

## Supplement 1

### Supplement 1.1: Existing datasets of Lung Cancer Registration

Dataset	Author	Comments
<b>Cancer Outcomes and Service Dataset (COSD)</b> Began January 2013	National Cancer Registration and Analysis Service; Public Health England (previously known as the National Cancer Intelligence Network)	Data definitions for data collection for all cancers at national level. Some fields are generic for all cancer sites, others are tumour specific. Mandatory for all providers of cancer care to submit data on a monthly basis to COSD. Managed by the National Cancer Registration and Analysis Service (NCRAS) which can integrate these data with a number of other data feeds, including Hospital Episode Statistics (HES), the Systemic Anti-Cancer dataset (SACT) derived from electronic prescribing, the Radiotherapy Treatment Dataset (RTDS) taken from the radiotherapy treatment machines (Linear Accelerators) and NHS Digital's Diagnostic Imaging Dataset.
<a href="http://www.ncin.org.uk/collecting_and_using_data/data_collection/cosd_downloads_v7">http://www.ncin.org.uk/collecting_and_using_data/data_collection/cosd_downloads_v7</a>		
<b>Danish Lung Cancer Registry</b>		V4.1 October 2015
<a href="https://www.rkkp-dokumentation.dk/Public/Databases.aspx">https://www.rkkp-dokumentation.dk/Public/Databases.aspx</a>		
<b>European Network for Cancer Registration (ENCR)</b>	International Agency for Research on Cancer (IARC)	Recommendations for a Standard Dataset for the European Network of Cancer Registries published in 2005. Aimed to preserve the possibility for comparison between European Registries and rest of world and to promote wide-scale collaboration across Europe.
<a href="http://www.encr.eu/images/docs/recommendations/recommendations.pdf">http://www.encr.eu/images/docs/recommendations/recommendations.pdf</a>		
<b>International Consortium for Health Outcomes Measurement (ICHOM)</b> Lung Cancer data collection Reference Guide		Version 2.1 revised April 2015. Collaboration of patient representatives, clinicians and registry leaders from across the world, who have designed a dataset of outcome measures and case-mix variables specific for lung cancer. The aim is to use a standardised set of outcome measures to compare performance, encourage sharing of best practice,

		and improve the care provided to our patients.
<a href="http://www.ichom.org/">http://www.ichom.org/</a>		
<b>German Lung cancer parameters</b>	§	The standardized oncological basic dataset of ADT and GEKID was adopted in March 2008 and updated in February 2014. It applies to all cancers and is continuously supplemented with tumour-specific modules. With the standardized basic oncological dataset, an instrument has been created which sets a uniform oncological standard, prevents multiple documentation and enables comparable recording and evaluation of cancer treatments in all federal states and clinical structures in Germany.
<a href="http://www.tumorzentren.de/tl_files/dokumente/Module%20zum%20Basisdatensatz/Bundesanzeiger_BDS_28.04.14.pdf">http://www.tumorzentren.de/tl_files/dokumente/Module%20zum%20Basisdatensatz/Bundesanzeiger_BDS_28.04.14.pdf</a>		

Supplement 1.2: An example of coding for ethnicity

Office of National Statistics (ONS) UK.

Code	Ethnicity
<b>White</b>	
A	British
B	Irish
C	Any other White background
<b>Mixed</b>	
D	White and Black Caribbean
E	White and Black African
F	White and Asian
G	Any other mixed background
<b>Asian or Asian British</b>	
H	Indian
J	Pakistani
K	Bangladeshi
L	Any other Asian background
<b>Black or Black British</b>	
M	Caribbean
N	African
P	Any other Black background
<b>Other ethnic Groups</b>	
R	Chinese
S	Any other ethnic group
Z	Not stated

Supplement 1.3: Results of narrative evidence search on websites of international societies and other stakeholders related to lung cancer care as well as those on the national level accessible by taskforce members

Name of society/stakeholder	Website	Results
<b>International societies</b>		
European Association for Palliative Care (EAPC)	<a href="http://www.eapcnet.eu">www.eapcnet.eu</a>	White Paper on standards and norms for hospice and palliative care in Europe: part 1+2 [1]
European Lung Foundation	<a href="http://www.europeanlung.org">www.europeanlung.org</a>	Patient priorities project lung cancer [2]
European Organisation for Research and Treatment of Cancer (EORTC)	<a href="http://www.eortc.org">www.eortc.org</a>	European Organization for Research and Treatment of Cancer (EORTC) recommendations for planning and delivery of high-dose, high precision radiotherapy for lung cancer [3]
European Respiratory Society	<a href="http://www.ersnet.org">www.ersnet.org</a>	Thoracic Oncology HERMES [4-6]
European Society for Medical Oncology (ESMO)	<a href="http://www.esmo.org">www.esmo.org</a>	Designated Center of Integrated Oncology and Palliative Care Application [7]
European Society for Radiotherapy and Oncology  Advisory Committee on Radiation Oncology Practice (ACROP)	<a href="http://www.estro.org">www.estro.org</a>	ESTRO ACROP consensus guideline on implementation and practice of stereotactic body radiotherapy for peripherally located early stage non-small cell lung cancer [8]
European Society of Radiology (ESR)	<a href="http://www.myesr.org">www.myesr.org</a>	European Society of Radiology (ESR) and American College of Radiology (ACR) report of the 2015 global summit on radiological quality and safety [9]
European Society of Thoracic Surgeons (ESTS)	<a href="http://www.ests.org">www.ests.org</a>	Clinical guidelines for evaluating fitness for radical treatment (surgery and chemoradiotherapy) in patients with lung cancer (with ERS) [10]  European guidelines on structure and qualification of general thoracic surgery [11]

