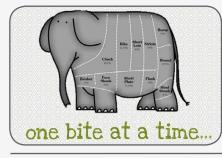
ADVANCES IN... REAL-LIFE RESPIRATORY MEDICINE

The Respiratory Effectiveness Group Newsletter

Price puts pen to paper: reflections on 2015/16

It's may not be the of the calendar year, but it <u>is</u> the end of REG's financial year. As such, it's not only a good time to balance the books, but also to reflect on the year that's passed and to think about what lies ahead.

The last time I put "pen to paper" for the REG newsletter was at the end of 2013. At the time, REG was celebrating its first anniversary and I was reflecting on what we'd managed to achieve in those early few months. I seem to remember calling the challenge that lay ahead of us (changing perceptions of real-life evidence) as "an elephant" that we would need to devour one digestible and deliverable bite at a time. It seems appropriate, in this issue, to look at some of those "bites" (namely the projects and activities) that we've been chewing on since then.



While we have been enormously busy and productive in the last year, I do acknowledge that the REG Head Office hasn't necessarily been as communicative as we could have been about all the work that's going on. We intend the new financial year (and this newsletter) to flag a positive change in our communication. Not only will we keep on being busy and productive, but we'll also make sure we keep you better updated so that we retain the community spirit that I feel characterises REG as a collaboration.

The pages that follow will provide a summary of our Research and Publications

portfolio; confirmation of the 2014/15 Research Pinboard Research grants and activities; our events calendar for the rest of the year; a summary of some of the other initiatives that we have underway and ... importantly, greater clarity around our organisational

structure and strategies. I also want to say a few personal words on the last of these points – organisational structure – as there have been a number of staffing changes in recent months and I want to make sure we enter this new year with clarity rather than confusion.

Both Ali and Thao have inhabited the shoes of the REG Director in the organisation's first two years and it is a role that is really too much for one person alone. Moving forward, Ali will take on the role of REG's Chief Scientific Officer and, Thao that of Chief Financial Officer. Ali will be the lead support for our working groups (and collaborators) and will work closely with you to develop research ideas and proposals and to oversee our research portfolio from study concept through to publication. Thao will keep us in the black and remain the primary contact for all REG supporters. Reflecting our commitment to improved communication, we are appointing a Communications Officer (Zoe Mitchell) who will work closely with Ali (from June) to keep you updated of all our plans and activities. Mylee Durack will work closely with Thao and continue to provide greatly appreciated admin support.

From a strategic perspective, we also intend to call more on the wealth of knowledge and experience that we have in our Council to develop activity plans for the years that follow and to guide REG onwards in a sustainable and impactful way.

Finally...I continue to be impressed and touched by your support and enthusiasm for the organisation and by the numbers of you who turn out at our events and participate in our activities. Rotterdam, in particular, was a wonderful mix of highquality science, debate and ... dare I say it... fun (as the photo below testifies)! Surely that means we're doing something right...?



Newsletter Contents

Staffing & Structure:

An overview of the roles within the REG team and the respective roles of the Working Groups and the REG Council...

turn to p2 for more information

REG 2015 Events Calendar

An overview of the upcoming events REG will be running at the time of the ATS in Denver, and a forward plan for future REG events in 2015...

turn to p3 for more information

REG Publications Summary

Recent REG publications and a look back at what we've been saying since the intiaitive began in 2012/13...

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REG Research 2013/14

Review and update on the current status of the REG studies, launched in 2013/14...

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REG 2014 Pinboard – Funding

A summary of all ideas submitted to the pinboard in 2014 – how they were ranked, what supporter interest has been expressed and **what REG wil be funding in the coming year**...

turn to p6 for more information

REG Initiatives

Selected highlights of the ad hoc initiatives that REG has been supporting and planning in recent months – a reflection of our commitment to remain a nimble organisation that can be responsive to new opportunities as they arise...

turn to p7 for more information

Staffing and structure

REG Staff, Council, Working Groups: who's doing what?

Respiratory Effectiveness Group Team

As a non-for-profit social enterprise, REG has appointed a team of contractors to support the delivery of our many and varied activities.

The team roles are summarised in the diagram to the right (indicated by the white boxes). Only the roles of Chief Financial Officer (Thao Le) and Chief Scientific Officer (Alison Chisholm) are full-time roles. Our Admin Support (Mylee Durack) and Communications Officer (Zoe Mitchell) both work parttime and we draw on Accountancy support and Meeting & Events Support on an ad hoc (or per-event) basis.

