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Early View

Task force report

ERS Statement on harmonised standards for lung cancer registration and lung cancer services in Europe

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ERS Statement on harmonised standards for lung cancer registration and lung cancer services in Europe

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Take home message:

Written by Europeans for Europeans, the minimum dataset and manual for lung cancer services will help to improve standards for our patients.

Abstract

Introduction

The European Respiratory Society taskforce for harmonised standards for lung cancer registration and lung cancer services in Europe recognised the need to create a single dataset for use in pan-European data collection, and a manual of standards for European lung cancer services.

Methods

Existing national and international datasets were reviewed with the results of a survey of clinical data collection on lung cancer in 35 European countries. These two different sources of evidence were considered by the multidisciplinary taskforce. A similar process was followed for the manual of lung cancer services where existing guidelines and national or international recommendations for lung cancer services were used to develop a manual of standards for services in Europe.

Results

Essential and minimum datasets for lung cancer registration were developed to enable all countries to collect the same essential data and some to collect data with greater detail. A manual specifying standards for lung cancer services in Europe was developed.

Conclusion

Despite the wide variation in the socio-political landscape across Europe, the ERS is determined to encourage the delivery of high quality lung cancer care. The manual of lung cancer services and minimum dataset for lung cancer registration will both support this aspiration.

Introduction

Lung cancer is the second most common cancer in men and women in Europe and the commonest cause of cancer related death (1). Europe accounts for a quarter of all lung cancer deaths globally despite representing an eighth of the worlds' population (2). Recent advances in techniques for diagnosis, staging and treatment have seen a modest improvement in outcomes and there is hope that further developments in molecular targeted treatments and immunotherapy, as well as potential combination treatments and the expected implementation of low radiation dose CT screening will improve outcomes further (3). However, improvements in clinical services vary greatly across Europe due to a variety of organisational, economic and socio-political factors. To help drive the adoption of best clinical practice that is delivered more equitably, an agreed service specification is needed and agreement on the metrics by which the service can be measured. This requires a description of the standards for lung cancer services and a uniform cancer registration system to measure the activity.

In 2015, the European Respiratory Society (ERS) approved a taskforce to create a pan-European thoracic oncology dataset and develop internationally agreed standards for European thoracic oncology centres. The membership of the taskforce was derived from a previously successful taskforce on quality management in lung cancer and hence includes a multidisciplinary group with a keen interest in the development of harmonised international standards. The two main aims of this group were to develop:

1. a pan-European dataset;
2. a manual of standards for lung cancer services in Europe.

Lung cancer registration in Europe: the need for a pan European dataset

Cancer data collection in Europe began in the 1950's with the establishment of cancer registries. However, it was not until the 1990's that they were widespread enough to allow meaningful comparative research to be done. The EUROCARE series of large scale publications has demonstrated the variation in epidemiological features and outcomes in a large number of European countries (4, 5). These publications have sparked interest from the public and politicians alike and they have been the catalyst for many developments at

the national and international level to improve the outcomes for individuals with cancer. The number of cancer registries involved in EUROCARE studies has grown, and the level of population coverage improved; but there remain large parts of Europe that are not accounted for in these studies (6). Data items and their definitions are not universally agreed, and so comparisons cannot always be standardised. Furthermore, few registries collect sufficient clinical details at the individual patient level to support meaningful comparisons of outcome within and between countries.

The European Union's strategy against cancer has focussed on the importance of cancer registration. It has funded several initiatives including the European Action Against Cancer Programme (1985-2008); the European Partnership for Action Against Cancer (EPAAC) (2009-2014) (7) and the EU Cancer Control Joint Action (CANCON) (8). The European Network Cancer Registries (ENCR) were set up in 1990 as a joint venture with several other international cancer research groups to promote the quality of cancer registration across Europe, and the use of these data for clinical and public health research. The ENCR has published a minimal dataset for cancer registries as well as an optional dataset (9). These are generic for every cancer rather than being lung cancer specific.

Lung cancer services in Europe: the need for harmonised international standards

Europe has a diverse healthcare structure generated by diversity in social, political and economic factors. However, in thoracic oncology, the aim of the healthcare system is to provide the best standard of care to provide patients with the best outcomes. In general, countries have a combination of large centres, usually based in large hospitals with a concentration of expertise and technology, and smaller healthcare providers, with less equipment and less comprehensive services. Some countries have primary care services in addition that play a crucial role throughout the lung cancer pathway. A previous ERS taskforce report described the differences in the healthcare infrastructure for 38 European countries (10). The diversity across Europe has undoubtedly contributed to the variation in healthcare outcomes and agreement on the standards centres should adopt is one way to mitigate this effect.

Methods

Group composition

The taskforce was chaired by Anna Rich and Torsten Blum with a further 25 members from nine countries around Europe. All members have a specialist interest in lung cancer, and represent different aspects of the multi-disciplinary team: pathology, pulmonology, radiation oncology, medical oncology, thoracic surgery, palliative care, a lung cancer specialist nurse, and a medical statistician. Patients views were represented through the European Lung Foundation's (ELF's) lung cancer patient advisory group (PAG).

Conflicts of interest

All taskforce members declared and signed conflict of interest statements at the beginning of the project and updated them at project finalisation.

Working methods

The taskforce met at face-to-face meetings held at the ERS congress in Amsterdam in September 2015. The aims and objectives of the project were discussed and agreed, and the proposal for two workstreams, lead by Anna Rich (minimum dataset) and Torsten Blum (manual for lung cancer services) was ratified. Further face-to-face meetings were held in London in May 2016, the ERS congress in London in September 2016, and then in London March 2017. A final face-to-face meeting was held at the congress in Milan in September 2017 when the final report was discussed in detail. Conference calls and email correspondence were also used to discuss and amend the detail within the minimum dataset and the manual of lung cancer services as they were developed. Agreement within the taskforce group achieved >90% prior to inclusion within the report.

- *Review of existing datasets*

Datasets in use or in development were reviewed before and during meetings of the taskforce. This included the work from an allied project (11) as well as national datasets from countries represented on the taskforce. Supplement 3.1 reports the datasets reviewed, and key facts regarding their development. The aim was to understand the similarities and differences in data collected and to derive a harmonised dataset that would

encompass, as far as possible, existing data collected as well as extending this to a minimum dataset. Existing datasets from ENCR and the International Consortium for Health Outcome Measures (ICHOM) were used as reference datasets (9, 12). These were chosen for their comprehensiveness and because they were developed by international groups. However, the taskforce identified that these datasets were too detailed and ambitious to be applied as harmonised standards in Europe where a more pragmatic approach was needed.

Membership of the taskforce included professionals who have considerable experience in developing and implementing national audits. This expertise was used to make realistic proposals for a European dataset. The data items were chosen on the basis of consensus opinion, with a majority of >90% agreement.

- *Evidence search and review of existing manuals*

Members of the taskforce performed a narrative search of existing manuals for lung cancer services including relevant websites or printed publications of related international societies and other stakeholders, and national level publications accessible by taskforce members (see Supplement 3.3). Given that a systematic search on the national level was beyond the means of this taskforce, the group accepted a potential selection bias based on the limitation to only those European countries represented on the taskforce.

Subsequently, Dr. Torsten Blum browsed repeatedly during the course of this taskforce through the websites of the named international societies and other stakeholders for substantial online or referenced printed publications. Retrieved evidence from this narrative search as well as reports identified by other taskforce members were amalgamated by Dr. Blum and then discussed during taskforce meetings. All searches on the international level were last updated by him in November 2017. Detailed results are provided in Supplement 3.3.

The previous ERS taskforce on quality management in lung cancer care has revealed that there were more than 150 lung cancer guidelines worldwide, and more than 80 within Europe (10). There was significant variation in the quality of these guidelines: in terms of the underlying evidence used, the specific aspects of the lung cancer pathway being

addressed and the publication date. Only a minority of these guidelines addressed in any meaningful way, the detail with respect to infrastructure and pathway processes, to inform our aspired manual of standards for lung cancer services.

The taskforce has not performed systematic evidence searches in medical data bases on its own, but used relevant results from a GRADE based systematic review of the literature on quality management in lung cancer with a focus on the impact of defined lung cancer services. This was the subject of a parallel ERS taskforce that will be published in full separately. Overall, published material was found to be very limited and of low quality.

An agreed list of standards for lung cancer services in Europe was developed during taskforce meetings and interim discussion. The recommended manual of standards for lung cancer services is based on a review of available evidence and is complemented by the inclusion of patient perspective as well as the clinical experience of the taskforce members.

European Lung Foundation's (ELF's) Patient Advisory Group

ELF's lung cancer patient advisory group (PAG) was established to support a range of research activities relating to lung cancer. The PAG is made up of people who have received a diagnosis of lung cancer (either undergoing treatment or survivors), caregivers of people with lung cancer, and representatives of lung cancer patient organisations. Every member responded to an advert on the ELF website and were interviewed informally by phone or skype before being accepted onto the PAG. The PAG allows individuals to self-select which projects they can most usefully support, based on their experience and interests, and also allows them to withdraw at any time if health issues arise.

The taskforce regarded it as essential to create a dataset and manual that were meaningful to patients and ELF staff member, Jeanette Boyd, was invited to attend taskforce meetings and to facilitate the gathering of views from PAG members regarding the development of both the pan-European dataset and manual for lung cancer services. Five members provided feedback for the dataset (4 patients and 1 patient organisation representative from Czech Republic, Italy and UK) and 4 members provided feedback for the manual of lung cancer services (2 patients, 1 caregiver and 1 patient organisation representative from Denmark, Ireland, Poland and the UK). Views were gathered by sharing documentation by

email and requesting feedback. Jeanette Boyd collated and analysed the feedback using a qualitative approach and presented this to the taskforce for consideration. In addition, Dr Torsten Blum conducted semi-structured telephone interviews with PAG members for feedback relating to the manual of lung cancer services.

Manuscript preparation

The taskforce final report was written by Dr Anna Rich and Dr Torsten Blum, with editing and some modification provided by Prof David Baldwin. Prof Micheal Peake was invited to write the subsection regarding the National Lung Cancer Audit of England and Wales, as an external co-author. The paper was then circulated to all members of the taskforce and revisions made by Dr Rich. The statement paper and supplements were reviewed, edited and approved by all members of the taskforce before submission.

Glossary of Terms

Abbreviation	**Definition**
.csv	Comma separated values
.xml	Extensible markup language
COSD	Cancer Outcomes and Services Dataset
CT	Computed tomography
DLCG	Danish Lung Cancer Group
DLCR	Danish Lung Cancer Registry
DNPR	Danish National Patient Registry
DPR	Danish Pathology Register
ECOG	Eastern Cooperative Oncology Group
ELF	European Lung Foundation
ENCR	European Network Cancer Registries
EORTC	European Organisation for Research and Treatment of Cancer
ERS	European Respiratory Society
EU	European Union
GRADE	Grading of Recommendations Assessment, Development and Evaluation
HAS	Haute Autorite de la Sante (France)
IASLC	International Association for the Study of Lung Cancer
ICD	International Classification of Disease
ICHOM	International Consortium for Health Outcome Measures
IFCT	French Intergroup of Thoracic Oncology
INCa	Institut National du Cancer (France)
LCNS	Lung Cancer Nurse Specialist
LUCADA	Lung Cancer Data
MDT	Multi-Disciplinary Team

NCI	National Cancer Institute (United States of America)
NCRAS	National Cancer Registration and Analysis Service
NHS	National Health Service
NLCA	National Lung Cancer Audit
OECI	Organisation of European Cancer Institutes
PAG	Patient Advisory Group
PCR	Pathological Confirmation Rate
PET-CT	Positron Emission Tomography-Computed Tomography
PIN	Personal Identification Number
PROMs	Patient Reported Outcome Measures
PS	Performance Status
QoL	Quality of Life
RCP	Royal College of Physicians
SES	Socio-Economic Status
SNOMED	Systematized Nomenclature of Medicine
WHO	World Health Organisation

Part 1. Development of a pan-European lung cancer dataset

Two national lung cancer datasets stood out as exemplars of data completeness and use of data to drive improvement in services and outcomes; they are described below.

Drivers, development and implementation of two national lung cancer audit programmes: Denmark and England

Drivers

The two main drivers for the development of both of these well-established audit programmes were i) preliminary comparative data, in the 1990s, suggesting poorer outcomes than in other countries; and ii) evidence for unwarranted variation in clinical practice. EUROCARE-1 reported 5 year survival in lung cancer in England and Denmark as being below 8% (4). This prompted the Royal College of Physicians of London, with funds provided by the English Government, to sponsor a snapshot audit (13). This audit, involved 52 hospitals between 1995 and 1996, showed large variations in the care of lung cancer patients and led to efforts to establish a longer term, population-based lung cancer audit programme. In Denmark, similar variations were apparent. The healthcare system was organised so that diagnostics and treatment was provided by a large number of hospital departments with very different approaches to the disease. The Danish Lung Cancer Group (DLCG) was formed with the primary aim of improving the clinical management and survival of Danish lung cancer patients. A secondary aim was to produce a platform for lung cancer research. The DLCG produced national guidelines for the management of lung cancer (14) and adopted a strategy to implement the guidelines and concurrently monitor the implementation by reporting to a national registry – The Danish Lung Cancer Registry (DLCR).

Development and implementation

The Danish Lung Cancer Registry

The DLCR started in 2000 and now contains data on around 70,000 patients. Between 2000 and 2012, inclusion of patients relied on clinicians identifying and reporting patients to the DLCR, but since 2013, patients are identified from the first diagnostic codes for lung cancer in the Danish National Patient Registry (DNPR). The latter helped improve data completeness and reduce the workload for clinicians. Participation has since become mandatory by law, so data completeness is now more than 95% of new cases. The basic database is derived from the DNPR and the Danish Pathology Register (DPR) and includes procedures and treatment. This is supplemented and validated online by clinicians to form the DLCR. All departments involved in the diagnosis and treatment of lung cancer in Denmark are responsible for the validation and supplementation of data (15).

