



Development of the International Severe Asthma Registry (ISAR): a modified Delphi study

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Background

- **Registries** are valuable tools for the disease surveillance
- However, a majority of severe asthma registries are **limited** to regional or national settings, each collecting unique set of data fields
- There is a **lack** of a **standardised variables** in existing registries, disabling the exchange of data across registries
- The **aim** of this study was to use a **modified Delphi process** to reach consensus on relevant and **feasible** set of variables for collection in a **clinical setting** to be collected for the International Severe Asthma Registry (ISAR), that was most

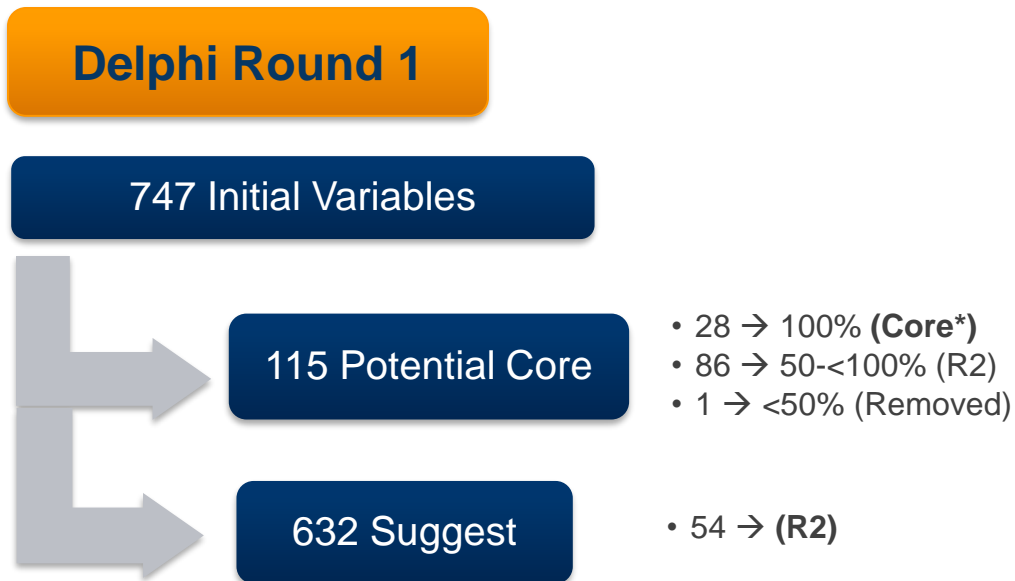


Methods

- **Delphi panel**
 - 27 experts (with a chair) in the field of severe asthma research
 - Represented 16 countries
- **Panel selection criteria**
- **The process:** 3 iterative rounds. In each round:
 - Panel members were issued an electronic ISAR Delphi workbook to vote and comment for the inclusion of variables
 - Variables with ‘undecided’ consensus for inclusion/exclusion → submitted for evaluation in the subsequent round
- **Criteria for consensus**
 - Variables receiving $\geq 66.6\%$ consensus were selected as ISAR Core variables.
 - Variables receiving 50%-66.6% consensus (“undecided”) were circulated for another round of review
 - Variables receiving $< 50\%$ consensus were removed.

Results

- A total of **747 variables** were identified and compiled from longstanding severe asthma registries: UK and Australia
- The Delphi workbook consisted of
 - **Potential Core:** 115, **common** to UK and Australia
 - **Suggested:** 632, **unique** for either registry



*Core Variable: Set of standardized variables that will be captured by ALL countries participating in the ISAR.

Delphi Round 2

140 Nominated Variables

86 Potential Core

- 74 → consensus (**Core**)
- 8 → undecided (**R3**)
- 4 → no-consensus (removed)

54 Suggest

- 9 → consensus (**4 R3**)
- 45 → no-consensus (removed)

Delphi Round 3

12 Nominated Variables

8 Potential Core

- 3 → consensus (**Core**)
- 5 → no-consensus (removed)

4 Suggest

- 1 → consensus (**Core**)
- 3 → no-consensus (removed)

Total of 106 variables were chosen

R3 results were discussed the second ISC meeting (May, 2017)

- Undecided variables added to core: 1 (Date of Bone Densitometry)
- Inapplicable variables removed : 12

Final ISAR Core:
95 (83 data entry)

Conclusion & Implications

- The Delphi process was utilized to gain anonymized international consensus on a set of standardised variables
- **Less than 100** core variables offers relatively small data entry burden for healthcare professionals
- The first international severe asthma registry (ISAR) now allows for exchange of data across registries worldwide.
 - The international scientific community will have access to **larger databases** to conduct research with **improved power**, which further increases the **precision** of research results
 - Ultimately, the ability to identify severe asthma **phenotypes** and **best clinical management** practices will be heightened