Use of these

key established contractors keeps our organisational overheads low and maximises the value of support available to fund REG initaitives and events.

Research

Lead

Chief

Scientific Officer

Comms

Officer

Oversight Committee

Chair of Council

Meeting &

Events Management

The Working Groups



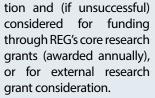
In the last 6 months, we have appointed a number of working groups to focus our activities within key interest areas in real-life research. These Working Groups will be responsible for leading on the proposal, development and oversight of future REG activities within their respective areas of specialty. Working Group proposals will be shared with REG supporters for their funding considera-

The Council

Going forward, we intend to make more effective use of our REG Council. Council members will convene once-ayear (in person) to review our current activities (against our original objectives) and to develop a strategic plan for the year ahead. Additional meetings may take place throughout the year, as required. This year's Meeting will take place in *Amsterdam before the ERS conference, on Friday 25th September.* In addition to the existing members,

Working Group leads will be invited to sit on the Council to ensure the activities of these core groups are represented and appropriately incorporated into our future plans.

When David Price completes his term as REG Chairman, we also propose to appoint a **Chair** of **Council** – more information will follow in due course.



Clinical

Governance Lead

Accounts

Finance Support

Chief

Finance Officer

Admin.

Support

Working Group ideas are not limited to study proposals only, they might also include the development of consensus or position statements; systematic reviews; conference session proposals; expert panel meetings; educa-

tional events, or anything

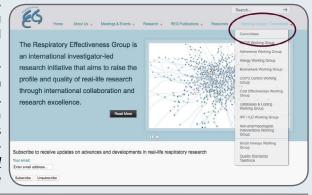
else that the group feel would be of value.

The groups have a nominated lead, but are **open** to all REG collaborators. Please note, participation in a working group does not oblige you to particiapte personally in <u>all</u> of the activities that the a project-by-project basis. Working Group Meetings will be held

group proposes - you can opt-in/out on

at the time of the REG Summits and at opportunistic points in the respiratory conference calendar, such as at the time of other key congresses where a number of group members are likely to be present.

The working group meetings arranged for the coming year (so far) are summarised on the **Events Calendar Page** (p3). A webpage for each REG working group is also being set up on the REG site, which will detail on-going activities and future meeting dates (see below).





Events: a more strategic approach

2015 REG Events Calendar

We started REG with the intention that it would bring together those working in real-life respiratory research around the world, and across different sectors (Pharmaceutical; Outcomes Research; Clincial Research, etc).

In 2015...we have already held a main summit; a regional summit, and still have a number of "piggy-back" meetings and our AGM & Council meeting planned for the coming months (as summarised on the right).

To manage our REG Team's resource (and avoid risk of "event fatigue" among you all) the future Events Strategy we will be as follows:

- 1 Main REG Summit per year (typically in Europe in the late in the year or early in the new year). The AGM and Council Meetings will take place here, and there will be opportunities for the Working Groups to convene.
- 1 REG Regional Summit (e.g. in Asia-Pacific or Latin America). The

· Collaborators' Meetings at key respiratory congress events, e.g.: ERS; ATS.

REG 2015 EVENTS CALENDAR

JANUARY:

22–24th: REG Summit, Rotterdam

APRIL:

- 25-26th: REG Asia-Pacific Summit, Singpore
- 28^{th:} **REG Sesssion World Asthma** and Allergy Congress, Singapore: The Evolving Role of Real Life Research In Respiratory Medicine (3-4pm)
- MAY: 2015 ATS, Denver
- 16–17th: REG Collaborators' and Working Group Meetings (see below for details)
- 20th: **REG Collabrator-led Symposium** (see below for details)

· Ad hoc Working Group Meetings (subject to member availability) at key respiratory congress events.

| UNE: | EAACI Conference, Barcelona |
|------|--|
| 'th | Allergy Working Group Meeting (2-3pm) |

- 7th Biomarkers' Working Group Meeting (5-6pm)
- 7^{th:} **REG Symposia:**

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- Challenging guideline constructions in asthma (#6) - Uncovering primary care databases (#10)
- 11th: Taxonomy of Adherence **Expert Panel Meeting**

SEPTEMBER: ERS 2015, Amsterdam:

25th: **REG AGM REG Council meeting**

The Council meeting will be scheduled to follow immediately after the AGM.

