

EL8: Health care registers

From cradle to grave

Reading

- A. Hiyoshi [1] gives a brief and recent introduction and to all registers covered in this lecture.
 - J. F. Ludvigsson *et al.* [2] provides an excellent overview of the Swedish population registers and their use in medical research.
 - The Personal Data Act (PUL) has been replaced by GDPR.
 - The former Regional Ethical Review Boards were replaced in 2019 by a single national authority, the Swedish Ethical Review Authority (Etikprövningsmyndigheten)
 - The legislation governing legal gender recognition has been revised, with a new law adopted in 2024 and entering into force in 2025.
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Recommended references:

- H. L. Brooke *et al.* [3] introduces the Swedish cause of death register
- J. F. Ludvigsson, P. Svedberg, O. Olén, G. Bruze, and M. Neovius [4] describes The longitudinal integrated database for health insurance and labour market studies (LISA) and its use in medical research
- Å. H. Everhov *et al.* [5] have investigated the completeness of the national patient register (focus on the introduction, discussion and conclusions)
- L. Emilsson, B. Lindahl, M. Köster, M. Lambe, and J. F. Ludvigsson [6] gives an overview of the Swedish Quality Registers. Some things have changed since then, but most of it is still relevant.

Types of registers

National health registers

- mandated by law
- Sometimes with regional data collection and yearly updates
- Governed by state authority

Quality registers

- Voluntary for health care providers but commonly adopted
- opt-out for individuals
- A typically Swedish concept
- more than 100 in Sweden
- But similar data collections in other countries by other names

- Governed by regional authorities
- Collaboration within The Swedish Association of Local Authorities and Regions (SALAR/SKR)

| Authority | National registers / systems | Notes |
|---|---|---|
| National Board of Health and Welfare (Socialstyrelsen) | National Patient Register, Medical Birth Register, Cause of Death Register, Cancer Register, Prescribed Drug Register, Dental Health Register | Main authority responsible for Swedish health data registers |
| Public Health Agency of Sweden (Folkhälsomyndigheten) | National Vaccination Register, SmiNet (notifiable communicable diseases) | Registers related to infectious disease surveillance |
| Swedish eHealth Agency (E-hälsomyndigheten) | National prescription database (dispensed prescription data) | Data on dispensed medicines from pharmacies |
| Statistics Sweden (SCB) | LISA database, Population Register, Education Register, Income and Tax Register | Socioeconomic and demographic registers often linked to health data |
| Swedish regions / national quality register organisations | National Quality Registers (e.g. SWEDEHEART, Swedish Hip Arthroplasty Register, National Diabetes Register) | Clinical quality registers maintained by healthcare organisations |



Swedish Medical Birth Register

- Established in 1973
- Covers pregnancies resulting in delivery in Sweden
- Includes **live births and stillbirths** from gestational week 22+0
- Contains information reported by **maternal care, delivery care, and neonatal care**

Main variables include:

- mother's **previous pregnancies**, smoking status, delivery clinic
- **gestational age**, pain relief, and mode of delivery
- **diagnoses and procedures** for mother and child
- child's **sex, weight, length, head circumference, and condition at birth**

National Register of Congenital Anomalies

- Surveillance register for congenital malformations (ICD-10) and chromosomal abnormalities
- For live births and stillbirths (≥ 22 weeks gestation)
- Also includes anonymised data on terminated pregnancies due to fetal anomalies

Background

- monitoring of congenital anomalies started in 1964 following the Thalidomide (Neurosedyn) scandal
- integrated with the Medical Birth Register in 1973
- reporting expanded in 1999 to include terminated pregnancies due to fetal anomalies

Population registration

- Maintained by the Tax Agency
 - administrative register used for **legal residence and taxation**
- Personal identity number assigned at birth (at the hospital)
- Legal sex registered as part of the personal identity number
- Child's given name decided by parents and reported to the Tax Agency within 3 months
- Registration of municipality of residence (and thereby county)
- Registration district (earlier parish, now district)
- Registered residential address
- Migration events (immigration and emigration)
- Changes of address within Sweden
- Marital status and family relations
- Date of death

The Total population Register (RTP)

- maintained by Statistics Sweden (SCB)
- based on data from the Population registration
- structured for statistical analysis and research
- used as the sampling frame for surveys and register-based studies

Childhood

During childhood and school years, health information is collected through:

- Child health services (BVC)
- School health services
- Vaccination records
- Examinations by school nurses or physicians
- dentists etc

In contrast to many other stages of life in Sweden, these data are **not collected in a national register**.

