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Achieving Thoracic Oncology data collection in Europe

a precursor study in 35 Countries

Rich, Anna; Baldwin, David; Alfageme, Inmaculada; Beckett, Paul; Berghmans, Thierry; Brincat, Stephen; Burghuber, Otto; Corlateanu, Alexandru; Cufer, Tanja; Damhuis, Ronald; Danila, Edvardas; Domagala-Kulawik, Joanna; Elia, Stefano; Gaga, Mina; Goksel, Tuncay; Grigoriu, Bogdan; Hillerdal, Gunnar; Huber, Rudolf Maria; Jakobsen, Erik; Jonsson, Steinn; Jovanovic, Dragana; Kavcova, Elena; Konsoulova, Assia; Laisaar, Tanel; Makitaro, Riitta; Mehic, Bakir; Milroy, Robert; Moldvay, Judit; Morgan, Ross; Nanushi, Milda; Paesmans, Marianne; Putora, Paul Martin; Samarzija, Miroslav; Scherpereel, Arnaud; Schlessler, Marc; Sculier, Jean-Paul; Skrickova, Jana; Sotto-Mayor, Renato; Strand, Trond-Eirik; Van Schil, Paul; Blum, Torsten-Gerriet

Published in:
BMC Cancer

DOI:
10.1186/s12885-018-5009-y

Publication date:
2018

Document version:
Final published version

Document license:
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Citation for pulished version (APA):

Rich, A., Baldwin, D., Alfageme, I., Beckett, P., Berghmans, T., Brincat, S., Burghuber, O., Corlateanu, A., Cufer, T., Damhuis, R., Danila, E., Domagala-Kulawik, J., Elia, S., Gaga, M., Goksel, T., Grigoriu, B., Hillerdal, G., Huber, R. M., Jakobsen, E., ... Blum, T.-G. (2018). Achieving Thoracic Oncology data collection in Europe: a precursor study in 35 Countries. *BMC Cancer*, 18, Article 1144. <https://doi.org/10.1186/s12885-018-5009-y>

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RESEARCH ARTICLE

Open Access



Achieving Thoracic Oncology data collection in Europe: a precursor study in 35 Countries

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Abstract

Background: A minority of European countries have participated in international comparisons with high level data on lung cancer. However, the nature and extent of data collection across the continent is simply unknown, and without accurate data collection it is not possible to compare practice and set benchmarks to which lung cancer services can aspire.

Methods: Using an established network of lung cancer specialists in 37 European countries, a survey was distributed in December 2014. The results relate to current practice in each country at the time, early 2015. The results were compiled and then verified with co-authors over the following months.

Results: Thirty-five completed surveys were received which describe a range of current practice for lung cancer data collection. Thirty countries have data collection at the national level, but this is not so in Albania, Bosnia-Herzegovina, Italy, Spain and Switzerland. Data collection varied from paper records with no survival analysis, to well-established electronic databases with links to census data and survival analyses.

Conclusion: Using a network of committed clinicians, we have gathered validated comparative data reporting an observed difference in data collection mechanisms across Europe. We have identified the need to develop a well-designed dataset, whilst acknowledging what is feasible within each country, and aspiring to collect high quality data for clinical research.

Keywords: Lung Cancer, Epidemiology, Audit, Data collection, Datasets

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Background

Whilst Europe contains one eighth of the world's population, it accounts for a quarter of all reported cases of cancer [1]. Lung cancer remains the commonest cause of death from cancer in both men and women across Europe and has one of the worst prognoses of all cancers [2]. It constitutes an enormous health burden across the continent and its incidence corresponds to the historic tobacco smoking rates. In the absence of a therapeutic breakthrough, the cancer community must ensure that it implements current best practice as effectively as possible. Our priorities should be to improve outcome by: reducing smoking prevalence through public health campaigns, improving early diagnosis, eradicating inequality in access to investigations and treatment, assuring access to novel therapies and reducing the number of patients who present via the emergency department when their prognosis is much worse [3].

Several publications have documented a variation in outcome from lung cancer across Europe in the last 15 years [2, 4], but there has been minimal attention to correlating these differences in outcome with clinical practice and clinical resources. It is not clear how much this variation depends on the historical, cultural and political background of a country. The number of independent countries in Europe has significantly increased in the last twenty-five years, and there is a self-evident wide variation in population size, economic stability and healthcare infrastructure. As an example of the diverse healthcare infrastructure in Europe, Table 1 illustrates the variation in access to primary care which was recorded in 2011 [5]. Without this information, it is difficult to make comparisons between countries, and impossible to learn from different practices and identify the key elements within the whole pathway that limit the implementation of an optimal standard of care in each country.

A recent taskforce of the European Respiratory Society (ERS) entitled European Initiative in Quality Management in Lung Cancer Care (EIQMLCC) provided evidence of the extent of variation in healthcare infrastructure, and also performed a feasibility study, the European Lung Cancer Audit (EuLuCA), collecting prospective data on patients with a new diagnosis of lung cancer [6]. Data collection is a key component in quality management and allows accurate evaluation of the epidemiological trends over time and a meaningful analysis of the variation in clinical care provision. However, despite this being a recommended approach [7], datasets currently developed for international use are likely to be beyond the ability of the majority of European countries to populate. This study aims to benchmark the European position in relation to the feasibility of collecting pan-European data by assessing the current practice with respect to data collection, and

also to gauge the feasibility of, and interest in, a pan-European database for thoracic malignancy.

Methods

Based on the network of lung cancer specialists established during the EIQMLCC taskforce who had participated in the EuLuCA project, a survey was distributed to 37 European countries in December 2014 (see Additional file 1). This survey was designed by the co-authors specifically to investigate the current status of data collection in Europe. The participants, all lung cancer physicians, gave written consent to participate in the project. They were also asked their opinion on 3 qualitative questions: what key challenges to prospective thoracic oncology data collection exist in their country; what is required to improve data acquisition and whether they would be willing to participate in a pan-European data collection programme.

Results

Thirty-five of 37 countries returned completed surveys, a response rate of 95%. The participating countries are shown in Table 2; they comprise countries with a variety of socio-political structures and represent 64% of all European countries, as defined by the World Health Organisation. The countries within our cohort represent 68% of the population of Europe, or 93% of the population if Russia and the other former states of the USSR are excluded. Several countries of the former USSR fall within the region of central Asia, despite the WHO inclusion within Europe. Co-authors also sent examples of data collection forms, annual reports and the contact details of the individuals responsible for data collection in thoracic oncology in their country (Additional file 2).

