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Endo-ERN Steering Committee / Advisory Board meeting

Date: Tuesday 20 January 2026

Time: 09:30 – 11:30 hrs

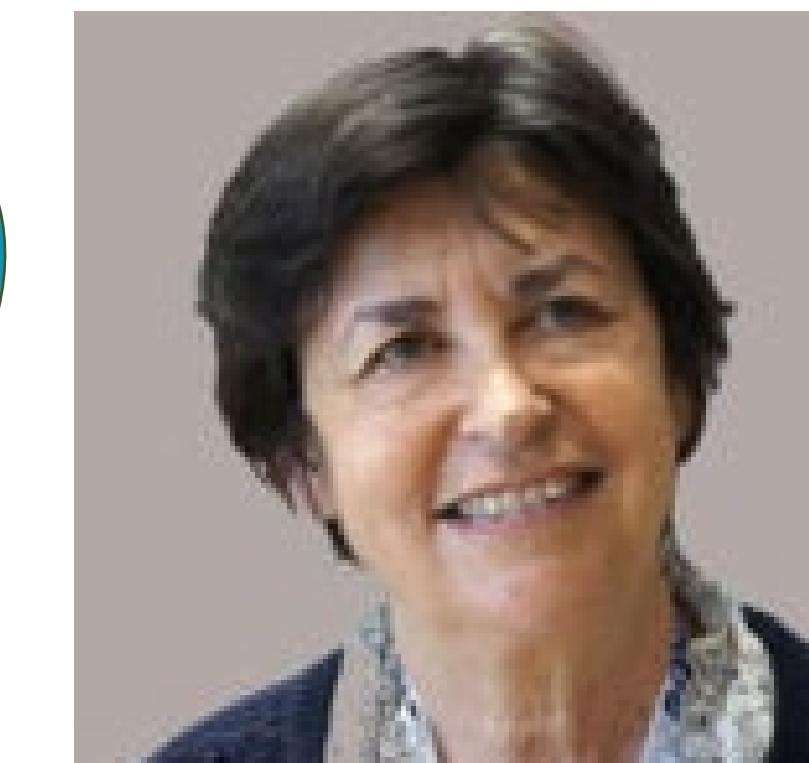


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IN MEMORIAM

Jette Kristensen

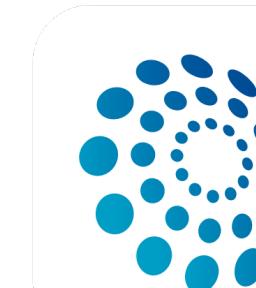


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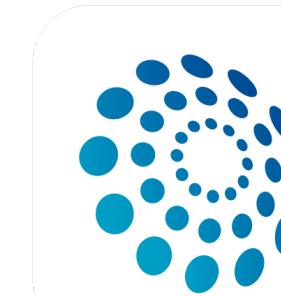
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Agenda

1. Review (outstanding) action points previous meeting
2. Work Package updates (8 minutes each)
3. Working Groups updates (8 minutes each)
4. Other RD project updates
5. AOB & questions



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Review outstanding action points previous SCAB meeting

1. Pre-plan MTG-specific HCP meetings 2026

MTG	Date	Time
1	To be scheduled	
2	18 March 2026	16:00 – 17:00
3	25 February 2026	16:00 – 17:00
4	Next meeting @ GA	
5	26 January 2026	15:00 – 16:00
6	20 February 2026	12:00 – 13:00
7	4 February 2026 2 September 2026	16:00 – 17:00
8	15 October 2026 (TBC)	

2. Pre-plan minimum 5 webinars for early 2026



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WP1 Management & Coordination

Alberto Pereira, Adult Chair Endo-ERN

Olaf Hiort, Paediatric Chair Endo-ERN

Charlotte van Beuzekom, Project Manager Endo-ERN



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New ePAG MTG1 Adrenal

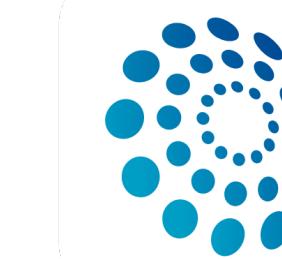
[Teresa Valencia](#)

