NABCOP National Audit of Breast Cancer in Older Patients

NABCOP 2022 Annual Report Methodology

Contents

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Data receipt and processing

Routine data collection

Patient-level data on many aspects of breast cancer care are routinely collected in hospitals and mandatorily submitted to national organisations. These existing electronic data flows are used by the National Audit of Breast Cancer in Older Patients (NABCOP) in order to reduce the burden of data collection on staff and patients. The NABCOP uses this patient data, collected by the National Cancer Registration and Analysis Service (NCRAS) in England and the Wales Cancer Network (WCN), to report on breast cancer care for older women.

For patients in England, the NCRAS provided data from its Cancer Analysis System (CAS), which collates patient data from a range of national data feeds across all NHS acute hospitals. These data feeds include:

- National cancer registrations, which include information directly from hospital pathology systems;
- A screening flag from the NHS Breast Screening Programme (NHSBSP) and Association of Breast Surgery (ABS) screening audit (previously provided by the Screening Histories Information Manager (SHIM) system);
- Cancer Outcomes and Services Dataset (COSD) data items;
- Systemic Anti-cancer therapy (SACT) data;
- Radiotherapy dataset (RTDS);
- Hospital Episode Statistics (HES) data, including Admitted Patient Care (APC); Outpatients (OP); Accident & Emergency (A&E);
- Date and cause of death from the Office for National Statistics (ONS).

Data from the above sources were provided for the cohort of women diagnosed from 01-Jan-2014 to 31-Dec-2019. These data were used to describe the care, treatment and outcomes of women aged 50 and over, as well as providing the cohort for analysis within the prescriptions chapter of the NABCOP 2022 Annual Report.

In addition, two further datasets were provided for patients in England, linked to the NABCOP 2014-19 cohort via the pseudonymised patient identifier:

1. Data on endocrine therapy, bisphosphonates, anticoagulants and dementia-related prescriptions dispensed from April 2015 to March 2021 were provided from the Primary Care Prescription Database (PCPD);
2. Data from the National Cancer Patient Experience Survey (CPES) conducted between 2015 to 2019.

For patients in Wales, the WCN provided national cancer registrations data using the Cancer Network Information System Cymru (Canisc) electronic patient record system. The cancer record for each patient was linked to the following data:

- Patient Episode Database for Wales (PEDW);
- Date and cause of death from the Office for National Statistics (ONS).

Data from the above sources were provided for the cohort of women diagnosed from 01-Jan-2014 to 31-Dec-2020.

Appendix 1, Table A1_1 provides more detail on the data sources listed above and the information they contain. Additionally, a data specification document is published online at **www.nabcop.org.uk**; which provides a comprehensive list of those data items the NABCOP receives from the NCRAS and WCN, along with their data source (e.g. COSD, HES etc).

The NABCOP cohort – patient inclusion

The NCRAS and WCN extracted all the data, described in the previous section for patients fulfilling the following criteria:

Include:
- Women
- Aged 50 years or over at the point of diagnosis (no upper age limit)
- Registered diagnostic ICD-10 code of C50 (invasive breast cancer) or D05 (non-invasive breast cancer)
- With a valid diagnosis date (from 01/01/2014 to the most recently available date)

Exclude:
- Women whose cancer was only reported on their death certificate

Note: Inclusion of data on men were not considered for the NABCOP, primarily due to the low incidence

meaning analyses considering variation by age and across NHS organisations would be infeasible. Other sources provide information on annual incidence of male breast cancer.

The NABCOP team then applies the following exclusion criteria[1] to define the cohort for analysis:

1. Date of diagnosis is the same as ONS date of death.
2. There is a previous diagnosis of breast cancer before 01/01/2014.
3. The registration is for bilateral breast cancer.
4. The patient has multiple cancer registrations during the audit period.
5. Diagnosed and treated outside of an NHS organisation in England or Wales.
6. Place of diagnosis is not provided or the patient is assigned to an NHS organisation with no active breast unit.
7. Diagnosed and treated within an NHS organisation with less than 30 allocated registrations of breast cancer, in women aged 50 years and over, per year.
8. ICD-10 code not recorded as C50 or D05.1 (ductal carcinoma in situ).

Data for women diagnosed in 2020

In addition to Cancer Registration data for women diagnosed up to the end of 2019, NCRAS provided data from the Rapid Cancer Registration Dataset (RCRD) for women diagnosed from 01-Jan-2018 to 31-May-2021, linked to CWT, RTDS, SACT, HES, and ONS data.

For patients diagnosed and treated in Wales, the WCN provided the usual registration data which included women diagnosed in 2020. For women diagnosed in 2019 and 2020 data from Cancer Standards and the Radiotherapy Data were also provided.