Working Group Meetings TBC:

REG events at the 2015 ATS Conference

May 16th

Venue: Crowne Plaza, Denver, Colorado **Room: Altitude Room**

07.30-09.00: Collaborators' Meeting

- 09.00-11.00: Small Airways Study Group Meeting
- 13.00–14.00: Taskforce Meeting
- 14.00–15.00: Cost-Effectiveness Workshop (Part II) - open to all!

16.30–18.00: IPF/ILD Working Group Meeting

May 17th

Venue: Crowne Plaza, Denver, Colorado **Room: Altitude Room**

07.30-09.00: ACOS Working Group Meeting

13.00–15.00: AZ/REG Evidence Planning

16.00-18.00: COPD Control Working Group

May 20th

Time: 13.30–15.30; Four Seasons Ballroom, 3-4 Lower Level, Colorado Convention Center (Session D83)

Scientific Session – Developed by REG Collaborators Jerry **Krishnan and Barry Make**

High Profile Effectiveness and Efficacy Research with conflicting results - which to believe?

| | | SATURDAY MAY 16 TH (7.30–9.00am) VENUE: Growne Plaza Hotel (Altitude Room); 1450 Glenarm Place, Deriver, CO 80202, USA CHAIRS: Jerry Krishnan (ATS Leady, Richard Martin (N. American Lead) & David Price (Chairman) ATTENDEES: REG Collaborators & Supporters; non-suppoters by invitation | | | |
|-------|--|---|--|--|--|
| | | | | | |
| G | COLLABORATORS' MEE | TING – AGENDA | | | |
| 40 | Welcome & Introductions | Richard Martin | | | |
| -7.55 | REG Research: update & call for participation | David Price & Group Discussion | | | |
| | 2014 REG Pinboard Announcements Call for participation: Database Checklist Delphi | | | | |
| | - Future Research Prioritisation Avenues: | | | | |
| | Working Groups Pinboard? | | | | |
| | – Questions & Answers | | | | |
| -8.05 | Future Plans: staffing & events update | David Price, Alison Chisholm, Thao Le | | | |
| | - Revised staffing structure: who are your key contacts? | | | | |
| | Working Group & Council Structure: who does what? 2015/16 Events: when will we see you next? | | | | |
| | EAACI Events ERS Events – AGM & Council Meeting | | | | |
| | 2016 REG Summit | | | | |
| | - Questions & Answers | | | | |
| -8.20 | Driving Quality Standards | Nicolas Roche & Group Discussion | | | |
| | – EAACI/REG Taskforce Update: Quality Standards in Asthma Compartative Effectiveness Research – What else should we be doing? | | | | |
| | what else should we be doing? • ERS Vision – "Real Life Evidence" | | | | |
| -8.35 | A word from REG's Supporters | | | | |
| | Invited Industry perspectives on REG activities & real-life re | search priorities | | | |
| 50 | PCORI: New funding source for comparative effective research | Jerry Krishnan | | | |
| 00 | Open Discussion: Feedback & Ideas Forum | Group Discussion | | | |
| | CLOSE | | | | |
| | | | | | |

Publications: review papers, position papers, letters to editors

What have we shared with the world beyond REG in 2013?

2015 is destined to be the "**year of the publication**" for REG. As a group, we have a number of important publications to our name (summarised below), but our communications to date have largely consisted of position papers, letters to editors and reviews, with a view to raising awareness and promoting discussion about the strengths and limitations of different sources of evidence and how they can be best integrated to help guide clinical decision making. However...

Original REG Research

A number of the studies REG launched in 2013/14 are now approaching their conclusion. Indeed, a singificant number of research manuscripts are now under development (as detailed below, and summarised in the p4 research summary):

- Asthma endpoint validation study
- COPD Eosinophil study
- Oral steroid burden in refractory asthma
- Bi-directional relationship between ICS adherence and asthma outcomes
- UK Asthma "State of the Union"
- Paediatric step-up study

newsletter goes to press), we've just received news that the *Primary Care Respiratory Journal* has accepted an the first REG original research paper: **Initial treatment step up options in children already treated with inhaled corticosteroids: a retrospective UK database analysis** authored by Steve Turner, Kathryn Richardson, Annie Burden, Mike Thomas, Clare Murray and David Price – huge congratulations to you all.

