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ORIGINAL ARTICLE

Lung cancer registries in Denmark, Finland, Norway and Sweden: a comparison and proposal for harmonization

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ABSTRACT

Background: Lung cancer is the leading cause of cancer-related death in all Nordic countries which, though similar in demographics and healthcare systems, have noticeable differences in lung cancer survival. Historically, Denmark and Finland have had higher lung cancer incidences and lower survival than Norway and Sweden. All four countries have national cancer registries. Data in these registries are often compared, but their full potential as a source of learning across the Nordic countries is impeded by differences between the registries. In this paper, we describe and compare the Nordic registries on lung cancer–specific data and discuss how a more harmonized registration practice could increase their usefulness as a source for mutual learning and quality improvements.

Methods: We describe and compare the characteristics of data on lung cancer cases from registries in Denmark, Finland, Norway and Sweden. Moreover, we compare the results from the latest annual reports and specify how data may be acquired from the registries for research.

Results: Denmark has a separate clinical lung cancer registry with more detailed data than the other Nordic countries. Finland and Norway report lung cancer survival as relative survival, whereas Denmark and Sweden report overall survival. The Danish Lung Cancer Registry and the Swedish Cancer Registry do not receive data from the Cause of Death registries in contrast to the Finnish Cancer Registry and the Cancer Registry of Norway.

Conclusion: The lung cancer registries in Denmark, Finland, Norway and Sweden have high level of completeness. However, several important differences between the registries may bias comparative analyses.

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Introduction

Lung cancer is the second most common cancer in both men and women in the Nordic countries [1,2] and is the leading cause of cancer-related death in all Nordic countries [3–5]. The organization of cancer care has been increasingly harmonized between the countries [6], and Denmark, Sweden and Norway have implemented fast-track lung cancer pathways to ensure an accelerated diagnostic process and referral to treatment with minimal delay [7].

All four countries generally have high standards of living and tax-funded, income-independent healthcare provided to all citizens and are therefore able to generate population-based national registries [8,9]. The unique personal identification number provided to all residents at birth or immigration enables linking of individual data across national registers, including follow-up for death or emigration. In each country, the registration of causes and date of death is mandatory in the national cause of death registries.

All Nordic countries have nationwide cancer registries. The Danish Cancer Registry is the oldest, founded in 1942, while the Cancer Registries of Norway, Finland and Sweden were founded in 1952, 1952 and 1958, respectively [10].

In addition to the Danish Cancer Registry (DCR), the Danish Lung Cancer Registry (DLCR) was established in 2000 and has since monitored and registered interventions and outcomes of Danish lung cancer patients [4,11]. Finland does not have a specific lung cancer registry; Norway has a lung cancer registry within their national cancer registry and Sweden has a national lung cancer quality registry separate from their national cancer registry. The national cancer registries are used mainly to monitor the incidence, mortality and quality of cancer care at a national and regional level, but they have also been used to compare incidence and

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outcomes, such as survival, in international comparative studies and reports [5,12,13].

In spite of the similarities between the Nordic countries, noteworthy differences remain in reported lung cancer–specific outcomes, where patients in Denmark and Finland historically have had the highest overall incidence and mortality [2]. Several not mutually exclusive causes for these discrepancies have been suggested; differences in the prevalence of tobacco smoking [14] and in alcohol consumption [15], and a higher burden of comorbidity. But differences in registration practices [16] may also bias direct comparison of survival rates [4]. In order to relevantly conduct more detailed comparative studies regarding lung cancer care and survival, it is imperative that we obtain more knowledge about the completeness, identification of patients and the variables in the respective national registries concerning lung cancer. More specific comparisons such as stage-specific survival, smoking related variables and comorbidities could make the registries a valuable source for mutual learning and quality improvement across the Nordic countries. Overall comparisons between the national cancer registries at a general level have been reported [10,17], but no formal comparison of the data regarding lung cancer has yet been published. The aims of the present paper are to describe the cancer registries in Denmark, Finland, Norway and Sweden with regards to lung cancer and discuss differences between the registries and how they could become more harmonized.

