

Main Thematic Groups (MTGs)

All activities within Endo-ERN are organized by Main Thematic Group (MTG). The MTGs were established according to the usual classification of endocrine conditions.



European
Reference
Network



Endo-ERN

European Reference Network
on Rare Endocrine Conditions

- 1 Adrenal
- 2 Disorders of Calcium & Phosphate Homeostasis
- 3 Genetic Disorders of Glucose & Insulin Homeostasis
- 4 Genetic Endocrine Tumour Syndromes
- 5 Growth & Genetic Obesity Syndromes
- 6 Hypothalamic and Pituitary Conditions
- 7 Sex Development & Maturation
- 8 Thyroid

Member Short Guide

European Patient Advocacy Group (ePAGs) & Patient Information



ePAGs are members of our work packages and MTGs and bring the patient experience to every Endo-ERN. They also provide patient information in multiple languages that might be helpful for your patients.



Sign up for our newsletter to be kept up-to-date on Endo-ERN activities



Registries

The aim of the registries is to offer patients, health care professionals, and researchers the opportunity to participate and use high-quality, patient-centred registries for rare endocrine and bone/mineral conditions.



e-REC (e-reporting)

This registry only captures new clinical encounters and no personal data. From 2023 e-REC will be an integral part of the Endo-ERN Continuous Monitoring (CM) programme, with a requirement for patient data (outcome measure number TBD) to be submitted via the e-REC registry.

Core Registry

Core Registry captures Patient Reported Outcome Measures (PROMs) and allows a clinician to monitor a patient for a longer period. It also includes Condition Specific Modules which cover the work of dedicated multidisciplinary study groups.

Questions about CM aspect of e-REC contact the Endo-ERN project office: EndoERN@amsterdamumc.nl.



Education & Training

There is a substantial amount of educational content available to Endo-ERN members that will help you expand the knowledge in your team. You will find links below to the various activities.



Webinars



Publications

Educational Library



Endorsed Events



Clinical Exchange Programme



Clinical trials

Virtual Consultations

ERNs were created by the European Commission to ensure accessibility of expertise and that, when it comes to rare disease, the medical knowledge and expertise travel, rather than the patients.



A virtual consultation can be used to:

- Establish a diagnosis
- Discuss possible new treatments or treatments not available locally
- Optimize and improve existing treatment

You, as an expert healthcare provider (HCP) working in an Endo-ERN Reference Centre (RC), can participate in virtual consultations using the Clinical Patient Management System (CPMS). You can participate or initiate patient panels that invite in-depth discussion of cases online with other expert colleagues. A report is issued to the treating physician with recommendations to help manage the patient's care and a possible diagnosis.

Getting Started with Virtual Consultations

- 1 Register to use CPMS
- 2 Identify your expertise in the system
- 3 Use the secure system to exchange expertise across the network



Training resources including videos are available.



Use of CPMS is a measurable element in the annual Continuous Monitoring (CM).