The database contains demographic and patient characteristics, details of treatment including surgery, type and duration of chemotherapy and type and duration of radiation. Vital status is derived monthly from the Danish Civil Registration System and age at diagnosis confirmed from the personal identification number (PIN). During the 18 years of data collection in the DLCR major improvements in treatment outcomes have been recorded (16). DLCR has developed a number of indicators using scientific evidence and the national guideline recommendation. The indicators are reported monthly and annually to all participating departments, hospitals and healthcare authorities. A comprehensive system of audits ensures that differences in quality measures and failure to meet standards are evaluated.

A number of publications based on the DLCR have appeared since 2009, documenting the effects of a national registry. The two major lessons that have been learned are firstly that high data quality and completeness is essential to ensure participation of clinicians in working with data and results from the database. Meaningful audit depends on the accuracy and credibility of data; only once clinicians were convinced of this, was it possible to shift the focus from data quality to the findings. Secondly, involvement of hospital and regional management in the process of implementation is important to facilitate the

changes in services and clinical practice that are recommended from the findings of the audit (17). Centralization in Denmark is traditionally met with resistance from local stakeholders, and the involvement of management has played a central role. The DLCR has shown that regional differences have decreased as the number of departments involved in treating lung cancer patients has halved (17).

The DLCG has in 2017 formulated an ambitious goal to double survival from lung cancer before 2030 (18) and it is widely recognized that the DLCR plays a crucial part in achieving this goal.

The National Lung Cancer Audit (UK)

In 1999, a multi-disciplinary 'Intercollegiate' Lung Cancer Group published: 'Lung Cancer: A core dataset' (19). From the outset, the aim was to achieve as near total population coverage as possible; and in order to make achieving this more likely, the size of the dataset was limited. It has evolved over the years (20), but the number of fields requiring completion for any one patient is usually less than 50.

In 2004 the English Government, through the National Clinical and Patient Outcomes Programme, which funds over 30 National Clinical Audits in England, began to support the central functions of a national lung cancer audit programme. Wales joined the programme in 2006, and collated data from Scotland and Northern Ireland have been included in reports whenever possible.

The principles of the audit and findings were regularly presented at regional and national multi-professional clinical meetings to encourage clinical engagement, which was initially limited. However, despite non-mandatory participation, the proportion of patients captured by the audit rose from 40% in 2005 to 100% in 2009 and has remained at that level since. In 2009 participation was mandated by formal contract between the Department of Health and provider hospitals.

A bespoke database was developed (called LUCADA - LUng CAncer DAta) in one of the National Health Service's (NHS) central computing systems, allowing direct, secure data entry of individual patient data or compiled grouped data on multiple patients as .csv or

.xml formatted files. This system also allowed each hospital to see its own grouped data at any time with comparative, anonymised data from other hospitals.

Multi-Disciplinary Teams (MDT) were well established (21) and these teams were used as the focus for data collection, some appointing data coordinators or building the work into the roles of MDT co-ordinators or even Lung Cancer Nurse Specialists. Each local hospital developed or purchased its own software for data collection, though by the late 2000s over 80% were using one of two systems. Data completeness improved rapidly, for example, completeness of performance status and stage data fields reached >80% by 2009 (22) and have exceeded 90% since (23).

The first annual report was published and made available to the general public in 2006 (24). The hospitals were identified along with their activity, data completeness and outcomes. This lead to a great deal of press activity and complaints from hospitals that their data were not accurate, but this served as a vital driver behind the rapid improvements in participation and data completeness that followed. Reports and anonymised spreadsheets of data are now available to the public via the RCP website (25).

Data quality and completeness are major issues for any large scale population-based audit. Co-morbidity proved to be difficult to collect, both incomplete and inconsistent. As with the DLCR, the Charlson Index is used, derived from in-patient diagnostic codes. Until recently detailed data on combination therapies and second and subsequent lines of treatment has been limited; this is now collected through two other databases, one for radiotherapy and one for systemic therapy. Palliative care, primary care and Patient-Reported Outcome Measures (PROMS) have so far not been routinely linked to the NLCA.

The NLCA has changed the culture of the Thoracic Oncology community in the UK; raising awareness of local and regional activity, patterns of care and outcomes of patients with lung cancer and mesothelioma. Surgical resection rates have doubled since the audit began and less dramatic improvements have been seen in a wide range of other indicators of high quality care (25). The 1 and 5 year survival rates have increased in recent years (26) and appear to parallel the improvements in treatment rates. There have been a large number of peer-reviewed publications that have emerged using the NLCA data and these have been

influential in recommendations for the commissioning of services. In 2014 the NLCA team at the Royal College of Physicians began working directly with the National Cancer Registration and Analysis Service (NCRAS) in Public Health England and to a large extent now uses data collected in the national Cancer Outcomes and Services Dataset (COSD) as the basis of their analyses and reports.

Patient perspectives on the development of a pan-European lung cancer dataset

The European Lung Foundation's (ELF's) lung cancer patient advisory group (PAG) was asked specific questions about the development of a pan-European dataset and the views outlined below are from five individuals with experience of lung cancer from the Czech Republic, Italy and the United Kingdom.

Value of a pan-European dataset

PAG members were in agreement that the implementation of a lung cancer dataset across Europe would be particularly useful in:

- developing and monitoring diagnostic standards;
- developing and monitoring standards of care in lung cancer;
- assisting evidence-based analysis of data across countries;
- establishing what treatments work and for whom.

Patient access to data would be of interest and value to patients as a way to understand more about their condition and what could be viewed as usual/unusual in comparison with others. This would give individuals a useful comparator to discuss their condition with clinicians. In light of this, patient access to the data should be considered as part of any dataset development.

Gathering data

It was noted that patients could provide valuable input in defining the relevant importance of different quality of life (QoL) data, and the considerations to be aware of when collecting these. Patients felt it was important for QoL data to be collected verbally, directly from patients, to ensure consistency, and to identify patterns across the pathway which could

then lead to identification of relevant support where appropriate. A crucial factor for the successful gathering of information from the patient is the level of trust that exists between clinician and patient. The QoL questionnaire EORTC QLQ-C30 was identified by the Task Force as a possible resource, as this is already a standardised tool in use (27). The PAG members thought that some of the questions were relevant, but that a subset of these questions might be more effective.

PAG members suggested that there could be a beneficial role for caregivers, nurses and hospice staff in helping gathering QoL information and assisting patients, especially at times of high stress and anxiety. They identified these times as often being at the point of diagnosis and/or when patients may not have much energy, for example during chemotherapy, or when receiving palliative care. This will vary with each individual and further discussions would be beneficial to ensure data were both sensitively and effectively gathered. Patient reported outcomes have demonstrated positive impact on treatment outcomes and their use is expected to increase in the future (28). Specific recommendations on PROs are not dealt with in this recommendation.

The PAG thought QoL data collection would be most valuable at diagnosis, post primary treatment (3 months) and at the end of primary treatment (6 months). Several PAG members also felt that it would be helpful to gather data after 12 months. It was also suggested that collecting QoL from patients at the end of a 5 year recurrence-free-follow-up could be valuable in sharing hope among patients.

PAG members recommended that the gathering of co-morbidity data should be patient-led and clinician reported. The data should emerge from a discussion and agreement between the clinician and patient. This would have the additional advantage of patients being better informed about potential co-morbidities and provide opportunities for pre-agreement with their clinician about what to do should symptoms appear, potentially leading to lower patient anxiety in the long term.

Implementation topics of importance to patients

Implementation topics were identified that were important to patients including: informed patient consent; data protection and data security; data use and patient knowledge of how

it is used; and information about clinical trial involvement. Providing personalised data summaries with pan-European comparison would also be a valued option.

ELF would recommend that patient representatives are fully involved in future discussions about dataset development to ensure that all patient issues have been considered and any potential challenges addressed before any future roll-out across Europe.

Recommendations for a pan-European dataset for lung cancer registration

The proposed pan-European dataset for lung cancer registration can be divided into four sections, with data items relating to: basic patient features, tumour details, extended patient features, and details of the lung cancer pathway and process. The tables include data items which should be mandatory in the minimum dataset (marked in black) as well those which are desirable (marked in blue). For practical utility, all four tables are also listed in Supplement 1. Data items in the minimum dataset were felt to be essential for basic epidemiology required to evaluate key clinical outcome measures, and are already collected in a majority of European countries (11). The minimum dataset for lung cancer (including tracheal cancer) is for all patients with an International Classification of Disease (ICD v10) code of c33, or c34.

Basic patient features

Table 1 illustrates data items for basic patient features. A record of ethnicity is important for several reasons. There is evidence of significant variations in the prevalence of somatic mutations in adenocarcinoma of the lung based on ethnicity (29, 30). There is also evidence of variation in the route to accessing healthcare services based on patient ethnicity (31-33). However, it is difficult to find one coding system for ethnicity that would capture the needs of every country in Europe. The ICHOM dataset definition (12) states that individual countries should determine the definition, and therefore this data item is not suitable for cross country comparison. So, the taskforce concluded that it was not possible to propose one list of ethnicity codes that would be relevant for every country in Europe (an example of a coding system is shown in supplement 3.2). The educational level of an individual was chosen as a surrogate for the socio-economic status. Some countries have well established linkage between registries or independent lung cancer audit programmes and census data

which allow them to stratify an individual's socio-economic status (SES). However, these are the minority, and although socio-economic status is a very important indicator of access to healthcare generally, as well as key clinical outcomes in thoracic oncology (34-36), a compromise was agreed. The taskforce adopted a simple outline of educational level achieved based on ICHOM (primary, secondary or tertiary) (12). It was recognised that there is wide variation in the level of educational status achieved in different countries, and that it is not an ideal surrogate for SES but despite this limitation it was thought educational level would be a data item which could be captured.

Five data items relate to the diagnosis of lung cancer, how it was made with the inclusion of pertinent dates; these will be powerful points of reference when interpreting the lung cancer pathway and processes within each country or between countries. Delays in referral to a lung cancer specialist have been proposed as a reason for differences in outcomes so the date of referral to a lung cancer specialist is included. It is acknowledged that the route to a lung cancer specialist varies across Europe, and it often does not involve a primary care physician (10). There is a hierarchical basis to the date of diagnosis, which is taken from the ENCR minimum dataset for Cancer Registries (9). The date of the *final* pathology report, reflects the need to identify delays in obtaining a complete pathological diagnosis consequent upon increasingly complex processing. The mode of presentation is an essential data item as it is known to influence prognosis.

The basis of diagnosis (clinical/radiological or pathological) is crucial because of the association with prognosis: a more precise identification of the denominator for the whole cohort, allows international comparisons to reduce selection bias. Comparisons must use the same denominator because cohorts that only include patients with pathological confirmation do not include those patients with an often worse prognosis, who are diagnosed purely on the basis of a high level of clinical suspicion; such patients are often too unwell or too frail to undergo further tests. There is evidence that the likelihood of obtaining pathological confirmation in individuals believed to have lung cancer is affected by several factors. These include: age (37), their social-economic status (38), and performance status (PS) (39). Equally, factors relating to the lung cancer service could account for variation in pathological confirmation rates (PCRs), and hence the recommendation for agreed standards amongst lung cancer services in Europe (see part 2). Internationally there

is no agreed PCR, but research from the National Lung Cancer Audit of England, found that higher PCRs were most strongly associated with survival in patients with stage I/II disease who had a PS of 0-1 (40). Thus, a stratified approach to pathological confirmation, based on clinical features, was suggested rather than a single benchmark figure for PCR. The basis of diagnosis is the same as that defined by ICHOM (12).

Tumour details

Data that specify details of the tumour (see table 2) are essential for international comparisons because of the strong influence on prognosis, type of treatment offered and prediction of treatment response. The pathological subtype is vital, and we know that different countries within Europe use different systems. The majority use the International Classification Diseases -Oncology-3rd edition which incorporates all subtypes according to the current 2015 World Health Organization Classification of Lung Tumors (41) including the new lung adenocarcinoma classification originally proposed by IASLC, ATS and ERS (42). However Denmark uses Systematized Nomenclature of Medicine (SNOMED). The taskforce recommends that data are entered into the system using whichever classification is standard practice within each country. Retrieval of specific pathological sub-types could then be reconstructed with automated algorithms. For those countries without a specific pathological classification system, we have created a small but clinically relevant list of pathological subtypes. The field of molecular analysis is expected to expand in the future and so there is a need to have a data collection system which can include new definitions as clinical practice changes. These changes could be incorporated during a revision programme every two years, in order to balance clinical development with practical utility.

Stage of disease at diagnosis is compliant with the International Association for the Study of Lung Cancer (IASLC) staging system (43). The basis of the stage reflects access to certain procedures as well as national guidelines for diagnosing lung cancer, so there are data fields to record which investigations have been performed prior to the formation of a 'final pre-treatment clinical stage'. The version of the staging system (7 or 8) is selected first, and then the individual T, N and M stage is entered. However, further details about tumour size, the number and location of nodes and metastases then follow. Sub-classification of the extent of N2 disease is included as part of the desirable dataset, which could then be used

to categorise the patient cohort based on either the Robinson classification (44) or the IASLC staging project (assuming N1 disease is also subclassified-see table) (45). This level of detail from a pan-European cohort of individuals with lung cancer, will allow comprehensive and very detailed analysis of the prognostic value of the current IASLC staging system.

Extended patient features

Table 3 illustrates the extended patient features. The main data item in this section is Performance Status (PS) of the individual at the time of diagnosis with lung cancer. The Eastern Cooperative Oncology Group (ECOG) system (46) for recording this feature (also known as the World Health Organistion PS) is the most widely used method, although there is evidence that PS is only routinely collected in less than a third of European countries (11). It is paramount that this becomes a routine patient feature collected in all registries or audit programmes given the important role it plays in predicting outcome (39, 47-50).

