

Appendix 1; An overview of the epidemiology of lung cancer in Europe

The incidence and mortality of lung cancer in Europe

Details of cancer incidence and mortality in Europe and elsewhere in the world have been collated by the GLOBOCAN project lead by the International Agency for Research on Cancer (IARC). The incidence data are derived from local population based cancer registries whilst the mortality data are derived from the WHO database [1].

An analysis of the GLOBOCAN database [2] reveals that within Europe the highest incidence of lung cancer for both sexes combined (after standardising for age) is present in Hungary, followed by Poland and Serbia. The pattern is the same for the incidence of lung cancer in men – but for women Denmark has the highest incidence followed by Hungary and then Iceland. In every country in Europe the lung cancer incidence is higher in men than women, although there is striking heterogeneity in the country level differences between men and women throughout Europe (table 1).

In contrast Cyprus, Portugal and Sweden have the lowest incidence of lung cancer for both sexes combine, whilst the lowest incidence for males is found in Sweden (table 1). After accounting for the effects of age, the overall incidence of lung cancer in Hungary is more than four times greater than that seen in Cyprus. Only four countries had an age standardised overall cancer incidence of less than 20 per 100,000 person years (Cyprus, Portugal, Sweden and Malta). If all of the countries with an incidence rate higher than this could reduce their incidence to 20 cases per 100,000 person years then this would reduce the number of new lung cancer cases diagnosed each year in Europe by approximately 120,000 (30%).

In absolute terms the highest number of lung cancer cases come from Russia, Germany, the UK and Italy and together these countries account for roughly half (47%) of all of the cases of lung cancer in Europe.

In general the prognosis of lung cancer is poor and for this reason the mortality rates from lung cancer in Europe closely follow the incidence rates (table 1).

Survival from lung cancer in Europe

Information on survival from lung cancer has been co-ordinated by the EUROCARE project which collects data from a number of cancer registries in Europe. A recent analysis of 12 years of data (1988 to 1999) from 18 countries in Europe has highlighted that variations in survival from lung cancer in Europe exist though these are less marked than the variations in disease incidence [3]. In a recent, more detailed, analysis comparing England to Norway and Sweden; the five-year survival figures from lung cancer were 6.5%, 9.3% and 11.3% for men and 8.4%, 13.5% and 15.9% for women respectively [4]. A large excess of early deaths appear to explain the low survival figures for England, in keeping with other data suggesting that people with lung cancer in England tend to present with advanced disease [4]. Similar more detailed data do not exist for other European countries.

Smoking and lung cancer in Europe

There is no doubt about the efficacy of reduction in tobacco consumption in reducing incidence and mortality from lung cancer [5]. There is evidence that the overall European mortality from lung cancer in men has fallen over the past 40 years, whilst in women it is still climbing and this has been linked to the change in smoking prevalence [6]. It is important therefore to have accurate European data on which to base any recommendations for future health interventions. The European Union conducts regular surveys of the prevalence of

smoking in EU countries by interviewing approximately 1000 people in each country. The survey, called the 'Eurobarometer', reported in 2010 that in Europe 29% of adults were current smokers, 22% were ex-smokers and 49% had never smoked [7]. There is heterogeneity in the smoking prevalence by country in Europe with the highest levels of smoking being in Hungary and Bulgaria and the lowest levels in Sweden and Finland [7]. Information on smoking prevalence is also available from local surveys and in a recent publication by Bogdanovica et al these have been collated and compared to the Eurobarometer data [8]. In general the estimates from the Eurobarometer data were marginally higher than those from local estimates. The European Commission has called for implementation of a Europe-wide ban on smoking in public places by 2012 [9].

References

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4. Holmberg L, Sandin F, Bray F, et al. National comparisons of lung cancer survival in England, Norway and Sweden 2001-2004: differences occur early in follow-up. *Thorax* 2010;65(5):436-41.
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Table S1: Details of cancer incidence and mortality in Europe with permission of GLOBOCAN(8)

Country	total number of cancers	ASR for both sexes	ASR for men	ASR for women	Mortality rate for both sexes
Albania	1198	30.4	44.0	18.6	27.0
Austria	4022	25.9	36.9	16.9	21.9
Belarus	3911	26.1	59.3	4.7	24.3
Belgium	7196	35.5	57.1	17.5	29.1
Bosnia Herzegovina	1503	24.1	41.7	9.5	21.2
Bulgaria	3996	29.0	53.7	8.5	24.6
Croatia	2932	34.1	60.0	13.8	31.4
Cyprus	177	12.7	22.0	4.9	12.6
Czech Republic	6463	34.0	55.5	17.1	27.6
Denmark	4177	38.4	43.3	34.6	34.6
Estonia	762	30.5	64.1	9.0	25.8
Finland	2287	20.2	31.2	11.7	16.9
France (metropolitan)	32430	30.0	47.7	14.7	23.6
FYRO Macedonia	901	31.3	57.8	7.7	26.6
Germany	49869	28.1	42.4	16.4	22.6
Greece	6667	29.3	52.2	9.5	26.6
Hungary	9049	52.0	80.9	30.7	46.0
Iceland	148	30.5	31.6	29.4	25.2
Ireland	2020	30.6	37.9	24.4	23.8
Italy	36640	26.7	45.4	11.4	22.2
Latvia	1058	25.8	55.2	7.1	24.0
Lithuania	1522	25.9	55.6	6.5	22.8
Luxembourg	261	30.9	46.4	18.2	23.7
Malta	139	17.9	32.9	5.9	17.1
Montenegro	336	34.7	56.5	16.7	31.0
Netherlands	10867	36.0	47.4	27.2	30.7
Norway	2567	29.3	35.3	24.7	22.9
Poland	25808	40.9	71.2	18.6	34.9
Portugal	3288	16.4	29.0	6.0	15.7
Republic of Moldova	1081	21.0	39.5	7.1	19.3
Romania	10384	30.0	54.6	9.8	26.8
Russian Federation	56767	25.5	55.2	7.0	22.7
Serbia	6337	40.7	66.1	18.5	36.7
Slovakia	2235	26.7	49.2	10.6	22.5
Slovenia	1246	33.3	54.7	16.2	28.0
Spain	23211	28.8	53.3	7.7	23.8
Sweden	3266	17.1	18.2	16.4	17.5
Switzerland	3893	26.7	38.4	17.0	19.7
Ukraine	17498	22.1	46.4	6.2	18.4
United Kingdom	40366	31.3	38.2	25.8	25.9

Legend: ASR = age standardised rate per 100,000 person years. FYRO Former Yugoslav Republic of. Data downloaded on 21 June 2012.

Appendix 2: European national and international societies, charities and professional bodies

Societies, charities and professional and public organizations can influence quality management by setting standards, promoting good practice and lobbying governments. Establishing the number and type of organizations in Europe may therefore be an important tool for future implementation of better lung cancer care. Lung cancer management is multidisciplinary so many organizations will have a wider remit than lung cancer and therefore have competing interests. By developing a comprehensive list of organizations it may be possible to initiate jointly agreed priorities in lung cancer quality management.

A list of organizations was compiled by a combination of on-line searches and asking the members of the Taskforce to provide lists via Taskforce meetings and email. These were, where possible, classified according to type (medical professional society, charity, etc.). The results were then presented at a taskforce meeting and any known omissions corrected. Where possible national representatives were also invited to comment on any omissions and ensure the accuracy of the data.

The list of organizations is presented in Table 2. The list of professional organizations reflects the multidisciplinary nature of lung cancer care with at least 18 being entirely dedicated to thoracic oncology. Many of the larger organizations such as the ERS and the European Lung Foundation (ELF) have subgroups that are not listed. Some, but not all national organizations are part of larger affiliations, for example the Forum of European Respiratory Societies (FERS) for respiratory medicine/pneumology. There are a variety of international oncology societies to which some national societies are affiliated. In some instances there are two separate international organizations, e.g. the European Society of Thoracic Surgeons (ESTS) and the European Association for Cardio-Thoracic Surgery (EACTS).

Few countries have specific Lung Cancer specialist nurse societies and there are only two European/International oncology nurse societies (European Oncology Nursing Society and the International Society of Nurses in Cancer Care).

Patients organizations, coalitions and leagues or foundations exist in nearly all European countries with only a few exceptions and some are affiliated to the Global Lung Cancer Coalition and the European Cancer Patient Coalition. Most national lung cancer foundations or leagues are members of the Association of European Cancer Leagues.

This preliminary work has resulted in the creation of an extensive list that includes professional bodies, patient groups and charities. Although some countries lacked specialty specific societies, in others there appeared to be duplication. The latter was present even at the international level. It is recognised that the list given in table 2 is not comprehensive and if any omissions are noted, the EIQMLCC would welcome corrections. Indeed, for this to be a contemporary resource for development of pan-European initiatives it is essential that table 2 is corrected, augmented and updated on a regular basis, perhaps as a web-based solution.

Table S2: Table of European national and international societies, charities and professional bodies

COUNTRY	RESPIRATORY SOCIETY	THORACIC SURGERY SOCIETY	OTHER RELEVANT SOCIETIES	NURSING SOCIETY	PATIENT ORGANIZATION OR CHARITIES
EUROPE	European Respiratory Society. www.ersnet.org/	European Society of Thoracic Surgeons. www.ests.org/ European Association for Cardio Thoracic Surgery. www.eacts.org/	European Society of Medical Oncology. www.esmo.org/		European Lung Foundation. www.european-lung-foundation.org/
ALBANIA	Albanian Respiratory Society	No data available	Albanian Oncology Society (SHONKSH)	No data available	No data available
AUSTRIA	Österreichische Gesellschaft für Pneumologie	Österreichische Gesellschaft für Thorax- und Herzchirurgie	Österreichische Gesellschaft für Hämatologie und Onkologie www.oegho.at Österreichische Gesellschaft für Chirurgische Onkologie (ÖGRO)	AHOP.Arbeitsgemeinschaft Hämatologischer Onkologischer Pflegepersonen in Österreich	Österreichische Krebshilfe www.krebshilfe.net Lungenkrebsforum Austria www.lungenkrebsforum-austria.at Lungenliga Österreich www.lungenliga.at
BELARUS*	National Respiratory Society	Society of Thoracic surgeons	Belarus Society of Therapeutic Radiology and Oncology, www.omr.med.by Belarusian Society of Oncologists	No data	No data
BELGIUM	Belgian Thoracic Society (Societe Belge de Pneumologie – Belgische Vereniging voor Pneumologie) www.bvp-sbp.org	Belgian Association for Cardio-Thoracic Surgery. www.bacts.org	Belgian Society of Medical Oncology, www.bsmo.be Belgian Association of Radiotherapy and Oncology (BVRO/ ABRO) www.abro-bvro.be	Société Belge des Infirmier(e)s en Oncologie, a member of EONS Vereniging voor Verpleegkundigen Radiotherapie en Onkologie Belgian Association for Nurses in Radiotherapy and Oncology (VVRO)	VAINCRE Flemish League against Cancer - www.elcwp.org Vlaamse Ligategen Kanker www.tegenkanker.be Foundation Against Cancer www.cancer.be Amis de L'institut Bordet www.amis-bordet.be
BOSNIA and HERZEGOVINA	Respiratory Society in B&H (Respiratorno udruženje u BiH) www.pulmo.co.ba Association of Pulmonologists of the Republic of Srpska (Udruženje pulmologa Republike Srpske) www.lungclinic-banjaluka.com	Thoracic Surgeons – within The Association of Surgeons of the Federation B&H (Udruženje hirurga Federacije BiH) www.udruzenje-hirurg.ba	Udruženje onkologa u BiH,	No data	None
BULGARIA	Bulgarian Respiratory	Bulgarian surgical society	Bulgarian Oncological society (Medical	Bulgarian Oncology	Bulgarian cancer

	Society (BRS)	(thoracic surgeons) – www.bgss.eu/	Oncologists) Bulgarian association of radiology (radiologists), www.medun.acad.bg/bar/r&r.htm	Nursing Society	association www.bulgariancancerassociation.org Association of patients with oncological diseases www.oncobg.info/
CROATIA	Croatian Respiratory Society Croatian Thoracic Society (includes pulmonology and oncology specialists as well as thoracic surgeons)	Croatian Society of Cardiothoracic Surgery and Anesthesiology Within Croatian Surgical Society	Croatian Society for Oncology Croatian Society of Medical Oncology (Hrvatskodrustvo zainternisticku onkologiju)	Professional Society of Oncology and haematology	Lung cancer patients organisation "JEDRA" – udruženje oboljelih od rakapluca. www.jedra.com.hr
CYPRUS*	Thoracic Society of Cyprus (Society of respiratory physicians, thoracic surgeons etc.)		Cyprus Oncology Society	Cyprus Oncology Nursing Society	The Cyprus Association of Cancer Patients and Friends Cyprus Anti-cancer Society, www.anticancersociety.org.cy
CZECH REPUBLIC	Czech pneumology and phthisiology society (Česká pneumologická a ftizeologická společnost): www.pneumologie.cz	The Thoracic Surgical Society	Czech Society for Oncology, www.linkos.cz Czech Society for Radiation Oncology, Radiobiology and Radiophysics www.srobf.cz	Czech Nurses Association Oncology (a member of EONS)	Czech Association of Patients, www.pacienti.cz League Against Cancer Prague, www.lpr.cz
DENMARK	Danish Society of Respiratory Medicine	Danish Society of Cardiothoracic Surgery	Danish Society of Clinical Oncology, www.dsko.org , Danish Cancer Society, www.cancer.dk Danish Lung Cancer Group. www.lungecancer.dk	The Danish Cancer Nursing Society	Danish Lung Cancer Association (member of GLCC) Danish Cooperation of Patients Organisation
ESTONIA	Estonian Society of Pneumology	Estonian Society of Thoracic Surgery	Estonian Society for Oncology	Estonian Oncology Nursing Society	Estonian cancer society, www.cancer.ee
FINLAND	Finnish Respiratory Society (Suomen Keuhkolääkäriyhdistys)	Finnish Association for Cardiothoracic Surgery	Cancer Society of Finland, www.cancer.fi Finnish Society of Oncology (Suomen Onkologiyhdistys), Finnish Society for Radiotherapy and Oncology (SOY)	Finnish Oncology Nursing Society	Society of Finnish Cancer Patients (Suomensyöpäpotilaat ry. in Finnish) www.syopapotilaat.fi/organisaatio.php
FRANCE	Société de Pneumologie de Langue Française (SPLF)	Société Française de Chirurgie Thoracique et Cardiovasculaire	Société Française du Cancer, www.sfc.asso.fr , Société Française de Radiothérapie Oncologique, www.sfro.org , Institut National du Cancer, www.e-cancer.fr	Ass. Française des Infirmières de Cancerologie	Ligue nationale contre le cancer, www.ligue-cancer.net
GEORGIA*	Georgian Respiratory Association	Society of Thoracic Surgery	Georgia Society of Clinical Oncology,	Georgian Nursing Association	No data available.