Methods

For each registry, we obtained a description of the registry itself, the latest status or annual report, and other potentially relevant studies/publications based on data from the registries. We invited researchers from all four countries to participate in this study to ensure the most detailed information about each of the registries.

Completeness of the registries was defined according to Parkin and Bray as the extent to which a new cancer diagnose is captured by the registry [18].

Results

Selected data within each registry are shown in Table 1.

In the sections below, we present the registries of each country and the respective results based on the most recently published reports. The latest results from each registry are presented in Table 2.

The Danish cancer registry and the Danish lung cancer registry

Since 1942, the Danish Cancer Register (DCR) has collected information on diagnosis, disease stage and vital status from all new cancer patients in Denmark [19–21]. The purpose of the DCR is to collect data on new cases of cancer, in order to monitor incidence and prevalence of all cancers in Denmark, with mandatory reporting since 1987 [20]. The DCR does not contain data on clinical characteristics, diagnostic procedures, comorbidity or treatment complications (Table 1).

The Danish Lung Cancer Registry (DLCR) was established by the Danish Lung Cancer Group (DLCG) in 2000 [22]. The primary purpose of DLCG and later of the DLCR was to improve survival and the quality of lung cancer care in Denmark [22]. As a consequence of the latter aim, DLCR has from the start included detailed information about treatment complications as well as information about waiting time during the patient's pathway from suspicion of lung cancer to the final treatment. A secondary purpose has been to provide a platform for epidemiological lung cancer research [11]. DLCR has monitored the interventions and outcomes of all Danish patients diagnosed with lung cancer with a high level of completeness [4,11]. Since 2003, lung cancer patients have been identified in the Danish National Patient Registry (DNPR) by diagnostic codes C34 and C33, according to the International Classification of Diseases, 10th Revision (ICD-10) [23]. The database collects supplementary information from the Danish Pathology Register, which contains information from all Danish departments of pathology with data coded according to the international systematized nomenclature of medicine clinical terms (SNOMED) classification, including information on topography and morphology. Furthermore, the entries in the DLCR are validated and supplied with additional clinical information from practicing clinicians through an online platform, while data on comorbidity and diagnostic procedures are obtained from the DNPR. All departments involved in the diagnostic process and/or treatment of lung cancer in Denmark report data to the DLCR, which is mandatory by law [11]. Vital status is retrieved from the Danish Civil Registration System once a month [24]. Unlike the DCR, the DLCR does not receive information from the Cause of Death Register. Thus, the DLCR contains data on patient characteristics, diagnostic procedures, histology, tumor stage, lung function, performance status, comorbidity (as Charlsons comorbidity index), treatment, possible treatment complications and vital status (Table 1) [25]. Survival is reported as observed overall survival based on yearly cohorts (Table 2). In the DLCR, variables concerning diagnostic work-up and surgical treatment are specific and up to date. However, data on oncological therapy are currently not regarded as adequate [25] and it is currently not possible to extract which type of oncological treatment was given and whether it was with curative or palliative intent.

Of the incident lung cancer cases in 2020, 93.7% were morphologically verified [25]. A study comparing data in the DLCR to data in the DCR was published in 2020 [26]. The agreement between the registries was 87%, with main discrepancies being date of diagnosis while the agreement of the DLCR was 94.4% of the population of eligible patients [26].

Researchers can apply for data from the DLCR by applying The Danish Clinical Quality Program – National Clinical Registries [27].

The Finnish cancer registry

Founded in 1952, the Finnish Cancer Registry (FCR) maintains the national population-based cancer registry on behalf of the Finnish Institute for Health and Welfare. Registration

Table 1. Comparisons of the Nordic cancer registries.

