

NABCOP Annual Report Methodology

Data receipt and processing

What data do the NABCOP receive for analysis?

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 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.
- Date and cause of death from the Office for National Statistics (ONS).

Additionally the NABCOP received English Cancer Patient Experience Survey (CPES) data, completed by patients in England between 2015 and 2018.

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

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

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).

Which patients are data provided for?

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 diagnosis date between 01/01/2014 to 31/12/2018 (inclusive)

Exclude:

- Women whose cancer was only reported on their death certificate

Note that inclusion of data on men are not considered for the NABCOP at this time, 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 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).

How are data prepared for analysis?

The NABCOP project team, based at the Clinical Effectiveness Unit (CEU)¹ receives 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 software², 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 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.

² Stata® is a statistical package for data analysis, data management, and graphics (<https://www.stata.com/>)

Measures of 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 which is offered to a patient. These factors can then be taken into account when the audit produces information on NHS organisations so that their statistics can be compared.

This section provides information on the measures of fitness the NABCOP receives or derives for the purpose of analysis.

Performance Status

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].³

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 1, Table A1_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. 0–5).
- the value provided has an associated date that is prior to the date of treatment starting⁴ 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.

Comorbidity

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]⁵ to describe these.

The CCI is a commonly used scoring system for medical comorbidities. It consists of a grouped score that is calculated based on the absence (0) and presence (≥ 1) of 14 pre-specified medical conditions. The CCI was calculated using information on secondary diagnoses (ICD-10 codes) in the hospital admission data (HES/PEDW) recorded within the 24-month period prior to a patient's diagnosis of breast cancer. The conditions covered are detailed in [Appendix 1, Table A1_3](#).

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.

Frailty

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 measure of frailty used in this report is based on the 'cumulative deficit' model [Clegg *et al* 2016], and describes frailty in relation to 32 different symptoms, signs, diseases and disabilities (referred to as deficits). The index counts the number of deficits recorded in hospital admissions around the time of diagnosis, as well as in the previous two years.

³ 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

⁴ Based on dates for surgery or anti-cancer treatments.

⁵ 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.

The Secondary Care Administrative Records Frailty (SCARF) Index⁶ translates the 32 deficits into ICD-10 codes that can be identified within the diagnosis fields of hospital admissions data. This methodology has been internally validated, and it produces the type of pattern that would be expected from a measure of frailty. See **Appendix 1, Table A1_4** for the list of deficits used within the SCARF Index.

ASA score

The American Society of Anaesthesiologists (ASA) 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.

⁶Jauhari 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

Statistical methods

Statistical analysis

For the majority of the indicators presented within the NABCOP Annual Reports, the results are reported as percentages (%). Results are typically provided as an overall figure and broken down by age at diagnosis, (and by diagnosing NHS organisation in the online NHS tables). Note that within tables in the annual report, the total percentage may not equal 100% owing to rounding errors.

In descriptive analyses of continuous variables, the distribution of values is described using appropriate statistics (e.g. mean and standard deviation or median and interquartile range). 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.

All analyses were undertaken by the NABCOP project team at the Clinical Effectiveness Unit, Royal College of Surgeons of England.

Assigning NHS organisation of diagnosis

Details of the organisation at which each patient was diagnosed are provided in both the England and Wales datasets. For England, the NHS trust of diagnosis is assigned by the NCRAS.

There are some patients however, where either no organisation is assigned or the organisation assigned does not fulfil the criteria for including the patient in the NABCOP (e.g. private hospital code; small trust numbers; tertiary centre; hospital in a different country to the data provider; organisation has no active breast unit). For such cases, 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 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 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.

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 2, Table A2_1** 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 1, Table A1_5**).

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).

Coding receipt of treatment

Primary surgery

Information on patterns of surgery was derived using the data in the routine hospital datasets (HES for English patients; PEDW for Welsh patients) as well as the cancer registration treatment datasets. We identified when a patient underwent different types of surgery by searching for admissions in which the relevant OPCS procedure codes appear. A list of procedure codes is provided in **Appendix 1, Table A1_6**.

For the NABCOP analyses considering use of surgery, we consider the receipt of surgery within 12 months of diagnosis. 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 here 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.