Excitingly (and very timely as this

The study steering committees are busy working on the other papers mentioned and you will be kept updated as each is appears in print.

REG Reviews

In terms of recent and on-going review papers, David was invited to write a review article based on his presentation from REG's symposium at last year's ERS: *The implications of reallife on asthma management: is there any evidence available?*

The resultant review (co-authored by the session chairs, Nicolas Roche and Guy Brusselle, and by Alison Chisholm



and Daryl Freeman) and was published in the March issue of *Breathe* (title: **Real**world research and its importance in respiratory medicine).

There is one other review on the way, at this point in time – a summary of current controversies and challenges in allergic rhinitis management (for Expert Review of Clinical Immunology).

REG Summit Abstract Book

The abstracts from the Rotterdam Summit are now published online in open access journal *Pragmatic and Observational Research*.

A reminder of some of REG's existing publications...

A list of REG's published papers are available online – visit the REG website (www.effectivenessevaluation.org) and navigate to the publications page from the top menu bar. The **Publications Page** also includes light-touch instructions for REG authors (developed by the REG Publications Committee) on how to acknowlege REG's support within your paper, recommendations for describing the databases used and interpreting the research available online, etc.

Supplements

ARCH SUPPLEMENT: Helping to Further the Science of Pragmatic Research Annals of the American Thoracic Society, 20 February, 2014:

- S83 The Arch Conference Declaration: Helping to Further the Science of Pragmatic Research (Martin RJ et al)
- S85 Respiratory Guidelines—Which Real World? (Wong GWK, et al)
- S92 Complementing the Randomized Controlled Trial Evidence Base: Evolution Not Revolution (Price D, et al)
- S99 Quality Standards for Real-World Research: Focus on Observational Database Studies of Comparative Effectiveness (Roche N, et al)
- S105 The "E" in Cost-Effectiveness Analyses: A Case Study of Omalizumab Efficacy and Effectiveness for Cost-Effectiveness Analysis Evidence (Campbell JD, et al)
- S112 Integrating Patients into Meaningful

Real-World Research (Bartlett SJ, et al)

 S118 Phase IV Implementation Studies: The Forgotten Finale to the Complex Intervention Methodology Framework (Pinnock H, et al)

Summit abstract books

- Inaugral Summit (June 2014): Abstracts from the Respiratory Effectiveness Group's inaugural summit, June 2014. The Royal College of General Practitioners, London, 28–29 June 2014
- 2015 Rotterdam Summit: In Press Pragmatic and Observational Research Visit: www.dovepress.com

Correspondence

- "Feasibility and Ethics". Price D, et al. American Journal of Respiratory and Critical Care Medicine, 2013;188:1368-1369.
- · Integrating real-life studies in

the global therapeutic research framework. Roche N, et al. Lancet Respir Med, 2013;1:30–32.

Reviews

- Integrating Evidence for Managing Asthma in Patients Who Smoke. Price D, et al. 2014 March;6:114-120.
- Efficacy versus effectiveness trials

 informing guidelines for asthma management. Price D, et al. Curr Opin Allergy Clin Immunol. 2013; 13:50-7.
- Real-life Asthma Treatment Strategies: The missing piece of the jigsaw. Price D, et al. Treatment Strategies – Respiratory. 2013;3:37–46.

Research

 Opportunities to diagnose chronic obstructive pulmonary disease in routine care in the UK: a retrospective study of a clinical cohort. Jones RCM, et al. Lancet Respir Med 2014.

REG Research Studies launched in 2013/14

"If REG is going to be more than a discussion group, it needs to undertake its own research..."

Asthma endpoint validation



Observational study outcomes are often challenged by reviewers because their endpoints differ from those of RCTs. This study aims to compare and contrast RCT and observational study endpoints and to explore what each tells us. In particular the studywillevaluatewhethertheobservational endpoints used by REG are predictive of future risk and responsive to therapy. Status: Initial study outputs were presented at the ERS in 2014. A mansucript (looking at the predictive quality of our endpoints) is in early-stage development. Additional short reports (e.g. on the ability to use observational outcomes as proxies for PROs) are under consideration.

Asthma risk predictors study The study aims to better understanding patient characteristics (clinical, lifestyle and demographic) associated with frequent asthma exacerbations with a view to developing risk scores that will assist in better identification of patients at risk of future exacerbation with a view to modifying that risk.

