

Privacy Notice

What is the purpose of the Oesophago-Gastric Cancer Audit?

The National Oesophago-Gastric Cancer Audit (NOGCA) is being carried out by a partnership between the Clinical Effectiveness Unit at the Royal College of Surgeons, NHS Digital, the Association of Upper Gastrointestinal Surgery of Great Britain and Ireland (AUGIS), the British Society of Gastroenterology (BSG) and the Royal College of Radiologists (RCR).

The Audit measures the quality of care received by patients with oesophago-gastric cancer and oesophageal high-grade dysplasia within NHS services in England and Wales. It is designed to evaluate the care pathway followed by patients once they have been diagnosed with either condition, and to answer questions related to the care they receive and their outcomes.

By auditing the care delivered by cancer services, NOGCA 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.

How are patient data collected, and what level of data is collected?

All adult NHS patients with a diagnosis of oesophago-gastric (OG) cancer or oesophageal high-grade dysplasia (HGD) in England and Wales are eligible to be included in NOGCA. Patient data are supplied to the Audit from NHS hospitals and are stored in a secure IT system hosted by NHS Digital.

Hospitals provide information about the care that patients receive for OG cancer or HGD. The Audit also collects identifiable information (NHS number, date of birth and postcode) that enables the Audit to link information submitted by other hospital teams for the same patient. Details of the information the Audit collects can be found here:

www.nogca.org.uk/resources/nogca-data-proforma/

To reduce the need for hospital staff to collect additional data, the Audit also links the submitted data with other information held in the national hospital databases (Hospital Episode Statistics and Patient Episode Database Wales), national death register (Office for National Statistics), chemotherapy and radiotherapy, Cancer Registrations, Cancer Outcomes & Services Dataset, Cancer Waiting Times and the National Cancer Patient Experience Survey. The linkage of the datasets is performed by NHS Digital or the data controllers for individual data sets. The audit data submitted by hospitals remains to be controlled by those organisations.

Following linkage, the NOGCA project team receives only de-identified datasets for analysis. This data is then stored in a secure IT environment at the Royal College of Surgeons of England (RCS). Role-based access controls mean that access to the data is only available for approved individuals. Furthermore, the data security is maintained through the use of passwords and encryption. The RCS adheres to the UK General Data Protection Regulation (GDPR) and other legislation that relates to the use of pseudonymised/de-identified patient data. The data received by the NOGCA team are kept for the period defined by the relevant data controllers.

Data Controllers for the Audit

NOGCA is commissioned by the Healthcare Quality Improvement Partnership (HQIP) as part of the National Clinical Audit and Patient Outcomes Programme on behalf of NHS England and the Welsh Government.

NHS England, Digital Health and Care Wales (DHCW) and HQIP are the joint data controllers for the patient data submitted directly to the Audit by NHS hospitals – NHS England with HQIP for English and DHCW with HQIP for Welsh data.

HQIP's Data Protection Officer can be contacted at the following email address: data.protection@hqip.org.uk. For further information, please review HQIP's GDPR Statement: <https://www.hqip.org.uk/about-us/our-gdpr-statement/#.YpTli51KhPY> Contact details for HQIP can be found [here: https://www.hqip.org.uk/contact-us/#.YpS4eJ1KiUn](https://www.hqip.org.uk/contact-us/#.YpS4eJ1KiUn)

NHS Digital combines the data submitted to the Audit with information held in other national databases. The data controllers for these other national datasets are detailed below. Click the hyperlinks for further information about them:

- NHS Digital - English hospital data from [Hospital Episodes Statistics dataset \(HES\)](#), data on [chemotherapy \(SACT\)](#), [radiotherapy \(RTDS\)](#), [cancer registrations](#), [cancer outcomes and services \(COSD\)](#) and [cancer waiting times \(CWT\)](#)
- Digital Health and Care Wales – Welsh hospital data from [Patient Episode Database Wales \(PEDW\)](#) and [radiotherapy data \(RTDS\)](#)
- Office for National Statistics and NHS Digital - [death register](#)
- NHS England – [National Cancer Patient Experience Survey \(CPES\)](#)

Legal basis for processing personal data

NOGCA has approval for processing health care information under Section 251 (reference number: ECC 1-06 (c)/2011) for all patients diagnosed with OG cancer in England and Wales. More information on section 251 is available here: <https://www.hra.nhs.uk/about-us/committees-and-services/confidentiality-advisory-group/confidential-patient-information-and-regulations/>

NOGCA has processes 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.

