

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

Lakmini Bulathsinhala¹, Nevaashni Eleangovan¹, Liam G. Heaney², Andrew Menzies-Gow³, Peter G Gibson^{4,5}, Matthew Peters⁶, Mark Hew⁷, Job FM van Boven⁸, Lauri Lehtimäki⁹, Eric van Ganse¹⁰, Manon Belhassen¹⁰, Erin Harvey^{4,5}, Luis Perez de Llano¹¹, Anke H. Maitland-van der Zee¹², Nikolaos Papadopoulos^{13,24}, J Mark FitzGerald¹⁴, Celeste Porsbjerg¹⁵, G. Walter Canonica¹⁶, Vibeke Backer¹⁵, Chin Kook Rhee¹⁷, Katia Verhamme¹⁸, Roland Buhl¹⁹, Borja G Cosio²⁰, Victoria Carter¹, Chris Price¹, Thao Le¹, Martina Stagno d'Alcontres²¹, Gokul Gopalan²², Trung Tran²², David Price^{1,21,23}

¹Optimum Patient Care, Cambridge, UK, ²UK Severe Asthma Registry, Queen's University Belfast, Belfast, Northern Ireland, ³UK Severe Asthma Registry, Royal Brompton & Harefield NHS Foundation Trust, London, UK, ⁴Australasian Severe Asthma Network, Priority Research Centre for Healthy Lungs, University of Newcastle, Newcastle, Australia, ⁵Hunter Medical Research Institute, Department of Respiratory and Sleep Medicine, John Hunter Hospital, New Lambton Heights, Australia, ⁶University of Sydney Medical School, Sydney, Australia, ⁷Alfred Health, Melbourne, Australia, ⁸Department of General Practice, Groningen Research Institute for Asthma and COPD (GRIAC), University Medical Center Groningen, University of Groningen, Groningen, The Netherlands, ⁹Allergy Centre, Tampere University Hospital; University of Tampere, Tampere, Finland, ¹⁰Claude Bernard University Lyon, Lyon, France, ¹¹Spanish Society of Pulmonology and Thoracic Surgery, Madrid, Spain, ¹²University of Amsterdam, Amsterdam, The Netherlands, ¹³University of Athens, Athens, Greece, ¹⁴The Institute for Heart Lung Health, Vancouver, Canada, ¹⁵Bispebjerg Hospital, Copenhagen University, Copenhagen, Denmark, ¹⁶Personalized Medicine Asthma & Allergy Clinic, Humanitas University & Research Hospital, Milan, Italy, ¹⁷Catholic University of Korea, Seoul, South Korea, ¹⁸Ghent University, Gent, Belgium, ¹⁹Mainz University Hospital, Mainz, Germany, ²⁰Son Espases University Hospital-IdISBa-Ciberes, Mallorca, Spain, ²¹Observational and Pragmatic Research Institute, Singapore, ²²AstraZeneca, Gaithersburg, USA, ²³Academic Primary Care, University of Aberdeen, Aberdeen, UK, ²⁴University of Manchester, UK

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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A maximum of 2 graphs, tables or diagrams may be included in addition to the word count and must be in original format and not an image

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Celeste Porsbjerg, Erin Harvey, G Walter Canonica, J Mark FitzGerald, Job van Boven, Manon Belhassen, and Vibeke Backer declare no relevant conflicts of interest concerning this paper.

Email addresses of all authors:

Lakmini Bulathsinhala: lakmini@optimumpatientcare.org
Nevaashni Eleangovan: neva@optimumpatientcare.org
Liam G. Heaney: l.heaney@qub.ac.uk
Andrew Menzies-Gow: A.Menzies-Gow@rbht.nhs.uk
Peter G Gibson: peter.gibson@newcastle.edu.au
Matthew Peters: Matthew.Peters@sswahs.nsw.gov.au
Mark Hew: m.hew@alfred.org.au
Job FM van Boven: jobvanboven@gmail.com
Lauri Lehtimäki: Lauri.lehtimaki@uta.fi
Eric van Ganse: eric.van-ganse@univ-lyon1.fr
Manon Belhassen: manon.belhassen@univ-lyon1.fr
Erin Harvey: erin.harvey@newcastle.edu.au
Luis Perez de Llano: eremos26@hotmail.com
Anke H. Maitland-van der Zee: a.h.maitland@amc.uva.nl
Nikolaos Papadopoulos: ngpallergy@gmail.com
J Mark FitzGerald: mark.fitzgerald@vch.ca
Celeste Porsbjerg: porsbjerg@dadlnet.dk
G. Walter Canonica: canonica@unige.it
Vibeke Backer: backer@dadlnet.dk
Chin Kook Rhee: chinkook@catholic.ac.kr
Katia Verhamme: k.verhamme@erasmusmc.nl
Roland Buhl: roland.buhl@unimedizin-mainz.de
Borja G Cosio: borja.cosio@ssib.es
Victoria Carter: victoria@optimumpatientcare.org
Chris Price: chris@optimumpatientcare.org
Thao Le: thao@optimumpatientcare.org
Martina Stagno d'Alcontres: martina@opri.sg
Gokul Gopalan: Gokul.Gopalan@astrazeneca.com
Trung Tran: trung.tran1@astrazeneca.com
David Price: david@optimumpatientcare.org