PHARMO Data Network

First published: 01/02/2024

Last updated: 17/10/2024

Data source | Human | Hospital discharge records | Other | Pharmacy dispensing records | Primary care medical records

Administrative details

Administrative details

PURI

https://redirect.ema.europa.eu/resource/45066

Data source ID

45066

Data source acronym

PHARMO Data Network

Data holder

The PHARMO Institute for Drug Outcomes Research (PHARMO Institute)

Data source type

Hospital discharge records

Other

Pharmacy dispensing records

Primary care medical records

Data source type, other

Electronic health records,The PHARMO Data Network is a population-based network of healthcare databases and combines data from different healthcare settings in the Netherlands .These different data sources, including general practitioner, in- and out-patient pharmacy, clinical laboratory, hospitals, cancer registry, pathology registry and perinatal registry, are linked on a patient level through validated algorithms.

Main financial support

Funding from industry or contract research

Care setting

Hospital inpatient care

Hospital outpatient care

Primary care – GP, community pharmacist level

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

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.

Yes

Description of the qualification

ISO 9001 certification

Data source website

https://pharmo.nl/

Contact details

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Data source regions and languages

Data source countries

Netherlands

Data source languages

Dutch

Data source regions

Drenthe

Flevoland

Fryslân

Gelderland

Groningen

Limburg

Noord-Brabant

Noord-Holland

Overijssel

Utrecht

Zeeland

Zuid-Holland

Data source establishment

Data source established

01/01/1998

Data source time span

First collection: 01/01/1998

The date when data started to be collected or extracted.

Publications

Data source publications

Houweling LM, Bezemer ID, Penning-van Beest FJ, Meijer WM, van Lingen RA, Herings RM. First Year of Life Medication Use and Hospital Admission Rates: Premature Compared with Term Infants. The Journal of pediatrics. 2013163(1):61-66.

Kuiper, Josephina G., et al. "A population-based linked cohort of cancer and primary care data: A new source to study the management of cancer in primary care." European Journal of Cancer Care 31.1 (2022): e13529.

Houben, Eline, et al. "Cohort profile: The PHARMO Perinatal Research Network (PPRN) in the Netherlands: A population-based mother–child linked cohort." BMJ open 10.9 (2020): e037837.

Kuiper, Josephina G., et al. "Existing data sources for clinical epidemiology: the PHARMO database network." Clinical Epidemiology (2020): 415-422.

Overbeek, Jetty A., et al. "Completeness and Representativeness of the PHARMO General Practitioner (GP) Data: A Comparison with National Statistics." Clinical Epidemiology (2022): 1-11.

Studies

List of studies that have been conducted using the data source

Real-world effectiveness of extrafine vesrus standard particle inhaled corticosteroids: A comparative effectiveness analysis of extrafine (EF) hydrofluoroalkane beclometasone (HFA-BDP) and Ciclesonide versus commonly prescribed standard particle inhaled corticosteroids for patients prescribed asthma therapy in The Netherlands (Extrafine vesrus stand particle ICS effectiveness)

POST-APPROVAL SAFETY STUDY (PASS) OF THE UTILIZATION PATTERN OF APIXABAN IN THE NETHERLANDS

An Observational Post-Authorization Safety Study (PASS) of MOVENTIG® (Naloxegol) Among Patients Aged 18 Years and Older Treated with Opioids Chronically

Evaluation of the Use of Nepafenac in Selected European Populations

Safety Evaluation of Adverse Reactions in Diabetes - Drug utilisation studies (SAFEGUARD)

Identification of type 2 diabetes cases in a set of databases participating to the EMIF project

A multinational active safety surveillance study of crizotinib in Europe and the United States

Real-world effectiveness of extra-fine Ciclesonide (Alvesco®) versus standard particle inhaled corticosteroid (ICS)

A non-interventional post-authorisation safety study (PASS) of vortioxetine in Europe

