

Comparison of Data Fields Captured by Regional Severe Asthma Registries Participating in the International Severe Asthma Registry (ISAR)

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Background

The International Severe Asthma Registry (ISAR) uses 95 standardized core variables to monitor severe asthma worldwide. It is populated by data gathered by pre-existing and newly developed national/regional severe asthma registries. This abstract compares data fields captured by national registries pre- and post-participation in ISAR.

Methods

Local registries were identified by an online search and by approaching known opinion leaders in severe asthma. Data fields captured by these registries were compared with ISAR core variable and additional bolt-on lists, and level of agreement assessed (>7/10 registries collecting an ISAR variable = good agreement). Additional non-ISAR core variables collected by local registries were also compared across registries.

Results

10 severe asthma registries, active in May 2018, were initially included in ISAR (i.e. DE, KR, IE, USA, Nordics, ES, UK, NL, IT and the SAWD registry [NZ, AU, SG]). There was good agreement between these registries and ISAR for many demographics, smoking & asthma history, co-morbidity, laboratory tests (e.g. blood IgE, blood EOS count [BEC]), pulmonary function tests and biomarkers of airway inflammation (e.g. FeNO, sputum EOS count), allergen tests, medication use (& steroid dose) and clinical management (e.g. adherence) data fields. However, prior to inclusion in ISAR many registries did not collect information on some of the following: asthma control, min. inclusion age, severe asthma definition, ethnicity/race, BMI, body surface area, exacerbations, highest BEC, diagnostic tests, or anti-IL-5 use. ISAR bolt-on variables (e.g. other co-morbidities, exacerbation date, rescue steroid use and safety variables) were also collected by only a minority of registries. All ISAR core- and bolt-on variables are now collected across ISAR participating registries, incl. key biomarkers (i.e. sputum EOS count, highest BEC and FeNO). Importantly, many local registries also collect additional variables on top of those mandated by ISAR.

Conclusions

ISAR is the first global effort to standardise and consolidate data collection across regional registries, ensuring widespread collection of key variables, particularly biomarkers. ISAR and local registries complement each other. ISAR provides a global view of severe asthma. Local

registries collect ISAR core-, bolt-on and registry-specific-variables most relevant to local clinical management. This abstract is written on behalf of the ISAR Working Group.

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