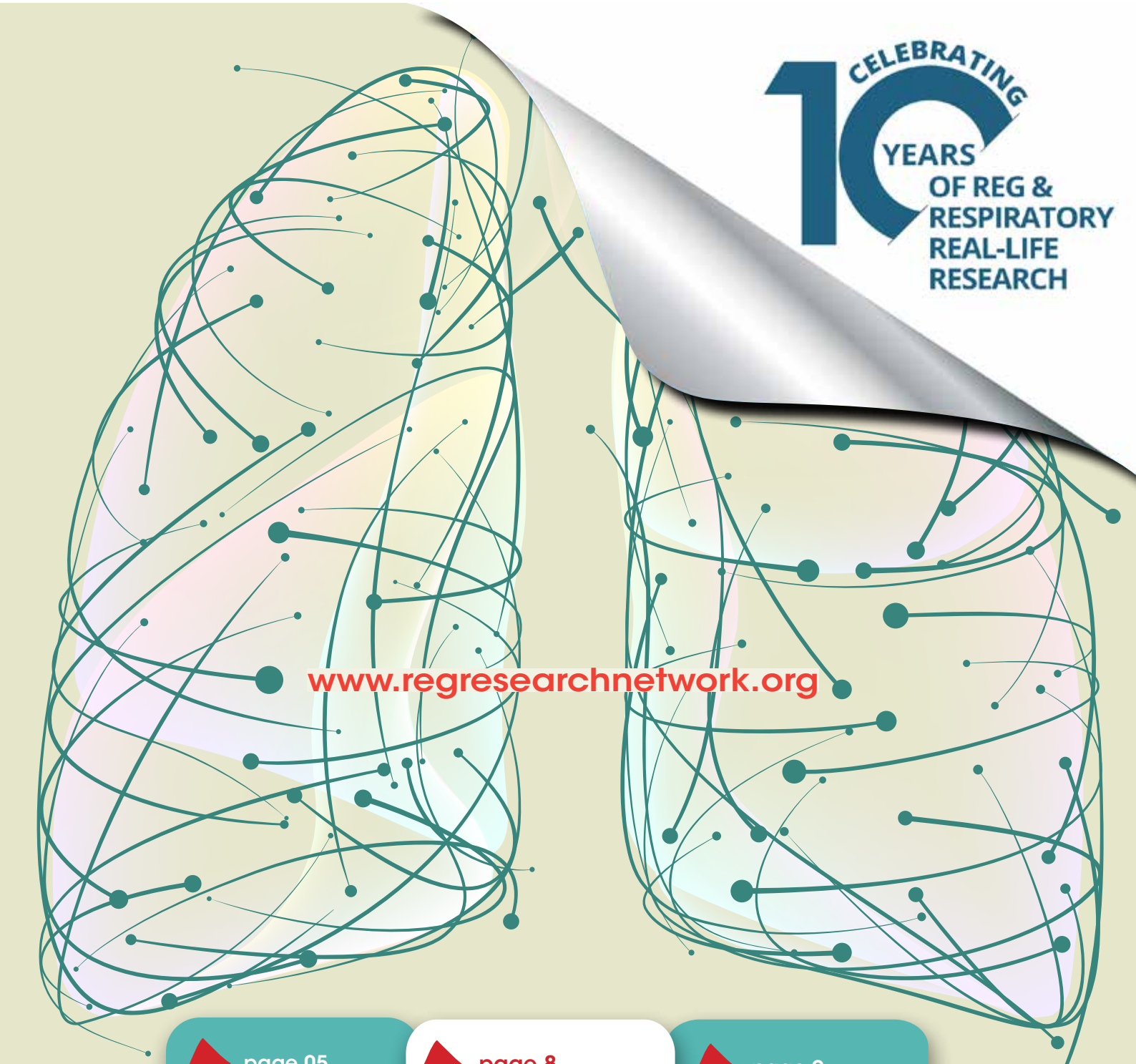
REG

Respiratory Effectiveness Group

ADVANCES

in Real-life Respiratory Research

The Respiratory Effectiveness Group Newsletter
ISSUE FEBRUARY 2024



CELEBRATING 10 YEARS OF REG & RESPIRATORY REAL-LIFE RESEARCH

www.regresearchnetwork.org

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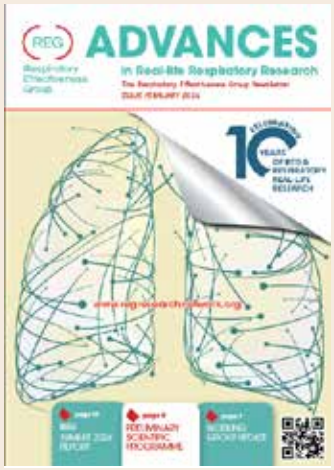

THE RESPIRATORY EFFECTIVENESS GROUP NEWSLETTER
ISSUE FEBRUARY 2024

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REG President

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Respiratory Effectiveness Group

enquiries@regreseachnetwork.org
@RespirEffect
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EDITORIAL

Giorgio Walter Canonica
REG President

DEAR COLLEAGUES,

As I reflect on my tenure as President of REG, I am grateful for the experiences, challenges, and support that have defined the past two years. Working alongside the dedicated REG Board and Oversight Committee has been a privilege, and their commitment to advancing real-life research for individuals with respiratory conditions has been crucial to our shared successes.

