AutoInflammatory Diseases Alliance Registries

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Data source | Human | Disease registry

Administrative details

Administrative details

Data source ID

1000000651

Data source acronym

AIDA Registries

Data holder

University of Siena

Data source type

Disease registry

Main financial support

Funding by own institution

Funding from public-private partnership

Funds from patients organisations, charity and foundations

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.

No

Description of the qualification

undefined

Data source website

https://aidanetwork.org/en/aida

Contact details

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Main

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Data source regions and languages

Data source countries

Algeria

Argentina

Australia

Austria

Belgium

Brazil

Canada

Chile

China

Colombia

Cyprus

Czechia

Denmark

Dominican Republic

Egypt

Ethiopia

France

Germany

Ghana

Greece

India

Iran, Islamic Republic of

Ireland

Israel

Italy

Japan

Jordan

Kazakhstan

Lebanon

Libyan Arab Jamahiriya

Martinique

Mexico

Morocco

Netherlands

New Zealand

Norway

Peru

Poland

Portugal

Romania

Russian Federation

Saudi Arabia

Singapore

Slovenia

South Africa

Spain

Switzerland

Taiwan

Tunisia

Türkiye

Ukraine

United Kingdom

United States

Uruguay

Data source languages

English

Data source establishment

Data source established

25/06/2020

Data source time span

First collection: 25/06/2020

The date when data started to be collected or extracted.

Publications

Data source publications

The Autoinflammatory Diseases Alliance Registry of monogenic autoinflammatory diseases.

Development and implementation of the AIDA International Registry for patients with Behçet’s disease.

Development and Implementation of the AIDA International Registry for Patients With VEXAS Syndrome.

Development and Implementation of the AIDA International Registry for Patients With Still's Disease.

Development and Implementation of the AIDA International Registry for Patients with Non-Infectious Uveitis.

Development and Implementation of the AIDA International Registry for Patients with Non-Infectious Scleritis.

Development and Implementation of the AIDA International Registry for Patients With Undifferentiated Systemic AutoInflammatory Diseases.

Development and implementation of the AIDA international registry for patients with Schnitzler's syndrome.

Development and implementation of the AIDA International Registry for patients with Periodic Fever, Aphthous stomatitis, Pharyngitis, and cervical Adenitis

syndrome.

A patient-driven registry on Behçet’s disease: the AIDA for patients pilot project.

Development and implementation of the international AIDA network spondyloarthritis registry.

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

Autoinflammatory disease

Still's disease

Behcet's syndrome

Immune-mediated uveitis

Immune-mediated scleritis

VEXAS syndrome

PFAPA syndrome

Schnitzler's syndrome

Axial spondyloarthritis

Castleman's disease

Disease details (other)

Monogenic autoinflammatory diseases; undifferentiated autoinflammatory disease.

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-10

Prescriptions of medicines

Captured

Prescriptions vocabulary

not coded

Dispensing of medicines

Not Captured

Dispensing vocabulary

not coded

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

Not coded (Free text)

OMIM

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

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?

Captured

Genetic data vocabulary

HGNC

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

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

Not coded (Free text)

OMIM

Medicinal product information

Captured

Medicinal product information collected

Active ingredient(s)

Brand name

Dosage regime

Dose

Route of administration

Medicinal product vocabulary

Not coded (Free text)

Quality of life measurements

Captured

Quality of life measurements vocabulary

other

Quality of life measurements, other

BDQOL for Behcet's syndrome

Lifestyle factors

Captured

Lifestyle factors

Alcohol use

Tobacco use

Sociodemographic information

Captured

Sociodemographic information collected

Age

Country of origin

Ethnicity

Sex

Quantitative descriptors

Population age groups

Paediatric Population (< 18 years)

Neonate

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)

Population

Population size

5344

Active population size

12345

Population by age group

Age group	Population size	Active population size
Paediatric Population (< 18 years)	1234	5678

Median observation time

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

0.10

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

0.10

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.frontiersin.org/journals/medicine/articles/10.3389/fmed.2022.980679/full

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

Description of data collection

- Retrospective and prospective
- Via REDCap platform
- Organised into 11 registries collecting data on monogenic autoinflammatory diseases, PFAPA syndrome, undifferentiated systemic autoinflammatory disease, Behçet's disease, Schnitzler's syndrome, VEXAS syndrome, Still's disease, noninfectious uveitis, noninfectious scleritis, spondyloarthritis, and Castleman's disease
- Mostly physician-driven

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

Other

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

Patient's consent withdrawal

Event triggering creation of a record in the data source

Diagnosis; follow-up visit (at least every 12 months); change of treatment regimen

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

The registries described were not created through linkage with other data sources (not pre-linked).

Linkage description, possible linkage

The registries can potentially be linked to other external data sources on an ad-hoc basis, provided appropriate authorisation and common identifiers are available.

Data management specifications that apply for the data source

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?

No

Data source preservation length (years)

10 years

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