National data collection

Thirty countries collect data on a national level, with the majority using a national registry for all cancers. Several countries have a data collection programme for lung cancer in addition to a Cancer Registry, namely: Denmark, England and Wales, Germany, Hungary, The Netherlands, Norway, Scotland and Slovenia. Other countries have a specific thoracic surgery database, such as France, The Netherlands and Norway. There is no universal national data collection for lung cancer in Albania, Bosnia Herzegovina, Italy, Spain and Switzerland. The Albanian Respiratory Society has a register of lung cancer patients; described as a labour intensive paper record completed by senior doctors, and with limited clinical and survival data, with no formal analysis. There are two entities to Bosnia Herzegovina, the Federation of Bosnia Herzegovina and the Republic of Srpska. There is regional data collection for all cancers in Bosnia Herzegovina, with data collected electronically by the Federal Institute of Public Health.

Table 1 Access to primary care (survey from 2011 part of ERS taskforce) [5]

| Country | Remarks |
|--|---|
| “free for everyone” | |
| Austria | |
| Belarus | |
| Denmark | |
| Hungary | |
| Ireland | For those individuals with a ‘medical card’. |
| Italy | |
| Kyrgyzstan | |
| Lithuania | |
| Malta | |
| Poland | |
| Portugal | |
| Spain | |
| Turkey | |
| Ukraine | |
| United Kingdom | |
| “free but Insurance pay” | |
| Albania | Single level of Health Insurance which is mandatory in order to allow access to public hospitals. Additional voluntary Health Insurance in order to access private hospitals. |
| B & H | Public health care is organised at the cantonal level; with Insurance paid by employers to the Public Fund. |
| Croatia | Two levels of Health Insurance, basic and additional. |
| Czech Republic | |
| Estonia | There is a State-run Health Insurance. |
| Netherlands | Mandatory basic level of Health Insurance which is paid by everyone in employment. There are voluntary supplements available too. |
| Romania | National Public Health Insurance agency. |
| Serbia | Mandatory Social Health Insurance Scheme. |
| Slovakia | Mandatory Health Insurance, paid for by employer or State. 3 companies at present, 1 State run, 2 are private. |
| Slovenia | Health Insurance scheme run by the Government |
| Switzerland | Compulsory Basic level of Health Insurance. Additional ‘complementary’ health Insurance available too. |
| “Pay at time of consultation” | |
| Bulgaria | 1.2E assuming individual paid contribution to National Health Fund. If not met contributions to National Health Fund then 10-15E. |
| Cyprus | Given inadequate Primary care physicians, if choose to see one privately will have to pay 50E. |
| Germany | 10E per visit, or 40E per year and consultations are free. |
| Iceland | 4E. Department of Health covers the rest via taxation. |
| Ireland | If not got a medical card (see above) then pay 60E. Some or all of this can be claimed from private Insurance scheme (50% population). |
| Norway | 22E per visit, up to maximum of 260E per year including primary and secondary care appointments and prescription charges etc. In-patient stay is free. Government does collect income tax of which some goes to Department of Health. |
| Sweden | 24E per visit, up to maximum of 180E per year. |
| “Pay a certain amount/proportion” | |
| Belgium | 10% paid by patient, 90% paid by ‘social security’. |
| Finland | 13.7E/visit for first 3 visits, then free. |
| France | 23E at time of appointment but individual can claim back 70% of this from Social Security. |
| Greece | 3-10E |
| Luxembourg | Individual pays 20% of 39.9E (ie 8E). Compulsory Public Health and Longterm Care Insurance means Government pays 80% of primary and secondary care consultation costs. |

Table 2 Basic features of data collection in 35 European countries

| | Year est. | Mandatory | Consent | Form | Verbal | other | Data Completeness (%) | Year | Histo only | Clinical | C-R | DCO |
|------------------------|-----------|-----------|------------|------|--------|----------|-----------------------|------|------------|------------|-----|------------|
| Albania | 2011 | No | No | | | | 90% | 2013 | No | Yes | Yes | No |
| Austria | 1969 | Yes | No | | | | Not available | N/A | Yes | | | |
| Belgium | 2006 | Yes | No | | | | 90–94 | 2013 | No | Yes | Yes | |
| B & H | 2004 | Yes | No | | | | 59 | 2011 | No | Yes | Yes | Yes |
| Bulgaria | 1952 | Yes | No | | | | 70–79 | 2011 | Yes | | | |
| Croatia | 1959 | Yes | No | | | | 80–89 | 2013 | Yes | | | |
| Czech Rep | 1977 | Yes | No | | | | 95–100 | 2013 | No | Yes | Yes | No |
| Denmark | 2000~ | Yes | No | | | | 95–100 | 2013 | No | Yes | Yes | Yes* |
| Eng & Wales | 2003~ | Yes | No | | | | 95–100 | 2013 | No | Yes | Yes | No* |
| Estonia | 1953 | Yes | Yes | Yes | | | 95–100 | 2011 | No | No | Yes | Yes |
| Finland | 1953 | Yes | No | | | | 95–100 | 2012 | No | Yes | Yes | Yes |
| France | 1975 | No | No | | | | < 50% | 2013 | No* | No | Yes | No |
| Germany | 1929 | Yes | Yes | Yes | | | 70–79 | 2013 | No | Yes | Yes | Yes |
| Greece | 2013 | Yes | No | | | | < 50% | 2013 | No | Yes | Yes | Yes |
| Hungary | 1970~ | Yes | No | | | | 70–79 | 2013 | Yes | | | |
| Iceland | 1955 | Yes | No | | | | 95–100 | 2013 | No | Yes-rarely | Yes | Yes-rarely |
| Rep. Ireland | 1991 | No | No | | | | 90–94 | 2012 | No | No | Yes | Yes |
| Italy | 1996 | No | Yes | | Yes | | 51 | 2013 | Yes | | | |
| Lithuania | 1984 | Yes | No | | | | 95–100 | 2013 | No | Yes-rarely | Yes | Yes-rarely |
| Luxembourg | 2013 | Yes | Yes | | | implicit | Not available | N/A | No | Yes | Yes | Yes |
| Malta | 1957 | Yes | No | | | | 95–100 | 2013 | No | Yes | Yes | Yes-rarely |
| Moldova | 1983 | Yes | Yes | Yes | | | 50–59 | 2012 | Yes | | | |
| Netherlands | 1989 | No | Yes | | | implicit | 95–97 | 2013 | No | Yes | Yes | No |
| Norway | 1953 | Yes | No | | | | 97 | 2009 | No | Yes | Yes | Yes |
| Poland | 1952 | Yes | No | | | | 80–89 | 2012 | Yes | | | |
| Portugal | 1988 | Yes | No | | | | 60–69 | 2011 | No | Yes | Yes | Yes |
| Romania | 1981 | Yes | No | | | | < 66% | 2011 | No | Yes | Yes | Yes |
| Scotland | 1958 | Yes | No | | | | 95–100 | 2013 | No | Yes | Yes | Yes |
| Rep. Serbia | 1990 | Yes | No | | | | 60–69 | 2013 | No | No | Yes | Yes (PM) |
| Slovakia | 1952 | Yes | No | | | | 70–79 | 2008 | No | No | Yes | Yes |
| Slovenia | 1950 | Yes | No | | | | 90–94 | 2010 | No | Yes | Yes | Yes |
| Spain | 1960 | No | Yes | Yes | | | Not available | N/A | No | No | Yes | No |
| Sweden | 1958 | Yes | No | | | | 95–100 | 2013 | No | No | Yes | No |
| Switzerland | 1969 | No | No | | | | 95–100 | 2013 | No | Yes | Yes | Yes |
| Turkey | 1993 | No | No | | | | < 50% | 2009 | No | Yes | Yes | No |

