87%	80%	64%	52%	34%	31%	42%	28%
> 0.1 to 2	53%	52%	65%	50%	17%	11%	21%	17%	46%	31%
> 2 to 5	35%	37%	31%	46%	51%	56%	53%	60%	39%	54%
> 5	12%	12%	4%	4%	32%	33%	25%	24%	15%	15%
Lymph node involvement where nodes resected										
% with nodes examined	22%	22%	84%	65%	59%	39%	20%	11%	40%	15%
Number of malignant lymph nodes (if examined)										
% with malignant nodes reported	N/A	N/A	100%	100%	88%	92%	N/A	N/A	99%	99%
0 malignant nodes	N/A	N/A	75%	72%	6%	10%	N/A	N/A	32%	32%
1–3 malignant nodes	N/A	N/A	21%	23%	11%	16%	N/A	N/A	54%	49%
4–9 malignant nodes	N/A	N/A	4%	5%	8%	10%	N/A	N/A	13%	18%
10+ malignant nodes	N/A	N/A	0%	0%	75%	64%	N/A	N/A	1%	1%

Characteristic at diagnosis	DCIS (n = 15,667)		Early invasive (n = 109,018)		Advanced non-metastatic (n = 5544)		Metastatic (n = 6550)		Unknown stage ^a (n = 10,383)	
	50–69 years	70+ years	50–69 years	70+ years	50–69 years	70+ years	50–69 years	70+ years	50–69 years	70+ years
ER status										
<i>% with ER status reported</i>	27%	33%	91%	89%	88%	85%	77%	72%	73%	69%
Positive	80%	83%	87%	87%	75%	76%	78%	79%	84%	88%
Negative	20%	17%	13%	13%	25%	24%	21%	21%	16%	12%
HER2 status										
<i>% with HER2 status reported</i>	4%	5%	89%	81%	88%	76%	74%	64%	69%	58%
Positive	34%	15%	12%	10%	24%	18%	24%	17%	18%	11%
Negative	57%	77%	81%	83%	70%	73%	69%	75%	77%	82%
Borderline	9%	7%	7%	7%	6%	9%	7%	8%	5%	7%
WHO performance status^b										
<i>% with WHO PS reported</i>	30%	29%	39%	37%	48%	39%	47%	33%	21%	19%
0	92%	71%	89%	58%	80%	41%	59%	32%	83%	32%
1	7%	18%	9%	24%	15%	28%	23%	28%	10%	21%
2+	1%	11%	2%	18%	5%	32%	18%	40%	7%	47%
Charlson Comorbidity Index (CCI)										
<i>% with CCI calculated</i>	92%	93%	94%	93%	95%	89%	92%	92%	83%	85%
0	90%	77%	91%	75%	90%	70%	81%	59%	87%	54%
1	8%	16%	7%	15%	7%	16%	13%	22%	9%	21%
2+	2%	7%	2%	11%	3%	14%	5%	19%	4%	25%
electronic Frailty Index (eFI)										
<i>% with eFI calculated</i>	92%	93%	94%	93%	95%	89%	92%	92%	83%	85%
Fit	80%	57%	83%	58%	82%	53%	63%	36%	78%	37%
Mild-moderate frailty	15%	24%	13%	19%	13%	17%	25%	23%	13%	17%
Severe frailty	4%	19%	4%	23%	6%	30%	12%	41%	8%	46%

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

Figure 4.3 provides more detail on the change in breast cancer severity by age. 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 70–89 years at diagnosis, the percentage of stage 1 cancers decreased with age, with the percentage of stage 2 cancers increasing. There was a small increase in the percentage of women with metastatic breast cancer (stage 4).

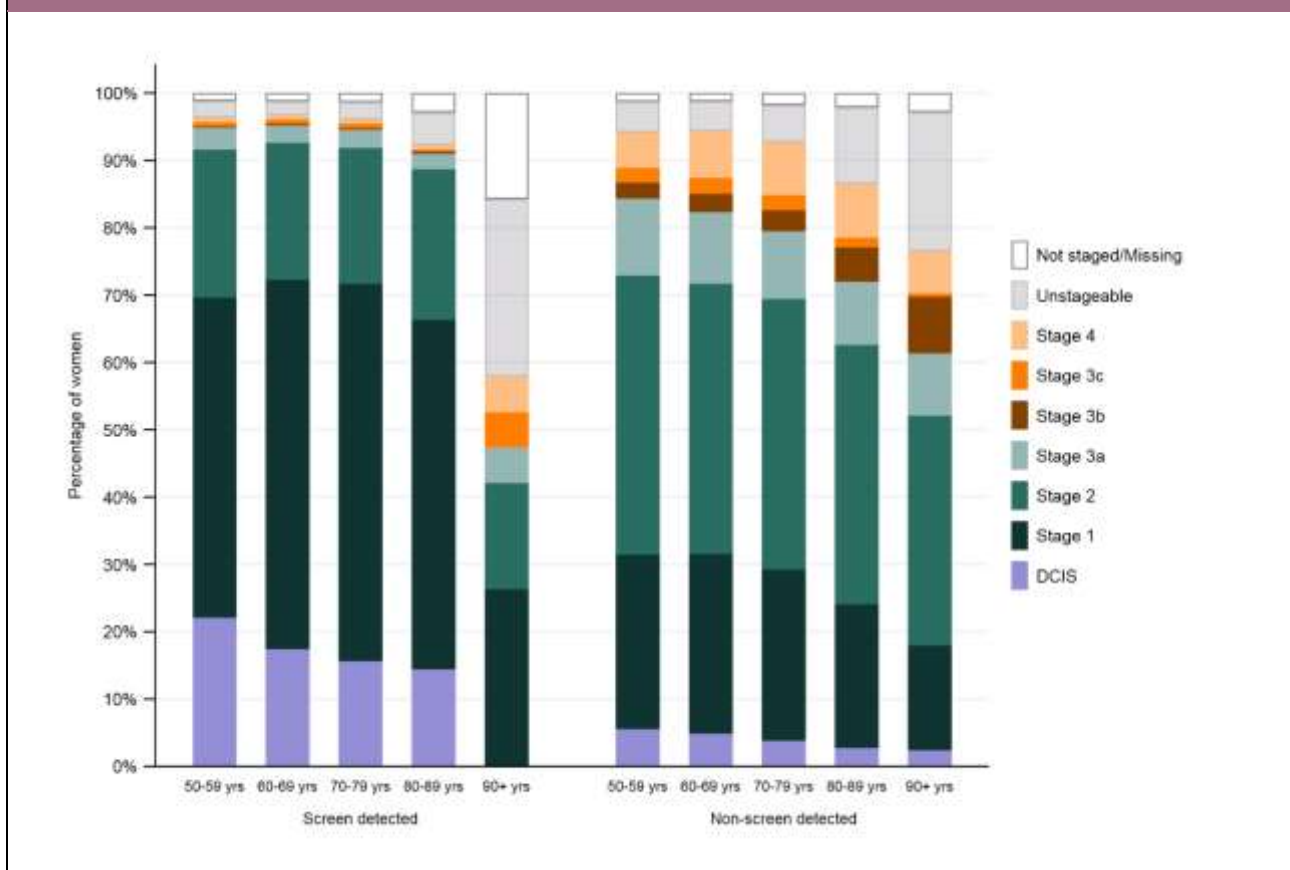
The other noticeable feature in **Figure 4.3** is the percentage of women with breast cancer reported as ‘unstageable’, which increases with age. This rises from 5% among women aged 50–69 years to more

than 20% among women over 95 years. There are various possible reasons for this:

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

In relation to the second point, we observed that, among women aged 50–69 years, the percentage of women with staging information did not substantially differ for women whose pathway to diagnosis was screening (96%) compared with those diagnosed with non-screen detected breast cancer (94%).

Figure 4.3: Distribution of breast cancer severity (overall stage) by method of presentation and age at diagnosis



4.2 Recorded molecular marker status

Determining treatment plans for patients and the delivery of primary systemic or adjuvant treatment requires details 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 as well as information on cancer stage [NICE 2018]:

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

What do we see within this audit group?

For women diagnosed with invasive breast cancer in 2017, the overall percentage of women with ER and HER2 status was 91% and 85% respectively.

The completeness of reporting is less in older women and there was a steeper fall-off for HER2 status reports:

- In England, ER status completion fell from 92% (women aged 50–59 years) to 78% (women aged 90+ years); while HER2 status completion fell from 88% (women aged 50–59 years) to 62% (women aged 90+ years).
- In Wales, ER status completion fell from 94% (women aged 50–59 years) to 91% (women aged 90+ years); while HER2 status completion fell from 89% (women aged 50–59 years) to 74% (women aged 90+ years).

These patterns are similar to those presented in the NABCOP 2018 Annual Report.

Recommendations for NHS organisations submitting data to the NCRAS and Canisc

- In line with NICE guidance, full tumour characterisation, including assessment of ER and HER2 status should be carried out for all patients with invasive breast cancer and recorded at multidisciplinary team meetings.

Numerator	1. Women with ER status recorded 2. Women with HER2 status recorded
Denominator	Women diagnosed with invasive breast cancer
Country	England & Wales
Time frame	Women diagnosed in 2017

5. Diagnosis and supportive care

This chapter focuses on those elements of diagnosis which illustrate the care pathway and supportive care received for women diagnosed with breast cancer. It covers the route by which a woman presents with breast cancer, how it is then diagnosed and whether there is contact with a breast clinical nurse specialist.

5.1 Route to diagnosis

Numerator	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	
Time frame	Women diagnosed in 2017	

Patients typically present with suspected breast cancer to a breast clinic, within an NHS trust in England or local health boards in Wales, through 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 50–70 years to undergo a mammogram assessment every three years (women aged 47–73 years are eligible in some regions of England as part of the AgeX trial³); or
3. referral after a clinical assessment and/or investigation performed for another disease (e.g. computerised tomography) has identified a potential breast cancer.

Less commonly, diagnosis may be after an emergency presentation.

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].

What do we see within this audit group?

As shown in **Table 5.1**:

- 47% present via GP
- 43% present from screening
- 5% present from other specialties
- 1% diagnosed after emergency presentation

There was variation in routes when looking across NHS organisations (**Figure 5.1**), although emergency presentation was low in all. These patterns are similar to those presented in the NABCOP 2018 Annual Report.

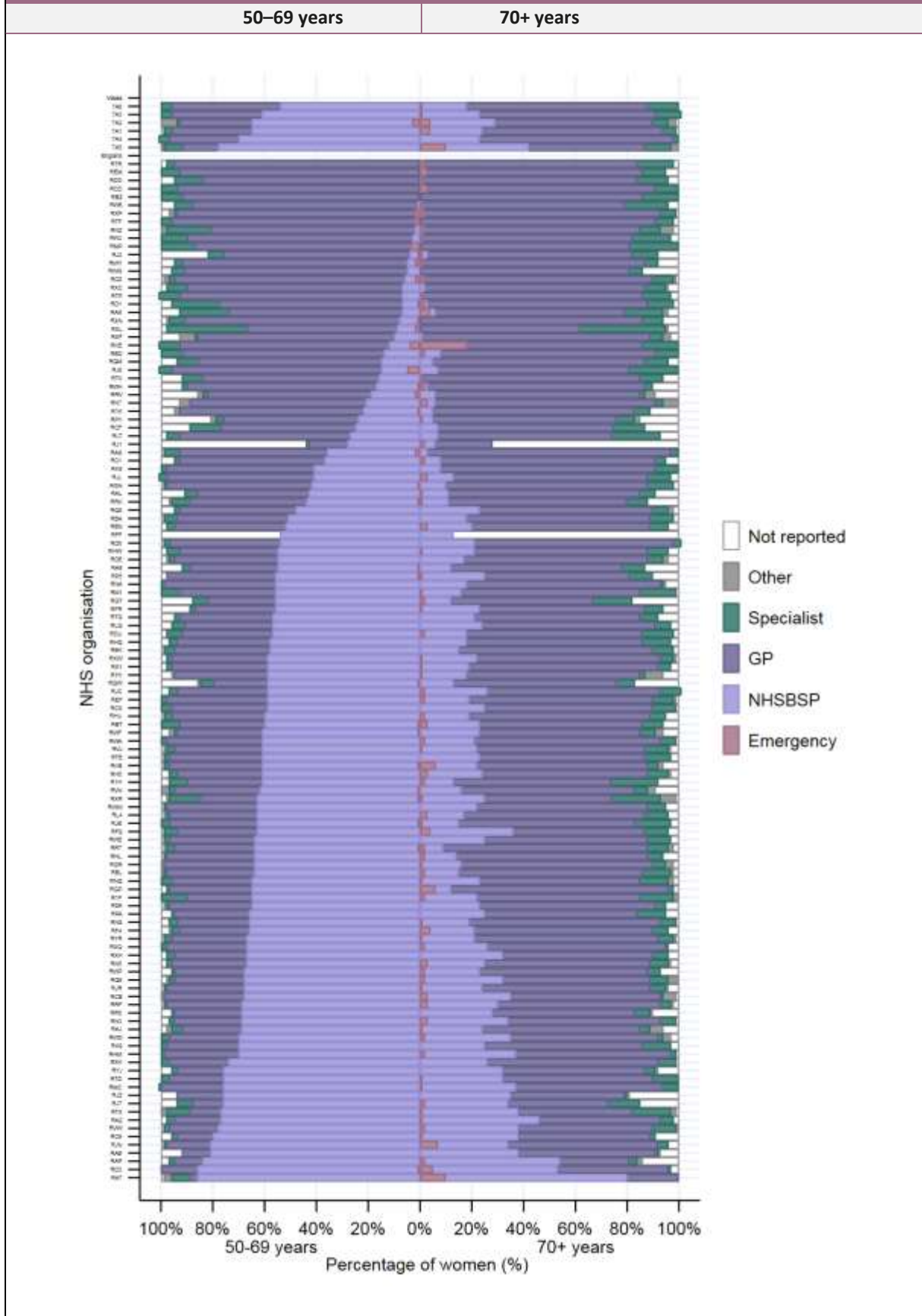
Table 5.1: Route to diagnosis by age at diagnosis

Reported route to diagnosis	50–69 years	70+ years	Overall
Referral from GP	34%	67%	47%
NHS screening programme	59%	19%	43%
Referral from other specialties	3%	8%	5%
After emergency presentation	0.3%	1%	0.7%
Other	0.4%	0.8%	0.6%
<i>Unreported</i>	3%	5%	4%

Note: Among 464 women with multiple referral sources reported for the same date: 54% were reported to have screen detected cancer and so are included within 'NHS screening programme' in the table above; the remaining 46% were not included in the table above.

³ NHS Breast Screening Programme. AgeX Trial: <http://www.agex.uk>

Figure 5.1: Referral route to diagnosis by diagnosing NHS organisation and age at diagnosis



5.2 Triple diagnostic assessment in a single visit

What is the evidence base for this process?

Performance of triple 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 visit clinic. 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 – ultrasound of the symptomatic breast area or mammography abnormality. A mammogram (for patients aged over 40 years and not referred through the NHS Breast Screening Programme; screened patients will have already had imaging). The axilla may also be imaged.
- Histopathology assessment – tissue biopsies are obtained from areas in the breast (\pm 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 2002]

Numerator	Women receiving triple diagnostic assessment in a single visit
Denominator	Women with non-screen detected early invasive breast cancer
Country	England & Wales
Time frame	Women diagnosed in 2017

This indicator describes the percentages 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 at the time of screening. Such women are therefore not included within this assessment of performance.

