



Respiratory
Effectiveness
Group

ADVANCES

in Real-life Respiratory Research

The Respiratory Effectiveness Group Newsletter

ISSUE WINTER 2019-20



 page 6

REG SUMMIT 2020

BARCELONA, SPAIN

www.regresearchnetwork.org

 page 5

REG NEW
PUBLICATIONS

 page 16

INTERNATIONAL SEVERE
ASTHMA REGISTRY ISAR





THE RESPIRATORY EFFECTIVENESS GROUP NEWSLETTER ISSUE WINTER 2020

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CONTENTS



3 EDITORIAL
Nikos Papadopoulos
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4 REG TEAM UPDATE
Michael Walker
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5 REG PUBLICATIONS 2019

6 REG SUMMIT 2020

7 SUMMIT 2020
PROGRAMME

10 WORKING GROUPS
UPDATE

14 WHAT REG MEANS
TO ME

16 INTERNATIONAL SEVERE
ASTHMA REGISTRY ISAR

19 REG SUPPORTERS



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ONE SMALL STEP FOR MAN...

DEAR FRIENDS

This is my last editorial as REG President. Two years have passed since I've taken the role and in reflection I am certainly happy with the progress (and hope you are too!). Among the targets for the period, was to establish an internal structure with responsibilities divided between Board members, who have now become Vice-Presidents, and a regular 2-year turnover for the Chair, with the ultimate intention of bringing in

more and varying intellectual input. We also worked towards refining REG's image, redefining it as a 'think-tank' and, most importantly, strengthening its financial position through key projects. In this regard, the REG Summit has an important role as a forum in which the visions of our think-tank are argued and develop. All the above have worked out, as the numbers confirm, for which I wish to thank all the members of the Board as well as the Executive team headed by our CEO, Michael Walker. Coming up in the driving seat, is Sinthia Bosnic-Anticevich, to whom I wish every success and promise my continued support! I am certain she will enrich the organization with her enthusiasm and creativity!

Stepping down from the President's post doesn't mean I will distance myself from the organization. In fact, I'm already increasing focus towards a project that we have recently initiated and is very close to my heart: PeARL, acronym for 'Pediatric Asthma in Real Life', intends to prioritize unmet needs and provide recommendations for asthma in young people, taking into account both the best available evidence and the consensus of the community. The intention is to produce guidance that will make sense in everyday practice.

For doing this, we will explore the divergent patient journeys and involve as many stakeholders as possible.

Within and beyond projects however, my call is for infusing research and advocacy activities with (at least) a mild political flare: our world is facing big challenges, and we cannot afford not to be continuously vigilant and active about them. Whatever treatment measures we take against respiratory diseases, we are only fooling ourselves if we don't consider the quality of the air that we breathe, or even more, the wider environmental conditions and their effects on our health. Prevention is the only viable way forward and groups such as REG should take leading roles in supporting and promoting a healthy environment as the current number one priority.

Nikos Papadopoulos
REG President

REG TEAM UPDATE



Michael Walker
REG CEO

The REG Team has seen some changes. I am very pleased to welcome Graham Lough to the REG team as scientific researcher. Graham joins us from Queen Margaret University, Edinburgh, Scotland, where he has been conducting several research projects including distribution of healthcare resources to Palestine refugees in the Middle East. Graham joined the team to replace Naomi Launders who left REG after the ERS Congress. Naomi is undertaking a PhD at University College London and Public Health England in the use of real-world data to examine physical health comorbidities in patients with mental illness. On behalf of all the REG collaborators and supporters, I would like to warmly thank Naomi for all her hard work, professionalism

and team support at REG and wish her all the best for the continuation of her academic studies.

The second half of 2019 included a full schedule of REG Working Group meetings during the ERS congress in Madrid. Thank you to everyone who participated. Several important projects are gaining momentum as the foundations are put in place to execute in 2020.

Overall, 2019 was a busy year for many of the working groups with 8 new publications and another 5 manuscripts submitted or in final preparation. New projects are in development and some are just starting, and these will be discussed in more detail during the working group meetings at the Summit on Thursday 19th March.

The last few months have been focused on the preparation of the REG Summit 2020 which will be held in Barcelona from 19th – 21st March. The

programme and speakers have now all be finalised and the schedule for the working group meetings has been prepared. We hope that many of you will be participating in the Summit which is open to all collaborators and sponsors.

I would like to acknowledge the support from a number of long-term sponsors. Without their ongoing support a lot of the work of the REG would not be possible. I hope others are encouraged by the activities of REG and the Summit in March and will collaborate with us later this year or plan to in the future.