The NOGCA team process patient information to evaluate and improve the quality of care received by patients with OG cancer and oesophageal HGD within publicly funded (NHS) services in England and Wales, which is in the public interest.

We also process personal data regarding hospital staff that is necessary for managing data collection and the Clinical Outcomes Publication process, e.g. contact information for clinical teams and staff members involved in NOGCA This information enables NHS Digital/NOGCA 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.

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 the NHS Digital staff on the NOGCA team can access the whole dataset within the data collection tool.

Patient confidentiality

The patient-level information received and managed by the NOGCA team is treated as confidential. When analysing the data to produce the information on patient care and outcomes, the NOGCA team use only de-identified data, which excludes identifiable information such as name, address or postcode.

When publishing data, the Audit reports statistics at the group level (e.g. national, regional, or for a specific patient group), which do not allow individuals to be identified. To ensure this, the Audit follows guidelines issued by the Office for National Statistics on publishing statistics – Review of the Dissemination of Health Statistics: Confidentiality Guidance (PDF): <https://www.ons.gov.uk/file?uri=/methodology/methodologytopicsandstatisticalconcepts/disclosurecontrol/healthstatistics/confidentialityguidanctcm77181864.pdf>

Management of patient-level data by the NOGCA team

The NOGCA team are based at the Royal College of Surgeons of England (RCS) and NHS Digital. Both the RCS and NHS Digital adhere to the 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 levels of security built into it, such as ID password security which prevents unauthorised users gaining access and data encryption.

Who do we share data with?

NOGCA only shares patient-level data following a strict governance procedure to ensure compliance with the General Data Protection Regulation (GDPR). Researchers may apply to HQIP if they want to use the Audit data for a research study. These requests undergo a stringent approvals process as outlined here: www.hqip.org.uk/national-programmes/accessing-ncapop-data

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

All patients can opt to have their information removed from the NOGCA database by contacting the NHS Digital's Enquiries team (enquiries@nhsdigital.nhs.uk or 0300 303 5678). Opting out from the Audit is different to registering for [National Data Opt-outs](#), from which NOGCA is exempt, to minimise the adverse impact on patient safety. For more information on opting out choices please see www.nogca.org.uk/patient-choices

For information on how to exercise your individual data protection rights or if you have any concerns about how your data is being used, please contact the Audit at the following email address: og.cancer@nhs.net

For information about how to access, correct or erase information held in other datasets the Audit uses, please consult the policy of the relevant data controller:

- NHS Digital: www.digital.nhs.uk/your-data
- Office for National Statistics: www.ons.gov.uk/aboutus/transparencyandgovernance/dataprotection
- NHS England: <https://www.england.nhs.uk/statistics/statistical-work-areas/cancer-patient-experience-survey/> and <https://www.ncpes.co.uk/faq/>
- Digital Care and Health Wales: <https://dhcw.nhs.wales/about-us/keeping-patient-information-safe/>
- HQIP: <https://www.hqip.org.uk/about-us/our-gdpr-statement/#.YpTgyZ1KhPY>

Changes to our fair processing policy

We keep our fair processing policy under regular review and we will always include the latest version on the NOGCA web page.

The privacy policy was last updated on 18th November 2022.

How to contact us

Please contact us if you have any questions about our privacy policy or information the Audit holds about you. Email address: og.cancer@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: <https://ico.org.uk/>

Glossary

data controller – the main decision-maker, who exercise their overall control over the purposes and means of how personal data is used and processed

data processor - act on behalf of, and only on the instructions of, the relevant data controller

GDPR article 6 (1) (e) - "processing is necessary for the performance of a task carried out in the public interest or in the exercise of official authority vested in the controller"

GDPR article 9 (2) (i) - "processing is necessary for reasons of public interest in the area of public health, such as protecting against serious cross-border threats to health or ensuring high standards of quality and safety of health care and of medicinal products or medical devices"