Preparation for analysis

The NABCOP project team, based at the Clinical Effectiveness Unit (CEU)[2] received the national data from the NCRAS and WCN between October and December in the year prior to publication of the annual report. A series of steps are performed to prepare the complex and large datasets for analysis.

Specifically, using specialised statistical software[3], the project team:

Clean the datasets received.

- Checking the datasets for discrepancies
- Identifying and removing duplicate records
- Data augmentation (combining multiple sources of information).

↓

Merge the relevant datasets.

This involves restructuring the English and Welsh datasets so that they have the same format and can be analysed simultaneously.

↓

Where necessary, derive new information (data items) by combining different data items.

For example, the Charlson comorbidity index is calculated using patient diagnosis information in HES and PEDW in the two years prior to the cancer diagnosis.

↓

Conduct analyses and present audit results.

In aggregated tables and graphs for annual reports and other outputs (such as peer reviewed articles and papers).

[1] For analysis using the RCRD for England it was not possible to apply exclusions 2, 3 or 4; additionally it was not possible to distinguish D05.1 tumours from D05 tumours

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

[3] Stata® is a statistical package for data analysis, data management, and graphics (https://www.stata.com/)

Definition of variables

Patient fitness

We are interested in the fitness of a patient at the point of diagnosis, and when treatment decisions are made. This is because the NABCOP aims to understand what patient and tumour factors influence the choice of treatment(s) offered to a patient. These factors are taken into account when the audit produces information by individual NHS organisation so their statistics can be compared.

The **World Health Organization (WHO) performance status (PS)** classification is a measure of how disease(s) impact(s) a patient's ability to manage on a daily basis, [Oken *et al* 1982].[4] The NABCOP uses all available data on WHO PS to understand treatment decisions for a patient; the table below highlights where the value is recorded in the data the NABCOP receives (see **Appendix 2** for the definition of each WHO PS value).

WHO Performance Status sources		
Country	**Source**	**Associated date**
England	COSD	MDT discussion date
England	SACT	Regimen/cycle start date
Wales	Canisc	Investigation date

WHO PS at diagnosis is then calculated for a patient based on the following criteria, that:

- the value recorded is valid (i.e. 0–4).
- the value provided has an associated date that is prior to the date of treatment starting[5] and within two months of diagnosis.

Where there are multiple records of a patient's WHO PS that fulfil the above criteria, the value closest to diagnosis is taken. Where multiple values have the same date the highest (i.e. worst) is taken. Historically this information is poorly recorded within routine data.

The presence of comorbidities is not captured within a single data item by the national registration services. The NABCOP team therefore uses the Royal College of Surgeons of England (RCS) modified **Charlson Comorbidity Index (CCI)** [Armitage *et al* 2010][6] to describe these. The CCI is a commonly used scoring system for medical comorbidities, consisting of a grouped score calculated based on the absence (0) and presence (≥1) of 14 pre-specified medical conditions (**Appendix 3**). The CCI was calculated using information on secondary diagnoses (ICD-10 codes) recorded in HES APC/PEDW within the 24-month period prior to a patient's diagnosis. For the purpose of analysis, the CCI is grouped into three categories:

- (0) none of the 14 pre-specified comorbidities;
- (1) only 1 of the 14 pre-specified comorbidities;
- (2+) 2 or more of the 14 pre-specified comorbidities.

Among older patients, frailty plays an important role in what breast cancer treatments are offered to patients. This is because in frail women, the ability to tolerate stressors such as surgery, radiotherapy or chemotherapy may be significantly reduced, which can lead to morbidity and mortality. NHS organisations are recommended to screen for frailty using a formal assessment tool, although assessment is limited by the lack of an agreed instrument and the potential inaccuracies of simple tools. The **Secondary Care Administrative Records Frailty (SCARF) Index**[7] is based on the 'cumulative deficit' model [Clegg et al 2016], and describes frailty in relation to 32 different symptoms, signs, diseases and disabilities (referred to as deficits; **Appendix 4**). The index translates the 32 deficits into ICD-10 codes and counts the number of deficits in HES APC/PEDW records within the 24-month period prior to a patient's diagnosis. This methodology has been internally validated, and it produces the type of pattern that would be expected from a measure of frailty.

[4] Oken MM, Creech RH, Tormey DC, Horton J, Davis TE, McFadden ET, et al. Toxicity and response criteria of the Eastern Cooperative Oncology Group. American Journal of Clinical Oncology. 1982;5(6):649-56

[5] Based on dates for surgery or anti-cancer treatments.

[6] Armitage JN, van der Meulen JH, Royal College of Surgeons Co-morbidity Consensus G. Identifying co-morbidity in surgical patients using administrative data with the Royal College of Surgeons Charlson Score. Br J Surg. 2010;97(5):772-81.