Spanish National Association of Addison's Disease and other
Rare Endocrine Disorders

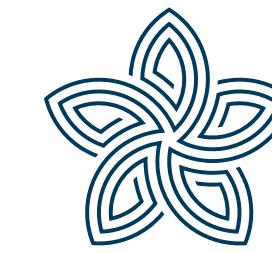


Adisen

Asociación Nacional de Addison
y Otras Enfermedades Endocrinas



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ESE and ESPE RD Committees



ESE RD Committee

<u>(co)Chairs</u>	<u>Term</u>
Elena Valassi (ESE)	2024 – 2028
Alberto Pereira (Endo-ERN)	2019 – 2027

Endo-ERN representatives

Gudmundur Johannsson	2020 – 2026
Marek Niedziela	2024 – 2028
Luca Persani	2024 – 2028
Dimitra Vassiliadi	2024 – 2028

Alignment procedures committee composition



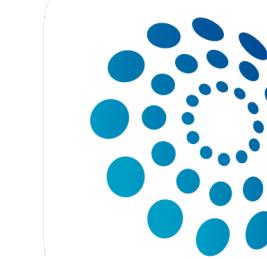
ESPE RD Advisory Committee

<u>(co)Chairs</u>
Evangelia Charmandari
Marek Niedziela

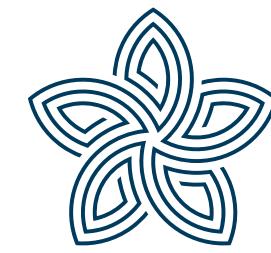
Endo-ERN representatives

Olaf Hiort
Nicole Reisch (?)
Pietro Maffei

Funding grants



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Current EU4Health grant 2023-2027

- Deliverables
 - All deliverable reports submitted in time
 - Under evaluation by EC and external evaluators
- 1st Period report
 - Covering 1 Oct '23 – 31 Dec '25
 - Technical and financial report
 - Grant partners informed about obligations/deadlines
 - Submission deadline total report to EC = end February '25

Submitted deliverables – due Nov 2025

Nr.	Name
D1.4	Organisation General Assembly Y2
D2.2	Dissemination report 1
D3.2	Evaluation report 1
D3.5	Indicators report Y2
D4.1	CPMS activities report Y1+Y2
D5.1	Registry activities report Y1+Y2
D6.1	Training activities report Y1+Y2
D7.1	CPG/CDST activities report Y1+Y2
D7.3	First new CPG produced
D8.1	Report activities WP8
D9.1	Report activities WP9

Future ERN grants

- Multi-annual Financial Framework 2028-2034
- High Level Meeting - Declaration

Endocrine Connections - special issue 2025



Lead author	Paper title	Status
Felix Reschke	Challenges and Strategies for Transitioning Adolescents with Rare Forms of Diabetes to Adult Care: Perspectives and Evidence-Based Approaches	ACCEPTED
Nienke Biermasz	Quality of care for patients with prolactinoma diagnosed under the age of 25 years	Under review
Hedi Claahsen	Enhancing Transition Care for adolescents and young adults with adrenal insufficiency in the Netherlands: A Holistic Model for Improved Patient Outcomes	ACCEPTED
Corinna Grasemann	Continuity of Care in Klinefelter Syndrome: Age-Adapted Modules for Standardized Clinical Data Collection (I-KS)	ACCEPTED
Violeta Iotova	Feasibility of transition research in pituitary disease using patient registries	ACCEPTED
Ana Priego	The EuRRECa Core Registry and its potential for studying transition of care in Endo-ERN reference centres	Waiting for submission
Emily White	First 5 Years of Endo-ERN: Evaluation of the Network and Member Expert Centres & Creation of Endo-ERN Performance System Acromegaly: The Patient Journey	Under review Waiting for submission
Judit Toke	Transitional care of patients with congenital adrenal hyperplasia - our experiences and challenges in a tertiary adult referral center in Hungary	Under review
George Mastorakos	TRANSITION of pediatric patients on GH treatment in Greece	Waiting for submission
Andrea Isidori	Mapping Transition of Care for Rare Endocrine Conditions: Findings from a Cross-Sectional Survey by the Endo-ERN ToC Working Group	Under review
Violeta Iotova	Editorial	Waiting for submission

