

Netherlands Cancer Registry

First published: 01/02/2024

Last updated: 28/11/2025

Data source

Human

Cancer registry

Administrative details

Administrative details

Data source ID

1111117

Data source acronym

NCR

Data holder

[Integraal Kankercentrum Nederland \(IKNL\)](#)

Data source type

Cancer registry

Main financial support

National, regional, or municipal public funding

Care setting

Hospital inpatient care

Hospital outpatient care

Data source qualification

If the data source has successfully undergone a formal qualification process (e.g., from the EMA, ISO or other certifications), this should be described.

No

Data source website

[About the Netherlands Cancer Registry](#)

Contact details

Jelle Evers j.evers@iknl.nl

Main

j.evers@iknl.nl

Peter Prinsen p.prinsen@iknl.nl

Alternate

p.prinsen@iknl.nl

Data source regions and languages

Data source countries

Netherlands

Data source languages

Dutch

Data source establishment

Data source established

01/01/1989

Data source time span

First collection: 01/01/1989

The date when data started to be collected or extracted.

Publications

Data source publications

[Prognostic factors analysis for oral cavity cancer survival in the Netherlands and Taiwan using a privacy-preserving federated infrastructure](#)

[Prospective Dutch colorectal cancer cohort: an infrastructure for long-term observational, prognostic, predictive and \(randomized\) intervention research](#)

[The Risk of Second Primary Cancers in Prostate Cancer Survivors Treated in the Modern Radiotherapy Era](#)

Studies

List of studies that have been conducted using the data source

[DARWIN EU® Multiple myeloma: patient characterisation, treatments and survival in the period 2012-2022](#)

[DARWIN EU® Overall survival in patients with locally advanced or metastatic non-small cell lung cancer treated with selected immunotherapies as first line of treatment](#)

[DARWIN EU® - Chondrosarcoma: patient demographics, treatments, and survival in the period 2010-2023](#)

TARGET EU: Comparative effectiveness and safety studies using the target trial emulation and estimand frameworks

DARWIN EU® – Prevalence of selected cancers

DARWIN EU® - Acute myeloid leukaemia: incidence, patient characteristics, treatments, and survival in the period 2015-2024

DARWIN EU® - Characterisation of systemic treatments for the management of ovarian cancer

DARWIN EU® - Enhanced Preparedness of the DARWIN EU Network for regulatory questions in oncology – DARWIN OncoNet

TARGET-EU: Nivolumab plus ipilimumab with chemotherapy versus pembrolizumab with chemotherapy in patients with non-oncogenic metastatic non-small-cell lung cancer with <1% PD- L1 tumour expression

TARGET-EU: Clinical benefit of bevacizumab in metastatic colorectal cancer

Data elements collected

The data source contains the following information

Disease information

Does the data source collect information with a focus on a specific disease? This might be a patient registry or other similar initiatives.

Yes

Disease details (other)

Details around all cancer diagnoses in the Netherlands and primary treatment provided

Rare diseases

Are rare diseases captured? In the European Union a rare disease is one that affects no more than 5 people in 10,000.

Yes

Pregnancy and/or neonates

Does the data source collect information on pregnant women and/or neonatal subpopulation (under 28 days of age)?

No

Hospital admission and/or discharge

No

ICU admission

Is information on intensive care unit admission available?

No

Cause of death

Not Captured

Prescriptions of medicines

Captured

Prescriptions vocabulary

ATC

other

Prescriptions vocabulary, other

own vocabulary

Dispensing of medicines

Not Captured

Advanced therapy medicinal products (ATMP)

Is information on advanced therapy medicinal products included? A medicinal product for human use that is either a gene therapy medicinal product, a somatic cell therapy product or a tissue engineered products as defined in Regulation (EC) No 1394/2007 [Reg (EC) No 1394/2007 Art 1(1)].

No

Contraception

Is information on the use of any type of contraception (oral, injectable, devices etc.) available?

No

Indication for use

Does the data source capture information on the therapeutic indication for the use of medicinal products?

Captured

Indication vocabulary

Other

Indication vocabulary, other

ICD-O

Medical devices

Is information on medicinal devices (e.g., pens, syringes, inhalers) available?

No

Administration of vaccines

No

Procedures

Does the data source capture information on procedures (e.g., diagnostic tests, therapeutic, surgical interventions)?

Captured

Procedures vocabulary

Other

Procedures vocabulary, other

own vocabulary

Healthcare provider

Is information on the person providing healthcare (e.g., physician, pharmacist, specialist) available?

The healthcare provider refers to individual health professionals or a health facility organisation licensed to provide health care diagnosis and treatment services including medication, surgery and medical devices.