What do we see within this audit group?

Overall, 67% of women were estimated as having received triple diagnostic assessment in a single visit. There was no difference by age at diagnosis (67% for 50–69 years; 68% for 70+ years).

- Of these, 37% were based on matching mammogram and biopsy dates.
- Of these, 63% were based on matching first seen and biopsy dates.

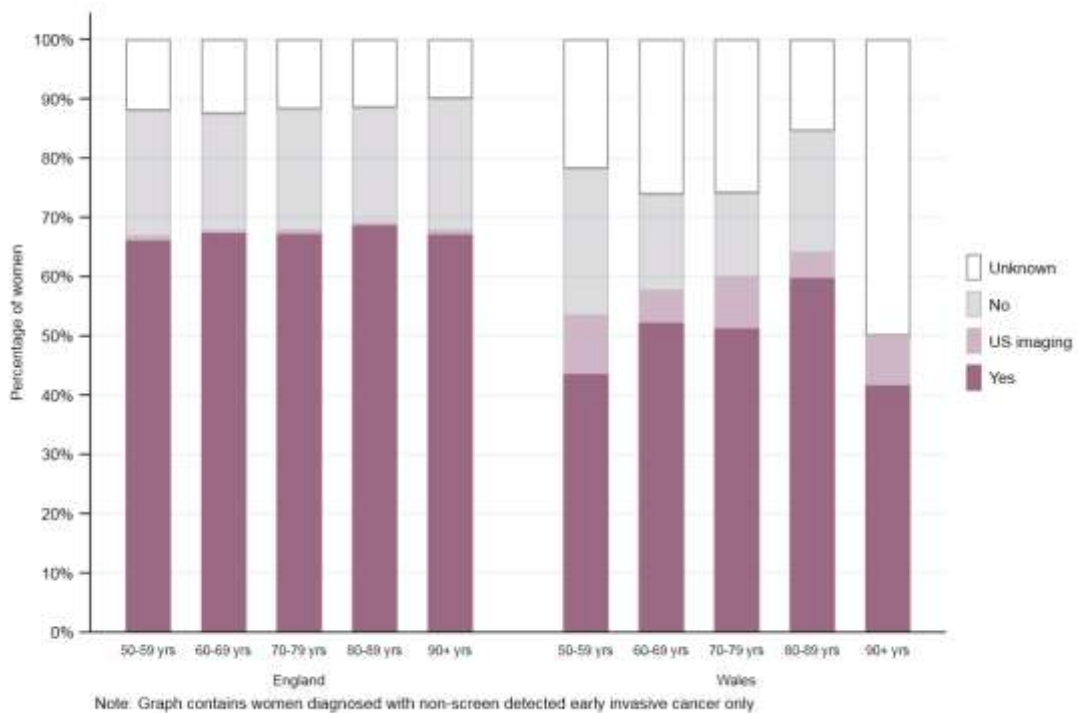
There was a difference according to country of diagnosis, with 50% of women with non-screen detected cancer diagnosed within Wales estimated as receiving triple diagnostic assessment in a single visit compared with 67% in England (Figure 5.2).

There was variation by NHS organisation (Figure 5.3).

12% of women were missing a mammogram and/or biopsy date. Among these, three in four women were missing a biopsy date.

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 increases to 81% (81% for 50–69 years; 82% for 70+ years).

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



Key: US imaging = ultrasound imaging; the 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 5.3 shows the percentage of women calculated as receiving a triple diagnostic assessment in a single visit, for each diagnosing NHS organisation, split by age at diagnosis.

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 this group are being managed correctly, but we cannot label these women as receiving triple diagnostic assessment in a single visit.

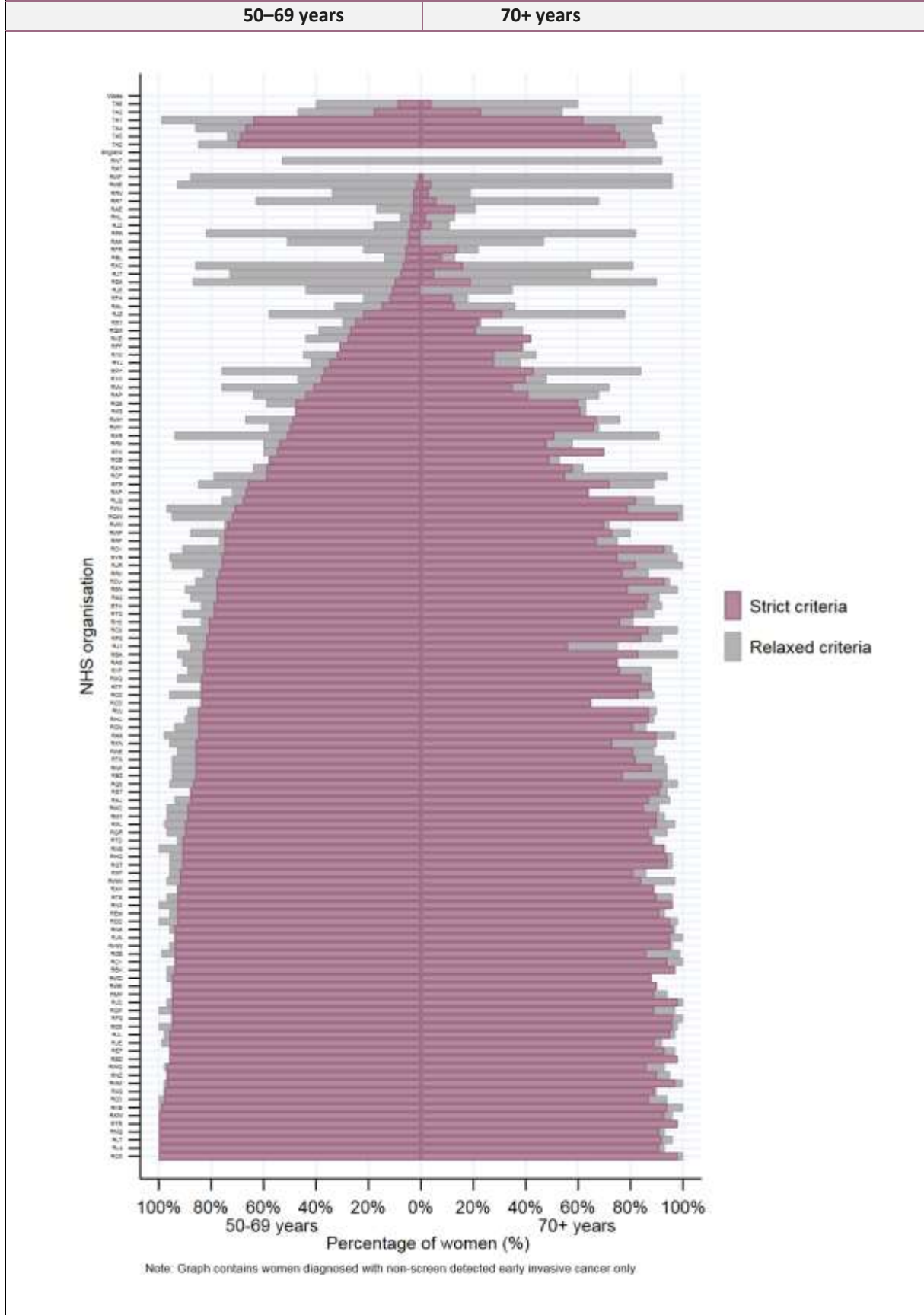
Unfortunately, there is no other national source of information on how well breast cancer units are providing triple assessment against which our results can be compared. The provision of timely triple assessment is a basic tenet of breast cancer care and compliance should be accurately recorded.

Recommendations

NHS organisations must ensure that:

- women are able to receive triple assessment at their initial clinic visit after referral for suspected breast cancer, in line with NICE recommendations
- dates of assessment for all investigations performed at a triple assessment clinic are submitted to the national cancer registration services.

Figure 5.3: Percentage of women receiving triple diagnostic assessment in a single visit, by diagnosing NHS organisation and age at diagnosis



5.3 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	Women seen by a breast clinical nurse specialist/named key worker
Denominator	All women
Time frame	Women diagnosed in 2017

What do we see within this audit group?

- Data on clinical nurse specialist contact were reported for 74% of women aged 50 years and over who were diagnosed in 2017 (75% for 50–69 years; 74% for 70+ years).
- 56% of women diagnosed in Wales had data on clinical nurse specialist contact compared with 76% for women diagnosed in England (an improvement on the 68% reported for women diagnosed between 2014 and 2016, in England, reported in the 2018 annual report).
- Among women for whom data exist, 95% had contact with a clinical nurse specialist (96% for 50–69 years; 94% for 70+ years); 98% of women diagnosed within Wales had contact with a clinical nurse specialist compared with 95% in England (**Figure 5.4**).
- There was variation across NHS organisations in the completeness of these data (**Figure 5.5**).
- The missing data limit the audit’s ability to evaluate conclusively how well NHS organisations are performing against this measure.

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

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

- 95% 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, 78% of respondents said that it had been ‘quite easy’ or ‘very easy’ to do so. This was comparable across the age groups.

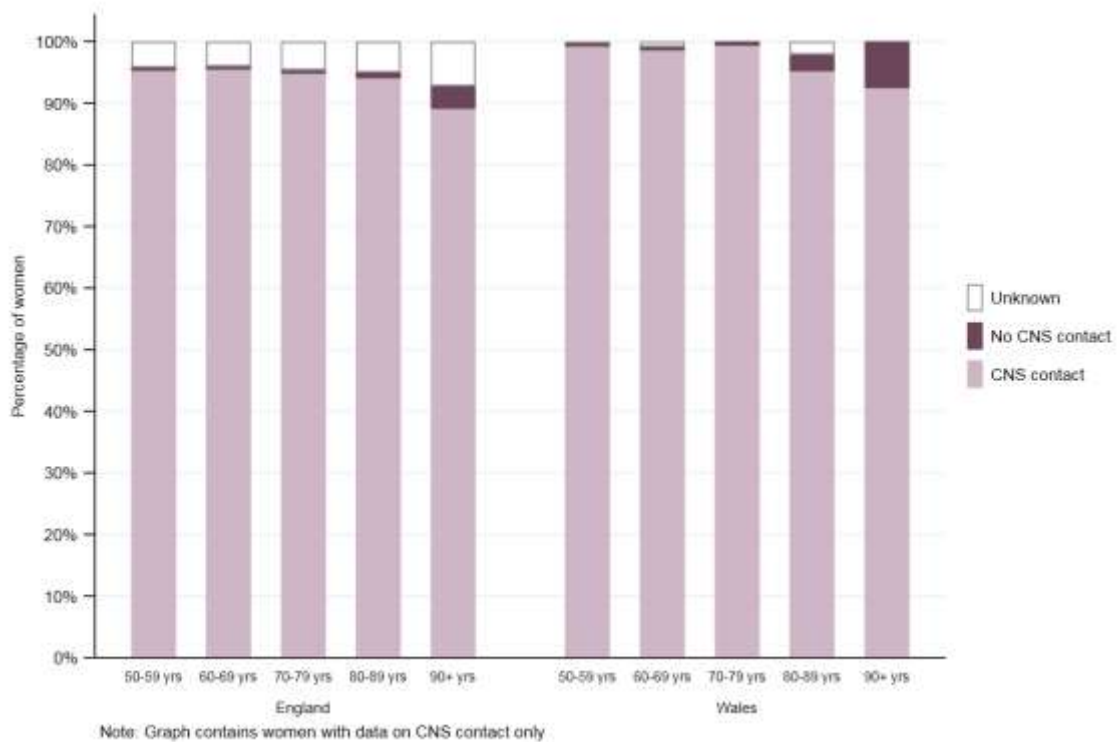
The information from women diagnosed in 2017 and the results of the English CPES suggest that, overall, NHS breast cancer units are performing well on this indicator.

Recommendations

NHS organisations must ensure that:

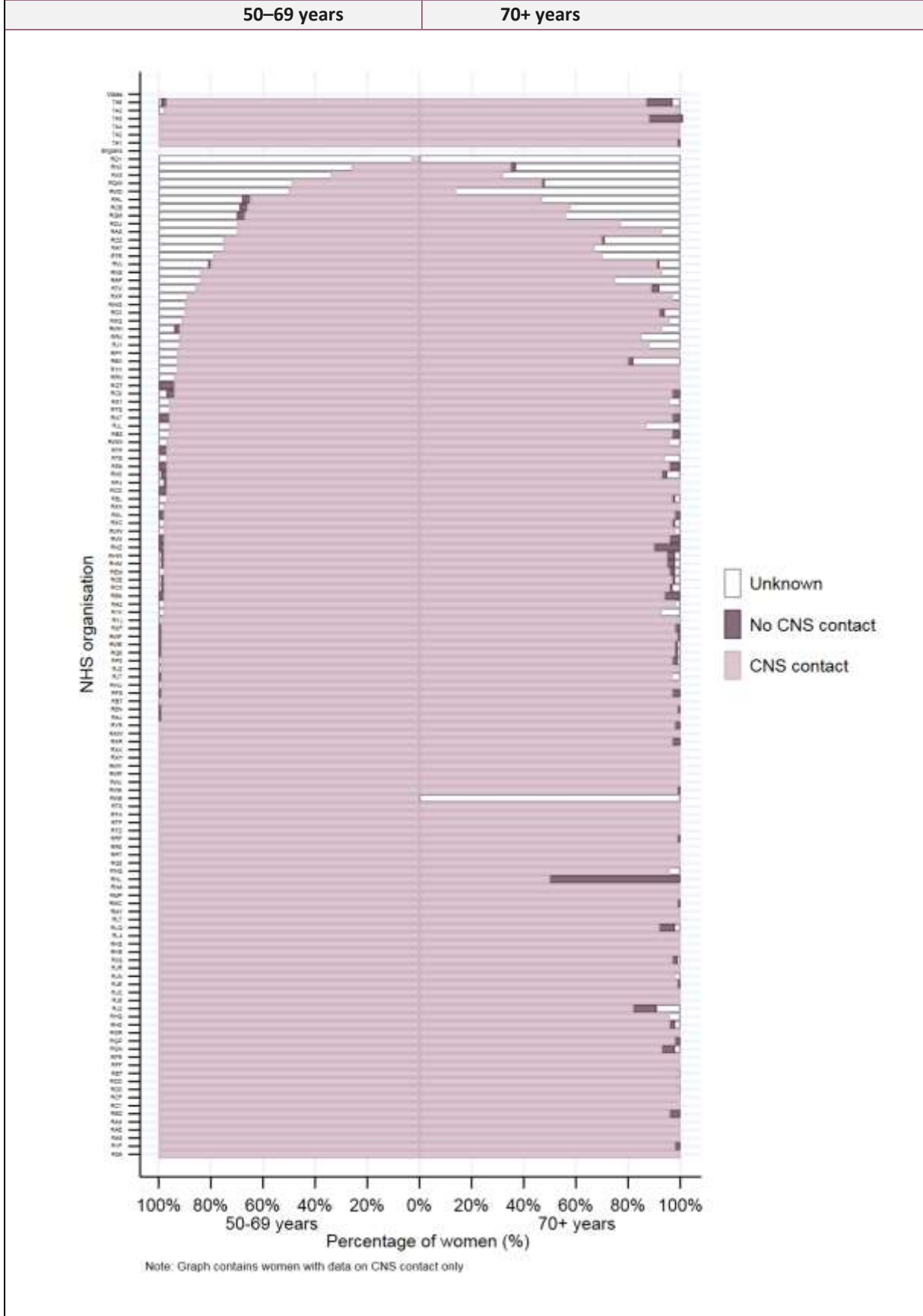
- women are assigned a named breast clinical nurse specialist to provide information and support
- data on the assignment of a named breast clinical nurse specialist are submitted to the national cancer registration services.