Endocrine Oncology - special issue 2026/27



General

- More clinical focused (relatively younger) journal
- Waiting for first impact factor, promising numbers

Topics of interest

- Gonadal diagnoses
- Side effects of immunotherapy
- Endocrine consequences of childhood cancer (cross-ERN collaboration with Paedcan?)
- Ultrarare: carney complex, aggressive pituitary tumors
- Cross-collaboration with other cancer-ERNs like EURACAN?

Proposal

- 8-10 papers (1 per MTG, 1 per WG)
- Free of charge, open access
- 2-4 guest editors



Next steps

- Coordination office sends invitation to all members
- MTG selection by MTG chairs
- Launch portfolio of possible papers during GA Athens



Upcoming Meetings 2026



General Assembly 20-21 April, Athens, Greece

Monday 20 April

09:00 – 10:00 SCAB meeting

10:30 – 17:30 Plenary program

19:30 – 21:30 Dinner with Acropolis view

Tuesday 21 April

09:00 – 14:00 Plenary program

Closing lunch

Please make sure to book your travel/hotel and dinner ticket!

ECE2026 9-12 May, Prague, Czechia

Endo-ERN symposium 12 May & booth

- Introduction on Endo-ERN initiatives (focus EndoCompass paper) - *Alberto Pereira/Olaf Hiort*
- WG Genomic Testing - *Thomas Eggermann*
- The pediatric thyroid cancer registry – *Hanneke Van Santen*, UMC Utrecht, NL
- The reduced life expectancy and treatment options for RTHbeta – *Irene Campi*, I.R.C.C.S. Istituto Auxologico Italiano Milan, Italy
- ePAG presentation on patient journeys (*TBD*)

ESPE 2026 8-10 September, Marseille, France

Endo-ERN symposium & booth



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WP2 Communication & Dissemination

Aimee Casey, Communication Manager, Endo-ERN



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Social media update January 2026

	Current total	Increase from September
LinkedIn	978	+246
Facebook	490	+34
YouTube	743	+99
Most popular newsletter	Clinical practice	

Patient Resources Process

<https://endo-ern.eu/patient-resources/>



- Materials sent to project office via online form
- Short summary in English describing the content and purpose of the materials
- ePAG submitted materials should indicate if any medical information is included.
- The MTG chairs will review the submission and decide whether to accept and reject it based on the summary.

We will include the following disclaimer: *This resource was contributed by Endo-ERN member name in language. The relevance of the topic has been reviewed by the appropriate Main Thematic Group (MTG). English summaries and translations into other languages were produced with the assistance of AI. Local-language versions have not been independently validated by Endo-ERN.*

A screenshot of the 'Patient Resources' page. At the top, there are three filter dropdowns: 'Filter by MTG', 'Filter by Condition', and 'Filter by Language', followed by a 'Reset Filters' button. Below the filters is a grid of 16 colored boxes, each representing a different resource. The resources are: 'ERN Registries and Rare Disease Collaboration Across EU...', 'DSDNederland', 'Let's Cure ACC', 'EuRREB: Centraal Register voor baanbrekend onderzoek', 'Central Registry for Ground-Breaking Rare Disease Resear...', 'Mundhygieneinformationen für Patienten mit Phosphatdiab...', 'XLH AND TEETH', 'Oral hygiene info – hypophosphatemia', 'XLH und Zähne', 'Orphanet: The rare disease information portal', 'Schildklier Organisatie Nederland', 'Vivre sans Thyroïde', 'Turner Syndrome Support Society', 'Klinefelter's Syndrome Association', 'SOD ITALIA Associazione Italiana SOD/ONH', and 'De Nederlandse Hypofyse Stichting'. Each box contains a small icon and a brief description.



