

REG Summit 2019 WORKING GROUP MEETING MINUTES: Databases and Coding

Meeting details		
Meeting location	Divani Palace Acropolis, Athens, Greece.	
Meeting date	Thursday 28 th March	
Meeting time	16:30	
Chair	Katia Verhamme	
Attendees	Grant Maclaine Alexander Mathioudakis Helena Binetskaya	Janwillem Kocks Michael Walker Sarah Lucas
Objectives		
1	Update on current project	
2	Identify new project ideas	

Items	
	Update on progress with Towards Optimum Reporting of Pulmonary Effectiveness Databases and Outcomes (TORPEDO).
	Katia presented the results from phase 3 of the Delphi exercise.
Update on current project	64 Invites to participate in third round were sent out – 39 people replied (61%) 5 people who did not select any of variables were excluded for analysis Variables will be included in list of minimal criteria if at least >66% agreement between respondents. The majority of the responders were from Europe, but still need to check participants in terms of roles/affiliations to societies.
	Participants were asked to indicate which variables they felt were a minimum requirement for: 1. A prospective clinical asthma (field) study with original data collection; 2. A prospective clinical COPD (field) study with original data collection; 3. A retrospective asthma database study or 4. A retrospective COPD database study.



There was good agreement with results showing clear differences between what would be required for COPD and asthma studies and what variables participants would require for a retrospective study compared to a prospective study.

Next steps: Job to check of the methodology to ensure everyone in 3rd round responded to 1st round. This should then be written up for publication.

Following this REG and the working group members should begin collating a list of all the currently available databases, which will then be checked to determine whether they contain these minimum variables.

Common Data Model was discussed.

New project ideas

It was felt REG could play a role in helping to ensure that respiratory information is effectively coded. Perhaps by producing a data dictionary. It needs to be ensured that the minimum variables determined by the TORPEDO project are mapped correctly into the common data model.

This working group should consider developing a protocol for a project around the common data model. Possibly conducting a literature search in respiratory epidemiology. Katia is going to look into potential Ehden funding for such a project.