EMIF Use Case 17 - Investigating the relationship in paediatric population between dosing of antibiotics (prescribed, dispensed or administered) and patient’s weight. (EMIF UC17)

Estimating prevalence and incidence of acute myocardial infarction in a set of heterogeneous sources of observational health data collaborating in the EMIF Platform

A PHARMO Study on the Utilization of Pioglitazone in Clinical Practice in The Netherlands with Regard to Diabetic Treatment Regimen and Co-morbidities

Drug utilization study of mirabegron (Betmiga®) using real-world healthcare databases from the Netherlands, Spain, United Kingdom and Finland (Mirabegron DUS)

Drug utilization study of cyproterone/ethinylestradiol (Diane®-35 and generics) in the Netherlands, UK and Italy

Adherence, persistence and switching patterns – once- and twice-daily direct oral anticoagulants (QD versus BID DOACs)

Drug Utilisation Study for Olodaterol

Impact of EU label changes for systemic diclofenac products: post-referral prescribing trends

A Retrospective Cohort Study to Assess Drug Utilisation and Long-Term Safety of Galcanezumab in European Patients in the Course of Routine Clinical Care (I5Q-MC-B002)

Drug-drug interactions between dicloxacillin/flucloxacillin and DOACs

Impact of EU label changes for hydroxyzine products: post-referral prescribing trends

The relationship between the month of birth and ADHD treatment

Intravenous Iron Postauthorisation Safety Study (PASS): Evaluation of the Risk of Severe Hypersensitivity Reactions

A pharmacoepidemiological study of Rivaroxaban use and potential adverse outcomes in routine clinical pratice in the Netherlands

The BRodalumab Assessment of Hazards: A Multinational Safety (BRAHMS) study in electronic healthcare databases

Dulaglutide Modified-Prescription-Event Monitoring Study and network database study: a multi-database collaborative research program of observational studies to monitor the utilisation and safety of dulaglutide in the EU

Risk of Skin Cancer and Lymphoma in Users of Topical Tacrolimus, Pimecrolimus, and Corticosteroids: Protopic JOint European Longitudinal Lymphoma and skin cancer Evaluation (JOELLE) Study

Risk of Skin Cancer and Lymphoma in Users of Topical Tacrolimus, Pimecrolimus, and Corticosteroids (JOELLE)

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 of the Utilisation and Prescribing Patterns of Xeljanz® (tofacitinib) in the European Union Using Secondary Data Sources

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

Utilisation of low-dose rivaroxaban in patients with atherosclerotic cardiovascular disease in the united kingdom and the netherlands

A post-authorisation/post-marketing observational study to evaluate the association between exposure to AZD1222 and safety concerns using existing secondary health data sources (COVID-19)

Non-interventional post-authorization multi-database safety study to characterize the risk of angioedema and other specific safety events of interest in association with use of Entresto® (sacubitril/valsartan) in adult patients with heart failure

An Observational Post-Authorization Safety Study to Assess the Safety of Ad26.COV2.S Using European Healthcare Data through VAC4EU (COVID-19)

A Drug Utilisation Study extension (DUS ext.) of valproate and related substances, in Europe, using databases (VALNAC09343)

Non-interventional post-authorization multi-database safety study to assess the risk of myotoxicity, hepatotoxicity and acute pancreatitis in statin-exposed heart failure patients with or without concomitant use of sacubitril/valsartan (Entresto®)

FINErenone druG Utilization Study and assessment of Temporal changes following availability of different treatment options in patients with chronic kidney disease and type 2 diabetes (FINEGUST)

Strengthening Use of Real-World Data in Medicines Development: Metadata for Data Discoverability and Study Replicability (MINERVA)

Comparison of the Risk of Cancer Between Patients With Type 2 Diabetes Exposed to Dapagliflozin and Those Exposed to Other Antidiabetic Treatments