Countries not in bold do not have a national dataset. *B&H* Bosnia and Herzegovina. *DCO* death certificate only. *N/A* not applicable. *PM* post-mortem only. Year est.; year that registry established

~ = Lung cancer specific data collection established. Histo only; only those patients with a histological or cytological diagnosis are recorded in the dataset. If no, then are cases confirmed on clinical grounds alone, or clinico-radiological grounds (C-R), and finally are cases included if the diagnosis of lung cancer is based on the death certificate only (DCO). Denmark; DCO*; accepted as diagnosis in National Cancer Registry, not in the National Lung Cancer Registry. England and Wales; DCO*; accepted as diagnosis in the National Cancer Registry not in the National Lung Cancer Audit. France; The Epithor surgical database would be histological confirmed cases only, the National Cancer Registry is not

However, there is no data collection in the Republic of Srpska. In Italy there are 43 local cancer registries, of which 38 collect data on all cancer types, but 5 registries collect data on only certain cancer types, or for certain age groups. In contrast, there is national data collection for

patients with mesothelioma in Italy, via the National Institute for Insurance against Accidents at Work (INAIL). The absence of national data collection in Spain and Switzerland is related to health care infrastructure. In Spain, there are 17 autonomous communities who control

their own healthcare, and set their own agendas and priorities. In Switzerland, there are 26 cantons (regions) covered by 18 local cancer registries without a nationally defined dataset; currently only 15 of the 18 registries combine data at a national level.

Basic features

Table 2 illustrates the basic features of these collection systems, showing the year cancer registration was established and where data collection is mandatory, and where patient consent is required. Data collection in half of our surveyed countries began between 1950 and 1980; with another nine countries starting between 1980 and 2000. Bosnia Herzegovina is the only country without a national data collection programme, but where data collection is mandatory at a regional level, in the Federation of Bosnia Herzegovina. Of those countries with a national programme for data collection, reporting is not mandatory in Germany, Rep. Ireland, the Netherlands and Turkey. Patient consent is required in 7 of the 35 countries, some at national and some at regional level. In some countries, such as Slovenia, Slovakia and Belgium, consent is not required for the national cancer registry, however patients need to consent for their data to be entered into the regional/hospital based lung cancer registries.

Data completeness

Data completeness reflects the percentage of individuals with lung cancer reported in the regional or national datasets, as a percentage of the expected number of cases of lung cancer in that country, per year. It was quite variable. Seventeen of 35 countries reported completeness of >90%. Bosnia Herzegovina, Greece, Italy, Moldova and Turkey reported data completeness of less than 60%, and in France although the data collected on patients in the Cancer Registry is below 50% complete; hospital records, collecting non-individualised data are 95–100% complete. Portugal, Romania and Rep. Serbia report data completeness between 60 and 69%, and Bulgaria, Germany, Hungary and Slovakia report completeness between 70 and 79% and Croatia and Poland report completeness between 80 and 89% (see Table 2). These data were based on the most up-to-date complete year of data collection, at the time of the survey, and are based on national or regional reports or publications. They were unavailable in three countries, Austria, Luxembourg and Spain.

Data items

Twenty-eight countries include all patients diagnosed with histology, cytology or on the basis of clinical and radiological evidence. Seven countries (20%) collect data on only those patients with histologically confirmed

disease, excluding other patients (Austria, Bulgaria, Croatia, Hungary (Koranyi pulmonology registry), Italy, Moldova and Poland). In contrast, some countries extend their denominator and also include those diagnosed on death certificate only, although some required confirmation at post-mortem.

Table 3 illustrates the data items collected by each country. Every country, except Austria, included date of diagnosis and sex, and all except Hungary and Republic of Serbia collected date of birth. These two countries record age at diagnosis instead. Every country records histology, and almost all use the WHO International Classification of Diseases for Oncology, 3rd edition. However in Denmark the SNOMED (Systematized Nomenclature of Medicine) system is used. Almost every country uses the ERS/ATS/IASLC system to classify adenocarcinoma [8]; exceptions were Germany, Malta, Moldova, Romania and Switzerland. Every country except Austria, Iceland and Malta record both TNM status and stage. Performance status (PS) was recorded in less than half of the countries surveyed. Belgium, Czech Republic, Denmark, England and Wales, France, Germany, Rep. Ireland, Luxembourg, Moldova, Norway, Poland, Scotland, Rep. Serbia and Sweden recorded PS in a national registry; whereas Albania, Italy and Spain record PS at a regional level. A similar number of countries record the smoking status of a patient. This information, however basic (current, ex, or never smoker), was recorded in: Austria, Croatia, Czech Republic, Denmark, Greece, Rep Ireland, Luxembourg, Moldova, Poland, Sweden and Turkey. Albania, Italy and Spain record smoking status at a regional level. The lung cancer registry of Slovenia, with 2/3 coverage, collects PS, smoking status, co-morbidity and molecular markers, although the national cancer registry does not. Socio-economic status (SES) was only recorded in five national datasets, namely: Denmark, England and Wales, Moldova, Poland and Scotland (calculated from patient's postcode). Albania and Italy recorded SES at a regional level. Some countries record the occupation of an individual which could be used to infer their SES (Finland, the Republic of Ireland, Lithuania, Slovakia and Slovenia). In Norway, information on income and educational status can be obtained from Statistics Norway and the Norwegian patient register which can be linked to the Cancer Registry. It was not feasible to define which of these data items were mandatory in each country.

Lung function, either spirometry or transfer factor, was only recorded in Albania, Denmark, England and Wales and at a regional level in Spain. Co-morbidity was only recorded in 9 countries as routine practice, although the majority did report this feature in research projects. Table 4 illustrates the different measures of co-morbidity, performance status and quality of life (QOL) used across Europe.