Vaccination Register

- National register maintained by the Public Health Agency of Sweden (Folkhälsomyndigheten)
- Established in **2013**
- Primarily covers vaccinations given within **national vaccination programmes**

Includes

- vaccine administered
 - date of vaccination
 - dose number
 - healthcare provider
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Purpose

- monitor vaccination coverage
- detect changes in uptake
- support surveillance of vaccine-preventable diseases

Limitations

- vaccinations given outside national programmes (e.g. travel vaccines or by occupational health services) may not be fully captured
- reporting comes from many providers (regions, schools, private clinics)
 - therefore coverage may vary for some vaccines

Military conscription

The conscription register contains information from military conscription examination

- physical measurements (e.g. height, weight)
 - cognitive ability tests
 - psychological assessments
 - health status and diagnoses
 - physical fitness
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Important characteristics:

- covers most Swedish men born roughly **1951–1990**
- Inactive 2010-2016
- Both men and women since 2017 (but only approximately 25 %)
- examinations typically performed at **age 18–19**
- data collected by the **Swedish Armed Forces**

Implications for research:

- provides rich health and ability data in **late adolescence** for historic cohort
- widely used in epidemiological and social science research
- mainly includes **men**, which limits generalisability

Swedish Dental Health Register

- National register maintained by the National Board of Health and Welfare (Socialstyrelsen)
- Established in **2008**
- Includes adults (≥ 20 years)

Main variables include:

- dental diagnoses
- dental procedures (treatment codes)
- dental status (e.g. number of remaining teeth)
- treatment dates
- treatment costs and reimbursement

Important characteristics:

- based on reports submitted within the national dental care subsidy system
- includes both public and private dental care providers

Screening registers

- breast cancer (mammography)
- cervical cancer
- colorectal cancer

These programmes aim to **detect disease at an early stage** in otherwise healthy individuals.

Data from screening programmes are often stored in **regional systems** and coordinated nationally through:

- national screening programmes
 - national quality registers
 - regional cancer centres (RCC)
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Typical variables include:

- invitation to screening
- participation
- screening results
- follow-up examinations
- detected diagnoses

Screening data are important for studies of:

- participation in preventive care
- early disease detection
- effectiveness of screening programmes

National Patient Register (NPR)

- National register maintained by the National Board of Health and Welfare (Socialstyrelsen)
- Covers **specialised health care in Sweden**
- Data are collected by **regions and healthcare providers** and then reported to the national register

Coverage

- inpatient care since the **1960s**
 - nationwide coverage since **1987**
 - specialised outpatient care since **2001**
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Each record represents a **healthcare contact or episode of care**.

Examples of contacts included:

- hospital admissions
 - outpatient specialist visits
 - psychiatric specialist care
 - day surgery or day care procedures
-

Main variables include:

- diagnoses (**ICD codes**)
- procedures (**KVÅ codes – Swedish classification of healthcare interventions**)
- case-mix classification (**DRG codes**)
- dates of admission and discharge
- hospital or clinic
- patient demographics

Historical note:

- earlier records used **ICD-8 and ICD-9**
 - today diagnoses are classified using **ICD-10-SE**
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Important limitations:

- **primary care is not included**
- coverage before 1987 is incomplete
- coding practices may vary between regions and over time

Additional considerations:

- reporting is **nationally standardized but based on regional data collection**
- historically, some psychiatric care has been **less consistently reported**
- many outpatient contacts require a **physician encounter**, but coding practices for contacts involving other professionals (e.g. nurses or psychologists) may vary

Despite these limitations, the NPR is widely used for:

- epidemiological research
- disease surveillance
- health services research

Primary care data

Primary care accounts for a large share of health care contacts in Sweden, but **there is still no comprehensive national primary care register** comparable to NPR.

- most primary care data are stored in **regional electronic health record systems**
- reporting practices differ between regions
- national coverage for research and statistics is therefore limited

Recent developments

- there have been long-standing discussions about establishing a national primary care register
- the National Board of Health and Welfare has begun collecting some aggregated primary care statistics
- several pilot initiatives and data collections are ongoing

Prescribed Drug Register (PDR)

- National register maintained by the National Board of Health and Welfare (Socialstyrelsen)
- Covers dispensed prescription drugs from Swedish pharmacies
- Established in 2005
- Nationwide coverage

| Profession | Prescribing rights |
|--------------|---|
| Physicians | Broad prescribing rights (most medications) |
| Dentists | Medications related to dental care |
| Midwives | Selected medications (e.g., contraceptives) |
| Nurses | Limited list of medications after additional training |
| Optometrists | Certain diagnostic eye medications |

Main variables include:

- drug classification (**ATC code**)
- date of dispensing
- amount dispensed
- dosage information
- prescribing clinic or prescriber category

The register contains **drugs dispensed at pharmacies**, not all prescriptions written by physicians.