Status: The baseline analysis has been completed and the risk prediction modelling is about to commence.

COPD and blood eosinophils

The aim of this study is to use primary care clinical records to explore the relationship between blood eosinophil count and future exacerbation risk in COPD.

Status: The paper is in development – a study outline has been circualted and prompted great discussion among the steering committee.

Spin off study: Using the same dataset, a COPD risk prediction study has been carried out that explores patient characteristics associated with frequent COPD exacerabations. The findings of this analysis were presented at the REG Summit in 2014 and a manuscript is now at an advanced stage.

Adherence & outcomes

The aim of the study is to utilise a routine care dataset that is devoid of the artificial adherence controls imposed in RCTs to explore to what extent adherence may be considered an asthma outcome, and/or a predictor of asthma outcomes by investigating the bi-directional relationship between database markers of ICS adherence and asthma control.

Status: The Phase I mapping of adherence patterns (and how these vary depending on duration of gap between treatment periods and the implications of counting / discounting carry-over effects) is almost complete. The longitudinal interaction between adherence and outcomes will then be modelled (Phase II analysis).

A paper summarising the Phase I adherence pattern mapping will commence shortly. A second paper will follow completion of the bi-directional analysis of ICS adherence and outcomes.

Oral steroid burden in refractory asthma

The study aims to use observational data to compare the prevalence and new incidence of comorbidities in patients on long-term oral steroids to (age-, gender-matched) controls with the goal of developing cost models to estimate the financial burden associated with refractory asthma and management of steroid-induced morbidities.

REG's role: REG has supported the ethical review and approval of the protocol and provided the dataset for analysis.

Status: The prevalence analysis is complete (new incidence yet to be completed). An initial paper has been written by the lead research team in Belfast.

Cardio- and cerebrovascular risk associated with nicotine replacement therapy (NRT)

The aim of the study is to evaluate the cardiovascular risk profile of nicotine replacement therapy.

Status & REG's involvement: The study has been co-funded by a Medical Research Council data grant and REG funding.

Status: The analysis is complete, but the CV codelist used for the analysis is being reviewed to ensure robustness.

Multi-component assessment of COPD: an evaluation of ADO and DOSE indices and the GOLD categories in international primary care datasets

The study used primary care data to compare severity assessments of COPD using the GOLD categories to other multidimensional COPD indices (ADO and DOSE), drawing on records for 5486 patients with COPD from UK Sweden, and Holland.

Status: The study is complete and a manuscript is in development.

Paediatric Step-up

The aim of the study, is to use an observational dataset to explore the:

- Pattern of step-up prescribing in paediatrics
- Comparative outcomes associated with different step-up options
- Implications of switching children with asthma between ICS inhaler devices.

Status: The study is complete and the first of three papers has just been accepted for publication. The accepted paper compares and contrasts the characteristics of children who are stepped up from ICS to the different treatment options. The two remaining papers will report the comparative effectiveness of the different step-up management options.

Spin off study:

Using the same dataset, a future risk analysis is underway considering which patient characteristics are associated with future exacerbation risk. The study analysis is still on-going at the time of writing.



In 2014/15 we launched a **Research Ideas Pinboard** to invite research ideas from REG collaborators and supporters. The aim was to identify real-life research needs and priorities for the appropriation of core REG reseach grants. The pinboard was closed to new ideas in June-July 2014... and the ideas were reviewed and prioritised by our Research Review Committee (rankings announced in the November newsletter). It is now time to announce the studies REG will be funding in 2014/15! The studies that will be funded through core REG grants are **highlighted in yellow below**, specifically: the 2 top-ranked research ideas plus 2 studies proposed by the IPCRG's UNLOCK group that require data provision only.

Alison will be in touch with the lead

Investigators for Studies 1 & 2 and will work with you to develop full study protocols. Discussions are already underway with the UNLOCK teams.

