The Cancer Registry of Norway

First published: 01/02/2024

Last updated: 27/03/2026

Data source **Human** **Cancer registry** **Disease registry**

Administrative details

Administrative details

Data source ID

1111128

Data source acronym

CRN

Data holder

The Norwegian Institute of Public Health

Data source type

Cancer registry

Disease registry

Main financial support

National, regional, or municipal public funding

Other

Care setting

Hospital inpatient care

Hospital outpatient care

Other

Primary care – GP, community pharmacist level

Primary care – specialist level (e.g. paediatricians)

Secondary care – specialist level (ambulatory)

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.

Yes

Data source website

Cancer Registry of Norway

Contact details

Siri Larønningen siri.laronningen@fhi.no

Main

siri.laronningen@fhi.no

Anna Skog anna.skog@fhi.no

Alternate

anna.skog@fhi.no

Data source regions and languages

Data source countries

Norway

Data source languages

Norwegian

Data source establishment

Data source established

01/01/1952

Data source time span

First collection: 01/01/1952

The date when data started to be collected or extracted.

Publications

Data source publications

Larsen, I. K., Småstuen, M., Johannesen, T. B., Langmark, F., Parkin, D. M., Bray, F., & Møller, B. (2009). Data quality at the Cancer Registry of Norway: an overview of comparability, completeness, validity and timeliness. European journal of cancer, 45(7), 1218-1231.

Enerly, E. ., Holmstrøm, L. ., Skog, A. ., Knudsen, K. O. ., Nygård, J. F. ., Møller, B., & Ursin, G. (2021). INSPIRE: A new opportunity for cancer pharmacoepidemiology research. Norsk Epidemiologi, 29(1-2).

Annual reports from clinical cancer registries. Norwegian only.

INSPIRE:kidney cancer. Systemic anti-cancer treatment of kidney cancer. Oslo: Cancer Registry of Norway, 2022. ISBN: 978-82-473-0116-6

INSPIRE:lungekreft. Evaluering av pilotprosjekt. (Norwegian only) Oslo: Cancer Registry of Norway, 2021. ISBN: 978-82-473-0090-9

INSPIRE:brystkreft. Medikamentell kreftbehandling. (Norwegian only) Oslo: Cancer Registry of Norway, 2022. ISBN: 978-82-473-0115-9

Cancer Registry of Norway. Norwegian Institute of Public Health. Cancer in Norway 2024 - Cancer incidence, mortality, survival and prevalence in Norway. Oslo: Cancer Registry of Norway, 2025.

Studies

List of studies that have been conducted using the data source

Population-based retrospective nested case-control study evaluating effectiveness of GARDASIL™ /GARDASIL™9 against adult-onset recurrent respiratory papillomatosis (AoRRP) in Sweden, Denmark, and Norway (V503-088)

Nested case-control study evaluating effectiveness of immunization of girls and women of childbearing potential with GARDASIL(TM)/GARDASIL(TM) 9 against juvenile-onset recurrent respiratory papillomatosis (JoRRP) in Sweden, Denmark, and Norway (V503-095)

DARWIN EU® – Prevalence of selected cancers

DARWIN EU® - Multiple myeloma: patient characterisation, treatments, and survival in the period 2012–2024

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

Data elements collected

The data source contains the following

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)

All types of cancer, precancerous lesions and selected benign tumors, C00-96, D32-33, D35.2-4, D42-D43. D44.3-5, D45-47

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

Yes

ICU admission

Is information on intensive care unit admission available?

No

Cause of death

Captured

Cause of death vocabulary

ICD-10

Other

Cause of death vocabulary, other

ICD6-9, depending on year of death

Prescriptions of medicines

Captured

Prescriptions vocabulary

ATC

Dispensing of medicines

Captured

Dispensing vocabulary

ATC

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

ICD-10

Other

Indication vocabulary, other

ICDO-2, ICDO-3

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

SNOMED CT

Procedures vocabulary, other

Ongoing project to map surgical cancer procedures to SNOMED CT. Procedures from the Norwegian patient registry coded in NCMP, NCSP, NCRP.

