

Health Impact - Swedish Population Evidence Enabling Data-linkage

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Data source

Human

Birth registry

Cancer registry

Death registry

Disease registry

Drug registry

Hospital discharge records

Hospital inpatient records

Hospital outpatient visit records

Population registry

Primary care medical records

Vaccination registry

Administrative details

Administrative details

Data source ID

1000000562

Data source acronym

HI-SPEED

Data holder

[Register Epidemiology Group, School of Public Health and Community Medicine, Institute of Medicine, University of Gothenburg](#)

Data source type

Birth registry
Cancer registry
Death registry
Disease registry
Drug registry
Hospital discharge records
Hospital inpatient records
Hospital outpatient visit records
Population registry
Primary care medical records
Vaccination registry

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

Description of the qualification

The OMOP CDM mapped part of the data has been approved by DARWIN EU. We are already a DARWIN EU data partner, known as SMPA-GU.

Data source website

[SCIFI-PEARL](#)

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Data source regions and languages

Data source countries

Sweden

Data source languages

English

Swedish

Data source establishment

Publications

Data source publications

[Nyberg F, Franzén S, Lindh M, Vanfleteren L, Hammar N, Wettermark B, Sundström J, Santosa A, Björck S, Gisslén M. Swedish Covid-19 Investigation for Future Insights – A Population Epidemiology Approach Using Register Linkage \(SCIFI-PEARL\). Clin Epidemiol. 2021;13:649-659.](#)

Studies

List of studies that have been conducted using the data source

[DARWIN EU® - RR2 Drug utilisation study of prescription opioids](#)

DARWIN EU® – Trends in utilisation of Attention-Deficit Hyperactivity Disorder (ADHD) Medications

Safety of mRNA COVID-19 vaccines during pregnancy

DARWIN EU® - Incidence, period prevalence, and characterisation of individuals with paediatric pulmonary arterial hypertension

DARWIN EU® - Determinants for use of GLP1 receptor agonists – a drug utilisation 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

SNOMED

Prescriptions of medicines

Not Captured

Dispensing of medicines

Captured

Dispensing vocabulary

ATC

RxNorm

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

Medical devices

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

Yes

Administration of vaccines

Yes

Procedures

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

Captured

Procedures vocabulary

Other

Procedures vocabulary, other

KVÅ (similar to NOMESCO)

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

SNOMED

Medicinal product information

Captured

Medicinal product information collected

Active ingredient(s)

Brand name

Dosage regime

Dose

Formulation

Package size

Route of administration

Strength

Medicinal product vocabulary

ATC

RxNorm

Quality of life measurements

Not Captured

Lifestyle factors

Not Captured

Sociodemographic information

Captured

Sociodemographic information collected

Age

Country of origin

Education level

Health area

Marital status

Sex

Socioeconomic status

Quantitative descriptors

Population Qualitative Data

Population age groups

All

In utero

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 (\geq 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 database covers the full Swedish population (officially registered inhabitants) since 2015.

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
Household
Mother-child
Sibling

Population

Population size

12056974

Active population size

10588727

Population by age group

Age group	Population size	Active population size
Paediatric Population (< 18 years)	2199922	2090271
Neonate	1274	0
Infants and toddlers (28 days - 23 months)	200612	189841
Children (2 to < 12 years)	1215442	1141197
Adolescents (12 to < 18 years)	782594	759233
Adult and elderly population (≥ 18 years)	9857052	8498456
Adults (18 to < 65 years)	6690268	6233593
Adults (18 to < 46 years)	4077054	3764045
Adults (46 to < 65 years)	2613214	2469548
Elderly (≥ 65 years)	3166784	2264863
Adults (65 to < 75 years)	1222433	1059751
Adults (75 to < 85 years)	1178915	886481
Adults (85 years and over)	765436	318631

Median observation time

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

10.70

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

11.00

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).

[SCIFI-PEARL/HI-SPEED](#)

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 data are held by Swedish national and regional registers. Medical care events including inpatient and specialist outpatient care visits, drug dispensing, cancer diagnosis, cause of death, etc, are reported and recorded at the national level, and primary health care visits are reported to the corresponding region. Demographic and socioeconomic data including education level, income, living region, marital status, etc, are reported and recorded at the national level once per year (at the end of the corresponding year).

Event triggering registration

Event triggering registration of a person in the data source

Birth

Immigration

Other

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

Present in Swedish population on 1 Jan 2015, or birth/immigration after that.

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

Death

Emigration

Event triggering creation of a record in the data source

hospital discharge, specialist encounter, primary care encounter, and more, and other health care events, dispensation of a medicinal product, registration of a person (for sociodemographic data).

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

All data sources are linked by deterministic data linkage (Swedish national unique personal ID) and pseudonymized with project ID for linked database.

Linkage description, possible linkage

The data could potentially be linked to many other Swedish sources, conditional on ethics and data holder approvals.

Linked data sources

Pre linked

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

Yes

Data source

[Landspatientregisteret \(National Patient Register\)](#)

Data source, other

Total Population Register, Migration Register, LISA Register of sociodemographic and economic data, Multi-generation Register, National Patient Register, National Prescribed Drug Register, National Cancer Register, Medical Birth Register, National Cause of Death Register, SmiNet national notifiable disease register, National Vaccination Register, Primary Healthcare Register for Stockholm region, Primary Healthcare Register for Västra Götaland

Region. Could potentially be linked to many other Swedish sources, conditional on ethics and data holder approvals.

Linkage strategy

Deterministic

Linkage variable

National personal identifying number used for linkage.

Database uses Study ID after pseudonymization.

Linkage completeness

Close to 100%.

Data management specifications that apply for the data source

Data source refresh

Quarterly

Every 6 months

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)?

No

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

Informed consent, other

Ethics needed if not already covered by available approvals.

Data source last refresh

20/03/2025

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

6,00 months

Data source ETL status

Completed

CDM name (other)

Nordic CDM

Data source ETL CDM version

5D

Data source ETL frequency

6,00 months

Data source ETL status

Completed