[7] Jauhari Y, Gannon MR, Dodwell D, et al. Construction of the secondary care administrative records frailty (SCARF) index and validation on older women with operable invasive breast cancer in England and Wales: a cohort study. BMJ Open 2020;10:e035395. doi: 10.1136/bmjopen-2019-035395

The American Society of Anaesthesiologists (**ASA score**) classification is a scoring system based on perioperative health and comorbidities of a surgical patient. It is used to assess the physical status of patients before surgery, and patients are given a score ranging from 1 to 5. A higher ASA score denotes a higher risk of perioperative complications in the short and long term.

As the score is predominantly assigned to patients having surgery, its use is limited for the NABCOP towards understanding treatment decisions, as those patients not receiving surgery will not have an anaesthetic assessment and assigned an ASA score.

Socioeconomic status

The Index of Multiple Deprivation (IMD) is a relative measure of deprivation which ranks every small area in England (Lower-layer Super Output Areas (LSOAs), containing ~1,500 residents/650 households) from 1 (most deprived area) to 28,844 (least deprived)[8]. The five categories used within the NABCOP analyses are calculated by dividing the ranks into five equal groups and correspond to the most deprived 20 percent down to the least deprived 20 percent.

NHS organisation of diagnosis

The NABCOP presents organisation-level findings by the NHS organisation of diagnosis. Where this information is not provided for a patient, or where the organisation assigned does not fulfil the pre-specified inclusion criteria[9] for including the patient in the NABCOP, the following steps are followed in order to assign a diagnosing NHS organisation:

1. Use the surgery provider code (as provided within HES/PEDW) which fulfils the NABCOP pre-specified inclusion criteria; use the provider code associated with the earliest record of primary surgery (breast conserving surgery or mastectomy).
2. Use the MDT provider code for English patients, which fulfils the NABCOP pre-specified inclusion criteria; use the provider associated with the earliest MDT discussion date.

Patients provided by the NCRAS can have a Welsh local health board code assigned, with no further record of treatment within an English NHS trust. These patients cannot be included in the NABCOP analysis. This is due to the uncertainty around whether the full care pathway for such a patient is captured within the data provided. The same is true for patients provided in the WCN data with an English trust code assigned as the place of diagnosis and no record of further treatment within a Welsh local health board.

Appendix 5 provides detail of those small trusts or tertiary centres for which patients were reassigned, where possible, or not included.

Coding of key patient characteristics

The NABCOP uses data on patient characteristics provided from several data sources. Broadly, information on patient characteristics are captured within the cancer registry datasets, typically being measured around the time of diagnosis. The NABCOP focuses on measures of fitness as well as method of presentation. For the latter characteristic patients are grouped as screen-detected "Yes"/"No". Specifically, a woman is classed as having screen detected cancer where the data item screen detected is reported as "Yes" or where the referral route reported is screening. Information on screen detected status influences the coding of the route to diagnosis section; whereby route is considered to be screening where screen detected status is reported as "Yes".

Coding of key tumour characteristics

The NABCOP uses data on tumour characteristics provided from several data sources. **Appendix 6** defines the key tumour characteristics in terms of the data source and what analyses they are used in. More specifically, where a woman's breast cancer stage is not reported in the primary data sources, this is calculated from their individual T, N, M stage, using the UICC TNM classification system (**Appendix 7**).

In the NABCOP Annual Report, women are reported as having "unknown" overall stage, if there is lack of full information on all three (TNM) components; or if the stage recorded in the datasets contradicts the ICD-10 diagnosis (e.g. stage 0 recorded for ICD-10 code of C50, invasive cancer).

[8] https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/853811/IoD2019_FAQ_v4.pdf
[9] A private hospital code provided; the organisations diagnoses less than 30 patients aged 50+ years with breast cancer each year; the organisation is a tertiary centre; the hospital is in a different country to the data provider; the organisation has no active breast unit.

Treatment allocation

A patient was considered to have received surgery for breast cancer where they were identified as having received a mastectomy or breast conserving surgery within 12 months of their diagnosis date.

Those women for whom there was no breast surgical information reported in HES/PEDW, or for whom surgery was more than 12 months after diagnosis, are described as having 'no surgery'. In many cases, this will be because women had another course of treatment, such as primary endocrine therapy (PET). However, in some cases, it will be because the surgery was performed in independent healthcare providers in England and Wales. Independent hospitals do not generally contribute treatment information to the national cancer registration services datasets received by the NABCOP.

Breast conserving surgery

HES APC (England) and PEDW (Wales) records were used to identify patients who had breast conserving surgery (BCS) using the OPCS-4 procedure codes B28.1, B28.2, B28.3, B28.5, B28.7, B28.8, B28.9, B41.1, B41.2, B41.9. Where information was missing in HES/PEDW the Cancer Registration treatment records were used to identify receipt of BCS, with the same OPCS-4 codes used.

