



Adult severe asthma registries: a global and growing inventory

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Rationale

Currently, severe asthma inter-registry variability in data being collected is unknown

Aim

To examine data that ISAR and non-ISAR countries report collecting that enable global research and support individual country interests

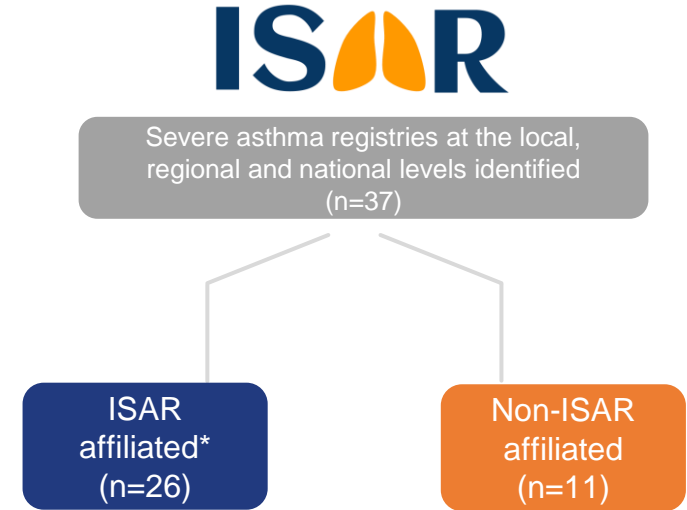
Methods

Registries were identified by **online searches** (up to August 2022) and approaching **36 severe asthma experts globally**

Participating registries provided data collection specifications or confirmed variables collected

Variables summarized:

- Core variables (results from ISAR's Delphi study)
- Steroid-related comorbidity variables
- Biologic safety variables (serious infection, anaphylaxis, and cancer)
- COVID-19 variables
- Additional variables (not belonging to the aforementioned categories)

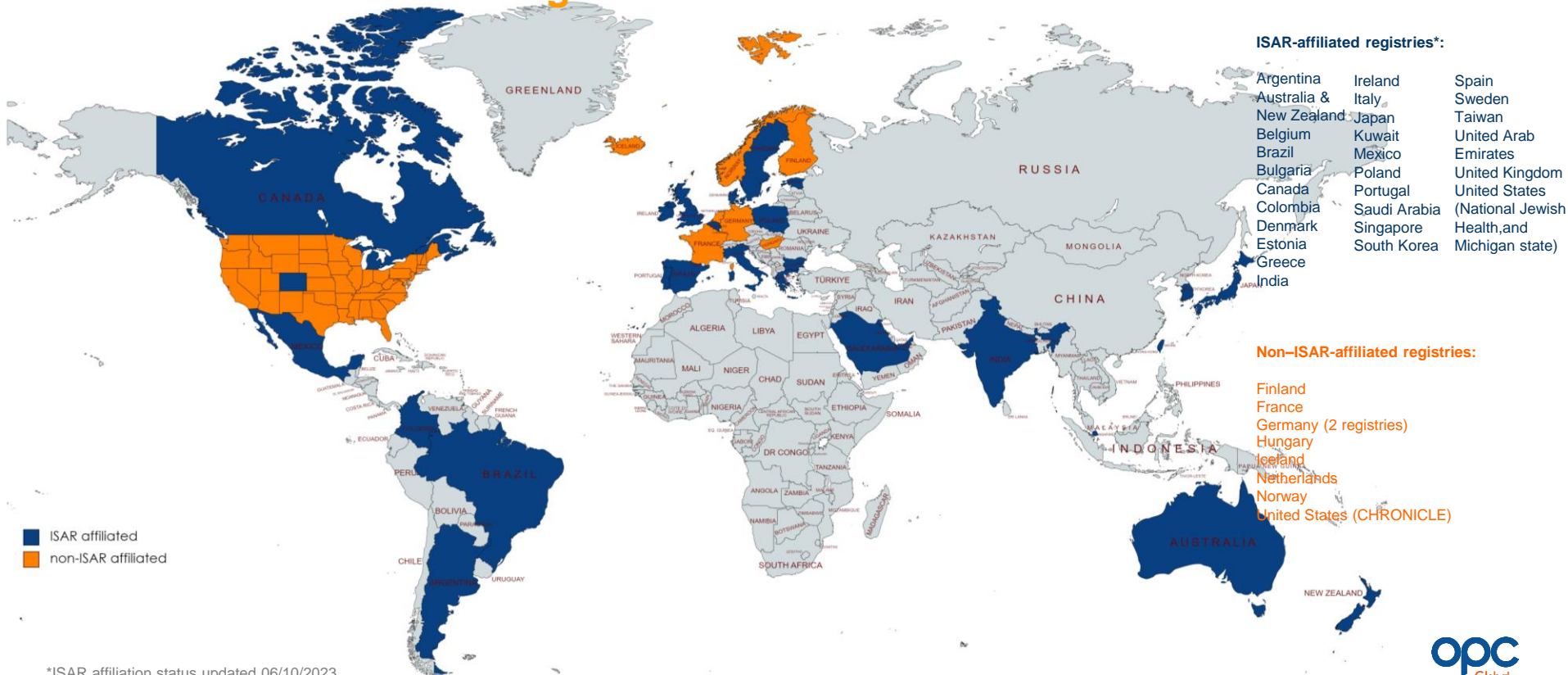


*contributing data to ISAR

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Severe asthma registries from across the globe

37 Registries across 35 countries



*ISAR affiliation status updated 06/10/2023

Majority of severe asthma registries collect >90% of ISAR's core variables and most registries collect safety variables



25 ISAR-registries and 4 non-ISAR registries reported **collecting >90% of the 65 core variables**



24 registries reported collecting **additional variables** including data from asthma questionnaires



8 registries are **linked to databases** such as electronic medical records and national claims or disease databases



The **majority of severe asthma registries** reported collection of **>90% of ISAR's core variables**



Most registries reported collecting safety variables and OCS comorbidity data, reflecting a **common goal of documenting OCS burden and safety events in patients**



The ISAR initiative has fostered data standardisation across countries. This enables collection of unified data and **increases statistical power for severe asthma research**



Maintaining **individuality** alongside standardized variables supports registries to develop **locally relevant research priorities and clinical interests**



Severe asthma registries can **inform local health policy**, be **incorporated into clinical guidelines**, and be translated into **quality improvement programs** that **enhance the care of asthma patients globally**