

Update Endo-ERN grant

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Funded by
the European Union

ERN Success stories



Rare Diseases

European Reference Networks

A success story for patients living with a rare disease



February 2025



ENDO ERN

European Reference Network on rare endocrine conditions
<https://endo-ern.eu/>

Members

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
- 20 patient representatives from 10 countries are also collaborating.



Disease areas

- 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
- Thyroid

Guidelines, care pathways, and patient journeys

- 4 guidelines written by Endo-ERN
- About 60 guidelines co-authored and/or endorsed by Endo-ERN
- 1 care pathway
- 3 patient journeys

Training and education

- 70+ Endo-ERN webinars organised since 2019
- Joint webinar programme with European Endocrine societies (adult and paediatric)
- Endo-ERN symposium at European Endocrine Societies Annual Conferences
- 17 clinical exchanges (20 health care providers, 12 countries) since 2021
- Endorsement / accreditation of educational activities

Clinical Patient Management System (CPMS)

- 250 CPMS case discussions since 2017

Research and patients' registries

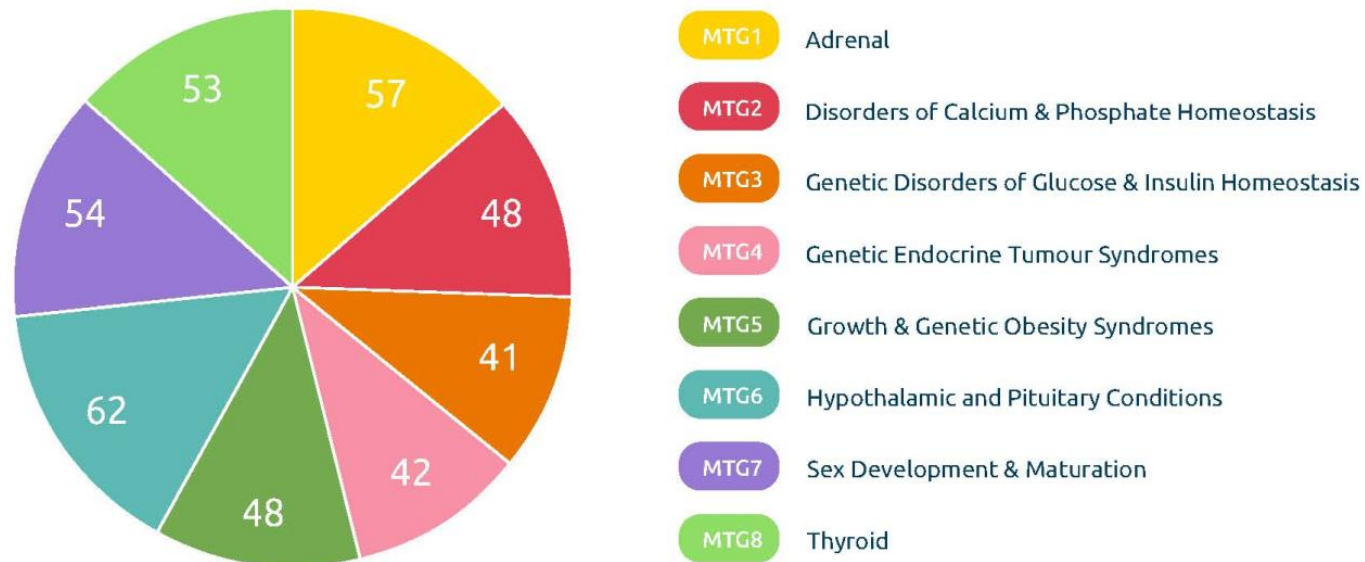
- About 200 relevant research projects or clinical trials involving at least two healthcare providers from two different Member States
- 3 850 patients recorded in the core registry (<https://eurreb.eu/>), a shared platform with ERN BOND

Update activities



Management & Coordination	WP1	→	Daily management and coordination
Dissemination	WP2	→	Development stakeholder targeted communication strategy plan
Evaluation	WP3	→	Implementation HCP performance system
Healthcare and CPMS	WP4	→	Implementation CPMS 2.0
Registries, data management and analysis	WP5	→	Further development EuRREB registries
Education and Training	WP6	→	Enrolment educational & training program
Clinical Practice Guidelines and Clinical Decision Support Tools	WP7	→	Development Endo-ERN clinical practice guidelines & CDST's
Capacity building and best practice sharing for Ukraine	WP8	→	Supporting and providing Ukrainian healthcare providers with the available expertise from our network
Other activities for Ukraine	WP9		

Main Thematic Groups (MTGs)



Enlargement of disease areas:

- for the ERN: bound to EU call
- for the HCP: further protocolled enlargement for disease areas across the network

Endo-ERN sustainability



What: Endo-ERN **multi-beneficiary** grant
Grant duration: 1 October 2023 - 1 October 2027 (4 years)



Key points to note

- a. Interim report
- b. Sustainability (MFF, EU4Health, Life Sciences)
- c. Next ECG with EC meeting 20/21 May in Rome

Future focus



Further development of Endo-ERN, based on:

- 1 Integration of Endo-ERN into the national health care systems of Member States (JARDIN)
- 2 Integration of Endo-ERN with the European Health Data Space ([EHDS](#)) (EuRREB)
- 3 Integration of Endo-ERN research activities with current and future European RD research initiatives / structures (ERICA, ERDERA etc)



