Norwegian Linked Health registry at University of Oslo, Pregnancy cohort

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Data source | Human | Birth registry | Hospital inpatient records | Hospital outpatient visit records | Pharmacy dispensing records | Primary care medical records

Administrative details

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Data source ID

1000000410

Data source acronym

NLHR@UiO:PERINATAL

Data holder

Pharmacoepidemiology and Drug Safety Research Group (PharmaSafe), University of Oslo

Data source type

Birth registry

Hospital inpatient records

Hospital outpatient visit records

Pharmacy dispensing records

Primary care medical records

Main financial support

Funding by own institution

Care setting

Hospital inpatient care

Hospital outpatient care

Primary care – GP, community pharmacist level

Primary care – specialist level (e.g. paediatricians)

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

NLHR_PERINATAL_CDM homepage at Pharmasafe

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

15/09/2020

Data source time span

First collection: 01/01/2004

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

DARWIN EU® – Benzodiazepine use during pregnancy: a descriptive study characterising exposure, pregnancy loss, and covariates to inform future safety studies

DARWIN EU® - Cancer incidence during pregnancy

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

Anxiety disorder

Depression

Bipolar disorder

Diabetes mellitus

Postpartum haemorrhage

Pre-eclampsia

Migraine

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

Not Captured

Prescriptions of medicines

Not Captured

Prescriptions vocabulary

ATC

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?

Not Captured

Medical devices

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

No

Administration of vaccines

No

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.

No

Clinical measurements

Is information on clinical measurements (e.g., BMI, blood pressure, height) available?

Yes

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

Package size

Strength

Medicinal product vocabulary

ATC

Quality of life measurements

Not Captured

Lifestyle factors

Not Captured

Sociodemographic information

Captured

Sociodemographic information collected

Age

Sex

Quantitative descriptors

Population age groups

Infants and toddlers (28 days – 23 months)

Children (2 to < 12 years)

Adolescents (12 to < 18 years)

Adults (18 to < 65 years)

Adults (18 to < 46 years)

Adults (46 to < 65 years)

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

This data set cover people (mother-father-child related to a pregnancy record in Birth registry) in the entire country of Norway, covering all individuals with a pregnancy event > GW12 from 2008 to 2019, their children and partners.

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 pregnancies lasted less than 12 weeks; Liveborn offspring born before 2004

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

Mother-child

Population

Population size

1.939.851

Active population size

1.939.851

Population by age group

Age group	Population size	Active population size
All	1.939.851	1.939.851
Paediatric Population (< 18 years)	889.865	889.865
Infants and toddlers (28 days – 23 months)	55.483	55.483
Children (2 to < 12 years)	600.938	600.938
Adolescents (12 to < 18 years)	233.444	233.444
Adult and elderly population (≥18 years)	1.049.986	1.049.986
Adults (18 to < 46 years)	951.464	951.464
Adults (46 to < 65 years)	98.520	98.520
Elderly (≥ 65 years)	2	2

Median observation time

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

15,90

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

15,90

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

Description of data collection

Datasets are retrieved directly from registry owners.

Event triggering registration

Event triggering registration of a person in the data source

Birth

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 (NorPD) and Norway Control and Payment of Health Reimbursement (KUHR). 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

Informed consent for use of data for research

Waiver

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

15/09/2020

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 status

Completed