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.

Yes

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?

Captured

Genetic data vocabulary

Other

Genetic data vocabulary, other

Currently, only individual markers, with gene name. E.g. PDL-1.

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.

Captured

Biomarker data vocabulary

Other

Biomarker vocabulary, other

Local codes and gene/marker names

Patient-reported outcomes

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

Yes

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

ICD-10

Other

SNOMED CT

Diagnosis / medical event vocabulary, other

Medical events from the Norwegian patient registry coded in NCMP, NCSP, NCRP

Medicinal product information

Captured

Medicinal product information collected

Active ingredient(s)

Dosage regime

Dose

Route of administration

Strength

Medicinal product vocabulary

ATC

Quality of life measurements

Captured

Quality of life measurements vocabulary

other

Quality of life measurements, other

EORTC QLQ-C30 (all cancers where we collect PROM). I addition: Prostate cancer EPIC-26, Breast cancer EORTC QLQ-BR23, Colorectal cancer EORTC QLQ CR-29, Lung cancer EORTC QLQ-LC13, including some additional parameteres on sun exposure for melanoma.

Lifestyle factors

Not Captured

Sociodemographic information

Captured

Sociodemographic information collected

Age

Country of origin

Gender

Health area

Quantitative descriptors

Population Qualitative Data

Population age groups

Paediatric Population (< 18 years)

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)

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

100%

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)

The CRN does not include temporary residents that do not have a permanent Norwegian identification number.

Population

Population size

1248241

Active population size

347877

Population by age group

Age group	Population size	Active population size
Paediatric Population (< 18 years)	12205	1732
Term newborn infants (0 – 27 days)	173	0
Infants and toddlers (28 days – 23 months)	1759	21
Children (2 to < 12 years)	6054	786
Adolescents (12 to < 18 years)	4219	925
Adults (18 to < 46 years)	111701	22667
Adults (46 to < 65 years)	380711	84936
Elderly (≥ 65 years)	743624	238542
Adults (65 to < 75 years)	355340	94072
Adults (75 to < 85 years)	289553	104627

Age group	Population size	Active population size
Adults (85 years and over)	98731	39843

Median observation time

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

3.14

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

8.37

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).

CRN metadata catalogue (ELVIS)

CRN data delivery unit

Biospecimen access

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

Yes

Biospecimen access conditions

Patient consent if alive, or exemption from consent if patient is deceased.

Access to subject details

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

Yes

Description of data collection

Data holder: The Norwegian Institute of Public Health

Reporting cancer cases to the CRN is mandatory for all physicians in Norway. Information on cancer is reported directly from hospitals/clinics to the CRN automatically from ICT systems (like pathology reports) or manually by filling out a form (like diagnostic work-up). Data is collected, recorded and validated through built-in and continous quality checks. The CRN have coders specially trained in cancer coding, including pathology details, diagnostic work-up, treatment, follow-up, relapses/metastasis et.c. The CRN adheres to rules for coding and registration as defined by IACR (International Association of Cancer Registries), as well as classification rules defined by using ICD-10, SNOMED CT, Norwegian coding of medical procedures etc.

The CRN has extensive trace back routines and routinely sends reminders to hospitals and clinicians for more information to ensure complete and coherent data.

Data collection from different sources:

- Pathology: Reported automatically from ICT systems to the CRN (continuously)
- Clinical information (diagnostic work-up): Reported manually by the patients' physician

- Systemic anti-cancer treatment: Reported automatically from ICT system to the CRN (quarterly)
- Radiation therapy: Reported annually from each radiation clinic
- Patient reported outcome measures: Reported by patients electronically (some cancers) at baseline and at one year follow up (or other, depending on what is relevant for the specific type of cancer)
- Norwegian population registry (alive/dead, emigration status, address et.c.): Data updated monthly
- Norwegian patient registry (hospital admission and discharge information): Data updated monthly, every four months and yearly).
- Cause of death registry (information on causes of death for cancer patients, and cancer reated deaths): Data updated annually

Please refer to https://www.fhi.no/contentassets/1d3cf9facb9747a1b9148cb23a7f7c54/cin_report_erratu

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 only de-registration done is if the cancer diagnosis is withdrawn (confirmation from the healthcare system that the patient did not have cancer). Registration in the CRN is mandatory, with no opt-out for patients.