The journey, despite its challenges, has been characterized by resilience and an unwavering commitment to our mission. Virtual meetings, navigating time zone nuances, and addressing global challenges compelled us to adapt, fostering a stronger and more connected REG community in the process.

I extend my sincere appreciation to Michael Walker, our dedicated REG CEO, and his exceptional team, Dr. Graham Lough and Dr. Valeria Perugini. Their tireless efforts and pragmatic approach have played a pivotal role in steering REG towards its goals.

As I transition from the presidency, I take pride in the successful collaborations that have shaped REG's narrative. Our partnership with EAACI, notably, stands out as a significant achievement. Together, we facilitated a ground-breaking collaboration to integrate real-world evidence (RWE) into guidelines. This initiative brought together regulatory authorities such as FDA, EMA, and NICE, leading respiratory academic organizations from Europe and the USA, representatives from GINA and GOLD, patient organizations, and world-renowned methodologists. It is a testament to the global impact and influence REG wields in shaping the future of respiratory research and care.

Looking ahead, I am confident that REG, under the capable leadership of Marc Miravitlles will continue to flourish. I wish him every success in his endeavours and offer my continued support.

To each member and collaborator, your contributions and commitment have been vital to REG. Engage with our working groups, participate in leadership projects, and collectively advancing the cause of respiratory research.

As we move forward, I express my sincere gratitude, and I anticipate REG's ongoing success.

Warm regards,

Giorgio Walter Canonica
Professor Respiratory Medicine - Humanitas University
Head Personalized Medicine Asthma & Allergy Clinic - Humanitas Clinical & Research Hospital-IRCCS
Milano-Italy

REG TEAM UPDATE

Michael Walker
REG CEO

2023 was another busy year for the REG team with our projects progressing well. The PIF in COPD project successfully wrapped up recruitment and the Virtual ILD MDT survey has been submitted for publication. New ideas have been discussed and developed, and we're looking forward to rolling them out this year. We will continue to further expand our network of collaborators as we grow our research ideas and areas, as well as establish new collaborations with our partners.

In the past few months, our focus has been on preparing for the REG Summit 2024 in Vienna, scheduled for March 14th – 16th. The programme and speakers have now all been finalised. This year, in celebration of REG's 10-year anniversary, we're going back to a brainstorming format for research ideas, reminiscent of our early years. This session will cover various diseases across the working group spectrum and is set for Thursday, March 14th. We encourage all collaborators and supporters to join us at the Summit and participate in the exciting open research brainstorming.

In this issue, you will find an update on the projects as well as the tremendous work of the International Severe Asthma Registry (ISAR) and the next installment of Clinical Management Perspectives looking at the monitoring of asthma in paediatric patients.

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

I look forward to meeting our many collaborators and supporters at the REG Summit 2024 in Vienna.

Respiratory Effectiveness Group

www.regsummit2024.org

THE RESPIRATORY EFFECTIVENESS GROUP

REG SUMMIT 2024

14-16 March

REG SUMMIT 2024

REG looks forward to the forthcoming REG Summit in Vienna. This gathering 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 real-life respiratory research.

The REG Summit is a well-known meeting of global respiratory key opinion leaders engaged in real-life research and generation of Real World Evidence. REG collaborators (researchers, clinicians, general practitioners and allied health professionals) have conducted numerous database and prospective pragmatic trials and continue to seek solutions to the many complex issues faced by respiratory patients.

The REG Summit 2024 marks an important milestone for the organisation as it celebrates its 10-year anniversary. Commencing on Thursday, 14th March, this year's summit takes us back to our roots with a return to a brainstorming format for research ideas, reminiscent of our early years. This session will explore various diseases across the working group spectrum. We encourage all collaborators and supporters to join us at the Summit and actively participate in the exciting open research brainstorming. For those unable to attend in person, online participation options will be available. The scientific programme follows all day on Friday 15th and concludes at 13:00 on Saturday 16th March.