I look forward meeting our many collaborators and supporters at the REG Summit 2020 in Barcelona.



REG RECENT PUBLICATIONS IN 2019



Point-of-care biomarkers in asthma management: time to move forward

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Alving, K., Diamant, Z., Lucas, S., Magnussen, H., Pavord, I. D., Piantentini, G., Price, D., Roche, N., Sastre, J., Thomas, M., Usmani, O., Bjermer, L., Respiratory Effectiveness Group, Biomarkers Working Group. (2019) 'Point-of-care biomarkers in asthma management: time to move forward', *Allergy*, IN PRESS.

ONLINE LINK

<https://onlinelibrary.wiley.com/doi/abs/10.1111/all.14045>

Management Of Community-Acquired Pneumonia: An Observational Study In UK Primary Care

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Launders, N., Ryan, D., Winchester, C.C., Skinner, D., Konduru, P. R., Price, D. B. (2019) 'Management Of Community-Acquired Pneumonia: An Observational Study In UK Primary Care', *Prag Obs Res*, 10, 53-65.

ONLINE LINK

<https://www.dovepress.com/management-of-community-acquired-pneumonia-an-observational-study-in-u-peer-reviewed-article-POR>



The importance of real-life research in respiratory medicine: manifesto of the Respiratory Effectiveness Group: Endorsed by the International Primary Care Respiratory Group and the World Allergy Organization

REFERENCES

Roche, N., Anzueto, A., Bosnic Anticevich, S., Kaplan, A., Miravittles, M., Ryan, D., Soriano, J. B., Usmani, O., Papadopoulos, N. G., Canonica, G. W., Respiratory Effectiveness Group Collaborators. (2019) 'The importance of real-life research in respiratory medicine: manifesto of the Respiratory Effectiveness Group: Endorsed by the International Primary Care Respiratory Group and the World Allergy Organization', *Eur Respir J*, 54 (3).

ONLINE LINK

<https://erj.ersjournals.com/content/54/3/1901511.long>



The relationship between real-world inhaled corticosteroids adherence and asthma outcomes: a multilevel approach

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Vervloet, M., van Dijk, L., Spreeuwenberg, P., Price, D., Chisholm, A., Van Ganse, E., Pinnock, H., Rand, C. S., Eakin, M. N., Schermer, T., Souverein, P. C., Dima, A. L., Respiratory Effectiveness Group's Adherence Working Group. (2019) 'The relationship between real-world inhaled corticosteroids adherence and asthma outcomes: a multilevel approach', *J Allergy Clin Immunol Pract*. IN PRESS.

ONLINE LINK

<https://www.sciencedirect.com/science/article/abs/pii/S2213219819307809?via%3Dihub>



REG SUMMIT 2020

This year **Barcelona will host the REG Summit 2020**. The Summit will bring together real-life research experts from around the world to discuss the latest findings and new areas for collaboration in their respective fields of respiratory research.

The REG Summit is a well-known meeting of global respiratory key opinion leaders who actively conduct real-life research using and creating real world evidence. REG collaborators (researchers, clinicians, general practitioners and allied health professionals) have conducted numerous database projects as well as prospective pragmatic trials and continue to seek answers to the many complex issues faced by respiratory patients.

The REG Summit **starts on Thursday 19th March** with the REG Working Groups meeting to review progress on projects as well as developing new ideas and areas for further investigation. **The scientific programme follows all day on Friday 20th and concludes at 13:00 on Saturday 21st March.**

The scientific programme will include robust and informative discussions and debate on the latest thinking on treatment strategies and

what are the needs to move the field forward to have a better understanding of how to improve patient outcomes. Participants will debate the hottest topics in the field, in a variety of interactive and informative sessions.

This year the programme welcomes an impressive list of experts who will be speaking on challenges and impact of the environment on lung health including a discussion on e-cigarettes and their role in smoking cessation, COPD exacerbations and their management, steroid avoidance in asthma, discussion on different issues in asthma management including in pregnancy and how to choose the right biologic for your patient, and a joint session looking at thresholds of referral across a range of conditions.

The meeting also provides an excellent opportunity for networking with some of the world's leading experts in the respiratory field.

The **REG summit 2020 will be the years' most important meeting in the field of real-life research** and everyone is encouraged to participate and get involved with the REG and its projects.

We look forward to seeing you in Barcelona!