PDR does not include

- drugs administered in hospitals
- over-the-counter drugs

- since 2009, many non-prescription drugs can also be sold outside pharmacies (e.g. supermarkets and petrol stations)
- most herbal medicines or dietary supplements

Dispensation does not guarantee that the patient **actually used the medication**

used for

- pharmacoepidemiology
- studies of drug safety and effectiveness
- studies of treatment patterns

Cancer Register

- National register maintained by the National Board of Health and Welfare (Socialstyrelsen)
- Established in **1958**
- Covers **all newly diagnosed malignant (and some benign) tumors in Sweden**
- Based on “primary tumour”

Reporting is **mandatory** for clinicians (“A-form”) and pathology laboratories (“B-form”).

Includes

- date of diagnosis
- tumor site and morphology
- stage and diagnostic basis
- reporting clinic and region

Diagnoses are classified using **ICD and ICD-O codes**.

Cancer reporting in Sweden is organised through **six healthcare regions**:

- Northern
- Uppsala–Örebro
- Stockholm–Gotland
- South-East
- **Western** (*VGR + [Northern] Halland*)
- Southern

Within each region, a **Regional Cancer Centre (RCC)** coordinates:

- cancer data reporting (combining A- and B-forms)
 - quality improvement
 - clinical guidelines
 - cancer care monitoring
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Strengths:

- one of the oldest nationwide cancer registers in the world

- high completeness due to mandatory reporting
- enables long-term studies of cancer incidence and survival

Limitations:

- limited information on **treatment and outcomes**
- additional clinical details often require linkage to **quality registers or NPR**

Other disease-specific registers

The Swedish Cancer Register is one of the few nationwide disease-specific health data registers.

Some other diagnoses are monitored through national systems, often related to infectious disease surveillance.

Examples:

- HIV (InfCare HIV register)
- notifiable infectious diseases reported through **SmiNet**
- tuberculosis surveillance systems
- hepatitis registers

Characteristics

- often linked to **infectious disease control**
- reporting may be **mandatory under the Communicable Diseases Act**
- maintained by the **Public Health Agency of Sweden**

Cause of Death Register

- National register maintained by the National Board of Health and Welfare (Socialstyrelsen)
- Established in **1952**
- Covers **all deaths among persons registered in Sweden**
- Information is based on **death certificates completed by physicians.**
- Diagnoses are classified using **ICD codes**. Currently ICD-10 (WHO version, not ICD-10-SE)

Each death certificate contains:

- **underlying cause of death**
(the disease or injury that **initiated the chain of events** leading to death)
- **contributing causes of death**
(other conditions that contributed to the death)

Example structure:

- Disease → complication → death
- Diabetes → kidney failure → death

This structure allows analyses of **both underlying and contributing causes of death.**

Strengths

- nationwide coverage since the **1950s**
- very long time series for mortality research
- standardized (international) classification using **ICD**

Limitations

- cause of death depends on **clinical judgement and available information**
- autopsy rates have decreased over time
- misclassification can occur, especially at **older ages** (multimorbidity)

i Note

The register is used when the cause of death is of importance. The date of death is otherwise also found in TPR and can often be accessed directly from the Tax Agency.

LISA

Not a health care register but often used for background data.

- Longitudinal Integration Database for Health Insurance and Labour Market Studies
- Maintained by **Statistics Sweden (SCB)**
- based on administrative registers from several authorities
- Established in **1990**, with data available annually from that year

The database contains **socioeconomic information for all individuals aged 16 and older registered in Sweden.**

Purpose

- provide background variables for research and statistics
- enable studies of **social determinants of health**

Main types of variables include

- education level
- income and taxation
- employment status
- occupation and workplace
- social insurance benefits
- family situation

used for

- adjustment for socioeconomic factors
- studies of inequalities in health
- labour market and health research

Social services registers (SoL)

Maintained by the **National Board of Health and Welfare (Socialstyrelsen)**.

Data reported under the **Social Services Act (SoL)**.

Examples

- social assistance (economic support)
- interventions for children and adolescents
- substance abuse treatment
- some elderly care services

Social insurance registers

Registers on sickness absence and social insurance are maintained by the **Swedish Social Insurance Agency (Försäkringskassan)**.