Table 3 Data items collected in current practice in 35 European countries

| | Date dx | Histo | TNM | Stage | PS | Smoking | comorbid | SES | FEV1 | KCO | EGFR | EML-4-ALK | MDT | 1st line | 2nd line | Last info date | Date of death |
|--------------|---------|-------|-----|-------|-----|---------|----------|-----|------|-----|------|-----------|-----|----------|----------|----------------|---------------|
| Albania | | | | | | | XXX | | | XXX | XXX | XXX | XXX | XXX | XXX | XXX | XXX |
| Austria | XXX | | XXX | XXX | XXX | | XXX | XXX | XXX | XXX | XXX | XXX | | XXX | XXX | XXX | |
| Belgium | | | | | | XXX | XXX | XXX | XXX | XXX | XXX | | | | | | |
| B & H | | | | | XXX | XXX | XXX | XXX | XXX | XXX | XXX | XXX | XXX | XXX | XXX | XXX | |
| Bulgaria | | | | | XXX | XXX | XXX | XXX | XXX | XXX | XXX | XXX | | XXX | XXX | XXX | |
| Croatia | | | | | XXX | | XXX | XXX | XXX | XXX | XXX | XXX | XXX | XXX | XXX | | |
| Czech Rep | | | | | | | | XXX | XXX | XXX | | | | | | | |
| Denmark | | | | | | | | | | | | | OOO | | | | |
| Eng & Wales | | | | | | XXX | | | | XXX | XXX | XXX | | | | | |
| Estonia | | | | | XXX | XXX | XXX | XXX | XXX | XXX | XXX | XXX | XXX | | | XXX | XXX |
| Finland | | | | | XXX | XXX | XXX | XXX | XXX | XXX | XXX | XXX | XXX | | | | |
| France | | | | | | XXX | XXX | XXX | XXX | XXX | | | | XXX | XXX | XXX | |
| Germany | | | | | | XXX | XXX | XXX | XXX | XXX | | XXX | | | | | |
| Greece | | | | | XXX | | XXX | XXX | XXX | XXX | XXX | XXX | XXX | | XXX | XXX | XXX |
| Hungary | | | | | XXX | XXX | XXX | XXX | XXX | XXX | XXX | XXX | | | XXX | XXX | XXX |
| Iceland | | | XXX | XXX | XXX | XXX | XXX | XXX | XXX | XXX | XXX | XXX | XXX | XXX | XXX | XXX | |
| Rep. Ireland | | | | | | | XXX | XXX | XXX | XXX | XXX | XXX | | | | | |
| Italy | | | | | | | | | XXX | XXX | | | XXX | | | | |
| Lithuania | | | | | XXX | XXX | XXX | XXX | XXX | XXX | XXX | XXX | XXX | XXX | XXX | XXX | |
| Luxembourg | | | | | | | | XXX | XXX | XXX | | | | | XXX | | |
| Malta | | | XXX | XXX | XXX | XXX | XXX | XXX | XXX | XXX | XXX | XXX | XXX | XXX | XXX | | |
| Moldova | | | | | | | | | XXX | XXX | XXX | XXX | | | | | |
| Netherlands | | | | | XXX | XXX | OOO | XXX | XXX | XXX | | | XXX | | XXX | XXX | |
| Norway | | | | | | XXX | XXX | XXX | XXX | XXX | | | | | | | |
| Poland | | | | | | | XXX | | XXX | XXX | | XXX | | | | | |
| Portugal | | | | | XXX | XXX | | XXX | XXX | XXX | | XXX | | | | | |
| Romania | | | | | XXX | XXX | XXX | XXX | XXX | XXX | XXX | XXX | XXX | | | XXX | |
| Scotland | | | | | | XXX | XXX | | XXX | XXX | | XXX | | | XXX | XXX | |
| Rep. Serbia | | | | | | XXX | XXX | XXX | XXX | XXX | | XXX | | | XXX | XXX | |
| Slovakia | | | | | XXX | XXX | XXX | XXX | XXX | XXX | XXX | XXX | XXX | | XXX | | |
| Slovenia | | | | | XXX | XXX | XXX | XXX | XXX | XXX | XXX | XXX | XXX | | XXX | XXX | |
| Spain | | | | | | | | XXX | | | | | | | | | |
| Sweden | | | | | | | XXX | XXX | XXX | XXX | | XXX | | | XXX | XXX | |
| Switzerland | | | | | XXX | XXX | XXX | XXX | XXX | XXX | XXX | XXX | XXX | | XXX | | |
| Turkey | | | | | XXX | | | XXX | XXX | XXX | XXX | XXX | XXX | XXX | XXX | | |

Legend: White box means data item is collected. XXX means data item is not currently collected. OOO means data item only sometimes collected
B&H Bosnia Herzegovina. *Date dx* date of diagnosis. *Histo* histological subtype. *PS* performance status. *Comorbid* co-morbidity. *SES* socioeconomic status. *KCO* transfer factor. *MDT* multidisciplinary team. 1st line and 2nd line refer to treatment given. Last info date = follow-up data recorded up to point of death or censorship for annual report

The Charlson Index [9] and ACE-27 [10] were the most popular methods for recording co-morbid state. Denmark is the only country to record data on quality of life (QOL) at diagnosis and after treatment. In the Czech Republic, data on QOL is recorded at diagnosis, and the majority of countries record QOL in the research setting only.

Recording the treatment given to a patient was not universal; neither was confirming discussion at a multi-disciplinary team (MDT) meeting. In fact, it appears MDTs are not mandatory in Romania; they exist in certain centres, but there is no strict guidance as to their composition. Almost every country

Table 4 Illustrates the variation in methods used to record performance status, co-morbidity and quality of life