Concordance between primary and secondary electronic healthcare databases: A multi-database self-controlled case series study

Impact of EU label changes and revised pregnancy prevention programme for oral retinoid containing medicinal products: utilization and prescribing trends

Impact of EU label changes and revised pregnancy prevention programme for medicinal products containing valproate: utilisation and prescribing trends

Effectiveness of heterologous and booster Covid-19 vaccination in 5 European countries, using a cohort approach in children and adults with a full primary Covid-19 vaccination regimen (Covid Vaccines Effectiveness (CoVE))

Cohort monitoring of Adverse Events of Special Interest and COVID-19 diagnoses prior to and after COVID-19 vaccination (ECVM)

Rapid Safety Assessment of SARS-CoV-2 vaccines in EU Member States using electronic health care datasources (CVM Covid19-Vaccine-Monitor-EHR)

Background rates of Adverse Events of Special Interest for monitoring COVID-19 vaccines (ACCESS-BGR)

Baricitinib Drug Utilisation Study: Assessment of Effectiveness of New Recommendations for Use Based on Secondary Data Sources in France, Germany, The Netherlands, and Sweden (I4V-MC-B038)

Post-authorisation Safety Study of Rimegepant in Patients with Migraine and History of Cardiovascular Disease in European Countries

The Impact of COVID-19 Pandemic on Drug Use: Implications for Regulatory Intervention Impact Studies

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

A real-world observational study of treatment patterns and outcomes for patients with neuromyelitis optica spectrum disorders (NMOSD) treated with inebilizumab (UPLIZNA) in Europe

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

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

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

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)

We have an established linkage with the Cancer Registry which holds disease specific information about cancer.Please see below for more information on elements provided above:Vaccines can be given by a Dutch regional health authority of which our data source does not have full visibility. When medical devices are received via a hospital procedure e.g. colostomy we can have access to the information but otherwise it may be incomplete. The data source does not cover e-health tools or related medical devices.Biomarker data may be available when present in the clinical guidelines and tested for, but this information may not be complete. Indication for use is only captured for high-cost medicines. However, for other drugs this can usually be derived through linkage to other sources of the PHARMO Data Network.

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?

Yes

Cause of death

Not Captured

Prescriptions of medicines

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?

Captured

Indication vocabulary

ICD-10

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

Procedures vocabulary, other

CVV codesCBV codesZA codes

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.

Captured

Biomarker data vocabulary

Other

Biomarker vocabulary, other

Biomarkers available through clinical lab data are coded according to the NHG-bepalingen. Biomarkers in oncology are captured according to the itemset list of the Netherlands Cancer Registry, if available. Biomarkers found in pathology specimen are found through free-text fields, not systematic, coded fields.

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?

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

ICD-9

ICPC

Medicinal product information

Captured

Medicinal product information collected

Active ingredient(s)

Brand name

Dose

Formulation

Strength

Medicinal product vocabulary

ATC

Quality of life measurements

Not Captured

Lifestyle factors

Captured

Lifestyle factors

Alcohol use

Tobacco use

Sociodemographic information

Captured

Sociodemographic information collected

Age

Gender

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

23% on average upon linkage, but it depends on which data sources covered in the PHARMO Data Network are needed to be linked. When solely considering hospital data for instance, 80% of hospitals are covered.

The GP data we have access to is representative of the Netherlands and covers ~20-25% of the Dutch population. The most current population size by age in the Netherlands can be found on this website https://www.cbs.nl/nl-nl/visualisaties/dashboard-bevolking/bevolkingspiramide .

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)

Regional sub-set - The longitudinal nature of the PHARMO Data Network system enables to follow-up more than 10 million persons of a well-defined population in the Netherlands for an average of twelve years. Currently, the PHARMO Data Network covers over 7 million active persons out of 17 million inhabitants of the Netherlands. Data capture is restricted to regions listed on question nº8, and thus do not represent a nation-wide data set.