No

Clinical measurements

Is information on clinical measurements (e.g., BMI, blood pressure, height) available?

Yes

Genetic data

Are data related to genotyping, genome sequencing available?

Not Captured

Biomarker data

Does the data source capture biomarker information? The term “biomarker” refers to a broad subcategory of medical signs (objective indications of medical state observed from outside the patient), which can be measured accurately and reproducibly. For example, haematological assays,

infectious disease markers or metabolomic biomarkers.

Not Captured

Patient-reported outcomes

Is information on patient-reported outcomes (e.g., quality of life) available?

No

Patient-generated data

Is patient-generated information (e.g., from wearable devices) available?

No

Units of healthcare utilisation

Are units of healthcare utilisation (e.g., number of visits to GP per year, number of hospital days) available or can they be derived? Units of healthcare utilisation refer to the quantification of the use of services for the purpose of preventing or curing health problems.

No

Unique identifier for persons

Are patients uniquely identified in the data source?

Yes

Diagnostic codes

Captured

Diagnosis / medical event vocabulary

Other

Diagnosis / medical event vocabulary, other

ICD-O

Medicinal product information

Captured

Medicinal product information collected

Active ingredient(s)

Medicinal product vocabulary

ATC

Quality of life measurements

Not Captured

Quality of life measurements, other

QLQ-C30

Lifestyle factors

Not Captured

Sociodemographic information

Captured

Sociodemographic information collected

Age

Living in rural area

Sex

Socioeconomic status

Quantitative descriptors

Population Qualitative Data

Population age groups

Paediatric Population (< 18 years)

Neonate

Preterm newborn infants (0 – 27 days)

Term newborn infants (0 – 27 days)

Infants and toddlers (28 days – 23 months)

Children (2 to < 12 years)

Adolescents (12 to < 18 years)

Adult and elderly population (≥ 18 years)

Adults (18 to < 65 years)

Adults (18 to < 46 years)

Adults (46 to < 65 years)

Elderly (≥ 65 years)

Adults (65 to < 75 years)

Adults (75 to < 85 years)

Adults (85 years and over)

Estimated percentage of the population covered by the data source in the catchment area

>95% coverage of the total population in The Netherlands.

Description of the population covered by the data source in the catchment area whose data are not collected (e.g., people who are registered only for private care)

Only patients who opted out are not covered in our registry

Population

Population size

3981734

Active population size

1451636

Population by age group

Age group	Population size	Active population size
Paediatric Population (< 18 years)	16978	3942
Adults (18 to < 46 years)	261360	115827
Adults (46 to < 65 years)	1028941	390244
Elderly (≥ 65 years)	2674455	941623
Adults (65 to < 75 years)	1050592	381405
Adults (75 to < 85 years)	1103988	406007
Adults (85 years and over)	519875	154211

Median observation time

Median time (years) between first and last available records for unique individuals captured in the data source

0.77

Median time (years) between first and last available records for unique active individuals (alive and currently registered) capt

0.86

Data flows and management

Access and validation

Governance details

Documents or webpages that describe the overall governance of the data source and processes and procedures for data capture and management, data quality check and validation results (governing data access or utilisation for research purposes).

[Data request for NCR data](#)

Biospecimen access

Are biospecimens available in the data source (e.g., tissue samples)?

No

Access to subject details

Can individual patients/practitioners/practices included in the data source be contacted?

No

Description of data collection

Data is collected manually from the EMR systems of the hospitals by data managers and entered into the database.

Event triggering registration

Event triggering registration of a person in the data source

Disease diagnosis

Event triggering de-registration of a person in the data source

Other

Event triggering de-registration of a person in the data source, other

The NCR works according to an opt-out process: patients can request to have their data removed.

Event triggering creation of a record in the data source

Diagnosis, lab measurement or other test result, treatment.

Data source linkage

Linkage

Is the data source described created by the linkage of other data sources (prelinked data source) and/or can the data source be linked to other data source on an ad-hoc basis?

No

Linkage description, possible linkage

Probabilistic linkage with other data sources in the Netherlands is possible

Data management specifications that apply for the data source

Data source refresh

Monthly

Informed consent for use of data for research

Not Required

Possibility of data validation

Can validity of the data in the data source be verified (e.g., access to original medical charts)?

Yes

Data source preservation

Are records preserved in the data source indefinitely?

Yes

Approval for publication

Is an approval needed for publishing the results of a study using the data source?

Yes

Data source last refresh

19/11/2025

Common Data Model (CDM) mapping

CDM mapping

Has the data source been converted (ETL-ed) to a common data model?

Yes

CDM Mappings

CDM name

OMOP

CDM website

Data source ETL CDM version

5.4

Data source ETL frequency

6,00 months

Data source ETL status

Completed