European Registries for Rare Endocrine and Bone Conditions (EuRREB)
Study Group Operating Procedures

The overall aim of EuRREB Study Groups is to help better define reported cases of a specific condition by performing a study with the data of a condition-specific module (CSM). To form a Study Group, members of the Working Group who advised on the development of the CSM (or any other interested parties) will apply to the Data Access Committee with a study proposal and a data request. We expect the Study Group to actively work together in order to collect and analyse the data gathered within the module. In addition we expect the Study Group to continue to improve the module and to generate new study proposals at least every 24 months. The Study Group will also be available to assist the Registries Team with any dissemination regarding the condition-specific module. One condition-specific module can host multiple Study Groups.

Members of the Study 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

Study Group specific agreements

- The Study Group lead will apply with the Data Request Form for access to the collected data
- The Study Group Lead is expected to organize at least two meetings a year to discuss the progress in the data collection and any data requests. To do so the Registries Team will support the planning of the meeting and provide the CSM data 4 weeks in advance in order for the Study Group lead to prepare. Additional meetings will have to be organized by the Study Group themself.
- The Study Group Lead will be responsible for drafting the agenda and slides of the Study Group meetings
- The Study Group Lead will be the main contact person for the Registries Team
- In the Study Group meeting with the Registries Team updates on the module and possible

alterations to the module can be discussed.

- Members of the Study Group will serve a 4-year term renewable for another year.
- Members of the Study Group should make every effort to attend all Study Group meetings. If members attend less than 50% of the scheduled meetings over a period of two years they may reconsider their membership.
- Study Group members should be active users of the Registries platforms e-REC and Core Registry or plan to become active within 12 months after installation, with the exception of patient representatives If not successful this should be discussed with the Registries Team. The Registries Team can provide the Study Group members seeking for approvals additional support documents and will supply the Joint Data Registries Agreement if needed.
- The Study Group will provide a short progress report every year to monitor their progress. The Registries Team will provide a template for this report. If the report is not handed in this might lead to dismantling of the Study Group.
- When a study has closed the group will be dismantled after 1 year unless a new study request has been put forward.

Overview of Working Groups and Study Groups