

VALIDERING AF DANSK LUNGE CANCER REGISTER

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COI

- AstraZeneca
- GSK



**Landspatient-
registret**

**Landsregistret for
Patologi**

**Dansk
Lunge Cancer Register**



The screenshot shows the web interface of the Dansk Lunge Cancer Register. It includes a header with the logo and name, a search bar, and several sections for data entry and reporting. The main section is a table with columns for patient ID, hospital, and cancer details. The table is partially filled with data.

Id	Hospital	Diagnose	Stadium	Behandling	Udfald
1	1	1	1	1	1
2	2	2	2	2	2
3	3	3	3	3	3
4	4	4	4	4	4
5	5	5	5	5	5
6	6	6	6	6	6
7	7	7	7	7	7
8	8	8	8	8	8
9	9	9	9	9	9
10	10	10	10	10	10

VALIDERING AF DANSK LUNGE CANCER REGISTER

International accepteret vurdering af registre*

1) Comparability

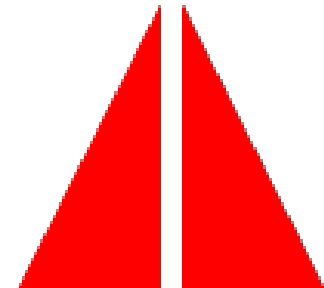
2) Timeliness

3) Completeness

4) Validity

Original Article

Dan Med J 2020;67(8):A04190257



Agreement between the Danish Cancer Registry and the Danish Lung Cancer Registry

Jane Christensen¹, Anne Mette Tranberg Kejs², Lise Kristine Højsgaard Schmidt³, Jes Søgaard², Margit Caroline Rasted³, Ole Andersen¹ & Erik Jakobsen⁴

1) Danish Cancer Society Research Center, Danish Cancer Society, 2) Documentation and Quality, Danish Cancer Society, 3) Data Quality and Documentation, Danish Health Data Authority, 4) Department of Thoracic Surgery, Odense University Hospital, Denmark