The subsequent data items would allow detailed evaluation of the clinical outcomes from lung cancer within and between countries. The majority of European countries do not collect many of these, and it would take significant investment and political support to achieve this. Co-morbidity is a fundamental part of the evaluation of a patient prior to making a treatment plan for them, and there is good evidence of the influence of co-morbidity on outcome (51-54). The Charlson Index was developed in the late 1970's and validated on a cohort of patients with breast cancer (55). It has subsequently been used in numerous studies, but it has limited functionality given the complexity of the score, the lack of clarity regarding severity of co-morbid disease, and the out-of-date weighting given to HIV/AIDS. The ACE-27 score is an alternative model used by some to quantify co-morbid disease (56), and some countries record specific co-morbid diseases, but the list is variable (11). Therefore the ICHOM list of co-morbid diseases (based on Sangha et al (57)) is recommended, but should be derived from the medical notes after consultation between the clinician and the patient. It was hoped this would ensure accurate recording of all known co-morbidities. The EORTC QLQ-C30 patient completed questionnaire is recommended for QoL (27). This is based on the fact it is a validated research tool (58), although our patient group felt only a subset of the questions were relevant. This should be recorded at diagnosis, after completion of first line treatment, and at six months post-

diagnosis. This may be difficult to achieve but quality of life for patients is a fundamental outcome measure, often neglected; and members of our patient advisory group felt that ideally we would also collect QoL data at 12 months and after 5 year survival, where applicable. A revised QoL questionnaire is in development, which incorporates elements of the QLQ-C30 with specific reference to side-effects from medical treatments including chemotherapy and targeted therapies (59).

Lung cancer pathway/outcomes

The final section of the European recommended minimum dataset relates to aspects of the lung cancer pathway, specifically the outcomes in terms of treatment and survival (see table 4). Patients in some countries have identified how important contact with a lung cancer nurse specialist (LCNS) is because they provide significant support to patients and their families throughout the lung cancer pathway. Although there is no accepted international definition the taskforce suggests the following: a LCNS is one whose primary role is to meet individuals with lung cancer at diagnosis, sometimes before, and then to provide support for the patient and their family in terms of education, access to benefits, liaising with primary care physicians, and emotional support. The role may include other duties such as administering chemotherapy, although this does not, on its own meet the essential elements of holistic care described above.

Treatment data items are shown in table 4 and provide a comprehensive list of treatment options and associated secondary questions, which would not apply to all. In order for meaningful analysis of lung cancer outcomes to take place, and the influence of treatment modalities on survival to be assessed, every effort must be made to capture all relevant information.

Part 2. Manual of standards for lung cancer services in Europe

Publications defining lung cancer service specification had variable content. Four broad areas were identified that distinguished them:

- geographic scope (international, national or regional setting);
- comprehensiveness of care (comprehensive cancer services, lung cancer specific services and those that provide only selected diagnostic or treatment modalities)
- publishing body, such as national or international healthcare authorities or medical societies, insurance companies or other non-governmental bodies reimbursing costs of care, foundations, or a combination of these bodies;
- the time point and up-to-dateness of publication.

No international initiatives could be identified which defined standards of care specifically for the entire lung cancer pathway although there are two examples of relatively comprehensive cancer care service definitions on the European level. These are the European Society for Medical Oncology Designated Centres of Integrated Oncology and Palliative Care accreditation programme, initiated in 2003 (60) and the Organisation of European Cancer Institutes (OECI) Accreditation and Designation-Programme, revised in 2015 (61). Several international medical societies have published statement papers on standards for selected parts of the lung cancer pathway which are listed in table 5.

The United States National Cancer Institute (NCI) established the first successful comprehensive cancer centre-programme in 1971, supported by the National Cancer Act. There are now 69 NCI-designated (Comprehensive) Cancer Centers, all of whom have a focus on basic, clinical and population based research (62). This has been reviewed in relation to developing centres in Europe to support, primarily, research(63).

The Bonnie J. Addario Lung Cancer Foundation have established their own foundation-based 'Centre of Excellence Program' currently encompassing 17 community hospitals as well as 17 Addario Lung Cancer Medical Institute hospitals in the United States of America and 3 in Europe, (Paris, France; Torino, Italy; and Barcelona, Spain) (64)

There are a number of other approaches which have been taken in order to formalise the lung cancer pathway within European countries, and these are described in the paragraphs below.

UK

In 1995, the report by Calman and Hine, a 'Policy Framework for Commissioning Cancer Services', set the basic standards for cancer services in England and Wales including multi-disciplinary team working as a core element of cancer services (65). Since then, the NHS has further developed and regularly updated standards of cancer centre-based care in the UK, and standards have been monitored through a national peer review process and the NLCA (19, 20, 22). Furthermore, a 'national optimal clinical pathway for suspected and confirmed lung cancer: from referral to treatment' has been published (66). Recently, Cancer Research UK has named one 'Lung Cancer Centres of Excellence', jointly based in London and Manchester, whose aim is to develop and promote high-level lung cancer research (67).

Denmark

In Denmark, as mentioned above, the DLCG with the national lung cancer registry and the national lung cancer guideline programme in collaboration with national healthcare authorities catalyzed a process of continuous improvement of lung cancer care which amongst others has implicated a re-organization with centralization of Danish lung cancer services (17). Supplement 3.4 depicts the lung cancer service in the region of Southern Denmark.

France

In France, there is a national taskforce against cancer which has developed following three national 'Cancer plans' (68). The first 'Cancer plan', launched by president Chirac (2003-2007) set the basis of a national strategy for multidisciplinary management of cancer. It legalized the compulsory multidisciplinary discussion of each individual cancer patient. Multidisciplinary teams (MDTs) are organized according to organ or system, and within thoracic oncology, pleural mesothelioma and thymic epithelial tumours fall within rare tumour boards (national), rather than the lung MDT. The MDT discussion must lead to a

consensual personalized treatment plan, which is a written document given to the patient during a structured consultation, and a nurse co-ordinator is also present offering psychological or social support if required. The plan is also sent to the general practitioner, and all corresponding doctors.

The first 'Cancer plan' also elaborated on accreditation of units caring for patients with cancer, and in particular on surgical units. A surgical unit should host at least 2 surgeons, have access to an intensive care unit, to an endoscopy suite, and frozen section analysis should be available on site. Minimum thresholds have been set per organ, which result in a minimal caseload of 20 major resections per surgeon (respectively 30 cases per unit, given some surgeons work on more than just cancer).

The ministry of health created a National Institute of Cancer (Institut National du Cancer, INCa) in 2005, which coordinates research and treatment in oncology. In this role INCa publishes an annual report and collaborates with 25 regional oncology networks, who coordinate screening and treatment at the regional level. INCa is also connected to the Higher Authority of Health (Haute Autorité de la Santé, HAS), which is in charge of editing guidelines and quality control. Finally, INCa has accredited and coordinates 8 inter-groups for clinical research including the French Intergroup of Thoracic Oncology (IFCT).

Two subsequent 'Cancer plans' have been launched by president Sarkozy (2009-2013) and Hollande (2014-2019). The third Cancer plan is an ambitious document (69) which aims to improve treatment, but in addition to act before diagnosis (prevention, screening) and after treatment (follow-up, social re-integration).

Germany

In 2008, the German Cancer Society in collaboration with the German Respiratory Society and the German Society of Thoracic Surgery initiated a certification programme for lung cancer centres as part of the German National Cancer Plan. In September 2016 there were 44 certified lung cancer centres in Germany and 2 in Switzerland. The certification process is composed:

- an annual updated parameter manual with mandatory and recommended elements of structure, process and outcome data which are used for self-assessment and subsequent external validation;
- annual visits to the respective lung cancer service by trained external specialists;
- an extensive evaluation of the results by an independent institute,
- followed by a final evaluation (70, 71).

The German parameter manual contains 10 chapters covering mainly medical aspects of the lung cancer pathway. Multi-professional/disciplinary working is encouraged and there are specific mandatory standards for centres. These include diagnosing and treating ≥200 new pathologically confirmed lung cancer patients/year, ≥75 anatomical lung cancer resections/year, and recording performance indicators such as 30-day mortality after anatomical lung cancer resections ≤5%, and proportion of broncho-/angioplastic resections on all anatomical resections ≥10 %. Clinical lung cancer registration and follow-up data collection is mandatory in every certified lung cancer centre and their close linkage to the newly established clinical cancer registries of the 16 German Federal States is promoted (70, 71). The process has seen improvements in multidisciplinary working.

Only 33% of all new cases of lung cancer in 2016 were covered by certified lung cancer centres. The main obstacles for broader implementation are the mandatory thresholds for new cases and surgical resections (70, 71). Other medical societies in Germany have established independent certification programmes related to lung cancer care (i.e. the 'Oncological Centres' of the German Society for Haematology and Medical Oncology, and the 'Thoracic Centres' of the German Society of Thoracic Surgery, the latter initiative appraising both benign and malignant disease) (72, 73).

Overview of the development of the manual of standards for lung cancer services in Europe

The taskforce group agreed on the following scope and core principles for development of the parameter manual of European standards for lung cancer services:

1. The primary target audience of the parameter manual is professionals involved in lung cancer care in Europe. The standards will also be important for lung cancer patients, their carers, and other stakeholders in lung cancer care.

2. The main aim is to harmonize and improve standards of lung cancer care throughout Europe. Multi-disciplinary team work and patient-centred care are central.

3. The parameter manual is composed of two sections covering (i) Infrastructure and organization of the lung cancer service and (ii) standards for lung cancer services at each stage of the lung cancer pathway.

4. Standards are divided into *essential* and *advanced*. *Essential standards* are defined as criteria which are mandatory for the lung cancer service to fulfill basic standards of effective care. *Advanced standards* are defined as those that go beyond that which is essential to provide higher-quality lung cancer care.

5. The underlying evidence base for the essential and advanced standards was graded into three levels: (i) 'Guideline': wherever possible, generally accepted clinical lung cancer guideline recommendations were used to conclude standards of the infrastructure or pathway for lung cancer services (i. e. the guideline recommendation 'Lung cancer patients who are potentially suitable for treatment with curative intent should be offered PET-CT before treatment' led to the essential standard in this manual 'The lung cancer service must provide or have access to PET-CT'; (ii) 'Literature review and assessment': these denoted standards were based on an assessment of the available non-guideline literature; (iii) 'Good practice': in the absence of any guideline recommendations or other literature, taskforce members and patient representatives used their clinical experience to reach conclusions about what consitutes good clinical practice for certain standards.

6. Acknowledging that differences in terminology can lead to differences in interpretation across Europe, a glossary for the terminology is provided in supplement 2.

The Patient Advisory Group (PAG) formulated patient priorities in lung cancer care which have been previously published in an ELF report (74). These patient priorities comprise proper patient involvement and provision of relevant and understandable information

needed for decision-making, quantitative and qualitative improvement of patient-professional contacts throughout the lung cancer pathway, better involvement of other professions, especially lung cancer nurses, supervision and psychological support for doctors and other professionals, specific communication training for professionals, and better linkage between lung cancer services.

Recommendations for a Pan-European manual of standards for lung cancer services

Organization of the Lung Cancer Service

This first section addresses the relevant organizational aspects of the lung cancer service as a whole (see Supplement 2). Although a multi-disciplinary network environment is an essential requirement, it was agreed that the specific membership should be determined according to the local and/or national setting. Advanced standards have been formulated to encourage lung cancer services with a full range of diagnostic and/or treatment facilities to offer these to partner organisations. It is important to note that there is no one infrastructure that every service should adopt. Every aspect of the lung cancer pathway should be available to the individual patient, but the delivery of this may vary at the local level.A real-life example of a multi-site lung cancer service from Denmark is included in Supplement 3.4.

The standards for *Patient- and Carer-centred Care* were elaborated by the members of the PAG. The evidence base for this is limited, although not strictly necessary where a patient expert group has commented and where there are several national lung cancer guidelines recommending shared decision making on the basis of easy to access and understand information (75).

The taskforce identified further *essential standards* in a lung cancer service which relate to:

- adherence to evidence-based care, with use of regularly updated guidelines;
- access to specialized care;

- timeliness of care;
- documentation, accessibility and provision of patient and carer-related information;
- communication and environment for communication;
- education for healthcare professionals, patients and carers (one example would be the Thoracic Oncology HERMES syllabus and curriculum (76-80));
- clinical cancer registration;
- quality assurance, quality improvement, risk management;
- collaboration with external healthcare professionals and other external stakeholders by the lung cancer service.

The utilization of the proposed pan-European dataset for lung cancer registration is recommended as an advanced standard. Advanced collaborative measures have been proposed by the taskforce group to facilitate local, regional, national and international networking.

Lung Cancer Pathway

The second section of the manual encompasses the entire lung cancer pathway within the lung cancer service from diagnosis, through treatment, follow-up, relapse and end of life or survivorship (see Supplement 2). The underlying international and national guidelines which provide recommendations related to most of the essential and advanced standards within this section are listed in table 5.

Cross-pathway care is included in this section. This is often important to ensure that patients experience is maximised when care is needed from services outside the lung cancer pathway which may include emergency care, intensive care, and services for specific symptom management. Palliative care is included here but it is noted that this should be provided throughout the entire pathway (see figure 1) (81).

Pre-existing statement papers and recommendations issued by other international medical societies have been reviewed and incorporated into the manual of standards where appropriate. These include: imaging (82), fitness for diagnostics and radical therapy (83), thoracic surgery (84), radiotherapy (85-93), and palliative care (94). Due to limited evidence

and heterogeneity among and within European countries, the taskforce group was unable to define standards for individual or institutional volumes of care and timeliness/waiting times.

The future: implementation of harmonised standards in Europe

The proposed pan-European lung cancer dataset and manual of standards for lung cancer services provides the opportunity to harmonise registration and quality of services in Europe. A previous ERS taskforce showed marked inequalities in lung cancer care among and within European countries (10), and importantly established a network of interested clinicians, who are ready to be involved with the implementation of these standards. Thus, we have so far identified variation, reviewed guidelines and this paper defines both a pan-European dataset and standards for lung cancer services.

Our proposed standards for lung cancer services and lung cancer registration comprise two essential parts of a lung cancer guideline cycle based on the model originally introduced by the European Commission in 2004 (see figure 2) (95, 96). Given the surplus of existing lung cancer guidelines, and as a consequence, substantial waste of human and financial resources, it is imperative that multiple uncoordinated initiatives on the international, national and regional level should be avoided. Therefore, the ERS will seek collaborations on a par with other leading European societies to define joint pan-European standards for lung cancer services and lung cancer registration based on this statement paper as well as multi-professional, patient-centred lung cancer guidelines. This would also save valuable resources on the national or regional level. Given the rapidly evolving field of lung cancer care, these standards will need to be revised on a regular basis to ensure their relevance and efficacy.