| | Performance status | | Co-morbidity | | | | Quality of Life (QOL) | | | | |
|--------------|--------------------|-----------|--------------|--------|----------|----------|-----------------------|--------|-------|-------|------------|
| | ECOG/WHO | Karnofsky | Charlson | ACE 27 | Specific | Other | EORTC | FACT-G | SF-36 | FACIT | Other |
| Albania | Yes | Yes | | | Yes | | | | | | None |
| Austria | Yes | | | | | Research | | | | | Research |
| Belgium | Yes | | Yes | | | | Yes* | | | | |
| B & H | Yes | | Yes | | | | Yes | | | | |
| Bulgaria | Yes | Yes** | | | Yes | | Yes* | | | | |
| Croatia | Yes | Yes | | | Yes | | | | | | None |
| Czech Rep | Yes | | | | | None | Yes | Yes | | | |
| Denmark | Yes | | Yes | | Yes | | Yes | | | | EORTC LC13 |
| Eng & Wales | Yes | | Yes | Yes | No* | | Yes* | | Yes* | | |
| Estonia | Yes* | Yes* | | | | None | | | | | None |
| Finland | Yes | Yes** | | | Yes | | | | | | Research |
| France | Yes | | Yes | | | | Yes | | | | |
| Germany | Yes | Yes | Yes* | | | | Yes* | | | | |
| Greece | Yes | Yes | Yes* | Yes* | Yes* | | Yes* | Yes* | Yes* | Yes* | |
| Hungary | Yes | Yes | | | | None | | | | | |
| Iceland | Yes | | | | Yes | | Yes* | | | | |
| Rep. Ireland | Yes | | | | | None | Yes* | | Yes* | | |
| Italy | Yes | Yes | | | Yes | | Yes | | | | |
| Lithuania | Yes | | | | | None | | | | | None |
| Luxembourg | Yes | | Yes | | | | | | | | None |
| Malta | Yes | Yes | | | Yes | | Yes | | | | |
| Moldova | | Yes | | | | None | | | Yes | | |
| Netherlands | Yes | | Yes | | | | Yes* | | | | |
| Norway | Yes | | Yes* | | | | Yes | Yes** | Yes** | Yes** | |
| Poland | Yes | | | | Yes | | Yes | | | | |
| Portugal | Yes | Yes** | Yes | | | | Yes* | | | | |
| Romania | Yes | | | | | None | | | | | None |
| Scotland | Yes | | | | | SLCFCSS | Yes* | | | | |
| Rep. Serbia | Yes | | | | Yes** | | Yes** | | | | |
| Slovakia | Yes | Yes | | | Yes | | Yes* | | | | |
| Slovenia | Yes | | | | Yes | | | | | | None |
| Spain | Yes | | | | Yes | | | | | | None |
| Sweden | Yes | | | | | No** | Yes | | | | |
| Switzerland | | Yes | Yes | | | | | | | | Variation |
| Turkey | Yes | Yes | | | | None | Yes* | Yes* | | | |

Legend: Charlson = Charlson Index [9]

ACE 27 Adult Co-morbidity Evaluation score [10], SLCFCSS Scottish Lung Cancer Forum Co-morbidity Scoring System [45], Specific specific co-morbid diseases are recorded, EORTC QLQ-C30 European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire [46], FACT-G Functional Assessment Cancer Therapy-General [47], SF-36 Short Form-36 [48], FACIT Functional Assessment Chronic Illness Therapy [49]

Yes* = research/clinical trials only

Yes** = infrequently

No* = no longer used

No** = Co-morbidity recorded only if it prevented planned treatment

recorded a date of death, the only exceptions at the time of the survey were; Albania, Estonia, Greece and Hungary.

Qualitative results

There were a number of themes which emerged when the national representatives were asked what the key

challenges were to universal data collection in their own country. Healthcare infrastructure with closer links between private and public sectors was cited as a requirement to facilitate a common hospital dataset with a unique patient identifier. Technological limitations, with no electronic patient record, and inadequate personnel to support a national dataset were issues for some. Motivation and education of clinicians was also identified as a barrier to universal uptake. Finally there was an acknowledgement from some that funding would be the key challenge, and a concern regarding the legality of a national patient dataset (Figure 1).

However, there was a very clear positive response towards the idea of a pan-European dataset of thoracic oncology. Twenty of the participants gave a definite positive response to this aspiration (57%), and a further 5 (14%) confirmed they would be keen if there were enough resources and assuming this did not result in duplication of work. Another 5 (14%) participants would support this work if there was national agreement, or it was made mandatory. One participant was quite neutral, and only 2 (6%) were opposed to the idea of a pan-European dataset.

Discussion

Main findings

The main finding of this study is that data are being collected in the majority of European countries, but the

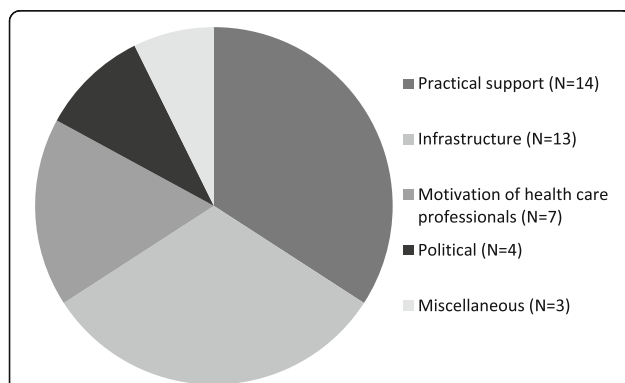


Fig. 1 Reported problems in achieving national data collection in 28 European countries. Legend: *Practical support* refers to the need for more funding and staff to support data collection. *Infrastructure* includes regional not national datasets, and those countries where private and university hospitals are not linked, or respiratory and oncology hospitals that work independently. It also includes the absence of a single patient identifier, and also those countries without electronic transfer of data. *Political will* was stated by 1 co-author as was concern regarding legal requirements and issues of patient consent by a further 3 co-authors. *Miscellaneous* includes quite specific difficulties encountered in three countries. One co-author stated an historical lack of interest in epidemiology as a whole as a barrier to better data collection. Three languages are spoken in one country and in another, patients are often treated abroad, which makes evaluating treatment outcomes and follow-up very difficult. Seven countries stated there were no difficulties in collecting data at a national level

nature, extent, and hence the usefulness of these data varies considerably. Surprisingly some basic demographic items as well as important factors predictive of outcome were omitted in some datasets, and do not form part of the European Network of Cancer Registries' (ENCR) recommendations [11, 12]. Socio-economic status and performance status are two of the most important predictors of outcome [13–17], yet data recording and completeness of these data items was highly variable. The majority of countries already use computerised reporting, with linkage to demographic information resources which allows survival analyses to be performed. However, in Albania, Estonia, Greece, Hungary, Malta and Romania these survival data are not collected, and the use of paper records remains current practice in Albania, Croatia, Lithuania and Romania. Many countries have a cancer registry, with good levels of data completeness, but they often lack the level of clinical detail required for evaluating quality management in thoracic oncology care.

We identified significant and important differences in the denominator used. The exclusion of cases which lack histological confirmation will make comparisons difficult because the size of the denominator will depend on the histological confirmation rate. Furthermore those countries that allow inclusion of death certificate only cases will have a comparatively poor outcome. It is clear from these two findings (variation in data items collected and denominator) that there needs to be agreement between interested parties (such as the ENCR, respiratory, oncology and surgical societies) on both patients included and the list of data items with specific definitions, ensuring feasibility of data collection in each country.

Another important finding from this survey is that within this selected group of clinicians, with only two exceptions, there was support to create a pan-European core dataset for thoracic oncology. This is an important area of development and one which demands the involvement of committed clinicians representing all disciplines.

Strengths and weaknesses

The main strength of this study is the high level of participation including 35 European countries. This has generated a comprehensive description of current practice in data collection in thoracic oncology from all areas of Europe. It is difficult to verify the self-reported data completeness levels given several countries do not report their data quality, and in those countries where data collection occurs at the local level, it is difficult to ensure we have correctly reported the data items used. A survey can only ever be descriptive and could be open to bias, but all the national representatives are physicians involved in thoracic oncology care and there was no

financial remuneration or pharmaceutical involvement which could have influenced the results. We therefore believe this to be an accurate reflection of current practice across Europe and the first survey to provide a pan-European picture.