Figure 5.4: Percentage of women in contact with a breast clinical nurse specialist, by country of diagnosis and age at diagnosis



CNS = clinical nurse specialist.

Figure 5.5: Percentage of women in contact with a breast clinical nurse specialist, by diagnosing NHS organisation and age at diagnosis



Note: Graph contains women with data on CNS contact only.

CNS = clinical nurse specialist.

6. Ductal carcinoma in situ

6.1 Treatment for ductal carcinoma in situ

What does the guidance say?

Surgical resection is the most important treatment for DCIS, and women may have either a mastectomy or breast conserving surgery. For women who have such 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 breast cancer 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 trial-based evidence to support DCIS treatment decisions in older women [Biganzoli *et al* 2012].

Numerator	Women who had mastectomy or breast conserving surgery
Denominator	Women diagnosed with DCIS
Country	England & Wales
Time frame	Women diagnosed from 2014–17

Overall, 15,667 (11%) women presented with DCIS, across the four-year period (14,518 in England; 1149 in Wales). DCIS is typically diagnosed among women aged between 50 and 70 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. Women aged 70+ years diagnosed with DCIS are currently less likely to be screen detected (84% for women aged 50–69 years; 50% for women aged 70+ years).

What do we see in this patient group?

The percentage of women who receive surgery for DCIS is related to a woman's age at diagnosis. Specifically:

- 93% of women aged 50–69 years received surgery compared with 81% of women aged 70+ years.
- Across all age groups, women with low-grade DCIS were less likely to receive surgery compared with those with high-grade DCIS. However, the overall rate of surgery decreased with increasing age (Table 6.1).

There was wider variation in the rate of surgery in women aged 70+ years between NHS organisations in England and Wales in comparison with women aged 50–69 years (Figure 6.1).

Following breast conserving surgery, 60% of women underwent radiotherapy and the rate of receipt was similar across the audit years.

- 63% of women aged 50–69 years received adjuvant radiotherapy following breast conserving surgery, compared with 47% of women aged 70+ years.
- 83% of women aged 50–69 years with high-grade DCIS received adjuvant radiotherapy following breast conserving surgery compared with 69% of women aged 70+ years.

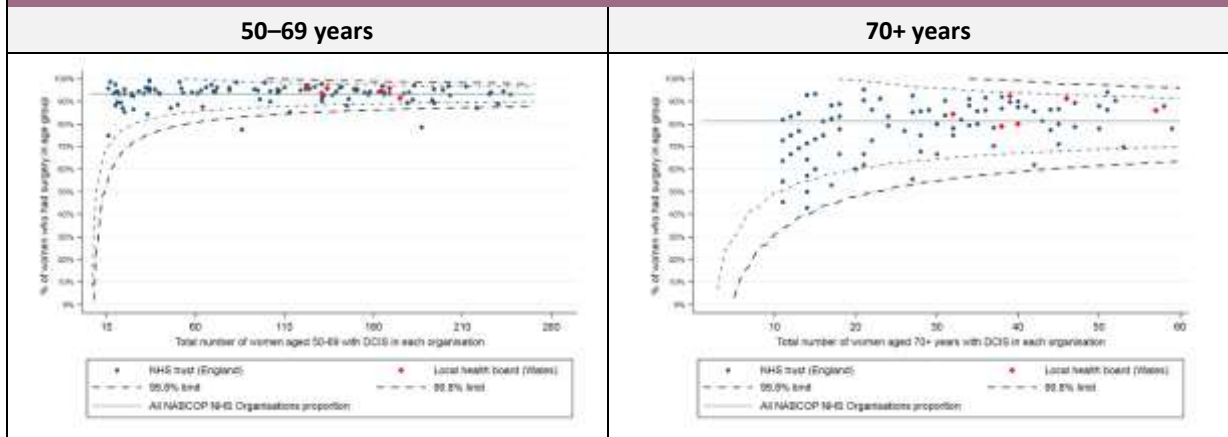
Overall, 1435/15,667 (9%) of women with DCIS did not receive surgical treatment. More than 60% of these women were alive three years following diagnosis (Figure 6.2). In the future, the NABCOP will aim to explore survival in more detail and describe the influence of patient and tumour characteristics on breast cancer specific and overall survival.

There has been minimal change to the rate of surgery in all age groups, across the four-year period described in this section. As shown in Figure 6.1, the rate of surgery is not associated with the number of women diagnosed with DCIS in each NHS organisation (unit volume).

Table 6.1: Impact of non-invasive grade on the likelihood of receiving surgery for DCIS, by age at diagnosis and method of presentation

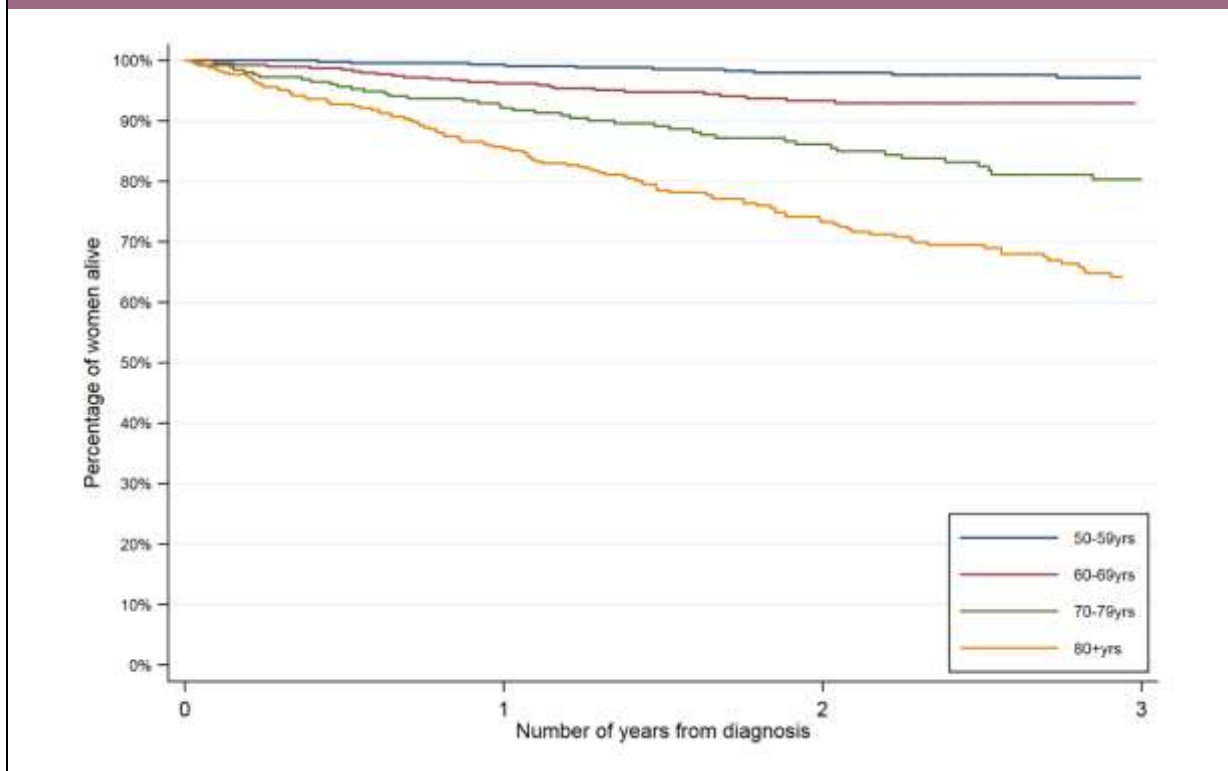
	Screen detected				Non-screen detected			
	50–69 years		70+ years		50–69 years		70+ years	
	Total no. of women	% having surgery	Total no. of women	% having surgery	Total no. of women	% having surgery	Total no. of women	% having surgery
All women	10347	95%	1590	94%	2135	86%	1595	69%
Non-invasive grade								
Low	807	86%	140	85%	294	74%	216	65%
Intermediate	2573	94%	432	93%	614	84%	518	71%
High	6508	96%	936	96%	1041	92%	596	78%
Unknown	459	89%	82	88%	186	76%	265	45%

Figure 6.1: 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 age, deprivation, method of presentation, electronic Frailty Index and Charlson Comorbidity Index.

Figure 6.2: Observed overall survival of women with DCIS who did not receive surgery, by age at diagnosis



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

- 81% 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.
- 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 comparable across the age groups.
- Among all the respondents who received radiotherapy, 60% completely agreed that they were given enough information about whether their treatment was working, in a way they could understand. Specifically, 77% of women aged 70+ years felt that they had been given enough information about the efficacy of their radiotherapy compared with 58% of women aged 50–69 years.
- On a scale of 0 (very poor) to 10 (very good), 95% of respondents gave their overall care a rating of 7 or higher. This was comparable across the age groups.

Recommendations

There is a lack of strong evidence concerning the management of DCIS in older women.

NHS organisations must ensure that:

- women are counselled appropriately about the gap in knowledge and guidelines and place emphasis on treating patients with DCIS using a risk-based, rather than age-stratified, approach (clinical research in this area should be prioritised)
- older women who undergo breast conserving surgery for high-risk DCIS, and have few comorbidities and frailty, are considered for radiotherapy
- women are given enough information about their radiotherapy. Clinical teams should ask for feedback from their patients, at regular intervals, to ensure that they have sufficient information and are engaged in a shared decision-making process.

7. Early invasive breast cancer

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

For purposes of reporting, women are described as having ‘no surgery’ if there was no surgical information in the audit datasets.

What is the evidence base for treatment decisions?

Women with ER-positive breast cancer are suitable for primary endocrine therapy but 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 was 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 benefit tends to be greater in younger patients. It is effective for patients with both ER-positive and -negative breast cancer. The absolute benefit may be less among patients with ER-positive breast cancer who also receive endocrine therapy. Among older patients, adjuvant chemotherapy is most commonly used in those with ER-negative breast cancer [Biganzoli *et al* 2012].

7.1 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	Women who had mastectomy or breast conserving surgery
Denominator	Women diagnosed with early invasive breast cancer
Country	England & Wales
Time frame	Women diagnosed from 2014–17

What do we see within this audit group?

There is variation with patient age in the percentage of women who receive surgery for early invasive breast cancer. Specifically:

- 95% (65,477 / 68,613) of women aged 50–69 years had surgery, compared with 74% (29,796 / 40,405) of women aged 70+ years (**Figure 7.1**)
- Women aged 70+ years with early invasive breast cancer were more likely to receive surgery for an ER-negative compared with ER-positive cancer (**Table 7.1**).
- The likelihood of surgery diminished as levels of fitness decreased and the size of the change was much larger for older women with ER-positive breast cancer (**Table 7.1**).
- Specifically, in women with no comorbidities (Charlson Comorbidity Index = 0) and ER-positive breast cancer, 97% of women aged 50–69 years receive surgery compared with 84% of women aged 70+ years (**Table 7.1**).
- There was variation across NHS organisations in the percentages of women aged 70+ years who received breast surgery for early invasive breast cancer (**Figure 7.2**).

Overall, 13% (13,745/109,018) of women with early invasive breast cancer did not receive surgical treatment. At three years from diagnosis:

- 50% of these women with ER-positive breast cancer, were alive (**Figure 7.3**)
- a lower percentage of women with ER-negative breast cancer were alive, irrespective of age (**Figure 7.3**).

In the future, the NABCOP will aim to explore survival in more detail and will describe the influence of patient and tumour characteristics on breast cancer specific and overall survival.

In total, there were 109, 018 women with early invasive breast cancer: 87% were ER-positive and 13% were ER-negative. There was no difference in the distribution of ER status between age groups (see **Chapter 4, Table 4.1**). The likelihood of primary surgery among women varied with different levels of fitness and ER status as shown in **Table 7.1**. For each variable, the percentage of women who had recorded surgery fell as levels of fitness decreased, although the size of the change was much larger for women aged 70+ years who had 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. The evidence base has shown this to be inferior to primary surgery for local disease control and survival (Ward *et al* 2018). 92% of women aged 70+ years who did not undergo surgery for ER-positive tumours were recorded to have primary endocrine therapy.

At all levels of fitness, women aged 70+ years with ER-negative breast cancer are more likely to receive surgery than women with ER-positive breast cancer (**Table 7.1**). The reason for the higher rate of surgery in this cohort may be because women who are ER-negative are not suitable for primary endocrine therapy.

