European Registries for Rare Endocrine and Bone Conditions (EuRREB)
Condition Specific Module Working Group Operating Procedures

The overall aim of the EuRREB Condition Specific Module Working Groups is to help better define reported cases of a specific condition by developing condition-specific module (CSM). The Working Group will be active for a maximum of 18 months, within that time period the Working Group will achieve to build and publish the CSM together with the Registries Team, created a paper about data collection, and created a guide about how to use the CSM. After these goals have been achieve, the Working Group will be dismantled. To form a Working Group, interested and motivated researchers, clinicians and patient representatives can apply to the Registries Team through an application form.

Members of the Working Group

Standard Roles	Name	Join	Demit
Lead Expert Member (ERN member)			
Expert Member 1 (ERN member)			
Expert Member 2 (non-ERN member possible)			
Expert Member ….			
Patient Member 1 (ERN e-PAG)			
Patient Member 2 (non ERN e-PAG possible)			
Patient Member……			
EuRREB representative			

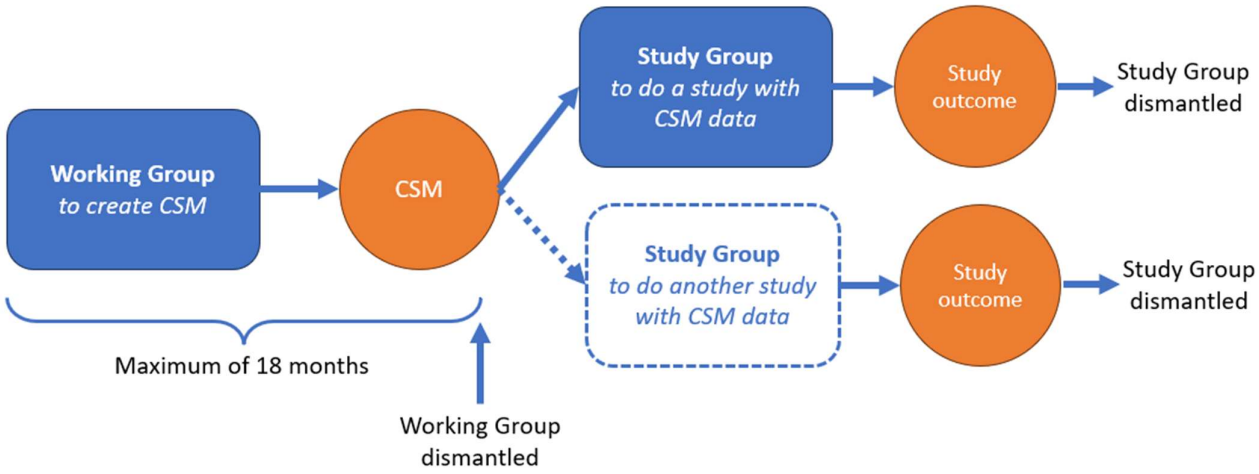
General remarks

- All papers and minutes must be treated in strictest confidence
- All members must act in the best interest of the project
- Any passwords and logins provided to members to enable their roles should not be shared with anyone

Working Group specific agreements

- The Working Group Lead and Registries Team are expected to organize at least one meeting every three months to discuss the progress in the developing of the condition-specific module.
- The Working Group Lead will be responsible for drafting the agenda of the Working Group meetings
- The Working Group Lead will be the main contact person for the Registries Team
- Members of the Working Group will serve a 18-month term renewable for another year if the Working Group remains active
- Members of the Working Group should make every effort to attend all Working Group meetings. If members attend less than 50% of the scheduled meetings over a

period of two years they may reconsider their membership.

- Working Group members should be or become active users of the Registries platforms e-REC and Core Registry after installation, with the exception of patient representatives. If not successful, this should be discussed with the Registries Team. The Registries Team will provide the Working Group members seeking for approvals additional support and will supply the Joint Data Registries Agreement if needed.
- The Working Group will provide a short progress report every year to monitor their progress.
- After the Working Group is dismantled, the Working Group members will be invited to create a Study Group by applying to the Data Access Committee with a study proposal and a data request in order to perform a study with the CSM data.

Overview of Working Groups and Study Groups