Understanding Practice in Clinical Audit and Registries tool: UPCARE-tool

A protocol to describe the key features of clinical audits and registries

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UPCARE tool for

The National Audit of Breast Cancer

in Older Patients (NABCOP)

FAQ

Who should complete the tool?

This tool is designed to be completed by individuals and organisations planning and implementing clinical audits and registries. It has been specifically designed for national clinical audits and registries commissioned by the Healthcare Quality Improvement Programme (HQIP; Part of the National Health Service in England) as part of the National Clinical Audit and Patient Outcome Programme (NCAPOP), but can be adapted and used by audits and registries in other settings.

What is the tool for?

The tool is a protocol for audits and registries. It has been designed to provide a "one-stop" summary of the key information about how clinical audits and registries have been designed and carried out. It is expected that this will be published openly for anyone to view, and help users of audit/registry data and audit/registry participants understand the methods, evaluate the quality and robustness of the data, and find information and data that is most relevant to them. For national clinical audits and registries commissioned by HQIP, the intention is that publishing this information openly will reduce the requirement for reporting ad hoc and contract monitoring data and information to HQIP and other national agencies.

What type of information is contained within UPCARE?

It is intended that the responses to the tool are factual and written concisely. Where possible, documents can be embedded and hyperlinks provided if information is published elsewhere. This document is intended to be a complete account of the information for the audit or registry. Please be vigilant about keeping any links included in the document up to date so readers can access full information about the audit or registry.

This tool is not intended to be used to formally "score" the quality of the responses. The design of this tool has been inspired by reporting checklists used for clinical guidelines (e.g. AGREE[1]) and in reporting research studies (e.g. STROBE[2], SQUIRE[3]).

Who is the intended audience for the tool?

The information contained within the UPCARE tool will enable audit and registry stakeholders to access in one place and in a standard format key information about the audit/registry and evaluate the integrity and robustness of the audit.

Examples of audit/registry stakeholders include:

- Patients / Carers / Public / Patient representative organisations
- Clinicians / Allied health professionals / Healthcare providers / Multi-disciplinary teams / Primary, secondary and tertiary care providers
- National agencies
- Commissioners
- Healthcare regulators

[1] AGREE stands for the Appraisal of Guidelines for Research & Evaluation. See https://www.agreetrust.org/practice-guidelines/ - last accessed 8 November 2019.

[2] STROBE stands for Strengthening the Reporting of Observational Studies in Epidemiology. See https://www.strobe-statement.org/index.php?id=strobe-home - last accessed 8 November 2019.

[3] SQUIRE stands for Standards for Quality Improvement Reporting Excellence. See http://www.squire-statement.org/ - last accessed 8 November 2019.

FAQ (cont'd)

How should the responses be written?

Please try and write responses clearly as this will help to make the tool accessible and useful. Some tips and suggestions for writing clearly include:

- avoiding technical jargon where possible
- using short paragraphs and bullet points
- using the "active" voice rather than passive
- keeping sentences short

Where information is published openly elsewhere please provide links and references rather than duplicating information that is already available

When and how often should I complete the tool?

The tool is intended to provide accurate and up to date information about the audit/registry, and so can be updated whenever and however frequently it is relevant to do so. For national clinical audits and registries commissioned by HQIP it is intended that the tool is updated annually, although audits can update the tool more frequently if they wish to.

Each version of the tool should include a date of publication and version number.

Where should the completed UPCARE report be published?

The completed tool should be published online e.g. on the website for the audit or registry.

How was UPCARE designed?

HQIP commission, manage and develop the NCAPOP (National Clinical Audit and Patient Outcomes Programme) under contract from NHS England and devolved nations. The work was led by HQIP who set up a Methodological Advisory Group (MAG) consisting of methodological, statistical and quality improvement experts. Meeting were held on a six monthly basis and the structure and content of the eight quality domains and their key items were agreed by the MAG. The tool was piloted by 5 programmes within the NCAPOP and re-edited in light of comments received. Other comments received by MAG members was also considered as part of the re-editing process. The final version of the UPCARE tool was signed off by the HQIP MAG and will be reviewed annually.

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Contents

Domain 1: Organisational information

1.1. The name of the programme

National Audit of Breast Cancer in Older Patients (NABCOP)

1.2. The name of the organisation carrying out the programme

The Clinical Effectiveness Unit of the Royal College of Surgeons

1.3. Main website for the programme

www.nabcop.org.uk

1.4. Date of publication and version number of the tool on your website

This 09/08/18 draft will be reviewed for publication once it has been signed off by HQIP.