Dissemination and implementation of these standards is vital. Although there are some examples of service improvement initiated through involvement of individual members of the taskforce, it is now important to actively manage the process of improving services, care and outcomes throughout Europe. This may be done using methods of service improvement that have been used in individual countries using our established network. Peer review is one such established method. This allows individuals and teams to review

each other's services, with reference to agreed standards (97). In the European setting this process could really drive up standards of care. The peer review process will involve clinicians visiting and evaluating services that may be very different, with the opportunity to suggest some profoundly helpful changes and to learn from one another. Following a recent feasibility project benchmarking lung cancer services in Glasgow and Berlin, the ERS will endeavour to support peer review projects on a pan-European scale.

In summary, the taskforces of the ERS Thoracic Oncology Assembly have so far provided important information about the variation in lung cancer care in a range of European countries with marked differences in social and political backgrounds. The next phase is to start the process of service improvement, whilst acknowledging the variable resources available in individual countries. It is envisaged that this current taskforce project will set the basis for a multi-national, multi-society and patient-centred lung cancer care collaboration with the clear aim to improve and harmonize standards of lung cancer care for the benefit of patients, their carers and professionals alike.

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Supplement 1

Pan-European Lung Cancer Dataset

Basic patient features		
Data item	**Definition**	**Detailed definition**
Date of birth	dd/mm/yyyy	
Sex	Male or female	1=male 2=female 999=undisclosed/unknown
Country of registration	**ISO-3166**	2 letter code
Education level	Numerical value **(ICHOM)**	Indicate highest level of education completed 0=None 1=Primary 2=Secondary 3=Tertiary (college, university) 999=Don't know
Date of referral	dd/mm/yyyy	Date on which referral made with respect to potential lung cancer. This could include, self-referral, primary to secondary care, within secondary care Option for missing/unknown.
Date of diagnosis	dd/mm/yyyy	Date the **first** histopathology/cytology sample was taken which confirmed malignancy, If date of histopathology sample not available then index date based on following criteria in descending order. (as per IARC) **1**. 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 (biopsy) b) date of receipt by pathologist c) date of the pathology report **2**. Date of admission to hospital because of this malignancy. **3**. When evaluated at an outpatient clinic only: date of first consultation at the out-patient clinic because of this malignancy. **4**. Date of diagnosis other than 1,2 or 3. **5**. Date of death, if no information is available other than the fact that the patient died of a malignancy. **6**. Date of death, if the malignancy is discovered at autopsy.
Date of final pathology report	dd/mm/yyyy	Date of **final** pathology report to include molecular analysis where appropriate Option for missing/unknown.
Mode of presentation	How was lung cancer first suspected? Numerical value	0=screening 1=symptoms 2=incidental finding 3=other (free text box to specify) 999=don't know
Basis of diagnosis	Numerical value **(ICHOM)**	1=Clinical 2=Histology 3=Cytology 999=unknown
	Clinical	Diagnosis made before death with or without diagnostic techniques (e.g. X-rays, endoscopy, imaging, ultrasound, exploratory surgery) **but** without a tissue diagnosis
	Histology	Histological examination of tissue from the primary tumour or metastasis, including all cutting and bone marrow biopsies. Also includes autopsy specimens.
	Cytology	Examination of cells whether from a primary or secondary site, including fluids aspirated using endoscopes or needles. Also including microscopic examination of peripheral blood films and trephine bone marrow aspirates

Tumour details		
Data item	**Definition**	**Detailed definition**
Histology	System used	International Classification Diseases -Oncology-3rd edition (ICD-O-3rd edition) (covers the entire 2015 World Health Organization (WHO) Classification of Tumours of the Lung) Systematized Nomenclature of Medicine (SNOMED)

		Based on which system is used, a list of possible options will appear, and the correct histology field can be ticked.
	If no recognised system used then drop down menu appears with a limited list	
	1	Small cell carcinoma
	2	Non-small cell carcinoma (NSCLC) NOS
	3	Squamous cell carcinoma
	4	Adenocarcinoma
	5	Large cell neuroendocrine carcinoma
	6	Carcinoid-typical
	7	Carcinoid-atypical
	8	Adenocarcinoma in situ
	9	Spindle/pleiomorphic/giant cell NSCLC
	10	Other (free text box appears)
	999	Unknown
Molecular analysis*	Was this performed?	0=No 1=Yes 999=don't know
Further questions only relevant if molecular analysis performed.	EGFR mutation **(ICHOM)** Numerical value	Indicate presence of EGFR activating mutation 0=No 1=Yes 2=Failed analysis 999=don't know
	If activating mutation found, on which exon?	0=not relevant 1=exon 18 2=exon 19 3=exon 21 999=don't know
	EGFR mutation T790M	Indicate presence of EGFR mutation of resistance 0=No 1=Yes 2=Failed analysis 999=don't know
	ALK translocation **(ICHOM)** Numerical value	Indicate presence of ALK translocation 0=No 1=Yes 2=failed analysis 999=don't know
	Ros 1	Indicate presence of Ros1 translocation 0=No 1=Yes 2=failed analysis 999=don't know
	BRAF	Indicate presence of BRAF mutation 0=No 1=Yes 2=failed analysis 999=don't know
	PD-L1 status	Indicate PD-L1 status 0=Not expressed 1=Some expression 2=failed analysis 999=don't know
	PD-L1 percent expression	0=not applicable (ie 0 above) 1=<1 2=1-9.9% 3=10-49% 4=>50%
	RET	Indicate presence of RET translocation 0=No 1=Yes 2=failed analysis 999=don't know
	MET	Indicate presence of MET amplification 0=No 1=Yes 2=failed analysis 999=don't know
	MET exon 14	Indicate presence of MET mutation exon 14 0=No

		1=Yes 2=failed analysis 999=don't know
	HER 2	Indicate presence of HER2 mutation 0=No 1=Yes 2=failed analysis 999=don't know
* Annual updates expected as molecular medicine develops		
Stage	***Final pre-treatment clinical stage***	
Basis of stage	What method was used to decide the final pre-treatment clinical stage? Numerical value	0=imaging only 1=imaging AND non-surgical pathology samples 2=imaging and surgical biopsies (mediastinoscopy, VATS procedure) 999=Don't know <u>Definition of non-surgical samples</u>; EBUS, EUS, percutaneous lung or pleural biopsy, pleural aspiration, bronchoscopy.
Investigations performed?	CT scan Numerical value	0=No 1=Yes 999=Don't know
	PET-CT	0=No 1=Yes 999=Don't know
	Bronchoscopy	0=No 1=Yes 999=Don't know
	EBUS	0=No 1=Yes 999=Don't know
	EUS	0=No 1=Yes 999=Don't know
	Mediastinoscopy	0=No 1=Yes 999=Don't know
	Histopathology or cytology from node outside chest	0=No 1=Yes 999=Don't know
	Sampling of pleura or pleural fluid aspiration (medical)	0=No 1=Yes 999=Don't know
	VATS thoracoscopy	0=No 1=Yes 999=Don't know
	Imaging of metastasis (e.g.; CT/MRI brain, MRI spine, MRI adrenal etc)	0=No 1=Yes 999=Don't know
	Histopathology of metastasis (eg liver biopsy)	0=No 1=Yes 999=Don't know
	Exploratory open thoracic surgery	0=No 1=Yes 999=Don't know
Tumour size	Numerical value	The longest single direction size (cm to one decimal point, e.g.3.2)
Staging system	Which staging system has been used?	UICC 7th or 8th Based on this answer; drop down menu appears for T, N and M stage.
Tumour stage	Mixed value	UICC Version 7; 1a through to 4 UICC Version 8; 1mi through to 4 999=Unknown/X
Nodal stage	Mixed value	Version 7 or 8; 0 to 3 999=unknown
Extent of N1 disease	Numerical value	0=Not applicable 1=Single station N1 disease 2=Multi-station N1 disease
Extent of N2 disease	Numerical value	**0=Not applicable** **1= microscopic N2 node found at final pathological (post-operative) specimen,**

		2= Single station N2 node without N1 disease ('skip' lesion) **3= Single station N2 node with N1 involvement** **4= Multi-station N2 disease** **5= Bulky or fixed multi-station N2 disease**
Metastasis stage	Mixed value	Version 7: 0 through to 1b Version 8; 0 through to 1c 999=unknown/X
Number of metastatic lesions	Numerical value	0=no metastatic spread (ie M0 above) 1, 2, 3 onwards 999=don't know
Site of metastases	Liver Numerical value	0=no 1=Yes If yes, specify number of metastatic lesions 1, 2, 3 onwards 999=don't know
	Brain	0=no 1=Yes If yes, number of metastatic lesions 1, 2, 3 onwards 999=don't know
	Adrenal	0=no 1=Yes If yes, specify number of metastatic lesions 1, 2, 3 onwards 999=don't know
	Bone	0=no 1=Yes If yes, specify number of metastatic lesions 1, 2, 3 onwards 999=don't know
	Other	Free text box to confirm site of spread

Extended patient features

Data item	Definition	Detailed definition
Performance status (final pre-treatment)	**ECOG (WHO)**	Numerical value 0-4 999=unknown
	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 on any self-care. Totally confined to bed or chair
	999	Unknown/not recorded
Smoking status	Numerical code **(ICHOM)**	1=never smoker (<100 cigarettes ever) 2=ex-smoker (stopped at least 1 year before inclusion, ie diagnosis) 3=current smoker 999=don't know
Smoking pack years	Numerical value	Simply the number of pack years smoked, regardless of ex or current smoker, Eg 20, 40, etc 999=don't know
Comorbidity at baseline **From medical consultation with patient**	**ICHOM** modified Self-administered Comorbidity Questionnaire (SCQ; Sangha et al 2003) Drop down menu; multiple options possible	Have you been told by a doctor that you have any of the following: 0=I have no other diseases 1=Heart disease (eg, angina, heart attack or heart failure) 2=High blood pressure 3=Leg pain when walking due to poor circulation 4=Lung disease (eg, asthma, chronic bronchitis, COPD, or emphysema) 5=Diabetes 6=Kidney disease 7=Liver disease 8=Problems caused by stroke 9=Disease of the nervous system (eg, Parkinson disease, multiple sclerosis) 10=other cancer (within the last 5 years) 11=Depression 12=Arthritis
Weight	Numerical value	In kg. 999=don't know
Height	Numerical value	In m 999=don't know
Lung function (at baseline)	Numerical value **(ICHOM)**	Observed FEV_1 (L) (e.g. 1.35) 999=don't know
	Numerical value **(ICHOM)**	Percent predicted FEV_1 (e.g. 56, would represent 56% predicted) 999=don't know

	Numerical value	Observed FVC (L) (e.g.. 2.3) 999=don't know
	Numerical value	Percent predicted transfer factor (KCO) (e.g. 85 would represent 85% predicted) Numerical value 999=don't know
Quality of Life		
At diagnosis	EORTC QLQ-C30	Score (maximum value 126)
At end of 1st line treatment	EORTC QLQ-C30	Score (maximum value 126)
At 6 months post diagnosis	EORTC QLQ-C30	Score (maximum value 126)

Lung cancer outcomes

Data item	**Definition**	**Detailed definition**
Lung Cancer Nurse Specialist (LCNS)	Contact made with LCNS	0=no 1=Yes 999=Don't know
Treatment		
Treatment intent (reflects the intent of the treating physician or MDT)	Numerical code	1=curative intent 2=non-curative intent 3=no active treatment 999=don't know
	Curative	This is single or multimodality treatment which is hoped will remove the threat of lung cancer on the patient's life expectancy.
	Non-curative	This is single or multimodality treatment which is expected to gain local control, or limit the progression of the disease, but unlikely to remove the threat of lung cancer on the patient's life expectancy.
	No active treatment	This would be those patients who decline, or are too frail for, radiotherapy or chemotherapy and simply receive medication for symptom control or a watch and wait policy
First line treatment given to primary tumour		
	Numerical code	Choose ***one option only*** from list below.
	1	Surgery alone
	2	Hyperfractionated radiotherapy
	3	External beam radiotherapy (curative intent but not CHART)
	4	Stereotactic Radiotherapy
	5	Radiofrequency/microwave ablation
	6	Brachytherapy
	7	Palliative radiotherapy to lung primary
	8	Concurrent chemo-radiotherapy
	9	Sequential chemo-radiotherapy
	10	Induction radiotherapy (pre surgery)
	11	Induction chemotherapy (pre surgery)
	12	Palliative Chemotherapy
	13	Targeted/biological therapy (TKI etc)
	14	Immunotherapy
	15	Interventional bronchoscopy
	16	Specialist palliative care
	17	Other (free text)
	999	Don't know/not recorded
First line treatment not given or change in treatment plan		0=Not relevant 1=Patient declined 1st line treatment offered 2=Patient deteriorated and no longer eligible for 1st line treatment 3=Hospital unable to provide 1st line treatment 4= other (free text)
Date of 1st line treatment	dd/mm/yyyy	Date of the start of 1st line treatment, ie date of operation, or first day of radiotherapy or chemotherapy regime, or appointment with specialist palliative care physician.
Type of operation Additional question only if option 1 above	Numerical value	0=incomplete resection (residual macroscopic disease evident) 1=segmentectomy 2=wedge resection 3=lobectomy 4=bi-lobectomy 5=sleeve lobectomy 6=pneumonectomy 999=don't know
Pathological stage Additional question only if option 1 above	Staging system used	IASLC version 7 or 8
	Pathological	Based on version used can then have drop down menu for pathological stage

	stage	
Nature of radiotherapy Additional questions only if options 2,3,4,7 or 10 chosen	Total dose given (Grey)	Absolute number.
	Number of fractions	Absolute number (eg 6)
	Number of days or radiotherapy treatment	Absolute number (eg. 12)
Nature of chemotherapy Additional question only if options 11 or 12 chosen	Numerical value	1=single agent chemotherapy 2= Doublet platinum-based chemotherapy 3=other (free text) 999=don't know
Additional supportive 1st line treatment given?		
	Numerical value	0=No 1=Yes If yes then further question appears
Type of additional supportive 1st line treatment		
	Numerical value	
	1	Stereotactic radiotherapy to brain metastases
	2	Radiotherapy for spinal cord compression
	3	Prophylactic Cranial Irradiation
	4	Whole brain radiotherapy
	5	Radiotherapy for oligometastases
	6	SABR for oligometastases
	7	Radiotherapy for SVCO
	8	Radiotherapy to mediastinum
	9	Specialist palliative care
	10	Surgical resection of metastases
	11	Pleural intervention (see below)
	12	Other (free text)
Date of first radiotherapy session	dd/mm/yyyy	
Nature of radiotherapy (1-8)	Total dose given (Grey)	Absolute number (e.g. 30)
	Number of fractions	Absolute number (e.g. 6)
	Number of days or radiotherapy treatment	Absolute number (e.g. 12)
Date of palliative care	dd/mm/yyyy	Date of first appointment with specialist palliative care physician
Date of surgery	dd/mm/yyyy	
Date of pleural intervention	dd/mm/yyyy	
Type of Pleural intervention	Numerical value	1=thoracocentesis 2=chest drain 3=pleurodesis 4=indwelling chest drain
How is the patient followed up after 1st line treatment?	Numerical value, please pick single item from list. Options are ranked in descending order. If multiple answers apply, please pick the first answer in the list	1=Regular out-patient visits with physician (member of MDT) 2=Follow up with lung cancer nurse specialist 3=Virtual follow-up after imaging 4=Phone contact with patient 5=Referred back to primary care doctor 0=No follow-up 999=don't know
Date of completion of 1st line treatment	dd/mm/yyyy	
Response to 1st line treatment?	Numerical value	0=Complete remission 1=Partial response 2=Stable disease

