

## DEVELOPMENT OF THE INTERNATIONAL SEVERE ASTHMA REGISTRY (ISAR): A MODIFIED DELPHI STUDY

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**Background:** Registries are valuable tools for the investigation and management of diseases. However, severe asthma registries are currently limited to regional or national settings. There is also a lack of a standardised method of data collection, thus hindering inter-registry data comparison. We aimed to establish a standardised list of variables to be collected for the International Severe Asthma Registry (ISAR) through expert consensus.

**Method:** A modified Delphi process was used to reach consensus on a minimum set of variables to capture in ISAR. The Delphi panel consisted of 27 experts in the field of severe asthma research with at least 5 years of well cited asthma research across 16 countries. Variables were compiled from existing severe asthma registries from the UK and Australia.

The process consisted of three iterative rounds. In each round, Delphi panel members were issued an electronic ISAR Delphi workbook to vote and comment for the inclusion of variables. Variables which did not achieve consensus for inclusion or exclusion were brought to the subsequent round. Finalisation of the list of core variables was deliberated in two face-to-face meetings of Delphi panel members.

**Results:** A total of 747 variables were identified and compiled, 115 were present in both registries and 632 unique for either registries. The final list consisted of 95 core variables which encompassed collection of patient demographics, medical history, patient-reported outcomes, diagnostic information, clinical characteristics, adherence and management plan. The panel also agreed on the inclusion criteria for ISAR to include patients on GINA (Global Initiatives for Asthma) Step 5, or patients with uncontrolled asthma on GINA Step 4.

**Conclusion:** We present the first global initiative for an international severe asthma registry with a standardised set of core variables. The establishment of ISAR is hoped to enable data comparison for severe asthma in a multinational setting for a better understanding of severe asthma identification and treatment.



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