International Severe Asthma Registry (ISAR): Mission statement

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Background

Regional/national severe asthma registries provide valuable country-specific information. However, they may be limited by having insufficient statistical power to answer many research questions, lack intra-operability and have fundamental differences in data collected, making cross comparisons difficult. A worldwide registry, which brings all severe asthma data together in a cohesive way, under one umbrella, permitting seamless sharing of data may increase our ability to understand severe asthma.

Method

The International Severe Asthma Registry (ISAR; http://isaregistries.org/) is a multi-country, multicentre, observational initiative. It retrospectively and prospectively collects data on severe asthma patients from pre-existing and new registries (that it helps to set up). It includes patients (≥18 years) receiving care (GINA Step 5 or uncontrolled on Step 4) at severe asthma secondary and tertiary care centres. ISAR aims to improve the care of adults with severe asthma globally (both in primary and secondary care). This aim will be realised by ISAR's key attributes as outlined here.

Results

ISAR is the first global severe asthma registry; a joint initiative where national registries retain ownership of their own data and open their borders and share data with ISAR for ethically-approved research purposes. Its strength comes from collection of patient-level, anonymous, longitudinal, real-life, standardized, high-quality data (using a core set of variables agreed by Delphi consensus) from countries across the world, combined with organizational structure, inclusivity/openness and clinical, academic and database expertise. This gives ISAR sufficient statistical power to answer important research questions, sufficient data standardization to compare across countries/regions and the structure and

expertise necessary to ensure its continuance, scientific integrity and the clinical applicability of its research.

<u>Conclusions</u>

ISAR offers a unique opportunity to implement existing knowledge, generate new knowledge and identify the unknown, so promoting new research. With its ability to capture data on a much broader range of severe asthma patients, to compare between registries and robustly assess the impact of therapeutic interventions, ISAR has the potential to become an important platform for the study and better understanding of severe asthma, supporting the appropriate use, and monitoring the impact, of novel asthma therapies.

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