



Severe Asthma Databases: A Global Comparison

Nevaashni Eleangovan

Optimum Patient Care



Background

- Severe asthma is a heterogenous disease with varying clinical manifestations.
- Current severe asthma registry landscape is a collection of several national and regional registries
- There are no comparisons of the information collected by such registries.
- The **aim** of this study was to **compare the data fields** currently captured by severe asthma registries across the **globe**.



Methods

- Severe asthma repositories were identified via web search, (Medline, EMBASE and Web of Science) and consultations with leaders of severe asthma registries.
- 10 repositories out of 18 identified were feasible for comparison
- Data dictionaries from the respective databases were used for systematic comparison and pooling of variables.
- A database of data fields were converted into indicator variables (as columns) and countries (as rows) was created.
- Categories of variables, such as demographics and diagnostics, were used for ease of reporting.



Global Overview of Severe Asthma Registries Compared



Severe asthma research databases reported

Country	Registry	Start Year	Number of patients	Number of sites (total = 255)
United Kingdom	UK Severe Asthma Registry (BTS)	2006	600	~7
United States	National Jewish Health EMR Severe Asthma Cohort (NJH)	2010	1300	1
Germany	German Asthma Network Registry (GAN)	2011	750	30
South Korea	Severe Asthma Registry in the Korean Academy of Asthma, Allergy and Clinical Immunology Cohort (KAAACI)	2011	74	20
Australia	Australian Severe Asthma Web-based Database (SAWD)	2013	463	~23
Ireland	Inhaler Adherence in Severe Unstable Asthma Cohort (INCA-SUN)	2015	190	1
Italy	Severe Asthma Network in Italy (SANI)	2016	450	61
Netherlands	Registry of Adult Patients with Severe asthma for Optimal Disease management (RAPSODI)	2017	150	3
Spain	Spanish Society of Pneumology and Thoracic Surgery's Severe Asthma Registry (SEPAR)	2017	43	~50
Nordic Countries†	Nordic Severe Asthma Registry (NSAR)‡	2018	N/A‡	<ul style="list-style-type: none"> • Denmark: 8 • Finland: 2 • Iceland: ~1 • Norway: ~40 • Sweden: ~8

†Nordic countries contributing to NSAR: Denmark, Finland, Iceland, Norway, Sweden