Comparison with published data

There is very little published literature regarding the variation in data collection across Europe. However, in the past 25 years, the use of data to evaluate lung cancer care and make comparisons between areas of the world has become more common. It was in 1989, during his presidency of the European Union that Francois Mitterrand initiated a health programme on cancer prevention and patient information from which the EURO-CARE papers have all arisen [2, 4, 18]. The EURO-CARE studies are an excellent example of how data have been used to assess health outcomes, and the results have led to a change in healthcare funding and structure. Although the EURO-CARE-5 database contains approximately 22 million patients, from 26 countries [19], the actual coverage within some of these countries is below 1% population, which can introduce geographical bias [20, 21]. And there is evidence that some countries have incomplete follow-up data, which for a cancer with a poor prognosis, such as lung, can lead to falsely reassuring survival results [22]. Furthermore, these studies lack the level of clinical detail, such as performance status and stage, which are required to make direct clinical comparisons between countries. There is also variation between countries and their Registries as to whether they rely on histologically confirmed cases only, and whether they accept individuals diagnosed by death certificate only. In both situations, the cohort of patients with cancer will be different for those Registries who accept patients based on a clinical or radiological diagnosis or post-mortem compared with those Registries which do not. This is particularly relevant for cancers with a short survival like lung, and could create a systematic bias causing survival figures to appear better than they are for the whole population.

The National Lung Cancer Audit (NLCA) in England was established in 2004, to allow prospective data collection on all patients given a diagnosis of lung cancer and mesothelioma. This dataset, validated in 2009 [17], has shown a year on year improvement in both data acquisition and data completeness and has been used to assess inequalities in outcome based on patient and hospital features [23–30]. There has also been a demonstrable improvement in key quality performance indicators over the lifetime of the NLCA [31, 32]. Other European countries have developed similar systems for data collection and used these data to evaluate current practice and address any inequality that may be seen, including Denmark, Norway and The Netherlands [33–38]. The

Danish Lung Cancer Group wrote clinical guidelines in 1998, and started prospective data collection in 2000. They have been able to demonstrate that the use of data collection to monitor guideline adherence, audit performance at the local level and benchmark standards nationally, has led to an objective improvement in lung cancer outcome measures [39].

The International Cancer Benchmarking Project (ICBP) was set up in 2009, linking established cancer registration programmes in 6 countries across 3 continents, in order to look at cancer outcomes. It is thus limited to only a few countries. Lung cancer survival has been studied within this group and variation described, with Denmark and the UK observed to have lower survival compared to Canada, Sweden, Norway and Australia [40]. Furthermore, the International Consortium for Health Outcomes Measurement (ICHOM) published a comprehensive revised data collection reference guide in April 2015. Their aim is to create a standardised set of measurements, which can be used to compare performance between countries, and allow clinicians to learn from each other, and improve the provision of lung cancer care [41]. Both the ICBP and ICHOM require a level of detail of data collection that is likely to be beyond the capability of many European countries for the foreseeable future; what is required is a pragmatic solution.

The expansion of the European Union, and greater freedom of movement across borders, has led to European ministers beginning to address the issue of collaboration between national health services [42]. However, many European countries have healthcare systems that have evolved as the political situation changes, for example the war of independence in Croatia led to significant damage to the previously thriving cancer services [43]. It is this variation in socio-political stability that creates widely disparate healthcare systems. In order to understand variation in lung cancer outcome, one must acknowledge the variation in infrastructure, facilities, and treatments which are available.

In 2006 Ludwig, an Austrian oncologist, recommended a pan-European action plan on cancer, with benchmarking of the quality and effectiveness of the various healthcare systems [44]. This survey could form the background upon which a pan-European core dataset on thoracic oncology is built. The mechanism would involve an iterative approach based on what is feasible in each country, slowly building a more detailed dataset; the vehicle could be the network already established by the ERS Taskforce.

Conclusion

Improving the standard of care for our patients should be the aim of every clinician involved in thoracic oncology care, and in order to evaluate different practices

across Europe we need to be able to understand the political and economic setting in which it is based. Data collection can play an important role in evaluating medical practice and ensuring that whilst a cure for lung cancer and mesothelioma may not be on the horizon, the delivery of best available treatments should be realistic. Data collection itself relies on adequate infrastructure, dedicated personnel, and financial investment in the information technology to support large scale datasets. The results of this study have shown that there is genuine interest in pan-European data collection and a pressing need to develop a standardised dataset that is feasible for all to collect. To this end, a European Respiratory Society taskforce is developing both an essential (redacted) and minimum dataset. This is an important project upon which to build as it will allow meaningful analyses across Europe that can be used to drive improvements in care for our patients.

Additional files

Additional file 1: Survey for EuLuCA representatives. (DOCX 20 kb)

Additional file 2: Additional information provided by lung cancer physicians regarding thoracic oncology data collection in 35 European countries. (DOCX 22 kb)

Abbreviations

ACE-27: Adult Co-morbidity Evaluation-27; ATS: American Thoracic Society; EQMLCC: European Initiative in Quality Management in Lung Cancer Care; ENCR: European Network of Cancer Registries; ERS: European Respiratory Society; EuLuCA: European Lung Cancer Audit; IASLC: International Association Staging in Lung Cancer; ICBP: International Cancer Benchmarking Project; ICHOM: International Consortium for Health Outcomes Measurement; INAIL: Italian National Institute against accidents at work; MDT: Multi-Disciplinary Team; NLCA: National Lung Cancer Audit; PS: Performance Status; QOL: Quality of Life; SES: Socio-Economic Status; SNOMED: Systematised Nomenclature of Medicine; TNM: Tumour Node Metastasis; WHO: World Health Organisation

Acknowledgements

Not applicable.

Funding

No research funding was received.

Availability of data and materials

Data sharing is not applicable to this article as no datasets were generated or analysed during the current study.

Authors' contributions

The following co-authors were participants in the survey: IA, PB, SB, OB, AC, TC, RD, ED, JK, SE, MG, TG, BG, GH, RH, EJ, SJ, DJ, EK, AK, TL, RM, BM, RM, JM, RM, MN, PP, MS, AS, MS, JS, RSM, TES, and PVS. The following authors were involved in the study design and developing the survey: AR, DB, T-GB, TB, MP, and JPS. The results were compiled by AR, and checked by all co-authors. The paper was written by AR and DB assisted in editing the final document. All the authors named have read the manuscript and have agreed to submit the paper to BMC Cancer in its present format.

