International Severe Asthma Registry

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Data source | Human | Disease registry

Administrative details

Administrative details

Data source ID

32463

Data source acronym

ISAR

Data holder

Optimum Patient Care (OPC)

Data source type

Disease registry

Main financial support

Funding by own institution

Funding from industry or contract research

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.isar.opcglobal.org/

Contact details

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Data source regions and languages

Data source countries

Argentina

Australia

Belgium

Brazil

Bulgaria

Canada

Colombia

Denmark

Ecuador

Estonia

Germany

Greece

Hungary

India

Ireland

Italy

Japan

Korea, Republic of

Kuwait

Mexico

Netherlands

Norway

Poland

Portugal

Saudi Arabia

Singapore

Spain

Taiwan

United Arab Emirates

United Kingdom

United States

Data source languages

English

Data source establishment

Data source established

15/06/2017

Data source time span

First collection: 15/06/2017

The date when data started to be collected or extracted.

Publications

Data source publications

International Severe Asthma Registry: Mission Statement

Development of the International Severe Asthma Registry (ISAR): A Modified Delphi Study

International severe asthma registry (ISAR): protocol for a global registry

International Severe Asthma Registry (ISAR): 2017-2024 Status and Progress Update

Studies

List of studies that have been conducted using the data source

Demographic and Clinical Characteristics of Severe Asthma Patients Worldwide

The Impact of Exacerbation Burden on Lung Function Trajectory in a Broad Asthma Population and Severe Asthma Population (Exacerbation and lung function trajectory)

Biologics in severe asthma: utilization patterns, causes for discontinuation and switches

The Characterization and Comparison of Eosinophilic and Non-eosinophilic Phenotypes of Severe Asthma

Biomarker Relatability in the International Severe Asthma Registry (BRISAR)

Hidden Severe Asthma in Primary Care versus ISAR Cohort

Impact of Initiating Biologics In Patients on Long-Term OCS Or Frequent Rescue Steroids (GLITTER)

Onset of asthma in severe asthma patients (PATH)

Effectiveness across severe asthma biologic classes (Anti-IL-5 vs Anti IgE) in patients eligible for both (FIRE)

Defining and Characterizing Responders to Biologic Treatment (BEAM)

Biologic Usage Patterns, Clinical Outcomes and Healthcare Resource Utilization (CLEAR)

Characteristics of type 2 asthma phenotypes and oral corticosteroid (OCS) use in the International Severe Asthma Registry (ISAR) (STAR)

CLinical oUtcomes before and after biologic treatMent by bIologic class, by iNdividuAl biologic, and by subgroups of baseliNe characTeristics (LUMINANT)

ImPact of comoRbidity In Severe asthMa patients (PRISM)

EffectIveness of bioloGics (by classes) in patieNts with dIfferent combination of T2 biomarkErs (IGNITE)

PhEnotypic Characteristics, coMorBidities and response to thErapeutic inteRventions associated with non-type 2 asthma (EMBER)

Exploring different composite definitions of responders and non-responders to biologic treatment for severe asthma (FULL BEAM)

Impact of biologic initiation on steroid burden and new-onset of potentially OCS-related outcomes in patients with severe asthma (SOLAR)

Patient characteristics, treatment patterns, clinical outcomes, and health care resource utilization in severe asthma subgroups: A retrospective analysis of the

International Severe Asthma Registry (EVEREST)

A global evaluation of the economic impact of time to initiation of biologic treatment of severe asthma patients

ENLIGHTEN: Assessment of quality improvement in the International Severe Asthma Registry

Assessing the impact of earlier access to biologics on remission and natural course of asthma (GLEAM)

Associations between biological and clinical response following treatment with anti-IL5/5R biologics (FLAME)

Sustainability of response to biologics in severe asthma and predictors of late failure among patients in an international registry (SHINE)

Assessing the impact of remission at 12-months post-initiation of biologic therapy on long-term clinical outcomes of patients with severe asthma (SPOTLIGHT)

Impact of biologics on inhaled corticosteroids reduction (MOON LIGHT)

Real-World Clinical Outcomes in Patients with Severe Asthma Treated with Tezepelumab: A Retrospective Observational Study of CHRONICLE and ISAR (SYNERGY)

Determining elements of remission that predict long term outcomes (GLISTEN)

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)

Severe Asthma

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?

No

Cause of death

Not Captured

Prescriptions of medicines

Not Captured

Dispensing of medicines

Not 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?

Not Captured

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

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.

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?

No

Diagnostic codes

Not Captured

Medicinal product information

Not Captured

Quality of life measurements

Not Captured

Lifestyle factors

Captured

Lifestyle factors

Tobacco use

Sociodemographic information

Captured

Sociodemographic information collected

Age

Ethnicity

Gender

Quantitative descriptors

Population Qualitative Data

Population age groups

Paediatric Population (< 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

Not possible to estimate as the data source is international and present in many different locations world-wide.

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 data is procured from different centres in a region or a country, namely the severe asthma clinics.

Population

Population size

38.527

Active population size

38.527

Median observation time

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

5,00

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

5,00

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

ISAR REDCap Cloud system, REDCap academic, country EMR or bespoke systems

Event triggering registration

Event triggering registration of a person in the data source

Disease diagnosis

Other

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

ISAR agreement

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

Other

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

If country asks for patient withdrawal, if country withdraws

Event triggering creation of a record in the data source

Clinic review

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

ISAR is using an electronic data capture system (EDC) that builds an anonymized database of severe asthma patients. ISAR data can be potentially linked into the EMR databases in some of the participating countries.

Linkage description, possible linkage

ISAR is using an electronic data capture system (EDC) that builds an anonymized database of severe asthma patients. ISAR data can be potentially

linked into the EMR databases in some of the participating countries.

Linked data sources

Pre linked

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

Yes

Data source, other

All countries hold linkage of ISAR patient ID and actually patient identifiers (eg. NHS number) at their own local site so we do not have access to PID details.

Linkage strategy

Deterministic

Linkage variable

ISAR ID (non PID variable)

Linkage completeness

ISAR ID maps to the unique patient identifier but this is kept local to the site sending the data and we do not have access to this.

Data management specifications that apply for the data source

Data source refresh

Every 6 months

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?

Yes

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

18/11/2025

Common Data Model (CDM) mapping

CDM mapping

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

No