GERMANY	Deutsche Gesellschaft für Pneumologie und Beatmungsmedizin, www.pneumologie.de	Deutsche Gesellschaft für Thoraxchirurgie, www.dgt-online.de	German Society for Hematology and Oncology, www.dgho.de , German Society for Radiation Oncology, www.degro.org Working group of medical oncology within the German Cancer Society, www.aio-portal.de German Cancer Society (Deutsche Krebsgesellschaft) – a member of GLCC, www.krebsgesellschaft.de Pneumologisch-Onkologische Arbeitsgemeinschaft (POA)	KOK Konferenz Onkologischer. Kranken und Kinderkrankenpflege	German Cancer Society (Deutsche Krebsgesellschaft) a member of GLCC, www.krebsgesellschaft.de Selbsthilfe Lungenkrebs, www.selbsthilfe-lungenkrebs.de
GREECE*	Hellenic Thoracic Society	Hellenic Society of Thoracic and Cardiovascular Surgery	Hellenic Society of Medical Oncology, www.hesmo.gr EEAO - Hellenic Society for Radiation Oncology	Sector of Oncology Nursing of the Hellenic National Graduate Nurses Association	Society of Volunteers Against Cancer, www.oekk.gr
HUNGARY	Hungarian Pulmonological Society www.tudogyogyasz.hu	Hungarian Society of Thoracic Surgery, www.mmst.hu	Hungarian Cancer Society, www.oncology.hu Hungarian Society for Radiation Oncology (HUSRO), www.oncol.hu Hungarian Society of Medical Oncology www.mkot.hu	Hungarian Cancer Society: section Oncology Nursing	Hungarian League Against Cancer, www.rakliga.hu
ICELAND	Icelandic Thoracic Society	Iceland Association for Thoracic Surgery	Icelandic Association of Clinical Oncology (IACO) Icelandic cancer society, www.krabb.is	Iceland Oncology Nursing Society	Patients support groups within Icelandic cancer society, www.krabb.is
IRELAND	Irish Thoracic Society- Society of lung physicians, thoracic surgeons. www.irishthoracicsociety.com	See Irish Thoracic Society.	National Cancer Control Programme www.hse.ie Irish Society for Medical Oncology Irish Cancer Society www.cancer.ie	Irish Association for Nurses in Oncology	See Irish Cancer Society, a member of GLCC
ITALY*	AIMAR Italian Union for Pneumology (UIP) AIPO - Associazione Italiana Pneumologi Ospedalieri, www.aiponet.it SIMER – Società Italiana di Medicina Respiratoria, www.simernet.it	Società Italiana di Chirurgia Toracica	Italian Association of Oncological Radiotherapy (AIRO), www.radioterapiaitalia.it Associazione Italiana di Oncologia Medica (AIOM), www.aiom.it	Associazione Infermieri di Assistenza Oncologica (AIAO) Associazione Italiana Infermieri di Oncologia (AIIO)	Il cancro Alleanza contro, Italian Cancer Association for Patients & Friends, www.aimac.it Italian League Against Cancer, www.legatumori.it Alliance for Lung Cancer Advocacy, Support and Education- Italian chapter (ALCASE Italy) Tribunale per i Diritti del

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LATVIA*	Latvian Society of Lung Physicians	Latvian Society of Thoracic Surgery	Latvian Association of Oncologists Latvian Therapeutic Radiology Association (LTRA)	Latvian Cancer Nurses Society	Latvian Cancer Society "Dzīvības koks"
LITHUANIA	Lithuanian Society of Pulmonologists Lithuanian Society of Pulmonology and Allergy	Lithuanian Society for Cardiothoracic Surgeons (LSCS)	Lithuanian Society for Radiation Therapy, www.lsts.lt Lithuanian Society of Oncology, www.lod-vuoi.lt Lithuanian Society of Medical Oncology Lithuanian Society of Radiation Therapy	Lithuanian Oncology Nursing Society	Society of patients with oncohematological diseases „Kraujas“
LUXEMBOURG	Société Luxembourgeoise de Pneumologie	Thoracic surgery is subgroup of the: "Société Luxembourgeoise de Chirurgie Viscérale"	Luxemburg Society of Oncology www.slo.lu	Groupement Soignant en Oncologie (GSO)	Fondation Luxembourgeoise contre le Cancer, www.cancer.lu
MALTA	No society	No society	No society	Maltese Oncology Nursing Association (MONA)	No society
MACEDONIA FYR	Macedonian Respiratory Society	Macedonian Association of Surgeons, within Macedonian Medical Society, www.mld.org.mk	Macedonian Association of Oncological Radiotherapy (ZROM) Macedonian Medical Society	No available data	No data except for children
MOLDOVA*	No society	No society	Society of Oncology www.onco.md/societatea-oncologilor.html Moldavian National Scientific Society of Oncologists	No data	No society
NETHERLANDS	Dutch Society of Pulmonologists (Nederlandse Vereniging van Artsen voor Longziekten en Tuberculose; NVALT)	Netherlands Association for Cardio-Thoracic Surgery, www.nvtnet.nl Subsociety of the Netherlands Society for Surgery www.heelkunde.nl/subvereniging/en/nvvl	Dutch Cancer Society, www.kwfkankerbestrijding.nl Dutch Society for Medical Oncology, www.nvmo.eu Dutch Society for Radiotherapy and Oncology, www.nvro.nl	Verpleegkundigen & Verzorgenden Nederland Oncologie (V&VN) www.venvn.nl	Longkanker Informatiecentrum (member of GLCC) Dutch Federation of Cancer Patient Organisation, www.nfk.nl
NORWAY	Norwegian association for lung medicine www.legeforeningen.no/Fagmed/Norsk-forening-for-lungemedisin/	Norwegian association for thoracic surgery	Norwegian lung cancer group www.nlcg.no Norwegian Cancer Society, www.kreftforeningen.no , Norwegian Society for Oncology, www.legeforeningen.no	Norwegian Society of Nurses in Cancer Care	Lung cancer association, www.lungekreftforeningen.no/ National association for heart and lung diseases (Landsforeningen for hjerte og lungesyke) www.lhl.no/

POLAND	Polskie Towarzystwo Chorób Płuc (Polish Respiratory Society)	Polish Society of Cardiothoracic Surgeons	Polish Lung Cancer Group (Polska Grupa Raka Płuca) www.polgrp.org.pl/ Polish Cancer Society, www.puo.pl Polish Society of Clinical Oncology (Polskie Towarzystwo Onkologii Klinicznej): http://ptok.pl Polskie Towarzystwo Onkologiczne: www.pto.med.pl/ Polish Society of Radiation Oncology (PTRO)	Polish Oncology Nursing Society	Stowarzyszenie Walki z Rakiem Płuc Gdański Szczecin www.rakpluca.org.pl/ and www.rakpluca.szczecin.pl/ Fundacja Rak'n'Roll. Wygrajźcie! http://raknroll.pl/
PORTUGAL*	Portuguese Respiratory Society	Portuguese Society for Cardiothoracic and Vascular Surgery	Portuguese Society of Oncology, www.sponcologia.pt , Portuguese Society of Radiotherapy Oncology, www.spro.pt	Portuguese Oncology Nursing Association	Pulmonale (a member of GLCC)
ROMANIA	Romanian Society of Pneumology (Societatea Romana de Pneumologie); www.srp.ro	Romanian Society of Thoracic Surgery; www.srct.ro/	Romanian Society of Radiotherapy and Medical Oncology; www.srrom.ro		Romanian Federation of Cancer Patients Association www.en.fabc.ro/ Hope Support Group
RUSSIAN FEDERATION*	Russian Respiratory Society	Russian Society of Thoracic Surgery	Russian Society of Clinical Oncology; www.rosoncweb.ru Russian Association of Oncologists; www.oncology.ru Russian Association of Therapeutic Radiation Oncologists;	Russian Nurses Association	Within Russian Cancer Society (RCS) Moscow Cancer Relief Society Movement against Cancer
SERBIA	Association for asthma and COPD in Serbia	Society of Thoracic and Cardiovascular Surgery	Serbian Society of Medical Oncologists, www.umos.org.rs	Association of Nurses of Serbia, Nurses Oncology section	None dealing with lung cancer patients, only website for advice
SLOVAKIA*	Slovak Society of Pulmonology and Phtisiology	Slovakia Thoracic Surgical Society	Slovak Oncological society; www.onkologia.sk/ Slovak Society for Radiation Oncology, Radiobiology and Radiophysics (S3R)	Slovak Association of Nurses and Midwives, Oncology Nursing Section	Cancer patient Slovakia; www.onkopacient.sk/ League against cancer: www.lpr.sk/ Second Breath (Občianske združenie Druhý dych); www.druhydych.eu/ Foundation to help cancer patients; www.npop.sk/
SLOVENIA	Slovenian Respiratory Society Slovenian Society of Lung and Allergy Diseases (Društvo pljučnih in alergijskih bolnikov Slovenije)	Society of Thoracic Surgeons of Slovenia	Slovenian Society of Medical Oncology	Oncology Nurses Section	Cancer Patients Association of Slovenia, www.onkologija.org

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SPAIN	Sociedad Española de Neumología y Cirugía Torácica; www.separ.es (Spanish Society of Pneumology and Thoracic Surgery)	Sociedad Española de Neumología y Cirugía Torácica www.separ.es (Spanish Society of Pneumology and Thoracic Surgery)	Spanish Society of Medical Oncology www.seom.org , Spanish Association of Radiotherapy and Oncology (SEOR) Spanish Lung Cancer Group www.gecp.org	Sociedad Española de Enfermería Oncología SEEO (Spanish Oncology Nursing Society)	Spanish Association of Lung Cancer Patients, http://aeacap.org – a member of GLCC. Spanish Association Against Cancer; www.aecc.es Society sponsored by pharmaceutical companies www.cancerpulmon.es
SWEDEN	Swedish Society of Respiratory Medicine www.slmf.se/	The Swedish Association for Cardio-Thoracic Surgery	Swedish Society of Oncology; www.onkologi.org	Swedish Cancer Nurses society	Swedish Lung Cancer Association Stödet, www.stodet.se
SWITZERLAND	Swiss Society of Pneumology www.pneumo.ch/	Swiss Society for Thoracic Surgery	Swiss Society for Medical Oncology, www.sgmo.ch Scientific Association of Swiss Radiation Oncology; www.sasro.ch	Swiss Oncology Nursing Society	Swiss Forum Lung Cancer (Forum Lungenkrebs Schweiz) – member of GLCC www.lungenliga.ch The Swiss Cancer League (KrebsligaSchweiz/ Ligue suisse contre le cancer); www.krebsliga.ch
TURKEY*	Turkish Thoracic Society	Turkish Cardiovascular Surgery Society	Turkish Society of Lung Cancer (Turk Akciger kanseri derneği–takd); www.turkishlungcancer.org/modul/Akciger_kanserleri_dernegi (AKAD) (Society of lung cancers) www.akad.org.tr/ Turkish Society for Radiation Oncology, radonk.org.tr , Turkish Medical Oncology Society; www.kanser.org	Turkish Oncology Nursing Society	No available data.
UKRAINE*	Ukrainian Association of Tuberculosis and Pulmonology	No available data	Ukrainian Society for Therapeutic Radiology and Oncology (USTRO) Ukrainian Chemotherapists Association	No available data	Public organisation “Win the cancer” www.rakpobedim.com.ua
UNITED KINGDOM	British Thoracic Society www.brit-thoracic.org.uk/	The Society for Cardiothoracic Surgery in Great Britain and Ireland; www.scts.org/	British thoracic oncology group; www.btog.org , United Kingdom Lung Cancer Coalition; www.uklcc.org.uk/	United Kingdom Oncology Nursing Society (UKONS) The National Lung Cancer Forum for nurses; www.nlcfn.org.uk/	Roy Castle Lung Cancer Foundation, www.roycastle.org British Lung Foundation (a member of GLCC);

			<p>The Association of cancer physicians; www.cancerphysicians.org.uk, The Royal College of Radiologists; www.rcr.ac.uk/ National Cancer Research Institute; www.ncri.org.uk, Royal College of Physicians; www.rcplondon.ac.uk Oncology Wales; www.wales.nhs.uk, Scottish radiological society; www.radiology.co.uk</p>		<p>www.lunguk.org Macmillan Cancer Support, www.macmillan.org.uk Cancer Research UK; www.cancerresearchuk.org</p>
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Legend: * details for these countries have not been verified by a local physician

Appendix 3: Search Strategy for Literature review on Quality Management in Lung cancer care.

Search terms for Pubmed

Population

Lung Cancer

Search (((lung cancer[MeSH Terms]) OR (lung) OR (pulmonary) OR (bronchial) OR (bronchus) OR (((broncho) OR bronchio) OR alveolar) OR bronchoalveolar) OR bronchioalveolar) OR (bronchogenic) OR (small cell) OR (oat cell)) AND ((cancer) OR cancers) OR ((neoplasm) OR neoplasms) OR ((tumor) OR tumors) OR ((tumour) OR tumours) OR ((carcinoma) OR carcinomas) OR ((sarcoma) OR sarcomas)))

Intervention

Referral

Search (((referral[MeSH Terms]) OR (admission, patient[MeSH Terms]) OR (admittance[Title/Abstract])) OR (admittances[Title/Abstract])) OR (admission[Title/Abstract] OR (admissions[Title/Abstract])) OR (referral[Title/Abstract]) OR referrals[Title/Abstract]))

Diagnostics

Search ((diagnostic[Title]) OR diagnostics[Title]) OR ((investigation[Title]) OR investigations[Title]) OR ((confirmation[Title]) OR confirmations[Title]) OR (staging, cancer[MeSH Terms]) OR ((staging[Title]) OR stagings[Title]) OR (diagnosis[MeSH Terms]) OR ((diagnosis[Title]) OR diagnoses[Title]))

Pathological confirmation

Search ((((((confirmation) OR approval) OR proof) OR agreement) OR validation) OR affirmation)) AND ((((((histology) OR histological) OR cytology) OR cytological) OR pathology) OR pathological)

Therapy

Surgery

Search (((((((surgery[Title/Abstract]) OR surgeries[Title/Abstract])) OR ((operation[Title/Abstract]) OR operations[Title/Abstract]))) AND (((thoracic[Title/Abstract])) OR (thorax[Title/Abstract])) OR (lung[Title/Abstract]))) OR (surgery[MeSH Terms]) OR (thoracic surgery[MeSH Terms]))

Systemic therapy

Search ((((((("targeted therapy"[Title/Abstract]) OR "targeted therapies"[Title/Abstract])) OR ("systemic therapy"[Title/Abstract]) OR "systemic therapies"[Title/Abstract])) OR ((chemotherapy[Title/Abstract]) OR chemotherapies[Title/Abstract])) OR (Molecular Targeted Therapy[MeSH Terms])) OR (chemotherapy[MeSH Terms]))

Radiotherapy

Search (((((irradiation) OR irradiations)) OR ((radiation) OR radiations)) OR ((radiotherapy) OR radiotherapies)) OR (radiotherapy[MeSH Terms]))

Radiochemotherapy

Search ((((((chemoradiotherapy[MeSH Terms])) OR chemoradiotherapy) OR chemoradiotherapies) OR radiochemotherapy) OR radiochemotherapies) OR chemoradiation)

Palliative/supportive therapy

Search (((hospice) OR hospices)) OR (((("supportive care") OR "supportive measure") OR "supportive measures") OR "supportive therapy") OR "supportive therapies")) OR (((terminal care[MeSH Terms])) OR (((("palliative care") OR "palliative medicine") OR palliation)) OR (medicine, palliative[MeSH Terms])))

Quality management

Quality management

Search (((total quality management[MeSH Terms])) OR (Quality Improvement[MeSH Terms])) OR ("quality management")

Lung cancer centres

Search (((("cancer unit"[Title/Abstract]) OR "cancer center"[Title/Abstract]) OR "cancer centres"[Title/Abstract]) OR "cancer units"[Title/Abstract]) OR "cancer centers"[Title/Abstract]) OR "cancer centre"[Title/Abstract]

Pathways/Fast track

Search Search AND (Search AND ((process) OR processes) OR ((tract) OR tracts) OR ((pathway) OR pathways) OR ((track) OR tracks) OR ((procedure) OR procedures) OR ((sequence) OR sequences) OR ((flow) OR flows) OR ((course) OR courses) OR ((clinic[Title/Abstract]) OR clinics[Title]) OR (clinical pathway[MeSH Terms]))

Multidisciplinary team

Search (((((((("multidisciplinary management") OR "interdisciplinary management")) OR ("multidisciplinary treatment") OR "interdisciplinary treatment")) OR ("multidisciplinary approach") OR "interdisciplinary approach")) OR ("expert team") OR "team of experts")) OR ("multidisciplinary thoracic") OR "interdisciplinary thoracic")) OR ("multidisciplinary lung cancer") OR "interdisciplinary lung cancer")) OR ("multidisciplinary cancer") OR "interdisciplinary cancer")) OR ("multidisciplinary lung cancer") AND "interdisciplinary lung cancer")) OR (((("interdisciplinary care")) OR ("multidisciplinary care")) OR ((MDT)) OR (Search AND (((((((tumour)) OR (cancer[Title/Abstract])) OR (multidiscipline)) OR (interdisciplinary)) OR (multiprofessional)) OR (multidisciplinary))) AND (((((((meeting) OR meetings)) OR (board) OR boards)) OR ((conference) OR conferences)) OR ((team) OR teams)) OR ((decision) OR decisions))))))

Quality assurance

Search ((Benchmarking[MeSH Terms])) OR (((((((((((((((assessment[Title/Abstract]) OR assessments) AND Title/Abstract OR ((assurance[Title/Abstract]) OR assurances[Title/Abstract]) OR ((certification[Title/Abstract]) OR certifications[Title/Abstract]) OR ((validation[Title/Abstract]) OR validations[Title/Abstract]) OR ((verification[Title/Abstract]) OR verifications[Title/Abstract]) OR ((confirmation[Title/Abstract]) OR confirmations[Title/Abstract])) OR (Clinical Audit[MeSH Terms])))) OR evaluation[Title/Abstract]) OR evaluations[Title/Abstract]) OR monitoring[Title/Abstract]) OR appraisal[Title/Abstract]) OR appraisals[Title/Abstract]) OR appraisement[Title/Abstract]) OR appraisements[Title/Abstract])) OR "peer review"[Title/Abstract]) OR Peer Review, Health Care[MeSH Terms]) OR (Outcome and Process Assessment AND (Health Care) AND MeSH Terms)))

Cancer registry/Audit/Survey

Search (((((((((((((((("data registry") OR "data registries") OR "tumour documentation") OR "tumour documentations") OR "tumor documentation") OR "tumor documentations") OR database[Title]) OR databases[Title/Abstract]) OR "cancer registry") OR "cancer registries") OR "cancer registration") OR "cancer registrations") OR "tumour registration") OR "tumour registrations") OR "tumor registration") OR "tumor registrations")))) OR

(((((survey[Title/Abstract])) OR (care survey, health[MeSH Terms])) OR (audits)) OR (Clinical Audit[MeSH Terms]))