The scientific programme will include robust and informative discussions and debates on the latest insights on treatment strategies. Our focus is on identifying the essential needs to propel the field forward and achieve a deeper understanding of how to enhance patient outcomes. Participants will debate the hottest topics within the field, in a variety of interactive and informative sessions designed to foster collaboration and facilitate knowledge exchange.

A distinguished line-up of experts will speak about new perspectives and address challenges in the management of COPD, the role of vaccines in respiratory patient care, severe asthma, chronic cough, rhinitis management, IPF management, and mild to moderate asthma.

The meeting has been endorsed by the Austrian Society of Pneumology and is accredited for CME points. This meeting presents an excellent opportunity for in-person networking with some of the world's foremost experts in the respiratory field, fostering connections with friends and colleagues.

The REG Summit 2024 will be the years' most important meeting in the field of respiratory real-life research, and everyone is encouraged to participate and get involved with the REG and its exciting projects.

We look forward to seeing you in Vienna!

REG SUMMIT 2024
PRELIMINARY SCIENTIFIC PROGRAMME
14-16 March 2024

THURSDAY 14TH MARCH

CET/Time	
12:00-18:30	**REG Working Group Research Ideas Brainstorming**
12:00-13:00	***LUNCH BREAK***
13:00-14:30	**Discussion**
14:30-15:00	***COFFEE BREAK***
15:00-17:00	**Discussion**

FRIDAY 15TH MARCH

CET/Time	
08:50-09:00	**Welcome** G. Walter Canonica, (Italy)
09:00-09:55	**VACCINES SESSION** **Chair: Dermot Ryan, UK** **- Epidemiologic perspective of vaccination in respiratory diseases,** Joan Soriano, Spain **- Vaccinations & the respiratory patient - Recommendations vs real-world use,** Tobias Welte, Germany
09:55-10:30	**ILD/IPF SESSION** **Chair: Pilar Rivera-Ortega, UK** **- Update on emerging drugs for the treatment of idiopathic pulmonary fibrosis: A look towards 2023 and beyond,** Luca Richeldi, UK **- Q&A**
10:30-11:00	***COFFEE BREAK***
11:00-12:30	**ASTHMA SESSION** **Chair: Arnaud Bourdin, France** **- Mild asthma, an update on anti-inflammatory reliever,** Alberto Papi, Italy **- When to institute triple therapy - Should all patients go through triple therapy and azithromycin before biologics?,** Michael Wechsler, USA
12:30-13:30	***LUNCH BREAK***
13:30-14:30	**COPD SESSION** **Chair: Therese Lapperre, Belgium** **- New definitions of exacerbation of COPD: Are they ready for clinical practice?** Marc Miravitlles, Spain **- What's next after triple therapy in COPD?,** David Halpin, UK **- Q&A**

FRIDAY 15TH MARCH

CET/Time	
14:30-15:15	**RHINITIS SESSION** **Chair: Ignacio Ansotegui, Spain** - **Novel therapies in rhinitis,** Ignacio Ansotegui, Spain - **Rhinitis & asthma - what does the RWE tell us?,** Philippe Gevaert, Belgium - **AIT & Biologics: a new opportunity of combination Treatment,** G. Walter Canonica, Italy - **Q&A**
15:15-15:45	***COFFEE BREAK***
15:45-16:30	**IN THE RESPIRATORY HOT SEAT:** **PRO/CON** **Chair: Celeste Porsbjerg, Denmark** - **Remission in severe asthma is attainable in most patients** **PRO:** Michael Wechsler, USA / **CON:** Alan Kaplan, Canada
16:30-17:15	**PRO/CON** **Chair: Job van Boven, Netherlands** - **DPIs are the devices of choice in COPD or asthma** **PRO:** Federico Lavorini, Italy / **CON:** Jane Scullion, UK