Domain 2: Aims and objectives

2.1. Overall aim

Note: A short description of the overall aim(s) of the programme

This audit was commissioned to evaluate the quality of care provided to women aged 70 years or older by breast cancer services in England and Wales. It will explore why older women with breast cancer appear to have worse outcomes than younger women and investigate apparent differences in the patterns of care delivered to older women. The Audit will examine the care pathway from initial diagnosis to the end of primary treatment, and compare how patterns of breast cancer care observed for women aged 70 years and over with those among women diagnosed aged 50-69 years. (See www.nabcop.org.uk for more details).

2.2. Quality improvement objectives

Note: A list or description of the key quality improvement (QI) objectives of the programme. A brief rationale for how the QI objectives were chosen. Please take into consideration evidence to support the QI objectives, including the COMET (Core Outcome Measures in Effectiveness Trials) initiative[4].

[4] The COMET initiative, established through funding from the Medical Research Council (MRC) North West Hub for Trials Methodology brings together people who are interested in developing and applying agreed standardised sets of outcomes known as core outcome sets (COS). The COMET website states that *'These [COS] sets should represent the minimum that should be measured and reported in all clinical trials, audits of practice or other forms of research for a specific condition.' (http://www.comet-initiative.org/about/overview, accessed 24 April 2018).*COMET has an online database of projects, trials, research etc., which can be searched to identify COS in a particular health area or population. The use of COMET and COS is endorsed by organisations such as the Health Research Authority (HRA), the National Institute for Health Research (NIHR), Cochrane Collaboration and other national and international organisations. See http://www.comet-initiative.org/ for full information (last *accessed 8 November 2019*)

The NABCOP has chosen three improvement goals for the 2019-20 year; based on findings and recommendations made by the audit in its first three years of work. These will be reviewed on an annual basis (following yearly reporting); through consultation with key stakeholders including patient groups, clinicians and commissioners.

1. Increase the rate of surgery for fit older women with early invasive breast cancer.

- Specifically, reduce the number of NHS organisations with fewer than 80% of fit women, aged 70+ years, diagnosed with early invasive breast cancer, having surgery.

Rationale for improvement goal: Surgery to the breast, and in most circumstances the axilla, should be recommended for all patients with early invasive breast cancer irrespective of age unless they have severe frailty, significant cognitive impairment or substantial co-morbidities that are highly likely to limit life expectancy to no more than a few years. Initial primary endocrine therapy in elderly patients with ER+ early invasive breast cancer is reasonable to allow fuller assessment, attention to treatable co-morbidities and to optimise fitness but should not, in the absence of the features described above, be considered a substitute for definitive surgical management. Breast services should regularly audit the outcomes of patients who do not receive standard care such as surgical resection for early invasive breast cancer.

2. Increase the use of a reliable, consistent description of patient fitness.

- Specifically, increase the use of the fitness assessment pro-forma piloted by the NABCOP. This has three parts that record different aspects of patient health:
  1. the Clinical Frailty Scale (CFS), a common measure of frailty
  2. the Abbreviated Mental Test Score (AMTS), a short series of questions asked to the patient to measure their cognitive ability
  3. three screening clinical questions on whether a patient has any major diseases e.g. dementia, cardio-respiratory disease, cancer.

  This information will be captured within COSD Version 9 from July 2020.

Rationale for improvement goal: There should be increased education and understanding in the breast cancer clinical community of estimation of life expectancy in the older patient. All breast services should have a formalised referral pathway either within their hospital or to community-based geriatric support services to allow optimisation of concurrent illness(es) and fitness to improve the likelihood that older patients with early breast cancer can undergo definitive treatment thus maximising their chance of permanent disease eradication.

3. Improve completeness of key clinical data items, specific to the audit.

- Specifically, by increasing awareness of the path to improving data integral to understanding treatment decisions, reduce the number of NHS organisations with less than 90% completeness for:
  - tumour size
  - T (tumour) stage
  - N (nodal) stage
  - M (metastasis) stage
  - ER and HER2 status for invasive breast cancer
  - World Health Organization performance status
  - Contact with a clinical nurse specialist.