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

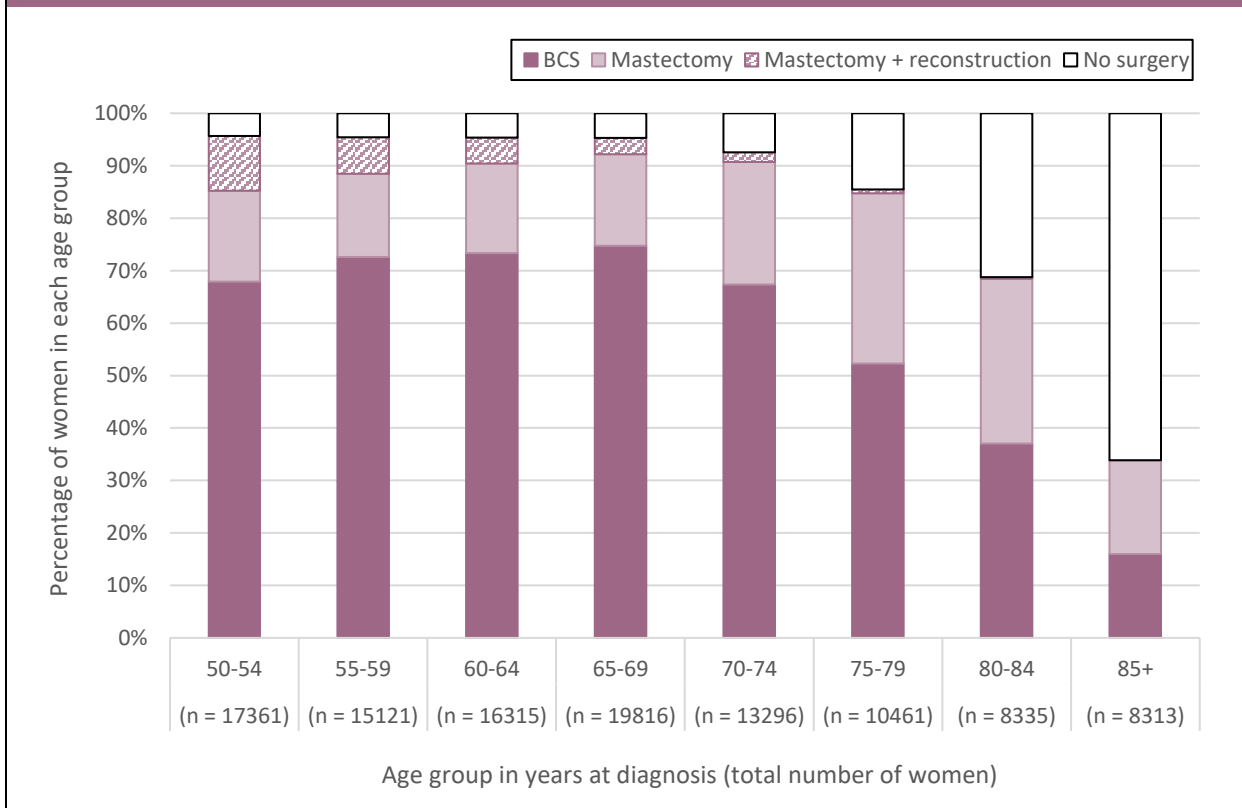
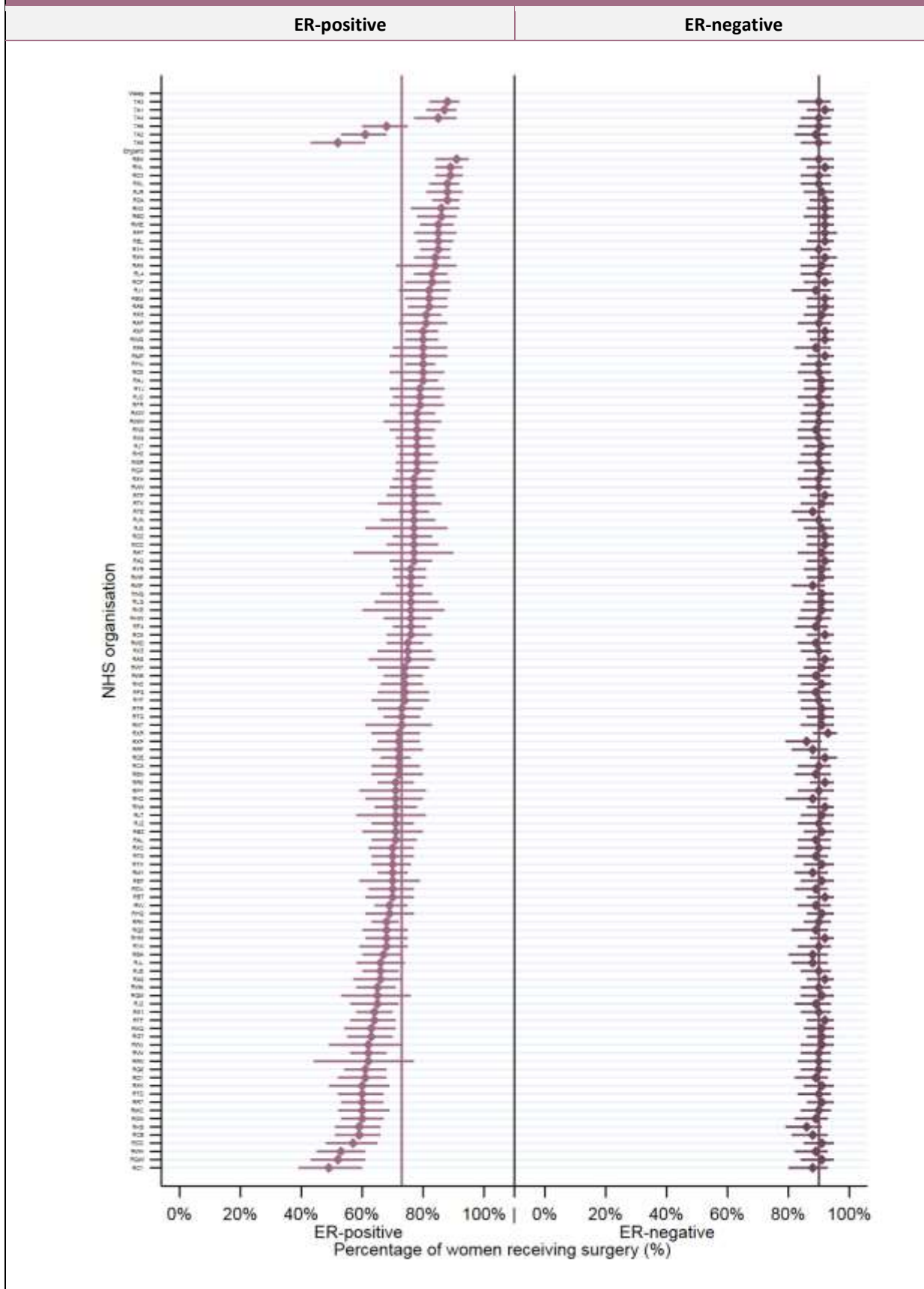


Table 7.1: Impact of patient fitness on the likelihood of receiving surgery for early invasive breast cancer, as measured by three different factors, by age at diagnosis and ER status

Measure of fitness	ER-positive				ER-negative			
	50-69 years		70+ years		50-69 years		70+ years	
	Total no. of women	% having surgery	Total no. of women	% having surgery	Total no. of women	% having surgery	Total no. of women	% having surgery
All women	54087	96%	31170	73%	8155	95%	4702	90%
Charlson Comorbidity Index								
0	46517	97%	21681	84%	7027	96%	3367	94%
1	3349	95%	4167	62%	508	94%	633	88%
2+	1028	87%	2969	38%	209	95%	457	77%
unknown	3193	82%	2353	38%	411	83%	245	69%
WHO performance status								
0	18727	96%	6814	87%	3253	95%	1043	95%
1	1741	94%	2794	71%	394	92%	466	94%
2+	423	77%	2021	29%	72	94%	324	74%
unknown	33196	96%	19541	73%	4436	90%	2869	63%
electronic Frailty Index								
Fit	42214	97%	16831	87%	6323	96%	2643	94%
Mild-moderate frailty	6448	96%	5594	79%	1032	96%	814	91%
Severe frailty	2232	90%	6392	46%	389	94%	1000	82%
unknown	3193	82%	2353	38%	411	83%	245	69%

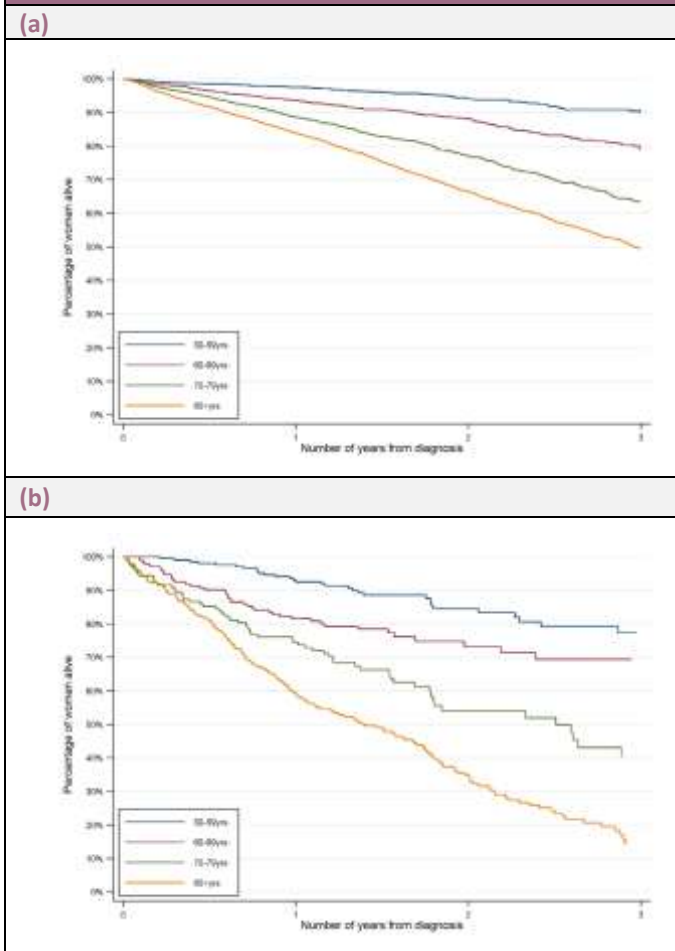
Note: This table does not include the 10,991 women with no recorded/unknown ER status

Figure 7.2: Risk-adjusted percentage (95% confidence interval) of women aged 70+ years receiving primary surgical treatment for early invasive breast cancer, by diagnosing NHS organisation and ER status



Note: Lines at 73% and 90% are the observed percentage of women aged 70+ years receiving surgery for ER-positive and -negative early invasive breast cancer, respectively. Risk-adjusted percentages and 95% confidence intervals are from random effects logistic regression model, adjusted for age, N stage, overall stage, invasive grade, ER status, HER2 status, deprivation, method of presentation, electronic Frailty Index and Charlson Comorbidity Index; NHS organisation included as a level.

Figure 7.3: Observed overall survival of women with (a) ER-positive and (b) ER-negative early invasive breast cancer who did not receive surgery, by age at diagnosis



Recommendations

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

NHS organisations must ensure that:

- there is consistent assessment and recording of comorbidity and frailty in breast clinics
- medical optimisation of women with ER-positive early invasive breast cancer is instituted to maximise potential for their suitability for surgery.

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

- Overall, 80% of respondents with more than one treatment option reported that, before their cancer treatment started, their options were explained to them completely (79% for 50–69 years; 82% for 70+ years).
 - Among women who did not have surgery, 73% of women aged 50–69 years reported that their options were explained to them completely, compared with 83% of women aged 70+ years.
 - Among those women who had surgery, there was no difference in response by age group or ER status.
- Overall, 82% of respondents reported that they were definitely involved as much as they wanted to be in decisions about their care and treatment (80% 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, 96% of women aged 50–69 years gave their overall care a rating of 7 or higher, compared with 88% of women aged 70+ years.
 - Among those women who had surgery, there was no difference in response by age group or ER status.

7.2 Radiotherapy treatment for early invasive breast cancer

Considering radiotherapy for women with early invasive breast cancer, we evaluated the use of adjuvant radiotherapy according to the primary surgical procedure. Specifically, postoperative radiotherapy is recommended for the great 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 high risk of recurrence.

What does the guidance say?

With regards to post-surgery treatment, 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. > 65 years, N0, ER+, G1/2) patients 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	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	
Time frame	Women diagnosed from 2014–17	

What do we see within this audit group?

Among women who had breast conserving surgery, 89% ($n = 58,745$) received postoperative radiotherapy.

Rates of radiotherapy varied by age (Figure 7.4), with lower reported use as age increased:

- 91% among women aged 50–69 years
- 84% among women aged 70+ years

This pattern changed little over the four-year period described in this section.

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

Rates of radiotherapy varied by age (Figures 7.4 and 7.5), with lower reported use as age increased:

- 67% among women aged 50–69 years
- 60% among women aged 70+ years

This pattern changed little over the four-year period described in this section.

There was variation by NHS organisation (Figure 7.6).

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

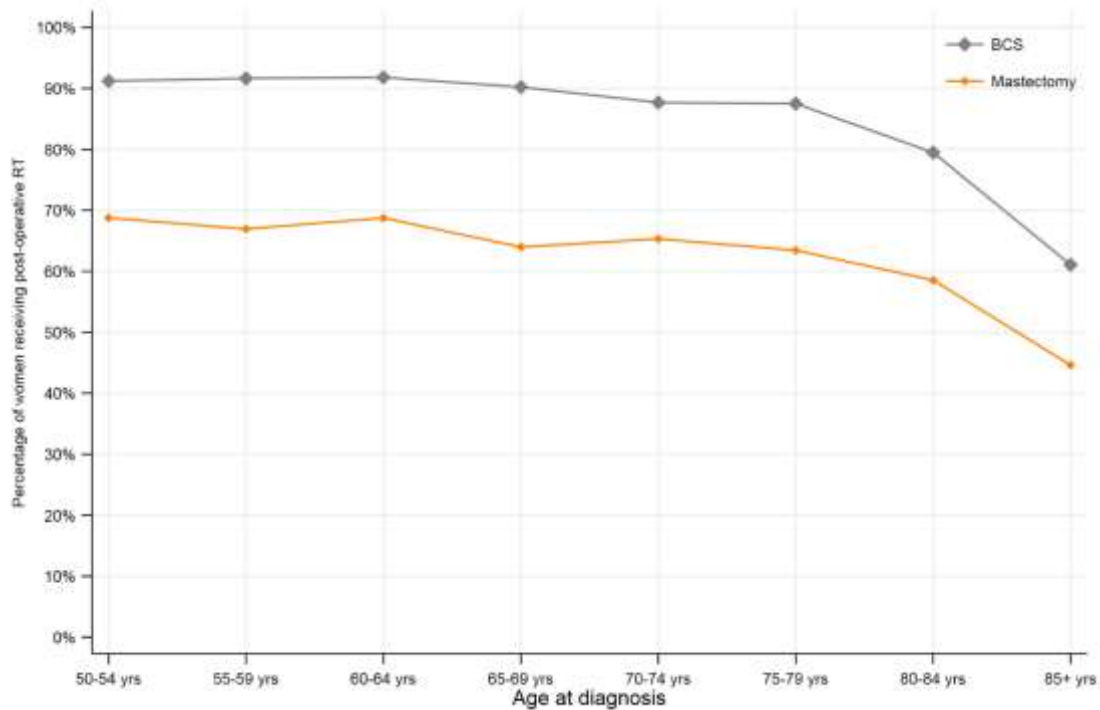
- 53% agreed completely that they were given enough information about whether their treatment was working in a way they could understand; this was comparable by age.

Recommendations

NHS organisations must ensure that:

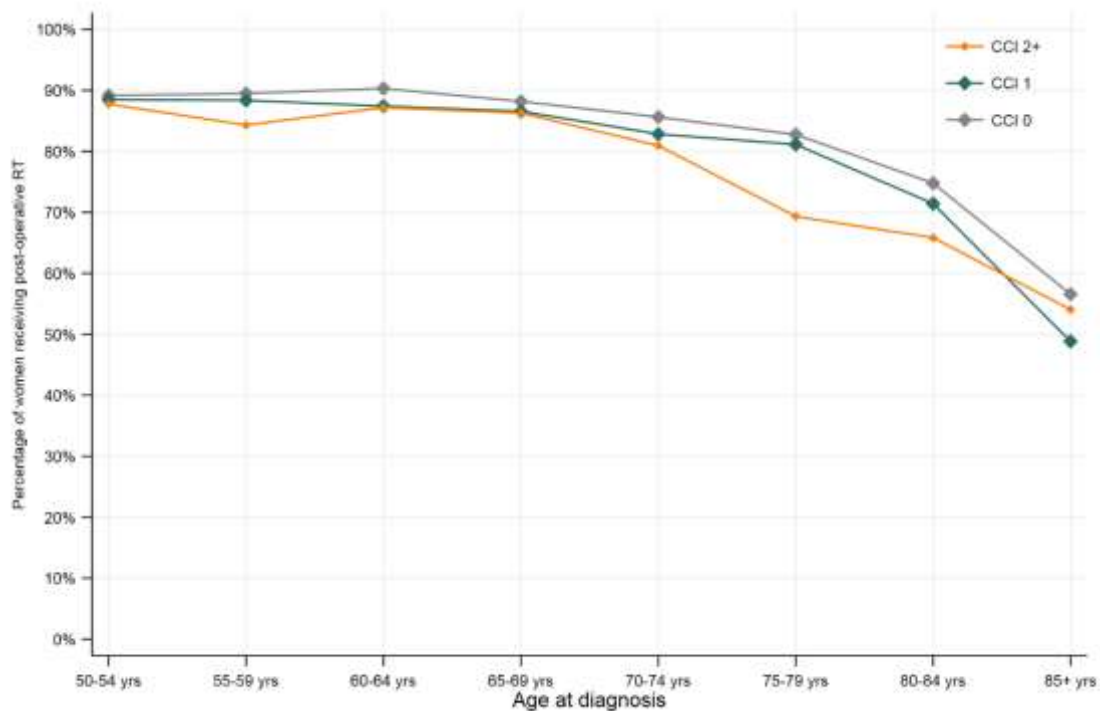
- women with high-risk early invasive breast cancer are counselled on the benefit and risk of adjuvant radiotherapy based on tumour characteristics and objective assessment of patient fitness, rather than chronological age alone
- women are given enough information about their radiotherapy treatment. Clinical teams should ask for feedback from their patients, at regular intervals, to ensure that they have sufficient information and are engaged in a shared decision-making process.

