

National Audit of Breast Cancer in Older Patients (NABCOP)

Information Governance Policy

What is the aim of the National Audit of Breast Cancer in Older Patients

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 explores why older women with breast cancer appear to have worse outcomes than younger women and investigates apparent differences in the patterns of care delivered to older women. The Audit examines the care pathway from initial diagnosis to the end of primary treatment, and compares 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).

Sources of information used by the Audit

The NABCOP uses existing sources of patient data collected by national organisations. The main source of data is the national Cancer Registration datasets in England and Wales.

The national Cancer Registration Services collect a limited amount of information on all people diagnosed with cancer. This includes information about the type of cancer and the treatments received, and the information is supplied by the medical staff involved in delivering care.

The information from the Cancer Registration Services is linked to other routine hospital datasets to provide some additional detail about surgical treatments (English hospitals use the Hospital Episode Statistics and Welsh hospitals use the Patient Episode Data for Wales). The information also includes data from the Office for National Statistics (ONS) on the dates of death so that the audit can examine duration of survival after cancer diagnosis. The linkage of data from these different sources is undertaken by the Cancer Registration Services.

Information supplied to the Audit by the Cancer Registration Services is anonymised. Common health care identifiers such as the NHS numbers or other potentially sensitive information that might identify individuals (such as postcode and date of birth) are not included in the supplied data. Data are converted into formats that reduce the risk of identification. For example, date of birth is converted to age at admission. The national Cancer Registration Services, together with the Healthcare Quality Improvement Partnership (HQIP), are the data controllers for the audit.

Management of patient data by the NABCOP team

The NABCOP team are located within the Clinical Effectiveness Unit (CEU) at the Royal College of Surgeons of England. The CEU conforms to the General Data Protection Regulation (GDPR)¹ and other legislation that relates to the collection and use of patient data, and has strict security measures in place to safeguard patient information. NABCOP stores the anonymised patient data on a secure

¹ <https://ico.org.uk/for-organisations/guide-to-the-general-data-protection-regulation-gdpr/>

computer to which only authorised audit team members have access. The IT system has various levels of security built into it, including:

- ID password security: the data is stored on a password protected system, which prevents unauthorised users gaining access. Users are required to have a complex password that is set to expire after a given period. This ensures passwords are updated regularly.
- The stored data files are encrypted.
- All system database accesses are recorded in a system log file that can be audited in the event of suspected security threats or data misuse.

Patient confidentiality

The information received and managed by the NABCOP team about patients and the clinical care is treated as confidential. The information is supplied to the Audit in an anonymised format, with individual patients only distinguished by a computer-generated label. The data will be retained only for the duration of the audit.

The Audit applied to the Confidentiality Advisory Group (CAG) of the NHS Health Research Authority (HRA) for legal authority to use the anonymised information on women being treated for breast cancer in England and Wales. CAG can give projects approval under Section 251 of the NHS Act 2006 to use health care information where patient consent is not practicable. NABCOP has section 251 approval.

NABCOP will not publish information that can enable individual patients to be identified. We will also not allow third-parties to access the data. We maintain the confidentiality and security of patient information in the following ways:

- All reports are produced at an aggregate level (national, regional, hospital).
- In each audit publication, the statistical information is reviewed to ensure the risk of identification is minimised, and where necessary, small numbers are suppressed. This assessment follows guidelines issued by the Office for National Statistics - Review of the Dissemination of Health Statistics: Confidentiality Guidance (PDF).

What if I do not want my information used by the Audit?

Patients can choose to opt-out of the audit, such that their details will not be stored or used for any purpose by the audit. For more information on how to opt-out from the audit, please visit:

<https://www.nabcop.org.uk/resources/information-patient-opt-data-sharing-nhs-digital/>

More information on NABCOP's privacy and fair processing of data practices

A notice containing further detail on NABCOP's privacy and fair processing of data practices can be found at <https://www.nabcop.org.uk/resources/privacy-fair-processing-notice/>