Mastectomy (with reconstruction)

HES APC (England) and PEDW (Wales) records were used to identify patients who had a mastectomy using the OPCS-4 procedure code B27 (for reconstruction the codes are B29.1-4, B29.8 B29.9, B30.1, B30.8, B30.9, B38.1, B38.2, B38.8, B38.9, B39.1-5, B39.8, B39.9, S48.2). Where information was missing in HES/PEDW the Cancer Registration treatment records were used to identify receipt of mastectomy (with reconstruction), with the same OPCS-4 codes used.

Adjuvant radiotherapy

For England, use of radiotherapy was determined from the RTDS. For Wales, Canisc was used to identify women receiving radiotherapy (along with the radiotherapy dataset provided for women diagnosed in 2019 and 2020).

Chemotherapy

For England, the SACT data item "drug group" was used to identify those women who received chemotherapy; records of the following drugs were used to flag chemotherapy for patients treated in England: cabazitaxel; capecitabine; carboplatin; cisplatin; cyclophosphamide; docetaxel; doxorubicin; epirubicin; eribulin; etoposide; fluorouracil; gemcitabine; methotrexate; mitomycin; mitoxantrone; paclitaxel; vindesine; vinorelbine.

For Wales, Canisc data were used; within these data there was no information on drug used or cycle dates so analysis beyond a "Yes/No" receipt of chemotherapy was not possible.

Dates

Diagnosis date

The date of diagnosis[10], which is used to define the audit group and subsequently used within relevant analyses, was provided within the NCRAS Registry dataset for English patients and within the Canisc dataset for Welsh patients. This is calculated using a methodology in accordance with the European Network of Cancer Registries.

Triple diagnostic assessment

In order to determine whether, for those patients not presenting through routine screening, triple diagnostic assessment was received in a single visit, the following conditions have to be met:

- Patient has a reported date of biopsy or cytology,
- Patient has a matching date of mammogram,
- OR patient has no mammogram date but has a matching date first seen (English patients only; reported within COSD).

Censor date for patients alive at the end of the audit period

For those patients with no ONS date of death, a "date last known alive" or censoring date is calculated for use in survival analyses.

- For English patients provided by the NCRAS, this is taken to be the vital status date provided; where this date is missing, the last reported date of death is used.
- For Welsh patients, the last reported date of death is used.

[10] Based on the data available this was the date of biopsy for most cases.

Assigning outcomes

Reoperation

This outcome was derived from HES APC/PEDW for women diagnosed with ductal carcinoma in situ or early invasive breast cancer, in England and Wales, between 1 January 2014 and 31 December 2019, who had breast conserving surgery (BCS). To create a variable for those patients who had a reoperation within 3 months of initial BCS, we identified those patients who had a first BCS within 12 months of diagnosis, calculated the difference in days between the first surgery date and any subsequent BCS or mastectomy date, and flagged those patients with a reoperation recorded within 3 months. Subsequent BCS or mastectomy procedures dated within seven days of the initial BCS were considered to most likely be due to a complication from the original surgery and so not counted as a reoperation.

Chemotherapy related overnight admission

This outcome was derived from HES APC/PEDW for women diagnosed with early invasive breast cancer in England, between 1 January 2014 and 31 December 2019 who had adjuvant chemotherapy and had at least one related overnight admission within 30 days of a cycle. Patients were flagged has having a chemotherapy related overnight admission where an overnight admission, recorded with a diagnostic (ICD-10) code (**Appendix 8**) indicating a chemotherapy related admission recorded, was within 30 days of a chemotherapy cycle.

Short-term mortality following chemotherapy for invasive breast cancer

This outcome was derived from ONS mortality data for women diagnosed with early invasive or metastatic breast cancer in England, between 1 January 2014 and 31 December 2019 who had chemotherapy and had death recorded within 30 days of any chemotherapy cycle.

Reported recurrence

Record of a recurrence for an individual patient were coded from the specific data items on recurrence or diagnosis of a non-primary cancer within the data received by the NABCOP.

In the data received for Wales, recurrence was calculated as "Yes" for a patient where at least one of local recurrence, regional recurrence, or a date of recurrence, was recorded.

In data for patients in England, recurrence is reported within COSD. For the NABCOP analyses a patient was coded as having a recurrence where at least one of the following was reported:

- Metastatic site of recurrence
- Date of recurrence
- Key worker seen for recurrence
- A care plan for recurrence
- Palliative specialist seen for recurrence
- Recurrence non-primary cancer pathway type
- Recurrence or metastases type reported as local, regional or distant within the non primary cancer pathway data
- Recurrence reason for referral within the non primary cancer pathway data

Death

Record of death for an individual patient was coded where a date of death was provided within the ONS data.

Patient experience

We analysed data captured by the following selected questions collected in the CPES questionnaires between 2015 and 2019: 14, 15, 16, 18, 22, 23, 41, 46, 49, 53 and 61 (question numbers as per the 2019 CPES questionnaire). These are listed in full, along with the possible responses, in **Appendix 9**.