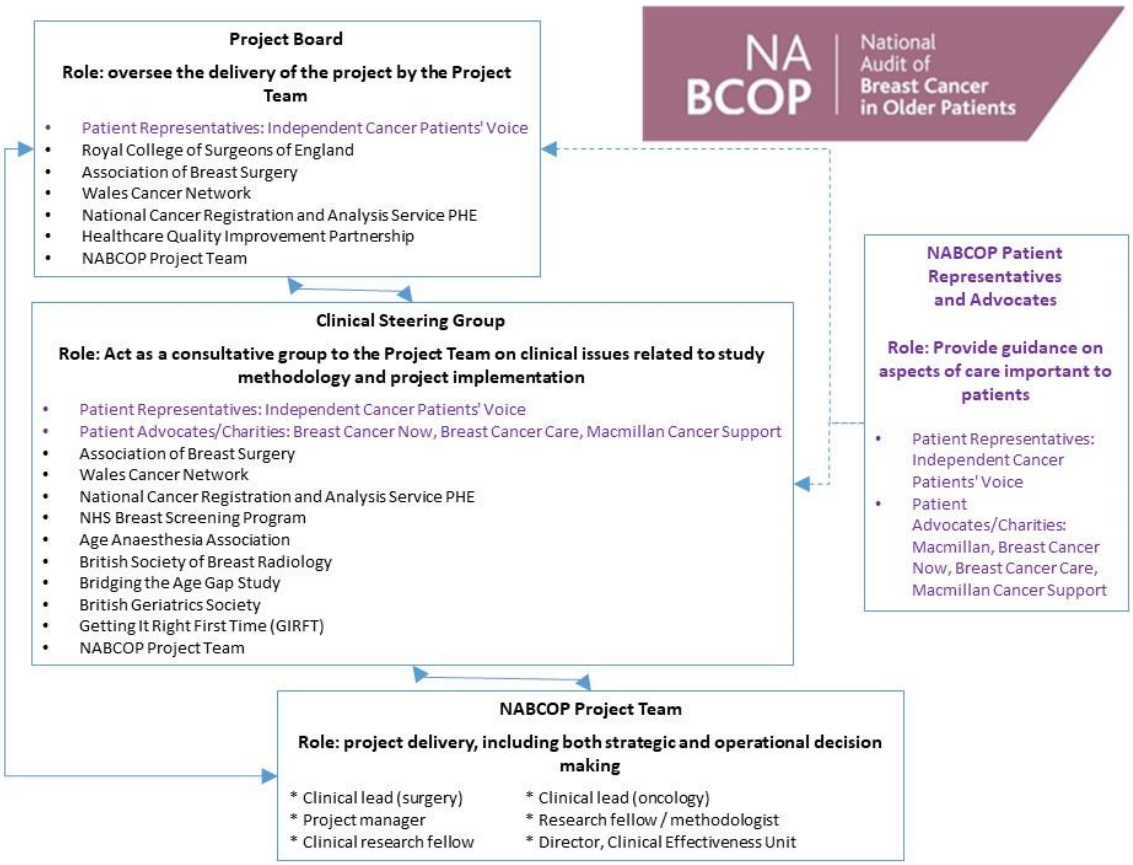
Rationale for improvement goal: Complete data is a basic requirement of the audit to understand the care pathway and treatment decisions made for older patients diagnosed with breast cancer. All women should be staged and have their tumour receptor status tested regardless of age. For NHS organisations in England this information can be monitored regularly using the CancerStats reporting portal[5] (described on the NABCOP website - https://www.nabcop.org.uk/resources/cancerstats-area/).

[5] Repository for all feedback on those national datasets for England, which are managed or supported by the National Cancer Registration and Analysis Service (NCRAS).

Domain 3: Governance and programme delivery

3.1. Organogram

Note: Please attach a diagram (e.g. organogram) describing how the programme is organised The diagram should demonstrate lines of accountability and responsibility, and include all governance groups, e.g. project team, Board, patient and public involvement, clinical reference groups, steering groups.



3.2. Organisations involved in delivering the programme

Note: A list of organisations with a formal role in delivering the programme. This includes organisations which:

- Are contracted to carry out elements of the programme
- Have a formal role in governing or steering the programme

For each organisation list:

- Name
- Website URL if available
- A description of its role in the programme

1.a. The Royal College of Surgeons (RCS) of England - www.rcseng.ac.uk

An independent professional body committed to helping surgeons 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. The RCS has representation on the Clinical Steering Group and Project Board.

1.b. The Association of Breast Surgery - https://associationofbreastsurgery.org.uk
A registered charity dedicated to advancing the practice of breast surgery and managing breast conditions for the benefit of the public. It is a multi-professional membership association, which promotes training, education, clinical trials, and drafting and following clinical guidelines.