Ethics approval and consent to participate

There was no indication to seek ethical approval for a study designed to ascertain a narrative perspective on the current state of data collection in lung cancer registration across Europe. The survey participants were lung

cancer physicians who gave implied written consent by responding to the invitation to participate in the study.

Consent for publication

Not applicable.

Competing interests

The authors declare that they have no competing interests. It was performed within a wider project working as part of a European Respiratory Society (ERS) taskforce, designing a pan-European minimum dataset for lung cancer registration and a manual for lung cancer services. Since the paper has been under review with BMC Cancer, the final report of the ERS taskforce has been submitted and accepted for publication in the ERJ; therefore this paper, and the results it contains, are cited in the taskforce final report.

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Received: 29 October 2017 Accepted: 29 October 2018

Published online: 20 November 2018

References

- Coleman MP, Alexe DM, Albrecht T, McKee M. Published by Institute of Public Health of the Republic of Slovenia; 2008. http://www.euro.who.int/_data/assets/pdf_file/0011/97823/E91137.pdf. ISBN 978-961-6659-20-8
- Verdecchia A, Francisci S, Brenner H, Gatta G, Micheli A, Mangone L, et al. Recent cancer survival in Europe: a 2000-02 period analysis of EUROCORE-4 data. *Lancet Oncol*. 2007;8(9):784–796. PubMed PMID: 17714993.
- Raine R, Wong W, Scholes S, Ashton C, Obichere A, Ambler G. Social variations in access to hospital care for patients with colorectal, breast, and lung cancer between 1999 and 2006: retrospective analysis of hospital episode statistics. *BMJ*. 2010;340:b5479 PubMed PMID: 20075152. Pubmed Central PMCID: 2806941. Epub 2010/01/16. eng.
- Sant M, Aareleid T, Berrino F, Bielska Lasota M, Carli PM, Faivre J, et al. EUROCORE-3: survival of cancer patients diagnosed 1990-94—results and commentary. *Ann Oncol* 2003;14 Suppl 5:v61–118. PubMed PMID: 14684501.
- Rich A, Baldwin D. Status of Lung Cancer Data Collection in Europe. *JCO Clinical Cancer Informatics* 2018 16.2.2018 published on line.
- Blum TG, Rich A, Baldwin D, Beckett P, De Ruyscher D, Faivre-Finn C, et al. The European initiative for quality management in lung cancer care. *Eur Respir J*. 2014;43(5):1254–1277. PubMed PMID: 24659546.
- KR AT, Van den Bulcke M. European Guide on Quality Improvement in Comprehensive Cancer Control. Slovenia: Cancer Control Joint Action; 2017.
- Tang Y, He Z, Zhu Q, Qiao G. The 2011 IASLC/ATS/ERS pulmonary adenocarcinoma classification: a landmark in personalized medicine for lung cancer management. *J thorac dis*. 2014;6(Suppl 5):S589–96 PubMed PMID: 25349710. Pubmed Central PMCID: 4209390.
- Charlson ME, Pompei P, Ales KL, MacKenzie CR. A new method of classifying prognostic comorbidity in longitudinal studies: development and validation. *J Chronic Dis* 1987;40(5):373–383. PubMed PMID: 3558716.
- Kaplan MH, Feinstein AR. The importance of classifying initial co-morbidity in evaluating the outcome of diabetes mellitus. *J Chronic Dis* 1974 Sep; 27(7–8):387–404. PubMed PMID: 4436428.
- Registries ENOC. Recommendations for a Standard Dataset for the European Network of Cancer Registries 2005.
- Registries ENOC. Standards and guidelines for cancer registration in Europe. International Agency for Research on Cancer; 2003. <http://publications.iarc.fr/Book-And-Report-Series/Iarc-Technical-Publications/Standards-And-Guidelines-For-Cancer-Registration-In-Europe-2003>.
- Maclay JD, Farley JM, McCowan C, Tweed C, Milroy R. Obtaining tissue diagnosis in lung cancer patients with poor performance status and its influence on treatment and survival. *Respir Med* 2017;124:30–35. PubMed PMID: 28284318.
- Reck M, Thatcher N, Smit EF, Lorigan P, Szutowicz-Zielinska E, Liepa AM, et al. Baseline quality of life and performance status as prognostic factors in patients with extensive-stage disease small cell lung cancer treated with pemetrexed plus carboplatin vs. etoposide plus carboplatin. *Lung Cancer* 2012;78(3):276–281. PubMed PMID: 23043970.
- Denton EJ, Hart D, Russell PA, Wright G, Conron M. Lung cancer and socio-economic status: inextricably linked to place of residence. *Intern Med J* 2017;47(5):563–569. PubMed PMID: 28105777.
- Quaglia A, Lillini R, Casella C, Giachero G, Izzotti A, Vercelli M, et al. The combined effect of age and socio-economic status on breast cancer survival. *Crit Rev Oncol Hematol* 2011 Mar;77(3):210–220. PubMed PMID: 20227888.
- Rich AL, Tata LJ, Stanley RA, Free CM, Peake MD, Baldwin DR, et al. Lung cancer in England: information from the National Lung Cancer Audit (LUCADA). *Lung Cancer* 2011 Apr;72(1):16–22. PubMed PMID: 20688413.
- Berrino F, Sant M, Verdecchia A, Capocaccia R, Hakulinen T, Esteve J. Survival of cancer patients in Europe: the EUROCORE study. *IARC Sci Publ*. 1995;132.
- De Angelis R, Sant M, Coleman MP, Francisci S, Baili P, Pierannunzio D, et al. Cancer survival in Europe 1999-2007 by country and age: results of EUROCORE-5—a population-based study. *Lancet Oncol*. 2014 Jan;15(1):23–34. PubMed PMID: 24314615.
- Rossi S, Baili P, Capocaccia R, Caldora M, Carrani E, Minicozzi P, et al. The EUROCORE-5 study on cancer survival in Europe 1999-2007: database, quality checks and statistical analysis methods. *Eur J Cancer* 2015;51(15): 2104-2119. PubMed PMID: 26421815.
- Zanetti R, Schmidtman I, Sacchetto L, Binder-Foucard F, Bordoni A, Coza D, et al. Completeness and timeliness: Cancer registries could/should improve their performance. *Eur J Cancer* 2015;51(9):1091–1098. PubMed PMID: 24393522.
- De Angelis R, Francisci S, Baili P, Marchesi F, Roazzi P, Belot A, et al. The EUROCORE-4 database on cancer survival in Europe: data standardisation, quality control and methods of statistical analysis. *Eur J Cancer* 2009;45(6): 909–930. PubMed PMID: 19128955.
- Rich AL, Tata LJ, Free CM, Stanley RA, Peake MD, Baldwin DR, et al. How do patient and hospital features influence outcomes in small-cell lung cancer in England? *Br J Cancer*. 2011;105(6):746–52 PubMed PMID: 21829191. Pubmed Central PMCID: PMC3171016.
- Rich AL, Tata LJ, Free CM, Stanley RA, Peake MD, Baldwin DR, et al. Inequalities in outcomes for non-small cell lung cancer: the influence of clinical characteristics and features of the local lung cancer service. *Thorax* 2011;66(12):1078–1084. PubMed PMID: 21785158.
- Khakwani A, Rich AL, Powell HA, Tata LJ, Stanley RA, Baldwin DR, et al. The impact of the 'hub and spoke' model of care for lung cancer and equitable access to surgery. *Thorax* 2015;70(2):146–151. PubMed PMID: 25182047.
- Khakwani A, Rich AL, Powell HA, Tata LJ, Stanley RA, Baldwin DR, et al. Lung cancer survival in England: trends in non-small-cell lung cancer survival over the duration of the National Lung Cancer Audit. *Br J Cancer*. 2013;109(8): 2058–65 PubMed PMID: 24052044. Pubmed Central PMCID: PMC3798968.
- Khakwani A, Rich AL, Tata LJ, Powell HA, Stanley RA, Baldwin DR, et al. Small-cell lung cancer in England: trends in survival and chemotherapy using the National Lung Cancer Audit. *PLoS One*. 2014;9(2):e89426 PubMed PMID: 24586771. Pubmed Central PMCID: PMC3931780.
- Khakwani A, Rich AL, Tata LJ, Powell HA, Stanley RA, Baldwin DR, et al. The pathological confirmation rate of lung cancer in England using the NLCA database. *Lung Cancer* 2013;79(2):125–131. PubMed PMID: 23218790.
- O'Dowd EL, McKeever TM, Baldwin DR, Anwar S, Powell HA, Gibson JE, et al. What characteristics of primary care and patients are associated with early death in patients with lung cancer in the UK? *Thorax* 2015;70(2):161–168. PubMed PMID: 25311471. Pubmed Central PMCID: 4316923.
- Powell HA, Tata LJ, Baldwin DR, Stanley RA, Khakwani A, Hubbard RB. Early mortality after surgical resection for lung cancer: an analysis of the English National Lung cancer audit. *Thorax* 2013;68(9):826–834. PubMed PMID: 23687050.
- Centre HaSCL. National Lung Cancer Audit Report 2013. 2013.
- Centre HaSCL. National Lung Cancer Audit Report 2014. 2014.
- Damhuis RA, Maat AP, Plaisier PW. Performance indicators for lung cancer surgery in the Netherlands. *Eur J Cardiothorac Surg* 2015;47(5):897–903; discussion –4. PubMed PMID: 25187534.
- Strand TE, Bartnes K, Rostad H. National trends in lung cancer surgery. *Eur J Cardiothorac Surg* 2012;42(2):355–358. PubMed PMID: 22402451.
- Strand TE, Rostad H, Damhuis RA, Norstein J. Risk factors for 30-day mortality after resection of lung cancer and prediction of their magnitude. *Thorax* 2007;62(11):991–997. PubMed PMID: 17573442. Pubmed Central PMCID: 2117132.
- Jakobsen E, Palshof T, Osterlind K, Pilegaard H. Data from a national lung cancer registry contributes to improve outcome and quality of surgery: Danish results. *Eur J Cardiothorac Surg* 2009;35(2):348–352; discussion 52. PubMed PMID: 19070503.
- Kaergaard Starr L, Osler M, Steding-Jessen M, Lidegaard Frederiksen B, Jakobsen E, Osterlind K, et al. Socioeconomic position and surgery for early-stage non-small-cell lung cancer: A population-based study in Denmark. *Lung Cancer* 2013;79(3):262–269. PubMed PMID: 23276505.
- Holmberg L, Sandin F, Bray F, Richards M, Spicer J, Lambe M, et al. National comparisons of lung cancer survival in England, Norway and Sweden 2001-2004: differences occur early in follow-up. *Thorax* 2010;65(5):436–441. PubMed PMID: 20435867.
- Jakobsen E, Green A, Osterlind K, Rasmussen TR, Iachina M, Palshof T. Nationwide quality improvement in lung cancer care: the role of the Danish Lung Cancer Group and Registry. *J Thorac Oncol* 2013;8(10):1238–1247. PubMed PMID: 24457234.
- Walters S, Maringe C, Coleman MP, Peake MD, Butler J, Young N, et al. Lung cancer survival and stage at diagnosis in Australia, Canada, Denmark,

