

Privacy/Fair Processing Notice

What is the aim of the National Bowel Cancer Audit?

The National Bowel Cancer Audit (NBOCA) is being carried out by a partnership between the Clinical Effectiveness Unit at the Royal College of Surgeons, NHS Digital and The Association of Coloproctology of Great Britain and Ireland (ACPGBI).

The Audit measures the quality of care received by patients diagnosed with bowel cancer within NHS services in England and Wales. It is designed to evaluate the care pathways followed by patients once they have been diagnosed with bowel cancer and to assess outcomes.

By auditing the care delivered by cancer services, we can highlight areas where hospitals are doing well, and areas in which the quality of care can be improved. By producing information for all NHS services, it allows cancer services to compare themselves with others in England and Wales, and share examples of good practice.

Where is patient data collected from?

All adult NHS patients newly diagnosed with bowel cancer within each audit period in England and Wales are eligible to be included in NBOCA. Patient data are supplied to the Audit from NHS hospitals, and are stored in a secure IT system hosted by NHS Digital.

The data collected from NHS hospitals provides us with information on the diagnosis and management of all patients newly diagnosed with bowel cancer including method of diagnosis, site of cancer, staging, treatment intent, patient fitness, surgical procedure, pathology results and post-operative treatments such as radiotherapy or chemotherapy.

To reduce the need for hospital staff to collect data twice, the Audit links these data with other information held in national hospital databases (Hospital Episode Statistics and Patient Episode Database Wales), the national death register (Office of National Statistics), the chemotherapy and radiotherapy datasets held by the Public Health England and another national audit called the National Emergency Laparotomy Audit (NELA). This provides further information on emergency bowel cancer patients. The Audit will also soon link its data to data from the Intensive Care National Audit and Research Centre (ICNARC).

All NBOCA data is stored in a secure, IT environment at the Royal College of Surgeons of England (RCS). Access to the data is only available for approved individuals and security is maintained through the use of passwords and encryption. The RCS conforms to the General Data Protection Regulation (GDPR) and other legislation that relates to the use of pseudonymised patient data.

Is it possible to identify individuals within the HES and ONS data?

All linkage is performed by NHS Digital and the NBOCA project team receives only de-identified datasets for analysis. The data does not include sensitive personal information such as name, address or postcode. Individuals are labelled with an anonymous identifier which makes it impossible to identify people without adding other information.

Data Controller

NBOCA is commissioned by the Healthcare Quality Improvement Partnership (HQIP) as part of the National Clinical Audit Programme on behalf of NHS England and the Welsh Government. HQIP are the data controllers for the patient data submitted to the audit directly by NHS hospitals.

Further information and contact details for HQIP can be accessed [here](#):

The NBOCA team combines the data on individuals with other information held in other national hospital databases. The data controllers for these other national datasets are detailed below. Click the hyperlinks for further information about them:

- NHS Digital - English hospital from Hospital Episodes Statistics dataset ([HES](#))
- NHS Wales Informatics Service (NWIS) – Welsh hospital data from Patient Episode Database Wales ([PEDW](#))
- Office for National Statistics - death register ([ONS](#))
- Public Health England - data on chemotherapy ([SACT](#)) and radiotherapy ([RTDS](#))
- Wales Cancer Network - cancer information on Welsh patients from Cancer Information System for Wales ([Canisc](#))
- HQIP - National Emergency Laparotomy Audit dataset ([NELA](#))
- Intensive Care National Audit & Research Centre ([ICNARC](#))

Legal basis for collecting personal data

NBOCA has approval for collecting health care information under Section 251 (reference number: CAG ECC 1-3(d)/2012) for all patients diagnosed with bowel cancer in England and Wales. More information on section 251 is available [here](#).

Legal basis for processing personal patient data

NBOCA has approval for processing data under articles 6 (1) (e) and 9 (2) (i) of the GDPR as the data are needed to carry out a task in the public interest to ensure high standards of quality and safety of healthcare.

How we protect your data

Local clinical teams enter patient data into a secure web-based tool provided by NHS Digital. Only doctors, nurses and clinical audit staff registered with the Audit can access the data collection tool. Security and confidentiality is maintained through the use of passwords and

a person specific registration process. Only NHS Digital staff can access the data collection tool.

Patient confidentiality and level of data collected

The patient-level information received and managed by the NBOCA team is treated as confidential. When analysing the data to produce the information on patient care and outcomes, the NBOCA team use de-identified data and so individual patients are not identifiable. The data is classified as personal data under the GDPR.

The NBOCA is also careful when publishing information to include graphs or tables that do not allow individuals to be identified. To ensure this, the Audit follows guidelines on publishing statistics issued by the Office for National Statistics – Review of the Dissemination of Health Statistics: Confidentiality Guidance (PDF).

Management of patient-level data by the NBOCA team

The NBOCA team are based at the Royal College of Surgeons of England (RCS) and NHS Digital . Both the RCS and NHS Digital conform to the General Data Protection Regulation (GDPR) and other legislation that relates to the collection and use of patient data. Both organisations have strict security measures in place to safeguard patient information held in the Data Collection system and when analysing the de-identified dataset. The Data Collection IT system has various levels of security built into it, such as ID password security which prevents unauthorised users gaining access and data encryption.

How do we analyse the data?

Our work produces a range of statistics which are reported at different levels of aggregation. This includes producing information by NHS hospital to support quality assurance activities within these organisations, as well as at a national and regional level to support policy makers and commissioners. This information is published in reports, peer reviewed journals and in presentations to patient groups, healthcare professionals and healthcare researchers. When presenting information in these ways, we do not publish information at the level of an individual.

The programme of work involves identifying patient groups within the data, and then describing trends and variation in the number of patients treated, differences in their characteristics (such as age, ethnicity, whether they suffer from other conditions), the treatments given and outcomes of care.

Who do we share data with?

The NBOCA only shares patient-level data following a strict governance procedure to ensure compliance with the General Data Protection Regulation (GDPR).

Researchers may apply to the NBOCA Data Controller (the Healthcare Quality Improvement Partnership, HQIP) if they want to use the patient data for a research study. These requests undergo a stringent approvals process as outlined [here](#).

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

NBOCA cannot identify patients within the data, and so cannot remove a person's information from the data supplied by NHS Digital.

All patients can opt to have their information removed from the NBOCA database by contacting NHS Digital. For more information on opting out, please click [here](#).

In some circumstances, an individual has the right to request their data are erased. This does not apply to an individual's health care record.

Provider team contact information held by the NBOCA

NHS Digital holds contact information (name, email address and hospital name) for key members of each extended provider team (Clinical Lead, MDT coordinator, audit department and cancer services designated contacts) on behalf of NBOCA. This information enables NHS Digital/NBOCA to distribute important updates about the audit, to administer organisational audit updates and contact providers during the outlier process. This information is not shared outside NHS Digital.

Our legal basis for collecting and processing contact information is legitimate interest, which is handled in accordance with the GDPR and will not be used for any other purpose without consent. None of the provider team contact information is special category personal data.

If you believe that any contact information we are holding on you is incorrect or incomplete, please contact us as soon as possible. We will promptly correct any information found to be incorrect.

Changes to our privacy policy

We keep our privacy policy under regular review and we will always include the latest version on this web page.

The privacy policy was last updated on 08/08/19.

How to contact us

Please contact us if you have any questions about our privacy policy or information we hold about you by email at: bowelcancer@nhs.net

Information about the requirements for the Audit to keep personal data secure and what to do to report a data breach, can be found on the website of the Information Commissioners Office, [here](#).