WORKING GROUP MEETINGS @ REG SUMMIT 2020

THURSDAY, 19TH MARCH 2020

	Room 1	Room 2
12:00-13:00	NETWORKING / LUNCH	NETWORKING / LUNCH
13:00-14:00	Quality Standards	
14:00-15:00	ILD/IPF	Adherence
15:00-16:00	Chronic Cough	COPD
16:00-16:30	COFFEE	COFFEE
16:30-17:30	Small Airways	Database & Coding
17:30-18:30	Cost Effectiveness	Biomarkers & Severe asthma
18:30-19:30	Technologies	Child health

FRIDAY, 20TH MARCH 2020

08:00-08:45	REG Supporters Meeting
17:30-18:00	REG AGM
19:00-19:30	Drinks reception
19:30-22:00	Dinner - networking

REG SUMMIT 2020

PRELIMINARY PROGRAMME

19 - 21 MARCH 2020 📍 TRYP BARCELONA APOLO HOTEL, BARCELONA, SPAIN

THURSDAY 19TH MARCH

13:00 – 19:30 **REG Working Group Meetings**

FRIDAY 20TH MARCH

08:00 – 08:45 **REG Supporters Meeting**

08:50 – 09:00 **Welcome**
Prof. Nikos Papadopoulos

09:00 – 10:00 **COPD: Focus on Exacerbations**
Chair: Dr Marc Miravittles

Update on COPD exacerbations | Prof. Daiana Stolz
Eosinophils are an appropriate AECOPD biomarker?
Pro | Dr Miriam Barrecheguren
Con | Prof. Alberto Papi

10:00 – 10:30 **Coffee Break**

10:30 – 12:00 **Environment and Lung Health**
Chair: Prof. Joan B Soriano

Impact of Global warming and Climate Change | Prof. Josep M Anto
Inhalers and F-gas | Prof. Omar Usmani
E-cigarette: is this a valuable aid to smoking cessation?
Pro | Prof. Linda Bauld
Con | Prof. Esteve Fernández

12:00 – 12:30 **Severe Asthma**
Chair: Prof. Leif Bjermer

How to avoid oral steroids in asthma | Prof. Giorgio Walter Canonica

12:30 – 13:30 **Lunch Break**

13:30 – 14:15 **ISAR Symposium**
Chair: Prof. David Price

Intro/Background – ISAR updates. | Victoria Carter

Highlights from ISAR

- **Eosinophilic and Non-eosinophilic Phenotypes of Severe Asthma** | David Price
- **The Role of Exacerbations on Lung Function Trajectory** | Liam Heaney & Shay Soremuken

- **BRISAR: Biomarker Relatability in ISAR (in collaboration with Alfred hospital and Monash University)** | Mark Hew & Eve Denton

- **Onset of Asthma in Severe Asthma patients (in collaboration with Woolcock Institute)** | Sinthia Bosnic Anticevich & Naeimeh Hosseini, Lakmini Bulathsinhala

New opportunities for academic research

1. OCS landscape: annual consumption, prevalence outcomes and side-effects of long-term OCS.
2. Characteristics of severe asthma patients with inflammatory phenotypes and low-FEV1
3. Characterization of health disparities across countries

14:15 – 15:00 **Early identification of IPF - what new tools can help?**

Chair: Dr Argyris Tzouveleakis

Speaker: Prof. Maria Molina Molina

15:00 – 15:30 **Coffee Break**

15:30 – 17:30 **Asthma Issues**

Chairs: Prof. Alberto Papi & Prof. Nikos Papadopoulos

Asthma in pregnancy | Dr Alan Kaplan

Asthma biomarkers in children | Prof. Sejal Saglani

Should SABAs be replaced as the reliever of choice?

Pro | Prof. Tim Harrison

Con | Dr Dermot Ryan

New biologics in severe asthma - how to choose? | Prof. Nick Hanania

17:30 – 18:00 **REG Annual General Meeting**

SATURDAY 21ST MARCH

09:00 – 09:30 **Influenza vaccines: current real life and futuristic scenarios**

Chair: Dr Miguel Román-Rodríguez

Speaker: Prof. Ab Osterhaus

09:30 – 11:20 **Thresholds for referral**

Chair: Prof. Mike Thomas

Wheeze/Asthma | Prof. Jan Willem Kocks

Allergic manifestations | Prof. Ted Popov

COPD | Prof. Nicolas Roche

Chronic/recurrent cough | Prof. Lorcan McGarvey

Pharmacy | Prof. Elizabeth Azzi

11:20 – 11:50 **Coffee Break**

11:50 – 12:50 **Key Note**

Chair: Prof. Sinthia Bosnic-anticevich

Personalised, precision or stratified respiratory medicine. The present and the future | Prof. Alvar Agustí