Quality indicators

Search (((("performance measure") OR "performance measures")) OR (((quality indicators[MeSH Terms])) OR ((((((((((quality indicator) OR quality indicators) OR quality index) OR quality indices) OR quality measure) OR quality measures) OR quality instrument) OR quality instruments) OR quality tool) OR quality tools)))

Inequalities

((equality[Title/Abstract]) OR equalities[Title/Abstract])) OR (((((((((((socio-economic[Title/Abstract]) OR (socioeconomic[Title/Abstract])) OR (socioeconomic factor[MeSH Terms])) OR ((equity[Title/Abstract]) OR equities[Title/Abstract])) OR ((gap[Title/Abstract]) OR gaps[Title/Abstract])))) OR ((inequality[Title/Abstract]) OR inequalities[Title/Abstract])))) OR (provision[Title/Abstract])) OR (((((((((((disparity[Title/Abstract]) OR disparities[Title/Abstract])) OR (disparity, healthcare[MeSH Terms])) OR ((restriction[Title/Abstract]) OR restrictions[Title/Abstract])) OR ((obstacle[Title/Abstract]) OR obstacles[Title/Abstract])) OR ((barrier[Title/Abstract]) OR barriers[Title/Abstract])) OR ((constraint[Title/Abstract]) OR constraints[Title/Abstract])) OR ((disadvantage[Title/Abstract]) OR disadvantages[Title/Abstract])) OR ((hindrance[Title/Abstract]) OR hindrances[Title/Abstract])) OR ((blockage[Title/Abstract]) OR blockages[Title/Abstract])) OR ((hurdle[Title/Abstract]) OR hurdles[Title/Abstract])) OR ((inequality[Title/Abstract]) OR inequalities[Title/Abstract])) OR ((restraint[Title/Abstract]) OR restraints[Title/Abstract])) OR ((blockade[Title/Abstract]) OR blockades[Title/Abstract]))))

Volumes of activity

(((((specialists[Title/Abstract])) OR (((("minimum volume") OR "minimum volumes") OR "minimal volume") OR "minimal volumes"))) OR (((("surgeon volume") OR ("surgeon speciality") AND "surgical speciality")) OR ("surgeon specialty")) OR (((("thoracic surgeon"[Title/Abstract]) OR "cardiothoracic surgeon"[Title/Abstract]) OR "cardio-thoracic surgeon"[Title/Abstract]) OR "general surgeon"[Title/Abstract])) OR (((("resection rate") OR "resection rates")) OR (((("operation volume") OR "surgical volume") OR "individual volume") OR ("resection volume") OR "surgery volume")) OR (((((((("minimum quantity") OR "minimum quantities")) OR (((((((("minimum amount") OR "minimum amounts") OR "minimal quantity") OR "minimal quantities") OR "hospital volume") OR "teaching hospital"[Title/Abstract]) OR "university hospital"[Title/Abstract])) OR ("large volume") OR ("low volume") OR low-volume)) OR ((high-volume)) OR ("high volume")))) OR (specialisation)) OR (specialist)) OR ("general hospital"[Title/Abstract])))) OR “institutional experience”

Comparison

Not applicable

Outcome

Waiting Times

Search (((((((((((("time to chemotherapy"[Title/Abstract]) OR "time until chemotherapy"[Title/Abstract]) OR "time to surgery"[Title/Abstract]) OR "time until surgery"[Title/Abstract])) OR (((((((("time to referral"[Title/Abstract]) OR "waiting time"[Title/Abstract]) OR "time to therapy"[Title/Abstract]) OR "time to diagnosis"[Title/Abstract]) OR "diagnostic time"[Title/Abstract]) OR "time until therapy"[Title/Abstract]) OR "time until diagnosis"[Title/Abstract])) OR (trajectory[Title/Abstract])) OR (timeline[Title/Abstract])) OR (waiting[Title/Abstract])) OR (delay[Title/Abstract])) OR (timing[Title/Abstract])) OR (timeliness[Title/Abstract])

Outcome

((((((((((((((hospital mortality[MeSH Terms])) OR (mortality[MeSH Terms])) OR (survival[MeSH Terms])) OR (survival rate[MeSH Terms])) OR (disease free survival[MeSH

Terms])) OR (progression free survival[MeSH Terms])) OR (quality of life[MeSH Terms]))
OR (patient satisfaction[MeSH Terms])) OR (satisfaction[MeSH Terms])) OR
(complications[MeSH Terms])) OR (complication, intraoperative[MeSH Terms])) OR
(postoperative complication[MeSH Terms])) OR ((complication) OR complications)) OR
(survival)) OR (mortality)) OR (quality of life)) OR ((patient satisfaction) OR patients
satisfaction)

Combinations of search terms for Pubmed

1. Referral practice and waiting times

Lung Cancer AND Waiting Times

2. Structure and process

Lung Cancer AND [Quality management OR Lung cancer centres OR Pathways/Fast track
OR Multidisciplinary team]

3. Volume of activity

Lung Cancer AND Volumes of Activity AND [Systemic therapy OR Surgery OR
Radiotherapy OR Radiochemotherapy]

4. Inequalities in lung cancer care

Lung Cancer AND Inequalities

5. Quality assurance

a) Cancer registries

Lung Cancer AND Cancer registry/Audit/Survey

b) Quality assurance and Outcome

Lung Cancer AND Quality assurance AND [Systemic therapy OR Surgery OR Radiotherapy
OR Radiochemotherapy OR Palliative/supportive therapy] AND Outcome

c) Quality indicators

Lung Cancer AND Quality indicators

Appendix 4: Search questions for literature review

Referral practice and waiting times

Are there reported delays in the care of lung cancer patients and what how do they affect outcome?

- a) referral
- b) diagnostics
- c) surgery
- d) systemic therapy
- e) radiotherapy
- f) radiochemotherapy

Structure and process

What structural and process elements of quality management have been applied to the lung cancer care continuum and how they affect outcome?

- a) lung cancer centre
- b) multidisciplinary decision team
- c) fast-track pathways

Volume of activity

What is the significance of volumes/minimum quantities for the different treatment modalities of lung cancer patients with regard to outcome?

- a) surgery
- b) systemic therapy
- c) radiotherapy
- d) radiochemotherapy

Inequalities in lung cancer care

What kinds of disparities do exist in the care of lung cancer patients and how do they affect outcome?

Quality assurance

What elements of the lung cancer care continuum are depicted by different outcome-related measures of quality assurance and what is the resulting impact on improvement of care?

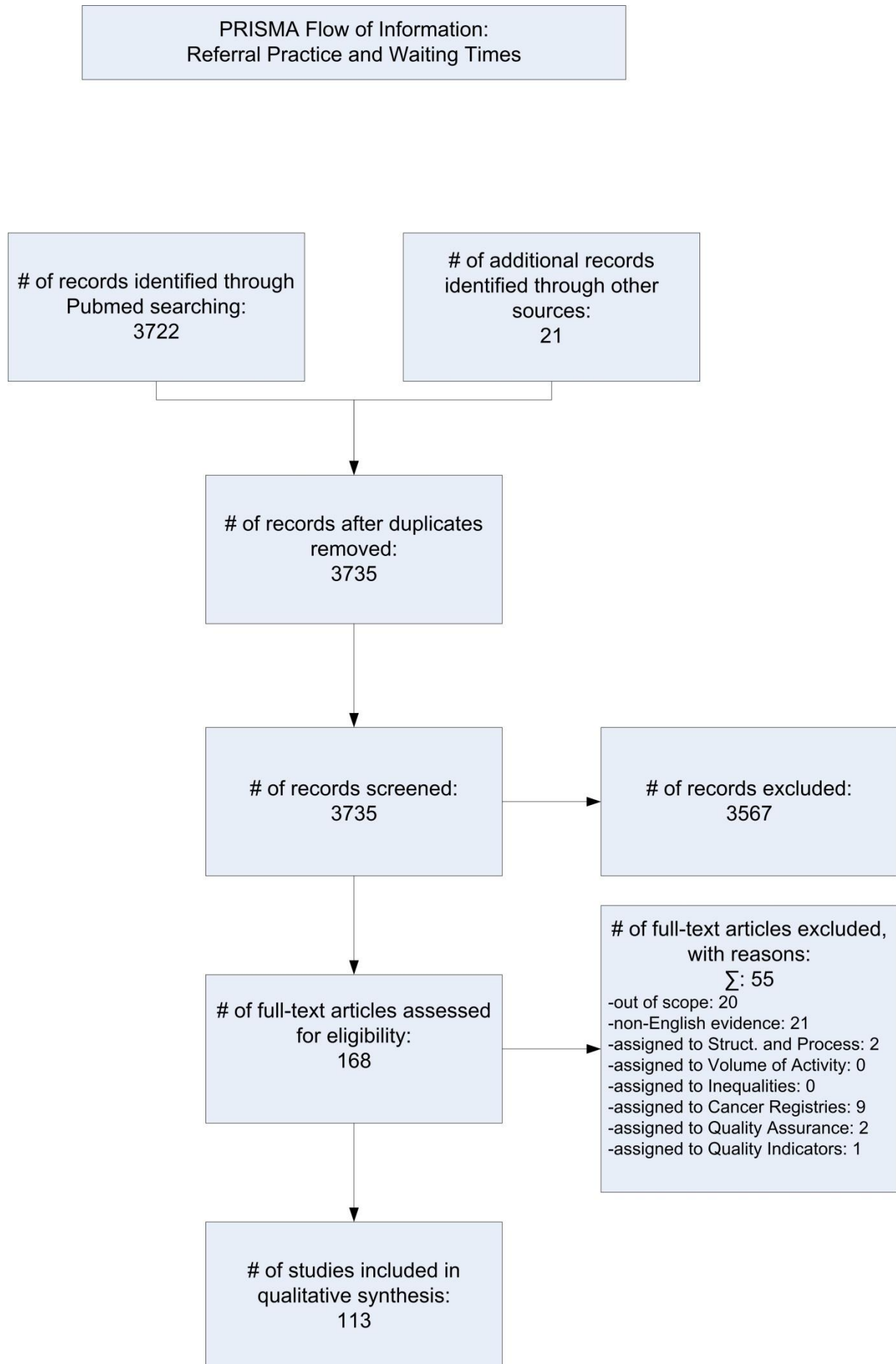
- a) cancer registries
- b) audits/surveys

What kinds of quality indicator systems for the depiction of elements of care in lung cancer patients have been reported and what is their benefit?

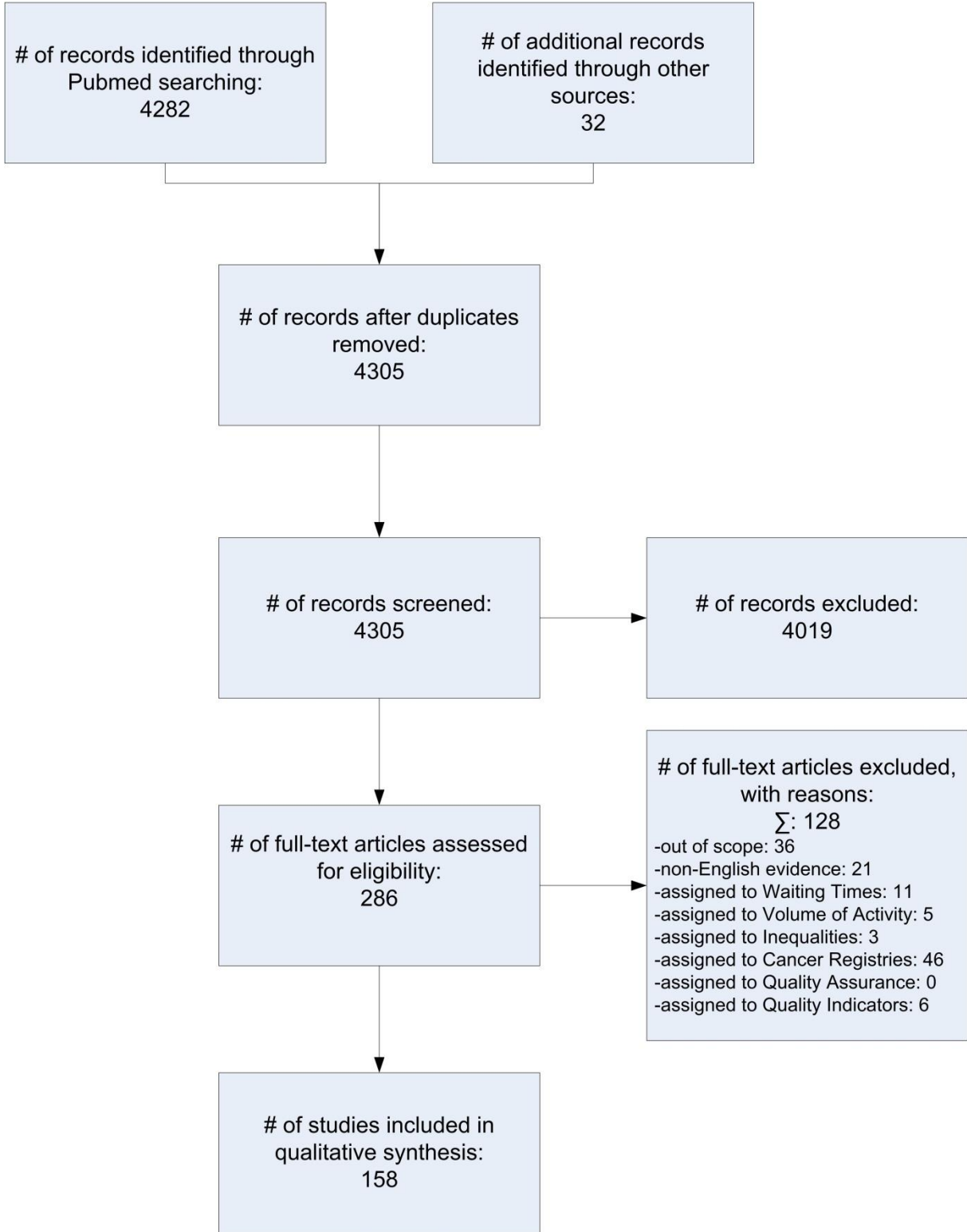
What kinds of benchmarking projects for the comparison of elements of care in lung cancer patients have been performed?

- a) benchmarking of institutions
- b) benchmarking of regions
- c) benchmarking of nations

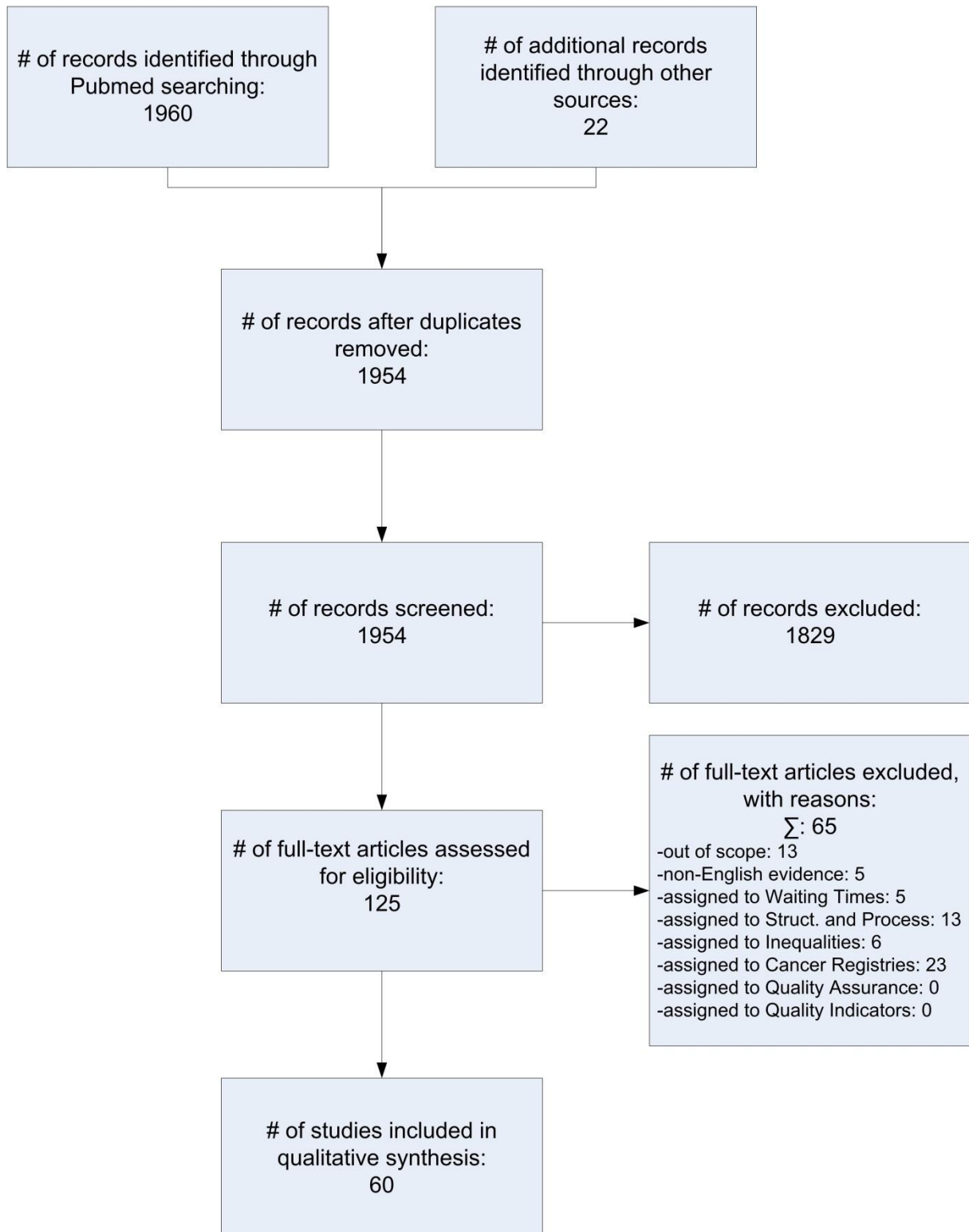
Appendix 5: PRISMA categorisation by subgroup of literature review