Figure 7.4: Observed percentage of women with early invasive breast cancer receiving radiotherapy, by type of primary surgery and age at diagnosis



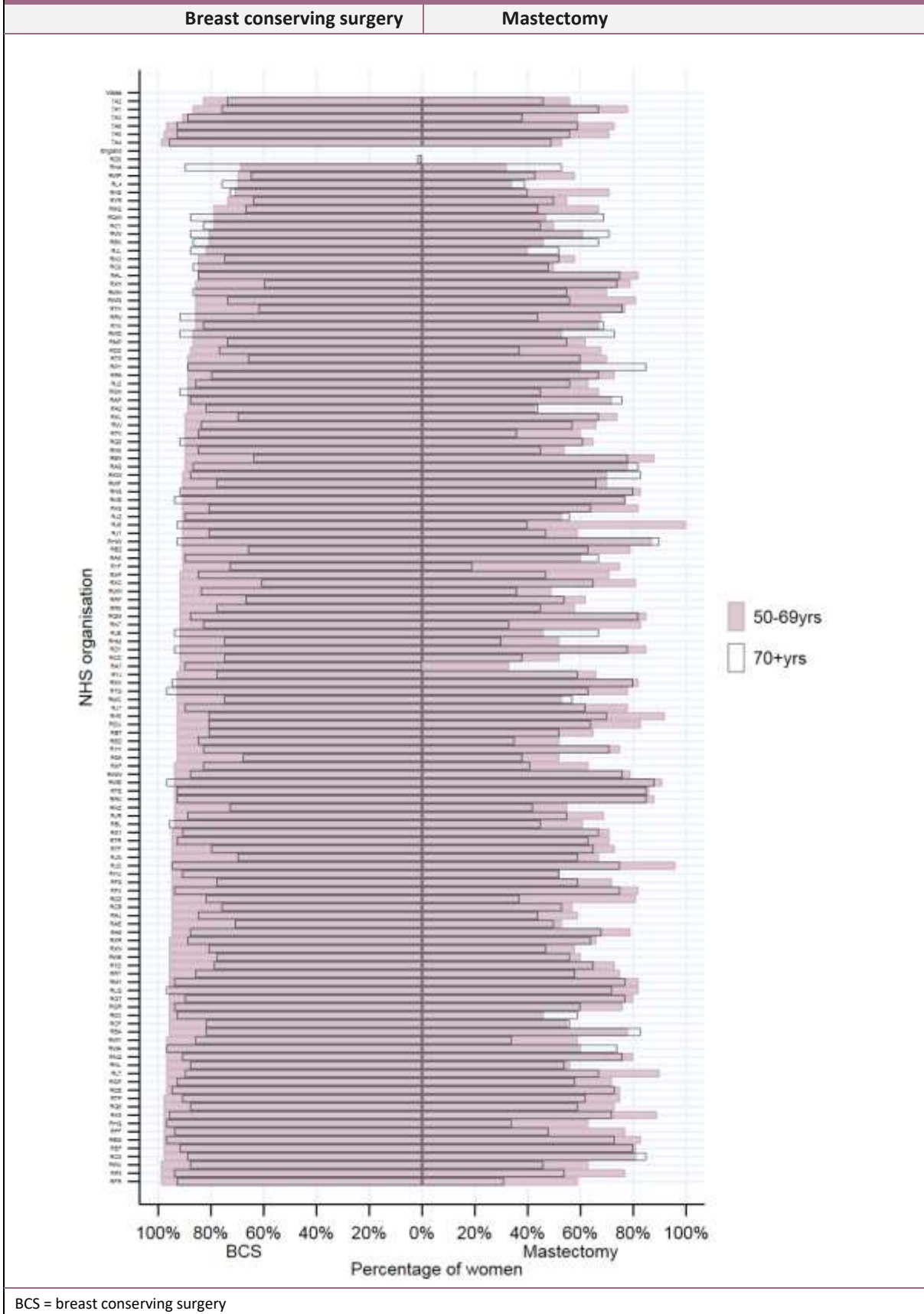
Note: post-mastectomy radiotherapy in women with node-positive early invasive breast cancer or node-negative T3 early invasive breast cancer.
BCS = breast conserving surgery; RT = radiotherapy.

Figure 7.5: Observed percentage of women with early invasive breast cancer receiving radiotherapy, by Charlson Comorbidity Index and age at diagnosis



CCI = Charlson Comorbidity Index; RT = radiotherapy.

Figure 7.6: 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



7.3 Chemotherapy treatment for early invasive breast cancer

Considering the use of chemotherapy for women with early invasive breast cancer, we evaluated use of adjuvant chemotherapy for those women with early invasive breast cancer. This section considers (1) all women, then focuses on women classified as having high-risk early invasive breast cancer: (2a) women with ER-negative, HER2-negative breast cancer and malignant lymph nodes (N+); (2b) 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 treatment of patients with HER2-positive breast cancers with chemotherapy and trastuzumab, regardless of ER status [Senkus 2015].

NICE guidance recommends that ER and HER2 status be collected for all invasive breast cancers [NICE 2018].

Numerator	Women who receive adjuvant CT
Denominator	Women diagnosed with early invasive breast cancer who had surgery (with no neo-adjuvant CT) <i>Groups:</i> (1) All women; (2a) ER-negative, HER2-negative, N+; (2b) HER2-positive
Country	England & Wales (England only in HER2-positive analysis)
Time frame	Women diagnosed from 2014–17

What do we see within this audit group?

(1) Considering **all women** with early invasive breast cancer (**Figure 7.7**), rates of adjuvant chemotherapy were considerably higher among younger women with ER-negative compared with ER-positive breast cancer.

(2a) Among women with **ER-negative, HER2-negative N+** early invasive breast cancer, who received primary surgery, 53% ($n = 815$) were identified as having received adjuvant chemotherapy.

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

- 73% among women aged 50–69 years
- 30% among women aged 70+ years

(2b) Among women with **HER2-positive** early invasive breast cancer, who received primary surgery, 59% ($n = 4,391$) were identified as having received adjuvant chemotherapy plus trastuzumab.

Rates of treatment varied by age (**Figure 7.8**), with lower reported use as age increased:

- 69% among women aged 50–69 years
- 36% among women aged 70+ years

These rates were both observed to have increased over the four-year period this section covers.

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 7.9**).

Variation by NHS organisation was observed regardless of age (**Figure 7.10**).

Note: HER2 status completion was lower among women aged 70+ years, compared with women aged 50–69 years (**Chapter 4, Table 4.1**).

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

Figure 7.7: Observed percentage of women with early invasive breast cancer receiving adjuvant chemotherapy, by ER status and age at diagnosis

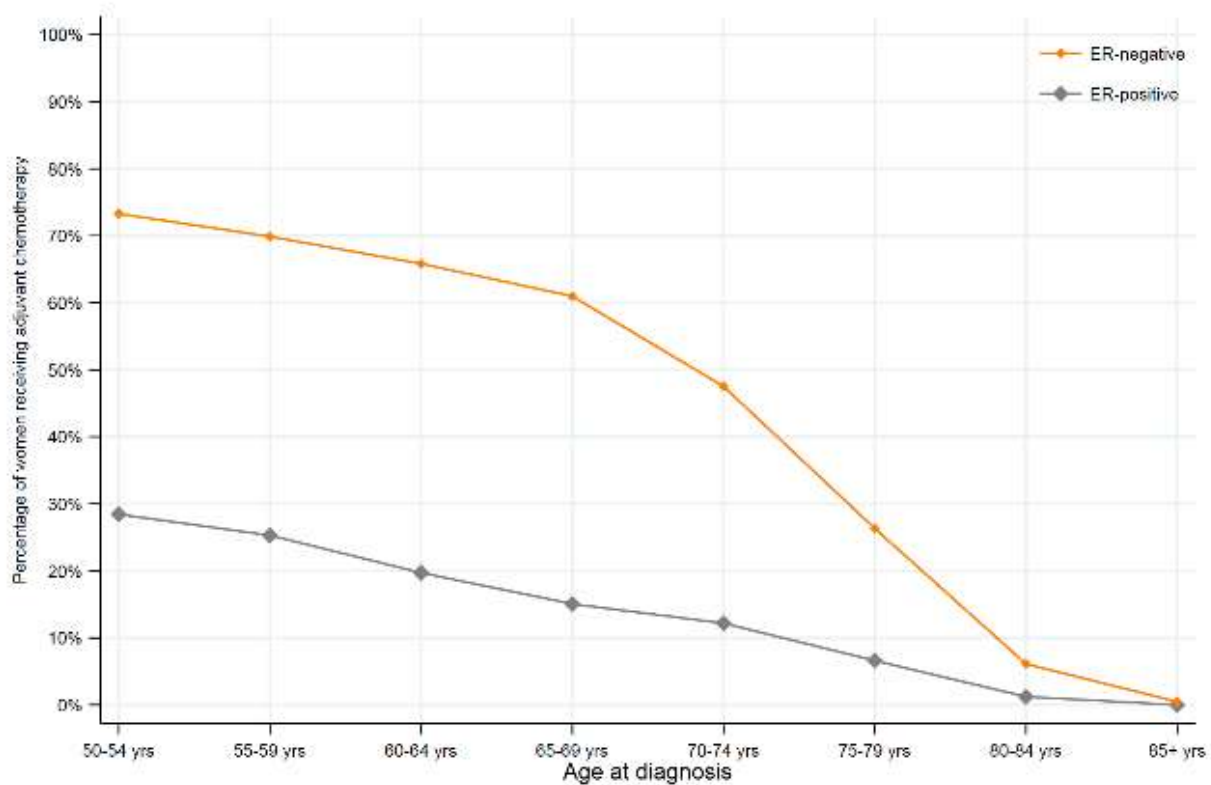
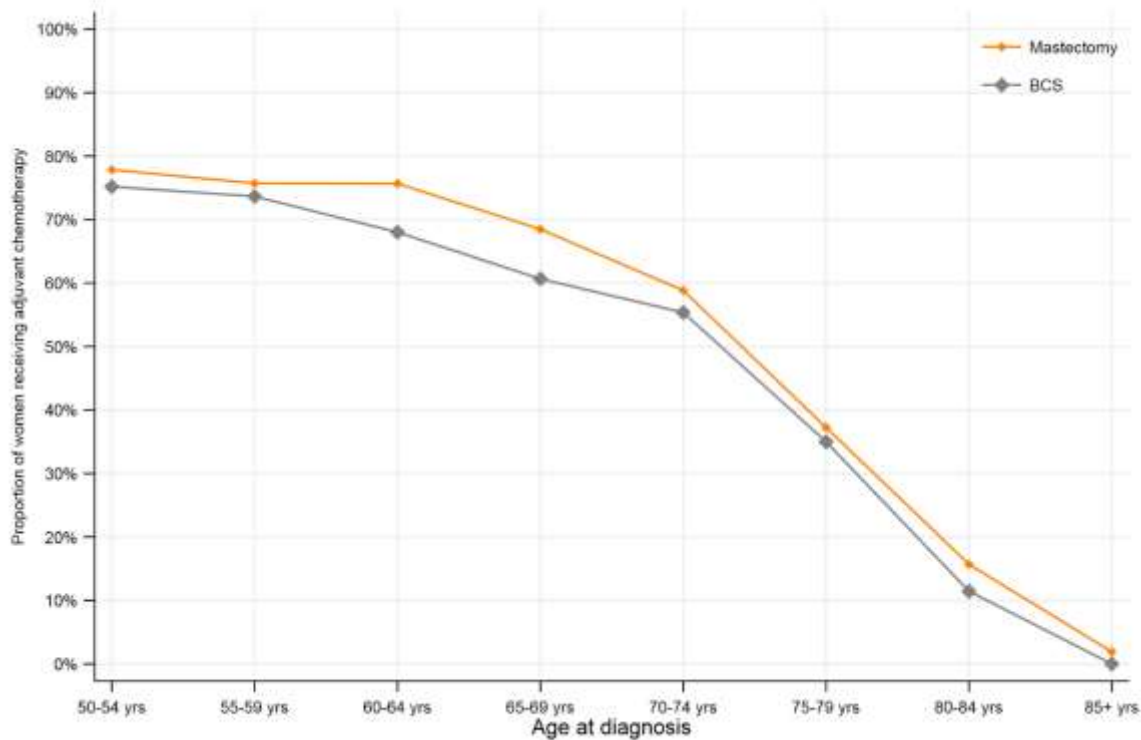
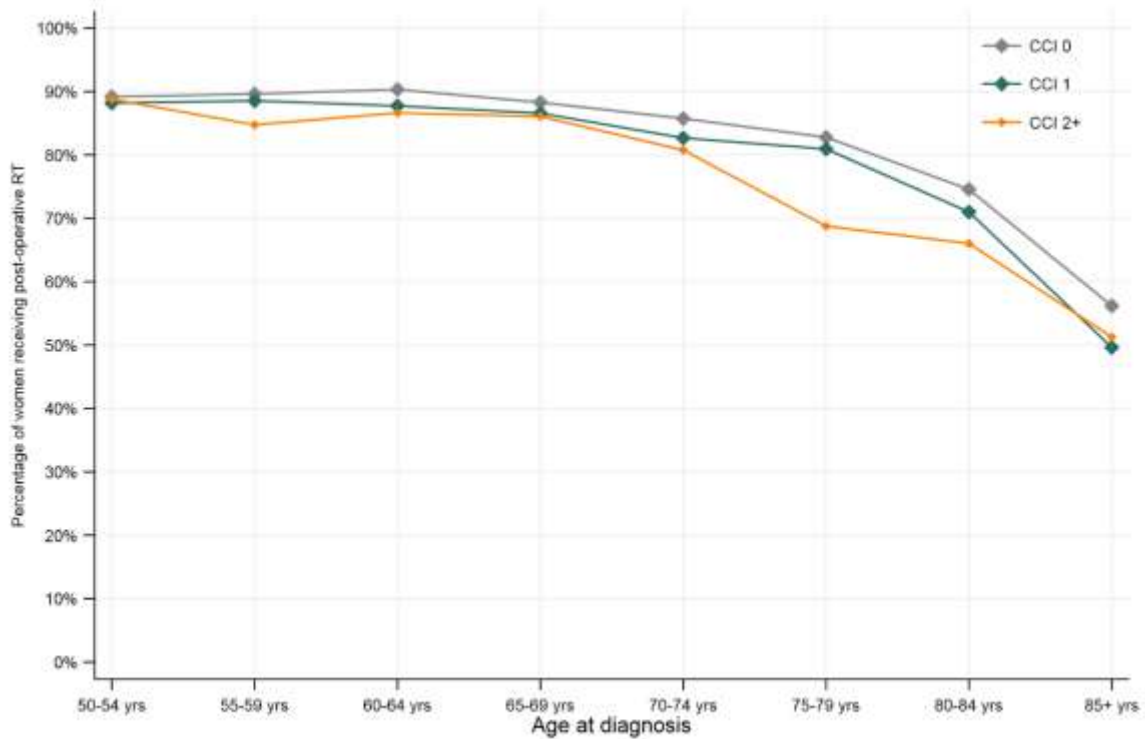


