Pedianet

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Data source

Human

Other

Population registry

Primary care medical records

Administrative details

Administrative details

Data source ID

20131

Data holder

Pedianet network (So.Se.Te)

Data source type

Other

Population registry

Primary care medical records

Data source type, other

Pediatric registry

Main financial support

European public funding

Funding from public-private partnership

National, regional, or municipal public funding

Care setting

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

https://www.pedianet.it/en

Contact details

Anna Cantarutti anna.cantarutti@unimib.it



anna.cantarutti@unimib.it

Data source regions and languages

Data source countries

Italy

Data source languages

Italian

Data source establishment

Data source established

01/01/2000

Data source time span

First collection: 01/01/2004

The date when data started to be collected or extracted.

Publications

Data source publications

https://www.pedianet.it/en/pubblications

Studies

List of studies that have been conducted using the data source

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

Exposure and coverage to routine schedule vaccines in different EU countries (ADVANCE-POC2)

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

Post-Authorisation Active Surveillance Study of Myocarditis and Pericarditis

Among Individuals in Europe Receiving the Pfizer-BioNTech Coronavirus Disease

2019 (COVID-19) Vaccine

Establish an EU catalogue of sources of real-world data, characterised by a common set of metadata and data quality measurements

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))

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

Post-Authorisation Safety Study of Comirnaty Original/Omicron BA.1 and Comirnaty Original/Omicron BA.4-5 in Europe

SAFETY-VAC: Network of Data Sources for Vaccine Safety Evaluation

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

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

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

Captured

Cause of death vocabulary

ICD-9

Not coded (Free text)

Prescriptions of medicines

Captured

Prescriptions vocabulary

ATC

Dispensing of medicines

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?

No

Indication for use

Does the data source capture information on the therapeutic indication for the use of medicinal products?

Captured

Indication vocabulary

ICD-9

Not coded (Free text)

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)?

Procedures vocabulary

ICD-9

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.

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?

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-9

Not coded (Free text)

Medicinal product information

Captured

Medicinal product information collected

Brand name

Dose

Formulation

Package size

Medicinal product vocabulary

ATC

Quality of life measurements

Not Captured

Lifestyle factors

Not Captured

Sociodemographic information

Captured

Sociodemographic information collected

Age

Deprivation index

Pharmaceutical copayment

Sex

Quantitative descriptors

Population Qualitative Data

Population age groups

Paediatric Population (< 18 years)

Term newborn infants (0 - 27 days)

Infants and toddlers (28 days - 23 months)

Children (2 to < 12 years)

Adolescents (12 to < 18 years)

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

3% of the Italian Paeditraic Population (<15 years)

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)

Any child enrolled by a participating family peadiatrician (FP) who belongs to the voluntary Pedianet Network can be part of the data source.

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 Sibling

Population

Population size

632824

Active population size

234231

Population by age group

Age group	Population size	Active population size
Neonate	1865	920
Infants and toddlers (28 days - 23 months)	27967	24572
Children (2 to < 12 years)	232015	182785
Adolescents (12 to < 18 years)	432359	93927

Median observation time

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

14.00

7.00

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

Data flows and management

Access and validation

Biospecimen access

Access to subject details

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

Yes

Description of data collection

The data is recorded during the medical examination carried out by the pediatrician.

Pedianet is an Italian network of more than 200 famely paediatricians (FPs) who use an established pediatric primary care database based on the Junior Bit software in their clinical practice. Data generated by Pedianet FPs are anonymized, in compliance with Italian regulations, stored in a protected "cloud" under a unique numerical identifier, and regularly checked for validation and quality control. Inclusion in the Pedianet database is voluntary; parents or legal guardians provided consent for their children's anonymized data to be used for research purposes in accordance with national and international regulations.

Event triggering registration

Event triggering registration of a person in the data source

Practice registration

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

Death

Loss to follow up

Practice deregistration

Event triggering creation of a record in the data source

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

Veneto paediatricians can integrate their outpatient routine clinical care data with data from the regional vaccination registry, hospital admissions, emergency department visits, and the COVID-19 swab registry. They can access the patient's Electronic Health Records and integrate these data into their pediatric primary care database.

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

Approval for publication

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

No

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

2.01, 2.2

Data source ETL frequency

Data source ETL status

Completed