NLCA Frequently Asked Questions

1. **What is the National Lung Cancer Audit?**

   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.

2. **What has the NLCA achieved so far?**

   All trusts in England contribute to the audit, and data is submitted on approximately 100% of incident cases. The quality of the data on individual cases has gradually improved, allowing robust risk adjustment to be carried out. An Annual Report has charted overall steady improvement in care, with more patients having access to surgery and to other anti-cancer therapies. It also highlights a wide variation in management and outcome that is in most cases independent of case-mix.

   As well as in an Annual Report, the NLCA data has been widely disseminated though abstracts at national/international meetings and in peer-reviewed publications. Local data has been used as a driver for numerous local service improvement projects. The data has also been used to underpin NICE guidelines, to inform research protocols and to guide national service developments.

3. **Why is the NLCA changing?**

   The NLCA is commissioned by the Healthcare Quality Improvement Partnership (HQIP) and until the end of 2014 the contract was held by the Health and Social Care Information Centre (HSCIC). In 2014, HQIP opened a retendering process to run the audit for the next 3-5 years. The contract was awarded to the Royal College of Physicians of London, who will be working in partnership with the National Cancer Registration Service, the Department of Epidemiology at the University of Nottingham, the National Forum for Lung Cancer Nurse Specialists, the Society of Cardiothoracic Surgeons (SCTS), The British Thoracic Oncology Group and the Roy Castle Lung Cancer Foundation to deliver the audit. The clinical leadership of the audit is unchanged: Dr Mick Peake, Dr Paul Beckett and Dr Ian Woolhouse.

Dr Woolhouse has taken over from Dr Peake as the senior clinical lead.

4. **What are the main aims of the audit over the next few years?**

   To drive further improvements in lung cancer care and outcomes by bringing the standard of all lung cancer MDTs up to that of the best.

5. **Will the audit still cover all the countries in the United Kingdom?**

   The audit is commissioned to collect data and report on patients treated in England and Wales. Our colleagues in Scotland and Northern Ireland are keen to contribute and we will be working with clinicians and managers in those countries to maintain and enhance their involvement in the audit.

6. **What is the main change that users will notice?**

   A new model of data collection and submission will be used, based on the Cancer Services Outcomes Dataset (COSD). New clinical indicators will be added, "Spotlight Audits" with supported Quality Improvement will be offered, and the use of PROMS/PREMS measures will be piloted. We will also be collecting and analysing the data according to **date of diagnosis**, rather than date first seen as we have done historically.

7. **What is COSD and what does it mean for data collection?**

   In January 2013 the COSD replaced the previous National Cancer Dataset as the new national standard for reporting cancer in the NHS in England. It incorporated a revised generic Cancer Registration Dataset (CRDS) and additional clinical and pathology site specific data items relevant to different tumour types. The COSD specifies the items to be submitted electronically by service providers to the National Cancer Registration Service (NCRS) on a monthly basis. It replaces the existing monthly NCRS upload and may include separate files from different hospital systems. The COSD also identifies the items that the NCRS will obtain from other sources such as Cancer Waiting Times, Cancer Screening Programmes and ONS. Data is submitted by NHS Providers of Cancer Services and will linked with data from other sources by the NCRS at patient level using NHS number in order to compile the full dataset.

   This means that 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 will no

longer exist. Instead, nationally mandated data flows are collated and analysed by the NCRS with the NLCA clinical team using the data to produce reports and recommendations.

8. **How are the data items in the new dataset different?**

   The COSD contains a list of core items and lung cancer-specific items - this combination is now the new lung cancer dataset.

   Most of the items in the legacy NLCA dataset map across to the same field in COSD. Some of the legacy data items are not included in COSD, but can be derived or obtained from other data sources. There are a few new data items such as smoking status and EGFR mutation status.

   The full dataset specification can be downloaded from http://goo.gl/3qCXqC but it is not for the fainthearted!

9. **What about co-morbidity?**

   The recording of co-morbidity in LUCADA was perhaps confusing for users. Subsequently, automated methods for calculating a Charlson co-morbidity score using Hospital Episode Statistics (HES) were developed and could be easily applied to the risk-adjustment models. However, it is not clear how accurate these calculations are, and they can only be applied to those patients who have had a hospital admission.

   COSD includes a field for a recording of the Adult Co-Morbidity Evaluation-27 (ACE-27) score and we will be looking into the feasibility of using this as our primary source of co-morbidity data.