Family linkage

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

Ad hoc

Population

Population size

10000000

Active population size

7000000

Median observation time

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

12.00

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

12.00

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?

Yes

Description of data collection

The collection, processing, linkage and anonymisation of the data is performed by STIZON. STIZON is an independent, ISO/IEC 27001 certified foundation, which acts as a Trusted Third Party (TTP) between the data sources and the PHARMO Institute.

Event triggering registration

Event triggering registration of a person in the data source

Birth

Disease diagnosis

Insurance coverage start

Other

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

Start of treatment or practice registration

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

Death

Emigration

Other

Practice deregistration

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

Loss to follow-up

Event triggering creation of a record in the data source

Multiple prompts depending on healthcare setting (e.g. hospital discharge, specialist visit, medicinal product dispensing etc.)

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

STIZON links the different sources on a patient level using a combination of deterministic linkage on a unique patient identification number, when available, and probabilistic linkage on patient characteristics. Validation of the linkage against name and address information for a sample of the patients resulted in a sensitivity and specificity of 0.98. The linkage is updated on a yearly basis.

Linkage description, possible linkage

Record Linkage. General Practitioner Database, In-Patient Pharmacy Database, Clinical Laboratory Database, Hospital Database, Cancer Registry, Pathology Registry, Perinatal Registry, and others upon request.
STIZON links the different sources on a patient level using a combination of deterministic linkage on a unique patient identification number, when available, and probabilistic linkage on patient characteristics. Validation of the linkage

against name and address information for a sample of the patients resulted in a sensitivity and specificity of 0.98. The linkage is updated on a yearly basis.

Linked data sources

Pre linked

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

No

Data source, other

Any data sources have the potential to be linked.

Linkage strategy

Other

Linkage variable

Unique patient identifier

Linkage completeness

98%

Pre linked

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

Yes

Data source, other

Cancer Registry

Linkage strategy

Other

Linkage variable

Unique patient identifier

Linkage completeness

98%

Pre linked

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

Yes

Data source, other

GP Data

Linkage strategy

Other

Linkage variable

Unique patient identifier

Linkage completeness

98%

Pre linked

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

Yes

Data source, other

Hospital Data (includes both admissions and specialist visits)

Linkage strategy

Other

Linkage variable

Unique patient identifier

Linkage completeness

98%

Pre linked

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

Yes

Data source, other

In-patient Pharmacy Data

Linkage strategy

Other

Linkage variable

Unique patient identifier

Linkage completeness

98%

Pre linked

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

Yes

Data source, other

Mortality Registry

Linkage strategy

Other

Linkage variable

Unique patient identifier

Linkage completeness

98%

Pre linked

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

Yes

Data source, other

Out-patient Pharmacy Data

Linkage strategy

Other

Linkage variable

Unique patient identifier

Linkage completeness

98%

Pre linked

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

Yes

Data source, other

Pathology Registry

Linkage strategy

Other

Linkage variable

Unique patient identifier

Linkage completeness

98%

Pre linked

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

Yes

Data source, other

Perinatal Registry

Linkage strategy

Other

Linkage variable

Unique patient identifier

Linkage completeness

98%

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?

No

Approval for publication

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

Yes

Informed consent, other

There is a committee to evaluate requests for data access

Data source last refresh

31/12/2021

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

ConcepTION CDM

CDM website

https://www.imi-conception.eu/

CDM release frequency

6 months

Data source ETL CDM version

2.2

Data source ETL frequency

6,00 months

Data source ETL status

Completed

Data source ETL specifications (link)

https://www.imi-conception.eu/

CDM name

OMOP

CDM website

https://www.ohdsi.org/Data-standardization/

Data source ETL CDM version

5.4

Data source ETL frequency

12,00 months

Data source ETL status

In progress

Data source ETL specifications (link)

https://ohdsi.github.io/TheBookOfOhdsi/ExtractTransformLoad.html