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**Bray 2009, Parkin 2009*



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Lung Cancer

journal homepage: www.elsevier.com/locate/lungcan



The Danish lung cancer registry: A nationwide validation study

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ABSTRACT

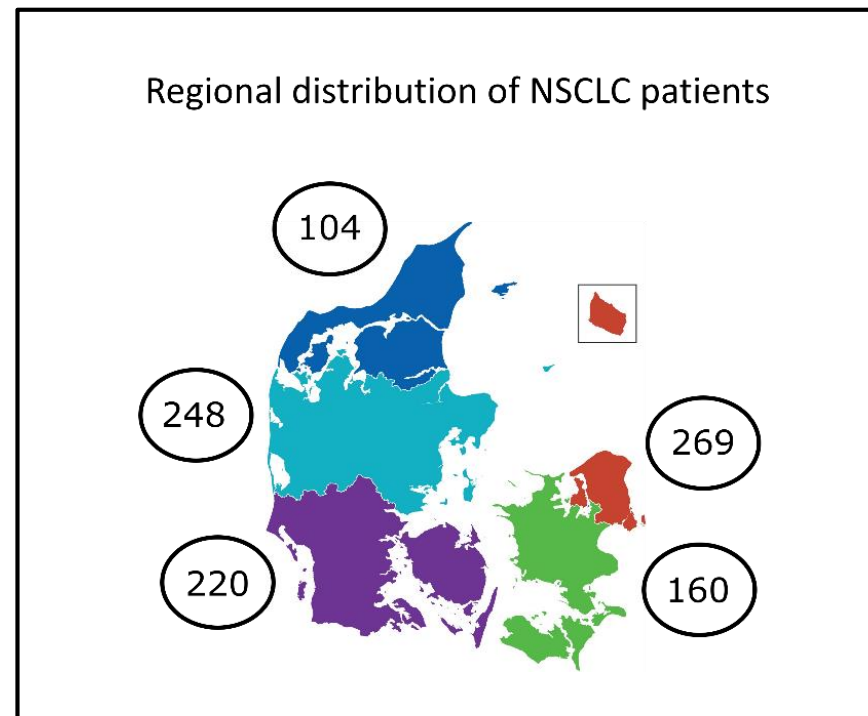
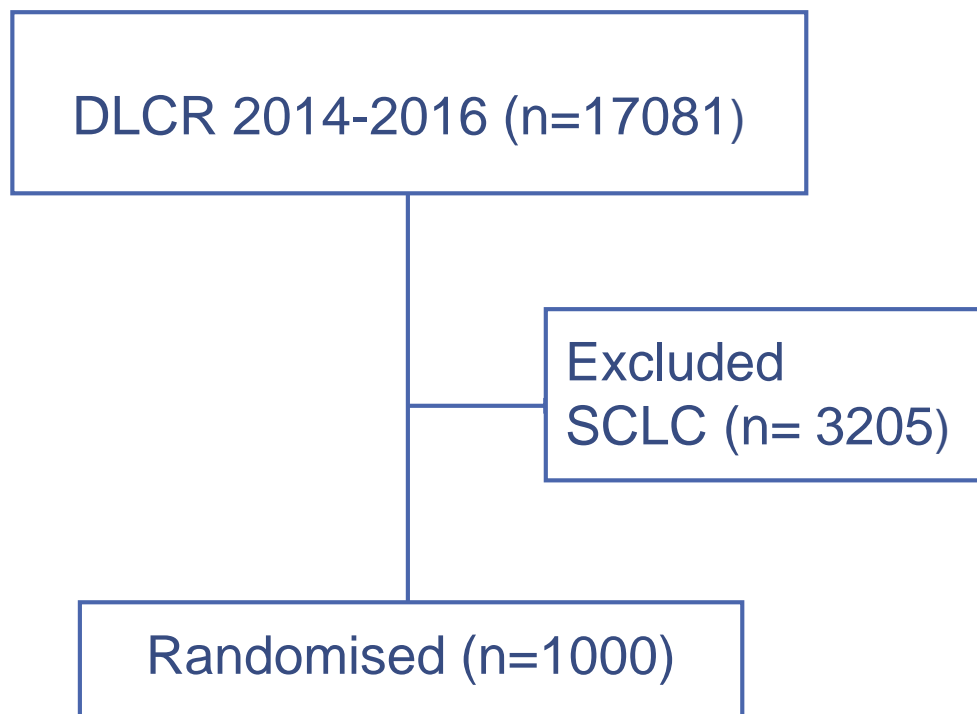
Background: This study evaluates the validity of the information in the Danish Lung Cancer Registry (DLCR). Since 2000, the DLCR has been a tool for monitoring interventions and outcome of all Danish lung cancer patients with the intent to streamline and improve treatment and survival. The DLCR receives information from the Danish Patient Registries in addition to clinical information from the treating physicians. In the year 2022, more than 50 papers have been published using DLCR as a data source. However, the DLCR has not previously been validated.

Methods: A random sample of 1000 patients diagnosed with non-small cell lung cancer from 2014 to 2016 and recorded in the DLCR were included for validation. Medical records were reviewed and were considered as the "gold standard" to which data listed in the DLCR were compared.

