Norwegian Linked Health registry at University of Oslo

First published: 15/01/2025

Last updated: 28/11/2025

Data source · Human · Birth registry · Death registry · Disease registry · Hospital inpatient records · Hospital outpatient visit records · Pharmacy dispensing records · Population registry · Primary care medical records · Vaccination registry

Administrative details

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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.

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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.

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

CONSIGN study: COVID-19 infection and medicines in pregnancy - a multinational registry based study

DARWIN EU® Effectiveness of Human Papillomavirus Vaccines (HPV) to prevent cervical cancer

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

DARWIN EU® - RR1 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

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

DARWIN EU® - Drug utilisation study in individuals with cystic fibrosis in Europe

DARWIN EU® - RR Characterisation of individuals with cystic fibrosis in Europe

Safety of mRNA COVID-19 vaccines during pregnancy

DARWIN EU® - RR Childhood hypertension and sartans prescribing in children

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

[DARWIN EU® – Proof-of-concept: Preparedness for annual seasonal influenza vaccine effectiveness studies - Vaccine coverage and incidence of influenza-related outcomes](#)

[DARWIN EU® - Encephalitis risk in pediatric varicella vaccine recipients](#)

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

Anxiety disorder

Depression

Bipolar disorder

Diabetes mellitus

Postpartum haemorrhage

Pre-eclampsia

Migraine

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

Hospital admission and/or discharge

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)

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

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 (≥ 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

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)?

No

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