New Patient Resources

- 20 plus Bulgarian patient materials for MTG3, MTG5, and MTG6
- MEN-1 layperson guideline (English, German, Spanish, Italian, Dutch)
- Recommended medical check-ups and examinations in XLH (English& German)

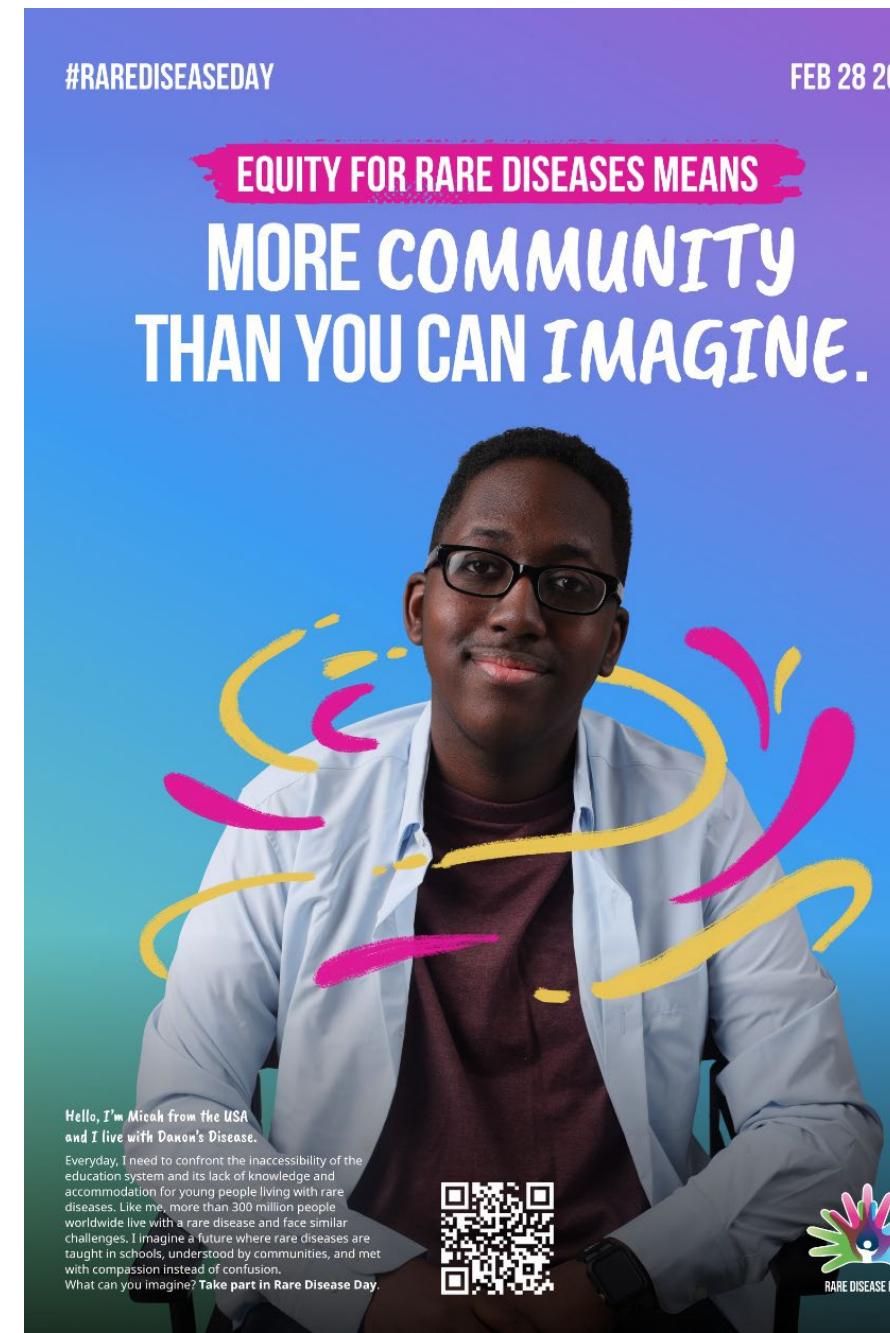
Patient Resources

Filter by MTG Filter by Condition Filter by Language Reset Filters

ERN Registries and Rare Disease Collaboration Across EU...	DSDNederland	Let's Cure ACC	EuRREB: Centraal Register voor baanbrekend onderzoek
Central Registry for Ground-Breaking Rare Disease Resea...	Mundhygieneinformationen für Patienten mit Phosphatdiab...	XLH AND TEETH	Oral hygiene info – hypophosphatemia
XLH und Zähne	Orphanet: The rare disease information portal	Schildklier Organisatie Nederland	Vivre sans Thyroïde
Turner Syndrome Support Society	Klinefelter's Syndrome Association	SOD ITALIA Associazione Italiana SOD/ONH	De Nederlandse Hypofyse Stichting