SATURDAY 16TH MARCH

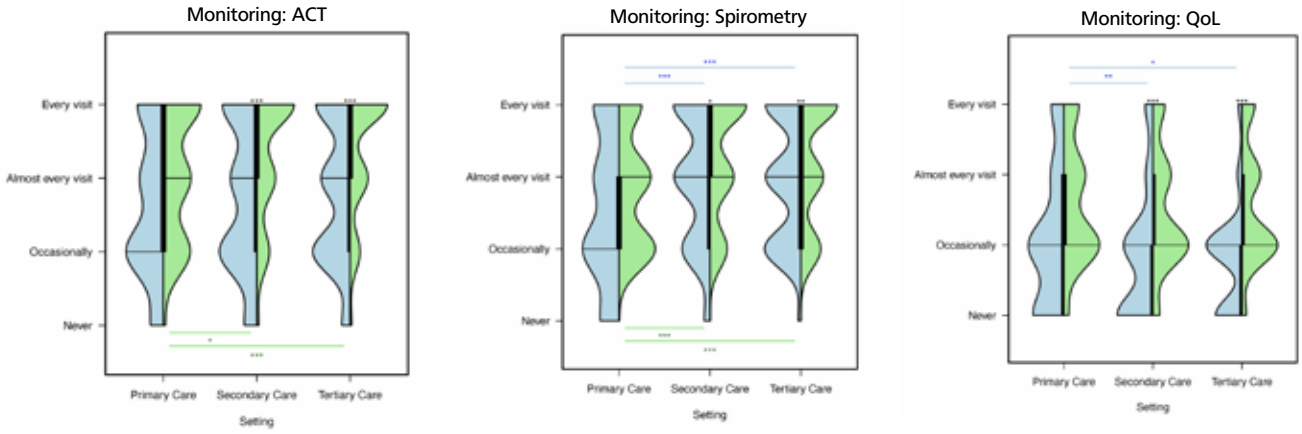
CET/Time	
09:00-09:45	**COUGH SESSION** **Chair: Alan Kaplan, Canada** - **Specific cough-targeting drugs: past, present, and future,** Surinder S Birring, UK
09:45-10:30	**MILD – MODERATE DISEASE MANAGEMENT SESSION** **Chair: Nikos Papadopoulos, Greece** - **Identifying which patients progress to severe asthma - new evidence from MANI registry,** Fulvio Braido, Italy - **Disease-modifying drugs in asthma,** Christian Virchow, Germany
10:30-11:00	***COFFEE BREAK***
11:00-12:15	**IMPROVING THE PATIENT JOURNEY IN SEVERE ASTHMA-LESSONS FROM ISAR AND FUTURE RESEARCH** **Chair: TBA by ISAR** - **Why is quality improvement needed (patient and specialist perspectives),** TBA by ISAR - **What has ISAR achieved to date in improving severe asthma care globally (standardized data collection),** Chin Kook Rhee, South Korea - **What remains to be achieved by ISAR (practice change goals based on prior research),** Celine Bergeron, Canada - **What are the future research needs for ISAR as a network?,** Matthew Peters, Australia
12:15-13:00	**KEYNOTE:** **Chair: Sinthia Bosnic - Anticevich, Australia** - **What Registries have taught us in the last decade?** **Panel:** David Price, UK / Nicolas Roche, France Fulvio Braido, Italy / Chin Kook Rhee, South Korea
13:00	**MEETING CLOSE**

CLINICAL MANAGEMENT PERSPECTIVE MONITORING ASTHMA IN CHILDREN

Nikos Papadopoulos
Professor of Allergy and Pediatric Allergy
at the University of Athens (NKUA)
Head, Pediatric Allergy Department
University of Athens
Athens, Greece

Most of the efforts on asthma management go towards drugs or biologics. This is not surprising, considering that hope and resources go side by side with pharmaceutical innovation. Nevertheless, all available data point towards major lost opportunities and treatment potential, independent of new molecules, through the proper use of our existing armamentarium, including correct use of medications and environmental measures.

To achieve the full potential of available treatment options in asthma, regular and consistent follow-up of patients is needed. No one would argue against the importance of asthma monitoring, however, its rules and priorities have not been, until recently, clearly delineated. How much time would one need to fully evaluate asthma? How often should patients be evaluated and what are the options for continuous monitoring between medical visits? Clearly, these considerations are highly dependent upon the healthcare system at each country, or even region. But it's important to know best practices and what others are doing. These considerations have been addressed in regard to paediatric asthma, by the PeARL think tank, initiated by REG and endorsed by several international organisations. The PeARL recommendations (in press) are based on Evidence appraisal and a Delphi Consensus, but, most importantly, considered the findings of a large survey that explored the actual monitoring practices around the world, in comparison to the perceived ideal situation [1]. The results were reassuring: only a very small proportion of treating physicians did not use basic tools, such as asthma control tests (Fig 1a) or spirometry (Fig 1b) and almost all recognized a need for improvement. There were also some surprises, such as the higher level of attention towards Quality of Life at the Primary Care level (Fig 1c). Both the information provided by the PeARL Survey and the subsequent recommendations can become crucial tools for improving the standard of paediatric asthma treatment worldwide.



Distribution of actual (left side in blue) and perceived ideal (right side in green) frequency of use of a) Asthma Control Test (ACT) b) Spirometry and c) Quality of Life (QoL) questionnaires, In Primary, Secondary and Tertiary Care settings

1. ***Papadopoulos*** et al. *JAMA Netw Open.* 2023;6(5): e2313120

WORKING GROUP UPDATE

ADHERENCE WORKING GROUP

The scoping project comprises two manuscripts, with the first nearing completion and the second in preparation. In the initial phase, the group explores existing knowledge and identifies areas for further exploration, while in the second phase, they will evaluate respiratory guideline adherence strategies and provide recommendations for enhancements. Manuscripts are currently being worked on and should be submitted in the coming months.