10. **Will data quality be maintained?**

    The lung cancer community can justifiably be proud of the quality of the data that it submits year on year to the NLCA and deterioration in the quality of the data is a real risk in the move to the new systems.

    The NCRS online portal CancerStats (https://nww.cancerstats.nhs.uk/users/sign_in) 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.

Appendix 1 details the key items for 2015 data collection.

11. **Will hospitals have to collect more data?**

    COSD is a nationally mandated dataset and all providers of cancer services across all tumour types have to provide a core dataset as well as some site-specific items. Organisations will need to ensure that their data collection systems (staff and IT) are robustly configured to deliver this. It is envisaged that once systems become automated and datasets linked, the burden of data collection will reduce rather than increase.

    Having provided data for several years to the NLCA, lung cancer teams have a big head start, especially considering that the COSD is based upon the historic NLCA dataset.

12. **Does the NLCA collect data on mesothelioma?**

    Yes and we hope to produce a mesothelioma-specific report, similar to that published in 2014, in 2016/17.

13. **How will you be reporting results back to trusts?**

    We plan to produce monthly data quality reports and quarterly indicator reports. These will be in electronic format. As before we will produce an Annual Report, published in early December, providing an overview of the National picture, as well as key results by Strategic Clinical Network (SCN) and by Trust. This will be backed up by an on-line spreadsheet containing more detailed analysis. This spreadsheet will include risk-adjusted estimates (adjusted for age, sex, stage, performance status and socio-economic deprivation).

    There will be some changes to the headline indicators that are reported on. For example, we will try to develop an overall “radical treatment rate”, as well as reporting 3 year rolling averages for measures where the denominator is relatively low (e.g. small cell lung cancer treatment).

    To bring the reporting into line with COSD, we will be reporting by date of diagnosis rather

than “date first seen”. It will be our ambition to bring forward the reporting timescales so that (for example) the deadline for submission of 2015 cases would be 31st March 2016, rather than 30th June as in previous years.

14. **What should we do with our audit results?**

    It is vital that the hard work of collecting data is translated into service improvements. Organisations must take ownership of their results, and should ensure that they are discussed and understood by the wider MDT and not just the MDT or audit lead.

15. **How are outliers identified?**

    We encourage organisations to look at both the non-adjusted and risk-adjusted results, but outliers will be identified based on the risk-adjusted results for the following measures:

    - ***Histo-cytological confirmation rate***
    - ***Anti-cancer treatment rate***
    - ***Non-small cell lung cancer resection rate***
    - ***Small cell lung cancer chemotherapy rate***
    - ***1 year survival***
    - ***Median survival***

    We will agree a detailed policy for identify and notifying organisations whose results are statistically significantly different. This will be based on the HQIP outlier policy and we will make available a copy of this policy in due course.

16. **What about patient outcome and experience measures?**

    Funding is promised in the new NLCA contract to deliver a one-year feasibility study of national collection of PROM and/or PREM in lung cancer. Assuming this funding is confirmed, this project is likely to start in 2016.

17. **What is the role of the NLCA in the Consultant Outcome Publication Programme?**

    In 2014, a partnership between the HSCIC, the NLCA team and the SCTS was able to analyse and report data on individual consultant surgeon operating on lung cancer patients, as part of a wider NHS Consultant Outcome Publication Programme (COP). In this report, individual surgeon activity was reported, but mortality was only reported at trust level.

In 2015 and beyond, the new NLCA contract mandates reporting for future rounds of the COP. The NLCA team will continue to work with the SCTS to deliver this work. In addition, there is significant pressure to report on individual surgeon mortality in future years despite the risk that such reporting might lead to a more risk-averse behaviour from surgeons and as a result negatively impact upon surgical resection rates.

18. **The data you have on my lung cancer service is wrong – what do I do?**

    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 some clinical validation of the data.

    After COSD data has been submitted, it can be overwritten by a new upload. Following analysis for the Annual Report, there will be an opportunity for trusts to view their own results and there may be an opportunity to include comments where data is incorrect; however, at this stage it will usually be too late to re-upload, re-analyse and re-write the Annual Report.

19. **How can researchers access the data?**

    The NLCA team is committed to sharing the data and ensuring the greatest possible use comes from the hard work of collection. The RCP is currently not able to process requests for data access until data sharing protocols have been finalised. There will be a formal process of application which will be outlined in due course on the RCP website.

