The PRES European Network of Registries for Autoinflammatory Diseases in Childhood

First published: 01/02/2024

Last updated: 17/10/2024

Data source | Human | Disease registry

Administrative details

Administrative details

Data source ID

30662

Data source acronym

EUROFEVER

Data holder

IRCCS Istituto Giannina Gaslini, Pediatric Rheumatology International Trials Organisation (PRINTO)

Data source type

Disease registry

Main financial support

European public funding

Care setting

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

https://www.printo.it/eurofever/

Contact details

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Main

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Data source regions and languages

Data source countries

Argentina

Armenia

Australia

Austria

Belgium

Brazil

Bulgaria

Canada

Chile

China

Croatia

Czechia

Denmark

Ecuador

France

Georgia

Germany

Greece

Hungary

Israel

Italy

Japan

Latvia

Lithuania

Netherlands

Norway

Oman

Poland

Romania

Russian Federation

Saudi Arabia

Serbia

Slovakia

Slovenia

Spain

Sweden

Switzerland

Türkiye

Ukraine

United Kingdom

United States

Data source languages

English

Data source establishment

Data source established

15/09/2009

Data source time span

First collection: 15/09/2009

The date when data started to be collected or extracted.

Publications

Data source publications

Please refer to the link provided to access the publication section.

Studies

List of studies that have been conducted using the data source

Survey on the collection of data on adverse events related to medicinal products through registries

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)

Autoinflammatory diseases

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

MedDRA

Prescriptions of medicines

Captured

Dispensing of medicines

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?

No

Indication for use

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

Captured

Indication vocabulary

ICD-10

MedDRA

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

ICD-10

MedDRA

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?

Captured

Genetic data vocabulary

Other

Genetic data vocabulary, other

Infevers

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.

No

Unique identifier for persons

Are patients uniquely identified in the data source?

No

Diagnostic codes

Captured

Diagnosis / medical event vocabulary

MedDRA

Not coded (Free text)

Medicinal product information

Captured

Medicinal product information collected

Brand name

Dose

Route of administration

Medicinal product vocabulary

Other

If 'other,' what vocabulary is used?

Drugs are chosen by the investigators from a list

Quality of life measurements

Captured

Quality of life measurements vocabulary

other

Quality of life measurements, other

VAS scale

Lifestyle factors

Not Captured

Sociodemographic information

Captured

Sociodemographic information collected

Age

Country of origin

Ethnicity

Gender

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)

Adults (65 to < 75 years)

Adults (75 to < 85 years)

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

Not available

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 - This project is conducted by the participating centres of the more than 50 countries belonging to the Paediatric Rheumatology INternational

Trials Organisation (PRINTO), or the Pediatric Rheumatology European Society (PRES). Data capture is restricted to participating centres in each country, and thus do not represent nation-wide data sets.

Family linkage

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

Ad hoc

Population

Population size

5072

Active population size

2527

Population by age group

Age group	Population size
Paediatric Population (< 18 years)	4667
Preterm newborn infants (0 – 27 days)	0
Term newborn infants (0 – 27 days)	181
Infants and toddlers (28 days – 23 months)	1406
Children (2 to < 12 years)	2560

Age group	Population size
Adolescents (12 to < 18 years)	520
Adults (18 to < 46 years)	335
Adults (46 to < 65 years)	60
Adults (65 to < 75 years)	9
Adults (75 to < 85 years)	1

Median observation time

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

6.40

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

8.04

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

Investigators enter data in a secure web platform developed by PRINTO.

Event triggering registration

Event triggering registration of a person in the data source

Disease diagnosis

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

Loss to follow up

Event triggering creation of a record in the data source

Hospital visit

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

Data management specifications that apply for the data source

Data source refresh

Yearly

Informed consent for use of data for research

Required for general use

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

Common Data Model (CDM) mapping

CDM mapping

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

No