Adjuvant therapy

Use of radiotherapy was determined from the RTDS, for those women diagnosed and treated in England, and from the Welsh radiotherapy dataset for those women diagnosed and treated in Wales. For the 2020 Annual Report this dataset was not provided for women diagnosed and treated in Wales, therefore use of radiotherapy was calculated solely from the Canisc data.

Use of chemotherapy was determined from the SACT data, for those women diagnosed and treated in England, and from the Canisc data for those women diagnosed and treated in Wales.

For the NABCOP analyses, receipt of adjuvant treatment within a pre-specified time frame following surgery (see **Appendix 2, Table A2_1**) was used to code receipt of adjuvant treatment as "Yes". Where the adjuvant treatment was either not reported, or it was reported as starting outside of the pre-specified time frame, the patient was considered not to have received the relevant treatment. The time frames

were used in order to more accurately conclude that the treatments were given for the index breast cancer episode and not for recurrence.

Dates

Diagnosis date

The date of diagnosis⁷, 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.

Risk adjustments

For indicators evaluating receipt of treatment, such as having surgery, statistical models were fitted to calculate a "risk adjusted" percentage to account for differences in case-mix, allowing comparison across organisations. To account for any clustering within NHS organisation multi-level, mixed-effects logistic regression models were fitted to the data. Such models included clinically relevant patient and tumour factors likely to contribute to treatment decisions. The

⁷ Based on the data available this was the date of biopsy for most cases.

models were then used to estimate the probability of an individual experiencing the outcome (e.g., receiving treatment); 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 2, Table A2_2**. 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.

Patient experience

We analysed data captured by the following seven questions collected in the CPES 2015, 2016 and 2018 questionnaires: 12, 16, 17, 18, 44, 47 and 59. These are listed in full, along with the possible responses, in **Appendix 3**. Results are reported as percentages (%), typically provided as an overall figure, but further broken down by age at diagnosis where a difference was observed.

Relative survival

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

In the NABCOP Annual Report we present graphical plots of relative survival for disease subgroups in order to show the impact of breast cancer on survival following diagnosis. 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.

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

Appendix 1

Table A1_1: 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 Services 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, prescription 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 2015-2018.
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.

Table A1_2: WHO Performance Status values and corresponding definition.

WHO PS	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

Table A1_3: Charlson Comorbidity Index – pre-specified conditions.

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	

Table A1_4: Secondary Care Administrative Records Frailty Index – pre-specified deficits.

Deficit			
Activity limitation	Diabetic complications	Hyotension	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

Table A1_5: TNM stage groupings.

Stage grouping	T stage	N stage	M stage	Key: Tumour size – T1 = 1-20mm; T2 = 21-50mm; T3 = 51+mm; T4 = tumour spread to skin or chest wall.
<i>DCIS / Stage 0</i>	Tis	N0	M0	
<i>Early breast cancer</i>				
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	
<i>Locally advanced disease</i>				
IIIB	T4	N0, N1, N2	M0	
IIIC	Any T	N3	M0	
<i>Metastatic disease</i>				
IV	Any T	Any N	M1	

Table A1_6: OPCS codes used to define surgical procedures for analysis.

Surgical procedure	OPCS code(s)
BCS	B28.1, B28.2, B28.3, B28.5, B28.7, B28.8, B28.9, B41.1, B41.2, B41.9
Mastectomy	B27
Reconstruction	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
SLNB	T86.2, T87.3, T91.1
AND	T85.2

Appendix 2

Table A2_1: 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	<i>Not available</i>	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	<i>Not available</i>	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		<i>Not available</i>	Treatment
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	Radiotherapy dataset – Start date within six months of primary surgical procedure (BCS or mastectomy) OR start date over six months after the primary surgical	Treatment

Item	Where data comes from		Indicator
	England	Wales	
	procedure, BUT only if chemotherapy is given in the interim.	procedure, BUT only if chemotherapy is given in the interim.	
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

Table A2_2: Details of the content of figures within the NABCOP 2020 Annual Report