		3=Progression 999=don't know
Date of relapse	dd/mm/yyyy	
How was relapse detected?		0=Planned imaging 1=Symptoms 2=Incidental finding with unrelated problem 999=don't know
Subsequent treatment to lung primary		
	Numerical code	***More than one*** treatment option can be chosen during the patient treatment programme (please confirm with dates below)
	1	Surgery
	2	Chemotherapy and radiotherapy in addition to surgery (tri-modality treatment)
	3	Hyperfractionated radiotherapy
	4	External beam radiotherapy (curative intent but not CHART)
	5	Stereotactic Radiotherapy (3-8 fractions)
	6	Radiofrequency/microwave ablation
	7	Brachytherapy
	8	Palliative radiotherapy to lung primary
	9	Concurrent chemo-radiotherapy
	10	Sequential chemo-radiotherapy
	11	Palliative Chemotherapy
	12	Targeted/biological therapy (TKI etc)
	13	Immunotherapy
	14	Interventional bronchoscopy
	15	Specialist palliative care
	999	Don't know/not recorded
Date of surgery	dd/mm/yyyy	
Date of first radiotherapy session	dd/mm/yyyy	
Nature of radiotherapy	Total dose given (Grey)	Absolute number (e.g. 30)
	Number of fractions given	Absolute number (e.g. 6)
	Number of days or radiotherapy treatment	Absolute number (e.g. 12)
Date first chemotherapy started	dd/mm/yyyy	
Date of last chemotherapy dose	dd/mm/yyyy	
Date of interventional bronchoscopy	dd/mm/yyyy	
Date of specialist palliative care	dd/mm/yyyy	Date of first appointment with specialist palliative care physician
Clinical trial	Is the patient part of a clinical trial?	0=No 1=Yes 999=Don't know
Date of death	dd/mm/yyyy	

Legend: data items in black are mandatory within the proposed minimum dataset; those in blue are desirable dataset.

Dd/mm/yyyy; Date, month and year.

Supplement 2

Manual of parameters for a lung cancer service in Europe- organisation

I. **Organization of Lung Cancer Service**
   1. **General Structure of Lung Cancer Service and adjacent Network**
   2. **Multidisciplinary Team Structure**
   3. **Patient- and Carer-centred Care**
   4. **Evidence-based Lung Cancer Care Programme**
   5. **Access to Care and Timeliness of Care**
   6. **Documentation, Accessibility and Provision of Patient- and Care-related Information**
   7. **Schedule of Meetings**
   8. **Education for Healthcare Professionals, Patients and Carers**
   9. **Clinical Cancer Registry**
   10. **Collaboration with External Healthcare Professionals and other External Stakeholders**
   11. **Quality Assurance and Quality Improvement, Risk Management**

I. Organization of Lung Cancer Service	**Derived from**
1. General Structure of Lung Cancer Service and adjacent Network	
Essential: The general structure of the lung cancer service must include a multi-disciplinary team composed of the disciplines and professions listed in detail in ➔ I.2. However, the underlying organizational form may vary according to the respective national health care system as well as the regional and local needs. In principle, various structural solutions are conceivable to achieve the demanded comprehensive multidisciplinary structure. These could include but not limited to (see figure 1): • all-on-one-site-solutions run by one provider • multiple-site-solutions run by one or more providers • one centralized site (i.e. PET CT, thoracic surgery service) and multiple satellite sites • clinical network solutions with all health care components addressing lung cancer care in a geographical region driven by a national health care system The lung cancer service must describe its internal structure as well as potential involvement of its adjacent network. Besides, the Lung cancer service should provide some basic epidemiological facts about itself (i.e. number of new lung cancer cases per year and the size of the general population covered by the service).	**Good practice**
Advanced: According to regional or local needs, the lung cancer service should provide their expertise in lung cancer care to other neighbouring services who cannot fulfil all criteria of this catalogue. Provision of expertise could include among other things: • Second opinion-services • Referral of patients from other services to the lung cancer service for certain diagnostics or treatment • Deployment of qualified personnel from the lung cancer service to other services • Teaching site for training of personnel of other services • Offering inclusion in clinical trials (regularly phase III optional early stage phase II or I)	**Good practice**
2. Multidisciplinary Team Structure	
Essential: The following disciplines and professions must be included the	**Good practice**

multidisciplinary team of the lung cancer service or available to in reasonable time: • Pulmonology • Radiology • Nuclear medicine • Pathology/Molecular biology • Thoracic Surgery • Medical Oncology/Pneumo-oncology • Radiotherapy • Palliative care medicine • Emergency medicine/Intensive care medicine • Lung cancer specialised Nurse • Physiotherapy service • Psychology service • Social work service • Data collection management/clinical lung cancer registry It is acknowledged that in certain national or regional health care settings specific disciplines or professions are not designated and/or their service portfolio is integrated in other disciplines or professions. In these particular cases, the lung cancer service should describe the equivalent alternative solution.	
Advanced: The following disciplines and professions should be included in the multidisciplinary team of the lung cancer service or should be available for access: • Nutrition counselling service • Pain management service • Hospice • Patient pathway coordination • Clinical research management (including study nurses) • Quality management for continuous evaluation and improvement of lung cancer service quality Depending on respective cultural habits, a separate Spiritual service could also be included in the multidisciplinary team of the lung cancer service.	**Good practice**
3. Patient- and Carer-centred Care	

Essential: The lung cancer service must give patient- and carer-centred care high priority and therefore install the following measures (if not already installed within superordinate institutional setting):
• Implementing and regular training of a good communication between patients/carers and healthcare professionals within the lung cancer service which focusses on:
  o Breaking bad news and informing patients and their carers on MDT discussions and recommendations (including incorporation of patient preferences)
  o Shared decision-making
• Structured approach in the lung cancer service to discuss and support patients in advance decision making and formulation of patient advance care directive
• Incorporation of patient input
• Provision of information about the lung cancer services (i.e. access and contact data, recognition of and proper reaction to potential side effects of treatment) with input from patients and/or reviewed by patients which are issued through various communication channels (i.e. leaflets, website) for patients and their carers
• Installation of a patient advocate/ombudsman
• Installation of a complaint management system for patients and their carers (➔ I.11)
• Cooperation with local, regional and/or national patient organization if applicable
	Good practice

• Organization of at least one annual patient event •	
Advanced: The lung cancer service should install the following patient- and carer-centres measures (if not already installed within superordinate institutional setting): • Provision of translators for patients unable to speak native language of respective country of lung cancer service • Performance of patient satisfaction surveys with subsequent evaluation and if needed adaption of own processes (➔ I.11) • Installation of a patient advocate/ombudsman • Installation of a complaint management system for patients and their carers (➔ I.11) • Organization of an education programme for patients and their carers (➔ I.8) • Consultation with patients on the design and development of new services within the lung cancer service	**Good practice**
4. Evidence-based Lung Cancer Care Programme	

Essential: The lung cancer service must build its own practices of care on valid scientific evidence, namely medical guidelines or other scientific evidence that is accepted by the international medical community* with the view to offer a personalised management plan to each patient. Accordingly, the lung cancer service must define one comprehensive guideline or separate guidelines as the valid scientific, internally consented basis for the following relevant parts within its covered lung cancer continuum:
• Diagnostics:
  ○ Initial Assessment
  ○ Functional Assessment, Appraisal of Fitness for Diagnostics and Therapy
  ○ Imaging
  ○ Endoscopy
  ○ Percutaneous Image-guided Biopsy Procedures
  ○ Mediastinoscopy
  ○ Medical Thoracoscopy, Video-assisted Thoracoscopy (VATS)
  ○ Tissue-based Tumour Sampling
  ○ Biofluid-based Tumour Sampling
  ○ Pathology and Molecular Diagnostics
  ○ TNM Description and Stage Grouping
• Medical Decision-finding and Care Planning with Patients and within the Multidisciplinary Team
• Tumour-specific Therapy
  ○ Thoracic Surgery
  ○ Systemic Therapy
  ○ Radiotherapy
  ○ Multimodal Therapy
• Re-Staging and Follow-up during and after Therapy
• Management of Progressive Disease and Relapse
• End-of-life Care, Death and Bereavement Period
• Survivorship
• Cross-pathway Care
  ○ Tumour- and Care-related Side Effect Management
  ○ Emergency Care
  ○ Palliative Care
  ○ Specialised Nursing
  ○ Physiotherapy and Rehabilitation
  ○ Social Work Service
  ○ Psychology
  ○ Nutrition Counselling
  ○ Pain Management
	Good practice

○ Smoking Cessation The lung cancer service must check at least annually its underlying evidence basis for own practices of care on currentness and update as needed. An annual operational meeting of all multidisciplinary team members should be held for these updates to ensure that all services of the clinical network follow similar processes and meet quality standards. According to national, regional and local conditions, the lung cancer service must provide written standard operating procedures adapted from the above-mentioned underlying evidence to its individual needs and circumstances. Likewise, the lung cancer service must check at least annually its local standard operating procedures on currentness and update as needed. *If qualified guidelines on specific topics are unavailable or out-of-date, the lung cancer service should refer to up-to-date, peer-reviewed systemic reviews/meta-analysis as second best or single publications as third best source of evidence.	
5. Access to Care and Timeliness of Care	
Essential: Depending on its own capacities, the lung cancer service must ensure equal and rapid access to its care independent from gender, ethnicity and socio-economic status of patients. The lung cancer service should ensure reasonable internal timeliness and avoid waiting time whenever possible. However, at present, specific maximum waiting times with prognostic relevance cannot be justified.	**Good practice** **Literature review and assessment**
Advanced: For the purpose of improvement of quality of care, the lung cancer service should measure and evaluate the following time intervals within its internal lung cancer pathway in its patients at least on a sample basis: • Time interval from date of admission to lung cancer services to date of first diagnosis • Time interval from date of diagnosis-confirming specimen collection to date of final pathology/molecular diagnostics report creation • Time interval from date of first diagnosis to date of MDT conference treatment recommendation • Time interval from date of first diagnosis to date of first treatment start	**Good practice**
6. Documentation, Accessibility and Provision of Patient- and Care-related Information	
Essential: The lung cancer service must provide an internal documentation and information system which is accessible to all of its healthcare professional and which provides all relevant patient- and care-related information, in compliance with national legal regulations.	**Good practice**
7. Schedule of Meetings	
Essential: The lung cancer service must provide a schedule of meetings which includes all relevant modes of communication as well as meetings within the lung cancer service as well as between the lung cancer service and external healthcare professionals, patients and their carers and other external stakeholders	**Good practice**
8. Education for Healthcare Professionals, Patients and Carers	
Essential: The lung cancer service should install a comprehensive educational and training programme as part of a professional development strategy. Beside national standards, the lung cancer service should also use the Thoracic Oncology HERMES syllabus and curriculum as basis for its own local training	**Good practice**

programme. Whenever possible, joint educational formats of multiple professions should be sought.	
Advanced: The lung cancer service could act as a training centre for other lung cancer specialists. The lung cancer service should offer a regular journal club for professionals. Preferably, the lung cancer service should be linked to a library or to electronic library services. The lung cancer service should install an educational programme for its patients and their carers.	**Good practice**
9. Clinical Cancer Registry	
Essential: The lung cancer service must install a clinical cancer registry for documentation of its own lung cancer patients as well as quality of case ascertainment.	**Good practice**
Advanced: If a national clinical lung cancer registry is already available, the lung cancer service should contribute its data derived from its own clinical cancer registry or use the national clinical cancer registry platform for its own needs according to applicable data security regulations. Beside national standards, the lung cancer service should also integrate the formulated standards for lung cancer registration within this ERS statement paper as basis of its own clinical lung cancer registry. However, duplication of registries should be avoided.	**Good practice**
10. Collaboration with External Healthcare Professionals and other External Stakeholders	
Essential: The lung cancer service must identify and list its collaborating external healthcare professionals (if applicable) and other external stakeholders as well as describe the existing interfaces between the lung cancer service and the external healthcare professionals/other external stakeholders. A good link to cooperating general practitioners should be sought in order to allow quick and complete transmission of patient information (i.e. MDT conference decision, treatment schedule)	**Good practice**
Advanced: The lung cancer service should aim to further develop its collaborations with external healthcare professionals via the following or similar measures: • At least annual network meetings with external healthcare professionals • Joint quality improvement initiatives with external healthcare professionals or other external stakeholders • Contribution of own clinical lung cancer registry data to regional, national and international epidemiological and/or clinical cancer registries, based on national legal regulations	**Good practice**
11. Quality Assurance and Quality Improvement, Risk Management	
Essential: If no superordinate quality assurance/improvement systems are available, the lung cancer service must install a basic quality assurance and quality improvement system in order to assure regular evaluation and if needed optimization of processes.	**Good practice**
Essential: The lung cancer service must perform at least annual satisfaction surveys among patients, external healthcare professionals and own staff members. Timeliness of care should be regularly evaluated in order to adapt and optimize internal	**Good practice**

processes. A core set of quality performance indicators should be assessed, i.e. recording of stage, surgical resection rates, overall survival	**Literature review and assessment**
Advanced: The lung cancer service should use one or more of the following measures for internal quality assurance and quality improvement as well as risk management: • Internal audits of the lung cancer pathway • Peer reviews • Regular internal morbidity and mortality conferences • Complaint management system for patients and their carers as well as external healthcare professionals • Risk management system • Regular evaluation of the own clinical lung cancer registry, including the set-up and usage of a comprehensive quality performance indicator system Participation in external quality assurance/improvement programmes or external certification programmes including visits by external auditors or external lung cancer specialists The lung cancer service should publish an annual report providing core information on its performance and development as well its future plans.	**Good practice**

