# Semmelweis University Clinical Data

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# Administrative details

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# PURI

https://redirect.ema.europa.eu/resource/1000000184

Data source ID

100000184

#### Data source acronym

SUCD

## Data holder

Semmelweis University

## Data source type

Emergency care discharge records Hospital discharge records Hospital inpatient records Hospital outpatient visit records

# Main financial support

National, regional, or municipal public funding

# **Care setting**

Hospital inpatient care Hospital outpatient care

# 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.

Yes

# **Description of the qualification**

We are a DARWIN EU data partner.

## Data source website

Semmelweis University website

# **Contact details**

# Zsolt Bagyura



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# Data source regions and languages

**Data source countries** 

Hungary

**Data source languages** Hungarian

# Data source establishment

# Data source established

01/01/2022

# Data source time span

**First collection:** 01/01/2014 The date when data started to be collected or extracted.

# **Publications**

# Data source publications

Mapping Hungarian procedure codes to SNOMED CT

Human cystic echinococcosis in Hungary (2000–2014): a retrospective case series analysis from a single-center study

Patterns of erythropoiesis-stimulating agent use for chemotherapy-induced anemia in lung cancer: results of a retrospective Hungarian real-life clinical data analysis

Mid-term results and predictors of restenosis in patients undergoing endovascular therapy for isolated popliteal artery steno-occlusive disease Restenosis rates in patients with ipsilateral carotid endarterectomy and contralateral carotid artery stenting

Incidence of and predisposing factors for pseudoaneurysm formation in a highvolume cardiovascular center

# Studies

# List of studies that have been conducted using the data source

DARWIN EU® - Monitoring prescription of essential medicines administered in ICU

# 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**

Not Captured

#### **Prescriptions of medicines**

Captured

## **Prescriptions vocabulary**

ATC

RxNorm

## **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?

Captured

# Indication vocabulary

ICD-10

## **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**

SNOMED CT

#### 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.

#### Captured

#### **Biomarker data vocabulary**

Other

#### Biomarker vocabulary, other

LOINC

## **Patient-reported outcomes**

Is information on patient-reported outcomes (e.g., quality of life) available?

No

## **Patient-generated data**

#### 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 CT

## **Medicinal product information**

Captured

#### Medicinal product information collected

Active ingredient(s)

Brand name

Dose

Formulation

Package size

Route of administration

Strength

# Medicinal product vocabulary

RxNorm

## **Quality of life measurements**

Not Captured

## Lifestyle factors

Not Captured

## Sociodemographic information

Captured

#### Sociodemographic information collected

Age Country of origin Living in rural area Sex

# Quantitative descriptors

# Population Qualitative Data

# Population age groups

All 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 ( $\geq$ 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

20%

# 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)

Semmelweis University is the largest provider of health care services in Hungary. Most of the departments cater for the most serious cases and patients requiring complex treatment, thus making the university a national health care provider. The overwhelming majority of patient data originates from Hungary, mainly from central region of the country: Budapest and Pest County.

# Family linkage

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

# Population

## **Population size**

2321050

# Population by age group

Age group	Population size
Paediatric Population (< 18 years)	333927
Neonate	88910
Children (2 to < 12 years)	134680
Adolescents (12 to < 18 years)	82291
Adult and elderly population ( $\geq$ 18 years)	1434073
Elderly ( $\geq$ 65 years)	395111
Adults (85 years and over)	39679

# Median observation time

Median time (years) between first and last available records for unique individuals captured in the data source 0.10

# 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?

Yes

# **Description of data collection**

Entries in the hospital information system

# Event triggering registration

## Event triggering registration of a person in the data source

Birth

Other

Practice registration

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

First visit in a univestiy clinic

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

Death

Other

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

We only know if a patient died if they die in one of Semmelweis University clinics, and for research purposes the death status could be queried from the Hungarian National Insurance Fund. We do not have otherwise de-registration.

## Event triggering creation of a record in the data source

Visit in a university clinic

# 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, possible linkage

By the unique identifiers (Hungarian social security number), it would be possible to link the databases

# Linked data sources

#### **Pre linked**

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

No

#### Data source, other

National Health Insurance Fund of Hungary

#### Linkage strategy

Deterministic

#### Linkage variable

Hungarian social security number: 9 digit number

# Data management specifications that apply for the data source

#### Data source refresh

Every 6 months

#### Informed consent for use of data for research

Required for intervention studies

#### 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

30/11/2024

# 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