Event triggering creation of a record in the data source

Information from health care personell about a cancer diagnosis, or information from the cause of death registry that cancer is stated as primary or secondary cause of death.

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?

Yes

Linkage description, possible linkage

Linkage uses the Norwegian personal identification number. How the linkage is done and by who depends on the specific project and in some cases the legal requirements for the registry. We (or Helsedataservice) would typically extract the relevant data set, collect the additional data set (from another registry), and link the data using personal identification number. The Cancer Registry will perform the OMOP-mapping and creating the ETL on a case by case basis (reusing ETL whenever possible).

Linked data sources

Pre linked

Is the data source described created by the linkage of other data sources?

No

Data source, other

All linkage depends on specific rules for each registry or cohort, including patient consent (where applicable). The CRN can be linked to all national health registries in Norway, such as:- The Cause of death registry (regular linkage annually)- Medical birth registry of Norway- Norwegian Surveillance System for Communicable Diseases (MSIS)- Norwegian Immunisation Registry (SYSVAK)- Norwegian Armed Forces Health Registry- Norwegian Patient Registry (NPR) (regular linkage)- Norwegian Cardiovascular Disease Registry- Norwegian Adverse Drug Reaction Registry- Norwegian Registry for Primary Health Care (KPR)- Norwegian Prescribed Drug RegistryThe CRN can also be linked to other registries and cohorts, after relevant approvals. For an overview of all health registries in Norway: https://helsedata.no/en/data-sources/?page=1&sort=0

Linkage strategy

Deterministic

Linkage variable

Primarily person identification number. All residents in Norway have a personal identification number from birth or immigration, that uniquely identifies individual residents.

Linkage completeness

We describe completeness as stated by each national health registry. All registries below are national and cover the whole intended population.
- The Cause of death registry contains information on deaths and causes of death in Norway from 1951 until today
- Medical birth registry of Norway contains information from 1967 to the present day about medical conditions during pregnancies, births and newborns in Norway
- Norwegian Surveillance System for Communicable Diseases (MSIS) contains information about infectious diseases in humans in Norway, from 1977 until today.

- Norwegian Immunisation Registry (SYSVAK). From 1976-2009 only child vaccinations. 2011 - 2020 all vaccinations to all groups in Norway (consent). 2020 - today all vaccinations in Norway (no consent).
- Norwegian Armed Forces Health Registry contains information on all persons in Norway who have been registered in or employed by the Armed Forces.
- Norwegian Patient Registry (NPR) (regular linkage) contains information from 1997 on everyone who is referred for or has received specialized healthcare at a hospital, outpatients' clinic or from contract specialists.
- Norwegian Cardiovascular Disease Registry contains information from 2012 until today about people with diseases of the heart and blood vessels, and about the treatment of these diseases
- Norwegian Adverse Drug Reaction Registry contains reports of suspected ADRS of medicinal products (including vaccines) received from from healthcare personnel and residents in Norway.
- Norwegian Registry for Primary Health Care (KPR) contains information from 2016 on applicants and recipients of healthcare in Norwegian municipalities.
- Norwegian Prescribed Drug Registry has information from 2004 on medicines dispensed by prescription from pharmacies in Norway.

For completeness of the CRN, see above or reference 2, Larsen et al 2009.

Data management specifications that apply for the data source

Data source refresh

Yearly

Informed consent for use of data for research

Other

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?

No

Informed consent, other

The patient can refuse the CRN to register tobacco use, occupation and/or life style factors

---

Data source last refresh

31/12/2024

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

https://www.ohdsi.org/Data-standardization/

Data source ETL CDM version

5.4

Data source ETL frequency

12,00 months

Data source ETL status

Completed