II. Lung Cancer Care Pathway

1. **Diagnostics**
    i. **Core Diagnostic Strategies**
    ii. **Initial Assessment**
    iii. **Functional Assessment, Appraisal of Fitness for Diagnostics and Therapy**
    iv. **Imaging**
    v. **Endoscopy**
    vi. **Percutaneous Image-guided Biopsy Procedures**
    vii. **Mediastinoscopy**
    viii. **Medical Thoracoscopy, Video-assisted Thoracoscopy (VATS)**
    ix. **Tissue-based Tumour Sampling**
    x. **Biofluid-based Tumour Sampling**
    xi. **Pathology and Molecular Diagnostics**
    xii. **TNM Description and Stage Grouping**
2. **Medical Decision-finding and Care Planning with Patients and within the Multidisciplinary Team**
3. **Tumour-specific Therapy**
    i. **Core Strategies for Tumour-specific Therapy**
    ii. **Thoracic Surgery**
    iii. **Systemic Therapy**
    iv. **Radiotherapy**
    v. **Multimodal Therapy**
4. **Re-Staging and Follow-up during and after Therapy**
5. **Management of Progressive Disease and Relapse**
6. **End-of-life Care, Death and Bereavement Period**
7. **Survivorship**
8. **Cross-pathway Care**
    i. **Tumour- and Care-related Side Effect Management**
    ii. **Emergency Care, Intensive Care**
    iii. **Palliative Care**
    iv. **Specialised Nursing**
    v. **Physiotherapy and Rehabilitation**
    vi. **Social Work Service**
    vii. **Psychology Service**
    viii. **Spiritual Care Service**
    ix. **Nutrition Counselling**
    x. **Pain Management**
    xi. **Smoking Cessation**
    xii. **Clinical Research**

II. Lung Cancer Care Pathway	**Derived from**
1. Diagnostics	
i. Core diagnostic strategies	
Essential: The lung cancer service must provide written standard operating procedures which describe its diagnostic strategies covering: • How to generally discuss and decide with patients on their diagnostic strategies based on best evidence-based practices and their status as well as their needs and desires • How to perform the initial assessment of patients • How to perform functional assessment and appraisal of fitness for diagnostics and therapy in patients with curative and palliative therapy intent • How to decide in which patients to seek pathological confirmation of suspected lung cancer and in which to avoid it	**Good practice**

• How to seek pathological confirmation in suitable patients with suspected lung cancer, addressing both obtaining adequate tumour material and performing adequate pathological and molecular analyses • How to search for presence of and – if suspected or proven – how to stage extent of primary tumour, logo-regional lymph node metastases and distant metastases, respectively, as well as how to derive stage grouping out of the findings Multidisciplinary team play in the diagnostic phase involves in particular pulmonology, thoracic surgery, radiology, nuclear medicine and pathology/molecular diagnostics – interdisciplinary interfaces must be described in written form within the named standard operating procedures.	
Advanced: Without slowing down processes, the lung cancer service should provide a rapid initial multidisciplinary appraisal of the imaging material and other findings by pulmonologist, thoracic surgeon and radiologist for uncertain or complicated cases to jointly specify the best diagnostic procedure for tumour sample collection in suitable patients. This recommendation should be based on patient-specific risk-benefit analyses for the eligible procedures and patient preferences.	**Good practice**
ii. Initial assessment	
Essential: The lung cancer service must ensure that in every patient as initial assessment a comprehensive patient history*, a multidimensional symptom assessment**, a complete physical examination*** and a blood analysis*** is performed and based on these findings a first fitness assessment for diagnostic and therapeutic procedures is made. *including occupational history, comorbidities, and socio-economic status **dimensions to be covered: physical, psychological, social and spiritual; Performance status and weight/height to be assessed ***including a focus on potential signs for paraneoplastic syndromes [i.e. sodium, calcium] and systemic inflammation [i.e. CRP and/or albumin]	**Guideline**
Functional Assessment, Appraisal of Fitness for Diagnostics and Therapy	
Essential: The lung cancer service must provide or have access to the following tests for functional assessment and appraisal of fitness for diagnostics and therapy (not all will apply in every patient): • Blood gas analysis • Spirometry • Body plethysmography • Diffusing capacity for carbon monoxide (via breath holding or single breath method) • Electrocardiogram • Spiroergometry • Echocardiography	**Guideline**
Staff requirements: All functional assessment tests should be performed by specifically qualified and trained personnel (ordinarily, pulmonologists and respective medical assistance personnel; echocardiography: cardiologists). Staff quantity should be sufficient. However, at present, a specific minimum number of staff cannot be justified.	**Good practice**
Volume of care: At present, a specific minimum individual or institutional volume threshold for number of imaging tests with prognostic relevance cannot be justified.	**Literature review and assessment**
Time standards: All functional assessment tests should be available in reasonable time. However, at present, a specific maximum time with prognostic relevance for performance of functional assessment test cannot be justified.	**Good practice** **Literature review and assessment**

iii. Imaging	
Essential: The lung cancer service must provide or have access to the following tests for imaging: • Conventional x-ray • Computed tomography (CT) • Magnetic resonance imaging • Lung perfusion and ventilation scintigraphy • Bone scintigraphy • Positron emission tomography/Computed tomography (PET/CT) • Ultrasound • Fluoroscopy [also needed for endoscopy ➔ II.1.v.] The lung cancer service should provide a direct link between imaging and image-guided biopsies ➔ II.1.vi	**Guideline**
Staff requirements: All imaging tests should be performed by specifically qualified and trained personnel (ordinarily, radiologists and/or nuclear medicine specialists and respective medical assistance personnel; ultrasound, fluoroscopy: multiple qualified disciplines). Staff quantity should be sufficient. However, at present, a specific minimum number of staff cannot be justified.	**Good practice**
Volume of care: At present, a specific minimum individual or institutional volume threshold for number of imaging tests with prognostic relevance cannot be justified.	**Literature review and assessment**
Time standards: All imaging tests should be available daily in emergencies or urgent cases, otherwise in reasonable time. However, at present, a specific maximum time with prognostic relevance for performance of non-emergency imaging tests cannot be justified.	**Good practice** **Literature review and assessment**
iv. Endoscopy	

Essential: The lung cancer service must provide or have access to the following endoscopy procedures:
• Flexible and rigid bronchoscopy with:
  ○ Forceps biopsies for central bronchial lesions or peripheral pulmonary lesions (under fluoroscopy)
  ○ Transbronchial needle biopsies for central bronchial lesions or peripheral pulmonary lesions (under fluoroscopy or EBUS mini probe)
  ○ Brushing and washing
  ○ Bronchoalveolar lavage (BAL)
• Endobronchial ultrasound (EBUS)
• Endoscopic ultrasound (EUS)
 	
Further, the lung cancer service must provide or have access to the following interventional endoscopic procedures (may already become relevant in diagnostic period; therapeutic period: ➔ II.8.i.):
• Recanalisation with one or more of the following procedures:
  ○ Laser
  ○ Electrocoagulation
  ○ Cryotherapy
• Stenting
	Guideline

Staff requirements: All endoscopic procedures should be performed by specifically qualified and trained personnel (ordinarily, pulmonologists or thoracic surgeons and respective medical assistance personnel).	**Good practice**

Staff quantity should be sufficient. However, at present, a specific minimum number of staff cannot be justified.	
Volume of care: At present, a specific minimum individual or institutional volume threshold for number of endoscopic procedures with prognostic relevance cannot be justified.	**Literature review and assessment**
Time standards: All endoscopic procedures should be available daily in emergencies or urgent cases, otherwise within reasonable time. However, at present, a specific maximum time with prognostic relevance for performance of non-emergency endoscopic tests cannot be justified.	**Good practice** **Literature review and assessment**

Advanced: The lung cancer service should provide or have access to one or more of the following endoscopic procedures:
• Flexible and rigid bronchoscopy with:
  ○ Central cryobiopsy probe
  ○ Peripheral transbronchial cryobiopsy probe (under fluoroscopy)
  ○ Peripheral endobrochial ultrasound (EBUS) mini probe (under fluoroscopy)
  ○ Navigational techniques
	Good practice

v. Percutaneous Image-guided Biopsy Procedures	
Essential: The lung cancer service must provide or have access to either one or both of the following percutaneous image-guided biopsy procedures: • Ultrasound-guided biopsy • Computed tomography-guided biopsy among other things for: • Pleurocentesis • Pericardiocentesis/pericardial drainage • Peritoneocentesis • Biopsy of pleural lesions • Biopsy of pulmonary lesions • Lymph node biopsy • Liver biopsy • Bone biopsy • Renal biopsy • Biopsy of cutaneous and subcutaneous lesions	**Guideline**
Staff requirements: All percutaneous image-guided biopsy procedures should be performed by specifically qualified and trained personnel (ordinarily, interventional radiologists, pulmonologists or thoracic surgeons as well as organ-specific disciplines and respective medical assistance personnel). Staff quantity should be sufficient. However, at present, a specific minimum number of staff cannot be justified.	**Good practice**
Volume of care: At present, a specific minimum individual or institutional volume threshold for number of percutaneous image-guided biopsy procedures with prognostic relevance cannot be justified	**Literature review and assessment**
Time standards: All percutaneous image-guided biopsy procedures should be available in reasonable time. However, at present, a specific maximum time with prognostic relevance for performance of percutaneous image-guided biopsy procedures cannot be justified.	**Good practice** **Literature review and assessment**
vi. Mediastinoscopy	

Essential: The lung cancer service must provide or have access to mediastinoscopy as a diagnostic procedure.	**Guideline**
Staff requirements: Mediastinoscopy should be performed by specifically qualified and trained personnel (ordinarily, thoracic surgeons and respective medical assistance personnel). Staff quantity should be sufficient. However, at present, a specific minimum number of staff cannot be justified.	**Good practice**
Volume of care: At present, a specific minimum individual or institutional volume threshold for number of mediastinoscopies with prognostic relevance cannot be justified.	**Literature review and assessment**
Time standards: Mediastinoscopy should be available in reasonable time. However, at present, a specific maximum time with prognostic relevance for performance of mediastinoscopy cannot be justified.	**Good practice** **Literature review and assessment**
vii. Medical Thoracoscopy, Video-assisted Thoracoscopy (VATS)	
Essential: The lung cancer service must provide or have access to video-assisted thoracoscopy as a diagnostic and therapeutic [➔ II.8.i] procedure.	**Guideline**
Essential: If the lung cancer service provides additionally medical thoracoscopy as a diagnostic and therapeutic [➔ II.8.i] procedure, patient selection criteria for each of the two procedures should be consented in written form by the pulmonology and the thoracic surgery department.	**Good practice**
Staff requirements: Medical thoracoscopy and video-assisted thoracoscopy (VATS) should be performed by specifically qualified and trained personnel (ordinarily, thoracic surgeons or pulmonologists and respective medical assistance personnel). Staff quantity should be sufficient. However, at present, a specific minimum number of staff cannot be justified.	**Good practice**
Volume of care: At present, a specific minimum individual or institutional volume threshold for number of medical thoracoscopies or video-assisted thoracoscopies (VATS) with prognostic relevance cannot be justified.	**Literature review and assessment**
Time standards: Medical thoracoscopy and video-assisted thoracoscopy (VATS) should be available daily in emergencies or urgent cases, otherwise within reasonable time. However, at present, a specific maximum time with prognostic relevance for performance of medical thoracoscopy and video-assisted thoracoscopy (VATS) cannot be justified.	**Good practice** **Literature review and assessment**
viii. Tissue-based Tumour Sampling	
Essential: Tissue-based tumour sampling can be performed by various methods. The lung cancer service must provide written standard operating procedures addressing in particular performance of and post-interventional sample handling in the following procedures: • bronchoscopic forceps probes, central and peripheral • bronchoscopic needle probes, central and peripheral • bronchoscopic cryobiopsy probes, central and peripheral (if applied) • EBUS probes, central and peripheral • EUS probes • Percutaneous ultrasound-guided probes • Percutaneous computed tomography-guided probes	**Guideline**

• Mediastinoscopic probes • Medical thoracoscopic probes (if applied) • Video-assisted thoracoscopic (VATS) probes	
ix. Biofluid-based Tumour Sampling	
Essential: Biofluid-based tumour sampling can be performed by various methods. The lung cancer service must provide written standard operating procedures addressing in particular performance of and post-interventional sample handling in the following procedures: • Blood sample • Bronchoalveolar lavage (BAL) • Brushing and washing • Sputum sample • Pleurocentesis • Pericardiocentesis • Peritoneocentesis • Spinal tap	**Guideline**
Advanced: The lung cancer service should provide the option to use blood or urine to obtain tumour samples for molecular diagnostics. Accordingly, the lung cancer service should provide written standard operating procedures addressing in particular performance of these specific biofluid-based tumour sampling methods and their post-interventional sample handling.	**Guideline**
x. Pathology and Molecular Diagnostics	
Essential: The lung cancer service must provide or have access to the following methods for pathology and molecular diagnostics: • Light microscopy • Immunohistochemistry • First generation sequencing (i. e. Sanger polymerase chain reaction [PCR]) • Fluorescence in situ hybridization (FISH) (depending on molecular testing strategies) Written standard operating procedures must be provided by the lung cancer service for each of these methods as well as the general diagnostic strategy with regard to pathology and molecular diagnostics.	**Guideline**
Advanced: The lung cancer service should provide the following method for molecular diagnostics: • Next generation sequencing (NGS)	**Good practice**
Essential: The lung cancer service must apply the 2015 World Health Organization Classification of Lung Tumours for pathological subtyping of lung cancer.	**Guideline**
Essential: The lung cancer service must be capable to detect the following routinely treatable molecular alterations within its molecular diagnostics or have access to an appropriate external cooperation partner: • EGFR mutations • EML-4-ALK rearrangements (alternatively, immunohistochemistry can be used as equivalent alternative to FISH) • ROS1 rearrangements as well as the common alteration (if needed in sequential testing for molecular alterations): • KRAS mutations	**Guideline**

