

National Oesophago-Gastric Cancer Audit

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 Surgeons, the British Society of Gastroenterology and the Royal College of Radiologists.

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, 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.

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

All adult 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. We also collect 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 we collect 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, the national death register, and the chemotherapy and radiotherapy datasets held by Public Health England. The linkage of the datasets is performed by NHS Digital.

Following linkage, the NOGCA project team receives only de-identified datasets for analysis. The data are 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. The data received by the NOGCA team are kept for the duration of the Audit.

Data Controller for the Audit

NOGCA 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. The Audit has been commissioned to run until May 2021. HQIP will review how long the data need to be stored when the Audit has finished.

NHS England and HQIP are the joint data controllers for the patient data submitted directly to the Audit by NHS hospitals. HQIP has a Data Protection Officer who can be contacted at the following email address: data.protection@hqip.org.uk. For further information, please consult HQIP's privacy policy: www.hqip.org.uk/about-us/privacy-policy

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 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](#))

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: www.hra.nhs.uk/about-the-hra/our-committees/section-251/what-is-section-251/.

NOGCA's legal basis for processing personal data is Public Task. We 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 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. We have conducted a legitimate interests assessment (LIA) which outlines the purpose and need for this information. The LIA is kept under review and will be updated as circumstances change.

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 NOGCA project team receives only de-identified datasets from NHS Digital, which do not include sensitive personal information such as name, address or postcode. The patient information received and managed by the NOGCA team is treated as confidential.

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. The Audit follows guidelines issued by the Office for National Statistics on publishing statistics - [Review of the Dissemination of Health Statistics: Confidentiality Guidance \(PDF\)](#).

Management of patient 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 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.

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 the NOGCA 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: www.hqip.org.uk/national-programmes/accessing-ncapop-data

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

All patients have the right to:

- See the information that the Audit holds about them
- Ask for the correction of inaccurate or incomplete personal data
- Request that their personal information is erased (this right only applies in certain circumstances)

- Request that the Audit limits the way that their personal data are used
- Object to the processing of their information
- Lodge a complaint with the Information Commissioners Office (ico.org.uk) about the processing of their personal information

For information on how to exercise these rights, 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 we use, please consult the policy of the relevant data controller:

- NHS Digital: www.digital.nhs.uk/about-nhs-digital/our-work/keeping-patient-data-safe/how-we-look-after-your-health-and-care-information
- Office for National Statistics: www.ons.gov.uk/aboutus/transparencyandgovernance/dataprotection
- Public Health England: www.gov.uk/government/organisations/public-health-england/about/personal-information-charter

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 10 October 2018.

How to contact us

Please contact us if you have any questions about our privacy policy or information we hold 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: ico.org.uk