Linkage of Swedish national registers for psychiatric research

First published: 22/11/2024

Last updated: 01/04/2026

Data source | Human | Birth registry | Death registry | Hospital inpatient records | Hospital outpatient visit records | Pharmacy dispensing records | Population registry

Administrative details

Administrative details

Data source ID

1000000360

Data holder

Department of Medical Epidemiology and Biostatistics, Karolinska Institutet

Data source type

Birth registry

Death registry

Hospital inpatient records

Hospital outpatient visit records

Pharmacy dispensing records

Population registry

Main financial support

National, regional, or municipal public funding

Care setting

Hospital inpatient care

Hospital outpatient care

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.

No

Data source website

Swedish national health registers

Contact details

Zheng Chang zheng.chang@ki.se

Main

zheng.chang@ki.se

Henrik Larsson Henrik.Larsson@oru.se

Alternate

Henrik.Larsson@oru.se

Data source regions and languages

Data source countries

Sweden

Data source languages

Swedish

Data source establishment

Data source established

01/01/2023

Data source time span

First collection: 01/01/1987

The date when data started to be collected or extracted.

Last collection: 31/12/2024

If data collection in the data source has ceased, the date new records last entered the data source.

Publications

Data source publications

ADHD Pharmacotherapy and Mortality in Individuals With ADHD. JAMA . 2024 Mar 12;331(10):850-860.

The First Decade with the Swedish Prescribed Drug Register - A Systematic Review of the Output in the Scientific Literature

Studies

List of studies that have been conducted using the data source

Drug-Drug Interactions Between ADHD and Cardiometabolic Medications: a Pharmacovigilance Study

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

Yes

ICU admission

Is information on intensive care unit admission available?

Yes

Cause of death

Captured

Cause of death vocabulary

ICD-10

Prescriptions of medicines

Not 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?

Yes

Indication for use

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

Not Captured

Indication vocabulary

Not coded (Free text)

Medical devices

Is information on medicinal devices (e.g., pens, syringes, inhalers) available?

Yes

Administration of vaccines

No

Procedures

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

Captured

Procedures vocabulary

ICD-10

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.

Yes

Unique identifier for persons

Are patients uniquely identified in the data source?

Yes

Diagnostic codes

Captured

Diagnosis / medical event vocabulary

ICD-10

Medicinal product information

Captured

Medicinal product information collected

Active ingredient(s)

Brand name

Dose

Package size

Route of administration

Medicinal product vocabulary

ATC

Quality of life measurements

Not Captured

Lifestyle factors

Not Captured

Sociodemographic information

Captured

Sociodemographic information collected

Age

Country of origin

Education level

Living in rural area

Marital status

Sex

Socioeconomic status

Type of residency

Quantitative descriptors

Population Qualitative Data

Population age groups

All

Paediatric Population (< 18 years)

Preterm newborn infants (0 – 27 days)

Term newborn infants (0 – 27 days)

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

The entire Swedish population and their family relationships since 1932.

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)

Individuals born after year 2021.

Family linkage

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

Permanently

Family linkage available between the following persons

Father-child

Mother-child

Sibling

Population

Active population size

10.000.000

Median observation time

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

33,00

Data flows and management

Access and validation

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

Event triggering registration

Event triggering registration of a person in the data source

Birth

Residency obtained

Event triggering de-registration of a person in the data source

Death

Emigration

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

Data management specifications that apply for the data source

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

31/01/2026

Common Data Model (CDM) mapping

CDM mapping

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

No