- NABCOP is a joint project by the ABS and the Clinical Effectiveness Unit of the RCS. The ABS has representation on the Clinical Steering Group and Project Board.

2. Wales Cancer Network - www.walescanet.wales.nhs.uk
This network provides the cancer dataset for Wales, and has representation on the Clinical Steering Group and Project Board.

3. National Cancer Registration and Analysis Service PHE - https://www.ncras.nhs.uk
This service provides the cancer dataset for England, and has representation on the Clinical Steering Group and Project Board.

4. The Healthcare Quality Improvement Partnership (HQIP) - https://www.hqip.org.uk
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 is the commissioner of this audit and has representation on the Project Board.

5. Organisations providing patient representation and advocacy on the Clinical Steering Group include: Independent Cancer Patients' Voice; Breast Cancer Now, Breast Cancer Care; and Macmillan Cancer Support. Additional information on these members can be found on the 'Clinical Steering Group' web page of the NABCOP website https://www.nabcop.org.uk/resources/clinical-steering-group/

6. Additional organisations with representation on the Clinical Steering Group include: NHS Breast Screening Program; Age Anaesthesia Association; British Society of Breast Radiology; Bridging the Age Gap Study; British Geriatrics Society; and Getting It Right First Time (GIRFT). Additional information on these members can be found on the 'Clinical Steering Group' web page of the NABCOP website https://www.nabcop.org.uk/resources/clinical-steering-group/

3.3. Governance arrangements

Note: Governance of the project should include representatives from all key stakeholders. Please describe the governance arrangements including:

- A list of individuals within each governance group described in the organogram (or the URL of where this information is available on the programme website)
- The process used for sign-off indicating that the audit or registry data/feedback/reports have been quality assured and are ready for release
- If available, the URL to publicly published meeting/Board minutes (e.g. by a board or steering group)

The audit is governed by a Programme Board, which meets on at least a six monthly basis, or at key milestones, for the duration of the contract to deliver the work. The group is chaired by Professor Kieran Horgan and includes the organisations listed in the organogram in section 3.1. The board is responsible for overseeing the audit and providing oversight and advice to the programme. The board is the guarantor of the data from the audit and is responsible for signing off the annual report. The chair of the Programme Board is the accountable officer of the programme.

The Clinical Steering Group reports to the Programme Board and is responsible for delivering the programme. Its membership, terms of reference, and actions are in the public domain on the 'Clinical Steering Group' web page of the NABCOP website https://www.nabcop.org.uk/resources/clinical-steering-group/ - *last accessed 8 November 2019*.

3.4. Declarations and Conflicts of interest

Note: Evidence that declarations and conflicts of interest have been considered, declared and where appropriate, mitigated appropriately :

- DOI / COI process and policy outlining how DOI and potential conflicts of interest are identified and managed
- A web URL to the publicly published DOI/COI register for all individuals involved in the programme and where appropriate, information about how these have been mitigated

Declarations and conflicts of interest (DOI and COI) for the programme, and decisions regarding whether these exist, are r comprehensively documented in the minutes of the Clinical Steering Group and Project Board. Most often we minute "None at this time." NABCOP also minutes appropriate actions made by the Chairs of these groups.
"Declaration of any (new) conflict of interest" is a standing agenda item for our Clinical Steering Group and Project Board meetings.
The minutes of the Clinical Steering Group are publicly available on the 'Clinical Steering Group' web page of the NABCOP website https://www.nabcop.org.uk/resources/clinical-steering-group/ - *last accessed 8 November 2019*.

Domain 4: Information security, governance and ethics

4.1. The legal basis of the data collection

Note: A description of the legal basis for the data collection, specific to each country where the data are collected. Examples include:

- Informed consent
- Section 251 (NHS Health and Social Care Act 2006) approval
- Other types of patient controlled data permission

This could include links to:

- Consent forms
- Information provided to patients about participation and usage of data
- Further information about how patients can control the use of their data
- Information about ethical committee review

The audit has approval under section 251 of the NHS Health and Social Care Act 2006 to collect identifiable data without consent (CAG approval number 16/CAG/0079). NABCOP does not receive patient identifiers. Instead, NABCOP receives datasets (from the English and Welsh Cancer Registration Services) in which patient records have been assigned a unique pseudonymised identifier that allows their records to be linked across different anonymised datasets – specifically prepared for NABCOP purposes. Therefore, NABCOP cannot identify patients.