For each question (excluding Q61), each response option was identified as a positive, negative or neutral response. Scores for use within graphs were calculated using the total number of positive responses as the numerator, and the total positive and negative responses as the denominator. Responses which were neutral, such as "Don't know / can't remember" were excluded from the calculation. Mapping of positive/negative/neutral responses can be found in **Appendix 9**. For Q61 (rating of overall care on a scale of 0 to 10) the percentage of respondents who rated their care as 10 (very good) were used as the numerator, with all recorded responses as the denominator.

Results are reported as percentages (%), typically provided as an overall figure, but further broken down by age at diagnosis and over time where a difference was observed. Further information, including national

CPES results and survey methodology, is available via the CPES website: https://www.ncpes.co.uk/

Some of the assessed CPES questions, their assigned number, or responses within the questionnaire have changed between the 2019 and 2015-2018 versions. The table in **Appendix 9** describes differences in question numbers and options for 2019 versus previous years.

Statistical analysis

All statistical analyses were conducted using Stata version 17.

Most results in the NABCOP 2022 Annual Report are descriptive. The results of categorical data items are reported as percentages (%). In descriptive analyses of continuous variables, the distribution of values is described using appropriate statistics (e.g. mean and standard deviation or median and interquartile range). Results are typically provided as an overall figure and broken down by age at diagnosis, (and by diagnosing NHS organisation in the online NHS tables). Note that within tables in the annual report, the total percentage may not equal 100%, owing to rounding errors.

We follow the Office for National Statistics (ONS) policy on the publication of small numbers to minimise the risk of patient identification from these aggregate results. Within figures showing findings by NHS organisation, percentages are not presented for those NHS organisations with less than 10 patients within the patient group of interest, over the six-year period.

Percentages are presented to zero decimal places, where the range of values is wide. Where the range of values is narrow percentages are presented to one decimal place to allow for clearer differentiation.

Adjusted outcomes

For analyses evaluating receipt of treatment across NHS organisations, including surgery, chemotherapy, and outcomes looking at reoperation rates following initial breast conserving surgery, statistical models were fitted to calculate a "risk adjusted" percentage to account for differences in case-mix, allowing comparison across NHS organisations. Such models included clinically relevant patient and tumour factors likely to contribute to treatment decisions. The models were then used to estimate the probability of an individual having the outcome (treatment or at least one reoperation); these individual probabilities were summed to calculate an expected number of outcomes. This was combined with the observed outcomes to produce the risk-adjusted indicator value for each NHS organisation (a method known as indirect standardisation). Details of the patient and tumour characteristics adjusted for are provided within **Appendix 10**. Categories of "unknown" were created where data items had missing, unintelligible or conflicting information, in order to ensure all patients contributed to the statistical models.

Funnel plots

Funnel plots are used to make comparisons, and graphically display variation, between NHS organisations. The plots are generated by plotting the rate for each NHS organisation against the total number of patients used to estimate the rate. The 'All NABCOP NHS Orgs %' is the average rate across all NHS organisations.

The funnel plots include control limits defining differences corresponding to two standard deviations (inner limits) and three standard deviations (outer limits) from the overall average. These limits get wider where organisations have a lower volume of patients and narrower where there is higher volume, reflecting the increased variability in results when there are fewer patients per organisation.

Relative survival

Estimates of relative survival were obtained using stpm2 and its post estimation commands, within Stata, with population mortality data from ONS to provide the baseline survival.

For those patients with no ONS date of death, a "date last known alive" or censoring date was calculated for use in survival analyses.

- For English patients provided by the NCRAS, this was taken to be the vital status date provided; where this date was missing, the last reported date of death was used.
- For Welsh patients, the last reported date of death was used.

Appendix 1: Cancer Registration data sources

Overview of the data sources and content provided for the NABCOP Annual Report.

Country	Data source	Content
England	Cancer registry	Data on all aspects of the cancer registration including information from hospital pathology systems.
England	COSD	Cancer Outcomes and Servives dataset (COSD) items, are submitted routinely by service providers via multidisciplinary team (MDT) electronic data collection systems to the National Cancer Data Repository (NCDR) on a monthly basis.
England	SACT	Systemic Anti-Cancer Therapy (SACT) data contains information on chemotherapy dates, regime(s) and dose.
England	RTDS	Radiotherapy dataset (RTDS) contains information on radiotherapy treatment including dates, prescripion region and dose.
England	HES	Hospital Episode Statistics (HES) is the administrative database of all NHS hospital admissions in England; records were supplied by NHS Digital to NCRAS.
England	CPES	Cancer Patient Experience Survey (CPES), completed by patients diagnosed in England from 2014-2019.
Wales	Canisc	Cancer Network Information System Cymru (Canisc) contains data on all aspects of the cancer registration including investigations
Wales	PEDW	Patient Episode Database for Wales (PEDW) is the administrative database of all NHS hospital admissions in Wales.
England & Wales	ONS	Office for National Statistics (ONS) death data including date of death and cause of death.