ALLERGY WORKING GROUP

The group has developed a proposal for a new prospective study on secondary prevention in moderate allergic asthma with AIT, which aims to identify and standardise priority clinical outcomes within the first year of AIT in allergic asthma patients and assess the real-world effectiveness of AIT in different regions. The proposal is currently under evaluation by potential funding partners. A manuscript is in preparation for a study on the impact of allergic rhinitis on health-related quality of life in Australia.

CHILD HEALTH WORKING GROUP

The group generated significant data last year, resulting in the publication of systematic reviews across various scientific journals as part of the Paediatric Asthma in Real Life (PeARL) project. This project is designed to identify and address critical clinical questions and policy needs in paediatric asthma, leading to the development of evidence-based recommendations. Currently, the group is collecting new data, focusing on biomarkers and treatments, with plans for imminent publication.

The analysis for the retrospective epidemiological database study, titled "Determining the prevalence of severe asthma in children in UK primary care," has begun using data from the OPCRD. This project aims to analyse the annual incidence and prevalence of severe asthma in the UK community using primary care data. It involves applying varied criteria to define severe asthma and exploring the rates of referrals to secondary care specialists. The study also includes a comparative analysis of characteristics between individuals with severe asthma who receive referrals and those who do not. The analysis will be complete in Q3 2024.

COPD WORKING GROUP

In September 2023, a significant milestone was achieved in the Peak Inspiratory Flow (PIF) in COPD patients project, where patient information from follow-up visits (1 and 2) was fully collected across 17 international centres. The database containing this invaluable information was subsequently locked, and a comprehensive dataset has been carefully prepared and will be used for the final analysis of this prospective observational study, which strives to determine the prevalence of suboptimal PIF in COPD patients and investigate its predictive value for exacerbations and symptom burden. Simultaneously, patient information from baseline visits has already been analysed and was used to prepare a manuscript, titled "Assessment of Peak Inspiratory Flow in Patients with Chronic Obstructive Pulmonary Disease: A Multicentre, Observational, Prospective, Real-life Study", submitted to the ResMed journal in December 2023.

Data analysis phase for PRECISE-X, focusing on the development of a risk prediction model for the initial severe exacerbation in COPD patients, is set to commence shortly. The CPRD has granted access to the database for the WG, facilitating the initiation of the analysis process. This project will complete in Q3 2024.

The proposal and budget for the triple therapy project are under review by supporters, aiming to secure funding. The project aims to investigate the effects of triple therapy on post-discharge outcomes in COPD patients, involving access to hospital databases from 12 international study centres.

COST EFFECTIVENESS WORKING GROUP

A research proposal for "A global evaluation of the economic impact of time to initiation of biologic treatment of severe asthma patients" has been developed. This project seeks to assess the national-level cost-effectiveness of biologic treatment, examining and comparing the economic impact and lifelong disease burden associated with early versus delayed treatment between countries. Feasibility is currently being evaluated.

DATABASES AND CODING WORKING GROUP

The WG is devoted to enhancing the appeal of the STANDOUT project, with a specific focus on attracting supporters. The core objective of this project is to standardise respiratory definitions and outcomes by leveraging real-world data.

ENVIRONMENT, EPIDEMIOLOGY AND AIRWAYS WORKING GROUP

The manuscript "Inhaler Choice: A Global Survey to Identify Patient & Healthcare Professional Priorities" has been submitted and under peer review. The project used surveys to identify the priorities of HCPs and asthma / COPD patients in inhaler device choice and planetary health. The REG opinion piece on the subject is currently under review by the REG board. Visit the study website for more details: https://www.regresearchnetwork.org/research-2/inhaler-choice-the-environment/.

ILD WORKING GROUP

The manuscript "Interstitial Lung Disease Diagnostic Pathway Post COVID-19 Era: Resource Disparities and Inequities" has been submitted and is under peer review. The project aimed to characterise ILD diagnosis across 64 countries. A poster was presented at ERS Congress 2023. For more information on the study, please visit the study website: https://www.regresearchnetwork.org/research-2/global-evaluation-of-the-interstitial-lung-disease-ild-diagnostic-pathway-in-the-post-covid-era/
Additionally, a research proposal was developed to provide a risk assessment tool for development of pulmonary hypertension in ILD patients utilising retrospective tertiary patient data and registry data of common diagnostic tests in ILD and pulmonary hypertension diagnosis.

SEVERE ASTHMA AND BIOMARKERS WORKING GROUP

Project opportunities and new ideas will be under discussion at REG-Summit 2024.