Rare disease day 2026



- JARDIN campaign – patient focus
- Social posting
- Newsletter
- Downloadable poster – internal communication
- Text for internal communication - intranet or newsletter





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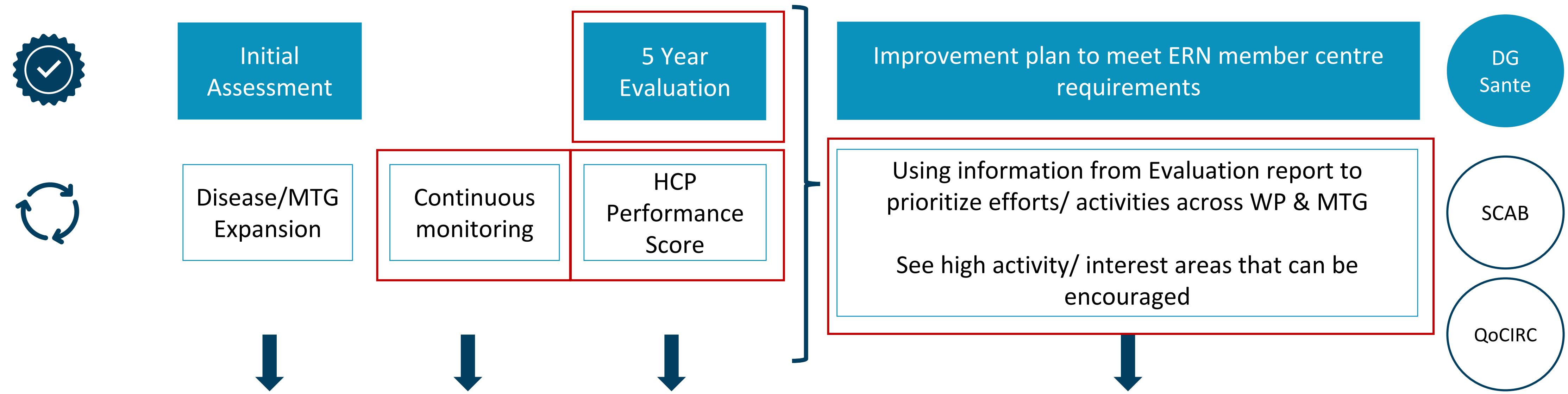
WP3 Evaluation

Emily White, Project Manager & Endo-ERN Operational Helpdesk Manager



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Evaluation in Endo-ERN – QI



Assessment Monitoring Evaluation & Quality Improvement System
AMEQUIS

Continuous Monitoring

2025 data collection started from January 1st 2026

Key reminders to all members:

- Update your e-REC prior to January 31st
- Request reports of total number of rare endocrine patients in your HCP in time (if necessary)

New data requested:

- Number of rare endocrine patients received/ referred from other EU countries in 2025 in your HCP
- Number of Ukrainian patients referred to or treated for rare endocrine conditions in your HCP in 2025
- Emergency/ potential crisis situations

do-ERN

Data no longer requested

- Accredited educational activities run by your HCP – only those with ERN direct involvement are being gathered
- Non-accredited educational activities and all details therein

Endo-ERN Performance Report 2024

This report is generated within the Endo-ERN HCP Performance system. This mandatory evaluation exercise assesses the activity level of each of our member HCPs based on information from sources shown here.

HCP Performance System

```

graph TD
    WPMTGAWGInput[WP/MTG/AWG Input] --> HCPPerformanceSystem
    EndoERNProjectRecords[Endo-ERN Project Records & Overview] --> HCPPerformanceSystem
    ExternalEUPartnerProjects[External EU Partner Projects & Societies] --> HCPPerformanceSystem
    ContinuousMonitoring[Continuous Monitoring] --> HCPPerformanceSystem
    HCPPerformanceSystem --> HCPPerformance
  
```

In 2024, Endo-ERN members...