All study ideas submitted were circulated to REG supporters for consideration as Investigator Initiated Study funding – some successfully; some not. The current status in this regard is detailed next to each study:

| Rank | Study Title | Funding Status |
|------|---|---|
| 1 | Asthma Management in Under 5's | REG CORE FUNDING CONFIRMED!! |
| 2 | Is the addition of oral antibiotics with oral corticosteroids in an acute asthma exacerbation of benefit in terms of time to next unscheduled GP visit with asthma; time to next oral corticosteroid prescription and use of SABA of the following 6 months? Is any effect seen antibiotic class specific? | REG CORE FUNDING CONFIRMED!! |
| 3 | UNLOCK study: are pharmacological RCTs relevant to real life asthma populations? | Data provision only – to be supported through Core REG Funds |
| 3 | Outpatient factors predictive of emergency department use and hospitalizations among patients with COPD | No funding currently secured |
| 5 | Are Patient Characteristics Predictive of Response to Step Up Treatment in Children with Asthma? | No funding currently secured |
| 6 | Incidence of Cardiovascular Disease in Newly Diagnosed COPD Patients in Primary Care | No funding currently secured |
| 6 | UNLOCK study: the prevalence of comorbidities in COPD patients and their impact on the quality of life and COPD symptoms in primary care patients | Data provision only – to be supported through Core REG Funds |
| 6 | Developing Validated Claims Based Algorithm for COPD Severity | No funding currently secured |
| 9 | A New Methodology for Assessing Mastery and Maintenance of Dry Powder Inhaler Technique in Adults with Asthma | Research idea now being addressed external to REG as a sponsor-funded study conducted by Research in Real Life. |
| 6 | Using Medicare Claims Data to Determine the Effect of Pulmonary Rehabilitation and CT Phenotypes on the Occurrence and Cost of Severe Exacerbations of COPD | Lead Investigator in discussion with potential supporter. Introduction to potential supporter made through REG. No further involvement from REG. |
| 9 | Development, Validation and Evaluation of a Short form of EXACT (Exacerbations of Chronic Pulmonary Disease Tool) Questionnaire for Clinical Use and Self-(tele) Monitoring | Proposal developed by REG at the request of a potential supporter. Proposal now with supporter for consideration. |
| 9 | Evaluation of fractional exhaled nitric oxide for predicting response to inhaled corticosteroids for patients with non-specific respiratory symptoms | Research idea now being addressed external to REG as a mult sponsor funded study conducted by Cambridge Research Organisation and Reseach in Real Life |
| 12 | Incidence and Predictors of Lung Cancers Arising in Patients in Primary Care with a Diagnostic Code for COPD | No funding currently secured |
| 12 | Are Inhaled Corticosteroids Being Prescribed for Respiratory Tract Infections? | No funding currently secured |
| 14 | Development of a Longitudinal Asthma Treatment Step Algorithm and Association with Asthma Outcomes | Proposal developed by REG at the request of a potential supporter. Proposal now with supporter for consideration. |
| 14 | Variation in RCP3Q Validity in Asthma Care | No funding currently secured |
| 16 | Identifying Severe Asthma in Primary Care through Mediation Dispensing Records | No funding currently secured |
| 16 | Antibiotics and Pneumonia Risk in Asthma – a US Study | No funding currently secured |
| 16 | Do Not Resuscitate Status in Comparative Effectiveness Research | No funding currently secured |
| 19 | Reporting Standards for Implementation Studies | This project/study was already underway, but was looking fo interested participants |
| 20 | Characteristics of Patients Hospitalized for Asthma and Relationship with Post- Hospital Changes in Maintenance Care | Lead Investigator in discussion with potential supporter. Introduction to potential supporter made through REG. No further involvement from REG. |
| 21 | Adherence to Asthma Controller Therapies in Adolescents | No funding currently secured |
| 21 | ACOS Diagnostic Validation Study: US Claims Database | Idea now being further developed by the ACOS Working Grou |
| 21 | Burden of Illness in Mild Asthma | No funding currently secured |
| 21 | Triple Therapy in COPD | Proposal developed by REG at the request of a potential supporter. Proposal now with supporter for consideration. |
| 25 | Is the survival of patients with IPF related to warfarin use | No funding currently secured |
| 25 | Future COPD risk: Red Flags Identifiable from Routine Care Data | Validation of REG COPD Risk Study (see previous page). Proposal developed by REG in collaboration with a potential supporter, but new validation dataset now required as proposed US dataset infeasible. |
| 27 | The Association Between Bronchiectasis, CV and Rheumatoid Comorbidities | No funding currently secured |
| 28 | The Role of Real-Life Research in Health Technology Assessment And the Economic Evaluation of Health Technologies | No funding currently secured |

Outside of the Pinboard ideas, what else has been happening?