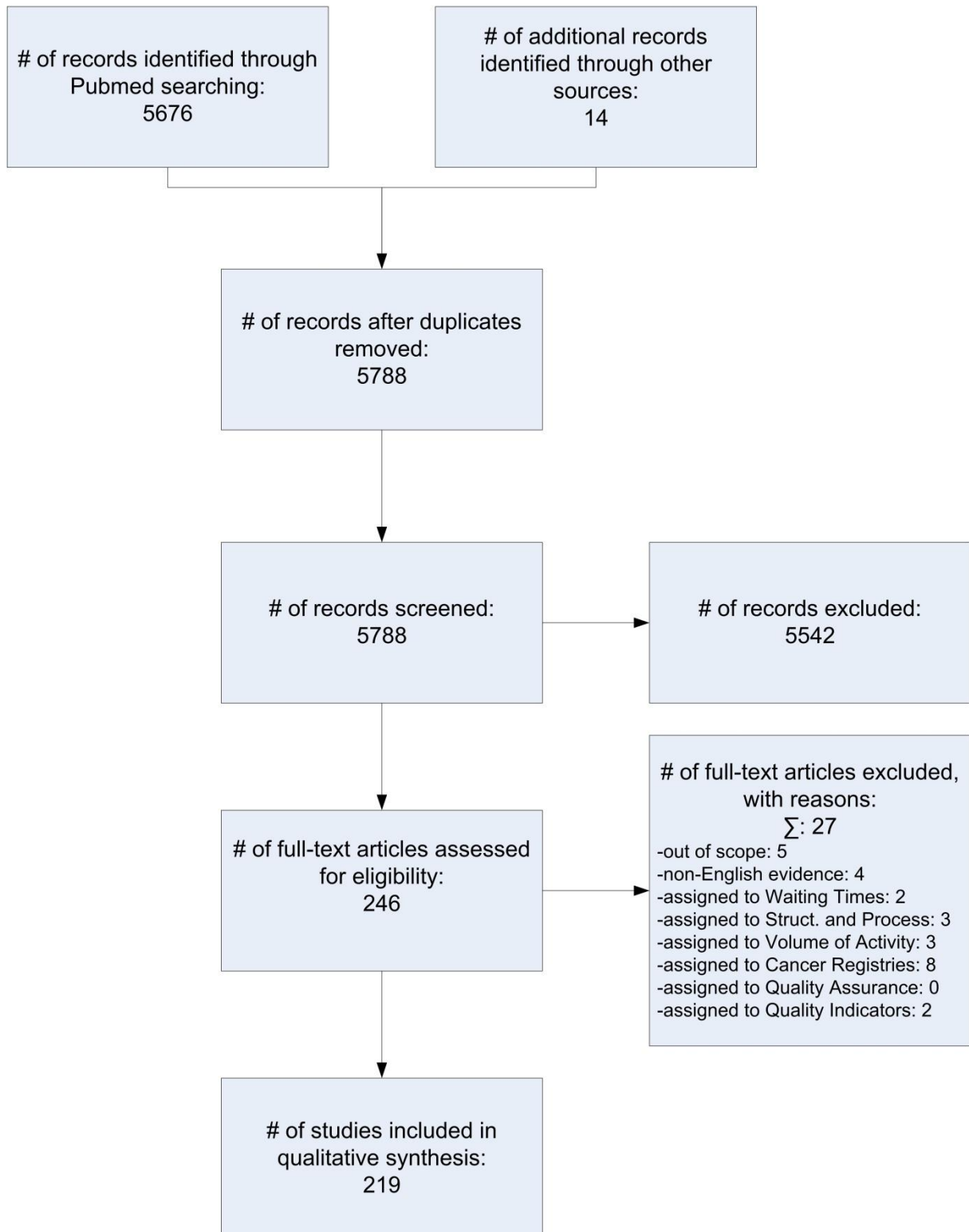
PRISMA Flow of Information:
Structure and Process



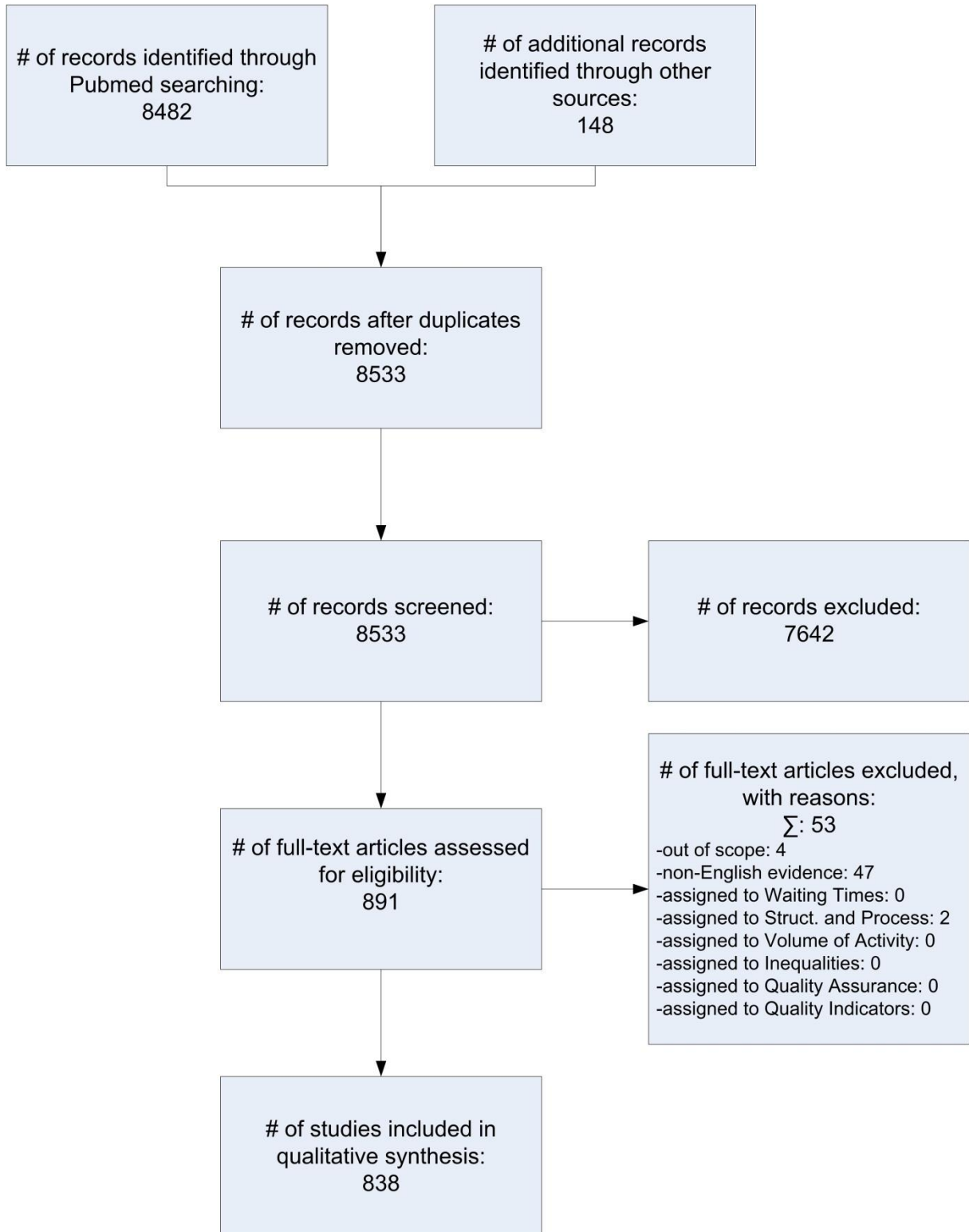
PRISMA Flow of Information:
Lung Cancer and Volumes of Activity



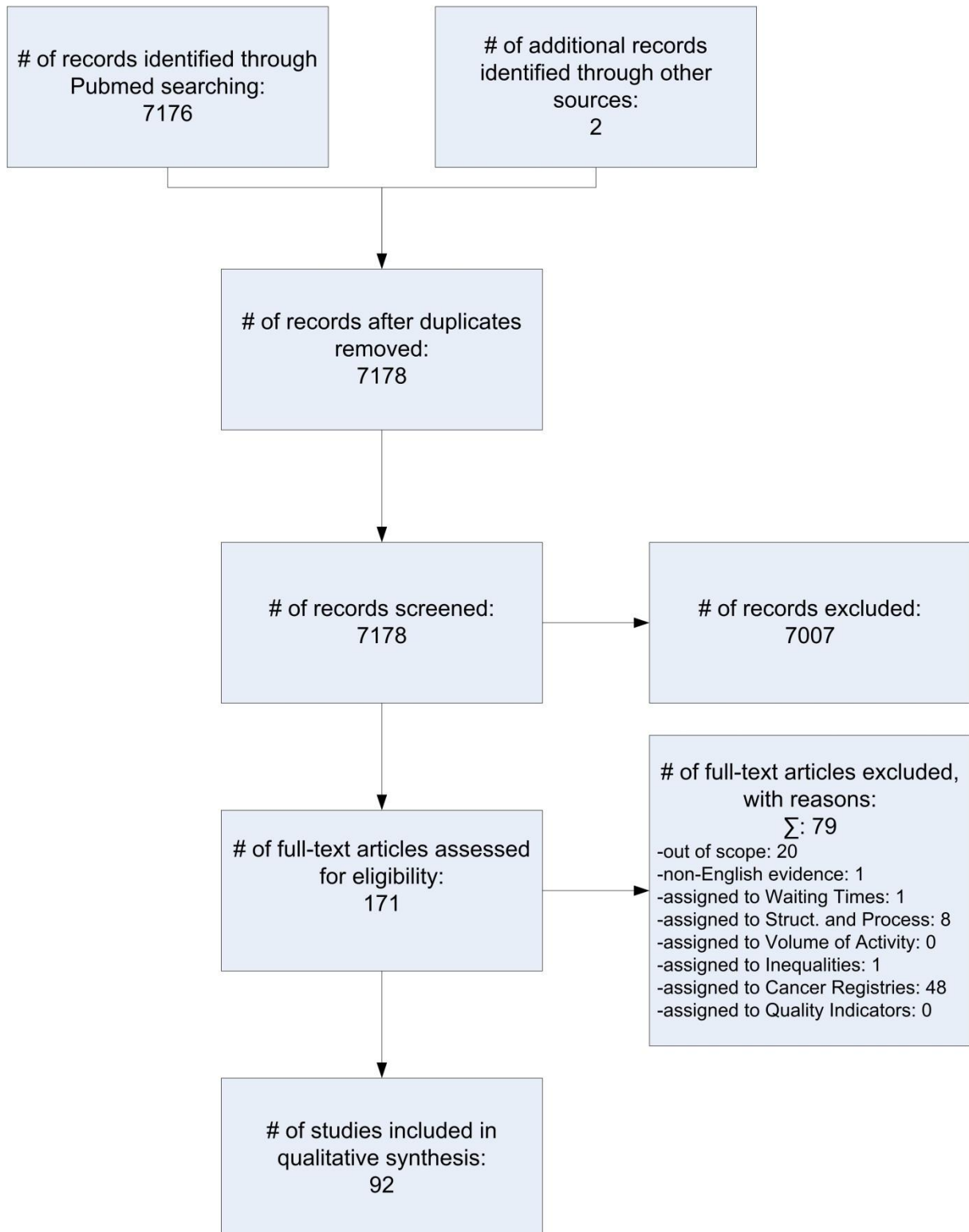
PRISMA Flow of Information:
Inequalities in Lung Cancer Care



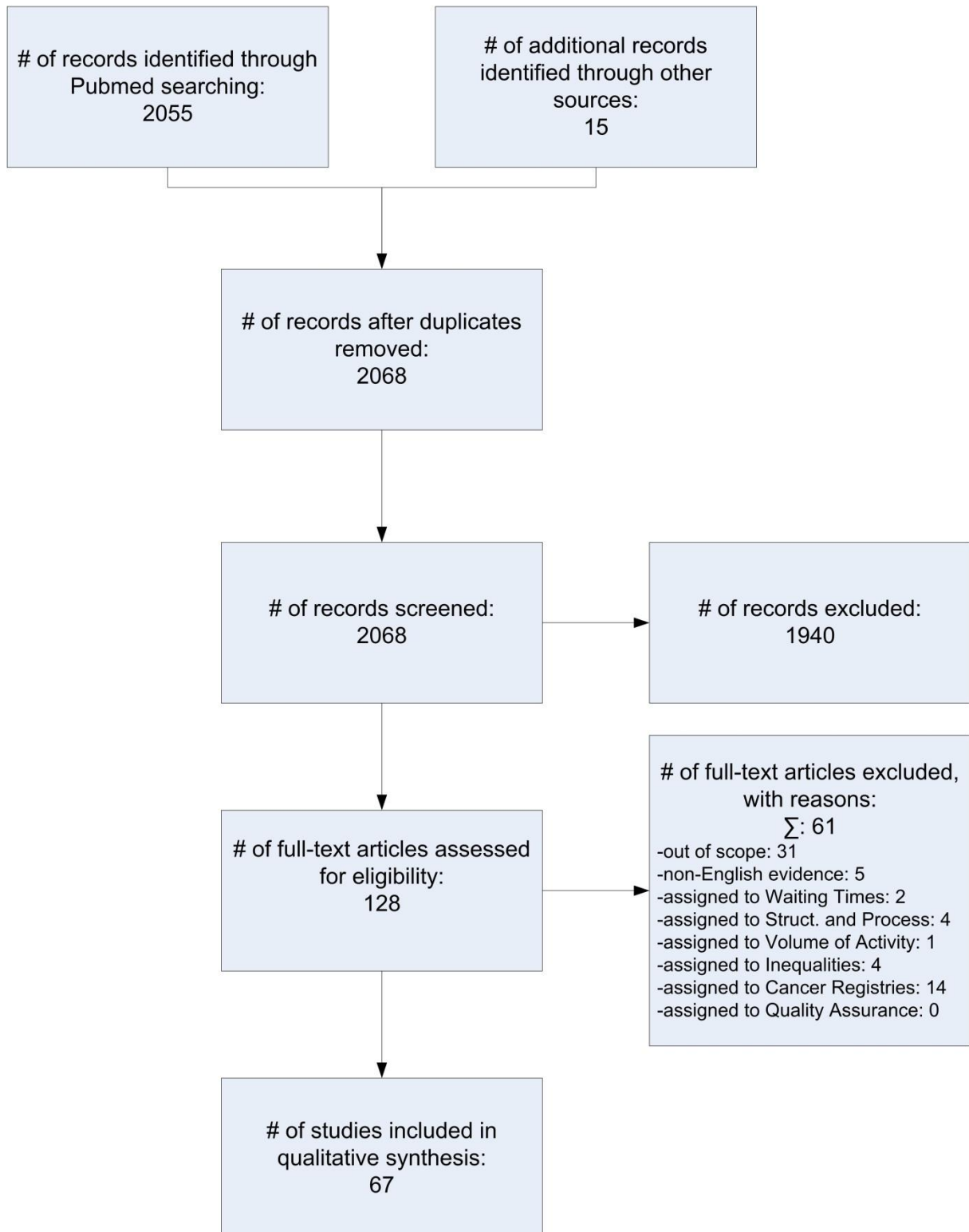
PRISMA Flow of Information:
Lung Cancer and Cancer Registries



PRISMA Flow of Information:
Lung Cancer and the Impact of Quality Assurance



PRISMA Flow of Information:
Lung Cancer and Quality Indicators



Appendix 6:

ERS Taskforce for the Quality Management of Lung Cancer Care

National survey

Name: _____

Place of work (city and country): _____

Part 1: National Health Care system

Please give a brief outline of the healthcare infra-structure in your country.

