

Immune Mediated Inflammatory Disease (IMID) Observatory

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Data source

Human

Administrative healthcare records (e.g., claims)

Diagnostic tests or procedures reimbursement

Disease registry

Drug registry

Emergency care discharge records

Hospital discharge records

Hospital inpatient records

Hospital outpatient visit records

Other

Pharmacy dispensing records

Population registry

Registration with healthcare system

Specialist ambulatory care records

Spontaneous reports of suspected adverse drug reactions

Administrative details

Administrative details

Data source ID

1000000263

Data source acronym

IMID Observatory

Data holder

LOGEX Life Sciences

Data source type

Administrative healthcare records (e.g., claims)

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Other

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Specialist ambulatory care records

Spontaneous reports of suspected adverse drug reactions

Data source type, other

Costing, administrative, clinical outcomes, diagnostics, prescription

Main financial support

Funding by own institution

Funding from industry or contract research

Funding from public-private partnership

Funds from patients organisations, charity and foundations

National, regional, or municipal public funding

Care setting

Hospital inpatient care

Hospital outpatient care

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

Data source website

<https://www.logex.com/imid-observatory>

Contact details

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Data source regions and languages

Data source countries

Finland

France
Germany
Netherlands
Spain
Sweden
United Kingdom

Data source languages

Dutch
English
Finnish
French
German
Spanish
Swedish

Data source establishment

Data source established

15/06/2022

Data source time span

First collection: 01/01/2017

The date when data started to be collected or extracted.

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

Psoriasis

Rheumatoid arthritis

Psoriatic arthropathy

Ankylosing spondylitis

Systemic lupus erythematosus

Sjogren's syndrome

Microscopic polyangiitis

Systemic scleroderma

Dermatomyositis

Myositis

Multiple sclerosis

Dermatitis atopic

Pemphigoid

Vitiligo

Alopecia areata

Cutaneous lupus erythematosus

Hidradenitis

Crohn's disease

Eosinophilic oesophagitis

Disease details (other)

Psoriatic arthritis, Granulomatosis with polyangiitis, systemic sclerosis, atopic dermatitis, chronic urticaria, hidradenitis suppurativa, ulcerative colitis

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.

No

Pregnancy and/or neonates

Does the data source collect information on pregnant women and/or neonatal subpopulation (under 28 days of age)?

No

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

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)].

Yes

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

Medical devices

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

Yes

Administration of vaccines

No

Procedures

Does the data source capture information on procedures (e.g., diagnostic tests, therapeutic, surgical interventions)?

Captured

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

Medicinal product information

Captured

Quality of life measurements

Not Captured

Lifestyle factors

Not Captured

Sociodemographic information

Captured

Quantitative descriptors

Population Qualitative Data

Population age groups

All

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)

Adult and elderly population (≥ 18 years)

Adults (18 to < 65 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)

Median observation time

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

2.50

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://logex.com/solutions/real-world-data/real-world-evidence/>

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?

No

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

Possibility of data validation

Can validity of the data in the data source be verified (e.g., access to original medical charts)?

No

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?

No

Common Data Model (CDM) mapping

CDM mapping

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

No