13:00 **Meeting Close**



Respiratory
Effectiveness
Group



THE RESPIRATORY
EFFECTIVENESS GROUP

REG

SUMMIT 2020

Capitalising on real-life research
for best clinical guidance

19-21
March 2020

BARCELONA
S P A I N

TRYP Barcelona
Apolo Hotel

SAVE
THE
DATE

www.regsummit2020.org



WORKING GROUP UPDATE

In September 2019, the REG team attended the European Respiratory Society congress. On the Saturday and Sunday prior to the main meeting eight of the working groups held meetings, exchanging new ideas, presenting new research from REG projects and identifying priorities in real-life respiratory research. Following the meetings, the REG team have been working with investigators and supporters to drive projects forwards. For 2019, eight REG publications have come out of the working groups, with another five in preparation or submitted.



WORKING GROUP UPDATE

COPD WORKING GROUP



The results from the COPD Working Group's Concept of control in COPD prospective observational study were presented at the Working Group meeting at ERS 2019 and have now been written up and submitted for publication. Having developed a network of centres and following the enthusiasm of the participating centres it has been decided by the Working Group to conduct another prospective observation study. This next study will be led by Omar Usmani and will investigate the predictive value of peak inspiratory flow in COPD exacerbations. Funding for this study has been secured from Boehringer Ingelheim and study setup is now underway.

The Real-Life WISDOM project is a database study to assess the implications of ICS withdrawal in the management of COPD; the data for this study is currently being analysed. Following the publication of a pilot study in 2018 into the trends of testing for and diagnosis of alpha-1 antitrypsin deficiency in the UK, it has been decided to seek funding for a more comprehensive study into the epidemiology and natural history of AATD.

CHILD HEALTH WORKING GROUP



The comparative effectiveness of the addition of antibiotics versus usual care in asthma exacerbations study found high levels of antibiotic prescribing for acute asthma exacerbations despite antibiotics not being recommended within guidelines. The addition of a single course of antibiotics alongside oral corticosteroids for the treatment of acute asthma exacerbations had only a mild effect compared to the usual treatment of oral corticosteroids alone. The results of this study are being prepared for publication.

Work is ongoing to finalise funding for the Paediatric Asthma in Real Life (PeARL) project, led by Nikos Papadopoulos, which aims to produce evidence-based recommendations regarding controversial aspects of paediatric asthma using knowledge gaps surveys, systematic reviews, meta-analyses and Delphi exercises.

ADHERENCE WORKING GROUP



The Working Group have completed the bi-directional relationship of adherence and control in asthma control study with a manuscript now published in JACI in practice; The Relationship Between Real-World Inhaled Corticosteroid Adherence and Asthma Outcomes: A Multilevel Approach concludes that patients may adapt their inhaled corticosteroid use to their current needs without this impacting later risk domain asthma control.

The Working Group have developed a proposal for 2 scoping reviews for which REG are now seeking funding; one review will assess how adherence is included within current guidelines and the second review will assess how precision medicine can be used to monitor and manage adherence. It is hoped these scoping reviews will help inform a future study that would combine database records and a prospective component to assess the different methods of adherence monitoring and the responsiveness and utility of database measures in predicting non-adherence.

WORKING GROUP UPDATE



DATABASES AND CODING WORKING GROUP

The Towards Optimum Reporting of Pulmonary Effectiveness Databases and Outcomes (TORPEDO) project which used a 3-phase modified Delphi, has resulted in proposed lists of minimally required variables for retrospective and prospective asthma and COPD studies, which is an important step in facilitating the sharing and merging of datasets. A manuscript of the results is currently being finalised before being submitted for publication. These lists of minimally required variables will allow the assessment of current data sources for their potential utility in asthma and COPD studies and provides a basis to aid the standardization of data collection and improve research efficiency. A proposal is being developed for the next phase of this work, which will involve compiling a list of available data sources and determining which of the minimally required variables for asthma and COPD studies they include, and a tool to aid the selection of variables for future prospective studies.



ALLERGY WORKING GROUP

The Allergy Working Group, chaired by Moises Calderon, had a follow-up meeting during the EAACI congress in Lisbon in June to discuss a new project looking at the impact of allergy immunotherapy (AIT) in airways disease. This new project in development is now called the GRAAIL Project, which is planned to be a registry of patients receiving AIT. The objectives, methodology and funding strategy for this ambitious project are being finalised and will be discussed further at the EAACI meeting in 2020.