	Denmark		Finland	Norway	Sweden	
	DCR	DLCR	FCR	CRN/NLCR	SCR	SNLCR
Founded	1942	2000	1952	1952	1958	2002
Year of the latest report	2020	2021	2020	2021	2018	2021
Incidence (per 100.000)	Women 66.1 Men 70.8 (Age standardized)	No	Women 33.7 Men 60.3 (Age standardized)	Women 53.9 Men 62.7 (Age standardized)	Women 36.7 Men 41.7	No
Histology	No	Yes	Yes	Yes	Yes	Yes
Molecular Pathology (EFGR, ALK, PD-L1)	No	Yes	No	Yes	No	Yes
Stage	No	Yes	Yes	Yes	Yes	Yes
Coding	ICD-10	ICD-10	ICD-O-3	ICD-O2 (Converted to ICD-10)	ICD-7	ICD-O3
Comorbidity	No	Yes (CCI)	No	No	No	Yes
Smoking history	No	Yes	No	No	No	Yes
Alcohol consumption	No	Yes (only surgical patients)	No	No	No	No
Diagnostic procedures	No	Yes	Yes	Yes	No	Yes
Treatment	No	Yes	Yes	Yes	Yes	Yes
WHO PS	No	Yes	No	Yes	No	Yes
Registration mandatory	Yes	Yes	Yes	Yes	Yes	Yes
Completeness (%)	Unknown	94.4	97.2	98.8	96.3	95
DCI/DCO available (%)	1	No	4.8	1.5	No	No
Morphologically verified (%)	89	94.3	82.4	90.4	90	93

Data from the annual reports.

DCR: Danish Cancer Registry; DLCR: Danish Lung Cancer Registry; FCR: Finnish Cancer Registry; CRN: Cancer Registry Norway; NLCR: Norwegian Lung Cancer Registry; SCR: Swedish Cancer Registry; SNLCR: Swedish National Lung Cancer Registry; PS: performance status; DCI: death certificate initiated; DCO: death certificate only.

Table 2. Results from the latest annual reports.

	Denmark		Finland	Norway	Sweden	
	DCR	DLCR	FCR	NCR/NLCR	SCR	SNLCR
Results from latest reports	2020	2021	2020	2021	2018	2021
Stage I (%)	Not available	25.4	Local: 6	26.4	Not available	22.6
Stage II (%)	Not available	8.3	Non-local: 47	7.5	Not available	7.0
Stage III (%)	Not available	18.1		18.7	Not available	18.7
Stage IV (%)	Not available	46.2		44.7	Not available	50.8
Unknown (%)	Not available	2.1	47	2.6	Not available	0.8
Treated with curative intent (%)	Not available	34.9	Not available	38.8	Not available	Not available
Surgically treated (%)	Not available	28.6	Not available	21.2	Not available	Not available
Post-surgery mortality rate (30 days) (%)	Not available	0.2	Not available	0.6	Not available	Not available
1-year survival (%)	Women 61, Men 53 (Relative survival)	55.1	Women 47, Men 38 (Relative survival)	Women 61.7, Men 56.1 (Relative survival)	No	53.0
5 -year survival (%)	Women 30, Men 24 (Relative survival)	23	Women 21, Men 14 (Relative survival)	Women 32.5, Men 25.6 (Relative survival)	Women 24.0 Men 16.8	21.0

began in 1953 and reporting by treating hospitals and pathology laboratories became mandatory in 1961 [28]. All invasive cancer cases, including suspected cases should be reported to the registry. Since 2007, the International Classification of Diseases for Oncology (ICD-O-3) has been used for coding cancer cases to the FCR database, these data are converted to ICD-10 for reporting purposes. Reported data concerning tumor and disease stage should preferably be based on the TNM classification, but data is still often missing. Thus, based on the best available information received, lung cancer cases are classified as either localized, non-localized, or unknown [28].

Vital status of cancer patients and data on emigration are updated continuously from the population information system. Data on cancer cases are linked annually to Statistics Finland for information on cause of death. In order to identify potential missing cancers that have not been reported to the FCR, Statistics Finland forwards all death certificates where cancer is mentioned to the registry (death certificate only (DCO) and death certificate-initiated cases). However, due to limited resources and focusing on high coverage, detailed clinical data is limited and the registry does not collect information on factors like smoking history, alcohol consumption, performance status or diagnostic procedures (Table 1) [29].

