

Endo-ERN

European Reference Network
on Rare Endocrine Conditions

Welcome Guide Endo-ERN

March 2022



European
Commission

Endo-ERN is a European Reference Network co-funded by the
European Union's Health Programme under grant agreement No 739572



European
Reference
Network



Welcome!

Dear Endo-ERN member,

Thank you for joining the European Reference Network on Rare Endocrine Conditions (Endo-ERN). With this guide we would like to welcome you to our network and make your integration to the ERN as easily as possible.

What is Endo-ERN?

The European Reference Network on Rare Endocrine Conditions (Endo-ERN) aims to improve access to high-quality healthcare for patients with hormonal disorders. Endocrine conditions are often complex and require a long period of care due to chronic disease without being life-threatening. Therefore, endocrine care requires equal distribution of paediatric and adult care. Endo-ERN aims to provide this care for patients throughout their entire lives and to reduce and ultimately abolish inequalities in care for patients with rare endocrine disorders in Europe, through facilitating knowledge sharing and facilitating related healthcare and research

Governance of Endo-ERN

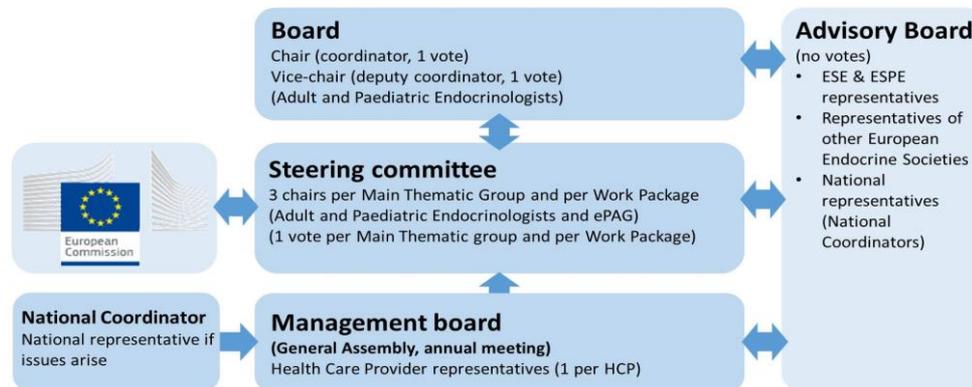


The **Endo-ERN board** consists of the Chair and Vice-chair. Covering adult endocrinology and paediatric endocrinology, each with equal rights. Their role is to coordinate all activities of the Steering Committee (SC), to organise and chair the SC meetings and the General Assembly, and to function as information link between Member States and the European Commission and between ERNs.

The **Steering Committee** includes all main thematic group chairs and work package chairs. It has 13 permanent votes. Each MTG and WP is led by several chairs – one paediatric, one adult physician, and ePAG patient representatives. This ensures active patient involvement in any strategic decision and action.

The **Management Board** consists of 1 representative per Reference Centre.

The **Advisory Board** consists of national coordinators and representatives of ESPE and ESE.





Endo-ERN Main Tools

- [Endo-ERN website](#)
- [Endo-ERN newsletter](#)
- [ERN Collaborative Platform](#) ERN members have access to the Collaborative platform. This platform can be used to store documents concerning your projects, save shared events, and to have discussions. It is restricted to ERN use only and is not to be used for the exchange of patient data. For this you will need an EU login to access the platform, then please request access to **ENDO**.
- [EUROPEAN website](#) For general information on ERN's
- [Contact information Endo-ERN](#)





What is expected from you?

Please carefully read the following points

- 1. Request access to CPMS (Clinical Patient Management System)**
- 2. Complete the contact details survey for our database**
- 3. Register for EuRRECa registry**
- 4. Contribute to the Continuous Monitoring Programme**
- 5. Participate in ERICA Expert Working Groups**



1. CPMS

[The Clinical Patient Management System \(CPMS\)](#) is a secure web-based application to support European Reference Networks in the diagnosis and treatment of rare or complex conditions across national borders.

CPMS will realise one of the ERNs core tasks; bringing expert specialised care to all patients in Europe. The system will allow for virtual consultation across national borders, ensuring that the needed expertise can travel to the patient, instead of the other way around.

Via the CPMS any doctor can ask for virtual consultation of Endo-ERN reference centres. This IT platform will enable a multidisciplinary team (MDT) to discuss highly specialised patient cases in a secure closed-off environment. The resulting advice can then be directly referred back to the patient by their own treating physician.

You will be notified when it is possible to create an CPMS account.

- [How to request authorization CPMS](#)
- [Login CPMS](#)
- [Contact Endo-ERN CPMS helpdesk](#)



Co-financed by the Connecting Europe
Facility of the European Union



2. Contact details database

The Endo-ERN database will enable to significantly improve the communication and dissemination within our network. Having the correct and updated details, it will be easier and quicker to find the correct person for a specific case or activity.

Therefore, a survey has been developed in order to create an up-to-date database with contact details of all individual Endo-ERN experts that are active within our network and/or can be approached for specific expert activities.

We would like to ask to you to identify the representative(s) for all of the MTG's which your HCP has been accepted for, with the correct details of experts.

To access the survey, please click on this link (or copy it to your browser):

<https://ec.europa.eu/eusurvey/runner/Contact-details-HCP-per-MTG>

Note that the contact details will be treated confidentially and that only the Coordinating Centre in Amsterdam will manage the database, together with the webmaster of Endo-ERN.



3. EuRRECa

The European Registries for Rare Endocrine Conditions (EuRRECa) is aimed at maximizing the opportunity to participate and use high quality, patient-centred registries for rare endocrine conditions.