- Seen 21,074 confirmed rare cases of rare endocrine patients
- Researcher with over 110 active clinical trials and studies
- Completed/Received over 300 rare disease specific training and educational activities
- Used the 67 guidelines and CDEs endorsed by Endo-ERN and highlighted
- Attended and gave talks to 121 congresses, conferences & meetings discussing rare endocrine diseases care
- Worked alongside experts from over 42 countries worldwide

How do we calculate your score?

There are 34 individual activity categories.

Possible Points

- 21 pts **mandatory** = 60% of total
- 20 pts **expected** = 25% of total
- 22 pts **bonus** = 15% of total

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for rare or low prevalence complex diseases
Network
Endocrine Conditions (Endo-ERN)

Mandatory Activities = each HCP has to complete to retain membership (max. 3 points per activity)

Disclaimer: The score generated within this report is based on activities as a member of our network, (nationally or locally).

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Endo-ERN ePAG Evaluation Report 2024

We thank our ePAGs for their efforts in 2024!

10 different countries are represented by Endo-ERN ePAGs. Continued efforts need to be made to include input from underrepresented countries in Europe.

Appendix 1 – Continuous Monitoring Indicators submitted by Endo-ERN

Endo-ERN ePAGs per country

Activities	Details	No. of ePAGs completing activity	No. of ePAGs completing all activities
3.2a Urgent MDT advice - Time in days (Referral-Panel closed in CPMs)	149 days	System generated data.	
3.2b Non-urgent MDT advice - Time in days (Referral-Panel closed in CPMs)	115 days		
4.1a Number of non-accredited education/training activities developed and delivered by the coordination team or by members of the ERN	25	4 clinical exchange, 16 webinars, 2 endorsed events (CME request pending), 3 nationally accredited in host country.	
4.1b Number of trainees who completed non-accredited training	534	273 additional activities reported by members that were rare disease focused/ relevant.	
4.1c Number of countries of origin of trainees who completed non-accredited training	43 countries	Approximation as some HCPs reported a world wide audience	
4.2a Number of accredited education/training activities developed and delivered by the coordination team OR by members of the ERN	6	5 accredited webinar arranged in 2024 by Endo-ERN coordination . 1 endorsed activities run by members of ERN with CME credits approved.	
4.2b Number of trainees who completed accredited training	535	288 activities reported by members that were rare disease focused/ relevant or had national accreditation only.	
4.2c Number of countries of origin of trainees who completed accredited training	43 countries	280 from webinars, 255 from i-DSD event	
		43 countries represented in i-DSD symposium alone.	

Some highlights from 2024:

- Johan de Graaf won 1st prize for his poster on orphan drug shortages at the ERICA RD Conference in Udine, December 2024.
- Arlene Smyth worked tirelessly with TSS UK to create a lay version of [Turners Syndrome CPG](#).
- Manuela Brosme drove efforts to gather input on DSD nomenclature from patients, clinicians and other stakeholders.



