



Respiratory  
Effectiveness  
Group

# ADVANCES

**in Real-life Respiratory Research**

The Respiratory Effectiveness Group Newsletter

**ISSUE SUMMER 2019**



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## REG DURING ERS 2019

[www.regresearchnetwork.org](http://www.regresearchnetwork.org)

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REG SUMMIT  
2019 ATHENS,  
GREECE

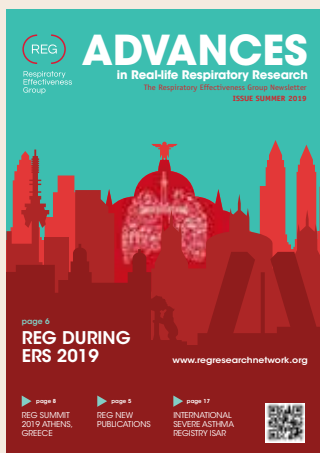
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REG NEW  
PUBLICATIONS

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INTERNATIONAL  
SEVERE ASTHMA  
REGISTRY ISAR





## THE RESPIRATORY EFFECTIVENESS GROUP NEWSLETTER ISSUE SUMMER 2019

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# HOW MANY REAL LIVES?

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## DEAR FRIENDS

**O**n first impression, the concept of real-life research appears to suggest that there is a real life (in contrast to many, unreal, artificial realities)! I challenged this, slightly, in my previous editorial. At the moment, with summer receding and while I'm about to move once again between my different homes, I thought it was pertinent to point out that, in fact, there are many more "real lives" than one!

I can see most of the REG audience spontaneously agreeing: we are a well-travelled, socially advanced bunch after all. However, most parts of our everyday lives are strongly conditioned by our, mostly 'western', social environments. Even more, each of our communities define - and sometimes strongly defend - their own version of reality. This is absolutely healthy and a source of richness and inspiration, to the extent that we do not forget the essence of difference and diversity.

Most of us passionately support diversity but, my impression is, we only vaguely understand it. And in these troubled times, we less and less discuss limits of acceptability: e.g. when differences become shocking, and then they are often rejected without dialogue or consideration. An increasing pattern of political correctness, that is far from real acceptance or even tolerance.

This may all sound political, philosophical or complete nonsense! They do refer however, to medicine and can easily focus on respiratory medicine on its every day, 'real-life' practice. To make it clearer: we form our opinions and subsequently develop guidelines, supposedly addressed to health care professionals and patients worldwide, most often considering our own, usually 'ideal' situation. We discuss about referrals from primary to secondary and/or tertiary care, with little attention to the fact that in many places, there is no secondary/tertiary care, while in others primary care is done by specialists. We propose 'life-saving' interventions that may cost a lifetime's savings per month, in any developing country. We come up with ingenious advances with little understanding of the different patient journeys.

In my view, it is REG's obligation not only to highlight the value of 'real life research' in methodological terms, but also to keep alive the discussion about difference, inclusivity, collaboration and unison. In reality we are less 'open' than we think, but self-awareness and a drive for improvement can lead us there and, as a side effect, help save the planet!

**Nikos Papadopoulos**  
REG President

# REG TEAM UPDATE

The very successful REG Summit was held in Athens from 28th to 30th March. The stimulating scientific programme provided participants with opportunities for in-depth discussions about the many issues and controversies that challenge everyday care of patients. On the day prior to the Summit meeting, REG Working Groups met to discuss and continue to develop their respective research projects. A report on the meeting can be found later in this issue.

The last few months have also been focused on the various REG research projects that are in development and an update can be read in this edition.

The REG Allergy Working Group held its meeting during the EAACI congress in Lisbon and a very exciting new project is in development. The upcoming ERS congress in Madrid is an important opportunity for our Working Groups to meet again and continue the progress of active projects or discuss the projects in development. It is

also a valuable opportunity to meet with our partners and supporters to continue to deliver our real-world research.

The rollout of the new REG corporate branding is now complete, with a new logo, look and style. Our new REG website is now live at the new web address [www.regresearchnetwork.org](http://www.regresearchnetwork.org). The change in domain name is to better reflect one of the core values of REG, of conducting real-life research with colleagues from around the world in a true network.

I would like to acknowledge the support from our long-term supporters. Without their ongoing collaboration a lot of the work of REG would not be possible. I hope others are encouraged by the activities of REG and the REG Working Group meetings and will collaborate with us later this year or plan to in 2020. I look forward to meeting our many collaborators and supporters at the ERS Congress in Madrid.

Lastly, I am very pleased to welcome Graham Lough to the REG team as a scientific

researcher. Graham joins us from Queen Margaret University, Edinburgh, Scotland, where he has been conducting several research projects. Graham joins the team to replace Naomi Lauenders who will be leaving REG to undertake 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 best wishes for the continuation of her academic studies.



Michael Walker  
REG CEO



# REG NEW PUBLICATIONS 2019



## Prevalence and Characteristics of Asthma-COPD Overlap in Routine Primary Care Practices

### REFERENCES

Krishnan J. A., Nibber A., Chisholm A., Price D., Bateman E. D., Bjermer L., Van Boven J. F., Brusselle G., Costello R. W., Dandurand R. J., Diamant Z., Van Ganse E., Gouder C., Van Kampen S. C., Kaplan A., Kocks J., Miravittles M., Niimi A., Pizzichini E., Rhee C. K., Soriano J. B., Vogelmeier C., Román-Rodríguez M., Carter V. and Roche N. (2019) "Prevalence and Characteristics of Asthma-COPD Overlap in Routine Primary Care Practices", *Ann Am Thorac Soc* [In Press].

### ONLINE LINK

<https://www.atsjournals.org/doi/abs/10.1513/AnnalsATS.201809-6070C>

## The characterisation of interstitial lung disease multidisciplinary team meetings: a global study

### REFERENCES

Richeldi L., Launders N., Martinez F., Walsh S. L. F., Myers J., Wang B., Jones M., Chisholm A. and Flaherty K. R. (2019) "The characterisation of interstitial lung disease multidisciplinary team meetings: a global study", *ERJ Open Res*, 5(2).

### ONLINE LINK

<https://openres.ersjournals.com/content/5/2/00209-2018>



## Quality standards in respiratory real-life effectiveness research: the REal Life Evidence Assessment Tool (RELEVANT): report from the Respiratory Effectiveness Group-European Academy of Allergy and Clinical Immunology Task Force

### REFERENCES

Roche N., Campbell J. D., Krishnan J. A., Brusselle G., Chisholm A., Bjermer L., Thomas M., Van Ganse E., Van den Berge M., Christoff G., Quint J., Papadopoulos N. G. and Price D. (2019) "Quality standards in respiratory real-life effectiveness research: the REal Life Evidence Assessment Tool (RELEVANT): report from the Respiratory Effectiveness Group-European Academy of Allergy and Clinical Immunology Task Force", *Clin Transl Allergy*, 9, pp. 20.

### ONLINE LINK

<https://ctajournal.biomedcentral.com/articles/10.1186/s13601-019-0255-x>

## The REal Life Evidence Assessment Tool (RELEVANT): development of a novel quality assurance asset to rate observational comparative effectiveness research studies

### REFERENCES

Campbell J. D., Perry R., Papadopoulos N. G., Krishnan J., Brusselle G., Chisholm A., Bjermer L., Thomas M., Van Ganse E., Van den Berge M., Quint J., Price D. and Roche N. (2019) "The REal Life Evidence Assessment Tool (RELEVANT): development of a novel quality assurance asset to rate observational comparative effectiveness research studies", *Clin Transl Allergy*, 9, pp. 21.

### ONLINE LINK

<https://ctajournal.biomedcentral.com/articles/10.1186/s13601-019-0256-9>





# REG DURING ERS 2019

The **Respiratory Effectiveness Group** will be attending the ERS 2019 Congress in Madrid, Spain and we are organising a number of meetings during the congress.

**The Working Group meetings will take place on Saturday 28th September and Sunday 29th September.**

The meetings will be held in the **NOVOTEL MADRID CAMPO DE LAS NACIONES, C/ Ámsterdam n°3 - 28042 Madrid, Spain.**

The hotel is located close to the ERS Congress venue and the **Metro stop** for the congress and the Novotel is "**Feria de Madrid**".

## SATURDAY, 28<sup>TH</sup> SEPTEMBER 2019

- 12:00-13:00 Cough Working Group
- 13:00-14:00 Adherence Working Group
- 14:00-15:00 Technologies Working Group
- 15:00-16:00 Database & Coding Working Group
- 17:00-18:00 Biomarkers & Severe asthma Working Group TBC
- 18:00-19:00 Child Health Working Group

## SUNDAY, 29<sup>TH</sup> SEPTEMBER 2019

- 12:00-13:00 ILD/IPF Working Group
- 13:00-14:00 COPD Working Group



Due to the limited availability of meeting rooms at this year's congress, time is limited for Working Group meetings. If you would like to request a meeting in reference to a specific project or Working Group that is not listed in the provisional timetable, or wish to organise a more informal meeting with other Collaborators or any member of the team, please contact [enquiries@regresearchnetwork.org](mailto:enquiries@regresearchnetwork.org) to schedule a time.



Respiratory  
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THE RESPIRATORY  
EFFECTIVENESS GROUP

**REG**

**SUMMIT 2020**

Capitalising on real-life research  
for best clinical guidance

**19-21**  
**March 2020**

**BARCELONA**  
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# REG

## SUMMIT 2019



MARCH 2019, ATHENS GREECE

# CAPITALISING ON REAL-LIFE RESEARCH FOR BEST CLINICAL GUIDANCE

This REG Summit was the most successful one ever with over 100 participants from 23 countries. Noted international speakers created seven plenaries, three pro-con debates and one panel discussion.

Successful meetings of 14 Working Groups were well attended with reviews of current outputs and wonderful ideas for new initiatives. We had twenty abstracts submitted/presented during our poster sessions.

The place of triple therapy in COPD was debated by Prof. Alberto Papi and Dr. Marc Miravittles. They came to the conclusion that ICS should be added to the COPD patient who needs it,







**28-30** ATHENS  
 March 2019 **GREECE**  
 DIVANI PALACE ACROPOLIS



a discussion that continues to this day! My personal take is ICS should be used for patients with COPD who have any hint of asthma, recurrent exacerbations, especially if the blood eosinophil count is > 300 and perhaps those who have required hospitalization for a COPD exacerbation. The role of immunotherapy in asthma was discussed by Prof. Moises Calderon, Prof. Frederic de Blay, Prof. Carmen Vidal, and our own Prof. Nikos Papadopoulos did a fascinating comparison of immunotherapy vs biologics!

Prof. David Price led a spirited discussion about the exciting future of the International Severe Asthma Registry.

Prof. Kevin Flaherty gave us insights on why an earlier diagnosis and thus earlier treatment of IPF could have improved outcomes in this devastating illness.

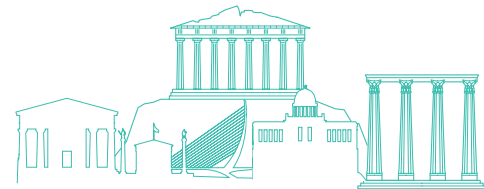
Prof. Ken Chapman and Prof. Mark Fitzgerald debated on the place of regular vs prn ICS in mild asthma, again agreeing that ICS is superior, but some ICS is better than none!

Controversies in pediatric asthma were reviewed. A debate re abandoning the term of 'preschool wheeze' by Prof. Adnan Custovic and Prof. Steve Turner was entertaining and thought provoking. Prof. Francine Ducharme gave an insightful talk on asthma severity measurements in children.

Prof. Jan Willem Kochs reviewed issues in inhaler technique and gave us tips on improving adherence in our patients.

I did a talk on vaccinating the patient with respiratory illness.





## CAPITALISING ON REAL-LIFE RESEARCH FOR BEST CLINICAL GUIDANCE

We had a tremendous panel reviewing all the treatments for severe asthma from non biologics to biologics including Anti IgE, anti IL5 and anti IL4-13 by Profs Mina Gaga, Peter Barnes, Liam Heaney, Andrew Menzies Gow and Walter Canonica. Prof. Papadopolous created the groundwork of a potential REG algorithm for choosing therapy in severe asthma.

Our conference ended with a key note talk by Prof. Jean Bousquet who described his real-life research with a new app called MASK which is gathering data from patients around the world under the ARIA (Allergic Rhinitis in asthma) banner. What a wonderful way to cap off a conference for Real-Life Research which is really the mantra of the Respiratory Effectiveness Group.

It is exciting to take the learnings from this summit and apply them to our upcoming conference in Barcelona in 2020. I look forward to seeing you there.



Alan Kaplan  
MD, CCFP(EM), FCFP  
REG Summit  
Programme  
Committee Chair



# WHAT REG MEANS TO ME

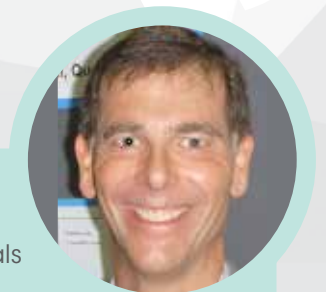
I am a paediatric clinical academic in respiratory medicine, with a special interest in asthma and allergic disease. Paediatric research is recognised to be challenging, with recruitment to trials often being difficult. It is not seen as a priority by funders or pharmaceutical companies. As a result, many clinical practices in children are based on the extrapolation of practice in adults, from evidence collected in adult studies. Pharmaceuticals in children are frequently used “off label”, with little or no evidence of their efficacy or even side effects in children. Such management and drug choices become embedded in clinical practice, thus making the possibility of clinical trials harder still.

Real-life research gives the paediatric community the opportunity to investigate these practices, in very large numbers of children, which would frequently not be possible by traditional randomised controlled trial (RCT) methods.

Over the last few years, the Respiratory Effectiveness Group (REG) has supported multiple paediatric research projects, by funding the acquisition of data from established clinical databases and providing expert statistical support for data analysis. This has enabled the publication of real world data that has in some instances led to new insights, and in others supported and enhanced data already published from small paediatric RCTs. However, there remain multitudes of paediatric questions that can be answered, at least in part, by real-life research. Over recent years REG has developed the expertise necessary to maximise the benefit from real world data. Their ongoing support of such studies is invaluable to the paediatric community.



**Dr Clare Murray**  
Consultant and Senior Lecturer in Paediatric  
Respiratory Medicine, University of Manchester, UK



While REG likely has differing meanings for its members, for me, it is a window into the future of respiratory medicine. REG’s composition of global KOLs interfacing with researchers and industry provides a unique critical mass of lung health professionals to address the lacunes in the current guideline for the delivery of respiratory care. The assembling of GOLD and GINA guideline authors, epidemiologists, physiologists, pharmacists, nurses, pediatricians, and respiratory and general practitioners along with global industry scientists from five continents allows for a clear definition of current and future needs for diagnosis and treatment both on a local and global scale. Collectively, REG members have a clear understanding of the limits of guideline application, current drug classes and delivery modes, and validated biomarkers. The result is a crucible of innovative ideas through **1)** the mining of the OPC Database to help fill in the generalizability gaps between RTC findings resulting from their defined homogeneous disease subjects, and real-world patients, **2)** discussions of how to optimize the delivery respiratory care with our current lung toolbox, and **3)** both the defining of needed technologies and the testing of emerging technologies to better refine and relate them to real-world practice needs. Through the passion of its members for improving respiratory health and their productivity in terms of publications and dissemination of ideas, and now squarely positioned at the crossroads of GINA, GOLD, ATS and ERS as a result of its members non-REG activities, REG is holding the compass as we move toward the future and address the unmet needs of respiratory health care.

**Ronald J. Dandurand, MD, FRCPC, FACP, FCCP**

Respirologist, CIUSSS de l’Ouest-de-l’Île-de-Montréal and Montreal Chest Institute, McGill University Health Centre Research Associate, Meakins-Christie Labs Oscillometry Unit and Centre for Innovative Medicine McGill University Health Centre Research Institute, Assistant Professor of Medicine, McGill University

## WHAT REG MEANS TO ME

Since I started being an active collaborator, back in May 2013, I already considered REG as a think tank of talented, influential respiratory experts aimed to introduce real-world evidence and metrics obtained from and interpreted for GPs, chest physicians, and anyone interested in respiratory conditions.

I think that the spirit of the original RAND corporation (Research And Development), created in 1948 by the Douglas Aircraft Company to offer research and analysis to the United States Armed Forces during the Cold War period, that was financed by the U.S. government and private endowments, corporations, universities and private individuals, also applies to REG. REG aims for interdisciplinary and quantitative problem-solving by translating theoretical concepts from high-level randomized controlled trials into novel observational designs in diverse populations.

We are poised to thinking outside the box, using administrative datasets, applying robust mathematical modelling and sophisticated statistical analysis. Science at REG is second to none.

As it is often the case, in REG the best

physician-scientists are approachable persons, humble and very down to earth, who find time to be efficient and effective in their research; they are star communicators, and funny!. Serious work is conducted in specific groups prior to the annual international conference, when then a lead summarizes progress and guides others to identify future avenues. Small group discussions, receiving opinions from different perspectives and backgrounds, and an agile agenda with plenty of time for brainstorming, rule in the annual meeting. I was privileged to participate in the organizing and scientific committees of Amsterdam 2018 and Athens 2019. Any interaction there with colleagues and friends such as Nikos, Alan, Sinthia, Marc, Omar, Chin Kook, Rupert, Job, Nicolas, and many others, plus the savoir faire of Michael Walker, is always enriching, both for the brains and for the soul. If only, I feel that more young blood should be invited to collaborate and actively participate, to ensure intergenerational progress. It is always a pleasure to collaborate within REG. Long live REG!

**Dr. Joan B Soriano, MD, PhD, FERS, FCCP**

Associate Professor of Medicine  
Hospital Universitario de la Princesa,  
Universidad Autónoma de Madrid, Spain



For me REG represents a community of researchers, health care professionals, patient representatives as well as representatives of respiratory societies and supporters all interested in and convinced of the importance of "Real World" Respiratory Research to improve the care of patients with (chronic) respiratory conditions.

REG offers the chance to meet and share ideas in an open way where research projects can be discussed with peers. REG not only offers the opportunity to meet with experts in the field of respiratory medicine but also facilitates fund raising, project management and publication of peer-reviewed manuscripts.

The small scope of the annual REG meetings - often at very nice locations - facilitates inter-active communication, camaraderie and sharing of research ideas. Each year, specific research themes are chosen ensuring that the majority of research conditions are at least once addressed.

Special interest groups under the form of Working Groups have been installed where people with similar research interests can meet, either via face-to-face sessions (REG annual meetings or at the yearly ERS conferences) or

via regular teleconferences. Me personally I joined the Database and Coding Working Group 5 years ago and I had the chance to work in close collaboration with Dr. Job van Boven from the University of Groningen on the "Towards Optimum Reporting of Pulmonary Effectiveness Databases and Outcomes" (TORPEDO) - study. By means of a Delphi exercise, this study had as its aim to develop a checklist with optimum and minimum required variables for respiratory research. Three Delphi survey rounds have now been completed and the manuscript is currently being drafted and will be presented at the upcoming ERS-REG meeting.

The growing need for international, high quality data sources enabling fast answers to important research questions underscores the importance of accurate coding and good quality data and makes me proud that I'm not only a member of REG but also of the REG - Database and Coding Working Group.

**Katia Verhamme**

Associate Professor of Use and analysis of observational data Department of Medical Informatics; Erasmus MC, Rotterdam, The Netherlands





# WORKING GROUP UPDATE

In March 2019, 11 of the REG Working Groups met at the REG summit in Athens to discuss ongoing projects and set future research priorities. The next Working Group meetings will be held at ERS 2019 in Madrid. So far in 2019, four REG publications have come out of the Working Groups, with more to follow later in the year.



# WORKING GROUP UPDATE



## ASTHMA-COPD OVERLAP WORKING GROUP

The Phase I ACO proof of concept study has been completed with the publication of a paper entitled 'Prevalence and Characteristics of Asthma-COPD Overlap in Routine Primary Care Practices' in the Annals of the American Thoracic Society. This study, led by Jerry Krishnan and Nicolas Roche, found that one in five individuals with a diagnosis of COPD, asthma, or both asthma and COPD in primary care settings have ACO based on the REG ACO Working Group criteria. The prevalence and characteristics of patients with ACO varies across the three source populations. The group is planning a phase II study to assess the implications of ACO; REG have determined that OPCRd contains sufficient numbers of patients meeting the required criteria for this study to be feasible and a proposal has been developed. Nicolas Roche and Chin Kook Rhee agreed to be principle investigators for this next phase.



## COPD WORKING GROUP

The data from the "Concept of control in COPD" prospective pragmatic trial is currently being analysed. At the REG summit 2019 Marc Miravittles presented initial results. A paper comparing the clinical characteristics between the Asian and Western patients in this study has been accepted for publication. With the network of sites that has been developed and the enthusiasm of the participating centres it has been decided by the Working Group to conduct another pragmatic trial. This next study will investigate the predictive value of peak inspiratory flow in COPD exacerbations; a proposal has been developed and funding is currently being sought.

The 'Real-Life WISDOM' project, led by Helgo Magnussen, has secured funding and a full protocol is currently being developed. This will be a database study to assess the implications of ICS reduction or withdrawal in the management of COPD.



## ALLERGY WORKING GROUP

The allergy Working Group, chaired by Moises Calderon, met at the REG summit to discuss the future direction of work within the group. While previous projects have focused on chronic rhinitis and rhinosinusitis, the group will now be focussing on allergy immunotherapy (AIT). Following the REG summit, the group also met at the European Academy of Allergy and Clinical Immunology (EACCI) congress in June 2019 where they further developed the idea of creating a registry of patients receiving AIT. The objectives, methodology and funding strategy for this ambitious project remain under discussion.



## CHILD HEALTH WORKING GROUP

The group met at the REG summit 2019 and discussed the ongoing project assessing the comparative effectiveness of the addition of antibiotics versus normal care in asthma exacerbations. Subsequently, data analysis has been completed and a final report produced.

The Paediatric Asthma in Real Life (PeARL) project, led by Nikos Papadopoulos, aims to produce evidence-based recommendations regarding controversial aspects of paediatric asthma using knowledge gaps surveys, systematic reviews, meta-analyses and Delphi exercises. The results of a survey sent to patient, clinician, researcher and industry groups have been analysed and are currently being written up for publication and four systematic reviews are currently being planned.



## QUALITY STANDARDS WORKING GROUP



The joint REG-Quality standards taskforce have created a tool to assess the quality of published real life evidence. The tool is now finalised and available on the REG website: <https://www.regresearchnetwork.org/relevant-tool-2/>. Two papers detailing the methodology behind the tool creation have been published in the Clinical and Translational Allergy journal. The group continue to discuss the ongoing dissemination and promotion of the tool.

## SMALL AIRWAYS WORKING GROUP



At the REG summit, the Working Group discussed current projects and the future direction of the group. Omar Usmani presented the proposed methodology for his "what is meant by dose" manuscript and received comments from the group. Ron Dandurand then presented his work to date on oscillometry. The future direction of this group remains under discussion.

## ADHERENCE WORKING GROUP



Sinthia Bosnic-Anticevich has kindly agreed to take on the role of Working Group chair. The Working Group held a meeting at the REG summit 2019 to discuss potential new project ideas. From the Working Group's ideas Sinthia and REG have begun developing a proposal for a scoping review that will assess how adherence is included in the current guidelines and how precision medicine can be used to monitor and manage adherence. This will lead into a research study using database records alongside a prospective study to assess the different methods of adherence monitoring and the responsiveness and utility of database measures in predicting non-adherence.

The manuscript for the 'bi-directional relationship of adherence and control in asthma control' study is currently undergoing revisions, and an abstract on these data will be presented by Marcia Vervloet the ESTACOMP meeting in Portugal.

## SEVERE ASTHMA AND BIOMARKERS WORKING GROUP



The 'Point-of-care biomarkers in asthma management: time to move forward' letter to the editor has been updated and submitted to Allergy. The letter highlights the importance of clinical biomarkers, including FeNO as a promising biomarker 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. This Working Group met at the REG summit and began discussing ideas for future projects.



# WORKING GROUP UPDATE



## DATABASE AND CODING WORKING GROUP

At the REG summit 2019 Katia Verhamme presented the results from the final phase of the Towards Optimum Reporting of Pulmonary Effectiveness Databases and Outcomes (TORPEDO) project. The final round of the Delphi exercise showed clear differences between the minimum required database variables expected by participants for COPD versus asthma studies and for retrospective versus prospective studies. The methodology has been checked before writing of a manuscript began. REG along with the Working Group members plan to collate a list of all the currently available databases, and will subsequently determine whether they contain these minimum variables. Katia has proposed that the Working Group should consider developing a project around the common data model.



## COST EFFECTIVENESS WORKING GROUP

This group met at the REG summit, where they discussed the production of a short Working Group summary including the skills of Working Group members and themes for collaboration. This could then be circulated to the other REG Working Groups and placed on the REG website. The rationale is that by highlighting the skills of this Working Group, the Working Group can build projects in collaboration with other Working Groups and add value to planned or existing projects.



## COUGH WORKING GROUP

This group did not meet at the REG summit, though work has continued to better characterise the presentation of cough in primary care. Analysis is underway for this project with results due to be presented at the next Working Group meeting at ERS 2019.



## ILD/IPF WORKING GROUP

The ILD/IPF Working Group met at the REG summit, 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 presented. The first phase of this project was published in European Respiratory Journal – Open Research in early 2019, and the second phase of this project is now seeking funding. The steering committee for this project met at the American Thoracic Society congress in May 2019 to discuss the methodology and technological requirements of the project.



## TECHNOLOGY WORKING GROUP

Ron Dandurand chaired the Working Group meeting at the REG summit and has since agreed to lead the Working Group. The group have several projects in development. A scoping review of smart inhalers is currently seeking funding, while a proposal for an opinion piece on the utility of oscillometry is also under review. Finally, the group have been discussing the possibility of examining how technology can be used to define and predict asthma exacerbations.





# INTERNATIONAL SEVERE ASTHMA REGISTRY **ISAR**

## ◆ ISAR So Far

The International Severe Asthma Registry concluded its second year of operation with the inclusion of patient-level data from an impressive 7,250 patients with severe asthma from 14 countries. 2019 has seen ISAR expand dramatically. We are now collaborating with 32 registries all over the world, and still going! (see figure)



### Legend:

(+) Collects standardised additional variables on top of the ISAR variables

(=) Collects ISAR variables

## ◆ Publication Updates

### Published:

The results of the Delphi procedure to define the ISAR core variable list has been published in JACI Pract. Find out how 27 international experts in the field of severe asthma rose to the challenge and reduced the initial set of 747 identified variables to just 95! Two further articles have been submitted to Chest. The first is the ISAR mission statement which highlights what ISAR brings to the severe asthma field (quite a lot!). The second article, provides the first description of an international managed severe asthma population and is a landmark publication for ISAR. Finally, look out for the ISAR protocol which will be submitted for publication shortly, as well as the article entitled 'severe asthma registries: a global comparison' which compares data fields captured by all the registries which contribute to ISAR.

## ◆ Ongoing Research Projects

During the closed session at REG, ISAR Steering Committee members (ISC) determined the 2019 Global Research Project and 4 prioritized research projects. A list of all core projects and prioritized research projects may be found at <http://isaregistries.org/isar-research-updates/>. The ISAR doors are open to new collaborators and partners using the 'join the registry' or 'register your interest' functions on the ISAR home page <http://isaregistries.org/>. Research ideas may be suggested by ISC members, country leads, and contributors and visitors to the ISAR webpage (which includes third party commercial and academic research organizations), by simply clicking the 'submit a proposal or research request' tab.

## ◆ ISAR at REG 2019

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.



The ISAR session, **Maximizing the first International Severe Asthma Registry**, was also held during REG 2019. Professor Chin Kook Rhee from South Korea presented the ISAR steering committee approved academic research project **Hidden Chronic Asthma in the COPD/ACO population** which he is leading.



Professor David Price along with Professor Walter Canonica presented the value of international severe asthma research and encouraged colleagues to join the open research projects of ISAR, highlighting the collaborative, academic orientation of ISAR.

But it's not all work! The OPC team enjoyed dinner with the ISAR Steering Committee members and research collaborators.



*ISC members from South Korea, Japan, Colombia, Kuwait and the OPC team during the ISAR dinner at REG summit 2019*



*ISAR researchers and/or collaborators from the UK, Denmark, Iceland and The Netherlands continued their lively discussions about severe asthma, and much more, well into the late night!*



## ◆ 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](http://www.isaregistries.org)

# 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 ERS Congress in Madrid.

You can always get in contact with the REG team by email at [enquiries@regresearchnetwork.org](mailto:enquiries@regresearchnetwork.org),

or write to Michael Walker, REG CEO at [michael@regresearchnetwork.org](mailto:michael@regresearchnetwork.org)

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