Keeping alive our initial intention to be a nimble and responsive organisation, we have been supporting a number of additional project ideas as they have arisen throughout the year.

A selection of these are featured (in brief) on this page and include: research ideas, expert panel meetings, and systematic reviews of the effectiveness evidence. They are typically ideas put forward by REG collaborators, or proposals developed by our working groups, that have captured the interest of some of the REG suporters.

I hope you'll agree that, when combined with the studies REG is supporting directly through our core research grants, they make up a really rich and varied mix of activities.

Systematic Review

The results of a meta-analysis comparing extra fine vs standard particle ICS were presented at the 2014 BTS. The authors concluded that (compared with larger-particle formulations) extra-fine ICS afforded no appreciable benefit in terms of efficacy and safety outcomes.

As these results contrast with some of the conclusions of REG's Small Airways Group's studies, we intend to conduct a review of the CER literature pertaining to ICS particle size to consider the evidence at-scale, and to resolve why there may be potential conflict between the efficacy and effectiveness data in this area – do the data conflict, or do the studies address different questions...?

AsthmaUK collaboration

The UK's National Review of Asthma Deaths was published in 2014. To mark its anniversary, Asthma UK decided to do some work to explore how commonly some of the risk factors identified by the NRAD occur in recent general practice, specifically: (i) LABA or LAMA use without ICS and (ii) \geq 12 SABA prescriptions a year without use of maintenance ICS.

REG supported Asthma UK to carry out this retrospective review by providing a recent extract from the Optimum Patient Care Research Database (OPCRD). The findings will inform an Asthma UK policy document, but will also be presented at the REG Regional Summit in Singapore this month.

Standardising coding



REG provides a unique opportunity for those working in real-life respiratory research to share practice and, through collaborative working, establish best practice standards and standardised research methods. In this spirit, REG has shared the codes it uses to identify exacerbations with Astrolab to support the work that REG collaborators Alex Dima & Eric van Ganse (and their Astrolab colleagues in Lyon) are doing through the European's FP7 grant (to provide new information about the benefit/risk rating bronchodilators and a number of related adherence evaluations).

Taxonomy of Adherence Expert Meeting

Through REG's Adherence Working Group (and guided by a planning committe involving: Job van Boven, Alex Dima, Gene Colice, Eric van Ganse and David Price), REG will be developing a **Road Map for Respiratory Adherence Research**.

Dovetailing with the end of EAACI in Barcelona, we will be bringing together approximately 10 international experts to discuss a range of adherence-related topics, including: taxonomy, behavioural determinants, technology-based approaches to measurement; interventions with proven effect, and more. It will be a (full!) one-day event that will, through a mixture of presentations and panel discussions, establish the current state of adherence research and identify unmet needs to guide future activities.



The meeting output will be written up and published as a supplement, special themed issue, or series of linked articles in a peer-reviewed journal (interest has been expressed by the editor of *JACI In practice*).

We hope the meeting will strengthen understanding of the current state of adherence research through collaborative discussions and provide a list of "targets" and "needs" for future research.

COPD Control

The concept of control has been extensively developed in asthma, but is not well defined/recognised in COPD. REG's COPD Control Working Group (Lead: Marc Miravitlles) supports the view that it should be defined in terms of impact its "impact" and "stability".

Through REG supporter funding, a study is now planned that will use reallife data to characterise control levels over time in an unselected COPD population and evaluate COPD outcomes over 1 year, stratified by control status.

REALISE Asia™ Delphi Study

For the last 2 months, REG has been undertaking a Delphi project to build on the findings of the **RE**cognise **A**sthma and **LI**nk to **S**ymptoms and **E**xperience (REALISE[™]) Asia survey.

The REALISE[™] Asia Survey found that patients' attitudes towards their asthma appears to play a significant role in their adherence to asthma medication and, as a result, to their overall level of disease management. The authors identified five types of asthma patients ("attitudinal clusters" of patients) and concluded that asthma management should be tailored to optimise outcomes for each.

Responding to these findings and with the ultimate goal of supporting more patient-centric care for patients managed in real-world pratice, the Delphi project aims to develop a number of tailored management recommendations for the 5 different patient types identified, specifically (although labels may change): (i) Well Adjusted; (ii) Rejectors; (ii) Lost; (iv) Endurers; (v) Worriers.