Appendix 2: WHO Performance Status

WHO Performance Status values and corresponding definition.

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

Appendix 3: Charlson Comorbidity Index

Pre-specified conditions included in the assignment of Charlson Comorbidity Index.

Conditions			
Myocardial infarction	Dementia	Diabetes mellitus	Metastatic solid tumour
Congestive cardiac failure	Chronic pulmonary disease	Hemiplegia or paraplegia	AIDS/HIV infection
Peripheral vascular disease	Rheumatological disease	Renal disease	
Cerebrovascular disease	Liver disease	Any malignancy	

Appendix 4: Secondary Care Administrative Records Frailty Index

Pre-specified deficits included in the calculation of the Secondary Care Administrative Records Frailty Index.

Deficit			
Activity limitation	Diabetic complications	Hypotension	Requirement for care
Anaemia	Falls	Ischaemic heart disease	Respiratory disease
Arthritis	Foot problems	Incontinence	Skin ulcer
Cardiac arrhythmias	Fragility fracture	Neurodegenerative disorders	Sleep disturbance
Cerebrovascular disease	Hearing impairment	Nutritional Problems	Social vulnerability
Chronic kidney disease	Heart failure	Osteoporosis	Thyroid disease
Cognitive and mental health problems	Heart valve disease	Peptic ulcer	Urinary system disease
Diabetes	Hypertension	Peripheral vascular disease	Visual impairment

Appendix 5: Small and non-approved NHS trusts

1. The registration dataset for 2014–19 included several NHS trusts at which fewer than 180 patients were diagnosed over the six-year period. These NHS trusts were not included in this report. They are: Lancashire & South Cumbria NHS Foundation Trust, Queen Victoria Hospital NHS Foundation Trust, Epsom & St Helier University Hospitals NHS Trust, Southport & Ormskirk Hospital NHS Trust, Yeovil District Hospital NHS Foundation Trust, and Homerton University Hospital NHS Foundation Trust.

2. A further four NHS trusts had fewer than 30 patients diagnosed in the most recent year this report presents data on (i.e. 2019) and as such are not included; these are: South Tyneside NHS Foundation Trust, University Hospitals Bristol NHS Foundation Trust, Weston Area Health NHS Trust, Salford Royal NHS Foundation Trust.

3. The Christie NHS Foundation Trust, Clatterbridge Cancer Centre NHS Foundation Trust and Velindre NHS Trust are tertiary centres that mainly provide oncological treatment for breast cancer patients. They have therefore not been included directly within the NABCOP report.

For all 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 6: Tumour characteristics coding

Details of data items used within the NABCOP Annual Report; data source and where they are used.

Item	Where data comes from		Indicator
	England	**Wales**	
Non-invasive grade	COSD BR4160	Canisc	Data completeness
Invasive grade	COSD BR4170	Canisc	Data completeness; risk-adjustment
ER status	COSD BR4220 COSD BR4230 (ER Score)	Canisc	Recorded molecular marker status; risk-adjustment
HER2 status	COSD BR4280 COSD BR4310 (HER2 ISH)	Canisc	Recorded molecular marker status; risk-adjustment
PR status	COSD BR4290 COSD BR4300 (PR Score)	Canisc	Data completeness
Whole tumour size	COSD BR4190	Canisc	Data completeness
DCIS size	COSD BR4180	Canisc	Data completeness
Tumour stage	COSD CR0520 COSD CR0620 COSD CR0910	Canisc	Data completeness; risk-adjustment
Nodal stage	COSD CR0540 COSD CR0630 COSD CR0920	Canisc	Data completeness; risk-adjustment
Metastases stage	COSD CR0560 COSD CR0640 COSD CR0930	Canisc	Data completeness
Overall stage	COSD CR0580 COSD CR0610 COSD CR0940	*Not available*	Data completeness; risk-adjustment
WHO performance status	COSD CR0510 SACT	Canisc	Data completeness; Receipt of surgery by age and patient fitness
Nodes excised	COSD CR0890	Canisc	Data completeness
Nodes positive	COSD CR0900	Canisc	Data completeness
Source of referral	COSD CR1600	Canisc	Route to diagnosis; risk-adjustment
Screen-detected status	Breast Screening Audit SHIM COSD CR1600 = screening	Canisc	Route to diagnosis; risk-adjustment
Date of biopsy	COSD CR1010 COSD CR0780	Canisc	Triple assessment in a single visit
Date of mammogram	COSD CR0320 COSD BR4030	Canisc	Triple assessment in a single visit
Date first seen	COSD CR0230	*Not available*	Triple assessment in a single visit
Clinical Nurse Specialist indication code	COSD CR2050	Canisc	Seen by a breast CNS
Receipt of surgery	OPCS codes in HES – operation date within 12 months of diagnosis.	OPCS codes in PEDW– operation date within 12 months of diagnosis.	Treatment
Receipt of chemotherapy	SACT – Start date within nine months of primary surgical procedure (BCS or mastectomy).	Canisc – Start date within nine months of primary surgical procedure (BCS or mastectomy)	Treatment
Receipt of trastuzumab		*Not available*	Treatment