TECHNOLOGY WORKING GROUP

Potential new project ideas will be discussed at the working group meeting at REG Summit 2024.

VACCINES WORKING GROUP

A number of collaborators have expressed interest in investigating the uptake and adherence of vaccine use recommendations in respiratory care. To this end, a proposal for the "Vaccine Uptake and Exacerbations in COPD Patients: A Retrospective Study" has been developed. The project aims to examine vaccine coverage and uptake trends in COPD patients, as well identify the clinical and economic impacts of vaccination. Support is being evaluated.

WHAT REG MEANS TO ME

REG is one of my preferred forums for sharing ideas, discussing clinical observations made by colleagues, and learning about different clinical approaches that may challenge my practice. The REG meetings are an inspiration for generating research ideas and collaborating with colleagues from different countries and continents. Through David Price's led Optimum Patient Care Research Database (OPCRD), the potential of registries for improving care and informing guidelines was and continue to be revealed. When I attended my first REG meeting in the UK, I had already initiated a registry of children with asthma seen in two tertiary care centres, who had consented to their data collected for clinical purposes, be used for research purposes and be merged with drug claims, medical services, and hospitalisation. It takes a lot of effort to generate high-quality data and David's OPRCD impact on improving care gave me the motivation to pursue and expand the Pediatric Asthma Database and Biobank (PADB) of the Montreal children' s Hospital and the Sainte-Justine University Health Centre.These registries allowed me and my colleagues to develop strong research projects on comparative efficacy and safety profile of treatment approach for asthma, that have impacted childhood asthma care. REG is a consortium of individuals who strongly believe that real-life effectiveness data is essential and complementary to randomized efficacy trials. Examining real-life data has been an inspiration for my work. Under the leadership of Nick Papadopoulos and colleagues, I was delighted to participate in the worldwide surveys to identified research priorities in childhood asthma management from the perspective of pediatric stakeholders, to review the impact of COVID-19 on practice adjustments regarding children with asthma and to report their health outcomes during the pandemic; the findings have been an eye opener. I look forward to contributing further to the advancement of care in childhood asthma and bouncing research ideas with colleagues that likewise see the immense value of collaborating in moving forward the field of real-life effectiveness and safety profile in childhood asthma.

FRANCINE M. DUCHARME
Departments of Pediatric and of Social and Preventive Medicine, University of Montreal, Montreal, Canada

The concept of REG Summit bringing together clinicians, researchers, clinical research organizations, and pharmaceutical companies to share ongoing and upcoming activities in the field of respiratory diseases is a highly valuable endeavor. Such a conference fosters a multidisciplinary approach to tackling respiratory diseases. Clinicians and researchers often work in silos, and this gathering provides a platform for them to share insights, leading to a more holistic understanding of these diseases.The clinicians' practical, patient-centered experiences combined with the researchers' theoretical and experimental knowledge can lead to more effective treatment strategies. With the involvement of clinical research organizations and pharmaceutical companies, there is a direct channel for translating research findings into practical treatments and drugs.This can accelerate the process from discovery to application, ultimately benefiting patients sooner. REG Summit is an educational setting for the wider medical community as the latest findings and practices in respiratory disease treatment and research can then be shared and disseminated with relevant healthcare professionals. By bringing together a diverse group of stakeholders, REG Summit could influence healthcare policy by highlighting gaps in current treatment and research, potentially guiding future funding and policy decisions. Respiratory diseases are a global challenge, and such conferences can provide a platform for sharing experiences and strategies from different countries and healthcare systems, enriching the global knowledge pool. The conference can also serve as a forum to discuss ethical considerations, especially in terms of clinical trials, patient consent, and data handling, ensuring that advancements in respiratory disease research align with ethical standards. Finally, REG Summit sets the agenda for future research priorities, identifying unmet needs, and focusing on areas where further study and investment are needed. Overall, the convergence of different expertise and perspectives in such a conference is not just beneficial but necessary for advancing our understanding and treatment of respiratory diseases. It epitomizes the collaborative spirit that is essential in modern medical science.

CHRISTINE CAZEAU, MD, MPH
Global Medical Launch & Alignment Head - Pulmonology, Rhinology, Allergy & Gastroenterology
Sanofi

WHAT REG MEANS TO ME

The Respiratory Effectiveness Group (REG) holds a special place in my heart as an allergist in Australia. This unique and self-selected assembly of experts has become an invaluable resource in my professional journey, continually shaping my perspectives on healthcare in respiratory medicine. What strikes me most about REG is the remarkable diversity of expertise within its ranks. As a member, I have had the privilege of interacting with professionals from various corners of the globe, each bringing their own insights and experiences to the table. This diversity enriches our discussions, pushing the boundaries of our understanding of respiratory health.