20. **How can I keep up-to-date on developments with the NLCA?**

    The best way is to join the NLCA mailing list by sending your details to: NLCA@rcplondon.ac.uk

    You can also get further information from the NLCA website at: www.rcplondon.ac.uk/resources/national-lung-cancer-audit

NLCA Key Items for 2015 Data

*Required for linkage

Demographics

COSD Data Item
***CR0010 NHS NUMBER**
***CR0100 PERSON BIRTH DATE**
***CR2030 DATE OF DIAGNOSIS (CLINICALLY AGREED)**
CR0080 POSTCODE OF USUAL ADDRESS (AT DIAGNOSIS)
CR3170 PERSON STATED GENDER CODE
CR0150 ETHNIC CATEGORY

Case Mix

COSD Data Item
CR0510 PERFORMANCE STATUS (ADULT)
LU10040 FEV1 PERCENTAGE
LU10050 FEV1 ABSOLUTE VALUE
LU10190 SMOKING STATUS

Process

COSD Data Item
CR1600 SOURCE OF REFERRAL FOR OUT-PATIENTS
CR 1580 REFERRAL TO TREATMENT START PERIOD
CR1360 DATE FIRST SEEN (CANCER SPECIALIST) if populated, else use CR0230 DATE FIRST SEEN
CR1400 ORGANISATION SITE CODE (PROVIDER FIRST CANCER SPECIALIST) if populated, else use CR1410 ORGANISATION SITE CODE (PROVIDER FIRST SEEN)
CR0230 PROCEDURE DATE (CANCER IMAGING)
CR0330 CANCER IMAGING MODALITY
CR0340 IMAGING ANATOMICAL SITE
CR0390 BASIS OF DIAGNOSIS (CANCER)
CR2050 CLINICAL NURSE SPECIALIST INDICATION CODE
CR0420 MULTIDISCIPLINARY TEAM DISCUSSION INDICATOR
CR0430 MULTIDISCIPLINARY TEAM DISCUSSION DATE (CANCER)
LU10000 PROCEDURE DATE (CT SCAN)
LU10010 PROCEDURE DATE (PET CT SCAN)
LU10070 PROCEDURE DATE BRONCHOCOPY
LU10060 MEDIASTINAL SAMPLING INDICATOR

Diagnosis
COSD Data Item
***CR0370 PRIMARY DIAGNOSIS (ICD)**
***CR0380 TUMOUR LATERALITY**
CR0400 MORPHOLOGY (SNOMED)
CR0520 T CATEGORY (FINAL PRE-TREATMENT)
CR0540 N CATEGORY (FINAL PRE-TREATMENT)
CR0560 M CATEGORY (FINAL PRE-TREATMENT)
CR0580 TNM CATEGORY (FINAL PRE-TREATMENT)
CR0620 T CATEGORY (INTEGRATED STAGE)
CR0630 N CATEGORY (INTEGRATED STAGE)
CR0640 M CATEGORY (INTEGRATED STAGE)
CR0610 TNM STAGE GROUPING (INTEGRATED)

Treatment
COSD Data Item
CR0460 CANCER CARE PLAN INTENT
CR0490 NO CANCER TREATMENT REASON
CR1370 TREATMENT START DATE (CANCER)
CR2040 CANCER TREATMENT MODALITY
CR1450 ORGANISATION SITE CODE PROVIDER TREATMENT START DATE (CANCER)
CR0710 PROCEDURE DATE
CR0720 PRIMARY PROCEDURE (OPCS)

Pathology
COSD Data Item
CR0780 INVESTIGATION RESULT DATE
CR0970 SPECIMEN NATURE
CR0850 MORPHOLOGY (SNOMED)
CR0810 PRIMARY DIAGNOSIS (ICD PATHOLOGICAL)
CR0820TUMOUR LATERALITY (PATHOLOGICAL)
CR0760 PATHOLOGY INVESTIGATION TYPE
CR0880 EXCISION MARGIN
CR0910 T CATEGORY (PATHOLOGICAL)
CR0920 N CATEGORY (PATHOLOGICAL)
CR0930 M CATEGORY (PATHOLOGICAL)
CR0940 TNM STAGE GROUPING (PATHOLOGICAL)
LU10090 EPIDERMAL GROWTH FACTOR RECEPTOR MUTATIONAL STATUS

Outcome
COSD Data Item
CR1270 PERSON DEATH DATE
CR1280 DEATH LOCATION TYPE

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