

Endo-ERN

Endo-ERN works on rare endocrine conditions. It covers Adrenal, Disorders of Calcium & Phosphate Homeostasis, Genetic Disorders of Glucose & Insulin Homeostasis, Genetic Endocrine Tumour Syndromes, Growth & Genetic Obesity Syndromes, Hypothalamic and Pituitary Conditions, Sex Development & Maturation, and Thyroid.

This ERN included 105 healthcare providers located in 27 countries in the EU and Norway, distributed as follows:

- 91 Full Members in 21 Member States
- 11 Associated National Centres in 5 Member States and 2 in Norway
- 1 National Coordination Hub in a Member State

In addition, 20 patient representatives from 10 countries collaborate in the ERN activities. Collaborative agreements are also in place with the 2 main professional scientific societies in the field (European Society of Endocrinology and European Society of Paediatric Endocrinology).

KPI# Endo-ERN Indicators overview

Coordination		2023	2024
1	ERN Member (HCP) Performance Indicator System	N/A	Yes
Dissemination		2023	2024
3	Number of downloaded documents from ERN website	4991	4375
4	Number of dissemination webinars	16	16
5	Number of webinars attendees	405	393
Healthcare and Clinical Patient Management System (CPMS)		2023	2024
6	Number of new patients referred to the HCPs of the ERN with the diagnosis of a disease or condition that falls within the scope of the ERN	19287	21052
7	Number of patient cases discussed in the IT platform for cross-border clinical discussions (CPMS)	161	149
8	Active participation in the new CPMS development, testing and roll-out	100%	92%
Registries: Indicators		2023	2024
10	Number of new patients uploaded to the ERN registry	12774	15983
11	Percentage of the total ERN patients that are uploaded to the registry (ies)	66%	76%
16	Mapping of the use of Orphacodes in all clinical units	48%	65%

EUROPEAN REFERENCE NETWORKS
Monitoring report 2025

Training and Education		2023	2024
17	Number of accredited Training Courses developed by the ERNs	51	6
18	Number of trainees who completed accredited Training Courses	4765	535
19	Number of countries of origin of trainees who completed accredited Training Courses	40	43
20	Number of non-accredited training courses developed by the ERN	82	25
21	Number of trainees who completed the non-accredited trainings	33127	534
22	Number of countries of origin of trainees who completed the non-accredited Training Courses	40	45

Clinical Practice Guidelines and other Clinical Decision Support Tools		2023	2024
23	Number of Clinical Practice Guidelines and other types of Clinical decision-making tools, adopted for diseases within the scope of the ERN	67	2
24	Number of new Clinical Practice Guidelines and other types of Clinical Decision-making tools written and released by the ERN	0	5