TECHNOLOGY WORKING GROUP

Ron Dandurand chaired the working group meeting at ERS 2019 in September and reviewed the working groups projects. A scoping review of smart inhalers is currently still seeking funding, while a proposal for an opinion piece on the utility of oscillometry is being finalised and support is likely. Finally, the group have been discussing the possibility of examining how technology can be used to define and predict asthma exacerbations and the potential to measure adherence, however, these projects require further discussion.



COUGH WORKING GROUP

Top line results of the Phase I project Burden of Cough in Adults seen in UK Primary Care were presented in the Cough Working Group meeting at ERS 2019 by Prof. Lorcan McGarvey. The results showed that cough consultations account for a high burden of primary care consultation. 4.8% of all patients with a consultation in the study period had a consultation for cough. There was a female predominance (57.3%). More patients were female in those under 65, while over 65 there were more male patients. Patients were more likely to be obese or current or ex-smokers than the general population. 49% of patients had a respiratory comorbidity, of which asthma was the most common (22.9%), followed by rhinitis (21.8% of which 6.9% was active in baseline) and COPD (15.4%). The most common non-respiratory comorbidities were depression (41.6%, of which 17% was active in baseline) and hypertension (32.7%). The final report of the project will be circulated with the study group and discussions have begun on the design for the Phase II project.

COST EFFECTIVENESS WORKING GROUP



The cost effectiveness group did not meet at ERS 2019. The working group plans to build projects in collaboration with other working groups and add value to planned or existing projects.

SMALL AIRWAYS WORKING GROUP



There was no Working Group meeting at the ERS 2019, however, there is some overlap of ideas with the Technologies Working Group. Omar Usmani is working on a manuscript "What is meant by dose?". The future direction of this group remains under discussion.

INTERSTITIAL LUNG DISEASE/IDIOPATHIC PULMONARY FIBROSIS WORKING GROUP



Phase I of the project The characterisation of interstitial lung disease multidisciplinary team meetings: a global study was published in European Respiratory Journal – Open Research in early 2019. The ILD/IPF working group met at ERS 2019, where the second phase of the project to characterise multidisciplinary team meetings used to diagnose ILD, and the effect these characteristics have on diagnostic agreement was further discussed. The methodology and technological requirements of the Phase II project continue to be a challenge and solutions are being further explored.

SEVERE ASTHMA AND BIOMARKERS WORKING GROUP



The Point-of-care biomarkers in asthma management: time to move forward letter that highlights the importance of clinical biomarkers, such as FeNO in the diagnosis and management of asthma, and the need to include data from real-life studies, alongside clinical trial data, when considering the inclusion of biomarkers into guidelines has been accepted for publication in Allergy. The Working Group met at ERS 2019 and began discussing potential ideas for future projects.



WHAT REG MEANS TO ME

I joined REG back in 2014, about five years ago. When Pirfenidone was approved in Japan and showed signs of developing globally, it was the first to fly to Singapore to talk about the treatment of IPF at the REG summit on the real world management of IPF. Subsequently, the Invitation to REG IPF / ILD Working Group was formed, and the ILD group evolved as a division of REG. Even for big markets such as COPD / Asthma, the rare disease IPF / ILD is an area where the message to real life practice is very important.

Prior to 2009, when there was no other treatment option than lung transplantation, accurate diagnosis of IPF has been of paramount importance. However, since 2009, discussions on IPF management have become active.

Real life practice includes early, advanced, and long-term treatments

of IPF that were excluded from clinical trials. I understand that REG offers real safety and usefulness. In the past, only classification-specific work was undertaken, but debate has also started on the treatment of complications and comorbidities encountered in the clinical course.

REG, on the other hand, is also helping to standardize clinical diagnostics, which differed by country and region. At present, a questionnaire survey on IPF diagnosis is underway, and it is playing a major role in evaluating the practicality of the international guidelines.

From this perspective, ERG has become a place for information sharing and collection in IPF clinical practice for me.

Arata Azuma

Nippon Medical School,
Graduate School of Pulmonary Medicine,
Tokyo, JAPAN



In my work as a respiratory clinician and clinical researcher, I have a special interest in improving the management of patients with COPD. I have experienced while working in different countries (Holland, Singapore, and currently Denmark), that the unmet needs of these patients as well as the management and clinical expression of their disease may differ considerably amongst countries and ethnicities. Hence, the importance of international collaborative real-life studies including patients with these different backgrounds and phenotypes.

