# Norwegian Linked Health registry at University of Oslo

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# Administrative details

### Administrative details

**Data source ID** 

1000000409

Data source acronym

NLHR@UiO

**Data holder** 

University of Oslo

#### **Data source type**

Birth registry

Death registry

Disease registry

Hospital inpatient records

Hospital outpatient visit records

Pharmacy dispensing records

Population registry

Primary care medical records

Vaccination registry

#### **Care setting**

Hospital inpatient care

Hospital outpatient care

Primary care - GP, community pharmacist level

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.

Yes

#### **Description of the qualification**

The majority of source data has been ETL-ed to OMOP and investigated by DARWIN EU in an onboarding process.

# Contact details

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# Data source regions and languages

#### **Data source countries**

Norway

#### **Data source languages**

Bokmål, Norwegian

**English** 

#### Data source establishment

#### **Data source established**

01/08/2024

#### Data source time span

First collection: 01/01/2008

The date when data started to be collected or extracted.

Last collection: 31/12/2023

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

### **Publications**

# Data source publications

https://doi.org/10.1016/j.ijmedinf.2024.105602

### **Studies**

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

DARWIN EU® - Association of venous thromboembolism with non-steroidal antiinflammatory drug use in women 15-49 years using hormonal contraceptives

DARWIN EU® Drug Utilisation Study of prescription opioids

DARWIN EU® – Utilisation of commonly used benzodiazepines during pregnancy and the incidence of pregnancy losses

DARWIN EU® - Use of antiretroviral therapies in paediatric patients

DARWIN EU® – Paracetamol prescribing and paracetamol overdose in Europe: a descriptive analysis of trends and patient characteristics

### 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.

Yes

#### **Disease details**

COVID-19

Influenza

Gonorrhoea

Rotavirus infection

Campylobacter infection

Salmonella bacteraemia

Bacterial infection

#### **Disease details (other)**

Campylobacteriosis, Pertussis/whooping cough, Pneumococcal infectious disease, Viral infection of central nervous system, Group B streptococci infection, Group A streptococci infection, Disease due to rotavirus, Systemic Haemophilus influenzae disease, Campylobacteriosis, Pertussis/whooping cough, Salmonella infection, Gonorrhea, Pneumococcal infectious disease, Viral infection of central nervous system, Group B streptococcus infection, Group A streptococcus infection, Systemic Haemophilus influenzae disease, Campylobacteriosis, Pertussis/whooping cough, Salmonella infection, Gonorrhea, Pneumococcal infectious disease, Viral infection of central nervous system, Group B streptococci infection, Group A streptococci infection, Systemic Haemophilus influenzae disease

#### 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

Yes
ICU admission
Is information on intensive care unit admission available?
No
Cause of death
Captured
Cause of death vocabulary
ICD-10
Prescriptions of medicines
Not Captured
Dispensing of medicines
Captured
Dispensing vocabulary
ATC
other
Dispensing vocabulary, other
Drug information contains all medicines that have been dispensed by
prescription from a pharmacy. Prescribed drugs are identified by a unique
product number (varenummer). https://wiki.vnr.fi/
Advanced therapy medicinal products (ATMP)

Hospital admission and/or discharge

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, other

Dispensed drug

#### **Medical devices**

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

No

#### **Administration of vaccines**

Yes

#### **Procedures**

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

Captured

#### **Procedures vocabulary**

ICPC-2

#### 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 ICPC-2 **Medicinal product information** Captured Medicinal product information collected Active ingredient(s) Dose Formulation

Package size

Strength

#### **Medicinal product vocabulary**

ATC

Other

#### If 'other,' what vocabulary is used?

Each marketed drug is identifiable using a specific product number (varenummer). https://wiki.vnr.fi/

#### **Quality of life measurements**

Not Captured

#### **Lifestyle factors**

Not Captured

#### **Sociodemographic information**

Captured

#### Sociodemographic information collected

Age

Country of origin

Marital status

Sex

Socioeconomic status

# Quantitative descriptors

# Population Qualitative Data

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

This data set covers the entire Norwegian population.

# 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**

6114138

#### **Active population size**

5495000

## Median observation time

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

16.00

# 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

**Immigration** 

Residency obtained

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

Death

**Emigration** 

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

Contacting health-care providers including GP and hospital visits

# 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?

No

#### Linkage description, pre-linked

Norway has a universal public health care system consisting of primary and specialist health care services covering the inhabitant population. Many population-based health registries were established in the 1960s with use of unique personal identifiers facilitating linkage between registries.

#### Linkage description, possible linkage

We harmonized data from the following registries: the Medical Birth Registry of Norway (MBRN), the Norwegian Prescribed Drug Registry (LMR), Norway Control and Payment of Health Reimbursement (KUHR), the Norwegian Surveillance System for Communicable Diseases (MSIS), the Norwegian Immunisation Registry (SYSVAK), the Norwegian Cause of Death Registry (DAR), and the National Registry (NR). Linkage between the registries was facilitated using project-specific person ID generated from unique personal identification assigned at birth or immigration for all legal residents in Norway.

# Data management specifications that apply for the data source

#### **Data source refresh**

Yearly

#### Possibility of data validation

Can validity of the data in the data source be verified (e.g., access to original medical charts)?

#### **Data source preservation**

Are records preserved in the data source indefinitely?

No

#### **Approval for publication**

Is an approval needed for publishing the results of a study using the data source?

No

#### Data source last refresh

29/10/2024

# 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