NABCOP's patient information can be found online https://www.nabcop.org.uk/resources/nabcop-patient-information-leaflet/

The National Cancer Registration and Analysis Service (NCRAS) in England and the Wales Cancer Network are allowed to collect data on patients diagnosed with cancer. Information about how patients can opt-out of data collection is provided. NHS Digital also provides information on patient opt-out of sharing their personal confidential health and social care data.

NABCOP's Privacy & Fair Processing Notice can be found online https://www.nabcop.org.uk/resources/privacy-fair-processing-notice/ - *last accessed 8 November 2019*.

4.2. Information governance and information security

Note: Include:

- The Information Governance Toolkit score and URL to the organisation's Information Governance Toolkit Assessment Report
- If the IG toolkit score is less than satisfactory, indicate how the organisation is improving its security processes to achieve a satisfactory score and when the programme will be re-assessed
- Details of any other information governance and security accreditations achieved by the registry (e.g. ISO 27001)

The NABCOP is run and managed by the Clinical Effectiveness Unit at the Royal College of Surgeons of England (RCS). The details of the RCS's security assurances are as below:

1) Type: Data Security and Protection Toolkit[6] (for 2018/19).
Organisation name: Royal College of Surgeons (RCS) of England.
Date published: 22/03/2019. Expiry Date: 31/03/2020.
Reference: 8HM21. Standards: Met.
Link to report: https://www.dsptoolkit.nhs.uk/OrganisationSearch/8HM21 - *last accessed 9 November 2019*.

(2) Type: Information Commissioner's Office (ICO) Data Protection Act (DPA) register.
DPA organisation name: The Royal College of Surgeons of England.
DPA Registration Number: Z5948910. Expiry Date: 24/10/2020.
Link to report: https://ico.org.uk/ESDWebPages/Entry/Z5948910 - *last accessed 9 November 2019*.

This indicates that the programme can be trusted to handle personal information securely.

[6] The Data Security and Protection Toolkit has replaced the Information Governance Toolkit in 2019 https://www.dsptoolkit.nhs.uk/

Domain 5: Stakeholder engagement

5.1. Approaches to involving stakeholders

Note: A description of how stakeholders are involved in designing and carrying out the programme. Examples of types of involvement that might be listed here include:

- Designing the programme
- Selecting quality metrics
- Defining aims and objectives
- Setting priorities
- Collecting data
- Contributing to data analysis and interpretation
- Governance
- Disseminating feedback and communications

Clinical input is provided by:

- Members of the Project Team and Clinical Steering Group (CSG) across all of the NABCOP activities, particularly providing their expertise on matters relating to selecting quality metrics (such as those being used by CQC inspectors and MyNHS /NHS Choices), and contributing to analysis and interpretation.
- They, as well as members of our Project Board (PB), have a key role in disseminating feedback and communications to clinicians in provider organisations and presenting key findings during professional annual conferences.
- Organisations represented on the PB and CSB are listed in the Organogram in Section 3.1: Including our data collection partners, key collaborators such as GIRFT, and HQIP; our funder.

Patients representatives and advocates are involved by:

- Providing representation on the audit's Clinical Steering Group (CSG) and Project Board; and through this membership providing input on selecting quality metrics, designing the programme, and providing strategy and governance to the programme.
- Convening as a subgroup of the CSG, when required, to provide a specific patient-orientated steer, such providing input on the public and patient versions of annual reports and developing patient friendly infographics of data from the audit.

The data collection partners in England (National Cancer Registration & Analysis Service (NCRAS)) and Wales (Wales Cancer Network (WCN)):

- Manage the data collection process including responding to user queries, communication with users regarding data quality and access to their own data and provision of linked de-identified data extracts to the NABCOP Project Team for

Domain 6: Methods

6.1. Data flow diagrams

Note: A data flow diagram showing each data flow into and out of the audit/registry. The diagram should indicate:

- What organisations are flowing data in/out of the programme
- What data items are within each data flow in/out of the programme
- The legal basis for each data flow, e.g. section 251, consent

The NABCOP Data Flow diagram can be found, online https://www.nabcop.org.uk/resources/nabcop-data-flow/ - *last accessed 8 November 2019*.

6.2. The population sampled for data collection

Note: A description of the patient population or sampling frame for data collection. This might include:

- Details of inclusion and exclusion criteria
- Standard nomenclature to define patient populations (e.g. ICD codes, SNOMED terms)

The 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 reports describe the process and outcomes of care for women over the age of 50, diagnosed with breast cancer since 1 January 2014 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.