Besides, the lung cancer service must be capable to detect the following treatment-relevant marker: • PD-L1	
Advanced The lung cancer service should be capable to detect the following routinely treatable molecular alterations within its molecular diagnostics or have access to an appropriate external cooperation partner: • RET rearrangements • MET exon 14 splice mutations • C-MET amplification • HER2 alterations	**Guideline**
Essential: The pathology report of the lung cancer service must include the following core information: a) small biopsy: • Macroscopic findings (quantity, localisation and diameter (in mm) of lesions) • Microscopic findings • Pathological subtyping according to the 2015 World Health Organization Classification of Lung Tumors • ICD-O-3 code • Immunohistochemical findings (according to 2015 World Health Organization Classification of Lung Tumors) • Molecular diagnostics findings (as listed above) a) Surgical resection specimen: • Macroscopic findings (quantity, localisation and diameter (in mm) of lesions; infiltration of adjacent structures; infiltration of surgical margins) • Microscopic findings • Pathological subtyping according to the 2015 World Health Organization Classification of Lung Tumors • ICD-O-3 code • Immunohistochemical findings (according to 2015 World Health Organization Classification of Lung Tumors) • Molecular diagnostics (as listed above) • Intrapulmonary, hilar and mediastinal lymph nodes with lymph node stations (quantity of positive lymph nodes, quantity of dissected lymph nodes) • Residual tumour classification • TNM-classification and stage grouping according to UICC 8	**Guideline**
Essential: The lung cancer service should be able to perform autopsies.	**Good practice**
Staff requirements: Pathology and molecular diagnostics should be performed by specifically qualified and trained personnel (ordinarily, pathologists and/or molecular biologists and respective medical assistance personnel). Staff quantity should be sufficient. However, at present, a specific minimum number of staff cannot be justified.	**Good practice**
Institutional requirements: Pathology and molecular diagnostics in the lung cancer service should participate in ring trials or other external accreditation measures for target-specific test-approvals.	**Guideline**
Volume of care: At present, a specific minimum individual or institutional volume threshold for number of pathological and molecular diagnostics with prognostic relevance cannot be justified.	**Literature review and assessment**

Time standards: Final results of pathology and molecular diagnostics should be available in reasonable time. However, at present, a specific maximum time with prognostic relevance for performance of pathology and molecular diagnostics cannot be justified.	**Good practice** **Literature review and assessment**
xi. TNM Description and Stage Grouping	
Essential: The lung cancer service must apply the UICC 8 version for TNM Description and Stage Grouping in lung cancer.	**Guideline**
2. Medical Decision-finding and Care Planning with Patients and within the Multidisciplinary Team	
Essential: The lung cancer service must define its modes of medical decision-finding and care planning throughout the entire lung cancer pathway in a written standard operating procedure. This standard operating procedure must take into account the related communication within the multidisciplinary team as well as between members of the multidisciplinary team and patients/carers.	**Guideline**
Essential: One core element of the medical decision-finding and care planning within the multidisciplinary team is the multidisciplinary team conference in which patient cases are presented and discussed among a multidisciplinary panel as well as recommendations with regard to diagnostic and therapeutic questions are consented. The lung cancer service must install and run a multidisciplinary team conference at least on a weekly basis. The multidisciplinary conference should be directed by a coordinator. The following disciplines must be present at each multidisciplinary team conference either in person or virtually via a web-conference tool (or equal measure): • Pulmonology • Radiology • Nuclear medicine • Pathology, Molecular biology • Thoracic Surgery • Medical Oncology/Pneumo-oncology • Radiotherapy Other disciplines or professions (i.e. palliative care medicine, lung cancer specialised nurse) may participate in the multidisciplinary team conference at any time or may be invited to join this meeting in selected cases. The following medical indications in patients with proven or suspected lung cancer lead to a case presentation in multidisciplinary team conference: • All patients with a first diagnosis of lung cancer • All lung cancer patients after surgical lung resection with curative intent with regard to adjuvant therapy • All lung cancer patients with a newly diagnosed relapse of their disease after treatment with curative intent • Selected patients with proven or suspected lung cancer with problems or specific multiprofessional questions during diagnostics or tumour-specific treatment Every case in the multidisciplinary team conference should be presented to the multidisciplinary panel by the doctor who knows the patient and his previous course of disease best. To provide all relevant information to everybody in the multidisciplinary panel for proper preparation, a registration system is mandatory in	**Good practice**

the lung cancer service. Every discussed MDT conference-case will be protocolled in written form. The written protocol must be made available to patients and their general practitioners or other referring physicians if requested and if also approved by the patient.	
Advanced: The lung cancer service should implement and run a tool for regular quality assessment of the multidisciplinary team conference (i.e. concordance rates of MDT conference recommendations and actual applied treatments as well reasons for deviation) and subsequent quality improvement.	**Good practice**
3. Tumour-specific Therapy	
i. Core Strategies for Tumour-specific Therapy	
Essential: The lung cancer service must provide written standard operating procedures which describe its strategies for tumour-specific therapy modalities covering: • How to generally discuss and decide with patients on their tumor-specific therapeutic strategies based on best evidence-based practices and their status as well as their needs and desires • How to select patients for specific thoracic surgical procedures and how to best perform these thoracic surgical procedures covering pre-, peri- and postoperative phase • How to select patients for specific systemic therapies including targeted therapies and immunotherapies and how to best perform these systemic therapies • How to select patients for specific radiotherapies and how to best perform these radiotherapies • How to select patients for multimodal therapies and how to best perform these multimodal therapies Multidisciplinary team play in the phase of tumour-specific therapies involves in particular thoracic surgery, oncology/pneumo-oncology, radiotherapy, pulmonology, radiology and pathology/molecular diagnostics – interdisciplinary interfaces must be described in written form within the named Standard operating procedures.	**Guideline**
ii. Thoracic Surgery	
Essential: The lung cancer service must provide or have access to the following thoracic surgical procedures: • Wedge resesction • Open segmentectomy • VATS-Segmentectomy • Open lobectomy • VATS-lobectomy • Pneumonectomy • Sleeve-lobectomy • Sleeve-pneumonectomy • Video-assisted mediastinoscopic lymphadenectomy (VAMLA) Complete lymph node dissection should be ensured in anatomical resections.	**Guideline**
Staff requirements: Thoracic surgery should be performed by specifically qualified and trained personnel (ordinarily, general thoracic surgeons and/or cardiothoracic surgeons and respective medical assistance personnel). Proof of individual experience could be furnished by a logbook, a personal catalogue of performed operations or similar measures. Anaesthetists specialised in narcosis in thoracic surgery and pain management, physiotherapists and intensive care professionals are in particular essential	**Good practice**

throughout the pre-, peri- and postoperative phases of patients undergoing thoracic surgery. Staff quantity should be sufficient. However, at present, a specific minimum number of staff cannot be justified.	
Institutional requirements: Thoracic surgery should be performed in dedicated general thoracic surgery services and/or cardiothoracic surgery services adequately covering the pre-, peri- and postoperative phases.	**Good practice**
Volume of care: At present, a specific minimum individual or institutional volume threshold for number of thoracic surgical procedures with prognostic relevance cannot be justified.	**Literature review and assessment**
Time standards: Thoracic surgery should be available daily in emergencies or urgent cases, otherwise within reasonable time. However, at present, a specific maximum time with prognostic relevance for performance of thoracic surgery cannot be justified.	**Good practice** **Literature review and assessment**
iii. Systemic Therapy	
Essential: The lung cancer service must provide or have access to the following types of systemic therapies or their combinations: • Chemotherapies • Targeted therapies • Immunotherapies The lung cancer service should be capable to offer systemic therapies on an out-patient and in-patient basis.	**Guideline**
Staff requirements: Systemic therapies including targeted therapies and immunotherapies should be performed by specifically qualified and trained personnel (ordinarily, oncologists and/or pneumo-oncologists and respective medical assistance personnel). Staff quantity should be sufficient. However, at present, a specific minimum number of staff cannot be justified.	**Good practice**
Institutional requirements: Systemic therapies including targeted therapies and immunotherapies should be performed in dedicated oncology services and/or pulmonology services.	**Good practice**
Volume of care: At present, a specific minimum individual or institutional volume threshold for number of systemic therapies including targeted therapies and immunotherapies with prognostic relevance cannot be justified.	**Literature review and assessment**
Time standards: Systemic therapies including targeted therapies and immunotherapies should be available in reasonable time. However, at present, a specific maximum time with prognostic relevance for performance of systemic therapies including targeted therapies and immunotherapies cannot be justified.	**Good practice** **Literature review and assessment**
iv. Radiotherapy	
Essential: The lung cancer service must provide or have access to the following types of radiotherapy/radiotherapy techniques: • Stereotactic body radiotherapy • Intensity modulated radiotherapy (i.e. volumetric modulated arc therapy	**Guideline**

[VMAT]) • Motion management	
Staff requirements: Radiotherapy should be performed by specifically qualified and trained personnel (ordinarily, radiation-oncologists/clinical oncologists, radiotherapists and medical physicists). Staff quantity should be sufficient. However, at present, a specific minimum number of staff cannot be justified.	**Good practice**
Volume of care: At present, a specific minimum individual or institutional volume threshold for number of radiotherapies with prognostic relevance cannot be justified.	**Literature review and assessment**
Time standards: Radiotherapy should be available in reasonable time. However, at present, a specific maximum time with prognostic relevance for initiation of radiotherapy cannot be justified.	**Good practice** **Literature review and assessment**
v. Multimodal Therapy	
Essential: The lung cancer service must provide written standard operating procedures for treatment situations in which multidisciplinary discussion and consent finding as well as multimodal treatment in a multidisciplinary team are essential. Amongst others, examples are: • NSCLC, stage IA • NSCLC, stage IIIA • NSCLC, stage IIIB - Pancoast • NSCLC, oligometastatic lung cancer disease • SCLC, limited disease	**Guideline**
4. Re-Staging and Follow-up during and after Therapy	
Essential: The lung cancer service must define as a written standard operating procedure and apply validated tools for re-staging of patients under or after treatment (i.e. RECIST 1.1, iRECIST). The lung cancer service must define and apply as a written standard operating procedure a joint follow-up strategy during and after therapy taking into account therapy response as well as assessment of general patient status and tumour- and therapy-related side effects. This follow-up strategy should be coordinated among concerned disciplines and ensure that patients are not lost to follow-up through the lung cancer service.	**Guideline**
5. Management of Progressive Disease and Relapse	
Essential: The lung cancer service must define as a written standard operating procedure and apply a structured approach for the management of progressive disease and relapse to its patients based on best evidenced-based practices as well as their needs and preferences.	**Guideline**
6. End-of-life Care, Death and Bereavement Period	
Essential: The lung cancer service must define as a written standard operating procedure and apply a structured approach for the management of end-of-life care and death of a patient as well as for the support of carers throughout the bereavement period.	**Guideline**
7. Survivorship	
Essential: The lung cancer service must define as a written standard operating procedure and apply a structured approach for the management of patients who have achieved survivorship addressing amongst other things physical rehabilitation,	**Guideline**

psychological support, resilience and social reintegration.	
8. Cross-pathway Care	
i. Tumour- and Care-related Side Effect Management	
Essential: The lung cancer service must provide written standard operating procedures on the management of the following tumour- and care related side effects: a) Tumour-related • Dyspnoea • Pain • Superior vena cava syndrome • Endotracheobronchial obstruction • Haemoptysis • Tracheobronchial-oesophageal fistula • Pleural effusion • Hoarseness • Cough • Fatigue • Bone metastases • Brain metastases • Spinal cord compression and neurological deficits • Cachexia/muscle wasting • Venous thromboembolic disease • Hypercalcaemia • Hyponatraemia/ syndrome of inappropriate antidiuretic hormone secretion (SIADH) b) Therapy-related • Post-thoracotomy pain • Pneumonia • Respiratory failure • Adverse cardiac events • Prolonged airleak • Bronchopleural fistula • Empyema • Pneumonitis/pulmonary fibrosis induced by radiotherapy or systemic therapies • Oesophagitis induced by radiotherapy or systemic therapies • Nausea/vomiting • Anaemia • Neutropenia • Thrombopenia • Dermatitis • Mucositis • Endocrinological disorders (i.e. hypophysitis, thyroiditis) • Allergic reactions or other autoimmune reactions • Extravasate	**Guideline**
ii. Emergency Care, Intensive Care	
Essential: The lung cancer service must provide or have access to an emergency care service for its patients as well as access to intensive care. The lung cancer service must define as a written standard operating procedure and apply a structured approach for the management of its lung cancer patients in case of medical emergencies taking into account best evidence-based practices as well as patient needs and preferences (i.e. potential pre-formulated limitations of	**Guideline**

therapeutic measures). Equally, the lung cancer service should offer psychological, social and spiritual support in case of respective crises.	
iii. Palliative Care	
Essential: The lung cancer service must provide or have access to a palliative care service for its patients seeking integration of palliative care throughout the entire lung cancer continuum depending on respective patient symptom load. Palliative care within the lung cancer service must include at least one of the following elements*: • Palliative care ward • In-patient palliative care liaison service • Out-patient palliative care liaison service • In-patient palliative care nurse • Out-patient palliative care nurse • Hospice *Collaboration with external palliative care services/hospices could be an alternative	**Guideline**
iv. Spiritual Care Service	
Essential: Depending on respective cultural habits, the lung cancer service should provide or have access to a spiritual care service for its patients.	**Good practice**
v. Specialised Nursing	
Essential: The lung cancer service should provide or have access to nursing specialised in lung cancer care for its patients. A nurse specialised in lung cancer care should have knowledge and understanding of the lung cancer pathway and treatments in order to facilitate support for patients and their carers. ***Advanced:*** The majority of patients should be seen by a specialised lung cancer nurse.	**Guideline**
vi. Physiotherapy and Rehabilitation	
Essential: The lung cancer service must provide or have access to a physiotherapy service for its patients. A collaboration with rehabilitation services should be sought. Patients after completion of first line therapy should be offered a disease-adequate rehabilitation measure. The lung cancer service must define as a written standard operating procedure and apply a structured multi-professional approach for the management of its lung cancer patients with the aim to achieve fitness for therapy with curative intent when potentially reversible causes have been identified in so far unfit patients.	**Guideline**
vii. Social Work Service	
Essential: The lung cancer service must provide or have access to a social work service for its patients. Every patient with a first diagnosis of lung cancer should be offered counselling by a social work service member or qualified professional.	**Guideline**
viii. Psychology Service	
Essential: The lung cancer service must provide or have access to a psychology service for its patients.	**Guideline**