Section	Figure Number	Denominator	Observed or risk-adjusted
5.1	5.2	Women diagnosed in 2018.	Observed number of women.
5.1	5.3	All women.	Observed % of women.
5.2	5.4	Women diagnosed in 2018. ICD-10 code C50.	Observed % of women.
6.1	6.1	Women diagnosed in 2018.	Observed % of women.
	6.2	Women diagnosed in 2018.	Observed % of women.
6.2	6.3	Women. ICD-10 code C50. Stage 1-3A. Method of presentation not screening.	Observed % of women.
	6.4	Women diagnosed in 2018. ICD-10 code C50. Stage 1-3A. Method of presentation not screening.	Observed % of women.
	6.5	Women diagnosed in 2018. ICD-10 code C50. Stage 1-3A. Method of presentation not screening.	Strict = Observed % of women; Relaxed = Observed % of women.
6.3	6.6	Women diagnosed in 2018 with data on CNS contact reported.	Observed % of women.
	6.7	All women.	Observed % of women.
7.1	7.1	Women. ICD-10 code D05. Grade reported.	Observed % of women.
	7.2	Women. ICD-10 code D05.	Risk-adjusted % of women. Logistic regression models fitted within each age group, adjusted for patient age and fitness at diagnosis, (W)IMD, method of presentation, non-invasive grade.
7.2	7.3	Women. ICD-10 code D05.	Observed % of women.
8.1	8.1	Women. ICD-10 code C50. Stage 1-3A. ER status reported.	Observed % of women.
	8.2	Women. ICD-10 code C50. Stage 1-3A. ER status reported.	Observed % of women.
	8.3	Women. ICD-10 code C50. Stage 1-3A. ER status reported.	Risk-adjusted % of women. 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.
8.2	8.4	Women. ICD-10 code C50. Stage 1-3A. Surgery within 6m of diagnosis.	Observed % of women.
	8.5	Women. ICD-10 code C50. Stage 1-3A. Surgery within 6m of diagnosis.	Observed % of women.
	8.6	Women. ICD-10 code C50. Stage 1-3A. Surgery within 6m of diagnosis.	Observed % of women.
8.3	8.7	Women. ICD-10 code C50. Stage 1-3A. Surgery within 6m of diagnosis. No prior chemo. ER status reported.	Observed % of women.
	8.8	Women. Diagnosed in England. ICD-10 code C50. Stage 1-3A. Surgery within	Observed % of women.

Section	Figure Number	Denominator	Observed or risk-adjusted
		6m of diagnosis. No prior chemo. HER2 positive.	
	8.9	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.
9	9.1	Women. ICD-10 code C50. Stage 4. ER status reported.	Predicted % of women. Random effects logistic regression models adjusted for patient age at diagnosis (spline at age 70 years), CCI/SCARF, tumour stage, nodal stage, HER2 status, ER status, invasive grade, (W)IMD, method of presentation.
	9.2	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.
10.2	10.1	All women.	Observed % of women
	10.2	All women.	Observed % of women
10.3	10.3	Women. ICD-10 code D05. No surgery.	Observed % of women. Line plot of relative survival estimates.
	10.4	Women. ICD-10 code C50. Stage 1-3A. ER status reported. No surgery.	Observed % of women. Line plot of relative survival estimates.
	10.5	Women. ICD-10 code C50. Stage 1-3A. ER status reported. No surgery. Charlson calculated.	Observed % of women. Line plot of relative survival estimates.
	10.6	Women, ICD-10 code C50, Stage 4.	Observed % of women. Line plot of relative survival estimates.

Appendix 3

Details of CPES questions used for analysis of patient experience.

12. Before your cancer treatment started, were your treatment options explained to you?

- 1 Yes, completely
- 2 Yes, to some extent
- 3 No
- 4 There was only one type of treatment that was suitable for me
- 5 Don't know / can't remember

16. Were you involved as much as you wanted to be in decisions about your care and treatment?

- 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

17. Were you given the name of a Clinical Nurse Specialist who would support you through your treatment?

- 1 Yes → Go to Q18
- 2 No → Go to Q20
- 3 Don't know / can't remember → Go to Q20

18. How easy or difficult has it been for you to contact your Clinical Nurse Specialist?

- 1 Very easy
- 2 Quite easy
- 3 Neither easy nor difficult
- 4 Quite difficult
- 5 Very difficult
- 6 I have not tried to contact my Clinical Nurse Specialist

44. Beforehand, did you have all of the information you needed about your radiotherapy treatment?

- 1 Yes, completely
- 2 Yes, to some extent
- 3 No
- 4 I did not need any information

47. Beforehand, did you have all of the information you needed about your chemotherapy treatment?

- 1 Yes, completely
- 2 Yes, to some extent
- 3 No
- 4 I did not need any information

59. Overall, how would you rate your care?
(Please circle a number)