Item	Where data comes from		Indicator
	England	**Wales**	
Receipt of radiotherapy	RTDS – Start date within six months of primary surgical procedure (BCS or mastectomy) OR start date over six months after the primary surgical procedure, BUT only if chemotherapy is given in the interim.	Radiotherapy dataset – Start date within six months of primary surgical procedure (BCS or mastectomy) OR start date over six months after the primary surgical procedure, BUT only if chemotherapy is given in the interim.	Treatment
Charlson comorbidity index (CCI)	ICD-10 codes in HES – dated within two years prior to diagnosis	ICD-10 codes in PEDW– dated within two years prior to diagnosis	Receipt of surgery by age and patient fitness; risk-adjustment
Secondary Care Administrative Records Frailty (SCARF) Index	ICD-10 codes in HES– dated within two years prior to diagnosis	ICD-10 codes in PEDW– dated within two years prior to diagnosis	Receipt of surgery by age and patient fitness; risk-adjustment
Deprivation	IMD quintiles from LSOA where not reported as IMD	WIMD quintiles calculated from LSOA in Canisc	Risk adjustment

Appendix 7: TNM stage groupings.

Stage grouping	T stage	N stage	M stage
DCIS / Stage 0	Tis	N0	M0
Early breast cancer			
IA	T1	N0	M0
IB	T0 / T1	N1(mi)	M0
IIA	T0 / T1 T2	N1 N0	M0
IIB	T2 T3	N1 N0	M0
IIIA	T0, T1, T2 T3	N2 N1, N2	M0
Locally advanced disease			
IIIB	T4	N0, N1, N2	M0
IIIC	Any T	N3	M0
Metastatic disease			
IV	Any T	Any N	M1

Key:

Tumour size –

T1 = 1-20mm;

T2 = 21-50mm;

T3 = 51+mm;

T4 = tumour spread to skin or chest wall.

Nodal status –

N0 = no cancer cells in lymph nodes;

N1-3 = increasing spread of cancer within lymphatic system;

mi = micrometastases.

Appendix 8: Coding for chemotherapy-related admission

The table below provides details of the diagnostic codes used to identify chemotherapy-related acute care visits in administrative data among patients receiving chemotherapy for early-stage breast cancer. The codes were validated in work by Krzyzanowska et al (2018)[11] which looked at using administrative data to accurately identify treatment-related complications.

Toxicity	Description	ICD-10 code
Neutropenia	Agranulocytosis- Including drug induced	D70
Fever	Other Specified Fever (Chills with fever; Persistent fever; Fever with rigors)	R508
	Fever unspecified (Fever NOS; FUO; Hyperpyrexia NOS ; Pyrexia NOS ; Pyrexia UO)	R509
Infection	Infectious and parasitic diseases	A00-B99
	Line associated Infection	T82.7
	Bronchitis	J20-J22
	Pneumonia	J12-J18
	Kidney Infection	N10, N390
	Acute cystitis	N300
	Cellulitis	L00-L08
	Empyema	J86
	Abscess of lung/mediastium	J85
	Other septicaemia	A41
	Septicaemia unspecified	A419
	Septicaemia other	A418
GI Toxicity	Diarrhea	K52
	Functional diarrhea	K59.1
	Nausea/emesis	R11
	Heartburn	R12
	Constipation	K59.0
	Obstruction	K56
	Stomatitis	K12
	Cachexia	R64.0
	Anorexia	R63.0
Other Systemic Treatment Related	Hyponatremia	E87.1
	Hypokalemia	E87.6
	Electrolyte disorder Magnesium disorder	E87.0, 2, 3, 4, 5, 7, 8 E834
	Dehydration/hypovolemia	E86
	Malaise/Fatigue	R53
	Syncope	R55
	Dizziness	R42
	Hypotension	I959
	Fe deficiency anaemia	D50
	Other deficiency anaemia	D51-D53
	Aplastic anemia	D60, D61
	Other and unspecified anemia	D62-D64
	Thrombocytopenia	D69.5, D69.6
	Other venous embolism and thrombosis	I82
	Rash and non-specific skin eruptions	R21
	Hyperglycemia	R73
	Phlebitis	I808

Note: ICD-10: International Statistical Classification of Diseases and Related Health Problems 10th revision; NOS= not otherwise specified; FUO= fever of unknown origin; UO= unknown origin

[11] Krzyzanowska MK, Enright K, Moineddin R, Yun L, Powis M et al. Can Chemotherapy-Related Acute Care Visits Be Accurately Identified in Administrative Data? *J Oncol Pract* 2018 Jan;14(1):e51-e58.