Every patient with a first diagnosis of lung cancer should be offered counselling by a psychology service member or qualified professional (i.e. specialised lung cancer nurse).	
Advanced: The lung cancer service should apply a validated tool to systematically screen lung cancer patients for their psychological support needs. Supervision of multidisciplinary team services as well as individual burnout screening/prevention and support measures for professionals should be provided by the psychology service or other qualified professionally	**Good practice**
ix. Nutrition Counselling	
Essential: The lung cancer service must provide or have access to a nutrition counselling service for its patients.	**Guideline**
Advanced: The lung cancer service should apply a validated tool to systematically screen lung cancer patients for their nutritional status.	**Guideline**
x. Pain Management	
Essential: The lung cancer service must provide or have access to a pain management service for its patients.	**Guideline**
Advanced: The lung cancer service should apply a validated tool to systematically screen lung cancer patients for pain.	**Guideline**
xi. Smoking Cessation	
Essential: The lung cancer service must provide or have access to a smoking cessation programme for its patients.	**Guideline**
xii. Clinical Research	
Essential: Every patient with lung cancer should be considered for local, national or international trials. ***Advanced:*** The lung cancer service should provide or have access to a clinical research service for its patients.	**Good practice**

Glossary of terms used in the manual of lung cancer services

Terminology used in the manual of lung cancer services	**Definition**	**Other terminology**
Carer	a family member or paid helper who regularly looks after a sick person	
Clinical cancer registry	an information system designed for the collection, storage an analysis of epidemiological and clinical data on patients with cancer	
Clinical research	a branch of science which explores efficacy and safety of medicines and other preventional, diagnostic or treatment regimens in patients	
Hospice	"An inpatient hospice admits patients in their last phase of life, when treatment in a hospital is not necessary and care at home or in a nursing home is not possible." [1]	
Lung cancer specialist	a physician specialised in lung cancer	
Medical Oncology	a medical discipline concerned with the prevention, diagnosis and treatment of cancer	Oncology
Medical physicists	"an individual who is competent to independently provide clinical professional services in one or more of the subfields of medical physics. • Therapeutic Medical Physics • Diagnostic Medical Physics • Nuclear Medical Physics • Medical Health Physics • Magnetic Resonance Imaging Physics" [2]	
Nutrition counselling	a service in which health professionals assess the dietary habits of individuals and provide qualified advice and information if change seems necessary	
Oncologist	a physician specialised in medical oncology	Medical oncologist
Pain management	a service in which health professionals assess the origin as well as the quality and quantity of pain in individuals and provide qualified advice, information and treatment modalities to overcome pain	
Palliative care	"an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual" [3]	
Pneumo-oncologist	a physician specialised in pneumo-oncology	
Pneumo-oncology	a medical sub-discipline concerned with the prevention, diagnosis and treatment of cancer in the field of pulmonology	Thoracic oncology
Psychology service	a service in which health professionals provide mental health care for individuals and their carers	
Pulmonologist	a physician specialised in pulmonology	Chest physician Pneumologist
Pulmonology	a medical discipline concerned with the anatomy, physiology, and pathology of the lungs and airways	Pneumology Respiratory care
Radio-oncologist	a physician specialised in radiotherapy	Clinical oncologist

Radiotherapist	an allied health professional who works in the field of radiotherapy	Radiation therapist
Radiotherapy	a medical discipline concerned with the treatment of diseases with radiation	Radio-oncology Radiation oncology
Social work service	a service in which health professionals provide socio-legal counselling, concerning reorganisation of occupational matters, securing of financial integrity as well as care and supply needs, and psychosocial counselling, addressing emotional needs and support, stigma, coping strategies, understanding of new/altered roles and relationships, and importance of social networks	
Specialised lung cancer nurse	a nurse who has knowledge and understanding of the lung cancer pathway and treatments facilitating support for patients and their carers	
Spiritual care service	a service in which health professionals provide mental health care for individuals and their carers	
Thoracic surgeon	a physician specialised in thoracic surgery	
Thoracic surgery	a medical discipline concerned with prevention, diagnostics, surgical treatment of diseases, malformations and injuries of the lung, bronchi, pleura, mediastinum and chest wall as well as the adjacent parts of the heart	

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Underlying evidence for lung cancer service parameter catalogue

Part of Lung Cancer Care Pathway	Chapter	Evidence
Initial assessment	II.1.ii.	ACCP [68], German lung cancer guideline [69], NICE [70]
Functional Assessment, Appraisal of Fitness for Diagnostics and Therapy	II.1.iii.	ACCP [71], BTS [72], ESTS/ERS [54], German lung cancer guideline [69], NICE [70]
Imaging	II.1.iv.	ACCP [73], ESR/ACR [53], German lung cancer guideline [69], NICE [70]
Endoscopy	II.1.v.	ACCP [73, 74], BTS[75], ESGE/ERS/ESTS [76], German lung cancer guideline [69], NICE [70], WABIP [77]
Percutaneous Image-guided Biopsy Procedures	II.1.vi.	ACCP [73, 74], German lung cancer guideline [69], NICE [70]
Mediastinoscopy	II.1.vii.	ACCP [73, 74], German lung cancer guideline [69], NICE [70]
Medical Thoracoscopy, Video-assisted Thoracoscopy (VATS)	II.1.viii.	ACCP [73, 74], German lung cancer guideline [69], NICE [70]
Tissue-based Tumour Sampling Biofluid-based Tumour Sampling Pathology and Molecular Diagnostics	II.1.ix. II.1.x. II.1.xi.	ACCP [73, 74], German lung cancer guideline [69], IASLC [78], NICE [70], WHO [79]
TNM Description and Stage Grouping	II.1.xii.	IASLC [80-85], UICC [86]
Medical Decision-finding and Care Planning with Patients and within the Multidisciplinary Team	II.2.	German lung cancer guideline [69], NICE [70]
Core Strategies for Tumour-specific Therapy	II.3.i.	BTS [72], German lung cancer guideline [69], NICE [70]
Thoracic Surgery	II.3.ii.	BTS [72], ESTS [55], German lung cancer guideline [69], NICE [70]
Systemic Therapy	II.3.iii.	ESMO [87-89], German lung cancer guideline [69], NICE [70]
Radiotherapy	II.3.iv.	BTS [72], EORTC [62], ESTRO/ACROP [64], German lung cancer guideline [69], NICE [70]
Multimodal Therapy	II.3.v.	BTS [72], German lung cancer guideline [69], NICE [70]
Re-Staging and Follow-up during and after Therapy	II.4.	German lung cancer guideline [69], iRECIST [90], NICE [70], RECIST [80]
Management of Progressive Disease and Relapse	II.5.	German lung cancer guideline [69], NICE [70]
End-of-life Care, Death and Bereavement Period	II.6.	EAPC [65], German lung cancer guideline [69], NICE [70]
Survivorship	II.7.	German lung cancer guideline [69], NICE [70]
Cross-pathway Care	II.8.	EAPC [65], German lung cancer guideline [69], NICE [70]

Legend: ACCP: American College of Chest Physicians, ACR: American College of Radiology, ACROP: Advisory Committee on Radiation Oncology Practice, BTS: British Thoracic Society, EAPC: European Association for Palliative Care, EORTC: European Organisation for Research and Treatment of Cancer, ERS: European Respiratory Society, ESGE: European Society of Gastrointestinal Endoscopy, ESMO: European Society for Medical Oncology, ESR: European Society of Radiology, ESTRO: European Society for Radiotherapy and Oncology, ESTS: European Society of Thoracic Surgeons, IASLC: International Association for the Study of Lung Cancer, NICE: National Institute for Health and Care Excellence, UICC: Union Internationale Contre le Cancer, WABIP: World Association for Bronchology Interventional Pulmonology

Supplement 3

Supplement 3.1: Existing datasets of Lung Cancer Registration

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

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

Supplement 3.2: An example of coding for ethnicity

Office of National Statistics (ONS) UK.

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

Supplement 3.3: Results of narrative evidence search on websites of international societies and other stakeholders related to lung cancer care as well as those on the national level accessible by taskforce members

Name of society/stakeholder	Website	Results
International societies		
European Association for Palliative Care (EAPC)	www.eapcnet.eu	White Paper on standards and norms for hospice and palliative care in Europe: part 1+2 [1]
European Lung Foundation	www.europeanlung.org	Patient priorities project lung cancer [2]
European Organisation for Research and Treatment of Cancer (EORTC)	www.eortc.org	European Organization for Research and Treatment of Cancer (EORTC) recommendations for planning and delivery of high-dose, high precision radiotherapy for lung cancer [3]
European Respiratory Society	www.ersnet.org	Thoracic Oncology HERMES [4-6]
European Society for Medical Oncology (ESMO)	www.esmo.org	Designated Center of Integrated Oncology and Palliative Care Application [7]
European Society for Radiotherapy and Oncology Advisory Committee on Radiation Oncology Practice (ACROP)	www.estro.org	ESTRO ACROP consensus guideline on implementation and practice of stereotactic body radiotherapy for peripherally located early stage non-small cell lung cancer [8]
European Society of Radiology (ESR)	www.myesr.org	European Society of Radiology (ESR) and American College of Radiology (ACR) report of the 2015 global summit on radiological quality and safety [9]
European Society of Thoracic Surgeons (ESTS)	www.ests.org	Clinical guidelines for evaluating fitness for radical treatment (surgery and chemoradiotherapy) in patients with lung cancer (with ERS) [10] European guidelines on structure and qualification of general thoracic surgery [11]
International Association for the Study of Lung Cancer (IASLC)	www.iaslc.org	Adenocarcinoma classification [12] Lung cancer staging recommendations [13-18]
Organisation of European Cancer Institutes	www.oeci.eu	OECI Accreditation and Designation [19]
Union Internationale Contre le Cancer (UICC)	www.uicc.org	Lung cancer staging recommendations [20]
World Association for	www.wabip.com	

Bronchology Interventional Pulmonology (WABIP)		
Other International Stakeholders		
European Union	www.europa.eu	Project cycle management [21]
World Health Organization	www.who.int	WHO classification of tumours of the lung [22] Definition of Palliative Care [23]
National societies/other stakeholders		
-Germany		
Deutsche Gesellschaft für Hämatologie und Medizinische Onkologie	www.dgho.de	Onkologisches Zentrum (Oncologic Centres) [24]
Deutsche Gesellschaft für Pneumologie und Beatmungsmedizin (German Respiratory Society)	www.pneumologie.de	German lung cancer guideline [25]
Deutsche Gesellschaft für Thoraxchirurgie (German Society for Thoracic Surgery)	www.dgt-online.de	Kompetenzzentrum Thoraxchirurgie (Certification of Thoracic Centres) [26]
Deutsche Krebsgesellschaft (German Cancer Society) Onkozert	www.dkg.de www.onkozert.de	Lungenkrebszentren (Certification of lung cancer centres) [27, 28]
-United Kingdom		
British Thoracic Society	www.brit-thoracic.org.uk	Guideline for diagnostic flexible bronchoscopy in adults [29] Guideline on radical management of patients with lung cancer [30]
Cancer Research UK	www.cancerresearchuk.org	Lung Clinical Expert Group: National Optimal Lung Cancer Pathway [31] Lung Cancer Centres of Excellence [32]
Expert Advisory Group on Cancer to the Chief Medical Officers of England and Wales		A Policy Framework for Commissioning Cancer Services [33]
National Institute for Health and Care Excellence	www.nice.org.uk	NICE guideline on the Diagnosis and Treatment of Lung Cancer (Update) [34]
-United States of America		
American College of Chest Physicians (ACCP)	www.chestnet.org	ACCP guideline on diagnosis and management of lung cancer, 3rd edition
Bonnie J. Addario Lung Cancer Foundation	www.lungcancerfoundation.org	Centers of Excellence [35]
National Cancer Institute	www.cancer.gov	NCI-Designated Cancer Centers [36]

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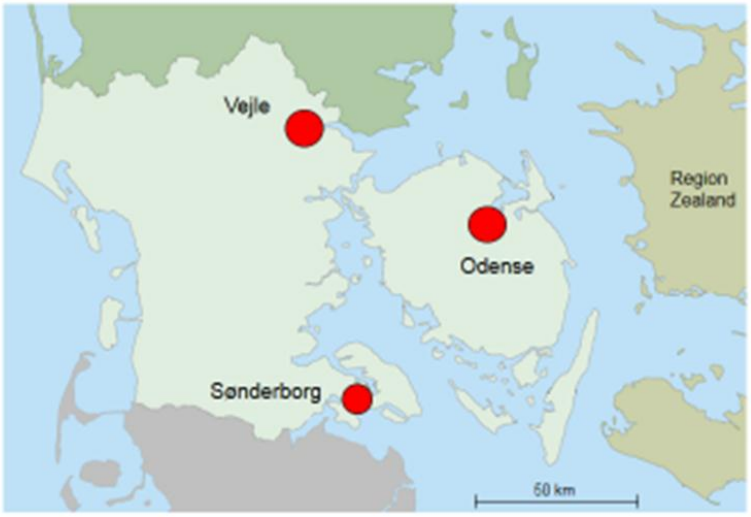
Supplement 3.4: Example of multi-site lung cancer service in Southern Denmark.

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

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



Selected results from 2016

Vejle:

449 first time diagnoses of lung cancer

63 patients had conventional radiotherapy with curative intent

Odense:

439 first time diagnoses of lung cancer

321 resections of lung cancer

204 patients had radiotherapy with curative intent (52% SBRT)

Sønderborg:

206 first time diagnoses of lung cancer

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