Figure 7.8: Observed percentage of women with HER2-positive early invasive breast cancer receiving adjuvant chemotherapy plus trastuzumab, by type of primary surgery and age at diagnosis



BCS = breast conserving surgery

Figure 7.9: Observed percentage of women with HER2-positive early invasive breast cancer receiving adjuvant chemotherapy plus trastuzumab, by Charlson Comorbidity Index and age at diagnosis



CCI = Charlson Comorbidity Index; RT = radiotherapy

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

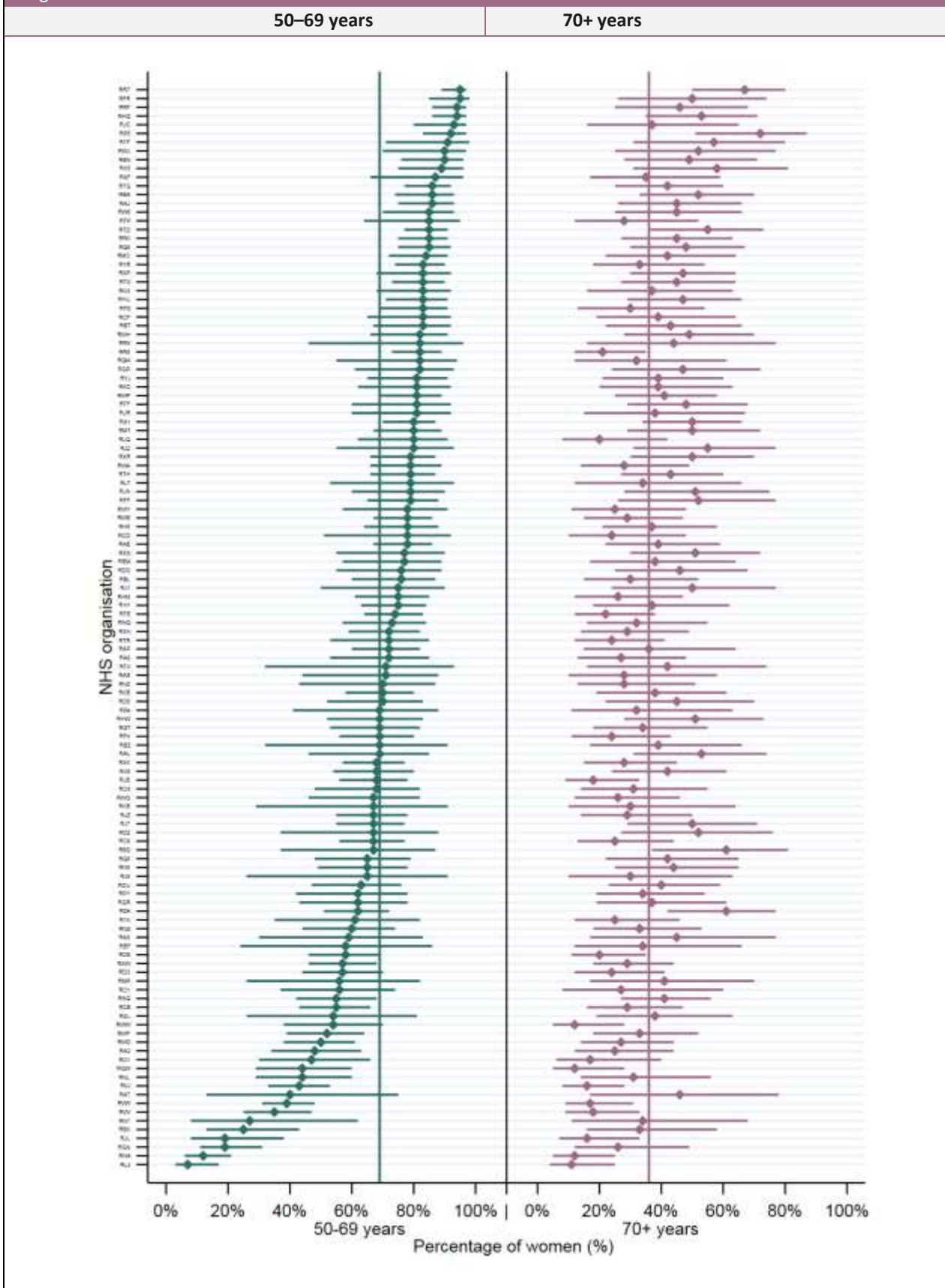
- 52% overall agreed completely that they were given enough information about whether their treatment was working, in a way they could understand. This was comparable across the age groups.

Recommendations

NHS organisations must ensure that:

- 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 have an objective assessment of likelihood of benefit and risk of chemotherapy based on tumour factors and patient fitness
- they evaluate their services for medical optimisation of older women, who would benefit from receiving chemotherapy
- women are given enough information about their chemotherapy treatment. Clinical teams should ask for feedback from their patients, at regular intervals, to ensure that they have sufficient information and are engaged in a shared decision-making process.

Figure 7.10: 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 69% and 36% 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 age, T stage, N stage, ER status, invasive grade, deprivation and Charlson Comorbidity Index; NHS organisation included as a level.

8. Metastatic breast cancer

8.1 Treatment for metastatic breast cancer at initial presentation

Patients with metastatic breast cancer are rarely cured of their cancer, but survival has improved over time as 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.

What does the guidance say?

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

- 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.

International Society of Geriatric Oncology/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	Women with metastatic breast cancer at initial presentation
Denominator	Women diagnosed with invasive breast cancer
Country	England & Wales
Time frame	Women diagnosed from 2014–17

What do we see within this audit group?

5% (6,550/131,495) of women were reported to have metastatic breast cancer at initial presentation. Most women presented via referral from the GP or another (non-breast) specialty (Table 8.1). The percentage presenting with metastatic breast cancer increased with age:

- 3% in women aged 50–69 years, to 7% in women aged 70+ years.

Among women with newly diagnosed metastatic breast cancer, ER status was unknown for 23% of women aged 50–69 years and 28% of women aged 70+ years. In those with a known ER status:

- 79% were ER-positive and 21% were ER-negative with similar percentages between the age groups
- 57% of women aged 50–69 years and 76% of women aged 70+ years with ER-positive metastatic breast cancer were recorded to have received endocrine treatment.

Older women with newly diagnosed metastatic breast cancer were less likely to receive chemotherapy (59% of women aged 50–69 years compared with 24% of women aged 70+ years; Figure 8.1); this pattern was observed irrespective of ER status and patient fitness (Figure 8.2).

Three years after a diagnosis of metastatic breast cancer, fewer than 50% of women aged 50–59 years were alive. In comparison, fewer than 20% of women aged 80+ years were alive (Figure 8.3). In the future, the NABCOP will explore survival in more detail, including reporting on the influence of patient and tumour characteristics, and morbidity from treatments, on breast cancer specific and overall survival.

Table 8.1: Route to diagnosis for women with newly diagnosed metastatic breast cancer, by age at diagnosis

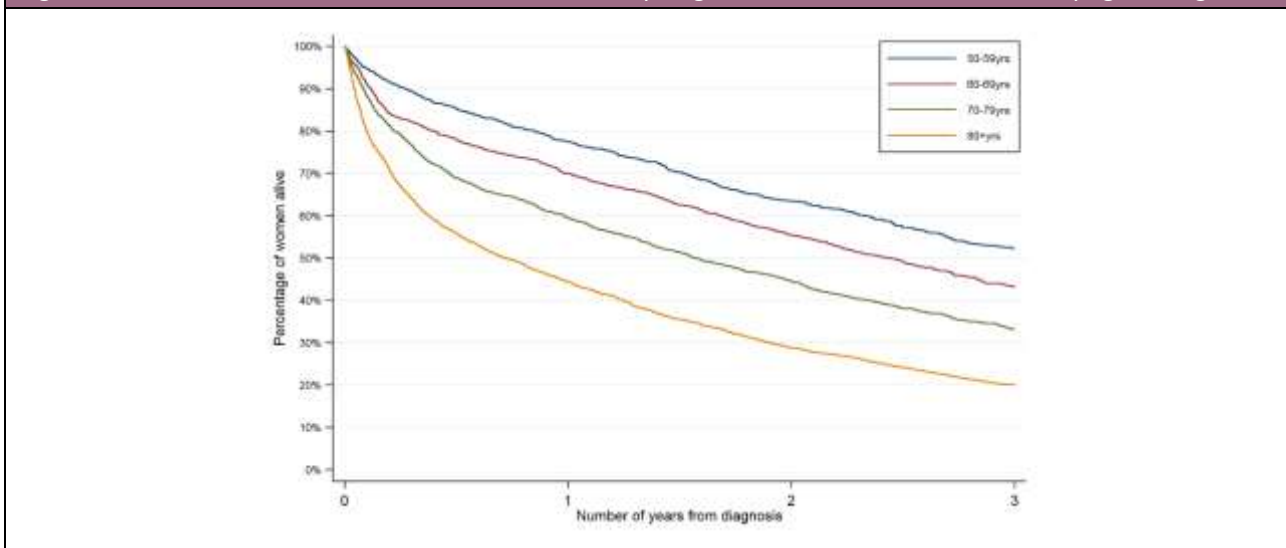
	50–69 years	70+ years
Reported route to diagnosis		
NHS screening programme	13%	2%
GP presentation	52%	50%
Referral from other specialties	17%	20%
After emergency presentation	5%	8%
Other	2%	2%
<i>Unreported</i>	12%	18%

Figure 8.2: Observed percentage of women with newly diagnosed metastatic breast cancer receiving chemotherapy as measured by two different patient factors, by ER status and age at diagnosis

Charlson Comorbidity Index							electronic Frailty Index						
Age at diagnosis	ER-positive			ER-negative			Age at diagnosis	ER-positive			ER-negative		
	0	1	2+	0	1	2+		fit	mild-mod	severe	fit	mild-mod	severe
50–59 yrs	68%	67%	63%	85%	36%	35%	50-59yrs	70%	61%	62%	77%	64%	47%
60–69 yrs	56%	41%	28%	94%	33%	38%	60-69yrs	59%	47%	32%	79%	63%	58%
70–79 yrs	41%	30%	21%	74%	27%	16%	70-79yrs	44%	36%	25%	64%	45%	23%
80+ yrs	19%	13%	6%	30%	15%	7%	80+yrs	20%	21%	8%	24%	13%	13%

Note: Higher percentages are shown in dark blue with a gradient down to light blue for lowest percentages.

Figure 8.3: Observed overall survival of women with newly diagnosed metastatic breast cancer, by age at diagnosis



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

- Overall, 69% of respondents with more than one treatment option had their treatment options explained to them completely (72% for women aged 50–69 years; 65% for women aged 70+ years).
- 73% of respondents felt that they were definitely involved as much as they wanted to be in decisions about their care and treatment. This was comparable across the age groups.
- Among all respondents who received chemotherapy, 62% agreed completely that they were given enough information about whether their chemotherapy was working in a way they could understand (60% for women aged 50–69 years; 66% for women aged 70+ years).
- On a scale of 0 (very poor) to 10 (very good), 93% of respondents aged 50–69 years and 97% aged 70+ years, gave their overall care a rating of 7 or higher.

Recommendations

NHS organisations must ensure that:

- ER status is assessed and recorded for women with metastatic breast cancer. All women who are ER-positive should be offered endocrine therapy, (although initial chemotherapy may be appropriate in some circumstances)
- consideration of chemotherapy for women with metastatic breast cancer is based on an objective assessment of likelihood of benefit, health and predicted life expectancy rather than chronological age alone
- women are given enough information about their chemotherapy treatment. Clinical teams should ask for feedback from their patients, at regular intervals, to ensure that they have sufficient information and are engaged in a shared decision-making process.

9. Fitness assessment for older women in breast clinics

The organisational survey performed as part of the **NABCOP 2017 report** highlighted variation in the assessment of comorbidity, cognition and functional status across NHS organisations. There is no universally accepted approach for these aspects of care, although there are specific tools for assessing multimorbidity recommended by NICE [2016], which include gait assessment, self-reported health status and the PRISMA-7 questionnaire.

A sub-group meeting of the NABCOP held in December 2017 (attendees detailed in **Appendix 1**) comprised geriatricians, breast surgeons, oncologists and anaesthetists. The meeting gathered insight on the experience of other specialties, discussed pre-existing fitness measures and created a consensus on a formal fitness assessment for older women, to be used in breast clinics.

The final NABCOP fitness assessment proforma was designed by the subgroup with two main purposes:

- to create a system to trigger the identification of a pre/frail patient, and
- to enable an improved understanding of, and future support for, clinical decision making and allow insight into potential reasons for those decisions.

The proforma contains the Clinical Frailty Scale, Abbreviated Mental Test Score (AMTS) and two screening questions on significant medical problems (**Appendix 3**).

9.1 Pilot study

The assessment proforma was piloted for eight weeks commencing in October 2018. All NHS organisations, who are part of the NABCOP in England and Wales, were eligible to participate. The pilot study was advertised at the Association of Breast Surgery conference and on Twitter, and organisations were also encouraged to volunteer through the NABCOP newsletter. In total, 11 NHS trusts in England volunteered to participate in the pilot study (**Appendix 3**). Participants were advised to complete the assessment during the first clinic visit, for the results to be available at the diagnostic multidisciplinary team meeting.

Qualitative formal feedback was collected from each participating organisation.

Figure 9.1 details the usefulness of each assessment component of the form, in the clinical setting.

Clinical Frailty Scale

91% (10/11) of participating trusts felt that the Clinical Frailty Scale was easy to complete, and would consider incorporating it into routine clinical practice. However, 4 of these 10 trusts would specifically use the tool for patients with fitness concerns. The one trust who felt the results of the Clinical Frailty Scale were **not** useful (**Figure 9.1A**) commented that *'even when we identified a need for a more comprehensive review, there were problems referring the patient for geriatric input'*.

Abbreviated Mental Test Score

The AMTS was an acceptable assessment to both patients and clinicians in 73% (8/11) of trusts. In the remaining trusts, one trust commented that some questions (e.g. date of the start of World War1) needed to be adapted for patients (and staff) in the present age. Although all trusts felt that the results of the AMTS were useful (**Figure 9.1B**), one commented that *'the approach taken and explanation given to patients about the potential utility of the information is important – as otherwise some patients might consider it condescending'*.