‡ NSAR will start recruiting patients from June 2018

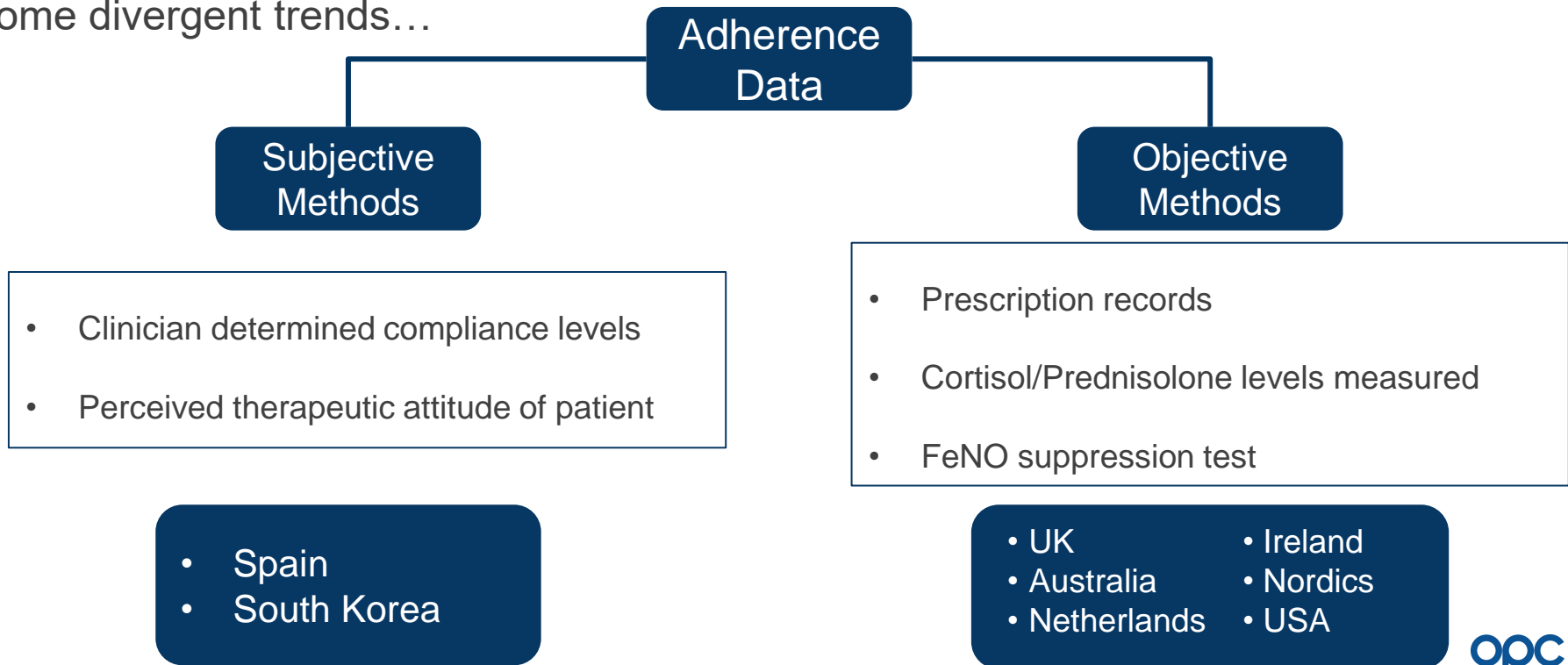
Results: Overview

Some common trends...

- **Medication:**
 - Asthma medications: All databases collect therapy information congruent with the Global Initiative for Asthma guidelines for severe asthma.
 - Other medications: Anti-histamine data was most prevalently collected (7 repositories).
- **Diagnostic tests:**
 - Blood eosinophil and Serum IgE levels were collected by all research databases
- **Comorbidities:**
 - Allergic Rhinitis, Nasal Polyps, Bronchiectasis and Chronic Rhinitis data are the most commonly collected respiratory comorbidities (8 to 10 repositories)

Results: Adherence Data*

Some divergent trends...