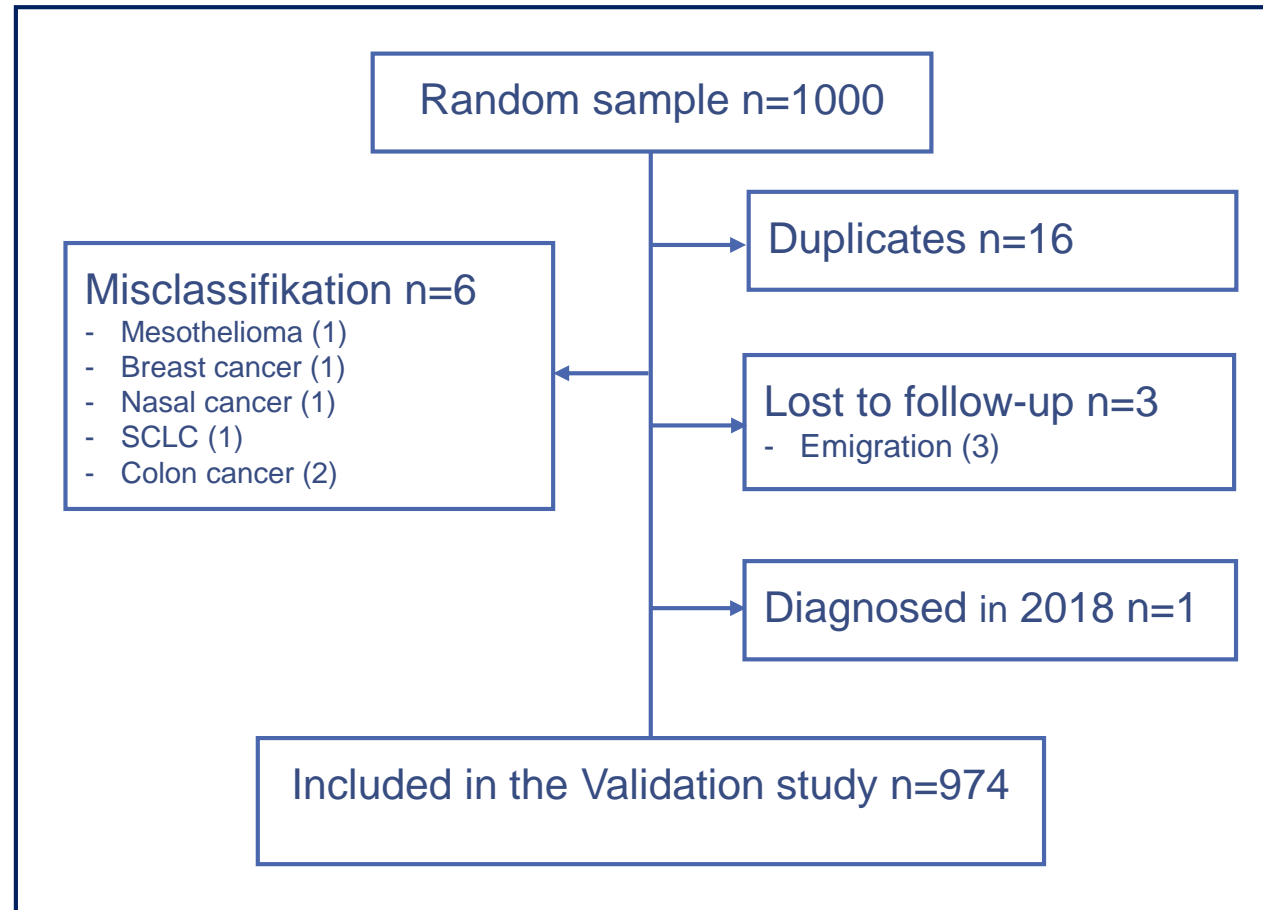
Results: Information was retrieved from medical charts for all patients. Agreement on stage at diagnosis was 90.1 % (95 % CI 88.0–91.9) and on date of diagnoses was 93.8 (95 % CI 92.1–93.2). Agreement on smoking status in pack years (+/- 10 pack years) was 91.2 % (95 % CI 88.6–93.2). The positive predictive value of treatment intent was 87.4 (95 % CI 85.1–89.6).

Conclusion: The data in the DLCR are complete, detailed and accurate. The comparison of data from the DLCR with the medical records revealed overall high validity of the data in the registry.

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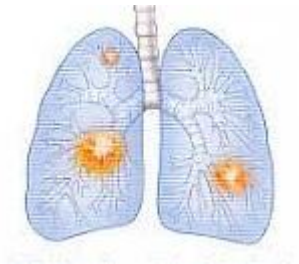


RESULTATER



OVERENSSTEMMELSE MELLEM DLCR OG JOURNALER

Stadie



90%

95%CI 88.0-91.9

Diagnosetidspunkt



94%

95%CI 92.1-95.2

Pakkeår



91%

95% CI 88.6-93.2

Behandlingssigte



92%

95% CI 90.5-94.7

OVERENSSTEMMELSE MELLEM DLCR OG JOURNALER

ECOG Performance Status	
1	Fuld aktiv
2	Kan ikke udføre tungt arbejde
3	Oppe 50% af dagen, kan ikke arbejde
4	Oppe mindre en 50%, brug for hjælp
5	Død



62%

95%CI 59.1-65.4

HVORNÅR ER ET REGISTER GODT NOK?

