# The Cancer Registry of Norway

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Data source    Cancer registry    Disease registry

## Administrative details

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**PURI**
https://redirect.ema.europa.eu/resource/1111128

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**Data source ID**
1111128

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**Data source acronym**
CRN

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**Data holder**
The Norwegian Institute of Public Health

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**Data source type**
Cancer registry
Disease registry

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**Main financial support**
National, regional, or municipal public funding
Other

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**Care setting**
Hospital inpatient care
Hospital outpatient care
Secondary care – specialist level (ambulatory)

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**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**

https://www.kreftregisteret.no/en/

# Contact details

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# 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 (10 registries). Norwegian only.

Cancer Registry of Norway. Cancer in Norway 2021 - Cancer incidence, mortality, survival and prevalence in Norway. Oslo: Cancer Registry of Norway, 2022. Cancer in Norway 2005-2020: https://www.kreftregisteret.no/Generelt/Rapporter/Cancer-in-Norway/

INSPIRE:kidney cancer. Systemic anti-cancer treatment of kidney cancer. Oslo: Cancer Registry of Norway, 2022. ISBN: 978-82-473-0116-6 Similar reports for lung cancer and breast cancer: https://www.kreftregisteret.no/globalassets/publikasjoner-og-rapporter/inspire/inspire_lungekreft_evaluering-av-pilotprosjekt.pdf (norwegian only) https://www.kreftregisteret.no/globalassets/bilder/ansatte_portrettbilder/inspire_brystkreft_medikament kreftbehandling_publisert_07_04_2022_hele.pdf (norwegian only)

# 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)
All types of cancer, ICD-10 C00 - C96

### 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

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**Cause of death**
Captured

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**Cause of death vocabulary**
ICD-10
Other

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**Prescriptions of medicines**
Captured

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**Prescriptions vocabulary**
ATC

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**Dispensing of medicines**
Captured

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**Dispensing vocabulary**
ATC

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**Advance 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

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**Contraception**

Is information on the use of any type of contraception (oral, injectable, devices etc.) available?
No

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**Indication for use**

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

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**Indication vocabulary**
ICD-10
Other

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**Medical devices**

Is information on medicinal devices (e.g., pens, syringes, inhalers) available?
No

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## Administration of vaccines
No

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

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## Procedures vocabulary
Other

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## 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

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

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## Genetic data
Are data related to genotyping, genome sequencing available?
Captured

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## Genetic data vocabulary
Other

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## 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

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## Biomarker data vocabulary
Other

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## 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

## 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

**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**
1330689

# Active population

**Active population size**
316638

# Median observation time

**Median time (years) between first and last available records for unique individuals captured in the data source**
0.08

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**Median time (years) between first and last available records for unique active individuals (alive and currently registered) capt**
0.11

# 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).
https://metadata.kreftregisteret.no/help

**Biospecimen access**

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

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**Biospecimen access conditions**
Patient consent if alive, or exemption from consent if patient is deceased.

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**Access to subject details**
Can individual patients/practitioners/practices included in the data source be contacted?
Yes

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**Description of data collection**
Data holder: Oslo University Hospital and 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 go through quality checks continuously. The CRN have coders specially trained in coding cancers, inluding 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, 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.kreftregisteret.no/globalassets/cancer-in-norway/2021/cin_report.pdf p

# 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 that the patient did not have cancer). Registration in the CRN is mandatory, with no opt-out for patients.

# 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 Registry

The 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

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**Linkage strategy**
Deterministic

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

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**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

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**Informed consent for use of data for research**
Other

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

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**Data source preservation**
Are records preserved in the data source indefinitely?
Yes

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**Approval for publication**
Is an approval needed for publishing the results of a study using the data source?
No

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

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**Data source last refresh**
31/12/2021

# 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**
In progress