The camaraderie and friendliness of the REG community have created a nurturing environment where individuals feel encouraged to ask questions, challenge assumptions, and investigate pressing healthcare issues. It's a testament to the group's commitment to fostering collaboration and shared knowledge. One of the most significant advantages of being part of REG is the opportunity for international collaboration with world-leading experts. The group serves as a conduit for presenting and discussing concepts in a small, collegial setting at international meetings and its specialized REG conferences. These interactions have not only broadened my horizons but also opened doors to collaborative research endeavors that I could have only dreamt of before. Furthermore, through REG, I have been fortunate to contribute to highly cited papers. It's an incredible feeling to know that my work has had a meaningful impact on the field and, more importantly, on patient care. REG members are united by a shared belief that today's healthcare practices should never be accepted as the best for patients tomorrow. This collective commitment to continuous improvement drives us to explore new avenues and challenge the status quo in the pursuit of better healthcare outcomes. In summary, REG is more than just a professional group; it's a community of passionate individuals dedicated to advancing respiratory medicine and, ultimately, improving the lives of patients worldwide. For me, REG is a source of inspiration, collaboration, and a driving force behind my unwavering commitment to the field of allergology and respiratory medicine.

PETE SMITH
Professor of Clinical Medicine in Molecular Immunology, Department of Clinical Medicine, Griffith University School of Medicine, Southport, Queensland, Australia, and honorary Professorship at the National centre for NeuroImmunology and Emerging Disease. Also Professorial Chair in Allergy at OPRI in Singapore

INTERNATIONAL SEVERE ISAR ASTHMA REGISTRY

ISAR Updates

The **International Severe Asthma Registry** (ISAR) enters its 7th year, with data from **18,531 severe asthma patients** (including 15,607 patients with prospective data) from 27 collaborating countries. ISAR is delighted to announce that a 3 year extension for the registry has been achieved (2024-2026) with support from AstraZeneca. This extension will support ISAR's vision to improve the lives of severe asthma patients worldwide though international collaboration.

ISAR in 2023: Publications

To view ISAR's publications and abstracts, please visit the **ISAR website**.

Pfeffer P, et al.
"Comparative effectiveness of Anti-IL5 and Anti-IgE biologic classes in patients with severe asthma eligible for both"
Allergy, 2023

Full Article

Conclusions: In real life, both Anti-IL5/5R and Anti-IgE improve asthma outcomes; Anti-IL5/5R was more effective than Anti-IgE in reducing asthma exacerbations and long-term OCS use in patients eligible for both.

Chen W, et al.
"Impact of Initiating Biologics In Patients with severe asthma and on Long-Term OCS Or Frequent Rescue Steroids"
JACI:IP, 2023

Full Article

Conclusions: In a real-world setting, initiation of biologics was associated with further improvements across multiple asthma outcomes, including exacerbation rate, OCS exposure, and health care resource utilization.

Scelo G, et al.
"Analysis of comorbidities and multimorbidity in adult patients in the International Severe Asthma Registry"
Ann Allergy Asthma Immunol, 2023

Full Article

Conclusions: In a global study, comorbidity or multimorbidity is reported in most adults with severe asthma and is associated with poorer asthma-related outcomes.

Cushen B, et al.
"Adult Severe Asthma Registries: A Global and Growing Inventory"
Prag Obs Res, 2023

Full Article

Conclusions: Standardised data collection has enabled individual severe asthma registries to collect unified data and increase statistical power for severe asthma research irrespective of ISAR affiliations.

Wechsler M.E, et al.
"Association between T2-related co-morbidities and effectiveness of biologics in severe asthma"
AJRCCM, 2023
In Press

Conclusions: These findings highlight the importance of systematic comorbidity evaluation. The presence of CRS+/-NP or NP may be considered a predictor of biologic effectiveness in patients with severe asthma.

ISAR in 2023: Events

We are pleased to share 2 new posters presented at the ATS conference, in Washington DC from the ISAR group, and 4 posters to be presented at the ERS conference, in Milan, Italy. To view ISAR's publications, abstracts, and slide sets, please access the **ISAR website**.

ATS 2023 | Location: Washington, DC Date: 19-24 May 2023

ISAR abstracts presented:
• Exploring what is possible in response and super-response to biologics.

ERS European Respiratory Society International Congress 2023 | Location: Milan, Italy Date: 9-13 September 2023

ISAR Research Working Group Meeting (9 September 2023)
• Formulating research questions to impact severe asthma.

QI Working group Meeting (9 September 2023):
• Advancement of ISAR's QI redcap platform QISAR, streamlining and improving data entry alongside QI support, powering change in clinical thinking and asthma outcomes through research and at the clinic. Information link **here**.

