Nivel Primary Care Database

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Data source   Human   Primary care medical records

Administrative details

Administrative details

Data source ID

1111223

Data source acronym

Nivel-PCD

Data holder

Netherlands Institute for Health Services Research (Nivel)

Data source type

Primary care medical records

Main financial support

National, regional, or municipal public funding

Care setting

Primary care – GP, community pharmacist level

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

NEN7510; ISO 27001

Data source website

https://www.nivel.nl/en/nivel-primary-care-database

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: 01/01/2011

The date when data started to be collected or extracted.

Publications

Data source publications

Immediate release fentanyl in general practices: Mostly off-label prescribing

Detection of primary Sjögren's syndrome in primary care: developing a classification model with the use of routine healthcare data and machine learning

Estimating Morbidity Rates Based on Routine Electronic Health Records in Primary Care: Observational Study

Electronic Health Record-Triggered Research Infrastructure Combining Real-world Electronic Health Record Data and Patient-Reported Outcomes to Detect Benefits, Risks, and Impact of Medication: Development Study.

Pattern of oral anticoagulant prescribing for atrial fibrillation in general practice: an observational study in The Netherlands

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 (other)

COVID-19 in a subset of approximately 400 patients (see https://pubmed.ncbi.nlm.nih.gov/37607170/)

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

No

ICU admission

Is information on intensive care unit admission available?

No

Cause of death

Not Captured

Prescriptions of medicines

Captured

Prescriptions vocabulary

ATC

Dispensing of medicines

Not Captured

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

ICPC-1

Medical devices

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

Yes

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?

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

ICPC-1

Medicinal product information

Captured

Medicinal product information collected

Brand name

Dosage regime

Dose

Route of administration

Strength

Medicinal product vocabulary

ATC

Z-index (G-standard)

Quality of life measurements

Not Captured

Lifestyle factors

Captured

Lifestyle factors

Tobacco use

Sociodemographic information

Captured

Sociodemographic information collected

Age

Gender

Health area

Living in rural area

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

8-10%

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)

We collect data from Dutch citizens registered at GPs participating in Nivel Primary Care Database. We do not collect data from patients of other GPs, and from patients not registrered at a GP. Almost all Dutch citizens are registered at a GP, exceptions are patients living in nursing homes for example.

Family linkage

Family linkage available in the data source permanently or can be created on an ad hoc basis

Ad hoc

Population

Population size

4040000

Active population size

1851000

Population by age group

Age group	Population size	Active population size
Paediatric Population (< 18 years)	737000	346000
Infants and toddlers (28 days – 23 months)	96000	37000
Children (2 to < 12 years)	413000	191000
Adolescents (12 to < 18 years)	243000	124000
Adults (18 to < 46 years)	1500000	638000
Adults (46 to < 65 years)	978000	491000
Elderly (≥ 65 years)	823000	375000
Adults (65 to < 75 years)	412000	209000

Age group	Population size	Active population size
Adults (75 to < 85 years)	271000	127000
Adults (85 years and over)	138000	38000

Median observation time

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

4.00

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

6.00

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://www.nivel.nl/sites/default/files/bestanden/governance-document-nzr-3.pdf

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?

Yes

Description of data collection

An extraction of the GP Electronic Health Record (outpatient electronic health record) is made. We receive weekly extractions for surveillance purposes and yearly extractions that are used for other research purposes. Data are pseudonimized within the GP practice and we receive pseudonimized data, consisting of coded fields and hardly and free text fields.

Event triggering registration

Event triggering registration of a person in the data source

Insurance coverage start

Other

Practice registration

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

Start of insurance coverage is related to birth, but we do not know the exact birth date

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

Insurance coverage end

Other

Practice deregistration

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

End of insurance coverage is related to death, but we do not know the exact death date for most of the cases.

Event triggering creation of a record in the data source

Prescriptions: prescription of a medicin; Contacts: claim of a contact; Journal: change in the patient record; referral: referral done via module of Zorgdomein; lab measurement: change in the lab measurement dossier

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

Linked data sources

Pre linked

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

No

Data source, other

Cancer registry (Nederlandse Kanker Registratie)

Linkage strategy

Probabilistic

Linkage variable

Pseudonimized combination of sex, birthdate and postal code

Linkage completeness

Almost 100%

Pre linked

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

No

Data source, other

Claims data

Linkage strategy

Deterministic

Linkage variable

Pseudonimized citizen service number

Linkage completeness

Almost 100%

Pre linked

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

Yes

Data source, other

GP-out-of-hours service use, paramedical health care use

Linkage strategy

Deterministic

Linkage variable

Pseudonimized citizen service number

Linkage completeness

Approximately 80% for GP out-of-hours services, and less for paramedical services

Pre linked

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

No

Data source, other

Pharmacy dispensing database (Stichting Farmaceutische Kengetallen)

Linkage strategy

Probabilistic

Linkage variable

Pseudonimized combination of sex, birthdate and postal code

Linkage completeness

Almost all can be linked (coverage SFK database 95%)

Pre linked

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

No

Data source, other

Sociodemographic data, mortality data, family linkage data (CBS)

Linkage strategy

Deterministic

Linkage variable

Pseudonimized citizen service number

Linkage completeness

Almost 100%

Pre linked

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

Yes

Data source, other

Zorgdomein (referral database)

Linkage strategy

Deterministic

Linkage variable

Pseudonimized citizen service number

Linkage completeness

Available from 2015 for approximately 100 GP practices, extended to almost 300 practices from 2021 on.

Data management specifications that apply for the data source

Data source refresh

Yearly

Informed consent for use of data for research

Required for intervention 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

Approval for publication

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

Yes

Data source last refresh

01/06/2023

Common Data Model (CDM) mapping

CDM mapping

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

No