This could include whether or not health care is private or publically funded, whether or not a system of primary then secondary and even tertiary level care exists, the number of doctors per 100,000 population. Or this could be a description of the pathway from diagnosis to treatment for someone with lung cancer.

In order to 'tick' the boxes; please click twice on the box you wish to select. In the text box that appears, please click on (default value) 'checked' and then click 'ok' at the bottom. **Or,** you can place an "X" next to the answer you wish to select. **Many thanks.**

1. Primary care: please tick **one** box that is the most accurate description for your country

Is the primary care physician:

- A:** Totally free for everyone?
- B:** Free up to a certain rate/fee; and then the individual must contribute?
If so, what is the rate/fee? Please state amount (Euro) _____
- C:** Payable at the time of the consultation?
If so, what is the rate/ maximum fee? Please state amount (Euro) _____

Is this for every consultation or does it cover a set period of time?

- D:** Free at the point of contact, but payable via insurance policies etc

2. Secondary care: please tick **one** box that is the most accurate description for your country

Is care in the hospital/clinic:

- A:** Totally free for everyone?
- B:** Free up to a certain rate/fee; and then the individual must contribute?
If so, what is the rate/fee? Please state amount (Euro) _____
- C:** Payable at the time of the consultation?
If so, what is the rate/ maximum fee? Please state amount (Euro) _____

Is this for every consultation or does it cover a set period of time?

D: Free at the point of contact, but payable via insurance policies etc

3. Referral process:

A: Can patients refer themselves directly to a hospital?

Yes/No

If Yes; go to **B:**

If No; go to **C:**

B: Can this be done at any time? Yes/No

C: Can a patient present directly to secondary care in an emergency?

Yes/No

D: Would **routine** practice be referral from primary to secondary care doctor?

Yes/No

E: Can a patient choose which hospital to be seen in?

Yes/No

F: Can patients chose which lung cancer physician they see?

Yes/No

*If patients pay for their appointments and medical treatment, or no delay please go to **question***

4

G: If there is a delay in appointment, can a patient chose to pay and be seen sooner?

Yes/No

4. Cost:

Please indicate who is being charged (*tick one box only and for parts A to G please state the currency*)

Patient Health authority/board Insurance company

A: What is the cost of a consultation with a Respiratory Physician? _____

B: What is the cost of a chest X-ray? _____

C: What is the cost of a bronchoscopy? _____

D: What is the cost of a chest CT scan? _____

E: What is the cost of a mediastinoscopy? _____

F: What is the cost of a PET/CT scan? _____

G: What is the cost of one night in hospital? _____

Part 2: Lung cancer specific care

For questions 1 to 4 please tick one box only

1. Who, in the majority of cases, provides chemotherapy for patients with lung cancer?

Respiratory physicians

Oncologists

Both Respiratory physicians/Oncologists in almost equal part

Other; please state _____

2. Who, in the majority of cases, provides radiotherapy for patients with lung cancer?

Respiratory physicians

Clinical Oncologists/Radiotherapist

Other; please state _____

3. Who, in the majority of cases, provides the surgery for patients with lung cancer?

Thoracic surgeons

Cardiothoracic surgeons

General surgeons

Other; please state _____

4. Who, in the majority of cases, provides palliative care for patients with lung cancer?

Palliative care physicians

Oncologists

Respiratory physicians

Lung cancer specialist nurses

Other; please state _____

- 1 5. What Lung cancer *staging system* is used? UICC 7 Other; please state
2 _____
- 3 6. Is it used universally throughout the country? Yes/No
4 If no; please give details _____ (and go to **question 8**)
- 5 7. What month and year did the UICC 7 get implemented in your country? _____
6
- 7 8. Is there a *national* system of data collection for patients with lung cancer? Yes/No
8
- 9 If no, does this occur at a local level? Yes/No
10 If you are not aware of any data collection, please go to **question 12**
- 11
- 12 9. Is data collection mandatory? Yes/No
13 If no, please give details _____
- 14 10. Is data collection electronic? Yes/No
15 If not, how is it collected _____
- 16 11. Who enters the data? (please tick one box which is the most accurate)
17 Physician only
18 Nurse only
19 Administration/clerical staff only
20 Mixture of staff entering data
21 Other; please specify _____
22
- 23 12. Does your country have *national* guidelines for lung cancer care;
24 **A:** Surveillance of solitary pulmonary nodules? Yes/No
25 Are they used universally? Yes/No
26 If not; please specify _____
27
- 28 **B:** Fitness for surgery? Yes/No
29 Are they used universally? Yes/No
30 If not; please specify _____
31
- 32 If other *national* guidelines exist, please state what they are:
33 _____
34
- 35 13. Does your country have *national recommendations* for;
36 **A:** Chemotherapy in advanced non-small cell lung cancer? Yes/No
37 **B:** Chemotherapy in small cell lung cancer? Yes/No
38 **C:** Chemo-radiotherapy in small cell lung cancer? Yes/No
39

40 **If there is any further information you would like to add please do so in the box below:**

46 *Many thanks*
47 *EIQMLCC*

Appendix 7: The Survey of local infrastructure

Survey of Lung Cancer Care across Europe

(to be completed by Lung cancer specialists describing local care pathways and facilities available)

Name: _____

Hospital/Health centre/Clinic: _____

Country: _____

–

Part 1: Local healthcare structure

- Does your national healthcare system operate a policy of...
 - Hospitals having responsibility for a specific geographical area and patient population
 - Hospitals having responsibility for a specific geographical area, but patients can choose to be treated anywhere in the country
 - Hospitals without any specific geographical area or patient population, whose patients come from anywhere in the country.
- Is your hospital a...
 - Hospital with a comprehensive lung cancer service (one with diagnostics, radiotherapy, chemotherapy, surgery and palliative care)
 - Hospital with a subset of lung cancer services (some but not all of the services above)
 - Specialist hospital managing a specific area e.g oncology, surgery, diagnostics
- What type of hospital (if applicable):
Diagnostics Radiotherapy Chemotherapy Surgery
- What is the catchment population served by this hospital?
- How many Respiratory Physicians/Pulmonologists (senior/board-certified) involved in lung cancer care work in this hospital?
- How many Physicians providing chemotherapy for lung cancer patients work in this hospital (be that Pulmonologist, oncologist, radiotherapist, radio-oncologist, thoracic surgeon)?
- How many Physicians providing radiotherapy for lung cancer patients work in this hospital (be that pulmonologist, radiotherapist, clinical oncologist, radio-oncologist)?
- How many Radiologists with a special interest in lung cancer work in this hospital?
- How many thoracic surgeons involved in lung cancer care work in this hospital?
- How many doctors providing specialist palliative care for lung cancer patients work in this hospital?
- How many lung cancer nurse specialists work in this hospital?
- Please give an approximate number of new patients with lung cancer seen in your hospital in 2010.
- Do specialists from different disciplines meet as a multidisciplinary team (MDT) to discuss management of individual patients?
- Who gives chemotherapy to patients in your hospital?
Pulmonologist Oncologist Radiotherapist
Thoracic Surgeon Radio-oncologist N/A
- Please give an approximate number of *new* patients with lung cancer seen in 2010.
- Please indicate what your local histological confirmation rate is:
<50% 50-75% 75-90% >90%

- Please indicate the resection rate within your local hospital/health centre/clinic for NSCLC:
5-10% 10-15% 15-20% 20-30%
 >30%
- Please indicate the proportion of your lung cancer patients that are entered into clinical trials:
<5% 5-10% >10%
- Do you have a local Lung Cancer dataset?
 - Is it electronic?
 - Is it linked to a national dataset?

B: Are the following treatment option available in your hospital/Health centre/clinic?
Please tick where treatments are available. If not available at your hospital, please indicate an approximation of the distance travelled to access these tools and the interval from referral.

Treatment modality	Please tick site of availability			Distance (km)			Interval (wks)		
	Hospital	Regionally	Nationally	<50	50-100	>100	< 2	2-4	> 4
Conventional radiotherapy									
CT guided IMRT/ rapid arc									
Stereotactic radiotherapy/ radiosurgery									
Tomotherapy									
Image guided radiotherapy									
4D CT scans									
Chemotherapy									
Thoracic surgery									

Please indicate whether certain treatments can be received as in patients/out patients/both?

Treatment modality	Options available to the patient			
	Unavailable	In patient	Out patient	Both
Radiotherapy				
Concurrent chemoradiotherapy				
Continuous Hyperfractionated Accelerated Radiotherapy (CHART)				
Chemotherapy				
Targeted therapies (TKIs)				

- How often do you have problems with access to services due to equipment maintenance/breakdown?
Never Sometimes Rarely Never

Appendix 8: Pubmed search strategy for lung cancer guidelines:

Search terms for Pubmed

Lung Cancer

Search (((lung cancer[MeSH Terms]) OR (lung) OR (pulmonary) OR (bronchial) OR (bronchus) OR (((((broncho) OR bronchio) OR alveolar) OR bronchoalveolar) OR bronchioalveolar) OR (bronchogenic) OR (small cell) OR (oat cell)) AND ((cancer) OR cancers) OR ((neoplasm) OR neoplasms) OR ((tumor) OR tumors) OR ((tumour) OR tumours) OR ((carcinoma) OR carcinomas) OR ((sarcoma) OR sarcomas)))

Guidelines

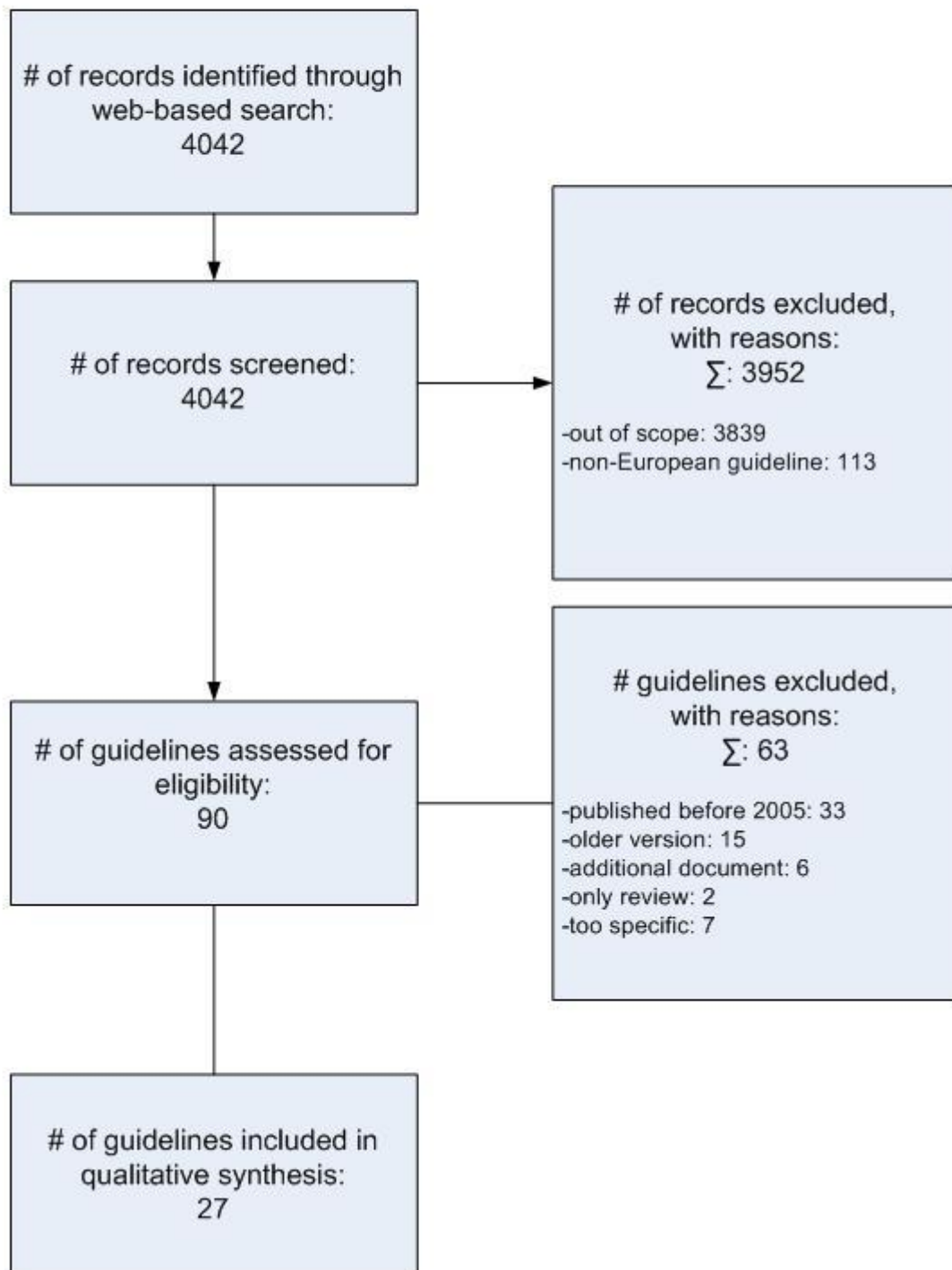
Search (((guideline) OR guidelines) OR ((directive) OR directives) OR ((recommendation) OR recommendations) OR (guideline[MeSH Terms])) OR appropriateness criteria

Combination of search terms for Pubmed

Lung Cancer AND Guidelines

Appendix 9: Guidelines relating to management of lung cancer

Lung Cancer Guideline Project - Flow of Information:
Pubmed search
(last search update on October, 28th 2012)



Lung Cancer Guideline Project - Flow of Information:
Guidelines International Network - www.g-i-n.net
(last search update on November, 17th 2012)

Search terms:
-lung cancer

of records identified through
web-based search:
75

of records screened:
75

of guidelines included in
qualitative synthesis:
11

of records excluded,
with reasons:
 Σ : 64

-out of scope: 5
-non-European guideline: 55
-too specific: 2
-too general: 1
-additional document: 1

List of guidelines included in qualitative synthesis:

- 1 Finland, Duodecim, 2008, Keuhkosyöpä
- 2 France, HAS/INCa, 2008, Cancer primitif non à petites cellules du poumon : pratiques chirurgicales. Recommandation pour la pratique clinique
- 3 France, INCa, 2009, Place de la tomographie par émission de positons au [18F]-FDG(TEP-FDG) dans la prise en charge des cancers bronchopulmonaires et pleuraux. Rapport sur l'état des connaissances
- 4 France, INCa, 2010, Cancer du poumon non à petites cellules - Formes localisées non opérables, localement avancées et métastatiques. Recommandations professionnelles
- 5 France, INCa, 2011, Cancer du poumon - Bilan initial. Recommandations professionnelles
- 6 Germany, DGP/DGT/DKG, 2010, Lungenkarzinom - Prävention, Diagnostik, Therapie und Nachsorge. S3-LL (DGP, DKG)
- 7 Netherlands, IKNL, 2011, Niet kleincellig longcarcinoom. National evidence-based guideline
- 8 Norway, Hdir, 2010, Nasjonalt handlingsprogram med retningslinjer for diagnostikk, behandling og oppfølging av lungekreft
- 9 Spain, AATRM, 2003, OncoGuia de pulmó
- 10 United Kingdom, NICE, 2011, Lung Cancer
- 11 United Kingdom, SIGN, 2005, Management of patients with lung cancer

Lung Cancer Guideline Project - Flow of Information:
 SAGE Inventory of Cancer Guidelines - www.cancerguidelines.ca
 (last search update on November, 19th 2012)

Selection in Advanced Search:
 Guideline content: Lung

of records identified through
 web-based search:
 220

of records screened:
 220

of guidelines included in
 qualitative synthesis:
 20

of records excluded,
 with reasons:
 Σ : 200

- out of scope: 37
- non-European guideline: 141
- published before 2005: 3
- older version: 7
- too specific: 12

List of guidelines included in qualitative synthesis:

- 1 Europe, EORTC, 2010, EORTC Recommendations for Planning and Delivery of High-Dose, High-Precision Radiotherapy for Lung Cancer
- 2 Europe, ERS/ESTS, 2009, The European Respiratory Society and European Society of Thoracic Surgeons clinical guidelines for evaluating fitness for radical treatment (surgery and chemoradiotherapy) in patients with lung cancer
- 3 Europe, ESMO, 2010, Early-stage and locally advanced (non-metastatic) non small cell lung cancer: ESMO Clinical Recommendations for diagnosis, treatment and follow-up
- 4 Europe, ESMO, 2010, Metastatic non small cell lung cancer: ESMO Clinical Recommendations for diagnosis, treatment and follow-up
- 5 Europe, ESMO, 2010, Neuroendocrine bronchial and thymic tumors: ESMO Clinical Recommendations for diagnosis, treatment and follow-up
- 6 Europe, ESMO, 2010, Small-cell lung cancer: ESMO Clinical Recommendations for diagnosis, treatment and follow-up
- 7 Europe, ESTS, 2006, ESTS guidelines for intraoperative lymph node staging in non-small cell lung cancer
- 8 Europe, ESTS, 2007, ESTS guidelines for preoperative lymph node staging for non-small cell lung cancer
- 9 16 Germany, German Respiratory Society/German Cancer Society, 2010, Prevention, Diagnosis, Therapy, and Follow-up of Lung Cancer: Interdisciplinary Guideline
- 10 Italy, AIOT, 2011, Treatment of advanced non-small-cell lung cancer: Italian Association of Thoracic Oncology (AIOT) clinical practice guidelines
- 11 Spain, SEOM, 2010, SEOM Clinical Guidelines for the Treatment of Non-small-cell Lung Cancer: An Updated Edition
- 12 Spain, SEOM, 2010, SEOM clinical guidelines for the treatment of small-cell lung cancer
- 13 Spain, SEPAR, 2011, SEPAR guidelines for lung cancer staging
- 14 United Kingdom, BTS, 2010, Guidelines on the Radical Management of Patients with Lung Cancer
- 15 United Kingdom, NICE, 2005, Cryotherapy for malignant endobronchial obstruction
- 16 United Kingdom, NICE, 2005, Photodynamic therapy for localised inoperable endobronchial cancer
- 17 United Kingdom, NICE, 2008, Endobronchial ultrasound-guided transbronchial needle aspiration for mediastinal masses
- 18 United Kingdom, NICE, 2010, Percutaneous Radiofrequency Ablation for Primary or Secondary Lung Cancers
- 19 United Kingdom, NICE, 2011, The Diagnosis and Treatment of Lung Cancer
- 20 United Kingdom, SIGN, 2005, Management of patients with lung cancer. A national clinical guideline

Lung Cancer Guideline Project - Flow of Information:
NHS Evidence - www.evidence.nhs.uk
(last search update on November, 19th 2012)

Search terms/Filter:
lung cancer; Filter: Types of Information →
Guidelines

of records identified through
web-based search:
819

of records screened:
819

of guidelines included in
qualitative synthesis:
12

of records excluded,
with reasons:
Σ: 808

-out of scope: 781
-non-European guideline: 4
-published before 2005: 1
-older version: 2
-additional document: 5
-too specific: 14

List of guidelines included in qualitative synthesis:

- 1 Europe, ERS/ESTS, 2009, ERS/ESTS clinical guidelines on fitness for radical therapy in lung cancer patients (surgery and chemo-radiotherapy)
- 2 Europe, ESMO, 2010, Early stage and locally advanced (non-metastatic) non-small-cell lung cancer: ESMO Clinical Practice Guidelines for diagnosis, treatment and follow-up
- 3 Europe, ESMO, 2010, Small-cell lung cancer: ESMO Clinical Practice Guidelines for diagnosis, treatment and follow-up
- 4 Europe, ESMO, 2012, Metastatic non-small-cell lung cancer (NSCLC): ESMO Clinical Practice Guidelines for diagnosis, treatment and follow-up
- 5 Europe, ESMO, 2012, Neuroendocrine bronchial and thymic tumors: ESMO Clinical Practice Guidelines for diagnosis, treatment and follow-up
- 6 United Kingdom, BTS, 2010, Guidelines on the radical management of patients with lung cancer
- 7 United Kingdom, NICE, 2005, Cryotherapy for malignant endobronchial obstruction – guidance
- 8 United Kingdom, NICE, 2005, Photodynamic therapy for localised inoperable endobronchial cancer – guidance
- 9 United Kingdom, NICE, 2005, Photodynamic therapy for advanced bronchial carcinoma
- 10 United Kingdom, NICE, 2010, Percutaneous radiofrequency ablation for primary or secondary lung cancers: guidance
- 11 United Kingdom, NICE, 2011, Lung cancer: full guideline
- 12 United Kingdom, SIGN, 2005, Management of patients with lung cancer - Full guideline

Lung Cancer Guideline Project - Flow of Information:
National Guidelines Clearinghouse - www.guideline.gov
(last search update on November, 19th 2012)

Selection in Guidelines by Topic:
Diseases → Neoplasms → Neoplasms
by site → Thoracic neoplasms

of records identified through
web-based search:
68

of records screened:
68

of records excluded,
with reasons:
Σ: 68
-out of scope: 17
-non-European guideline: 48
-too specific: 3

of guidelines included in
qualitative synthesis:
0

List of guidelines included in qualitative synthesis:
none

Table depicting Guidelines included in AGREE II evaluation with information on language and sources of retrieval

Country	Year of Publication	Language	Pubmed	GIN	SAGE	NHS Evidence	National Clearing-house	Home-page	Personal communication	Reference
Europe ELCWP	2005 <i>Non-small cell lung cancer: I. Early stages</i>	French/ English	x							Anonymous (2006) [Management of resectable non-small cell lung cancer. Guidelines of clinical practice made by the European Lung Cancer Working Party]. Revue medicale de Bruxelles 27:29-38
Europe ELCWP	2005 <i>Non-small Cell Lung Cancer: II. Unresectable Non-metastatic Stages</i>	French/ English	x							Anonymous (2006) [Management of unresectable non-metastatic non-small cell lung cancer. Guidelines of clinical practice made by the European Lung Cancer Working Party]. Revue medicale de Bruxelles 27:152-161
Europe ELCWP	2006 <i>Non-small cell lung cancer: III . Metastatic Disease</i>	French/ English	x							Anonymous (2007) [Treatment of non-small cell lung cancer: advanced (metastatic) disease. Guidelines of clinical practice made by the European Lung Cancer Working Party]. Revue medicale de Bruxelles 28:495-511
Europe ELCWP	2007 <i>Small Cell lung cancer: IV. Limited disease</i>	French/ English	x							Anonymous (2008) [Treatment of small cell lung cancer: limited diseases. Guidelines of clinical practice made by the European Lung Cancer Working Party]. Revue medicale de Bruxelles 29:159-167
Europe ELCWP	2007 <i>Small Cell Lung Cancer: V. Extensive disease</i>	French/ English	x							Anonymous (2008) [Treatment of small cell lung cancer: extensive diseases. Guidelines of clinical practice made by the European Lung Cancer Working Party]. Revue medicale de Bruxelles 29:455-470
Europe EORTC	2010 <i>European Organization for Research and Treatment of Cancer Recommendations for Planning and Delivery of High-Dose, High-Precision Radiotherapy for Lung Cancer</i>	English	x		x					De Ruysscher D, Faivre-Finn C, Nestle U et al. (2010) European Organisation for Research and Treatment of Cancer recommendations for planning and delivery of high-dose, high-precision radiotherapy for lung cancer. Journal of clinical oncology : official journal of the American Society of Clinical Oncology 28:5301-5310
Europe ERS/ESTS	2009 <i>ERS/ESTS clinical guidelines on fitness for radical therapy in lung cancer patients (surgery and chemo-radiotherapy)</i>	English	x		x					Brunelli A, Charloux A, Bolliger CT et al. (2009) The European Respiratory Society and European Society of Thoracic Surgeons clinical guidelines for evaluating fitness for radical treatment (surgery and chemoradiotherapy) in patients with lung cancer.

								European journal of cardio-thoracic surgery : official journal of the European Association for Cardio-thoracic Surgery 36:181-184 Brunelli A, Charloux A, Bolliger CT et al. (2009) ERS/ESTS clinical guidelines on fitness for radical therapy in lung cancer patients (surgery and chemo-radiotherapy). The European respiratory journal : official journal of the European Society for Clinical Respiratory Physiology 34:17-41
Europe ESMO 2010 <i>Small-cell lung cancer: ESMO Clinical Practice Guidelines for diagnosis, treatment and follow-up</i>	English	x		x				Sorensen M, Pijls-Johannesma M, Felip E (2010) Small-cell lung cancer: ESMO Clinical Practice Guidelines for diagnosis, treatment and follow-up. Annals of oncology : official journal of the European Society for Medical Oncology / ESMO 21 Suppl 5:v120-125
Europe ESMO 2010 <i>Neuroendocrine bronchial and thymic tumours: ESMO Clinical Practice Guidelines for diagnosis, treatment and follow-up</i>	English	x		x	2012			Oberg K, Hellman P, Kwekkeboom D et al. (2010) Neuroendocrine bronchial and thymic tumours: ESMO Clinical Practice Guidelines for diagnosis, treatment and follow-up. Annals of oncology : official journal of the European Society for Medical Oncology / ESMO 21 Suppl 5:v220-222
Europe ESMO 2010 <i>Early stage and locally advanced (non-metastatic) non-small-cell lung cancer: ESMO Clinical Practice Guidelines for diagnosis, treatment and follow-up</i>	English	x		x				Crino L, Weder W, Van Meerbeeck J et al. (2010) Early stage and locally advanced (non-metastatic) non-small-cell lung cancer: ESMO Clinical Practice Guidelines for diagnosis, treatment and follow-up. Annals of oncology : official journal of the European Society for Medical Oncology / ESMO 21 Suppl 5:v103-115
Europe ESMO 2010 <i>Metastatic non-small-cell lung cancer: ESMO Clinical Practice Guidelines for diagnosis, treatment and followup</i>	English	x		x				D'addario G, Fruh M, Reck M et al. (2010) Metastatic non-small-cell lung cancer: ESMO Clinical Practice Guidelines for diagnosis, treatment and follow-up. Annals of oncology : official journal of the European Society for Medical Oncology / ESMO 21 Suppl 5:v116-119
Belgium BVP-SBP 2005 <i>CONSENSUS RICHTLIJN: CHEMOTHERAPIE BIJ GEVORDERD NIET-KLEINCELLIG LONGCARCINOOM</i>	English						x	www.bvp-sbp.org

Bulgaria MOPE <i>ПОВЕДЕНИЕ ПРИ БЕЛОДРОБЕН КАРЦИНОМ</i>	2010	Bulgarian							x	Personal communication
Croatia <i>KLINIČKE UPUTE ZA DIJAGNOZU, LIJEČENJE I PRAĆENJE BOLESNIKA OBOLJELIH OD KARCINOMA PLUĆA NEMALIH STANICA</i>	2011	Croatian	x							Samarzija M, Gusic D, Radic J et al. (2011) [Clinical recommendations for diagnosing, treatment and monitoring patients with non-small cell lung cancer]. Lijecnicki vjesnik 133:361-365
Czech Republic <i>ZHOUBNÝ NOVOTVAR BRONCHU A PLÍCE</i>	2011	Czech							x	Personal communication
Denmark Danish Lung Cancer Group <i>LUNGECANCER</i>	2010	Danish						x	x	www.lungecancer.dk
Finland <i>Keuhkosyöpä</i>	2008	Finnish		x						www.duodecim.fi
France INCa <i>Standards, Options et Recommandations pour le traitement péri-opératoire des patients atteints d'un cancer bronchique non à petites cellules résécable d'emblée, opérables (rapport intégral)</i>	2007	French						x		www.e-cancer.fr
France INCa <i>Cancer du poumon non à petites cellules Formes localisées non opérables, localement avancées et métastatiques</i>	2010	French						x		www.e-cancer.fr
France INCa, SPLF <i>Cancer du poumon Bilan initial</i>	2011	French						x		www.e-cancer.fr
France INCA, SFMN <i>Place de la tomographie par emission de positons au [18F]-FDG (TE P-FDG) dans la prise en charge des cancers</i>	2009	French						x		www.e-cancer.fr

<i>bronchopulmonaires et pleuraux</i>									
France	2008	French						x	www.e-cancer.fr
SFCTCV <i>Cancer primitif non à petites cellules du poumon : pratiques chirurgicales</i>									
Germany/Austria	2010	German	x	x	x			x	Goeckenjan G, Sitter H, Thomas M et al. (2010) [Prevention, diagnosis, therapy, and follow-up of lung cancer]. Pneumologie (Stuttgart, Germany) 64 Suppl 2:e1-164
DGP, DGT, DKG <i>Prävention, Diagnostik, Therapie und Nachsorge des Lungenkarzinoms Interdisziplinäre S3-Leitlinie</i>									
Hungary	2011	Hungarian	x						Gyula O, Andras B, Zoltan B et al. (2012) [Basic principles for the prevention, diagnosis and therapy of lung cancer]. Magyar onkologia 56:114-132
<i>A tüdőrák megelőzésének, diagnosztikájának és kezelésének alapelvei</i>									
Ireland	2009	English						x	x www.irishthoracicsociety.com
Irish Thoracic Society Lung Cancer Subcommittee All Ireland Lung Cancer Working Group <i>Guidelines for the diagnosis and treatment of Lung Cancer Third Edition</i>									
Italy	2009	Italian						x	x www.aiom.it
AIOM <i>Neoplasie Polmonari</i>									
Italy	2011	English	x		x				De Marinis F, Rossi A, Di Maio M et al. (2011) Treatment of advanced non-small-cell lung cancer: Italian Association of Thoracic Oncology (AIOT) clinical practice guidelines. Lung cancer (Amsterdam, Netherlands) 73:1-10
<i>Treatment of advanced non-small-cell lung cancer: Italian Association of Thoracic Oncology (AIOT) clinical practice guidelines</i>									
Lithuania	2007	Lithuanian							x Personal communication
<i>Plaučių vėžio diagnostikos ir gydymo rekomendacijos</i>									
Moldava	2010	Moldavian							x Personal communication
MINISTERUL SĂNĂTĂȚII AL REPUBLICII MOLDOVA <i>TUMORILE MALIGNNE ALE PLĂMÎNULUI</i>									
Netherlands	2010	Dutch		x				x	www.oncoline.nl
NVALT									

Niet-kleincellig longcarcinoom Landelijke richtlijn, Versie: 2.0									
Netherlands 2011 NVALT Kleincellig longcarcinoom Landelijke richtlijn, Versie: 1.0	Dutch							x	www.oncoline.nl
Norway 2011 Helsedirektoratet Nasjonalt handlingsprogram med retningslinjer for diagnostikk, behandling og oppfølging av lungekreft	Norwegian		x					x	www.helsedirektoratet.no
Poland 2007 Polskiej Grupy Raka Płuca Drobnokomórkowy rak płuca — zalecenia diagnostyczno--terapeutyczne	Polish	x							Krzakowski M, Orłowski T, Roszkowski K et al. (2007) [Small-cell lung cancer diagnostic and therapeutic recommendations of Polish Lung Cancer Group]. Pneumonologia i alergologia polska 75:88-94
Poland 2010 Uaktualnione zalecenia dotyczące systemowego leczenia niedrobnokomórkowego raka płuca i złośliwego międzybłoniaka płucnej	Polish	x							Jassem J, Biernat W, Drosik K et al. (2010) [Updated recommendations on systemic treatment of non-small cell lung cancer and malignant pleural mesothelioma]. Pneumonologia i alergologia polska 78:418-431
Portugal 2009 RECOMENDAÇÕES NACIONAIS PARA DIAGNÓSTICO E TRATAMENTO DO CANCRO DO PULMÃO	Portuguese							x	Personal communication
Serbia 2011 NACIONALNI VODIČ DOBRE KLINIČKE PRAKSE KARCINOMA PLUĆA	Serbian							x	Personal communication
Slovakia 2009 Národné smernice pre optimálnu diagnostiku a terapiu bronchogénneho karcinómu	Slovakian							x	Personal communication
Slovenia 2005 SMERNICE ZA DIAGNOSTIKO IN ZDRAVLJENJE BOLNIKOV Z RAKOM PLJUČ	Slovenian							x	Personal communication
Spain 2008 OncoGuia Lung Cancer OncoGuia	English	x	x						Manchon Walsh P, Manchon P, Borrás JM et al. (2009) Lung Cancer OncoGuia. Clinical & translational oncology : official publication of the Federation of

									Spanish Oncology Societies and of the National Cancer Institute of Mexico 11:805-824 Ramirez J, Montero MA, Alejo M et al. (2009) Lung Cancer OncoGuia: surgical pathology report guidelines. Clinical & translational oncology : official publication of the Federation of Spanish Oncology Societies and of the National Cancer Institute of Mexico 11:825-827
Spain SEOM <i>SEOM clinical guidelines for the treatment of small-cell lung cancer</i>	2010 English	x			x				Artal Cortes A, Domine Gomez M, Font Pous A et al. (2010) SEOM clinical guidelines for the treatment of small-cell lung cancer. Clinical & translational oncology : official publication of the Federation of Spanish Oncology Societies and of the National Cancer Institute of Mexico 12:27-31
Spain SEOM <i>SEOM clinical guidelines for the treatment of non-small-cell lung cancer: an updated edition</i>	2010 English	x			x				Trigo Perez JM, Garrido Lopez P, Felip Font E et al. (2010) SEOM clinical guidelines for the treatment of non-small-cell lung cancer: an updated edition. Clinical & translational oncology : official publication of the Federation of Spanish Oncology Societies and of the National Cancer Institute of Mexico 12:735-741
Spain SEPAR <i>Guidelines for the Evaluation of Surgical Risk in Bronchogenic Carcinoma</i>	2005 English	x							Varela-Simo G, Barbera-Mir JA, Cordovilla-Perez R et al. (2005) [Guidelines for the evaluation of surgical risk in bronchogenic carcinoma]. Archivos de bronconeumologia 41:686-697
Spain SEPAR <i>SEPAR Guidelines for Lung Cancer Staging</i>	2011 English	x			x				Sanchez De Cos J, Hernandez JH, Lopez MF et al. (2011) SEPAR guidelines for lung cancer staging. Archivos de bronconeumologia 47:454-465
Sweden Socialstyrelsen <i>Nationella riktlinjer för lungcancervård 2011 – stöd för styrning och ledning</i>	2011 Swedish							x	www.socialstyrelsen.se
Turkey unknown unknown	2006 Turkish								x Personal communication
Ukraine <i>Локалізація (неускладнений пухлинний процес</i>	Ukrainian								x Personal communication