RESEARCH ARTICLE


The Danish National Lymphoma Registry: Coverage and Data Quality

Bente Arboe^{1*}, Tarek Christoffer El-Galaly², Michael Roost Clausen³, Peter Svenssen Munksgaard², Danny Stoltenberg⁴, Mette Kathrine Nygaard², Tobias Wirenfeldt Klausen⁴, Jacob Haaber Christensen⁵, Jette Sønderkov Gørløv¹, Peter de

Clinical Epidemiology

Dovepress

open access to scientific and medical research

 Open Access Full Text Article

ORIGINAL RESEARCH

Data quality in the Danish National Acute Leukemia Registry: a hematological data resource

This article was published in the following Dove Press journal:

Clinical Epidemiology

30 August 2013

Number of times this article has been viewed

Lene Sofie Granfeldt
Østgård^{1,2}

Background: The Danish National Acute Leukemia Registry (DNLR) has documented coverage of above 98.5%. Less is known about the quality of the recorded data.

PPV af data i Dansk Lymphom database:

87-100 %

PPV af data i Dansk Akut Leukæmi Database:

89-100%

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rkkp.dk

VALIDERING AF DANSK LUNGE CANCER REGISTER

Støttet af:

Kræftens Bekæmpelse

Aase og Ejnar Danielsens Fond

Dagmar Marshalls Fond

Dansk Forskningscenter for Lungekræft



Vejledere:

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Anja Gouliaev
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HOSPITAL

Table 2

Completeness and agreement of data registered in the DLCR compared to medical records. ECOG PS = Eastern Cooperative Oncology Group Performance Status.

Variable	Definition	n (correct/ observations)	Agreement, % (95 % CI)
Date of diagnosis	Date +/- 3 months	912/972	93.8 (92.1–95.2)
Stage at diagnosis	I, II, III, IV, unknown	846/939	90.1 (88.0–91.9)
Health Region	Capital Region of Denmark, Central Denmark Region, North Denmark Region, Region Zealand, Region of Southern Denmark	969/974	99.4 (98.6–99.7)
ECOG PS	0,1,2,3,4, unknown	555/891	62.3 (59.1–65.4)
Pack year	Correct +/- 10	540/592	91.2 (88.6–93.2)
Treated with curative intent		325/352	92.3 (89.0–94.7)
Treated with chemotherapy		382/417	91.6 (88.5–93.9)
Treated with radiation		323/406	79.6 (75.3–83.2)

Table 3

Sensitivity, Specificity and Predictive Values for variables in the DLCR. ECOG PS = Eastern Cooperative Oncology Group Performance Status. FEV1 = forced expiratory volume in the first second. DLCO = diffusing capacity of the lungs for carbon monoxide. VAT = video-assisted thoracic surgery.

Variable	N	Sensitivity, % (95 % CI)	PPV, % (95 % CI)	Specificity, % (95 % CI)	NPV, % (95 % CI)
Stage I-III A/IIIB-V	939	97.3 (96.2–98.3)	94.1 (92.5–95.6)	90.5 (88.6–92.4)	95.6 (94.3–96.9)
EGOC PS 0–1/2–4	848	78.7 (75.9–81.6)	74.8 (71.7–77.8)	91.7 (89.8–93.6)	93.2 (91.5–95.0)
Alcohol use (Surgical patients only)	144	45.0 (37.4–52.6)	47.4 (39.8–55.0)	93.1 (89.2–97.0)	92.5 (88.4–96.5)
FEV1 performed	644	100	100	100	100
DLCO performed	148	100	100	100	100
Curative intent (yes/no)	836	92.3 (90.5–94.1)	87.4 (85.1–89.6)	90.3 (88.3–92.3)	94.2 (92.6–95.8)
Chemo therapy (yes/no)	735	92.5 (91.1–94.8)	77.2 (74.1–80.2)	65.1 (61.7–68.5)	87.9 (85.6–90.3)
Radiation (yes/no)	735	80.8 (77.9–83.6)	72.9 (69.7–76.1)	64.2 (60.7–67.7)	73.6 (70.4–76.8)
Surgery (yes/no)	967	98.8 (98.1–99.4)	99.1 (98.5–99.7)	96.2 (95.1–97.4)	94.7 (93.3–96.1)
Surgical approach (VAT/thoracotomy)	151	87.4 (82.4–92.4)	100	100	71.4 (64.6–78.3)
Neo adjuvant treatment	135	98.4 (96.6–100)	78.3 (72.1–84.4)	20.5 (14.4–26.5)	81.8 (76.1–87.6)
Surgical complications (yes/no)	178	75.7 (69.5–82.1)	47.2 (39.8–54.5)	80.7 (74.9–86.5)	93.6 (90.0–97.2)