

Minutes – Databases & Coding Validation working group

Meeting location	Park Plaza Hotel, Amsterdam Airport
Meeting date	22nd March 2018
Meeting time	11:00 to 12:00
Chair	Katia Verhamme
Attendees	Manon Belhassen, Eric van Ganse, Mohsen Sadatsafavi, Giorgio Walter Canonica, Joan Soriano, Leif Bjermer, David Price, Janwillem Kocks, Ronan Ryan, Hilda de Jong, Rupert Jones, Derek Skinner, Tom O’Shea, Naomi Lauanders
Objective	<ul style="list-style-type: none"> • Provide update on current project- TORPEDO • Ideas for future projects

	<p>Update on current project</p> <p>1. Towards Optimum Reporting of Pulmonary Effectiveness Databases and Outcomes (TORPEDO)</p> <ul style="list-style-type: none"> ○ Aims and progress discussed Phase I complete – two round Delphi exercise with excellent agreement on majority of questions. Initial list compiled at the REG Summit 2017 in London, then sent to 22 collaborators, who provided extra variables. Phase II – Need to agree variables. These will be reviewed at this meeting. Contact with GADC – phase I expanded to cover low and middle income countries. Questions from Phase I have been put into an electronic format (SurveyMonkey). This can soon be sent out to 52 potential contacts once the format and content is finalised. It will be part of broader chronic disease initiative. In the future datasets from studies and registries could be included as well as databases. Have a list of variables, but need to define how they are organized in categories and agree definitions, and check terminology is clear. ○ Excel spreadsheet presented: General discussion on hierarchy of categories and what units. At this point it is just a list for participants to decide what should be included, and we need to be careful not to make those decisions for them. Also discussion around the meaning of “essential”. Concern raised that the electronic questionnaire may not be clear enough and so participants may tick those they want to include rather than exclude. Specific points on the variables Behaviour: Add diet. Biochemical measures: Creatinine – add GFR clearance, liver function and haemoglobin. Add all blood gas, not just oxygen saturation. Consider ordering by topic and organ e.g. renal function.
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	<p>Clinical assessment: Specify pre and post FEV1. Best PEF in the last 6-12 months? Where is it performed? Date of measurement. Vital capacity? Abbreviations need to be written in full. 6-minute walk test is included, but there are other tests. Should we include? Maybe say “exercise tests” generally.</p> <p>Need to standardize how we ask the questions – lung function test is split into many variables, whereas exercise test is general.</p> <p>Imaging: Repetition of some of the tests. Simplify to MRI, chest xray, HRCT. Remove repetition.</p> <p>Demographics: Move to below anthropology. Add number of people in household.</p> <p>Environmental: Add outdoor air pollution and occupational exposure. Change biomass exposure to household air pollution.</p> <p>Health care utilization: Reorganise. Add unscheduled medical contact and type of contact (telephone/face to face).</p> <p>Medication/adherence: Management/interventions: Broad. Needs reorganization. Missing mechanical ventilation, though do have positive pressure device and intubation listed.</p> <p>Medical history: Medical codes – may be ones to add.</p> <p>Morbidity: Move vaccination to a different group. Move premature birth to another group and expand to include birth weight, delivery method and gestation length. Asthma/COPD review is wrong. Expand depression/anxiety to psychological. CVD as a sub heading with details. Add in HIV and TB.</p> <p>Exacerbations: Mortality: Maybe add “contributing/secondary cause of death”. Add in autopsy confirmed diagnosis.</p> <p>QoF/patient reported outcomes: Add “or derived versions” where applicable. Add “paediatric AQLQ” and “Chronic Respiratory Disease Questionnaire”. SF12 in addition to HADS. EQ-5D is mentioned twice. Add mMRC dyspnea. Rename RCP3 field.</p> <p>Aim 2: data repository</p> <p>REG website lists not functioning – REG to update when it works.</p>
	<p>Ideas for future projects to be considered</p> <ul style="list-style-type: none"> • Common data model and translation tools. • Database assessment tool. – Revitalise UNLOCK element of it.
	<p>New project ideas/AOB</p> <ul style="list-style-type: none"> • TORPEDO is the main priority for the group. • Look at validation – automatic validation in databases, especially where looking at free text.
<p>Actions from WG meeting</p>	<p>Variable list to be finalised</p> <p>Questionnaire to be sent out</p>