Examples

- sickness benefit (sick leave compensation)
 - disability pension
 - parental leave benefits
 - work injury compensation
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Main variables

- benefit type
- start and end dates
- degree of compensation (e.g. 25–100%)
- diagnosis for sickness absence
- demographic information

Important characteristics

- based on **administrative data used for benefit decisions**
- widely used in research on **work ability, labour market participation, and health**

These registers complement health registers by providing information on **functional consequences of disease**, such as long-term sickness absence.

National Quality Registers

National quality registers collect detailed clinical information on specific diseases or treatments.

They are designed to:

- monitor and improve quality of care
- support clinical quality improvement

But they can also be used for research

Typical characteristics:

- focus on specific diagnoses, treatments, or procedures
- contain more detailed clinical data than national health data registers
- participation is generally voluntary for healthcare providers

There are currently **around 100 national quality registers** in Sweden.

Organisation

Quality registers are typically initiated by **clinical communities**.

Key actors include:

- steering groups for each register
- regional cancer centres and register centers
- The system is nationally coordinated by the **Swedish Association of Local Authorities and Regions (SALAR / SKR)**
- Registers are hosted by regions (who acts as data controllers)
- funded through national and regional support
- Quality registers therefore complement national health data registers by providing **more detailed clinical information**.

PROM/PREM

In addition to clinical data, many registers also collect:

- **PROM** – Patient Reported Outcome Measures
- **PREM** – Patient Reported Experience Measures

These variables capture:

- patients' own assessment of health status
- quality of care from the patient perspective

If collected longitudinally, comparisons before/after treatment becomes possible.

The Swedish register ecosystem

Sweden has a unique infrastructure of population-based registers that can be linked using the **personal identity number**.

| Register type | Examples | Maintained by |
|-------------------------|---|--------------------------------------|
| Population registers | Population Register / RTB | Statistics Sweden (SCB) |
| Socioeconomic registers | LISA database | Statistics Sweden (SCB) |
| Health data registers | NPR, MBR, PDR, Cancer Register, Cause of Death Register, Dental Health Register | National Board of Health and Welfare |

| Register type | Examples | Maintained by |
|---------------------------------|---|--------------------------------------|
| Infectious disease surveillance | National Vaccination Register, SmiNet | Public Health Agency of Sweden |
| Social insurance registers | Sickness absence, disability benefits | Swedish Social Insurance Agency |
| Social services registers | Social assistance, child welfare | National Board of Health and Welfare |
| Quality registers | ~100 disease- or treatment-specific registers | Regions (SALAR) |

Key characteristics:

- **Nationwide coverage** for many registers
- Longitudinal data spanning several decades
- Possibility of individual-level linkage across registers by the individual personal number

Limitations:

- some sectors lack national registers (e.g. **primary care, school health services**)
- coverage and data quality may vary across registers, health care providers (private vs public, secondary vs “tertiary” care and over time)

International perspective

Many countries maintain health-related registers, but the **structure and coverage vary considerably**.

Common challenges internationally:

- fragmented healthcare systems
- lack of unique personal identifiers
- multiple data holders (insurance systems, hospitals, regions)
- limited possibilities for linking data across sectors

As a result, nationwide longitudinal register studies are often more difficult to conduct than in the Nordic countries.

Countries with similar register infrastructures

The Nordic countries have relatively similar systems based on:

- nationwide administrative registers
- universal healthcare systems
- personal identification numbers

These countries are therefore often used in **comparative register-based research**.

Examples from other countries

Health data systems in other countries are often organised differently:

- United Kingdom: NHS administrative datasets
- Netherlands: population registers linked with health insurance data
- United States: insurance claims databases and cohort studies
- Canada: provincial administrative health data

These systems can provide valuable data, but often lack:

- nationwide coverage
- consistent linkage across registers
- very long follow-up periods

The Nordic register systems are therefore **widely used in international epidemiological research**.

Swedish Twin Registry

- Maintained by **Karolinska Institutet**
- Established in **1961**
- One of the **largest twin registers in the world**

Information on

- twins born in Sweden since the late 1800s
- zygosity (monozygotic / dizygotic)
- health outcomes
- lifestyle and environmental factors

The register currently includes **more than 190,000 twins**.

research use

Main purpose to study the role of **genetic vs environmental factors** in health and disease

Typical study designs:

- twin concordance studies
 - co-twin control studies
 - longitudinal follow-up
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- [3] H. L. Brooke *et al.*, “The Swedish cause of death register,” *European Journal of Epidemiology*, vol. 32, no. 9, pp. 765–773, 2017, doi: [10.1007/s10654-017-0316-1](https://doi.org/10.1007/s10654-017-0316-1).
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