EuRRECa provides two registry platforms.

- An e-reporting platform that acts as a surveillance registry for rare conditions (**e-REC**) - regular monthly reporting supports HCPs in the continuous monitoring process
- A **Core Registry** that can collect a minimum dataset for all rare bone and endocrine conditions.

The Core Registry also has condition-specific and generic outcome modules that can be completed by patients or clinicians.

The platforms support Endo-ERN and are open to all health care providers around the world

[Click here to Register for e-REC and/or the Core Registry](#)

Visit the EuRRECa website for further information

www.eurreca.net



EuRRECa
European Registries for
Rare Endocrine Conditions



4. Continuous Monitoring Programme

Every member of Endo-ERN is mandatory to contribute to the **ERN Continuous Monitoring Programme**, which is a very important exercise for ensuring and the continuity of ERNs.

All actors (Member States, ERNs and European Commission) have identified the need to establish a solid and valid ERN continuous monitoring and assessment system to allow a closer follow up of the activities performed by the networks and its members.

This system should help to build the AMEQUIS* system, to define appropriate outcomes of the ERNs, to identify areas of success and potential pitfalls and to demonstrate the value of the ERNs, ultimately learning from the experience.

*AMEQUIS = An integrated Assessment, Monitoring, Evaluation and Quality Improvement System for the European Reference Networks



Overview of indicators

Objective 1	To ensure that ERNs are operational	
1.1	Number of Member States with Health Care Providers as full members or affiliated partners in the ERN	
1.2	Number of full members of the ERN	
1.3	Number of affiliated partners of the ERN	
1.4	Number of patient organisations represented in the ERN	
Objective 2	To improve access to clinical advice, diagnosis, treatment and follow-up of patients	
2.1	Number of new patients referred to the Health Care Providers participating in the ERN with the diagnosis of a disease or condition that falls within the scope of the ERN	
2.2	Number of patients entered into CPMS by the ERN during the reporting period	
Objective 3	To optimise patient outcomes by combining healthcare professionals' skills & resources used	
3.1	Number of panels reviewed by the ERN with an outcome report produced during the reporting period.	
3.2	Time taken to provide multidisciplinary clinical advice between referral to the ERN and multidisciplinary clinical advice. 3.2.a - Non-urgent cases: days (median) 3.2.b - Urgent cases: days (median)	
Objective 4	To increase the capacity of professionals to recognize and manage cases of rare and complex conditions and diseases within the scope of the ERN	
4.1	Number of education/training activities not accruing higher education credits aimed at healthcare professionals delivered by the coordination teams or HCP members of the ERN	
4.2	Number of formal educational activities that are accruing higher educational credits aimed at healthcare professionals delivered by the coordination teams or HCP members of the ERN	
Objective 5	To reinforce clinical research in the field of rare and complex conditions and diseases by collecting data and carrying out research activities	
5.1	This indicator covers different activities involving ERN members in at least two Member States: 5.1.a - Number of Clinical Trials 5.1.b - Number of Observational prospective studies / Observational cohort or case-control studies / Number of case-series studies	
5.2	Number of accepted peer-reviewed publications in accredited scientific journals regarding disease-groups falling within the scope of the ERN and acknowledging the ERN.	
Objective 6	To ensure that patients referred to ERNs have equal access to high and quality healthcare services	
6.1	Number of Clinical Practice Guidelines and other types of Clinical Decision Making Tools, adopted for diseases within the scope of the ERN during the reporting period	
6.2.	This indicator is split into two sub indicators, for diseases within the scope of the ERN: 6.2.a - Number of new Clinical Practice Guidelines written by the ERN and released during the reporting period 6.2.b - Number of other types of new Clinical Decision Making Tools (clinical consensus statements or consensus recommendations), written by the ERN and released during the reporting period	
Objective 7	To guarantee that knowledge is spread outside the ERN so that more people can benefit from the ERN activities	
7.1	Number of congresses/conferences/meetings at which the ERN activities and results were presented	
7.2	Number of individual ERN website hits	
Objective 8	Complex and long-term indicators which need further development	
8.1	Level of patient satisfaction	<i>To be developed</i>
8.2	Health Care Provider Compliance to Clinical Guidelines	<i>To be developed</i>

You are requested to provide data on an annual basis.

The Coordinating Center will contact you in time when you need to provide your data.



5. ERICA

ERICA: European Rare Disease Research Coordination and Support Action
Coordinator: Prof. Alberto Pereira (also Endo-ERN coordinator)
Website: www.ericard.eu
Partners: All 24 ERN's, EURORDIS, EJP RD, Orphanet, Mapi Trust and EATRIS
Aim: To strengthening ERN's research and innovation capacity of,

Workpackages

- [WP2: Data Collection, Integration and Sharing](#) (to give support and boost on Registry project).
- [WP3: Patient Centred Research](#) (PCOM and PROMs Central repository (validated) for RDs.)
- [WP4: Clinical Trial support](#) (supporting Clinical trial engagement of ERNs)
- [WP5: Translation and Innovation](#) (to increase the translation and innovation capacity of ERNs)
- [WP6: Integration, Outreach& Dissemination](#) (incl. design of interactive ERN research web-platform)

Engagement of all ERN members in all project activities via specific Expert Working Groups (EWGs) – nominations via Endo-ERN coordinating office or directly via [ERICA office](#)

[ERICA Advisory Board](#) has representatives of all the biggest players in Europe on the RD field (If you are looking for a link with one of those infrastructures or for a feasibility study of research activity, to know who you need in the process, then those people can support/advise you hereby.)

- Subscribe to newsletter : <https://ericard.eu/newsletter/>



@ERICA_RD_EU