Appendix 9: CPES questions

Details of CPES questions used for analysis of patient experience.

2019 CPES Question		2019 answer option	Scoring	Question no. in 2015-2018 CPES	Previous answer options in 2015-2018 CPES
Q14	Before your cancer treatment started, were your treatment options explained to you?	1 Yes, completely	1	Q12	
		2 Yes, to some extent	0		
		3 No	0		
		4 There was only one type of treatment that was suitable for me	N/A		
		5 Don't know / can't remember	N/A		
Q15	Were the possible side effects of treatment(s) explained in a way you could understand?	1 Yes, definitely	1	Q13	
		2 Yes, to some extent	0		
		3 No, side effects were not explained	0		
		4 I did not need an explanation	N/A		
		5 Don't know / can't remember	N/A		
Q16	Were you offered practical advice and support in dealing with the side effects of your treatment(s)?	1 Yes, definitely	1	Q14	
		2 Yes, to some extent	1		
		3 No, I was not offered any practical advice or support	0		
		4 Don't know / can't remember	N/A		
Q18	Were you involved as much as you wanted to be in decisions about your care and treatment?	1 Yes, definitely	1	Q16	1 Yes, definitely 2 Yes, to some extent 3 No, but I would like to have been more involved 4 Don't know / can't remember
		2 Yes, to some extent	0		
		3 No	N/A		
			N/A		
Q22	Did hospital staff give you information about support or self-help groups for people with cancer?	1 Yes	1	Q20	
		2 No, but I would have liked information	0		
		3 It was not necessary	N/A		
		4 Don't know / can't remember	N/A		
Q23	Did hospital staff discuss with you or give you information about the impact cancer could have on your day to day activities (for example, your work life or education)?	1 Yes	1	Q21	
		2 No, but I would have liked a discussion or information	0		
		3 It was not necessary / relevant to me	N/A		
		4 Don't know / can't remember	N/A		
Q41	Did hospital staff tell you who to contact if you were worried about your condition or treatment after you left hospital?	1 Yes	1	Q41	
		2 No	0		
		3 Don't know / can't remember	N/A		
Q46	Beforehand, did you have all of the information you needed about your radiotherapy treatment?	1 Yes, completely	1	Q44	
		2 Yes, to some extent	0		
		3 No	0		
		4 I did not need any information	N/A		
Q49	Beforehand, did you have all of the information you needed about your chemotherapy treatment?	1 Yes, completely	1	Q47	
		2 Yes, to some extent	0		
		3 No	0		
		4 I did not need any information	N/A		
Q53	Once your cancer treatment finished, were you given enough care and support from health or social services (for example, district nurses, home helps or physiotherapists)?	1 Yes, definitely	1	Q51	
		2 Yes, to some extent	0		
		3 No	0		
		4 I did not need help from health or social services	N/A		
		5 I am still having treatment	N/A		
		6 Don't know / can't remember	N/A		
Q61	Overall, how would you rate your care? (scale from 0 to 10)	0-10	Scored if response = 10	Q59	

Appendix 10: Risk-adjusted percentages

Details of the characteristics adjusted for in those figures presenting risk-adjusted percentages within the NABCOP 2022 Annual Report.

Section	Figure Number	Denominator	Characteristics included in risk-adjusted statistical model
3.6	3.6.1	Women. ICD-10 code D05.	Logistic regression models fitted within each age group, adjusted for patient age and fitness at diagnosis, (W)IMD, method of presentation, non-invasive grade.
3.7	3.7.4	Women. ICD-10 code C50. Stage 1-3A. ER status reported.	Random effects logistic regression models fitted within each age and ER status group adjusted for patient age and fitness at diagnosis, (W)IMD, method of presentation, ER status, HER2 status, pre-treatment stage, invasive grade.
3.7	3.7.9	Women. Diagnosed in England. ICD-10 code C50. Stage 1-3A. Surgery within 6m of diagnosis. No prior chemo. HER2 positive.	Risk-adjusted % of women. Random effects logistic regression models adjusted for patient age and fitness at diagnosis, tumour stage, nodal stage, ER status, invasive grade, IMD.
3.8	3.8.1	Women. ICD-10 code C50, Stage 4.	Risk-adjusted % of women. Random effects logistic regression models adjusted for patient age and fitness at diagnosis, tumour stage, nodal stage, HER2 status, ER status, invasive grade, (W)IMD, method of presentation.