Norwegian Health Registers

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Data source | Human | Administrative healthcare records (e.g., claims) | Pharmacy dispensing records | Population registry

Administrative details

Administrative details

Data source ID

1111170

Data holder

The Norwegian Institute of Public Health

Data source type

Administrative healthcare records (e.g., 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 kari.furu@fhi.no

Main

kari.furu@fhi.no

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-Authorization Active Surveillance Safety Study Using Secondary Data to Monitor Real-World Safety of Spikevax in Europe (COVID-19)

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

A post-authorisation safety study (PASS) to evaluate the long-term cardiovascular and psychiatric safety profile of methylphenidate (MPH) in adult patients with attention deficit/hyperactivity disorder (ADHD) in European Countries (PASS on methylphenidate in adults)

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

NN9535-4447 Epidemiological assessment of the risk for pancreatic cancer associated with the use of semaglutide in patients with type 2 diabetes- A cohort study based on Nordic registry data

A post-authorization safety study (PASS) to evaluate the paternal exposure to valproate and the risk of neurodevelopmental disorders including autism spectrum disorders as well as congenital abnormalities in offspring - a population-based retrospective study

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

mRNA-1273-P910: Clinical course, outcomes and risk factors of myocarditis and pericarditis following administration of Moderna vaccines targeting SARS-CoV-2.

Characterization of neurodevelopmental disorders in children exposed in utero to valproate and/or other antiepileptic drugs with long-term follow-up: retrospective study of multiple European data sources (AVALON)

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: Network of Data Sources for Vaccine Safety Evaluation

ADEPT: The utilisation of antiseizure medications in pregnant women, other women of childbearing potential, and men: a multi-database study from 7 European countries

SAFETY-VAC: Background incidence estimation of flares of pre-existing chronic diseases using pan-European electronic healthcare data sources.

ADEPT: feasibility of estimating the risk of adverse pregnancy, neonatal and child outcomes following either in utero ASM exposure through the mother, or peri-conceptional ASM exposure through the father

DARWIN EU® - Background incidence rates of selected vaccine adverse events of special interest (AESIs) in Europe

Nested case-control study evaluating effectiveness of immunization of girls and women of childbearing potential with GARDASIL(TM)/GARDASIL(TM) 9 against juvenile-onset recurrent respiratory papillomatosis (JoRRP) in Sweden, Denmark, and Norway (V503-095)

SAFETY-VAC: Phenotype proposal and rates of immunocompromised populations in real-world data sources.

A Post-Authorisation Safety Study (PASS) of ABRYSVO (Respiratory Syncytial Virus Stabilised Prefusion Subunit Vaccine) in Pregnant Women and their Offspring in a Real World Setting in Europe and UK (C3671026)

DARWIN EU® - Characterising the use of JAK inhibitors in Europe: a Drug Utilisation Study

DARWIN EU® - Prevalence of hypertrophic cardiomyopathy (HCM) and obstructive hypertrophic cardiomyopathy (oHCM) in six European countries

A Drug Utilisation Study of Qsiva for Weight Management: A Postmarketing Cohort Database Study in Denmark, Finland, Norway, and Sweden

Qsiva Use Among Pregnant Women and Prescribed Contraceptive Use Among Qsiva Users of Childbearing Potential: A Postmarketing Cohort Database Study in Denmark, Finland, Norway, and Sweden

Identification, Characterisation, and Data Quality Assessment of Data Sources for Real-World Safety and Effectiveness Studies of Chimeric antigen receptor T-cell (CAR-T cell) therapies

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

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

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

Procedures vocabulary, other

NCSP, NCMP, NCRP

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 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

5500000

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

Event triggering creation of a record in the data source

Drug dispensing from pharmacy, Healthcare contact (visit physician, hospital), administration of vaccine, diagnosed with cancer

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