# Sweden National Cancer Register / Cancerregistret

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Data source | Human | Cancer registry

## Administrative details

### Administrative details

**Data source ID**

1111194

**Data source acronym**

NCR

**Data holder**

The Swedish National Board of Health and Welfare

**Data source type**

Cancer registry

**Main financial support**

National, regional, or municipal public funding

**Care setting**

Hospital inpatient care

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.

No

**Data source website**

https://www.socialstyrelsen.se/en/statistics-and-data/registers/national-cancer-register/

# Contact details

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**Main**

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# Data source regions and languages

**Data source countries**

Sweden

**Data source languages**

Swedish

# Data source establishment

**Data source established**

10/01/1958

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**Data source time span**

**First collection:** 10/01/1958

The date when data started to be collected or extracted.

# Publications

## Data source publications

https://www.socialstyrelsen.se/globalassets/sharepoint-dokument/dokument-webb/statistik/artikel-swedish-cancer-registry-2009.pdf

# Studies

## List of studies that have been conducted using the data source

A post-marketing registry-based prospective cohort study of long-term safety of risankizumab in Denmark and Sweden

Dulaglutide and Potential Risks of Pancreatic Cancer and Thyroid Cancer: A Non-Interventional PASS (H9X-MC-B013)

Cohort Study of Long-term Safety of Upadacitinib for the Treatment of Ulcerative Colitis and Crohn’s Disease in a Real-world Setting in Europe

Post-Authorisation Active Safety Surveillance Program Among Patients Treated With Tofacitinib for Polyarticular Juvenile Idiopathic Arthritis (pJIA) and Juvenile Psoriatic Arthritis (PsA) Using Nationwide Swedish Healthcare Registers

Comparative Cohort Study of Long-term Safety Outcomes of Risankizumab Compared to Biologic Treatments for Ulcerative Colitis and Crohn’s Disease in a

Real-world Setting in Sweden and Denmark

Drug Utilization Study Evaluating Additional Risk Minimization Measures for Upadacitinib in the Treatment of Atopic Dermatitis in Europe

An Active Surveillance Study to Monitor the Safety of Abrocitinib Among Real-World Patients with Atopic Dermatitis (AD) in the European Union (EU) (B7451084)

Postauthorisation Safety Study (PASS) of Avatrombopag and Haematological Malignancies in Patients With Primary Immune Thrombocytopaenia

## 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.

No

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### 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

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### Pregnancy and/or neonates

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

No

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### 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

Not Captured

### 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?

Not Captured

## 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)?

Not Captured

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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?

No

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## Genetic data

Are data related to genotyping, genome sequencing available?

Not Captured

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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.

Not Captured

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### 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-3, ICD-O-2, ICD-7

### Medicinal product information

Not Captured

**Quality of life measurements**

Not Captured

**Lifestyle factors**

Not Captured

**Sociodemographic information**

Captured

**Sociodemographic information collected**

Age

Gender

Health area

Other

# 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)**

All Swedish residents diagnosed with neoplasms in Swedish health care

## Population

**Population size**

2668745

**Active population size**

835158

## Population by age group

| Age group | Population size | Active population size |
|---|---|---|
| Neonate | 274 | 167 |

| Age group | Population size | Active population size |
|---|---|---|
| Infants and toddlers (28 days – 23 months) | 2660 | 1720 |
| Children (2 to < 12 years) | 8979 | 5602 |
| Adolescents (12 to < 18 years) | 7730 | 5435 |
| Adults (18 to < 46 years) | 364011 | 274682 |
| Adults (46 to < 65 years) | 704532 | 266705 |
| Adults (65 to < 75 years) | 733728 | 179679 |
| Adults (75 to < 85 years) | 636208 | 84528 |
| Adults (85 years and over) | 210623 | 16481 |

## Median observation time

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

0.00

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

0.00

# 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://www.socialstyrelsen.se/globalassets/sharepoint-dokument/dokument-webb/ovrigt/production-and-quality-can.pdf

**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 and coded by the 6 regional cancer centres and after quality control forwarded to NBHW

## 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**

All correctly registered entries in the cancer register is kept in the register. Data is only erased if it was incorrectly registered as a cancer

**Event triggering creation of a record in the data source**

Incident diagnosis of cancer in Swedish health care

# 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, pre-linked**

Linkage to all Other national registers (e.g. National patient register, Prescribed drug register, Medical birth register and Cause of death register) using an unique personal identification number.

# Linked data sources

**Pre linked**

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

Yes

**Data source, other**

Cancer registry Data and

**Linkage strategy**

Deterministic

**Linkage variable**

Personal identification number

**Linkage completeness**

All records with valid personal identification numbers can be deterministically linked on demand.

**Pre linked**

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

Yes

**Data source, other**

Data from statistic swedens population register

**Linkage strategy**

Deterministic

**Linkage variable**

Personal identification number

**Linkage completeness**

All records with valid personal identification numbers can be deterministically linked on demand.

**Pre linked**

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

Yes

**Data source, other**

Data regarding demographic variables

**Linkage strategy**

Deterministic

**Linkage variable**

Personal identification number

**Linkage completeness**

All records with valid personal identification numbers can be deterministically linked on demand.

## Data management specifications that apply for the data source

**Data source refresh**

December

**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

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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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### Data source last refresh

20/12/2021

## Common Data Model (CDM) mapping

### CDM mapping

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

No