

REG Summit 2019

WORKING GROUP MEETING MINUTES: Allergy Working Group

28th March 2019

Divani Palace, Athens, Greece

Meeting details	
Meeting location	Divani Palace
Meeting date	28 th March 2019
Meeting time	13.00-14.00
Chair(s)	Moises Calderon
Objectives	
1	Provide an update on current projects
2	Prioritise existing ideas for future projects and develop a plan for implementation
3	Identify new project ideas

Attendees: Vicky Kiritikos, George Christoff, Michael Walker, Dirk Jan Opstelten, Despo Ierodiaknou, Clare Murray, Ruth Murray, Glenn crater, Monica Ruiz Garcia, Nikos Papadopoulos, Pilar Rico Nieto

Items	
Future direction of the group	<ul style="list-style-type: none"> Moises Calderon presented his vision for the future direction of the group. While work on rhinitis will continue if there is interest, the role of AIT in allergic asthma, and a potential registry of AIT use in asthma.
Patient registries	<ul style="list-style-type: none"> Given that AIT is not well recorded in current medical record databases, particularly primary care databases such as the OPCRd, a registry may be required. Current registries should be investigated, if a suitable registry is not already in place then consider creating one. The registry should be international and focused on one disease and therapy, with simple data on clinical history and presentation. A core team will be formed, with national coordinators. Project definitions need to be created. Participants could then be selected/invited. The exact methodology and resources are yet to be defined. Focus would be on asthmatic patient pathways; causes of disease and phenotypes; diagnosis, diagnostic tools



	and procedures; and AIT initiation and patient/prescriber expectations.
Discussions	<ul style="list-style-type: none">• The EAACI registry has been in place for a number of years. It is a good example of what is required to set up a registry, and the time taken until results are able to be analysed. It may be possible to take an existing registry and expand it, in scope and participation.• It is important that each group has ownership of their own data. REG is therefore a good platform for a registry as they very open to collaborative research.• The first steps should be to see what is already in existence, and what are the similarities/differences in content and approach. This could be done as a Delphi/review or adhoc.• A lot can be learnt from ISAR. They act as custodians of the data but each collaborator is free to analyse and publish their own data. Some countries are more open to data sharing than others, and those without existing data collection in place may need support to set this up.• Countries should have control, but could also prepare reports for them to build relationships.• In the UK, Australia and US, AIT is not often used for asthma alone. There will be large geographical variation.• In the US it is hard to get data out of and coordinate the different payers. Could go to individual sites, but this is perhaps not as representative.• Key question from a registry would be where is AIT being used and when, how and for whom?• The scope of the database would need to be clear – would it include rhinitis patients with controlled asthma for example? Also, there is a lack of validated endpoints and clinical histories are very subjective which makes analysis hard. The lifetime of the registry would also need to be decided.
Summary	<ul style="list-style-type: none">• Agree to collaborate• Respiratory allergy and AIT seems the preference for the focus• A protocol to be developed for review



	<ul style="list-style-type: none">• Agreed next meeting of the WG would be at EAACI Congress
--	------------------------------------------------------------------------------------------------------------