Swedish Cause of Death Register

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Data source **Human** **Death registry**

Administrative details

Administrative details

Data source ID

1000000245

Data source acronym

CDR

Data holder

The Swedish National Board of Health and Welfare

Data source type

Death registry

Main financial support

National, regional, or municipal public funding

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 Cause of Death Register

Contact details

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Data source regions and languages

Data source countries

Sweden

Data source languages

Swedish

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

Brooke HL, Talbäck M, Hörnblad J, Johansson LA, Ludvigsson JF, Druid H, et al. The Swedish cause of death register. European Journal of Epidemiology. 2017;32(9):765-73.

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)

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

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

A Drug Utilization Study to Evaluate the Effectiveness of Risk Minimization Measures (RMMs) for Abrocitinib in the EU Using Electronic Healthcare Data (B7451085)

Beta-blockers in patients with heart failure with reduced ejection fraction and concomitant chronic obstructive pulmonary disease: cardiovascular and respiratory outcomes

Post-Authorization Safety Study to Assess the Effectiveness of the Newly Implemented Risk Minimization Measures for Topiramate: Drug Utilization Study

Applicability of past and ongoing steroidal and non-steroidal mineralocorticoid receptor antagonist trials in real-world patients with heart failure with reduced, mildly reduced, and preserved ejection fraction

Associations between Cardiac Resynchronization Therapy and Clinical Outcomes According to the Atrial Fibrillation Status in Patients with Heart Failure with Reduced Ejection Fraction

PaTernal exposure to vAlproate, further iNvestiGation on the risk of NeuroDevelopmental Disorders (NDD) and Major Congenital Malformation (MCM) in Offspring: A Non-Interventional Post-Authorization Safety Study (TANGO)

Semaglutide in patients with heart failure with reduced ejection fraction: safety and effectiveness – a target trial emulation

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

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

Captured

Cause of death vocabulary

ICD-10

ICD-9

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.

Yes

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

ICD-10

ICD-9

Medicinal product information

Not Captured

Quality of life measurements

Not Captured

Lifestyle factors

Not Captured

Sociodemographic information

Captured

Sociodemographic information collected

Age

Country of origin

Sex

Quantitative descriptors

Population Qualitative Data

Population age groups

All

Paediatric Population (< 18 years)

Adult and elderly population (≥18 years)

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

Close to 100% of all deaths in Sweden and of people living in Sweden but died abroad.

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)

People who, at the time of the death, were registered in Sweden, regardless of whether the death occurred within or outside the country. Thus, stillborns, persons who died during a temporary stay in Sweden or asylum seekers who have not yet obtained a residence permit are not included. Emigrated Swedes who are no longer registered in Sweden are also not included.

Family linkage

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

Ad hoc

Population

Population size

6289306

Active population size

0

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 Cause of Death 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

The register is based on the cause-of-death certificate, which contains information on the individual's cause of death. Data regarding country of birth, county and municipality of registration, etc., are taken from the source register RTB (the Total Population Register) provided by Statistics Sweden (SCB).

Event triggering registration

Event triggering registration of a person in the data source

Other

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

Death

Event triggering creation of a record in the data source

When a death has occured, a cause-of-death certificate, which contains information on the cause of death, is reported to the National Board of Health and Welfare. The collection of the new annual stock is finalised about four to five months after the end of the reporting period.

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

Population register at Statistics Sweden

Linkage description, possible linkage

Possible linkage with other registers in Sweden via personal identification numbers.

Data management specifications that apply for the data source

Data source refresh

Monthly

Yearly

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

31/12/2023

Common Data Model (CDM) mapping

CDM mapping

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

No