I was introduced to REG via Prof. David Price in 2015 when I became a member. REG has given me, and my former Singapore colleagues, the opportunity to collaborate on the "COPD control" study, where COPD patients from different centers in Asia and the UK were included in a prospective observational study, evaluating the concept of COPD control. The study has also resulted in a publication on differences between Asian and Western COPD patients. Furthermore, this collaboration has offered me to connect with a network of very experienced and passionate researchers in the field.

Attending the COPD working group meetings have been a great platform to meet with professionals and discuss the progress of studies and novel protocol ideas, as well as funding opportunities. These meetings have a nice informal character and are very inspirational and constructive. As I moved on to Denmark, I was able to continue my collaboration with REG, and I hope to contribute to many more studies. To me, REG means "teamwork", and the ability of working together internationally towards a common vision.

Thérèse Lapperre

Associate Research Professor and Senior Consultant
Dept. of Respiratory Medicine, Bispebjerg University hospital
Copenhagen, Denmark

During my clinical and research career I've seen the emergence of evidence based medicine. The problem has been the quality of the evidence and whether it's relevant to clinical practice. Real-life effectiveness studies have transformed the research evidence so that it can now inform how we treat people in the ordinary hospital settings and in primary care. The respiratory effectiveness group has championed commissioning, implementation and publication of innovative real-life studies but crucially it has moved to change the way that guidelines are written.

REG has a collegiate friendly group of people and the meetings are small by comparison to major conferences, but the huge advantage is that there are superb speakers researchers and Leaders in respiratory medicine and the pharmaceutical industry. And all of these people are accessible, providing a great venue for learning, sharing ideas, developing new projects and again crucially influencing policymakers.



Rupert Jones
Associate Professor (Research)
Peninsula Medical School (Faculty of Health: Medicine,
Dentistry and Human Sciences)
University of Plymouth

As Vice-President for methodology, I'm highly concerned by what I believe is the major goal of the Respiratory Effectiveness Group (REG), i.e., to promote high-quality real-life research (RLR) and especially comparative effectiveness research using real-life data. I strongly believe that such data is really crucial to complement registration randomized controlled trials (RCTs) and especially to assess the generalizability of their results, define the best target populations and check tolerance profile.

At the time REG was created, I was involved in its initial publications proposing a research framework in which RLR was clearly positioned. These publications underlined that RLR provided special research opportunities in areas where RCTs could not be performed for reasons related to feasibility, affordability and ethics. They also initiated the work of REG around quality.

To achieve its goals, REG has developed and published a quality assessment tool call RELEVANT (the REal Life EVIDence Assessment Tool), in collaboration with the European Academy of Allergy and Clinical Immunology. Such tools are of great importance to help stakeholders assess the quality of real-life research and decide whether and how the corresponding results can be translated into clinical practice. Along this line, REG has recently proposed a Manifesto in collaboration with the International Primary Care Respiratory

Group, that was published in the European Respiratory Journal. As a cornerstone of REG strategy, this document emphasizes the need for real-life effectiveness research to confirm and extend findings from RCTs and generate new hypotheses regarding subgroups or situations of interest. Accordingly, effectiveness research needs to be considered in decision processes by physicians and other healthcare providers, institutions, payers, guidelines developers and patients. During a long time RLR has been considered as synonymous to low or very low levels of evidence. However, some years ago the Grading of Recommendations Assessment, Development and Evaluation (GRADE) working group has specifically proposed to upgrade the level of evidence from observational research when one or more of three conditions are met: large magnitude of effect, presence of a dose-response relationship, plausible residual confounding increasing confidence in observed effects.

Altogether, I'm fully convinced that REG has a huge potential for triggering, guiding, helping and/or conducting high-quality RLR, thereby supporting major scientific advances especially in the field of treatment effectiveness. As such, REG can provide significant contributions to P4 (personalized, predictive, preventive and participative) medicine.

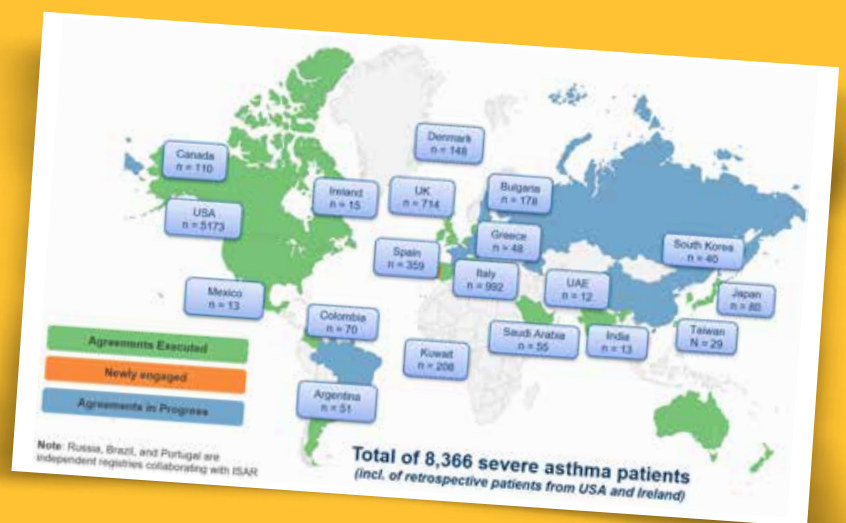
Nicolas Roche
Hôpital Cochin, APHP.
Centre Université de Paris, France
REG Vice-President for methodology