Joint ERS/REG session Building Sustainable Registries (12 September 2023)
• Highlighting barriers to establishing a registry and finding a route to success.
Posters presented: Link **here**

Upcoming ISAR Events 2024

Respiratory Effectiveness Group (REG) Summit
Vienna, Austri
14-16 March 2024

ISAR is thrilled to announce research from the registry will be showcased at REG 2024.

Join ISAR today!

To register interest as a collaborating country, or to submit a research request or proposal, please contact us **here**.

ISAR: INTERNATIONAL SEVERE ASTHMA REGISTRY

AN INTERNATIONAL COLLABORATION TO IMPROVE
THE LIVES OF SEVERE ASTHMA PATIENTS WORLDWIDE

QISAR QUALITY IMPROVEMENT TOOL: PRACTICE CHANGE MADE EASIER

ISAR's new quality improvement (QI) tool QISAR launching in 2024 will harmonize research data collection with clinical consultations, having the impact of **making severe asthma consultations more effective.** QISAR will minimize dual data entry by embedding data collection in clinical care, as inspired by the Denmark Severe Asthma Registry (DSAR) model. The tool will also **provide LIVE, interactive, longitudinal feedback to clinicians and patients**, as facilitated by OPC QI initiatives.

QISAR Key features:

1. **Patient questionnaires completed before clinics: Critical information at fingertips, saving clinician time**

2. **Streamlined data entry: Data not rekeyed**, instead carried forward and prompted for latest status. Questions in context, including medication switch when medication changes

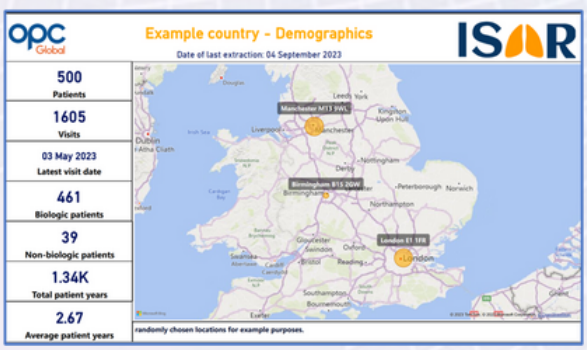
3. **Tailoring of country profiles: Easier to use, improved control, better data entry**
Controlled by country admin, including standard prescriptions for each country – defaults to improve data input and accuracy

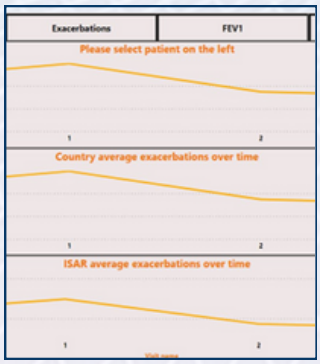
4. **Intelligent Imputations applied at earliest point (EDC): Saving time, improving data quality** Including check of exacerbations data against hospital admissions at point of entry

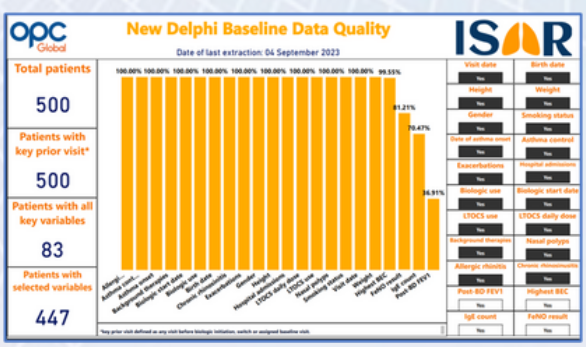
5. **Instant patient care report – based on DSAR scorecard. Review patient journey instantly, receive quality improvement support (CDS, Clinical Decision Support) to enable practice change and achieve the best possible outcomes in severe asthma care**
With individual country versions including predictive suggestions

Medications					
Biologic Drug	____	____	Omalizumab (Xolair)	Omalizumab (Xolair)	Benralizumab (Fasenra)
Biologic Status	____	____	Ongoing	Ongoing	Switched - Optimisation of current treatment
ICS (not combination therapy)	____	____	____	____	____
ICS Status	____	____	____	____	____
LABA	____	____	____	____	____
LABA Status	____	____	____	____	____
LABA/ICS COMBINATION	____	____	____	____	____
LABA/ICS Status	____	____	____	____	____
MOS	Prednisone	Prednisone	Prednisone	Prednisone	Prednisone
MOS Status	Ongoing	Ongoing	Ongoing	Ongoing	Ongoing

6. **Country dashboards: Data easily accessed, improving registry operations, supporting future research**







ISAR isar@optimumpatientcare.org https://www.isar.opcglobal.org

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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 discuss your ideas in more detail.

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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