# Norwegian Health Registers

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Data source

Administrative healthcare claims

Pharmacy dispensing records

Population registry

## Administrative details

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#### **PURI**

https://redirect.ema.europa.eu/resource/1111170

#### **Data source ID**

1111170

#### Data holder

The Norwegian Institute of Public Health

#### Data source type

Administrative healthcare claims Pharmacy dispensing records Population registry

#### **Main financial support**

National, regional, or municipal public funding

#### Care setting

Hospital inpatient care Hospital outpatient care Primary care – GP, community pharmacist level 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.

No

#### Data source website

https://helsedata.no/en/

### Contact details

### Kari Furu



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# Data source regions and languages

#### **Data source countries**

Norway

#### **Data source languages**

Norwegian

### Data source establishment

#### Data source established

15/06/1964

## **Publications**

### Data source publications

Norwegian Control and Payment of Health Reimbursements Database (KUHR)

Medical Birth Registry of Norway

Norwegian Surveillance System for Communicable Diseases (MSIS)

Norwegian Prescription Database (NorPD)

Norwegian Immunisation Registry SYSVAK

SARS-CoV-2 Vaccination and Myocarditis in a Nordic Cohort Study of 23 Million Residents

Comparative Risk of Major Congenital Malformations With Antiseizure Medication Combinations vs Valproate Monotherapy in Pregnancy.

A common data model for harmonization in the Nordic Pregnancy Drug Safety Studies (NorPreSS)

Association of Prenatal Exposure to Antiseizure Medication With Risk of Autism and Intellectual Disability

Stroke and bleeding risk in atrial fibrillation with CHA2DS2-VASC risk score of one: the Norwegian AFNOR study

### **Studies**

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

Post Conditional Approval Active Surveillance Study Among Individuals in Europe Receiving the Pfizer-BioNTech Coronavirus Disease 2019 (COVID-19) Vaccine

Long term, prospective, observational cohort study evaluating the safety profile in patients with highly active relapsing multiple sclerosis (RMS) newly started on oral cladribine? CLARION

Post-Authorisation Active Surveillance Study of Myocarditis and Pericarditis Among Individuals in Europe Receiving the Pfizer-BioNTech Coronavirus Disease 2019 (COVID-19) Vaccine

Retrospective cohort study evaluating effectiveness of GARDASIL™ against adult-onset recurrent respiratory papillomatosis in Norway

Post-Authorisation Safety Study of Comirnaty Original/Omicron BA.1 and Comirnaty Original/Omicron BA.4-5 in Europe

Long-term real-world safety of ozanimod – A post-authorisation safety study (PASS) in patients diagnosed with ulcerative colitis

Antipsychotics in pregnancy and the risk of adverse pregnancy outcomes - a nationwide study

SAFETY-VAC: a framework for the post-authorisation safety monitoring and evaluation of vaccines in the European Union (SAFETY-VAC)

The utilisation of antiepileptics in men and women of childbearing age, and pregnant women in Europe (ADEPT)

SAFETY-VAC: a framework for the postauthorisation safety monitoring and evaluation of vaccines in the European Union (SAFETY-VAC)

### 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

#### 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)?

No

### 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

#### **Prescriptions of medicines**

Not Captured

#### **Dispensing of medicines**

Captured

#### **Dispensing vocabulary**

**ATC** 

## Advance 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

Other

#### 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**

Other

#### **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.

No

#### 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)

Brand name

Formulation Package size Strength

#### Medicinal product vocabulary

**ATC** 

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

Not Captured

#### Lifestyle factors

**Not Captured** 

#### Sociodemographic information

Captured

#### Sociodemographic information collected

Age
Country of origin
Education level
Gender
Living in rural area
Marital status

Socioeconomic status

# Quantitative descriptors

# Population Qualitative Data

#### Population age groups

Paediatric Population (< 18 years)
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)
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

100%

**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)**All residents assigned a unique national personal identity number at birth or immigration and are covered in the healthcare and administrative registers. Norway has universal tax-financed healthcare services that report to register. Private healthcare is incompletely or not captured. However, private specialists with reimbursement appointment with the public health system are captured.

# Family linkage

Family linkage available between the following persons

Father-child Household Mother-child Sibling

# **Population**

Population size 5500000

# Active population

Active population size 5500000

# 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). https://helsedata.no/en/access-to-data/

#### 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**

Population-based data are routinely and prospectively collected on individuals lives and health mandated by law. The personal identity numbers are the key identifiers in all registers/databases, enabling easy, accurate and unambiguous individual-level linkage of the registers.

Data holders: Health Data Service, Norwegian Institute of Public Health Date established: 2004 for Prescribed Drug Register. 2008 for patient register (hospital, secondary care). 1964 for Population register. 1967 for Medical Birth Register. Different for each register

# Event triggering registration

Event triggering registration of a person in the data source

Birth

**Immigration** 

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

Death

**Emigration** 

# 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

The personal identity numbers are the key identifiers in all registers, enabling easy, accurate and unambiguous individual-level linkage of the registers

#### Linkage description, possible linkage

The personal identity numbers are the key identifiers in all registers and the data sources we may link to, enabling easy, accurate and unambiguous individual-level linkage of the registers and other data sources

#### Linked data sources

#### Pre linked

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

Yes

#### Data source, other

All national healthcare and administrative registers can be linked

#### Linkage variable

National and unique personal identity number assigned at birth or immigration

#### Linkage completeness

Near complete 100%

#### Pre linked

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

No

#### Data source, other

Cohort studies with biobanks, surveys, medical quality register for specific diseases

#### Linkage completeness

Depends on type of consent given by registered person

Data management specifications that apply for the data source

#### Data source refresh

Yearly

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

Other

#### 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?

No

#### Informed consent, other

You may need exemption from the duty of confidentiality

# Common Data Model (CDM) mapping

#### **CDM** mapping

Has the data source been converted (ETL-ed) to a common data model?

No