INTERNATIONAL SEVERE ASTHMA REGISTRY **ISAR**

◆ ISAR So Far

The International Severe Asthma Registry now houses data from 8,366 patients with severe asthma from 18 countries. In 2019, ISAR has expanded dramatically with the execution of 12 country agreements. With the current momentum, we are actively collaborating with 22 registries and in discussions to initiate partnerships with 12 more countries! (see figure)



◆ ISAR Publication

Updates:

ISAR has published its first dataset in CHEST fulfilling the Global Asthma Report's ambition for ongoing asthma monitoring worldwide. This study provides the first description of an international managed severe asthma population and facilitates a comparison of demographic and clinical characteristics across-country and health care systems. Click [here](#) to read the full article.

ISAR's mission statement has also been published in CHEST. Click [here](#) to discover more about ISAR; what it is, what it does and what makes it different from other severe asthma registries. Learn about our aims and aspirations for the future, and ISAR's key strengths which will ensure those aims become a reality.

The ISAR protocol was recently submitted to BMC Medical Research Methodology.

Two ISAR manuscripts, ISAR Inventory and Hidden severe asthma in primary care UK are currently being drafted and will be submitted in Q1 2020. The ISAR Inventory publication aims to compare all existing severe asthma registries to the ISAR variables. We are open to include any additional countries, even those that have not collaborated with ISAR. If your country's

severe asthma database or registries are interested, please contact us on our [website](#).

A big thank you to all our ISAR authors and contributors who have given of their time and expertise to ensure each ISAR publication is of the highest calibre.



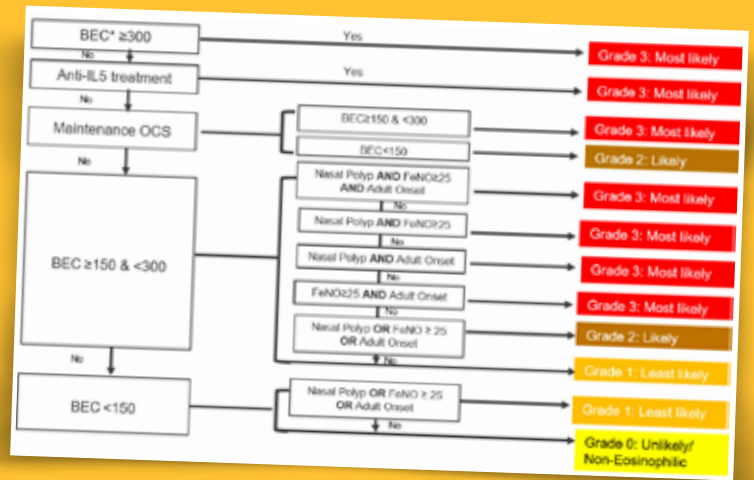
◆ ISAR website

The ISAR website has had a facelift. It now contains a new "Dissemination" tab for the latest news on ISAR abstracts and publications, and a "FAQ" tab which provides answers to frequently asked questions about ISAR.

www.isaregistries.org

◆ ISAR 2018 Global CORE project: The characterization and comparison of eosinophilic and non-eosinophilic phenotypes of severe asthma.

Informed by a systematic literature review and finalized by the ISC, a gradient algorithm to characterize eosinophilic and non-eosinophilic phenotypes was a key achievement for the project (Figure). The results showed that most of the ISAR cohort had an eosinophilic phenotype. These patients tended to be older and have fixed airway obstruction compared to the non-eosinophilic group. Conversely, prevalence of eczema and use of Anti-IgE prescriptions was significantly higher for those patients with severe non-eosinophilic asthma. The full report has been finalized.