Endo-ERN sustainability



Towards an EU action plan on rare diseases *W kierunku unijnego planu działania dla chorób rzadkich*

10 April 2025 | 09:00 - 17:30
Conference / Konferencja

11 April 2025 | 08:45 - 18:00
Side event / Wydarzenie towarzyszące

Medical University of Warsaw / Warszawski Uniwersytet Medyczny

What's next

- Implementation of the joint action JARDIN
- Using the new CPMS 2.0– Clinical Patient Management System
- Reform of EU pharmaceutical legislation
- Implementation of the European Health Data Space
- Work on ERN registries
- Improve Geographical access and disease expansion of the ERNs
- Revision of the evaluation procedure for ERNs
- Training and education activities of the ERNs
- Implementation of ERDERA (2025-2031)



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Polska Prezydencja w Radzie UE
Polish presidency of the Council of the EU
Présidence polonaise du Conseil de l'UE



VERITATIS
SPLENDOR



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Endo-ERN Research activities

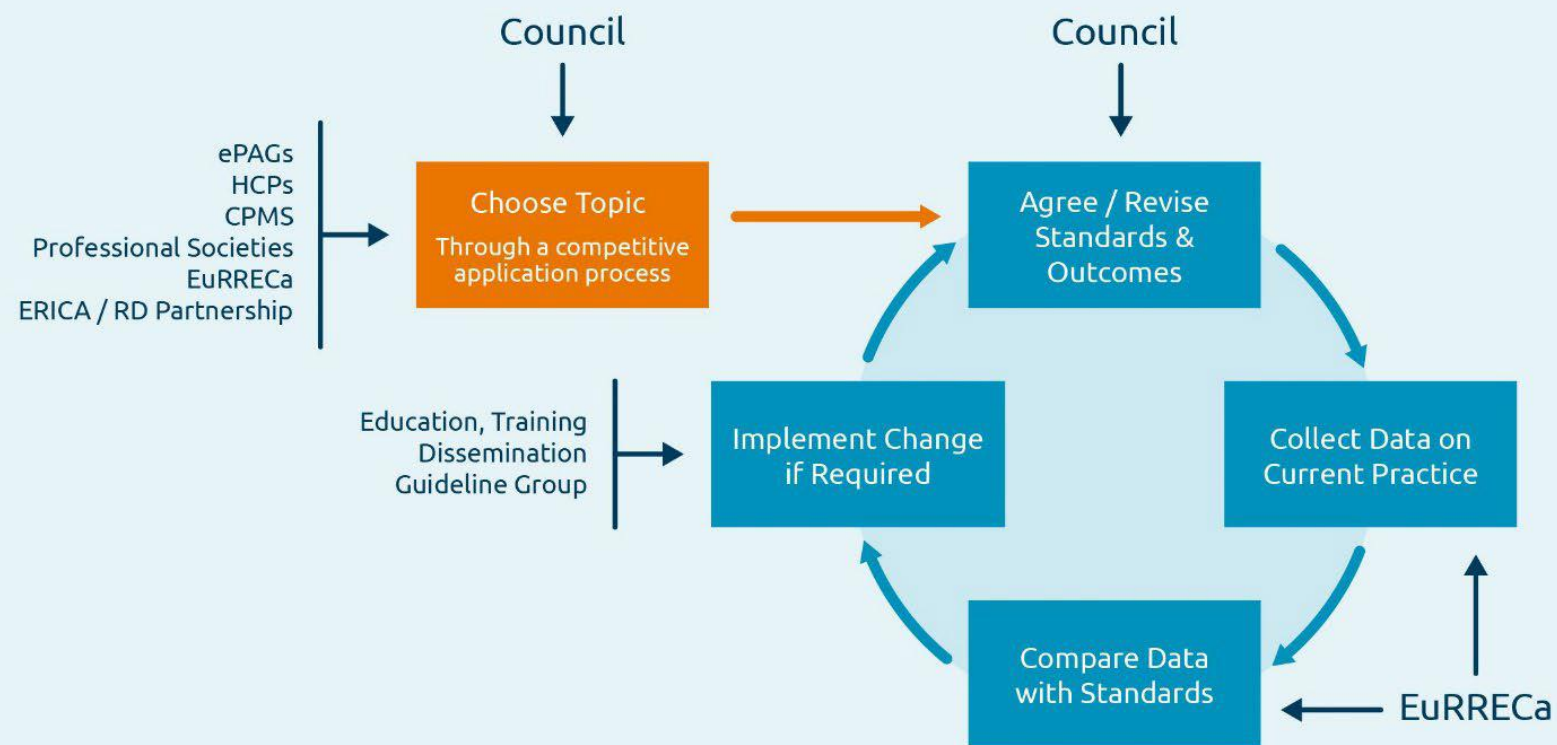


- Capture research activities & unmet needs / research priority topics within the network
- Some ERNs have a dedicated work package on Research, we initiated *the Quality of Care Improvement through Research Council* in WP1.
- Proposal: To install a 3rd transversal working group on Research, which includes the already started activities of the council and could include the funding of activities which stimulate or enhance research initiatives within our network.
- We already made a start with capturing the research activity within the network by collecting your scientific contributions at the joint congress.

→ Please complete the survey →



Quality of Care Improvement & Research Council



GA 2026: Athens, Greece

Local organizing committee:
Provisional dates:

Prof. Evangelia Charmandari & colleagues
20+21 April or 27-28 April 2026