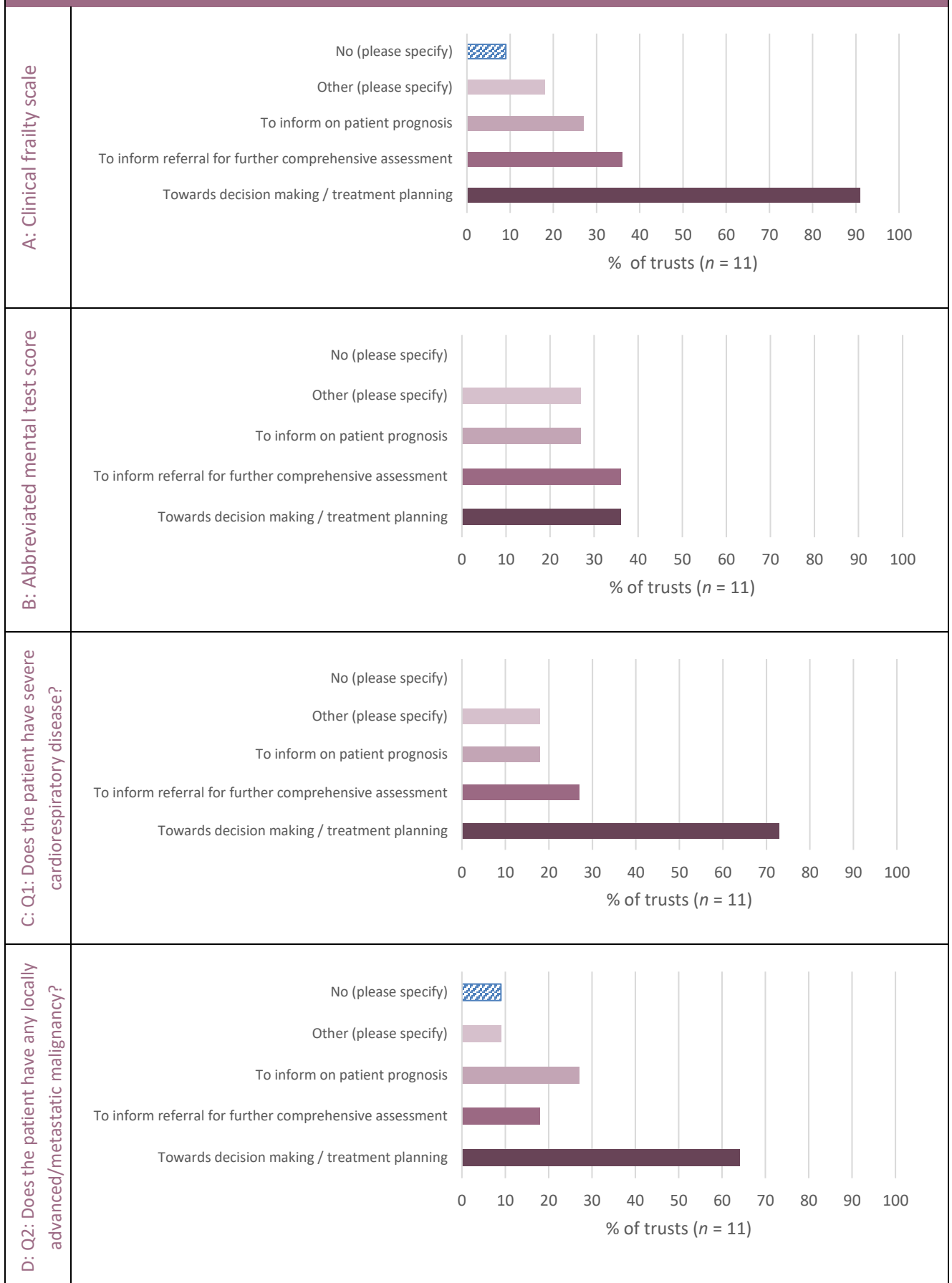
Question 1: Does the patient have severe cardiorespiratory disease?

The value of these screening questions are shown in **Figure 9.1C**. Trusts felt that question 1 was *'pragmatic'* and *'useful as some patients have severe disease without being frail'*. The results were also informative for some to guide further assessment, for example, for decisions on preoperative anaesthetic referrals.

Question 2: Does the patient have any non-breast locally advanced/metastatic malignancy?

10/11 of trusts considered that question 2 was useful (**Figure 9.1D**). The remaining trust did not encounter any patients with concurrent malignancy during the study pilot.

Figure 9.1: Participant response to the question 'Was *the assessment/question* useful?'



Six of eleven trusts were able to use the results of the assessment form at diagnostic multidisciplinary team meetings, while the remainder used this form following these diagnostic meetings. This was mainly due to logistics and time pressures in clinic.

All trusts would share the information with allied breast cancer specialists and the patient's GP. Four of eleven trusts would also share the assessment results with geriatricians in their trust, but felt that the *'care of the elderly has stretched resources. (We were) unable to agree a referral route, and unable to share the patient results'*.

What next?

Overall, the majority of those trusts participating in the pilot found the fitness assessment proforma for older women useful in clinical practice.

The NABCOP has taken the feedback from this initial pilot into account and will continue to the second stage of the pilot study. The aim of this is to develop a consistent and standardised method of fitness assessment for older women in breast clinics that can be incorporated into national routinely collected data.

Recommendations

Royal colleges and specialist associations involved in breast cancer care should collaborate and define the need for a reliable, consistent description of patient fitness.

References

- Bates T, Evans T, Lagord C, Monypenny I, Kearins O, Lawrence G. A population based study of variations in operation rates for breast cancer, of comorbidity and prognosis at diagnosis: Failure to operate for early breast cancer in older women. *Eur J Surg Oncol* 2014; 40(10): 1230–6.
- Biganzoli L, Goldhirsch A, Straehle C, Castiglione-Gertsch M, Therasse P, *et al.* Adjuvant chemotherapy in elderly patients with breast cancer: a survey of the Breast International Group (BIG). *Ann Oncol* 2004; 15: 207–10.
- Biganzoli L, Wildiers H, Oakman C, Marotti L, Loibl S, *et al.* Management of elderly patients with breast cancer: updated recommendations of the International Society of Geriatric Oncology (SIOG) and European Society of Breast Cancer Specialists (EUSOMA). *Lancet Oncol* 2012; 13(4): e148–60.
- Cancer Research UK. Breast cancer statistics. <http://www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/breast-cancer#heading-Zero>.
- Clegg A, Bates C, Young J, Ryan R, Nichols L, Ann Teale E, *et al.* Development and validation of an electronic frailty index using routine primary care electronic health record data. *Age Ageing* 2016; 45(3): 353–60.
- Early Breast Cancer Trialists' Collaborative Group, Darby S, McGale P, Correa C, Taylor C *et al.* Effect of radiotherapy after breast conserving surgery on 10-year recurrence and 15-year breast cancer death: meta-analysis of individual patient data for 10,801 women in 17 randomised trials. *Lancet* 2011; 378(9804): 1,707–16.
- Early Breast Cancer Trialists' Collaborative Group (EBCTCG), Peto R, Davies C, *et al.* Comparisons between different polychemotherapy regimens for early breast cancer: meta-analyses of long-term outcome among 100,000 women in 123 randomised trials. *Lancet* 2012;379(9814):432–444.
- Ellis-Brookes L, McPhail S, Ives A, Greenslade M, Shelton J, Hiom S, Richards M. Routes to diagnosis for cancer - determining the patient journey using multiple routine data sets. *Br J Cancer* 2012; 107(8): 1220–6.
- Hind D, Wyld L, Beverley CB, Reed MW. Surgery versus primary endocrine therapy for operable primary breast cancer in elderly women (70 years plus). *Cochrane Database Syst Rev* 2006(1): CD004272.
- Kerlikowske K. Epidemiology of Ductal Carcinoma In Situ. *J Natl Cancer Inst Monogr* 2010; 2010(41): 139–41.
- Kunkler IH, Williams LJ, Jack WJ, Cameron DA, Dixon JM. Breast-conserving surgery with or without irradiation in women aged 65 years or older with early breast cancer (PRIME II): a randomised controlled trial. *Lancet Oncol* 2015; 16(3): 266–73.
- Lavelle K, Sowerbutts AM, Bundred N, Pilling M, Degner L, Stockton C, *et al.* Is lack of surgery for older breast cancer patients in the UK explained by patient choice or poor health? A prospective cohort study. *Br J Cancer* 2014; 110(3): 573–83.
- Morgan JL, Collins K, Robinson TG, Cheung KL, Audisio R, Reed MW, *et al.* Healthcare professionals' preferences for surgery or primary endocrine therapy to treat older women with operable breast cancer. *Eur J Surg Oncol* 2015; 41(9): 1,234–42.
- National Cancer Intelligence Network. *The Second All Breast Cancer Report Focusing on Inequalities: Variation in breast cancer outcomes with age and deprivation*. Birmingham: West Midlands Cancer Intelligence Unit, 2011.
- National Institute for Health and Clinical Excellence. *Improving Outcomes in Breast Cancer*. Cancer Service Guideline (CSG1). London: NICE, 2002.
- National Institute for Health and Clinical Excellence. *Guideline on Early and Locally Advanced Breast Cancer*. NICE Guideline (CG80). London: NICE, 2009a.
- National Institute for Health and Care Excellence. *Advanced Breast Cancer: Diagnosis and Treatment*. Clinical Guideline (CG81). London: NICE, 2009b.
- National Institute for Health and Clinical Excellence (NICE). *Multimorbidity: Clinical Assessment and Management*. NICE Guideline (NG56). London: NICE, 2016.

National Institute for Health and Clinical Excellence (NICE). *Guideline on Early and Locally Advanced Breast Cancer*. NICE Guideline (NG101). London: NICE, 2018.

Office for National Statistics. *Cancer Registration Statistics, England, 2016*. London: ONS, 2018.

Quality Health. *National Cancer Experience Survey 2015: National Results Summary*. Chesterfield: Quality Health; 2015.

Richards P, Ward S, Morgan J, Lagord C, Reed M, Collins K, *et al*. The use of surgery in the treatment of ER+ early stage breast cancer in England: Variation by time, age and patient characteristics. *Eur J Surg Oncol* 2016; 42(4): 489–96.

Royal College of Radiologists. Postoperative radiotherapy for breast cancer: UK consensus statements. <https://www.rcr.ac.uk/clinical-oncology/service-delivery/postoperative-radiotherapy-breast-cancer-uk-consensus-statements>.

Senkus E, Kyriakides S, Ohno S, Penault-Llorca F, Poortmans P, Rutgers E, Zackrisson S, Cardoso F; ESMO Guidelines Committee. Primary breast cancer: ESMO Clinical Practice Guidelines for diagnosis, treatment and follow-up. *Ann Oncol* 2015;26 Suppl 5:v8-30.

Ward SE, Richards PD, Morgan JL, Holmes GR, Broggio JW, Collins K, Reed MWR, Wyld L. Omission of surgery in older women with early breast cancer has an adverse impact on breast cancer-specific survival. *Br J Surg* 2018;105(11):1454-1463.

Wedding U, Pientka L, Höffken K. Quality-of-life in elderly patients with cancer: a short review. *Eur J Cancer* 2007; 43(15): 2,203–10.

Welsh Cancer Intelligence and Surveillance Unit. Cancer Incidence in Wales, 2001–2016. 2019. <http://www.wcisuwales.nhs.uk/cancer-incidence-in-wales>.

Appendix 1: Project Board and Clinical Steering Group members

Project Board members (excluding project team)		
Name	Organisation	Role
Mr Nick Markham	Royal College of Surgeons of England	Project Board Chair Invited Review Mechanism Chair
Dr Jacinta Abraham	Velindre NHS Trust	Breast Clinical Oncologist and Medical Director
Ms Karen Clements	National Cancer Registration and Analysis Service, Public Health England	NABCOP/NCRAS Project Manager
Miss Marianne Dillon	Abertawe Bro Morgannwg University Health Board Wales Cancer Network	Breast Surgeon Breast Cancer Audit Lead for Wales
Dr Julie Doughty	Association of Breast Surgery	Vice President [Member from Mar 2019]
Ms Patricia Fairbrother	Independent Cancer Patients' Voice	Patient Representative [Member from Jun 2018]
Ms Janice Rose	Independent Cancer Patients' Voice	Patient Representative [Member from Mar 2019]
Mr Mark Sibbering	Association of Breast Surgery	President
Mr Mirek Skrypak	Healthcare Quality Improvement Partnership	Associate Director for Quality and Development
Ms Sophia Turner	Independent Cancer Patients' Voice	Patient Representative
Ms Sarah Walker	Healthcare Quality Improvement Partnership	Project Manager
Ms Maggie Wilcox	Independent Cancer Patients' Voice	Patient Representative [Member until Dec 2018]

Clinical Steering Group members (excluding project team)		
Name	Organisation	Role
Ms Karen Clements	National Cancer Registration and Analysis Service, Public Health England	NABCOP/NCRAS Project Manager
Miss Marianne Dillon	Abertawe Bro Morgannwg University Health Board Wales Cancer Network	Breast Surgeon Breast Cancer Audit Lead for Wales
Ms Patricia Fairbrother	Independent Cancer Patients' Voice	Patient Representative [Member from Jun 2018]
Prof. Deborah Fenlon	Swansea University	Professor of Nursing
Mr Ashu Gandhi	Association of Breast Surgery University Hospital of South Manchester NHS Foundation Trust NHS Breast Screening Programme	Chair of Professional Standards Oncoplastic Breast and Endocrine Surgeon Surgical Chair
Prof. Margot Gosney ¹	University of Reading Royal Berkshire NHS Foundation Trust	Professor of Elderly Care Medicine Honorary Consultant in Elderly Care Medicine
Ms Lis Grimsey	Association of Breast Surgery	Macmillan Nurse Consultant
Prof. Chris Holcombe	Royal Liverpool and Broadgreen University Hospitals NHS Trust National Breast Clinical Reference Group	Oncoplastic Breast Surgeon Deputy Chair
Ms Eluned Hughes	Breast Cancer Now [Merged with Breast Cancer Care from April 2019]	Head of Public Health and Information [Member until Mar 2019]
Ms Jackie Jenkins	Public Health England, Screening Quality Assurance Service	Deputy Director of Quality Assurance
Prof. Ian Kunkler	University of Edinburgh NHS Lothian	Professor of Clinical Oncology Clinical Oncologist
Miss Fiona MacNeill	Getting It Right First Time The Royal Marsden NHS Foundation Trust	Clinical Lead for Breast Surgery Consultant Breast Surgeon
Mr Andrew Murphy	National Cancer Registration and Analysis Service, Public Health England	Head of Cancer Datasets
Dr Emma Pennery	Breast Cancer Care [Merged with Breast Cancer Care from Apr 2019]	Clinical Director
Dr Stanley Ralph ¹	Age Anaesthesia Association Royal Derby Hospitals NHS Trust	Honorary Secretary Anaesthetist
Dr Alistair Ring	Royal Marsden NHS Foundation Trust	Medical Oncologist

