PRIDE (PRegnancy and Infant DEvelopment) Study

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Data source | Human | Other

Administrative details

Administrative details

Data source ID

1000001183

Data source acronym

PRIDE Study

Data holder

Radboud university medical center (Radboudumc)

Data source type

Other

Data source type, other

Prospective pregnancy register, not disease or medication specific

Main financial support

Funding by own institution

Care setting

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

www.pridestudy.nl

Contact details

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Main

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Data source regions and languages

Data source countries

Netherlands

Data source languages

Dutch

English

Data source establishment

Data source established

01/01/2011

Data source time span

First collection: 01/07/2011

The date when data started to be collected or extracted.

Publications

Data source publications

The PRIDE Study: evaluation of online methods of data collection

Studies

List of studies that have been conducted using the data source

The PRIDE-Asthma cohort: insight into the short- and long-term effects of asthma and asthma medication 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.

No

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

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

ICD

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

Not coded (Free text)

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?

Yes

Genetic data

Are data related to genotyping, genome sequencing available?

Not Captured

Genetic data vocabulary

Other

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?

Yes

Patient-generated data

Is patient-generated information (e.g., from wearable devices) available?

Yes

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

Medicinal product information

Captured

Medicinal product information collected

Active ingredient(s)

Brand name

Dosage regime

Dose

Route of administration

Strength

Medicinal product vocabulary

ATC

Quality of life measurements

Not Captured

Lifestyle factors

Captured

Lifestyle factors

Alcohol use

Diet

Frequency of exercise

Other

Tobacco use

Lifestyle factors included other

Illicit drug use, vaping

Sociodemographic information

Captured

Sociodemographic information collected

Age

Country of origin

Education level

Ethnicity

Living in rural area

Marital status

Socioeconomic status

Type of residency

Quantitative descriptors

Population age groups

In utero

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)

Adults (18 to < 46 years)

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

Based on convenience sampling, only a part of the Dutch pregnant population (~200,000 pregnancies/year) are captured. As of November 2026, >15,000 pregnancies are included.

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)

Voluntary participation, pregnant people <18 years of age and surrogate mothers are excluded.

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

15.000

Active population size

10.000

Population by age group

Age group	Population size	Active population size
In utero	500	500
Neonate	1.000	1.000
Children (2 to < 12 years)	8.500	8.500
Adults (18 to < 46 years)	12.000	9.750

Median observation time

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

3,50

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

3,00

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://doi.org/10.1111/ppe.12618

Biospecimen access

Are biospecimens available in the data source (e.g., tissue samples)?

Yes

Biospecimen access conditions

Research question in line with aims of data collection; fee for use

Access to subject details

Can individual patients/practitioners/practices included in the data source be contacted?

Yes

Description of data collection

Main method: online questionnaires (CastorEDC) completed at multiple time points during pregnancy, biannually after pregnancy until 7 years of age
Other moethds (optional for participants): linkage to healthcare records, community pharmacy dispensing records, and Dutch perinatal registry.

Event triggering registration

Event triggering registration of a person in the data source

Other

Event triggering registration of a person in the data source, other

Pregnancy

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

Death

Other

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

Miscarriage, induced abortion, stillbirth, ectopic pregnancy, molar pregnancy

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Event triggering creation of a record in the data source

Pregnant persons enroll themselves through the PRIDE Study website with online informed consent as early in pregnancy as possible. Median gestational age at enrollment is 9 weeks. Participation with multiple pregnancies is possible.

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

Pharmacy records

Obstetric records

Both for part of the population, depending on consent and calendar time of recruitment. Deterministic linkage.

Linkage description, possible linkage

Dutch perinatal registry

Well-baby clinics

Data management specifications that apply for the data source

Data source refresh

Monthly

Informed consent for use of data for research

Required for all studies

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

Data source preservation length (years)

15 years after last data collection years

Approval for publication

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

No

Data source last refresh

01/11/2026

Common Data Model (CDM) mapping

CDM mapping

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

No