- Norway, Sweden and the UK: a population-based study, 2004-2007. *Thorax* 2013;68(6):551–564. PubMed PMID: 23399908.
41. Measurement ICfHO. Lung Cancer; Data Collection Reference Guide. 2015.
 42. McCarthy M, Poses RM, Saghatchian M, de Povourville G, Tursz T, Gray A. Cancer funding throughout the world. *Lancet Oncol.* 2004;5(7):453–457. PubMed PMID: 15231253. Epub 2004/07/03. eng.
 43. Sansom C. Provision of cancer care in Eastern Europe. *Lancet Oncol.* 2002; 3(4):203–205. PubMed PMID: 12067679. Epub 2002/06/18. eng.
 44. Ludwig H. Keynote comment: inequalities and shortcomings in European cancer care. *Lancet Oncol* 2006;7(4):276–277. PubMed PMID: 16574541. Epub 2006/04/01. eng.
 45. Grose D, Morrison DS, Devereux G, Jones R, Sharma D, Selby C, et al. The impact of comorbidity upon determinants of outcome in patients with lung cancer. *Lung Cancer* 2015;87(2):186–192. PubMed PMID: 25498829.
 46. Bergman B, Aaronson NK, Ahmedzai S, Kaasa S, Sullivan M. The EORTC QLQ-LC13: a modular supplement to the EORTC Core Quality of Life Questionnaire (QLQ-C30) for use in lung cancer clinical trials. EORTC Study Group on Quality of Life. *Eur J Cancer* 1994;30A(5):635–642. PubMed PMID: 8080679.
 47. Cella DF, Tulsky DS, Gray G, Sarafian B, Linn E, Bonomi A, et al. The Functional Assessment of Cancer Therapy scale: development and validation of the general measure. *J Clin Oncol* 1993;11(3):570–579. PubMed PMID: 8445433.
 48. Ware JE, Jr., Sherbourne CD. The MOS 36-item short-form health survey (SF-36). I. Conceptual framework and item selection. *Med Care* 1992;30(6):473–483. PubMed PMID: 1593914.
 49. Webster K, Cella D, Yost K. The Functional Assessment of Chronic Illness Therapy (FACIT) Measurement System: properties, applications, and interpretation. *Health Qual Life Outcomes* 2003;1:79. PubMed PMID: 14678568. Pubmed Central PMCID: 317391.

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