Clinical Steering Group members (excluding project team)		
Name	Organisation	Role
Prof. Tom Robinson ¹	University of Leicester University Hospitals of Leicester NHS Trust	Head of Department and Professor of Stroke Medicine Honorary Consultant Physician
Ms Janice Rose	Independent Cancer Patients' Voice	Patient Representative [Member from Mar 2019]
Dr Nisha Sharma	Leeds Teaching Hospitals NHS Trust British Society of Breast Radiology	Director of Breast Screening (Leeds-Wakefield) and Clinical Lead for Breast Imaging Secretary
Dr Richard Simcock ¹	Macmillan Cancer Support	Chair of the Expert Reference Group for Cancer Care in Older People convened by Macmillan
Ms Sophia Turner	Independent Cancer Patients' Voice	Patient Representative
Ms Maggie Wilcox	Independent Cancer Patients' Voice	Patient Representative [Member until Dec 2018]
Prof. Lynda Wyld ¹	University of Sheffield Jasmine Breast Centre, Doncaster Bridging the Age Gap Study	Professor of Surgical Oncology Honorary Consultant Breast Surgeon Principal Investigator

Clinical Steering Group subgroup guest attendees (excluding project team)		
Name	Organisation	Role
Dr Michael Fertleman ¹	Charing Cross and St Mary's Hospitals	Lead Clinician for the Medical Care of Elderly Orthopaedic Patients (at both)
Dr Tania Kalsi ¹	Guy's & St Thomas' NHS Foundation Trust	Consultant Geriatrician
Dr Martin Vernon ¹	Manchester Royal Infirmary	Consultant Geriatrician Clinical Director, Community Adults and Specialist Services Directorate

Project team		
Name	Organisation	Role
Prof. Kieran Horgan	Leeds Teaching Hospitals NHS Trust	Consultant Breast Surgeon NABCOP Liaison for the Association of Breast Surgery reporting to the Clinical Standards and Audit Committee Chair Breast Cancer Expert Advisory Group of NCRAS
Prof. David Dodwell	University of Oxford	Consultant Clinical Oncologist Chair, Systemic Anti-Cancer Therapy Executive Committee UK Breast Cancer Group
Miss Catherine Foster	Clinical Effectiveness Unit, RCS	Research Coordinator
Mrs Melissa Gannon	Clinical Effectiveness Unit, RCS	Research Fellow/Methodologist
Miss Yasmin Jauhari	Clinical Effectiveness Unit, RCS	Clinical Research Fellow
Ms Jibby Medina	Clinical Effectiveness Unit, RCS	Project Manager
Prof. David Cromwell	Clinical Effectiveness Unit, RCS	Director

¹ We are grateful to the members of the assessing frailty, comorbidities and cognition (held 13 December 2017) subgroup for their expert input, to help shape this aspect of the audit's work.

Appendix 2: NHS organisations and geographical regions





Organisation code	Organisation name	Patients ≥50 years diagnosed 2014–17	Patients ≥50 years diagnosed in 2017	Organisation code	Organisation name	Patients ≥50 years diagnosed 2014–17	Patients ≥50 years diagnosed in 2017
Cheshire and Merseyside				Humber, Coast and Vale			
RBL	Wirral University Teaching Hospitals NHS Foundation Trust	1131	242	RCB	York Teaching Hospital NHS Foundation Trust	1730	427
RBN	St Helens and Knowsley Teaching Hospitals NHS Trust	763	202	RJL	Northern Lincolnshire & Goole NHS Foundation Trust	694	205
RBT	Mid Cheshire Hospitals NHS Foundation Trust	942	280	RWA	Hull University Teaching Hospitals NHS Trust	1524	407
REM	Aintree University Hospital NHS Foundation Trust	506	123	Kent and Medway			
RJN	East Cheshire NHS Trust	848	193	RN7	Dartford & Gravesham NHS Trust	275	61
RJR	Countess Of Chester Hospital NHS Foundation Trust	630	182	RPA	Medway NHS Foundation Trust	426	132
RQ6	Royal Liverpool and Broadgreen University Hospitals NHS Trust	1991	432	RVV	East Kent Hospitals University NHS Foundation Trust	1995	508
RWW	Warrington and Halton Hospitals NHS Foundation Trust	790	200	RWF	Maidstone & Tunbridge Wells NHS Trust	2343	566
East Midlands				Lancashire and South Cumbria			
RK5	Sherwood Forest Hospitals NHS Foundation Trust	698	165	RTX	University Hospitals Of Morecambe Bay NHS Foundation Trust	1574	448
RNQ	Kettering General Hospital NHS Foundation Trust	824	191	RXL	Blackpool Teaching Hospitals NHS Foundation Trust	557	147
RNS	Northampton General Hospital NHS Trust	936	239	RXN	Lancashire Teaching Hospitals NHS Foundation Trust	643	158
RTG	University Hospitals of Derby & Burton NHS Foundation Trust	2217	559	RXR	East Lancashire Hospitals NHS Trust	1214	310
RWD	United Lincolnshire Hospitals NHS Trust	1837	436	North Central and North East London			
RWE	University Hospitals Of Leicester NHS Trust	2368	575	R1H	Barts Health NHS Trust	1725	406
RX1	Nottingham University Hospitals NHS Trust	1945	495	RAL	Royal Free London NHS Foundation Trust	1231	394
East of England				RAP	North Middlesex University Hospital NHS Trust	1536	298
RAJ	Southend University Hospital NHS Foundation Trust	1282	319	RF4	Barking, Havering & Redbridge University Hospitals NHS Trust	1544	347
RC1	Bedford Hospital NHS Trust	431	110	RKE	Whittington Health NHS Trust	215	48
RC9	Luton & Dunstable University Hospital NHS Foundation Trust	1711	421	RRV	University College London Hospitals NHS Foundation Trust	374	99
RCX	The Queen Elizabeth Hospital King's Lynn NHS Foundation	691	175	North East and Cumbria			
RD8	Milton Keynes University Hospital NHS Foundation Trust	723	205	RNL	North Cumbria University Hospitals NHS Trust	897	246
RDD	Basildon & Thurrock University Hospitals NHS Foundation Trust	567	138	RR7	Gateshead Health NHS Foundation Trust	1708	489
RDE	East Suffolk & North Essex NHS Foundation Trust	2128	556	RTD	The Newcastle upon Tyne Hospitals NHS Foundation Trust	1779	441
RGN	North West Anglia NHS Foundation Trust	1203	281	RTF	Northumbria Healthcare NHS Foundation Trust	701	177
RGP	James Paget University Hospitals NHS Foundation Trust	636	119	RTR	South Tees Hospitals NHS Foundation Trust	655	148
RGR	West Suffolk NHS Foundation Trust	790	169	RVW	North Tees & Hartlepool NHS Foundation Trust	1556	416
RGT	Cambridge University Hospitals NHS Foundation Trust	1252	342	RXP	County Durham & Darlington NHS Foundation Trust	798	192
RM1	Norfolk & Norwich University Hospitals NHS Foundation Trust	1733	431	Peninsula			
RQ8	Mid Essex Hospital Services NHS Trust	1026	268	RA9	Torbay & South Devon NHS Foundation Trust	931	228
RQW	The Princess Alexandra Hospital NHS Trust	828	184	RBZ	Northern Devon Healthcare NHS Trust	266	62
RWG	West Hertfordshire Hospitals NHS Trust	660	161	REF	Royal Cornwall Hospitals NHS Trust	1301	302
RWH	East & North Hertfordshire NHS Trust	697	194	RH8	Royal Devon & Exeter NHS Foundation Trust	1442	390
Greater Manchester				RK9	University Hospitals Plymouth NHS Trust	1313	368
ROA	Manchester University NHS Foundation Trust	2347	598	Somerset, Wiltshire, Avon and Gloucestershire			
RMC	Bolton NHS Foundation Trust	1231	275	RA7	University Hospitals Bristol NHS Foundation Trust	187	39
RMP	Tameside & Glossop Integrated Care NHS Foundation Trust	272	45	RBA	Taunton & Somerset NHS Foundation Trust	1398	320
RRF	Wrightington, Wigan & Leigh NHS Foundation Trust	1110	306	RD1	Royal United Hospitals Bath NHS Foundation Trust	779	178
RW6	The Pennine Acute Hospitals NHS Trust	911	223	RNZ	Salisbury NHS Foundation Trust	440	106
RWJ	Stockport NHS Foundation Trust	477	111	RTE	Gloucestershire Hospitals NHS Foundation Trust	1876	463

Organisation code	Organisation name	Patients ≥50 years diagnosed 2014–17	Patients ≥50 years diagnosed in 2017
RVJ	North Bristol NHS Trust	2345	653
South East London			
RJ1	Guy's & St Thomas' NHS Foundation Trust	563	171
RJ2	Lewisham & Greenwich NHS Trust	688	155
RJZ	King's College Hospital NHS Foundation Trust	2073	583
South Yorkshire, Bassetlaw and North Derbyshire			
RFF	Barnsley Hospital NHS Foundation Trust	620	140
RFR	The Rotherham NHS Foundation Trust	652	181
RFS	Chesterfield Royal Hospital NHS Foundation Trust	921	232
RHQ	Sheffield Teaching Hospitals NHS Foundation Trust	1382	366
RP5	Doncaster & Bassetlaw Hospitals NHS Foundation Trust	1224	309
Surrey and Sussex			
RA2	Royal Surrey County Hospital NHS Foundation Trust	2299	541
RDU	Frimley Health NHS Foundation Trust	1588	417
RTK	Ashford & St Peter's Hospitals NHS Foundation Trust	336	105
RTP	Surrey & Sussex Healthcare NHS Trust	697	177
RXC	East Sussex Healthcare NHS Trust	801	181
RXH	Brighton & Sussex University Hospitals NHS Trust	1602	372
RYR	Western Sussex Hospitals NHS Foundation Trust	1984	518
Thames Valley			
RHW	Royal Berkshire NHS Foundation Trust	1185	256
RN3	Great Western Hospitals NHS Foundation Trust	1142	294
RTH	Oxford University Hospitals NHS Foundation Trust	1671	413
RXQ	Buckinghamshire Healthcare NHS Trust	1332	327
Wessex			
R1F	Isle Of Wight NHS Trust	463	114
RBD	Dorset County Hospital NHS Foundation Trust	383	90
RD3	Poole Hospital NHS Foundation Trust	1603	453
RDZ	The Royal Bournemouth & Christchurch Hospitals NHS	627	149
RHM	University Hospital Southampton NHS Foundation Trust	1581	385
RHU	Portsmouth Hospitals NHS Trust	1734	402
RN5	Hampshire Hospitals NHS Foundation Trust	1343	326
West London			
R1K	London North West University Healthcare NHS Trust	819	199
RAS	The Hillingdon Hospitals NHS Foundation Trust	355	80
RAX	Kingston Hospital NHS Foundation Trust	431	109
RJ6	Croydon Health Services NHS Trust	135	48
RJ7	St George's University Hospitals NHS Foundation Trust	1981	542
RPY	The Royal Marsden NHS Foundation Trust	1285	294
RQM	Chelsea & Westminster Hospital NHS Foundation Trust	358	103
RYJ	Imperial College Healthcare NHS Trust	1600	419

Organisation code	Organisation name	Patients ≥50 years diagnosed 2014–17	Patients ≥50 years diagnosed in 2017
West Midlands			
RBK	Walsall Healthcare NHS Trust	615	152
RJC	South Warwickshire NHS Foundation Trust	591	188
RJE	University Hospitals Of North Midlands NHS Trust	1927	420
RKB	University Hospitals Coventry & Warwickshire NHS Trust	1384	308
RL4	The Royal Wolverhampton NHS Trust	935	279
RLQ	Wye Valley NHS Trust	560	134
RLT	George Eliot Hospital NHS Trust	321	86
RNA	The Dudley Group NHS Foundation Trust	1006	240
RRK	University Hospitals Birmingham NHS Foundation Trust	2302	565
RWP	Worcestershire Acute Hospitals NHS Trust	1713	447
RXK	Sandwell & West Birmingham Hospitals NHS Trust	1239	303
RXW	Shrewsbury & Telford Hospital NHS Trust	1424	366
West Yorkshire			
RAE	Bradford Teaching Hospitals NHS Foundation Trust	1532	357
RCD	Harrogate & District NHS Foundation Trust	319	70
RCF	Airedale NHS Foundation Trust	333	101
RR8	Leeds Teaching Hospitals NHS Trust	2102	546
RWY	Calderdale & Huddersfield NHS Foundation Trust	564	136
RXF	The Mid Yorkshire Hospitals NHS Trust	735	171
Wales			
7A1	Betsi Cadwaladr University Local Health Board	2347	525
7A2	Hywel Dda University Local Health Board	1465	332
7A3	Abertawe Bro Morgannwg University Local Health Board	1686	414
7A4	Cardiff and Vale University Local Health Board	1188	323
7A5	Cwm Taf University Local Health Board	1218	332
7A6	Aneurin Bevan University Local Health Board	1391	354
Notes:			
1. The registration dataset for 2014–17 included several NHS trusts at which fewer than 120 patients were diagnosed over the four-year period. These NHS trusts were not included in this report. They are: South Tyneside NHS Foundation Trust, Epsom & St Helier University Hospitals NHS Trust, Southport & Ormskirk Hospital NHS Trust, Homerton University Hospital NHS Foundation Trust, Yeovil District Hospital NHS Foundation Trust, Queen Victoria Hospital NHS Foundation Trust.			
2. A further three NHS trusts had fewer than 30 patients diagnosed in the most recent year this report presents data on (i.e. 2017) and as such are not included; these are: City Hospitals Sunderland 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.			

Appendix 3: Fitness assessment for older patients in breast clinic

Clinical Frailty Scale* (Please circle the appropriate number)

 <p>1 Very Fit – People who are robust, active, energetic and motivated. These people commonly exercise regularly. They are among the fittest for their age.</p>	 <p>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).</p>	
 <p>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.</p>	 <p>8 Very Severely Frail – Completely dependent, approaching the end of life. Typically, they could not recover even from a minor illness.</p>	
 <p>3 Managing Well – People whose medical problems are well controlled, but are not regularly active beyond routine walking.</p>	 <p>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.</p>	
 <p>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.</p>	<p>Scoring frailty in people with dementia</p> <p>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.</p> <p>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.</p> <p>In severe dementia, they cannot do personal care without help.</p>	
 <p>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.</p>	<p>* 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.</p>	
 <p>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.</p>		

Abbreviated Mental Test Score

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

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

Glossary and abbreviations

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

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 p. 53).

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. The conditions covered by the index include: myocardial infarction, congestive cardiac failure, cerebrovascular disease, dementia, chronic pulmonary disease, rheumatological disease, liver disease, hemiplegia or paraplegia, renal disease, *any malignancy**, *metastatic solid tumour** and AIDS/HIV infection. The index is usually calculated without the conditions marked with * for use in analysis on cancer patients.

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, and may be described as the *HER2/neu* gene as this gene is responsible for the overproduction of HER2 protein in each cell. Breast cancer cells with higher levels of HER2 receptors (HER2-positive) are more aggressive and may grow more quickly. These receptors (often termed molecular markers) are the target of anti-HER2 therapies such as trastuzumab.

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 breast tissue.

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

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. The public health service in the United Kingdom.

NHS Breast Screening Programme – In this programme asymptomatic women aged 47–70 (or 50–73 in some areas) are invited for a mammogram every three years for the detection of early breast cancer.

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 kills 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.