EAACI Congress 2019
WORKING GROUP MEETING MINUTES:
ALLERGY

Meeting details	
Meeting location	Tivoli Oriente Hotel, Lisbon
Meeting date	Saturday 1st June 2019
Meeting time	11:00
Chair(s)	Moises Calderon & Pascal Demoly
Attendees	Eva Stylianou Karen Rance Pete Smith Mariechantal Arseneault Pablo Rodriguez Vicky Kritikos Santiago Quirce Kwok Yan Monica Ruiz Garcia Glenis Scadding Pilar Rico Nieto Desiree Larenas Linnemann Silvia Uriarte Obando Nikos Papadopoulos Peter Arvidsson Zuzana Diamant Helene Nguyen Susan Waserman Ruppert Ludwig Hahnstadt Dermot Ryan Susanne Thum-Oltmer Michael Walker

Objectives	
1	Planning discussion for new AIT Registry

Items	

AIT Registry Discussion	**Title:** The **G**lobal **R**espiratory **A**llergy and Allergen **I**mmunotherapy Real **L**ife Registry
	         The "**GRAIL-Registry**"
	
	General Points
	
	• Moisés Calderon, chair of the REG-AWG explained:
	    o The current structure of the REG-AWG which will include
	       ▪ previous and new members
	       ▪ academics, practitioners and industry members
	    o The aim of the meeting

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- The design of 3 recent previous or ongoing AIT surveys / registries.
- That after the previous meeting during REG-Summit in Athens (29 March 2019), it was decided that a **"Global Registry on Respiratory Allergy and AIT in Real Life"** will be designed and conducted by the REG Allergy WG
- Nikos Papadopoulos, President of the REG, endorsed the need for such a Registry.
- A long, active and positive discussion with all attendees took place during the Lisbon meeting:
  - Aims and design of the registry were fully discussed.
  - No financial model will be proposed until aims and design are properly established.
- Pascal Demoly, co-chair of the REG AWG, did a summary of the discussion.

Specific Points

1- Aims of the Registry:
- To improve outcomes of AIT to improve care
- Should be prospective but could be retrospective/prospective
- Current RWD tendencies recommended to be patient-centered
- Patients inclusion criteria should not be restrictive (e.g., we can make analyses in children but should rather not include only children)
- Patients selection should be broad representing Real Life practice
- Should be applicable to all countries, developed or developing countries and all types of AIT
- The Global Registry could cover:
  - clinical evolution (e.g., control, exacerbation, QoL?)
  - medication use (possibly linked to official reimbursement services, EHRs)
  - burden
  - comorbidities
- Not transversal design but long term follow up
- No controls will be included, but sub-groups analysis should be considered

2- Design of the registry:
- Design will be established when aims are defined
- Prospective, global, long-term, real-life practice
- Web-based, to support the aims of the registry
- We should consider using an "online platform" where
  - doctors can type or transfer patient's data (e.g., REDCap) and
  - patients can be called at certain periods to respond validated questionnaires and

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- o questionnaires balancing doctors' responses (what the patients feel about AIT indication, AIT effect, other) can be included
- The AIT prescriber can enter the data
- The number of fields should be big enough to be scientifically sound, however, we must consider that if the GRAIL-registry is too large, this will reduce the interest of the participants to continue introducing data in the e-platform
- Have a look at the SAGE registry (https://www.ncbi.nlm.nih.gov/pubmed/30954467)
- MASK AIR is free to enter data by patients but has the disadvantage of having only one outcome (VAS on single symptoms), patients are opting out quickly, does not cover all our aims, data retrieval will surely not be free
- Approach societies that have tried (AAAAI) or are in the process of doing (BSACI) such a registry: advices, possibilities of merge at one point.
- Find a way to appraise what happened before the patient is included in the registry

Finances of the registry:
- Money collected will be used to support the design of the registry and to cover expenses of e-platform.
- Starting with donations from AIT companies (unrestricted grants)

Action plan:
- Minutes of the Lisbon meeting will be circulated by Michael Walker (REG) to all the members of the REG Allergy WG.
- An individual reply is expected from all members of the REG Allergy WG, this will determine who is interested in taking part of the Global Registry. Natural selection process will be followed. Ways to get future centers could be proposed (e.g., via national or local societies, personal connections)
- REG Allergy WG Members who show interest and contribute to the development of the protocol and future design of the GRAIL-registry will be considered part of the "core-team"
- Participation and intellectual input from academics, practitioners and industry members will be always welcome and will be intellectually considered in equal terms.
- According to their interest and active participation via email, the REG Allergy WG will be divided in "sub-groups", then, specific tasks will be allocated.
- Nikos Papadopoulos and Desiree Larenas will assess the possibility to use the App of MASK-AIR. They will contact directly Prof Jean Bousquet. No fees should be paid. REG Allergy WG should have easy access to and

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ownership of data collection. Analysis and publication of data should be independent.

- Pascal Demoly will do search and will propose data-base platforms that can be used for the GRAIL Registry (e.g. RedCAP, others). Facilities and costs will be evaluated. Any suggestion at this stage is welcome.
- Pilar Rico (Spain) will provide information of logistics and costs from other groups/companies conducting international RWD DB studies as well as big data (e.g., groups from Spain and NY).
- Karen Rance (USA) will provide information/contacts about the AAAAI AIT-Registry.
- Glenis Scadding (UK) will provide information/contacts about the BSACI AIT-Registry.
- Vicky Kritikos (Australia) will provide personal support to the development of the Global Registry based on her experience from the Australian AIT-Registry.
- Next REG Allergy WG meeting will be planned during AAAAI.

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