◆ Congress:

ISAR has been incredibly busy with the congresses. In 2019, we submitted a total of 11 abstracts (1 for REG, 2 for ATS, 2 for EAACI, 3 for ERS, 2 for APSR and 1 for WAC) and presented 10 abstracts. That's not all! A total of 6 abstracts have recently been accepted for ATS 2020 (4 as posters and 2 as oral presentations) and 3 abstracts are planned for REG 2020!

Professor Andrew Menzie-Gow presenting the ISAR abstract entitled "Epidemiology of lung function in a global severe asthma population" in ERS 2019



Dr Dermot Ryan, Director of the Respiratory Effectiveness Group (REG), presenting ISAR's research on "Protocol to identify potential severe asthma in UK primary care" in ERS 2019



The South-Korean lead for ISAR, Professor Chin Kook Rhee, presenting the interesting demographic and clinical characteristic differences of patients with severe asthma in Japan and South Korea compared to the global ISAR population in APSR 2019

ISAR Abstracts in ATS 2020

Over 50 severe asthma leads from across the world came together during the REG Summit to discuss the progress and identify next key steps to deliver the ISAR international research projects within their study Working Groups.

ISAR received 22 research proposals from over 10 countries during the annual research prioritization exercise. The top five research topics for delivery in 2019 were prioritized by the ISC.

ABSTRACT TITLE	PRESENTATION TYPE:	PRESENTATION DATE:	PRESENTATION TIME:
Characterization Of Eosinophilic And Non-eosinophilic Severe Asthma Phenotypes And Proportion Of Patients With These Phenotypes In The International Severe Asthma Registry (ISAR)	Poster Presentation	Tuesday May 19, 2020	9:15 - 11:15
A Global Survey Of Blood Eosinophil Distribution In Severe Asthma Patients: Data From The International Severe Asthma Registry (ISAR)	Poster Presentation	Tuesday May 19, 2020	9:15 - 11:15
Biomarker Relatability In The International Severe Asthma Registry	Poster Presentation	Tuesday May 19, 2020	9:15 - 11:15
Global Access For Biologics In The Treatment Of Severe Asthma: A Challenge To Personalized Medicine	Oral Presentation	Tuesday May 19, 2020	14:15 - 16:15
Biologic Utilization Patterns: Data From The International Severe Asthma Registry (ISAR)	Poster Presentation	Wednesday May 20, 2020	13:00 - 15:00
The Impact Of Exacerbation Burden On Lung Function Trajectory In A Broad Uk Asthma Population: A Large Longitudinal Cohort Study	Oral Presentation	Wednesday May 20, 2020	8:45 - 10:45

FRIDAY, 20TH MARCH 2020 @ 13:30 - 14:15

ISAR SYMPOSIUM

CHAIR: DAVID PRICE

- Intro/Background – ISAR updates, Victoria Carter
- Highlights from ISAR:
 - Eosinophilic and Non-eosinophilic Phenotypes of Severe Asthma, David Price
 - The Role of Exacerbations on Lung Function Trajectory, Liam Heaney & Shay Soremuken
 - BRISAR: Biomarker Relatability in ISAR (in collaboration with Alfred hospital and Monash University), Mark Hew & Eve Denton
 - Onset of Asthma in Severe Asthma patients (in collaboration with Woolcock Institute), Sinthia Bosnic Anticevich & Naeimeh Hosseini
- New opportunities for academic research, Lakmini Bulathsinhala.
 - OCS landscape: annual consumption, prevalence outcomes and side-effects of long-term OCS
 - Characteristics of severe asthma patients with inflammatory phenotypes and low-FEV1
 - Characterization of health disparities across countries

ISAR Symposium @ REG 2020

Join us in this 45 minute session to learn more about ISAR, some projects which we will be concentrating on in 2020 and new opportunities for academic research.

Research updates

Two fully-funded 2020 Global Research Project will be prioritised and voted on during a closed session during REG 2020. These projects will be open for researchers to join and lead. Please submit your interest through our [website](#) or contact your country lead for further details. We look forward to seeing you at REG 2020!

ACKNOWLEDGEMENTS

The work of REG would not be possible without the contributions from our invaluable Supporters to fund innovative research projects developed by our expert Collaborators.

REG is looking to launch a number of ambitious research initiatives which offer the opportunity to impact clinical management guidelines and patient care.

We welcome any suggestions from Supporters and would be happy to meet to discuss your ideas in more detail. A good opportunity to meet could be at the upcoming REG Summit in Barcelona.

You can always get in contact with the REG team
by email at enquiries@regresearchnetwork.org,
or write to Michael Walker, REG CEO
at michael@regresearchnetwork.org

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