The aim of the FCR is to provide information to decision-makers and healthcare professional with the main focus being on cancer incidence and mortality with high coverage. Currently, there are plans to use the Care and Patient Registry to obtain more information concerning treatment in the future. Official cancer statistics are published twice annually and available online [28]. Cancer data are also widely used for research purposes both with and without the involvement of FCR researchers and can be requested from Findata [30]. For the period 2009–2013, the overall completeness of the FCR was estimated at 96% and 97.2% concerning respiratory cancers [31]. Of the incident lung cancer cases, 82.4% were microscopically verified and 4.8% were DCO.

The cancer registry of Norway and the Norwegian lung cancer registry

The Cancer Registry of Norway (CRN) has since the implementation of a directive from the Ministry of Health and Social Affairs in 1952, systematically collected data on cancer occurrence for the entire Norwegian population [32]. Data are provided from clinicians, hospitals, pathology departments and other national health registries. All physicians in Norway are obliged by law to register new cancer cases in the CRN including suspicion of cancer. The pathology-specific variables provide information on histological, cytological or autopsy data. The CRN receives information from the Cause of Death Registry, the Norwegian Patient Registry and is updated monthly by the Norwegian Population Register for vital status (death or emigration) [32,33]. The CRN classifies lung cancer as either localized, regional or metastatic based on the SEER classification system and ICD-O-3. For reporting purposes, the codes are converted into ICD-10. In 2009, the overall completeness of the CRN was estimated to be 98.8%, and 93.8% were morphologically verified. The completeness of lung cancer data in the CRN was 96.9% with 90.4% morphologically verified [34].

In 2013, CRN introduced a new registry specifically for lung cancer, the Norwegian Lung Cancer Registry (NLCR) [35]. It includes all Norwegian patients with lung cancer–specific ICD-10 codes (C34 or C33). The aim of NLCR is to improve quality of treatment provided to lung cancer patients as well as to serve as a data source for scientific studies. The CRN is responsible for collecting and storing the data in the NLCR. The NLCR is based on data forwarded electronically by treating physicians, surgeons and oncologists as well as pathology reports. The NLCR includes basic data found in the CRN such as reports on primary site of the tumor, time of diagnosis and death. In addition, it collects data on histology, targetable mutations, stage (TNM 8th edition), diagnostic procedures, performance status and treatment [35]. Currently, the Norwegian registries lack information on smoking status, as clinicians are prohibited to report these data to the registries without patient consent (Table 1). However, patient-related outcome reports, including data in smoking, have recently been implemented.

The NLCR has a high level of reporting concerning diagnostic work-up and surgical treatment, 91.8% and 100% respectively [35]. Data regarding radiotherapy is annually transferred from all radiation centers to the CRN. In 2019, a project regarding automatic extraction of specific data on medical oncological treatment from hospitals and pharmacies was introduced. At present about 85% of patients are covered by this project and select results are incorporated into the NLCR annual report.

Researchers can request data from the CRN by contacting the registry [32].

The Swedish cancer registry and the Swedish national lung cancer registry

The Swedish Cancer Register (SCR) was founded in 1958. It covers the entire population and is managed by the National Board of Health and Welfare [36]. It is mandatory for every healthcare provider to report newly detected cancer cases to the registry. Since 2005, cases have been coded by ICD-O-3 and ICD-7. For all incident cancers, the SCR contains data on patient characteristics, diagnostic procedures, histology and TNM stage (since 2004) including information from autopsy reports. The SCR does not contain data on performance status, comorbidities, smoking status, treatment or treatment complications (Table 1). The six Regional Cancer Centers located across Sweden's healthcare regions are responsible for registration, coding, verification, and the completeness of the registry. The regional centers report to SCR annually. The SCR does not receive data from the Cause of Death Register [36]. A study from 2008 on correlation between hospital discharge records and SCR found an overall underreporting of cancers of 3.7% [37].

The Swedish National Lung Cancer Register (SNLCR) was established in 2002 and includes more than 95% of all patients registered with a lung cancer diagnosis (C34) in the SCR by ICD-7/ICD-O-3. The aim of the SNLCR was to standardize, harmonize and improve the quality of management of the lung cancer patients, as well as for research purposes [37]. The SNLCR is a prospective, population-based register with detailed information on sex, age, smoking history, performance status, diagnostic work-up, histology, stage and planned primary treatment (Table 1). Vital status is updated by the National Population Register. The SNLCR does not include cancers discovered at autopsy, that is, there is no inclusion of DCO cases. In 2020, 93% of incident lung cancer patients were morphologically verified and the registry has included information on EGFR mutation status since 2010 [38].

