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International Severe Asthma Registry (ISAR): The Story So Far

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Rationale: Severe asthma registries differ in data collected and reflect country- and/or regional-specific variability. Pooling resources to generate a centralized severe asthma dataset would allow data to be shared seamlessly between countries and institutions. This can be done by opening severe asthma registry borders, sharing information gathered at national and regional levels, and optimized by standardizing the variables collected, producing one over-arching registry.

Methods: The International Severe Asthma Registry (ISAR; http://isaregistries.org/) is a multi-country, multicenter, observational real-life initiative, which retrospectively and prospectively collects data on severe asthma patients from pre-existing and new registries. Patients (aged ≥18 years) receiving care (GINA Step 5 or uncontrolled on Step 4) at severe asthma secondary and tertiary care centers were included. A Delphi process was used to obtain expert consensus on core variables collected. A collaboration agreement with each country covered method of transmission and storage of data, data security, compliance with data security standards, data protection, and list of core variables required for extraction from each local registry. The aim was to enrol 2000 new patients into ISAR annually.

Results: ISAR already partners with 9 national or regional registries in Europe (Bulgaria [local registry currently being developed alongside ISAR involvement], Greece, Ireland, Italy, Spain), North America (USA, Canada), and Asia (Japan, South Korea), with planned expansion to other regions of the world. Agreements are in process with the SAWD registry (including data from Australia, New Zealand, and Singapore), Denmark, Finland, Germany, Iceland, Netherlands, Norway, Sweden, and UK, with many more countries newly engaged from Europe (Austria, Estonia), Asia (India, Indonesia, Malaysia, Philippines, Vietnam), South America (Argentina, Brazil, Colombia), and Africa (Ethiopia, Kenya, Uganda), giving ISAR a truly global reach. It currently comprises data from 5,194 severe asthma patients and continues to grow (Table). New data is provided regularly, improving generalizability to the wider severe asthma population.

Conclusions: Combining registries from different countries ensures data capture on a broader range of severe asthma patients, intra-operability between registries, and facilitates robust assessment of the impact of therapeutic interventions. With such a large dataset, clinicians gain information on patient presentation and predictors of treatment success; patients gain a better understanding of the natural history of their disease (collective data being used to inform treatment guidelines); payers get evidence on how treatments are used and their effectiveness in different patient populations; and the pharmaceutical industry can assess the effectiveness and long-term safety of therapeutic agents in real-life.

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Table: International Severe Asthma Registry (ISAR) snapshot: August 2018

COUNTRY

	Sites	Patient data
AUSTRALIA	26	259
GREECE	1	10
IRELAND	1	46
ITALY	61	310
S. KOREA	20	441
SPAIN	15	54
UK	4	696
USA	1	3378
TOTAL		**5194**

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