6.3. Geographical coverage of data collection

Note: A description of the geographical coverage of the data collection. Include details of both:

- geographical areas eligible for inclusion
- geographical areas that actually participated in data collection

This could include:

- A text description of coverage
- An illustration or map to visualise the coverage
- Summary data
- Links to data files containing geographical identifiers

England and Wales.

6.4. Dataset for data collection

Note: A list (or web URL to online documentation such as a data dictionary) of the items included in the data collection. State how the dataset chosen aligns with the QI objectives and COMET Core Outcome Sets (COS) as described in section 2.2.

The datasets used for National Audit of Breast Cancer in Older Patients (NABCOP) are detailed in the NABCOP Combined Data Specification Including existing Cancer Outcomes and Services Dataset (COSD) items (versions 6, 7 and 8); National Radiotherapy Dataset (RTDS) items; and Systemic Anti-Cancer Therapy (SACT) Dataset items to be used for patients.

The NABCOP datasets are supplied by the national cancer registration services. For England, this is the National Cancer Registration and Analysis Service (NCRAS). For Wales, this is the Cancer Network Information System Cymru (CANISC).

The dataset for the time period 2014-2016 is published on www.data.gov

6.5. Methods of data collection and sources of data

Note: A description (or web URL to online documentation) of how the data were collected and the sources of data.

Examples include:

- Online, e.g. webtool or portal
- Retrospective case record review
- Linkage to existing data sources
- Extracts of administrative data
- Surveys
- Extractions from electronic health records

NABCOP does not directly 'collect' patient data. Instead, we use existing sources of patient data collected by national organisations. These include Cancer Network Information System Cymru (CANISC) and PEDW for Wales, and the following National Cancer Registration and Analysis Service (NCRAS) datasets for England:

- Registry (CAS)
- COSD (incl v7 updates)
- RTDS
- ONS Tracing
- SACT
- HES A & E
- Route to diagnosis
- CPES
- HES Inpatient

Therefore, there is no need for Trusts to formally register for this audit, or input data on patients through a separate Database portal.

NABCOP does not receive patient identifiers. Instead, NABCOP receives datasets (from the English and Welsh Cancer Registration Services) in which patient records have been assigned a unique pseudonymised identifier that allows their records to be linked across different anonymised datasets – specifically prepared for NABCOP purposes. Therefore, NABCOP cannot identify patients.

6.6. Time period of data collection
Note: The time period for data collection, using a start date (DD/MM/YYYY) and end date as applicable. For a continuous prospective data collection then this may only be a start date.
Data is received for women aged 50 and over diagnosed with breast cancer between 01/01/2014 and 31/12/2017.

6.7. Time lag between data collection and feedback
Note: A description of the time lag between data collection and feedback to participants in the programme – try and be as specific as possible. If 'real time' please describe exactly what this means, e.g. monthly, daily, minute-by-minute. This could also include details about time intervals for the various steps between data collection and feedback/publication such as waiting for linked data to be supplied or for sign off.
Feedback is via an annual report, which is published approximately 18 months after the end of data collection. The mechanisms contributing to this lag between data collection and publication/feedback are described, and presented graphically, by the NABCOP Analysis Timeline found online https://www.nabcop.org.uk/resources/nabcop-analysis-timeline/ - *last accessed 8 November 2019*.

6.8. Quality measures included in feedback
Note: A list (or web URL to online documentation) of the quality measures reported by the programme. Provide a mapping to classify these as: • Process metrics • Outcome metrics • Organisational/structure metrics Please state what metrics are provided at trust level and how often this trust level information is made available, e.g. quarterly, 6-monthly. If 'real time' please describe exactly what this means, e.g. monthly, daily.
The NABCOP has chosen three improvement goals for the 2019-20 year; based on findings and recommendations made by the audit in its first three years of work. These will be reviewed on an annual basis (following yearly reporting); through consultation with key stakeholders including patient groups, clinicians and commissioners. 1. Increase the rate of surgery for fit older women with early invasive breast cancer. 2. Increase the use of a reliable, consistent description of patient fitness. 3. Improve completeness of key clinical data items, specific to the audit. The detail and rationale behind these is described in the Quality Improvement Objectives, Section 2.2. The audit's 13 process and outcome indicators are detailed in the NABCOP Core Set of Indicators found online https://www.nabcop.org.uk/resources/nabcop-core-indicators/ - *last accessed 8 November 2019*.