Lung Cancer Database Sweden is a research database generated by record linkage between the SNLCR, the SCR, the Cause of Death Register, the National Patients Register, the Prescribed Drug Register and the National Population Register in Sweden [39–41].

Researchers can obtain access to data in the SNLCR or Lung Cancer Database Sweden following a formal request directed to the Regional Cancer Center – Central [42].

Registration of cancers is centrally handled in all countries other than Sweden, where six regional cancer centers provide data to the central cancer registry. For all registries, except the SCR and the DLCR, additional incident cases are found through linkage with the national causes of death registers.

NORDCAN

The NORDCAN database was founded in 2002 and includes information on cancer incidence, mortality and prevalence in the Nordic countries (Denmark, Finland, Iceland, Norway, Sweden and Faroe Islands) dating back to the 1970's and is regularly updated. In addition to serve as a research platform, the aim of NORDCAN is to provide comparable and timely data for policy makers, cancer societies, and the public [2]. The NORDCAN database receives information from the national cancer registries. The database offers a public online platform found on www.nordcan.iarc.fr [2]. However, data in NORDCAN is aggregated and cannot be combined with other databases. The latest 5-year relative survival of male lung cancer patients from NORDCAN (2016–2020) were 24%, 16%, 27% and 24% in Denmark, Finland, Norway and Sweden respectively and 31%, 26%, 33% and 31% for female patients [2].

Discussion

As data sources in the Nordic cancer registries are quite similar, data on incident lung cancers should overall be comparable. However, several potential confounding factors must be considered when comparing survival rates between the Nordic countries. Selective data collection and varying population coverage may contribute to the reported differences in survival between the countries [4,43], in addition to differences in reported survival (relative versus overall), comorbidities and smoking prevalence.

In the DCR, the FCR and the NCR additional incident cancers are detected through linkage with the national cause of death registers. Pukkala et al. estimated a 4% higher proportion of non-registered cancers in the SCR cases than in the other Nordic countries in 2018 [10]. The DLCR does not link data from the National Cause of Death Register. Christensen J et al. found less than 1% were from death certificate only (DCO) in the DCR in 2013–2014 [26], while Leinonen et al. found that 4.8% of the lung cancer cases were based on DCO in the FCR [28]. In a previous study from 2007, based on data from the FCR on 12 different cancer types including lung cancer, adjusting for cases by death certificates only, slightly reduced survival estimates [16]. Patients diagnosed with lung cancer based on DCO are more likely to be at a higher disease stage, compared to patients going through regular diagnostic work-up. By not linking the SCR and DLCR data to the Cause of Death Register, information bias caused by underreporting of patients with higher disease stage may be introduced. A proportion of the reported increased survival rate of Swedish lung cancer patients could be due to differences in registration practices, by the exclusion of patients only formally diagnosed after death. However, other studies have only found a minimal difference in survival-rates when including patients from hospital charts that had not been registered in the cancer register in the UK [44] and in simulation studies [45]. To which extent differences in registration practice affect differences in survival-rates, is unknown and cannot be further assessed in the present setting.

The DLCR differs from the other national registries as does its purpose. It has a greater level of detailed clinical information including treatment complications registered by the treating clinicians (Table 1). Based on data from available registries, the DLCR and FCR reports the lowest 5-year survival (Table 2). DLCR reports actually observed overall survival based on yearly cohorts of patients and not relative survival or survival based on the period method for patient cohorts that have not yet reached the intended observation period, for example, 5 years as in the DCR [21], the FCR [28] and the NCR [33] which is why the reported survival rates for the more recent years cannot be directly compared when survival rates are steadily improving. Relative survival is defined as the ratio of the observed survival in the group of patients to the survival expected in a group of people in the general population, who are similar to the patients with respect to sex, age and calendar time at the time of diagnosis [46]. It can be interpreted as the probability of patient survival in the absence of other causes of death or as an estimation of cancer related death. Thus, when comparing survival rates between these countries, the Finnish and Norwegian will tend to be higher due to this adjustment. Comparative relative survival rates for all Nordic countries are reported in NORDCAN [2]; however, it has no information regarding stage distribution and stage specific survival, which limits the mutual learning potential.