International Association for the Study of Lung Cancer (IASLC)	<a href="http://www.iaslc.org">www.iaslc.org</a>	Adenocarcinoma classification [12]  Lung cancer staging recommendations [13-18]
Organisation of European Cancer Institutes	<a href="http://www.oeci.eu">www.oeci.eu</a>	OECI Accreditation and Designation [19]
Union Internationale Contre le Cancer (UICC)	<a href="http://www.uicc.org">www.uicc.org</a>	Lung cancer staging recommendations [20]
World Association for Bronchology Interventional Pulmonology (WABIP)	<a href="http://www.wabip.com">www.wabip.com</a>	
<b>Other International Stakeholders</b>		
European Union	<a href="http://www.europa.eu">www.europa.eu</a>	Project cycle management [21]
World Health Organization	<a href="http://www.who.int">www.who.int</a>	WHO classification of tumours of the lung [22]  Definition of Palliative Care [23]
<b>National societies/other stakeholders</b>		
<b>-Germany</b>		
Deutsche Gesellschaft für Hämatologie und Medizinische Onkologie	<a href="http://www.dgho.de">www.dgho.de</a>	Onkologisches Zentrum (Oncologic Centres) [24]
Deutsche Gesellschaft für Pneumologie und Beatmungsmedizin (German Respiratory Society)	<a href="http://www.pneumologie.de">www.pneumologie.de</a>	German lung cancer guideline [25]
Deutsche Gesellschaft für Thoraxchirurgie (German Society for Thoracic Surgery)	<a href="http://www.dgt-online.de">www.dgt-online.de</a>	Kompetenzzentrum Thoraxchirurgie (Certification of Thoracic Centres) [26]
Deutsche Krebsgesellschaft (German Cancer Society)	<a href="http://www.dkg.de">www.dkg.de</a>	Lungenkrebszentren (Certification of lung cancer centres) [27, 28]
Onkozert	<a href="http://www.onkozert.de">www.onkozert.de</a>	
<b>-United Kingdom</b>		
British Thoracic Society	<a href="http://www.brit-thoracic.org.uk">www.brit-thoracic.org.uk</a>	Guideline for diagnostic flexible bronchoscopy in adults [29]  Guideline on radical management of patients with lung cancer [30]
Cancer Research UK	<a href="http://www.cancerresearchuk.org">www.cancerresearchuk.org</a>	Lung Clinical Expert Group: National Optimal Lung Cancer Pathway [31]  Lung Cancer Centres of Excellence [32]

Expert Advisory Group on Cancer to the Chief Medical Officers of England and Wales		A Policy Framework for Commissioning Cancer Services [33]
National Institute for Health and Care Excellence	<a href="http://www.nice.org.uk">www.nice.org.uk</a>	NICE guideline on the Diagnosis and Treatment of Lung Cancer (Update) [34]
<b>-United States of America</b>		
American College of Chest Physicians (ACCP)	<a href="http://www.chestnet.org">www.chestnet.org</a>	ACCP guideline on diagnosis and management of lung cancer, 3 <sup>rd</sup> edition
Bonnie J. Addario Lung Cancer Foundation	<a href="http://www.lungcancerfoundation.org">www.lungcancerfoundation.org</a>	Centers of Excellence [35]
National Cancer Institute	<a href="http://www.cancer.gov">www.cancer.gov</a>	NCI-Designated Cancer Centers [36]

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Supplement 1.4: Example of multi-site lung cancer service in Southern Denmark.

**The lung cancer service in the Region of Southern Denmark (population:1.2 mio)**

Two major and one minor diagnostic centre cover the region's need of invasive lung cancer diagnostics. PET-CT available in the two major centres. The patients are referred for diagnostics from the primary health service or from other hospitals in the region. Thoracic surgery, radiotherapy and chemotherapy are available for all patients from the region, but also patients from Region Zealand are having thoracic surgery and radiotherapy with curative intent in Odense. Three weekly pairwise MDT-conferences takes place between Odense-Vejle and Odense-Sønderborg by use of video-link.



Selected results from 2016

**Vejle:**

449 first time diagnoses of lung cancer  
63 patients had conventional radiotherapy with curative intent

**Odense:**

439 first time diagnoses of lung cancer  
321 resections of lung cancer  
204 patients had radiotherapy with curative intent (52% SBRT)

**Sønderborg:**

206 first time diagnoses of lung cancer