6.9. Evidence base for quality measures

Note: A list or description of the sources of evidence used to define the quality metrics. Examples include:

- Clinical guidance (e.g. NICE guidance)
- Clinical standards
- Systematic reviews
- Professional society recommendations
- Policy documents
- Clinical trials

As for Quality measures included in feedback, Section 6.8:

The NABCOP has chosen three improvement goals:
1. Increase the rate of surgery for fit older women with early invasive breast cancer.
2. Increase the use of a reliable, consistent description of patient fitness.
3. Improve completeness of key clinical data items, specific to the audit.
The detail and rationale behind these is described in the Quality Improvement Objectives, Section 2.2.

The evidence base for the audit's 13 process and outcome indicators are described in the NABCOP Core Set of Indicators document found online https://www.nabcop.org.uk/resources/nabcop-core-indicators/ - *last accessed 8 November 2019*.

6.10. Case ascertainment

Note: Describe the level of case ascertainment achieved. Include links or detail for additional information about methodology

The NABCOP receives data for all eligible cases (100%) from National Cancer Registration and Analysis Service (NCRAS) and the Wales Cancer Network.

6.11. Data analysis

Note: A description (or web URL to online documentation) of the methods of data analysis. Important considerations in the analysis of audit and registry data include:

- Missing data, and how these were handled
- Sources of measurement error and bias, and how these were addressed
- Methods and algorithms used for:
    - case mix adjustment
    - benchmarking
    - outlier detection
    - visualising and interpreting time series data
- Algorithms and statistical models used to process data

This might include:

- References for peer reviewed publications of methods used in the data analysis
- Links to:
    - analytical code
    - more detailed descriptions of the methods already published elsewhere

The methods used to analyse the NABCOP prospective audit data are described:

- On page 4 of the NABCOP 2019 Annual Report at https://www.nabcop.org.uk/reports/nabcop-2019-annual-report/
- In more detail in the NABCOP Annual Report Methodology 2019 document at https://www.nabcop.org.uk/content/uploads/2019/05/NABCOP_Annual_Report_Methodology_2019.pdf

6.12. Data linkage

Note: A description of any data linkage carried out as part of the audit or registry. Include details of:

- Data sources
- Methods of linkage
- Evaluation of the quality of data linkage

If no data linkage carried out, state "No linkage performed"
This could include details about the impact of patient opt outs where these apply, e.g. the proportion of patients before and after opt outs are applied; changes in key characteristics of patient group following opt out such as gender, ethnicity

NABCOP receives datasets (from the English and Welsh Cancer Registration Services) in which patient records have been assigned a unique pseudonymised identifier that allows their records to be linked across different anonymised datasets – specifically prepared for NABCOP purposes.

These include Cancer Network Information System Cymru (CANISC) and PEDW for Wales, and the following National Cancer Registration and Analysis Service (NCRAS) datasets for England:

- Registry (CAS)
- COSD (incl v7 updates)
- RTDS
- ONS Tracing
- SACT
- HES A & E
- Route to diagnosis
- CPES
- HES Inpatient

6.13. Validation and data quality

Note: A description of how data quality and analyses have been validated. Examples of validation include:

- Piloting and refining data collection methods and dataset changes
- Building in validation processes at the point of data entry
- Validation by clinical teams
- Data cleaning
- Statistical analyses of data quality (e.g. missing data)
- Validation of statistical models and algorithms
- Quality assurance and unit testing of analytical code

The completeness/quality of the audit data are described on pages 6-7 of the NABCOP 2019 Annual Report at https://www.nabcop.org.uk/reports/nabcop-2019-annual-report/

Domain 7: Outputs

7.1. The intended users or audience for the outputs

Note: A list or description of the intended users or audience of feedback data produced by the programme. Examples include:

- Clinical commissioning groups or Health Boards
- Specialist commissioners
- Trust/hospital boards
- Clinical teams
- Individual clinicians
- General public
- Patients
- Carers
- Policy makers
- Politicians
- Media
- National agencies

The audit designs and produces individual feedback for:

- The public and patients
- Trusts and Health Boards
- Clinical teams
- The Care Quality Commission

7.2. Editorial independence

Note: A statement about the independence of the programme in regards to the content, e.g. findings, recommendations.

As an independently commissioned audit, the contents of the outputs are written by the NABCOP Project Team and quality assured by the Board through the governance processes described in previous sections.