United Kingdom 2010 BTS/SCTS <i>Guidelines on the Radical Management of Patients with Lung Cancer</i>	English	x							Lim E, Baldwin D, Beckles M et al. (2010) Guidelines on the radical management of patients with lung cancer. Thorax 65 Suppl 3:iii1-27
United Kingdom 2004 NICE <i>Photodynamic therapy for advanced bronchial carcinoma</i>	English				x			x	www.nice.org.uk
United Kingdom 2005 NICE <i>Cryotherapy for malignant endobronchial obstruction</i>	English			x	x			x	www.nice.org.uk
United Kingdom 2005 NICE <i>Photodynamic therapy for localised inoperable endobronchial cancer</i>	English			x	x			x	www.nice.org.uk
United Kingdom 2008 NICE <i>Endobronchial ultrasound-guided transbronchial needle aspiration for mediastinal masses</i>	English			x	x			x	www.nice.org.uk
United Kingdom 2010 NICE <i>Percutaneous radiofrequency ablation for primary or secondary lung cancers</i>	English			x	x			x	www.nice.org.uk
United Kingdom 2011 NICE <i>The diagnosis and treatment of lung cancer</i>	English	x	x	x	x			x	Anonymous (2011) The Diagnosis and Treatment of Lung Cancer (Update). National Collaborating Centre for Cancer., Cardiff UK
United Kingdom 2005 SIGN <i>Management of patients with lung cancer A national clinical guideline</i>	English		x	x	x				www.sign.ac.uk

Legend: AIOM: Associazione Italiana di Oncologia Medica, AIOT: Associazione Italiana Oncologia Toracica, BTS: British Thoracic Society, DGP: Deutsche Gesellschaft für Pneumologie und Beatmungsmedizin, BVP-SBP: Belgische Vereniging voor Pneumologie-Société Belge de Pneumologie, DGT: Deutsche Gesellschaft für Thoraxchirurgie, DKG Deutsche Krebsgesellschaft, ELCWP: European Lung Cancer Working Party, ERS: European Respiratory Society, ESTS: European Society of Thoracic Surgeons, ESMO: European Society for Medical Oncology, INCa: Institut National Du Cancer, NICE: National Institute for Health and Clinical Excellence, NVALT: Nederlandse Vereniging van Artsen

voor Longziekten en Tuberculose, SCTS: Society for Cardiothoracic Surgery in Great Britain and Ireland, SEPAR: Sociedad Española de Neumología y Cirugía Torácica, SEOM: Sociedad Española de Oncología Médica, SFCTCV: Société Française de Chirurgie Thoracique et Cardio-Vasculaire, SFMN: Société Française de Médecine Nucléaire et d'imagerie moléculaire, SIGN: Scottish Intercollegiate Guidelines Network, SPLF: Société Française de Pneumologie de Langue Française

Appendix 10: Clinical focus of individual guidelines

Characteristic	N	%
Broad content		
Yes	44	79%
No	12	21%
Covered area		
Screening and prevention	12	21%
Diagnosis and staging	40	71%
Treatment	49	88%
Comprehensive	12	21%
Targeted patients populations (for guidelines with broad content only)		
Lung cancer all stages	22	39%
Lung cancer suitable for radical management	1	2%
NSCLC		
Early stages	1	2%
Stages I to III	1	2%
Resectable	2	5%
Inoperable non metastatic	1	2%
Unresectable	1	2%
Non metastatic	1	2%
Advanced	1	2%
Metastatic	2	5%
All stages	4	7%
SCLC		
Limited	1	2%
Extensive	1	2%
All stages	4	7%
Neuroendocrine bronchial tumors	1	2%

Appendix 11:The EuLuCA study protocol.

EuLuCA – European Lung Cancer Audit

An observational, non-intervention, study for the feasibility of prospectively collecting demographic and clinical data on lung cancer patients in a Pan-European setting.

Study protocol number: v 1.0

Date: 17th February 2012

Main study protocol sections – a quick reference

Study background and rationale	55
Study objectives	55
General study design	56
Detailed study design	57
Timeline	63
Funding	63
Appendices	65

Key Study Details and Personnel:**Title:** EuLuCA– European Lung Cancer Audit

An observational, non-intervention, study of the feasibility of prospectively collecting demographic and clinical data on lung cancer patients in a Pan-European setting.

Short title: EuLuCA: a Pan-European core dataset**Responsible Project Leader and Co-ordinating Investigator:** Torsten Blum

(on behalf of the European Initiative for Quality Management in Lung Cancer Care, a Task Force of the European Respiratory Society)

Assistant Coordinating Investigators: Jean-Paul Sculier, Anna Rich and Michael Peake.**Lead Analyst:** Anna Rich**Web-based data entry tool:** Paul Beckett**National Coordinators:** Listed in supplementary document *List of National Coordinators***Funding:** Applied for coverage of directly incurred costs by the Stiftung Oskar-Helene-Heim, Berlin**Planned observational study period:****First patient in:** May, 1st 2012**Last patient out:** May, 31st 2012

List of Abbreviations

ECOG	Eastern Cooperative Oncology Group
EIQMLCC	European Initiative for Quality Management in Lung Cancer Care
ERS	European Respiratory Society
ICD-10	International Statistical Classification of Diseases and Related Health Problems, 10th edition
ICD-O	International Classification of Diseases for Oncology
PS	Performance Status
TNM	Tumour, Lymph Nodes, Distant Metastasis
UICC	Union for International Cancer Control
WHO	World Health Organization

Table of Contents

Study background and rationale.....	55
Study objectives	55
1. Primary study objectives.....	55
2. Secondary study objectives.....	55
General study design.....	56
1. General	56
2. Setting	56
3. Estimate of number of participating <i>lung cancer units</i> and sample size	56
4. Overview of study procedure.....	56
Detailed study design:.....	57
1. Establishment of a Pan-European infrastructure	57
2. National arrangements before enrolment of lung cancer units	58
a) Ethic opinion	58
b) Insurance	59
3. Enrolment of local <i>lung cancer units</i> throughout Europe and study initiation	59
4. Patient inclusion.....	60
a) Eligibility criteria;	60
b) Duration of study.....	60
c) Patient information/informed consent	60
5. Data collection	60
6. Data processing	61
a) <i>Data anonymisation</i>	61
b) <i>Data transmission</i>	61
c) <i>Data amalgamation</i>	61
7. Monitoring	62
8. Study closure.....	62
9. Data analysis	62
10. Publication	62
11. Record retention and archiving.....	62

Time line	63
Funding	63
Appendix 1 – Parameter list.....	65
Appendix 2 – Patient consent form.....	67
Appendix 3 – EuLuCA web-based data entry tool.....	70
Appendix 4 – Signature forms	71
Appendix 5 – Study contract.....	78

Study background and rationale

Lung cancer remains the main cause of cancer related death worldwide. It is not possible to compare access to treatment and survival between European countries at the moment, because there is no central data repository or standardised method for collecting data on individuals with lung cancer.

The ERS taskforce, European Initiative for Quality Management in Lung Cancer Care, has carried out a national survey which has revealed that 24 countries have national datasets, or cancer registries. However it is not clear whether these datasets collect the same data at the same time point along the patient pathway, and in a manner that would allow direct comparison.

Our intention is to develop a Pan-European core dataset prospectively collecting data on individuals with lung cancer. However, we need to perform a feasibility study first to investigate the data security/data handling issues that exist and how to link the data in order to allow statistical comparisons.

Study objectives

1. Primary study objectives

1. To assess if prospective demographic and clinical data collection in lung cancer patients is feasible in a Pan-European context.
2. To identify problems with this process: be they linguistic, related to IT (information technology), related to data security, clinical governance, or cost.

2. Secondary study objectives

1. To investigate the demographic and clinical features of patients with lung cancer in multiple European countries, above what has been done before (EUROCARE series), specifically the comparison of stage (UICC version 7) and PS (ECOG).

General study design

1. General

This study is an observational study with a prospective, non-interventional design. The study will provide demographic and clinical information at baseline for patients with a new diagnosis of lung cancer in Europe.

2. Setting

The proposal is that data collection will take place at the local level, the *lung cancer units*, throughout Europe. A *lung cancer unit* in the context of this study is defined as a medical institution where lung cancer is diagnosed. This may include out-patient departments, specialized chest and oncology units or other in-patient departments.

For Denmark, England, and Scotland, the *Danish Lung Cancer Registry (Denmark)* as well as the *National Lung Cancer Audit (England)* and the *Cancer Registry of the Scottish Cancer Networks* have agreed to contribute their data to EuLuCA. The three National tumour audit programmes prospectively collect comprehensive data at the local level on a continuous basis with almost 100% coverage of all lung cancer patients and their demographic and clinical data. The well-developed infrastructure and excellent data quality of the three tumour Audit programmes will have a positive impact on the EuLuCA study outcomes.

3. Estimate of number of participating *lung cancer units* and sample size

The number of participating *lung cancer units* – beside those already covered in Denmark, England and Scotland – is not fixed, however, 10-100 participating *lung cancer units* in 5 or more European countries are anticipated. There is no restriction or minimum requirement on the number of patients seen in a *lung cancer unit*, nor the number of participating *lung cancer units* within a country.

4. Overview of study procedure

This study is composed of the following steps which will subsequently be described in detail:

1. Establishment of a Pan-European infrastructure
2. National arrangements *before* enrolment of *lung cancer units*
3. Enrolment of local *lung cancer units* throughout Europe and study initiation
4. Patient inclusion
5. Data collection
6. Data processing
7. Monitoring
8. Study closure
9. Data analysis
10. Publication
11. Record retention and archiving

Detailed study design:

1. Establishment of a Pan-European infrastructure

In order to establish a Pan-European infrastructure, there will need to be individuals who take on the responsibility of encouraging *lung cancer units* to participate in the Audit from the various regions within Europe, so called *national coordinators*. The duties of the national coordinators are as follows:

- Translation (if needed), of the patient consent form from English into the respective national language(s)
- Secure an insurance contract(s) (if required), to cover every aspect of the study design.
- Obtain approval (if required), from responsible ethical committees within their corresponding country.
- enrolment and support of *lung cancer units* within their corresponding country
- to be a contact person regarding this study within their corresponding country.

The co-ordinating investigator, the lead analyst, as well as every designated national coordinator must confirm his/her participation in this study as well as his/her obligation to fully observe the study protocol by signing and dating the corresponding form (Appendix 4 – Signature forms).

2. National arrangements before enrolment of lung cancer units

Procedure for all European countries except Denmark, England, and Scotland:

Regulations and policies in the context of EuLuCA (i.e. concerning patient information, insurance coverage, tumour documentation, data security, study contracts) vary throughout Europe. The national co-ordinator is responsible for clarification and fulfilment of all requirements in his/her designated country so that the participation in EuLuCA does not violate any national laws, regulations, or policies. Therefore, it is mandatory for the national co-ordinator to check the specific laws, regulations, and policies in the context of EuLuCA for his/her designated country. They will need to make the necessary arrangements to ensure these requirements are fulfilled.

Some European countries with existing National Tumour Audit programmes have already addressed these legal issues. Therefore, these countries are able to join the EuLuCA study with immediate effect.

On the contrary, in some European countries some basic requirements are mandatory before this study may be initiated by the responsible national co-ordinator:

- study approval by the responsible ethic committee(s) or written notification to the responsible ethic committee(s) (whatever applies in this particular European country)
- establish a requirement for insurance cover, and if required, arrange a comprehensive insurance contract

Unless these basic requirements are completed, this study **must not** be initiated in a given country by a national co-ordinator.

Procedure for Denmark, England, and Scotland: The responsible authorities of the *Danish Lung Cancer Registry (Denmark)*, the *National Lung Cancer Audit (England)* and the *Cancer Registry of the Scottish Cancer Networks* have been consulted and they have agreed to the study protocol of EuLuCA.

a) Ethic opinion

Policies regarding ethical approval vary throughout European countries. Depending on the national policy, an approval of the responsible ethics committee(s) will be obtained by the

national co-ordinator wherever mandatory. In the remaining nations, where approval is not mandatory, written notification with this study protocol will be sent to the responsible ethics committee(s) by the national co-ordinator.

An ethics committee opinion will also be sought for any amendment to the protocol in accordance with local requirements.

b) Insurance

Policies regarding the need for insurance of all or specific study issues vary throughout European countries. Depending on national policy, a comprehensive insurance contract will be arranged by the national co-ordinator.

3. Enrolment of local *lung cancer units* throughout Europe and study initiation

Procedure for all European countries except Denmark, England and Scotland: The enrolment of *lung cancer units* will be organized individually for each nation by the corresponding national co-ordinators.

Before the start of this observational study, each participating *lung cancer unit* – represented by the local principle investigator – will be informed in detail about the planned objectives of this study, its conduct, how to handle the data entry, and all other relevant aspects. It is the responsibility of the national co-ordinator to communicate with participating centres, either by a meeting, a web conference or a comprehensive phone call. In addition, each participating site will receive the study protocol containing the necessary documents and information.

In some European countries the inclusion of a study contract between EIQLCC (represented by the national co-ordinator) and the local *lung cancer unit* may be required. In these cases the participation of a *lung cancer unit* must be confirmed by the responsible local principle investigator and the national co-ordinator by signing and dating the project specific contract between the *lung cancer unit* and the European Initiative for Quality Management in Lung Cancer Care (Appendix 5 – Study contract).

Procedure for Denmark, England, and Scotland: The medical directors of the *Danish Lung Cancer Registry (Denmark)*, the *National Lung Cancer Audit (England)* and the *Cancer*

Registry of the Scottish Cancer Networks have agreed to participate in EuLuCA. Therefore no further enrolment is needed.

4. Patient inclusion

In order that a patient can be included in this study it is mandatory that the patient fulfils the eligibility criteria and has declared willingness by signing a patient consent form.

a) Eligibility criteria;

Inclusion criteria;

First diagnosis of a cytologically and/or histologically confirmed lung cancer (ICD-10 C34.0-C34.9) with the date of first diagnosis between May, 1st 2012 and May, 31st 2012.

Signed patient consent form

Exclusion criteria;

First diagnosis of cytologically and/or histologically confirmed lung cancer (ICD-10 C34.0-C34.9) with date of first diagnosis before May, 1st 2012 or after May, 31st 2012.

Diagnosis of lung cancer without cytological and/or histological confirmation

Thoracic malignancy which is not primary lung cancer (ICD-10 C34.0-C34.9) for example lymphoma, sarcoma, mesothelioma

Thoracic secondary tumours with an extrathoracic primary site.

Recurrent lung cancer.

b) Duration of study

Data collection will take place for a one month period, incorporating all patients with a date of primary diagnosis between May, 1st 2012 and May, 31st 2012.

c) Patient information/informed consent

Procedure for all European countries except Denmark, England and Scotland: Policies regarding patient information and the need for patient informed consent vary throughout European countries. Therefore, it is mandatory for the national co-ordinator to check the regulations in the context of EuLuCA for his/her designated country.

Some European countries do not require patients to give informed consent before enrolment in EuLuCA as their national tumour registry policies have already addressed this.

On the contrary, in other European countries, every eligible patient will have to give informed consent to declare his/her agreement for his/her demographic and clinical data to be collected. Informed consent forms are provided in the corresponding national languages (Appendix 2 – Patient consent form).

Procedure for Denmark, England and Scotland: According to the regulations of the *Danish Lung Cancer Registry (Denmark)*, the *National Lung Cancer Audit (England)* and the *Cancer Registry of the Scottish Cancer Networks* no additional requirements are needed to the pre-existing patient information policies.

5. Data collection

Procedure for all European countries except Denmark, England and Scotland: Data collection will take place exclusively within the *lung cancer unit*.

For that purpose, a web-based data entry tool has been developed for EuLuCA which creates a strictly anonymous dataset once patient information has been entered (Appendix 3 –

EuLuCA web-based data entry tool). Therefore, the transmission of patient sensitive data to EIQMLCC is **not** possible. However, the *lung cancer unit* is obliged to strictly adhere to all legal regulations for data security and patient privacy during the entire process of data entry within their setting.

All parameters to be assessed as well as their detailed definitions are listed in Appendix 1 – Parameter list.

By submitting the anonymous electronic case report form in the web-based data entry tool (Appendix 3 – EuLuCA web-based data entry tool), the responsible local principle investigator certifies that all patient information in this form has been thoroughly reviewed and is accurate. Only complete electronic case report forms can be submitted.

