COSD and registry data FAQ

What is the NLCA?

The National Lung Cancer Audit (NLCA) was developed in response to the finding in the late 1990s that outcomes for lung cancer patients in the UK lagged behind those in other westernised countries, and varied considerably between organisations within the UK. The audit began collecting data nationally in 2005, and since then has become an exemplar of national cancer audit. The audit was previously run by the Health and Social Care Information Centre (HSCIC) but the contract was awarded to the Royal College of Physicians in 2014.

What is LUCADA?

LUCADA was the name given to the bespoke lung cancer dataset that was previously used by NHS trusts to upload their lung cancer patient data. The NLCA no longer "collects" data; the term LUCADA (LUng CAncer DAta) has always referred to the online data collection system of the legacy NLCA and no longer exists; it has been replaced with Cancer Outcomes and Services Dataset (COSD).

What is COSD?

COSD is the national standard for reporting on all cancers in the NHS in England. COSD specifies the items to be submitted electronically by service providers to NCRAS on a monthly basis. http://www.ncin.org.uk/collecting_and_using_data/data_collection/cosd

What is NCRAS?

The National Cancer Registration and Analysis Service (NCRAS) is part of Public Health England and is responsible for all cancer registration in England. There are eight regional offices.

What is CancerStats?

CancerStats is the NCRAS online portal which provides detailed information about the quality of the COSD data as well as some summary clinical and process measures. Within the portal there is an area dedicated to the NLCA with real-time reporting of data completeness, local results and benchmarking. In the data completeness report, you can use the 'first seen' filter to display cases that were first seen at each trust. To access CancerStats an N3 connection is required. Please click on the link below to access the logon page where you can request an account: https://nww.cancerstats.nhs.uk/users/sign_in

What is cancer registry data?

This refers to the processed data that the NCRAS produce. The NCRAS has access to cancer data from a variety of sources including: Pathology, Radiology, Office for National Statistics (ONS), Hospital Episode Statistics (HES), Cancer Waiting Times (CWT) and Patient Administration Systems (PAS) as well as the information submitted via COSD. The NCRAS now also have access to the National Radiotherapy Dataset (RTDS) and the Systemic Anti-Cancer Therapy Dataset (SACT). The NCRAS also has remote access to a number of trusts throughout the country, in particular imaging systems. Registration officers use this functionality to find additional information or resolve data discrepancies. Using these multiple sources of data, the registration officers at NCRAS are able to then produce a completed registration dataset for every lung cancer. With access to these additional datasets, the NCRAS often identifies more lung cancer cases than those submitted just through COSD.

What happens to my COSD file once it goes to NCRAS?

The NCRAS combine the COSD with all of the other data sources described above to produce pathway completed registration dataset for each patient.

What are the deadlines for submitting COSD data?

Trusts are encouraged to validate and submit all data available on a monthly basis in-line with the COSD reporting timescales:
http://www.ncin.org.uk/collecting_and_using_data/data_collection/cosd

Data for patients diagnosed in the reporting month should be submitted by the COSD deadline, and then additional staging and treatment data should be submitted once available in a subsequent submission. It is expected that the majority of data will be submitted within six months of diagnosis. The main driver is to submit data as real time as possible as then it can be processed accordingly. This process is very different to the previous LUCADA collection, whereby trusts were given a cut-off date for the complete year.

How do the NCRAS identify lung cancer cases?

Each tumour record has a Primary Diagnosis (ICD10 code) which relates to the site of cancer the patient has. Details of this system can be found at
http://apps.who.int/classifications/icd10/browse/2016/en

The NCRAS will select all cases with codes C34-39 (lung cancer) and C45 (mesothelioma) with Group II (neoplasms) to produce the extract of data for the NLCA analysts.

How do NCRAS stage cancers?

The NCRAS registration officers review all data sources available when processing the data for each patient. Each patient, where possible, is given a 'registry stage'. This is the best stage at diagnosis that the registration officer can determine from all data available. **Integrated** MDT stage from COSD is the gold standard, or the **Clinical Pre-Treatment MDT Stage** checked against other sources e.g. pathology/imaging reports to confirm, particularly if the patient is seen at more than one trust. If there is no MDT stage, it will be assigned from pathology/imaging/remote access. The registry stage is in many ways an integrated stage, as it uses the most accurate information from clinical and pathological investigations. The registry stage is by far the most complete, quality assured and consistent stage.

How do NCRAS identify treatments?

All data sources are combined to produce the full pathway for each patient. For surgery PAS and HES are used in preference, then COSD and CWT. For other treatments COSD/RTDS/SACT takes precedence, then CWT and PAS/HES.

The NLCA team will determine which treatment information they would like to receive in each data extract, for example, the first treatment of each treatment type for all patients.

Will my data get overwritten if another organisation submits data on the same patient?

No, all data is combined for the patient. Rules and algorithms are in place to handle conflicting or duplicate data from different organisations. Cancer registration officers also use remote access or contact trusts to resolve data discrepancies.

How can I check my data?

Data completeness can be checked via CancerStats.

What if I disagree with the data?

If the analysis of your results looks wrong, it is much more likely that the submitted data was incorrect rather than any downstream analysis. We would encourage you to develop close links with the cancer audit staff in your organisations in order to ensure that data collection and submission protocols are agreed, and that there is clinical validation of the data. After COSD has been submitted, it can be updated by a new upload from the same organisation. Following analysis for the NLCA annual report, there will be an opportunity for trusts to view

their own results; however, at this stage it will usually be too late to re-upload, re-analyse and re-write the annual report.

I need more information; what should I do?

If your query relates to data submissions, your first point of contact should be with your regional Data Improvement Leads:

NCRAS office	Data Improvement Lead	Email address
National	Karen Graham	Karen.Graham6@nhs.net
East Midlands	Paul Stacey	Paul.Stacey@phe.gov.uk
Eastern	Karen Graham	Karen.Graham6@nhs.net
London	Michael Sharpe	m.sharpe@nhs.net
North West	Paul Stacey	Paul.Stacey@phe.gov.uk
Northern and Yorkshire	Christine Head	Christine.Head@phe.gov.uk
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South West	James Withers	James.Withers@phe.gov.uk
West Midlands	Donna Lloyd	Donna.Lloyd@phe.gov.uk
	Matthew Lynch	Matthew.Lynch@phe.gov.uk

For any other queries, you can contact the NLCA team:

Email: NLCA@rcplondon.ac.uk

Website: https://www.rcplondon.ac.uk/projects/national-lung-cancer-audit

Twitter: @RCP_NLCA