7.3 The modalities of feedback and outputs

Note: A description of how data are fed back to participants of the programme. Please also describe how outputs are agreed, i.e. the quality assurance process within the programme such as Board sign off.

Examples of types of feedback commonly used in audits and registries include:

- Summary written reports
- Comprehensive written reports
- Online feedback
- Dashboards
- Slidesets
- Data visualisations
- Infographics
- Data tables

- Interactive tools
- Maps
- Meetings and workshops
- Professional conferences
- Verbal feedback by a national peer
- Verbal feedback by a local peer
- Information resources for patients (e.g. NHS Choices)
- Data that will be adapted and synthesised by other organisations (e.g. CQC) and programmes (e.g. GIRFT)
- Press releases
- Case studies
- Examples of best practice

The audit provides feedback for the following types of participant:

- Public and patients: An "Easy Access" written annual report; including infographics.
- Clinicians: Feedback through comprehensive online annual reports and tables for their trust/health board; peer review publications.
- Trusts and health boards: Written comprehensive online annual reports and tables presented at Trust and Health Board level.

The reports are quality assured at team level, and Clinical Steering Group before submission to the Board for sign off. Sign off is required before submission of the report to commissioners/HQIP.

7.4 Recommendations

Note: The programme, in making specific recommendations about how to improve the quality or safety of healthcare services should provide a web URL to any documents making recommendations to participants

As a general principal, recommendations should:

- be specific, action oriented, and tailored to the intended audience
- agreed and signed off through an agreed process
- reviewed (e.g. annually)
- be underpinned by evidence and be supported by data collected by the programme
- be designed to have impact

Examples include:
"The audit made 12 recommendations for hospitals, clinicians and commissioners in the Annual Report. The link to the report is www.auditreport.org"

The audit made 9 recommendation for breast cancer units within NHS organisations, and for professional organisations involved in breast cancer care, on page 'v' of the most recent Annual Report - at https://www.nabcop.org.uk/reports/nabcop-2019-annual-report/

7.5 Comparators and benchmarking

Note: A description or list of if/how performance is compared between healthcare providers or areas, and the benchmark against which performance is measured.

This should provide a high level overview of how comparisons are made using the programme data, not a detailed list of all indicators and how they are individually used to benchmark or compare performance.

Examples of benchmarks include:

- National
- International
- Regional
- Organisational
- Clinical team
- Individual clinician
- Audit/registry standards
- Relative benchmarks (e.g. top 10%)
- Temporal (e.g. changes over time)
- Results from randomised controlled trials

The audit provides comparative performance data for Trusts and Health Boards:

- Nationally
- All NABCOP NHS Organisations in England and Wales

7.6 Motivating and planning quality improvement

Note: A short description of the approaches the programme uses to motivate and support quality improvement.

Programmes are not expected to provide a bespoke service to support trusts to interpret the findings or recommendations. The programme should, however, provide information in a format that is easy to digest and ready to use for the intended audience.

Examples of approaches include:

- Recommendations for action
- Action plans
- Education and training
- Supporting peer learning
- Providing positive feedback
- Workshops
- Including motivating statements as part of feedback

The NABCOP annual reports publish key findings and make recommendations on the quality of care received by patients.
https://www.nabcop.org.uk/reports/

The NABCOP also produces results for individual NHS organisations, to enable them to derive further benefit from the audit results – such as being able to review their performance in comparison to the national performance (NABCOP Annual Report 2019 NHS Organisation Data Viewer) and developing a local action plan. As per the NABCOP website:
https://www.nabcop.org.uk/resources/nabcop-2019-annual-report-supplementary-materials/

Other NABCOP quality improvement activities include:

- Collaborating with our data collection partners to produce tools to improve data quality for the audit; impacting on associated quality improvement work.
  https://www.nabcop.org.uk/resources/improving-data-completeness/
  https://www.nabcop.org.uk/resources/quality-improvement-resources/
- Audit communications (often in collaboration with Cancer Registry Data Improvement Leads, such as those for NCRAS), authorship of peer revived publications, and Conferences papers.
- Working with the Care Quality Commission (CQC) and Clinical Outcomes Publication (COP) to develop quality metrics. Publication of data via the COP makes unit-level provider performance data available via NHS Choices/ My NHS.

The clinical leads and the members of professional organisations in the Clinical Steering Group engage with their colleagues in trusts to discuss how trusts can action the recommendations. Potential outliers are to be followed up according to the NABCOP's Outlier Policy
https://www.nabcop.org.uk/resources/nabcop-outlier-policy/