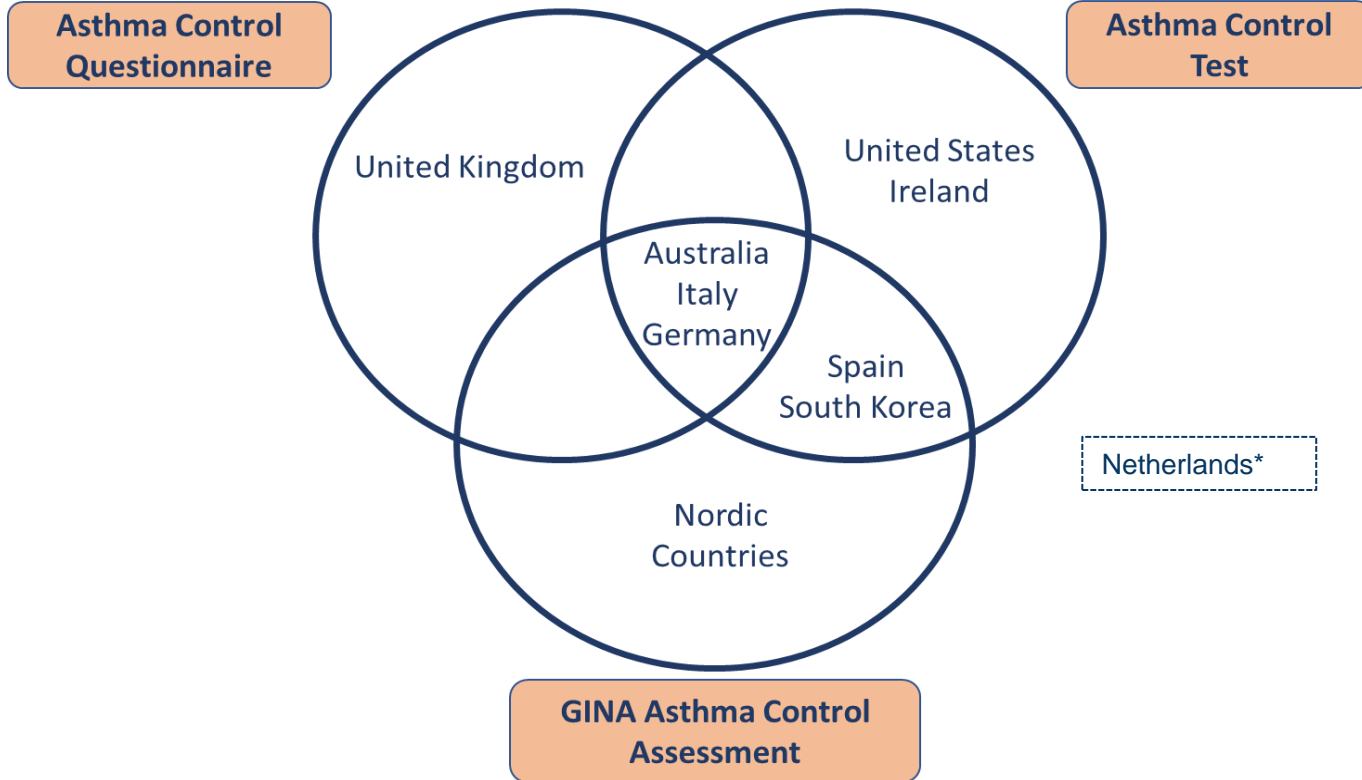


*No Adherence data fields listed for Germany and Italy

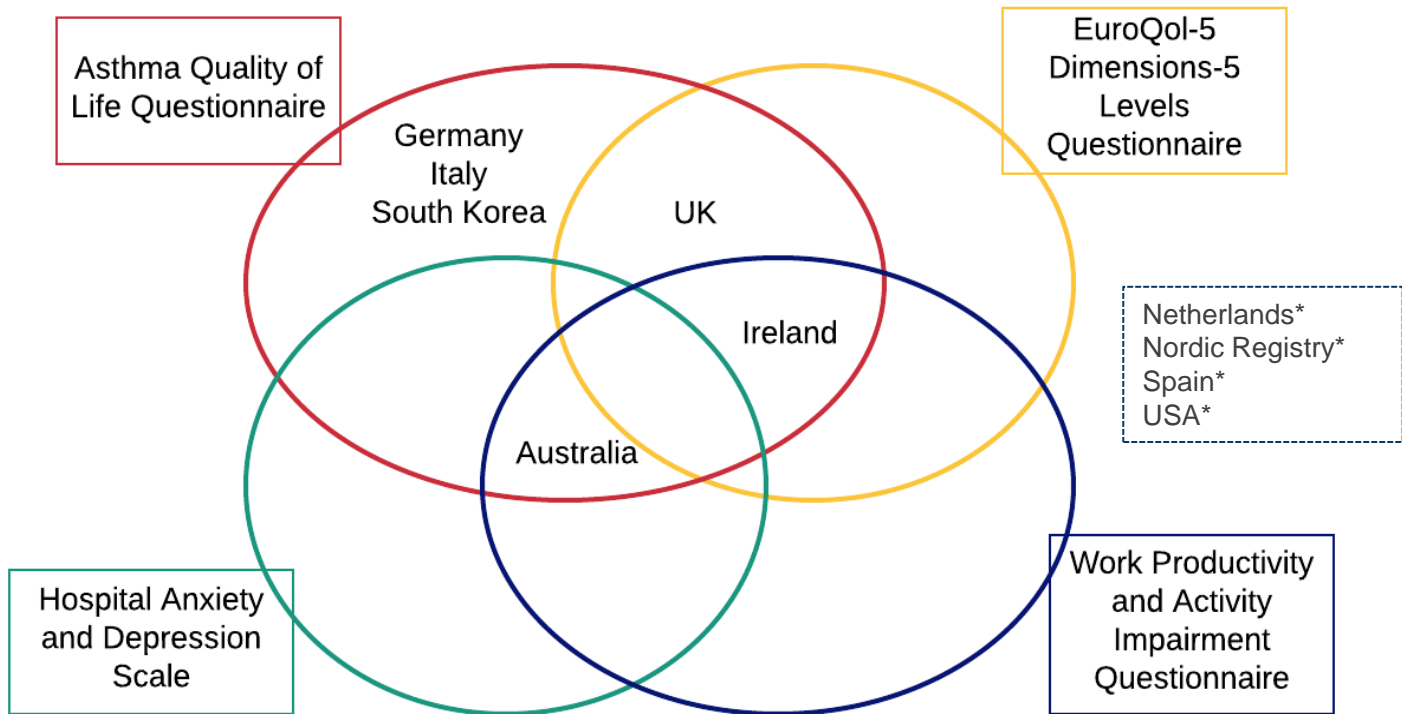
Results: Patient Education and Safety Data

Patient Education			Safety Data		
	Yes	No		Yes	No
Disease Education	<ul style="list-style-type: none"> • Germany • Netherlands • Spain 	<ul style="list-style-type: none"> • Australia • Italy • South Korea • UK • Ireland • Nordic Registry • USA 	Biologic use adverse event	<ul style="list-style-type: none"> • Spain • Italy • Netherlands • USA 	<ul style="list-style-type: none"> • Australia • Germany • South Korea • UK • Ireland • Nordic Registry
Inhaler use Education	<ul style="list-style-type: none"> • Australia • Germany • Ireland • Nordic Registry 	<ul style="list-style-type: none"> • Italy • Netherlands • South Korea • Spain • UK • USA 	Steroid use adverse event	<ul style="list-style-type: none"> • Germany • Ireland • Netherlands • USA 	<ul style="list-style-type: none"> • Australia • Italy • South Korea • Spain • UK • Nordic Registry

Results: Asthma Control Assessments



Results: Asthma Quality of Life Assessments



Conclusion

- Severe asthma databases across the globe converge on collecting similar data field categories in terms of medication, while they differ significantly on the specific data fields such as safety data.
- A standard list of variables captured across countries will increase the statistical power of future studies by allowing for data interoperability.
- This lead to conducting a Delphi exercise that chose a standard list of variables that all countries participating in ISAR will collect.