Procedure for Denmark, England and Scotland: The local *lung cancer units* in Denmark, England and Scotland will enter their prospectively collected lung cancer data routinely via their national tumour registry systems, the *Danish Lung Cancer Registry (Denmark)*, the *National Lung Cancer Audit (England)* and the *Cancer Registry of the Scottish Cancer Networks*.

6. Data processing

a) Data anonymisation

Procedure for all European countries except Denmark, England and Scotland: The data sets which are entered and transmitted by the lung cancer units are already anonymous so no further central anonymisation is necessary.

Procedure for Denmark, England and Scotland: The *Danish Lung Cancer Registry (Denmark)*, the *National Lung Cancer Audit (England)* and the *Cancer Registry of the Scottish Cancer Networks* will generate a strictly anonymous data file including all patients diagnosed in the study time period (1st to 31st May 2012) based on eligibility for EuLuCA. This data file will only contain the parameters addressed in EuLuCA (Appendix 1 – Parameter list).

b) Data transmission

Procedure for all European countries except Denmark, England and Scotland: The database will be locked for electronic transmission of anonymous patient data via the EuLuCA web-based data entry tool on 1st July 2012.

Procedure for Denmark, England and Scotland: The national co-ordinators for Denmark, England and Scotland will co-ordinate the electronic transmission of anonymous data from the *Danish Lung Cancer Registry (Denmark)*, the *National Lung Cancer Audit (England)* and the *Cancer Registry of the Scottish Cancer Networks* to the lead data analyst, Dr Anna Rich.

c) Data amalgamation

The lead data analyst, Dr Anna Rich, will amalgamate all data files sent in by the participating *lung cancer units* as well as the *Danish Lung Cancer Registry (Denmark)*, the *National Lung Cancer Audit (England)* and the *Cancer Registry of the Scottish Cancer Networks* to one single database for further analysis. Every case within the dataset will have a corresponding country code as well as a specific code for the originating *lung cancer unit*.

7. Monitoring

Procedure for all European countries except Denmark, England and Scotland: During the study period the national co-ordinator will monitor the progress of the study at each of the *lung cancer units* for whom he/she has responsibility. This must include at least one point of contact, directly after the end of the study period, and should take place via a personal meeting, a web conference or a comprehensive phone call. The national co-ordinator should provide information and support and confirm adherence to the study protocol.

Procedure for Denmark, England and Scotland: No further monitoring needed since data are assessed on routine basis.

8. Study closure

All participating *lung cancer units* will be notified by email of the formal study closure when the database has been locked.

9. Data analysis

The statistical package, STATA version 11, will be used to analyse the single database by the lead analyst, Dr. Anna Rich. Logistic regression will be used to assess the likelihood of receiving certain treatments within and between different European countries.

10. Publication

It is anticipated that the results of the study will be published in a peer review journal such as the European Respiratory Journal. This publication will state that this work was carried out on behalf of the ERS-Taskforce European Initiative for Quality Management in Lung Cancer Care (EIQMLCC) as a whole and all EIQMLCC-members will be included.

All participating *lung cancer units* as well as their corresponding principle investigators will be named in the acknowledgement-section of the paper.

11. Record retention and archiving

At the end of the study period, the anonymous data will be collated and stored by the lead data analyst, Dr Anna Rich, in an encrypted file (using Trucrypt software). There will no patient identifiers in the stored data.

Time line

February 2012

- Setup of Pan-European infrastructure (TB)
- First Europe-wide announcement providing general information (TB)
- Obtain study approval by responsible ethics committees (NC)

March 2012

- Second Europe-wide announcement providing detailed information (TB)
- Enrolment and initiation of local *lung cancer units* (NC)

May 2012

- Enrolment of patients (LCU)
- Data collection (LCU)
- Data transmission (LCU)

June 2012

- Data transmission (LCU)
- 1st follow-up contact (NC)

July 2012

- Closure of the on-line study data repository (1st July 2012) (AR)
- Formal notification of study closure to LCU (TB)
- Amalgamation of received datasets (AR)

August/September 2012

- Data analysis (AR)

October-December 2012

- Draft of publication (TB, AR)

Responsible persons are named in brackets: AR: Anna Rich; JPS: Jean-Paul Sculier; LCU: Lung Cancer Units; MP: Mick Peake; NC: National Coordinators Promoters; TB: Torsten Blum

Funding

This study will be conducted without funding from the pharmaceutical industry.

In order to cover directly incurred costs, such as the costs of submitting applications to ethics committees, an application for a financial grant has been submitted to the Stiftung Oskar-Helene-Heim, Berlin, Germany. This has been positively appraised by the scientific advisor of the Stiftung Oskar-Helene-Heim, but the final decision on the application by the board members is still pending.

The Stiftung Oskar-Helene-Heim (Walterhoeferstr. 11, 14165 Berlin, <http://www.stiftung-ohh.de>) is a non-commercial foundation with the primary objective to support scientific projects in the fields of respiratory medicine, orthopaedics and the treatment of abdominal diseases.

No costs for staff are anticipated as all personnel involved in this study have agreed to work on a voluntary basis.

Appendix 1 – Parameter list

The following parameters are intended to be assessed:

- Date of diagnosis
- Age at diagnosis (years)
- Sex (male or female)

- Histological subtype (according to ICD-O, 3rd edition)
 - Adenocarcinoma
 - Squamous cell carcinoma
 - Large cell carcinoma
 - Other specified non-small cell carcinomas
 - Not otherwise specified non-small cell carcinoma
 - Small cell carcinoma

- Pre-treatment stage (UICC version 7)
 - TNM
 - Stage

- Performance status (WHO/ECOG) at the date of diagnosis
 - 0 Able to carry out all normal activity without restriction
 - 1 Restricted in physically strenuous activity but able to walk and do light work
 - 2 Able to walk and capable of all self care but unable to carry out any work. Up and about more than 50% of waking hours
 - 3 Capable of only limited self care, confined to bed or chair more than 50% of waking hours
 - 4 Completely disabled. Cannot carry out any self care. Totally confined to bed or chair
 - 99 Not recorded

- Treatment intended; which could be multi-modality
 - Surgery alone with curative intention
 - Surgery with Neoadjuvant treatment (CT +/- RT) and curative intention
 - Surgery with adjuvant treatment (CT +/- RT) and curative intent
 - Radiotherapy with curative intention
 - Radiotherapy with palliative intention
 - Concurrent radio- and chemotherapy
 - Sequential radio- and chemotherapy
 - Chemotherapy with palliative intention
 - Best supportive care (symptom control)
 - Other

Definitions

Date of diagnosis: Format *DD/MM/YYYY*

Date of first histological or cytological confirmation of this malignancy (with the exception of

histology or cytology at autopsy). This date should be, in the following order:

- a. date when the specimen was taken
- b. or date of receipt by the pathologist
- c. or date of the pathology report

Age at diagnosis: Format numeric years to one decimal place

The age at diagnosis is calculated by subtracting Date of birth from Date of diagnosis.

Appendix 2 – Patient consent form

- English version

(translations of the English patient informed consent form into the national languages of all participating non-English speaking countries are available as supplementary documents to this study protocol)

EuLuCA – European Lung Cancer Audit

An observational, non-intervention, study for the feasibility of prospectively collecting demographic and clinical data on lung cancer patients in a Pan-European setting.

Patient Consent Form

Dear Sir or Madam,

Thank you very much for your interest in the EuLuCA-study – a European Lung Cancer Audit. This patient consent form will provide you with comprehensive information regarding the purpose and the procedure of this study.

What is the background and purpose of the EuLuCA-study?

This study has been set-up by the European Initiative for Quality Management in Lung Cancer Care (EIQMLCC), an official Task Force of the European Respiratory Society. The overall goal of the EIQMLCC is to sustainably improve lung cancer care throughout Europe for the primary benefit of lung cancer patients.

The intention of the EuLuCA-study is to collect prospective data from as many institutions across Europe as possible, and then perform statistical analyses to begin to document and compare the demographic and clinical variation amongst patients with lung cancer across Europe.

What data will be collected within the EuLuCA-study?

With your permission the following details about you will be collected:

At the time of first diagnosis of lung cancer

- Date of diagnosis
- Age at diagnosis
- Sex
- Histological subtype
- Performance status
- Stage
- Intended treatment

What is the procedure for collecting data and how will data security be guaranteed?

Data collection will be performed only by the local institution in which you are currently treated. The local institution guarantees to conform to all applicable legal regulations (be they local or national). Your data will be anonymously entered onto an international website, which will afterwards generate a unique patient identity code. Therefore, no record of your confidential patient details (i.e. name, surname, date of birth, institutional patient/case number) will be made. It will be impossible to identify anyone based on this anonymous data.

How are the anonymous data subsequently handled by EIQMLCC?

The anonymous data will be electronically sent to the lead analyst of the EuLuCA study, Dr. Anna Rich (Nottingham, England). She will merge all the data into one comprehensive database and perform various statistical analyses within the framework of the EuLuCA-study. Our intention is to publish a paper based on these results in a scientific peer-reviewed journal. Furthermore, the general experiences gathered during this study will be helpful for future projects of this kind. However, EIQMLCC guarantees that all data will only be used for scientific, non-commercial purposes. **EIQMLCC will not pass any data to third parties.**

Has the EuLuCA-study been officially approved in my country?

Policies regarding ethics approval vary throughout European countries. Depending on the particular policy of your country, an approval of the responsible ethic committee(s) has been obtained by EIQMLCC wherever mandatory. In the remaining nations in which an approval by an ethic committee is not mandatory, a written notification on this study has been sent to the responsible ethic committee(s) by EIQMLCC.

Although there is ***no personal risk*** for you in participating in the EuLuCA-study, some European countries stipulate insurance cover is obtained. If required in your country, a comprehensive insurance contract has been arranged by EIQMLCC.

Consent

I have understood the purpose and procedure of the EuLuCA-study.

With my signature I give permission for the information outlined above to be recorded at my local institution and entered onto an anonymous Pan-European database for exclusively scientific, non-commercial purposes regarding lung cancer care in Europe by EIQMLCC.

Patient:

Signature _____ Date/Place _____

Print name _____

Doctor informing patient:

Signature _____ Date/Place _____

Print name _____

Appendix 3 – EuLuCA web-based data entry tool

EuLuCA web-based data entry tool

The EuLuCA web-based data entry tool has been developed by Dr Paul Beckett (Burton-on Trent, England). It allows the *lung cancer units* to enter individual patient data electronically onto a web-based central EuLuCA database.

The web-based data entry tool creates a completely anonymous dataset, without any patient sensitive information.

The EuLuCA web-based data entry tool can be found via the following link:
<http://www.eiqmlcc.org>

Every lung cancer centre has to register itself and to choose an individual username and password before being able to enter data.

Appendix 4 – Signature forms

- Responsible Project Leader and Coordinating Investigator
- Assistant Coordinating Investigators
- Lead Analyst
- National Co-ordinator

EuLuCA – European Lung Cancer Audit

An observational, non-intervention, study for the feasibility of prospectively collecting demographic and clinical data on lung cancer patients in a Pan-European setting.

Study protocol v 1.0 (17th February 2012)

Responsible Project Leader and Coordinating Investigator

I hereby agree to the terms of the protocol of this non-interventional study.

I am aware that the information in this study protocol may be subject to change and revision.

Signature

*Dr. Torsten Blum, M.B.A.
Lungenklinik Heckeshorn
HELIOS Klinikum Emil von Behring
Walterhöfer Str. 11
14165 Berlin
Germany
Phone: +49-(0)30-8102-2339
Email: torsten-gerriet.blum@helios-kliniken.de*

Date (Day Month Year)

EuLuCA – European Lung Cancer Audit

An observational, non-intervention, study for the feasibility of prospectively collecting demographic and clinical data on lung cancer patients in a Pan-European setting.

Study protocol v 1.0 (17th February 2012)

Assistant Coordinating Investigator

I hereby agree to the terms of the protocol of this non-interventional study.

I am aware that the information in this study protocol may be subject to change and revision.

Signature

*Dr. Anna Rich
Nottingham University Hospitals
City campus, Hucknall Road
Nottingham NG5 1PB
England
Phone: +44-(0)115-9691169 extn. 54184
Email: Anna.Rich@nottingham.ac.uk*

Date (Day Month Year)

EuLuCA – European Lung Cancer Audit

An observational, non-intervention, study for the feasibility of prospectively collecting demographic and clinical data on lung cancer patients in a Pan-European setting.

Study protocol v 1.0 (17th February 2012)

Assistant Coordinating Investigator

I hereby agree to the terms of the protocol of this non-interventional study.

I am aware that the information in this study protocol may be subject to change and revision.

Signature

Prof. Dr. Jean-Paul-Sculier
Year) *Oncologie thoracique*
Institut Jules Bordet
1 rue Héger-Bordet
1000 Bruxelles
Belgium
Phone: +32-02-5413191
Email: jean-paul.sculier@bordet.be

Date (Day Month

EuLuCA – European Lung Cancer Audit

An observational, non-intervention, study for the feasibility of prospectively collecting demographic and clinical data on lung cancer patients in a Pan-European setting.

Study protocol v 1.0 (17th February 2012)

Assistant Coordinating Investigator

I hereby agree to the terms of the protocol of this non-interventional study.

I am aware that the information in this study protocol may be subject to change and revision.

Signature

*Dr. Michael D. Peake
Glenfield Hospital
Groby Road
Leicester LE3 9QP
England
Phone: +44-(0)116-2502610
Email:mick.peake@uhl-tr.nhs.uk*

Date (Day Month Year)

EuLuCA – European Lung Cancer Audit

An observational, non-intervention, study for the feasibility of prospectively collecting demographic and clinical data on lung cancer patients in a Pan-European setting.

Study protocol v 1.0 (17th February 2012)

Lead Analyst

I hereby agree to the terms of the protocol of this non-interventional study.

I am aware that the information in this study protocol may be subject to change and revision.

Signature

*Dr. Anna Rich
Nottingham University Hospitals
City campus, Hucknall Road
Nottingham NG5 1PB
England
Phone: +44-(0)115-9691169 extn. 54184
Email: Anna.Rich@nottingham.ac.uk*

Date (Day Month Year)

EuLuCA – European Lung Cancer Audit

An observational, non-intervention, study for the feasibility of prospectively collecting demographic and clinical data on lung cancer patients in a Pan-European setting.

Study protocol v 1.0 (17th February 2012)

National Co-ordinator

I hereby agree to the terms of the protocol of this observational study.

I am aware that the information in this study protocol may be subject to change and revision.

Signature

Name
Name of institution
Address

Date (Day Month Year)

Phone
Email

Appendix 5 – Study contract

EuLuCA – European Lung Cancer Audit

An observational, non-intervention, study for the feasibility of prospectively collecting demographic and clinical data on lung cancer patients in a Pan-European setting.

Study protocol v 1.0 (17th February 2012)

Study Contract

Lung Cancer Unit (LCU)

and the European Initiative for Quality Management in Lung Cancer Care (EIQMLCC) (a Task Force of the European Respiratory Society) represented by

Name of EIQMLCC National Coordinator

conclude the following contract:

1. Participation in the observational study EuLuCA includes the prospective assessment of demographic and clinical data of lung cancer patients at first diagnosis in the *Lung Cancer Unit*.
The inclusion period for patients with lung cancer is strictly limited to a date of first diagnosis of lung cancer between 1st and 31st May 2012.
There exists neither a minimum nor a maximum number of patients that need to be included into the EuLuCA-study by each LCU.
2. The LCU guarantees that it will fully comply with the terms of the EuLuCA study protocol.
3. The LCU guarantees that it will inform every eligible patient regarding the purpose and procedure of the EuLuCA study, and obtain their written consent (using the EuLuCA patient consent form) before inclusion into the EuLuCA-study.
3. The LCU guarantees to obey all applicable institutional and national legal regulations as well as the EuLuCA study defaults concerning the data security of confidential patient information. All data will be anonymous and once transmitted to lead analyst, it will also be encrypted.
4. EIQMLCC will not pay any honoraria for the data assessment in the context of the EuLuCA study or reimburse any other costs related to the data assessment.
5. EIQMLCC possesses all rights on the anonymous dataset provided by the LCU. EIQMLCC guarantees that it will use the data only for scientific, non-commercial purposes. Furthermore, EIQMLCC will not pass any data to third parties. The LCU has the right to use its own data for scientific, non-commercial purposes.

6. A cancellation of this study contract is possible at any time for both parties without naming reasons. Cancellation must be in writing.
 7. Any changes or amendments to this study contract have to be issued in written form and must be signed by both parties.
- No other agreements outside those in the written study contract have been made.

Signatures:

CEO LCU:

Name:
Institution:
Address:

Date (Day Month Year)

Phone:
Email :

Principle Investigator LCU:

Name:
Institution:
Address:

Date (Day Month Year)

Phone:
Email:

EIQMLCC National Coordinator:

Name:
Institution:
Address:

Date (Day Month Year)

Phone:
Email: