



Respiratory  
Effectiveness  
Group

REG  
SUMMIT  
2018  
REPORT



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# REG SUMMIT 2018 REPORT

This year's REG Summit (2018), titled "Working together to make an impact" lived up to expectations. Taking place in Amsterdam, The Netherlands and being attended by 73 delegates from 22 countries, the event brought together a group engaged researchers, students and industry collaborators who are working together and looking for opportunities to establish new collaborations.

The REG 2018 Summit covering the spectrum of "Working together" from research major global initiatives, research collaborations, engagement with industry and working with professional bodies. The programme included plenary talks, interactive panel sessions and abstract sessions; 30 abstracts were presented over 3 dedicated parallel sessions. Congratulations to the REG 2018 Summit Scientific Programme Committee; Professor George Christoff, Dr Dermot Ryan, Dr Joan B Soriano, Professor Steve Turner and Associate Professor Omar Usmani, for their work in pulling together such a stimulating programme.



## DAY 1

◆ The opening plenary, **“Global Projects Session: Lessons in Maximising Collaboration and Impact”** kick-started the theme of “working together” with updates and insights from several major global projects, in which REG collaborates. Building on the theme of ‘working together’ highlighted in the opening plenary, a further two plenary sessions on Using Real-Life Evidence to Change Guidelines and Children Are Not Small Adults...Or Are they?, as well as five sessions covering Global Collaborations, Severe Asthma, Digital Health: Will the Promise be Realised...or does it change anything bar price?, Patient Perspectives and Behaviours, Community Medicine were held on Day 1. A Key Note Presentation on How to Change Perceptions on Real-Life Research to Impact Guidelines concluded the scientific program on Day 1.

◆ The opening plenary on **Global Projects Session: Lessons in Maximising Collaboration and Impact** included presentations relating to the COPD Control Project, The Interstitial Lung Disease Multidisciplinary Team (ILD MDT), the International Severe Asthma Registry (ISAR) and the European Association of Allergy and Clinical Immunology Allergy Immunotherapy Treatment (EAACI AIT) project. Professor Marc Miravittles (University Hospital Vall d’Hebron, Barcelona, Spain) presented on the COPD Control project which is currently being run in 7 countries, with 11 collaborators and aims to validate the concept of COPD control in clinical

practice. Currently the project is in the recruitment phase with 339 participants recruited and data collection expected to be completed by October 2018. This project will have significant impact on clinical decision making regarding an increase or decrease in medication to maintain COPD control. Ms. Naomi Launder (REG Senior Researcher), presented an update of the ILD MDT project on behalf of the project lead, Professor Luca Richeldi. The principal aim of the ILD MDT project is to generate knowledge of the ILD diagnostic process globally. The project is funded by grants received from the Three Lakes Foundation, Boehringer Ingelheim and Roche and has completed the first phase. Collaborators from 457 centres have been recruited from across North and South America, Europe, Africa, Asia-Pacific and the Middle East. A pragmatic approach to questionnaire dissemination was used, relying on the dedicated support from national pulmonary societies and individual investigators disseminating the questionnaire through their professional networks. Over the next few months, the results from phase I will be submitted for publication and the protocol for phase II will be finalised. Phase II is expected to begin in early 2019. An update on ISAR was presented by Ms. Victoria Carter (Research and Director at Observational and Pragmatic Research Institute). This presentation highlighted the challenges and opportunities associated with bringing

together collaborators from the UK, USA, Italy, Australia and South Korea to establish the first global severe asthma network. A full update on ISAR is presented in this issue of the REG Newsletter. Professor Antonella Muraro (past president of EAACI, currently University of Padua, Italy) presented an update on the EAACI AIT project. The aim of this project is to develop guidelines and involves a collaboration between many collaborators from across Europe. Good progress has been made which would not have been possible without the significant contribution of collaborators. Professor Muraro highlighted the significant benefit of collaboration and the way in which this can increase the impact of the project.

◆ The **Global Collaborations** session and commenced with a presentation from Dr. Manon Belhassen on therapeutic ratios that predict asthma control. The key finding being that low ICS therapeutic ratios reflected insufficient prescribing of ICS relative to all asthma therapy, which in turn lead to a deterioration of asthma control. A presentation on the latest Astrolab data by Professor Eric Van Ganse followed. Professor Van Ganse reported on the amount of consistency of medical care and self-management support in asthma and the finding that the amount and consistency of asthma primary care can be enhanced through involving practice nurses, making social expectations visible, and



# DAY 1



providing more training to enhance skills and confidence in asthma care delivery. Ms Naomi Laudners presented the latest findings from the global evaluation of Interstitial Lung Disease Diagnostic (ILD) Practice, Agreement and Accuracy project. This project aimed to describe ILD diagnostic practice globally. Responses from 457 centres across 64 countries were included in the analysis and results determined that ILD diagnostic practices of responding centres are broadly similar, with multidisciplinary team meetings widely implemented. However, dedicated ILD centres in academic institutions in well-resourced settings hold more formal diagnostic meetings and have better access to anti-fibrotics. A minimum standard MDT is hard to define and may depend on resources availability and the number of cases seen.

for questionnaire construction, the SAQ has better content validity compared with existing questionnaires and meets the criteria for construct and other validity. The SAQ maps onto the health economic measure, EQ-5D, and may have greater sensitivity to differences in oral corticosteroid dose compared to the Mini Asthma Quality of Life Questionnaire. Additionally, the key message for the development of the SAQ was that patient input and documentation of that input is key to achieving content validity according to FDA guidelines. Assistant Professor Enrico Heffler presented on the first results of the Severe Asthma Network in Italy (SANI); and followed this up with a presentation on Pharmacoeconomic evaluation of oral corticosteroid adverse events in patients with severe asthma. His work concluded that the use of oral corticosteroids in severe asthmatics has a high impact, both in terms of frequency than under a pharmacoeconomic point of view of its adverse effects. Therefore, one of the most

relevant unmet need in severe asthma is the reduction (possibly with novel biologic agents) of regular use of oral corticosteroids. In addition, Real life data from the SANI registry show in the severe asthmatics population there is a high prevalence of relevant comorbidities. Ms. Lakmini Bulathsinhala then presented the demographic and clinical characteristics of patients with severe asthma worldwide, from the ISAR. She reported that the demographic and clinical characteristics of patients with severe asthma from five geographically diverse countries support previously reported characteristics of severe asthma patients and that to decipher informative trends in asthma phenotypes and clinical management, country-specific distributions should be compared next.

◆ In the **Severe Asthma** session, Professor Rupert Jones presented on the development and validation of the Severe Asthma Questionnaire (SAQ). In the first instance, it was found that in terms of the FDA guidelines

◆ The third plenary of the day was entitled **"Digital health: Will the promise be realised?"** Talks by Professor Hilary Pinnock, Dr. Mike Baldwin, Professor Thyss van der Molen and Professor Richard Costello explored the themes of the use of technology to improve

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patient engagement and adherence, and the changing face of the patient-physician interaction. These presentations, and the discussion that followed, detailed the opportunities for improvements in patient-centred care while cautioning that health care systems need to change to incorporate these technologies and that digital health alone is not a panacea.

◆ A topical session, that explored a very relevant topic and close to many attendee's hearts was the plenary **Using Real-Life Evidence to Change Guidelines**. The series of presentations highlighted the value of real-life data and its impact through a number of examples. Professor Barbara Yawn presented "Oral and Inhaled Steroids: Friend or Foe?" and showed the risk/benefit of OCS needs to be weighed for each individual patient. The case was presented for revision of guidelines for the management of COPD so that it recommends a preference for LABA + LAMA before adding ICS so to reduce exacerbation risk without introducing the risks of ICS. Professor Rupert Jones presented on the Missed Opportunities for Diagnosis in COPD and the research initiative to explore this. This REG-funded project found that while early diagnosis of COPD is slowly improving, in the 2 years before diagnosis, there are opportunities to diagnose COPD that are missed. Lastly, Professor George Christoff presented on an Alternative View of Current Asthma Guidelines. He gave an overview of the need for guidelines and the

role they play in assisting the clinician and then compared the production method, content, evidence source, grading of quality of evidence and strength of recommendations across international asthma guidelines from GINA and NAEPP and country specific guidelines from Australia, Canada and the UK. Finally he gave an overview of recent literature concerning the use of and adherence to asthma guidelines.

◆ **"Patient Perspectives and Behaviours"** included a series of presentations identifying patient perspective and behaviours across the spectrum of conditions and patient populations including asthma, allergic rhinitis, adults and children. Professor Sinthia Bosnic-Anticevich from Australia presented research from a project looking at understanding the reasons behind patient self-selection of medications for allergic rhinitis (AR) in the community pharmacy, noting that a vast majority of patients self-select their treatment even when their symptoms are moderate to severe. It is only those patients who report an impact of their AR on their day to day living, who are more likely to consult a pharmacist i.e. the high incidence of self-selection of OTC treatments for allergic rhinitis symptoms in community pharmacy does not reflect the severity of the condition experienced by patients. A key message is that pharmacists are ideally placed to educate and counsel patients in this regard. Sinthia also presented work on Parent's Perspectives

on medication management for their children with asthma: understanding the influences on parents and a social network analysis. The group found that parents have developed their own health networks to aid them in the management of their children's asthma medications, often consisting of multiple individuals and resources apart from the traditional health care professionals. This research highlights the need to consider parent's health contacts and how they may drive and influence children's asthma outcomes and the importance of further exploring why parents' needs are not being met by health care professionals. Dr. Boudewijn Dierick presented on work absence in patients with asthma and/or COPD concluding that patients with asthma and/or COPD have a significantly higher work absence compared to the general population, more frequently in asthma and of longer duration in COPD patients and that age, anxiety and allergy could partially be driving some of these effects. Dr. Alan Kaplan from Canada presented patient perspectives on asthma medication and found that while asthma is an inflammatory disease requiring regular anti-inflammatory treatment, patients have fears about using inhaled corticosteroids.

◆ The **Community Medicine** session covered a broad range of important topics from the effects of comorbidities on the asthma to the frequency with which patients claim prescribed therapies. These series of

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presentations highlight some of the key challenges in the real-life respiratory medicine whether it be related to the translation of guidelines, the lack of evidence for real-life practices or the translation of medication prescribing to medication dispensing. In particular Ms. Naomi Launder reporting on findings from a study exploring the management of Community Acquired Pneumonia (CAP) in Primary Care in the UK. The authors reported that despite CRB65 scores (a composite score based on: confusion, raised respiratory rate, low blood pressure, age 65 or more) being incorporated into NICE guidelines in 2014, they are not well recorded for patients managed in primary care. The components of CRB65 are also poorly recorded, which raises the question of whether the NICE guidelines are being implemented in practice? Dr. Ron Dandurand presented on research associated with the characterisation of COPD by blood eosinophil counts (ECs) in community practice. The authors aimed to determine the prevalence of elevated ECs amongst COPD patients in the community and explore what subject parameters, if any, might be associated with a responsive COPD phenotype. DLco was the only subject parameter associated with elevated EC. Larger studies in independent populations are required to determine whether this was a chance finding due to the number of parameters surveyed, or whether the findings are indicative of a relative preservation of

the DLco suggesting a more asthma-like phenotype of COPD. Professor Nikos Papadopoulos presented results relating to the effectiveness of the addition of antibiotics to usual care in the management of asthma exacerbations. The message from this work was that the addition of antibiotics to oral steroids in the management of asthma exacerbations does have a small effect on reducing subsequent asthma/wheeze consultations, in adults, but more work is required to draw firm conclusions from this data. Lastly, Dr. Manon Belhassen presented novel findings from France on How often do asthma patients claim prescribed therapy? They concluded that in primary care, in their population, 73% of asthma patients claimed the completeness of their prescriptions in community pharmacy and showed the variability of prescribing vs. dispensing of asthma medicines.

The penultimate session for the day was entitled **Children Are Not Small Adults...Or Are They?** Lessons From Real-Life Data. In this session, Dr. Clare Murray presented data on the pre-school aged patient group and found that wheeze/asthma is commoner in pre-schoolers than older children and adults, pre-school wheeze does not predict asthma in adulthood, viruses are common in preschool acute episodes, less preventer medication is used and that exacerbations and hospital admissions are commoner, but mortality is lower. Dr. Mohsen Sadatsafavi presented the research of his team looking at asthma outcomes in children

across a number of Canadian provinces. They found that asthma control achieved in the 24 months following diagnosis, that the major determinant of remission was the worst the control, the lowest the likelihood of remission and that this was irrespective of perinatal factors, demographics, and disease characteristics.

The final session of the day was a key note presentation by Associate Professor Álvaro A. Cruz from the Federal University of Bahia, Brazil entitled **How to Change Perceptions on Real-Life Research to Impact Guidelines.** In an insightful presentation, topics explored included what are relevant guidelines' (e.g. GOLD, GINA) literature search strategies, how good is journal acceptance of real-life research papers, where real-life research evidence adds most value, and shared the work done in Brazil using database research. His final observations how to change perceptions on Real-Life Research to impact guidelines included: Real-life research is still underrecognized in guidelines, high-impact journals are opened to real-life research papers, real-life research is of unique value in accessing effectiveness and safety of large-scale interventions in public health and lastly the suggestion for real-life research to be better recognized by guidelines: propose it formally and send suggestions annually to GINA, GOLD, WHO, ATS, ERS.

*Day 1 concluded with drinks and the summit dinner, spent in the company of friends and collaborators.*



## DAY 2

Day 2 of the REG 2018 Summit further built on the theme of 'working together', commencing with an engaging plenary exploring the Means and Mechanisms for International Collaboration with professional bodies, following by sessions on Quality and Impact, Technologies and a final plenary on 7 Ages of Cough.

◆ In Day 2 opening plenary, **Means and Mechanisms for International Collaboration**, Professor Jerry Krishnan presented with regards to engagement with the ATS, Professor Nikos Papadopoulos with regards to EAACI and Professor Nicolas Roche with regards to the ERS. Professor Chin Kook Rhee presented on improving engagement with Asia. Work across geographical regions as well as working with important regional medical associations was recognised as the only way forward to help raise the understanding and value of real-life research in contributing to the improvement of patient care and outcomes. In doing so, engagement at

multiple levels is discussed from research initiatives to Task Force engagement, through SIGs and leadership roles.

◆ The **"Quality and Impact"** session covered a range of topics, including the observational of global study NOVELTY, presented by Dr. Maria Gerhardsson de Verdier from Astra Zeneca. The NOVELTY study, a 3-year long observational longitudinal study aims to describe the patient characteristics, treatment patterns and the burden of illness over time of people with a diagnosis of asthma and/or COPD in order to identify phenotypes and endotypes associated with differential outcomes. It is anticipated that

the findings of this study may support future development of personalised treatment strategies. With data collection from over 12,000 patients, 19 countries (except China) completed, baseline data is anticipated Q3 2018. Professor Rupert Jones presented on Database Studies in Uganda which brought into focus the plight of chronic respiratory diseases in Africa. To begin to address chronic lung disease in Africa (which have risen by 35% in the last 10 years) a review was made of existing datasets generated from cross-sectional surveys, longitudinal cohorts and other trials. It was found that many existing datasets with high quality data in Uganda have the



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potential to address the current respiratory disease burden and can be utilised for a relatively small investment to generate and optimise longitudinal datasets. Dr. Manon Belhassen presented the results of a claims data study looking at changes in asthma drug use in France between 2006 and 2016. The key observations were that the prevalence of asthma controller therapy use remained stable between 2006 and 2016 but fixed dose combination products tended to replace other asthma medications and that the use of oral corticosteroids increased during the period. Professor Nicolas Roche's presentation focused on the RELEVANT tool, the first quality checklist to assist in the appraisal of published observational comparative effectiveness research (CER) and the opportunities to implement the tool into research practice including collaborations with scientific societies, guidelines developers and other stakeholders. Dr. Alex Mathioudakis presented an assessment of the real life challenges of conducting clinical research in populations of paediatric patients with asthma. The key message was that there is a need for an international paediatric asthma network aiming to promote high-quality clinical research, the development of an international paediatric asthma registry and evidence-based recommendations. Finally, Ms. Lakmini Bulathsinhala presented a comparison of severe asthma databases globally and showed that severe asthma databases across the globe converge

on collecting similar data field categories, while they differ significantly on the specific data fields included. A standard list of variables captured across countries will increase the statistical power of future studies by allowing for data interoperability.

The penultimate session **"Technology"** also included late breaking abstracts. Ms. Naomi Launder presented on the "Assessing the availability, functionality, utility and acceptance of smart inhalers" project in which a review of the current availability, functionality, utility and acceptability of smart inhalers is being used to inform further research into the use of technologies to predict and detect exacerbations and to optimise patient adherence. This research, run internally by REG, is currently in progress. Dr. Alan Kaplan, presented on "A desktop helper for asthma management". This research highlights that a 'desktop helper' can guide clinicians to support a decrease in inhaler corticosteroid overuse in COPD in clinical daily practice. Dr. Ron Dandurand presented research on the topic question relating to the relative importance of spirometry and oscillometry in the management of respiratory disease. The findings indicate that while both spirometry and oscillometry demonstrate significant differences between subjects with and without a history of respiratory disease, oscillometry correlated more strongly with patient reported outcomes than spirometry. A disease defining threshold of 10-

20 cmH<sub>2</sub>O/L I oscillometry was confirmed. Dr. Mihaela Stefan presented on smoking cessation therapies in hospitalised surgical patients with COPD and found that despite strong evidence that smoking is associated with surgical complications and the potential benefit to initiating therapy during hospitalization, smoking cessation pharmacotherapy is rarely used in the postoperative period in patients with active smoking and with a COPD diagnosis. Dr. Alex Dima's research explored the bi-directional relationship between ICS adherence and asthma control, indicating that adherence evaluated by the interval between the issuing of prescriptions had a small positive association with asthma control, while overusing SABA, being prescribed antibiotics and asthma-related outpatient visits were negatively associated with adherence in the same interval. These results suggest that patients adapt their use of medication, despite the practices of health care providers which may be consistent with guidelines.

The final session of the scientific programme reviewed the 7 Ages of Cough, from birth and neonates all the way through to the elderly and the end of life. The session was an extensive review cough through the patient lifespan. It highlighted some of the challenges of identifying the causes of cough throughout early life, spanning all the way through to the end of life. This series of presentations delivered by Professor Nikolas Papadopoulos, Dr Lorcan



## DAY 2

McGarvey, Professor Leif Bjerner, Dr Omar Usmani, Professor Jacky Smith and Professor Chin Kook Rhee highlighted the complexity of this common yet highly variable symptom associated with a range of respiratory and non-respiratory causes.

### Moving forward

The output of the REG Summit 2018 will be published in the Respiratory Research journal in the coming months. On behalf of the organisers and the REG Team all participants and contributors are warmly thanked for their involvement in the 2018 Summit and to their unending efforts towards real-life research and its value for clinical practice.

Rest assured, planning for the Summit in 2019 has already begun and more details will be shared over the coming months. It is confirmed, so please mark the date in your calendar, the REG Summit 2019 will be held from 28 – 30 March 2019.

*We look forward to seeing you there.*



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TOURS & TRAVEL S.A.  
1, Kolofontos & Evridikis str.  
16121 Athens, Greece  
t 210 7414700, f 210 7257532  
w [www.erasmus.gr](http://www.erasmus.gr)