The DLCR was initiated in order to monitor and assess quality of diagnostics, treatment and outcomes between regions in Denmark, and by these means to identify the optimal clinical practice and thus ultimately to improve survival from lung cancer through mutual learning from the results obtained in other parts of the country. Moreover, the DLCR has also been used as data source in several research projects, which have resulted in publication of several peer reviewed papers [47]. A validation study on the DLCR compared to hospital charts has never been conducted however, Christensen J et al. assessed the data in the DLCR compared to the DCR and found an agreement of 87%, increasing to 95% if the time period were increased [26].

Norway does not have a separate lung cancer registry, but rather a lung cancer specific registry under their national cancer registry, which automatically will ensure agreement between the lung cancer registry data and the national cancer registry data. In Finland, there are currently no specific plans for a lung cancer-based quality registry but instead, the national population-based Cancer Registry can be used as a basic data source for including complementary data from other well-defined sources, such as The Care and Patient Registry and prescriptions database.

The Nordic cancer registries, with the exception of Norway, have limited information on specific medical oncological lung cancer treatment, and the registries are at present not suitable as a platform for research in this field. In Norway they have introduced automatic registration of medical oncology treatment given at hospitals and in the outpatient setting, to improve the registry. The DLCR is working on improving the data quality regarding medical oncological treatment using a similar methodology.

Having compared the available Nordic registries on lung cancer cases, the following variables should be included in each lung cancer specific registry in order to be able to use these for detailed studies regarding differences between the Nordic Countries on treatment and results. (1) Information on the patient including age, sex, comorbidity, and performance status. In addition, information on smoking and alcohol consumption, both factors known to influence survival [48], would be valuable. (2) Information on the lung cancer, including morphology, molecular pathology, and stage according to TNM8. (3) Information on treatment including surgery and specification of the oncological treatment (chemotherapy, radiation, targeted treatment, immunotherapy) and whether treatment was given with curative or palliative intent. (4) Information on outcomes including date and cause of death. At present, none of the Nordic registries include all the above-mentioned variables on lung cancer cases.

For specific lung cancer registries, we recommend the use of relative survival in the future to minimize the influence of differences between countries in general mortality and thus to aid comparisons. The harmonization could be accomplished by DLCR adapting the methods used by NCR and DCR. The proposed harmonization and mutual improvements of the content of the registries would provide a better foundation for more accurate and detailed comparative studies between the Nordic Countries, which again would improve the possibility for learning between the countries.

Strengths and limitations

The strength of this study is the comparison of the Nordic lung cancer registries with contributing authors from the four most populous Nordic countries. There are, however, limitations to the present comparison. It is not a comprehensive systematic comparison of all components in the respective lung cancer/cancer registries, but we have focused on the most significant aspects and differences. Furthermore, differences in the countries registration practice make direct comparison difficult. It has been one of the purposes of this paper to identify these differences. We have, however, not been able to assess the impact on reported outcomes of the selection and information bias introduced by the differences in registration practices.

Conclusion

Denmark, Finland, Norway and Sweden all have national registries including data on lung cancers. Even though the information in the Nordic Cancer Registries have many resemblances, there are still numerous differences in registration routines, classification systems and level of details in the registries. Consequently, direct comparisons of survival will be limited by these discrepancies. Denmark has a separate lung cancer registry which collects data independently of the DCR with more detailed information on diagnostic procedures and treatment with input from both the NPR and clinicians. Although the Nordic lung cancer registries are largely comparable, investigators and policymakers should be aware of possible differences in data quality and sources of error. If the contents of the registries were harmonized and elaborated to include important confounders, the registries could be an even more valuable source for mutual learning across the Nordic countries and thus likely lead to further quality improvements.

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Data availability statement

Data sharing is not applicable to this article as no new data were created or analyzed in this study.

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