Sweden National Cancer Register / Cancerregistret

First published: 19/09/2022

Last updated: 30/06/2026

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

National Cancer Register

Contact details

Åsa Persson dorcant@socialstyrelsen.se

Main

dorcant@socialstyrelsen.se

Data source regions and languages

Data source countries

Sweden

Data source languages

Swedish

Data source establishment

Data source established

10/01/1958

Data source time span

First collection: 10/01/1958

The date when data started to be collected or extracted.

Publications

Data source publications

The completeness of the Swedish Cancer Register – a sample survey for year 1998

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)

An Active Surveillance, Post Authorization Safety Study (PASS) of Serious Infection, Malignancy, Cardiovascular (CV) and Other Safety Events of Interest among Patients Treated with Tofacitinib for Moderately to Severely Active Rheumatoid Arthritis (RA) within the Swedish, Population based, Anti Rheumatic Treatment in Sweden (ARTIS) register. (Safety of tofacitinib in ARTIS)

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.

Yes

Disease details (other)

cancer, tumours

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)?

Yes

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

Administration of vaccines

No

Procedures

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

Not Captured

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?

No

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-3, ICD-O-2, ICD-9, ICD-7

Medicinal product information

Not Captured

Quality of life measurements

Not Captured

Lifestyle factors

Not Captured

Sociodemographic information

Captured

Sociodemographic information collected

Age

Health area

Marital status

Other

Sex

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%

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)

Completeness is lower for advanced, late stage tumours diagnosed with a poor prognosis, especially among older patients. For more information, please see "Register-based trace back of cancer on death certificates: An approach to estimating death certificate initiated cancer cases, 2005–2022", at https://www.socialstyrelsen.se/publikationer/register-based-trace-back-of-cancer-on-death-certificates-an-approach-to-estimating-death-certificate-

initiated-cancer-cases-20052022-2024-8-9189/

Family linkage

Family linkage available in the data source permanently or can be created on an ad hoc basis

Ad hoc

Population

Population size

3.861.567

Population by age group

Age group	Population size	Active population size
Adults (46 to < 65 years)	704.532	266.705
Adults (65 to < 75 years)	733.728	179.679

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).

Statistical register's production and quality – National Cancer Register

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 the National Board of Health and Welfare

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 are only erased if they are 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

Yearly

November

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

14/11/2025

Common Data Model (CDM) mapping

CDM mapping

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

No