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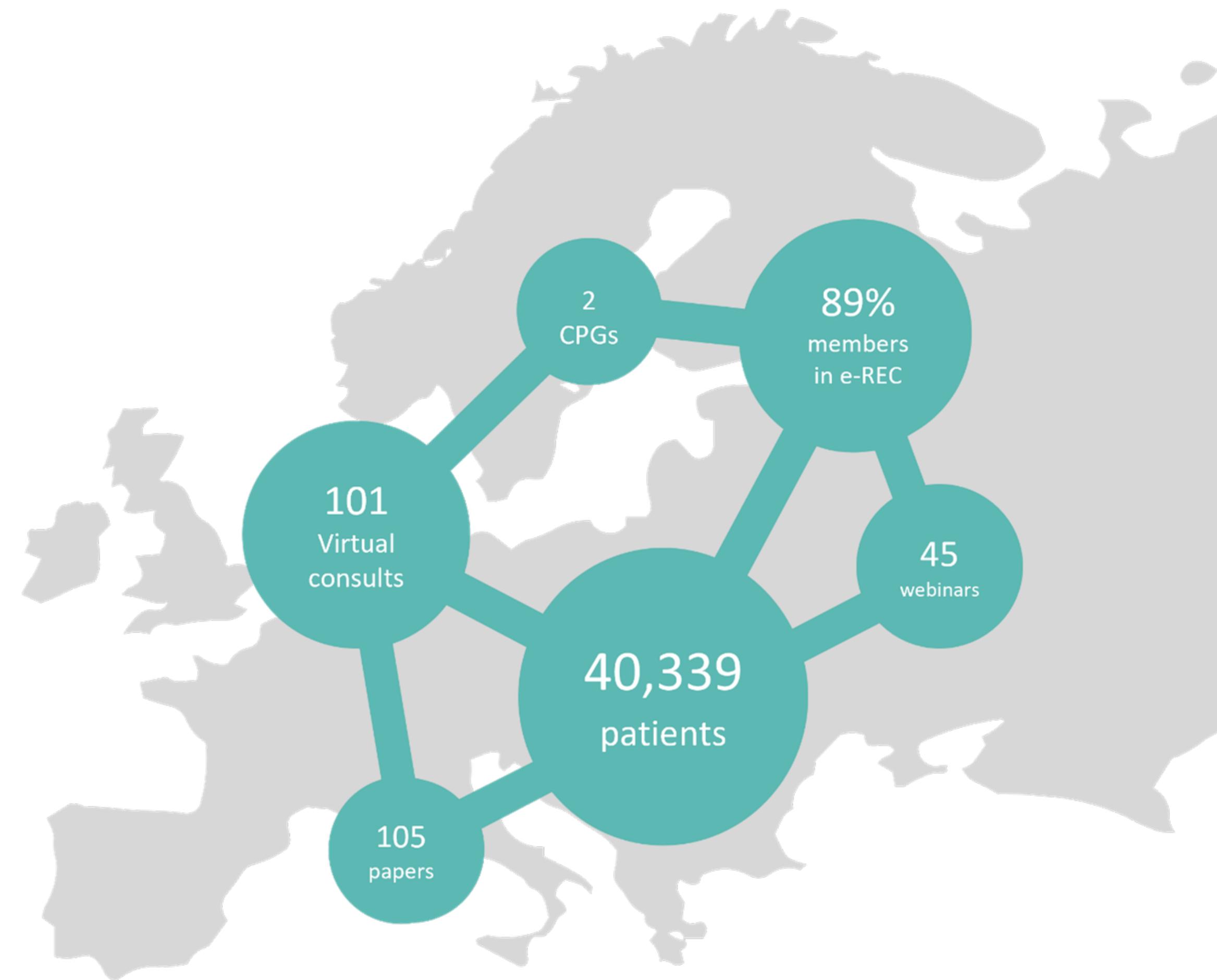
Key reports from 2025

- [ERN Monitoring Report 2023/2024](#)
- [Endo-ERN Indicators Deliverable \(report Y2\)*](#)
- [Evaluation Report \(Y1 &Y2\)*](#)
- [Endo-ERN ePAG Evaluation Report for 2024 – ongoing](#)

*Available upon request

Key achievements since ERN Grant onset in 2023

- Established & trained teams in each of our consortium HCPs
- Created and run our HCP performance system
- Obtained accreditation for webinar series
- Promotion of member activities through Endorsement requests
- Migration to CPMS 2.0 system for case consultations
- Built patient & members resources sections of our Website



Endo-ERN member activities since the start of this grant period (October 2023-October 2025).

Areas of Improvement & Goals for 2026



WP4 Healthcare & CPMS

Olaf Hiort, Paediatric Chair Endo-ERN

Greta Ginski, CPMS Operational Helpdesk Manager

Emily White, Project Manager & CPMS Operational Helpdesk Manager



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Current Statistics



Number of active users in 2025= 254

- 358 user roles

Discussions opened in 2025 = 47

- 302 since ERN started

Number of patients enrolled in 2025 = 72

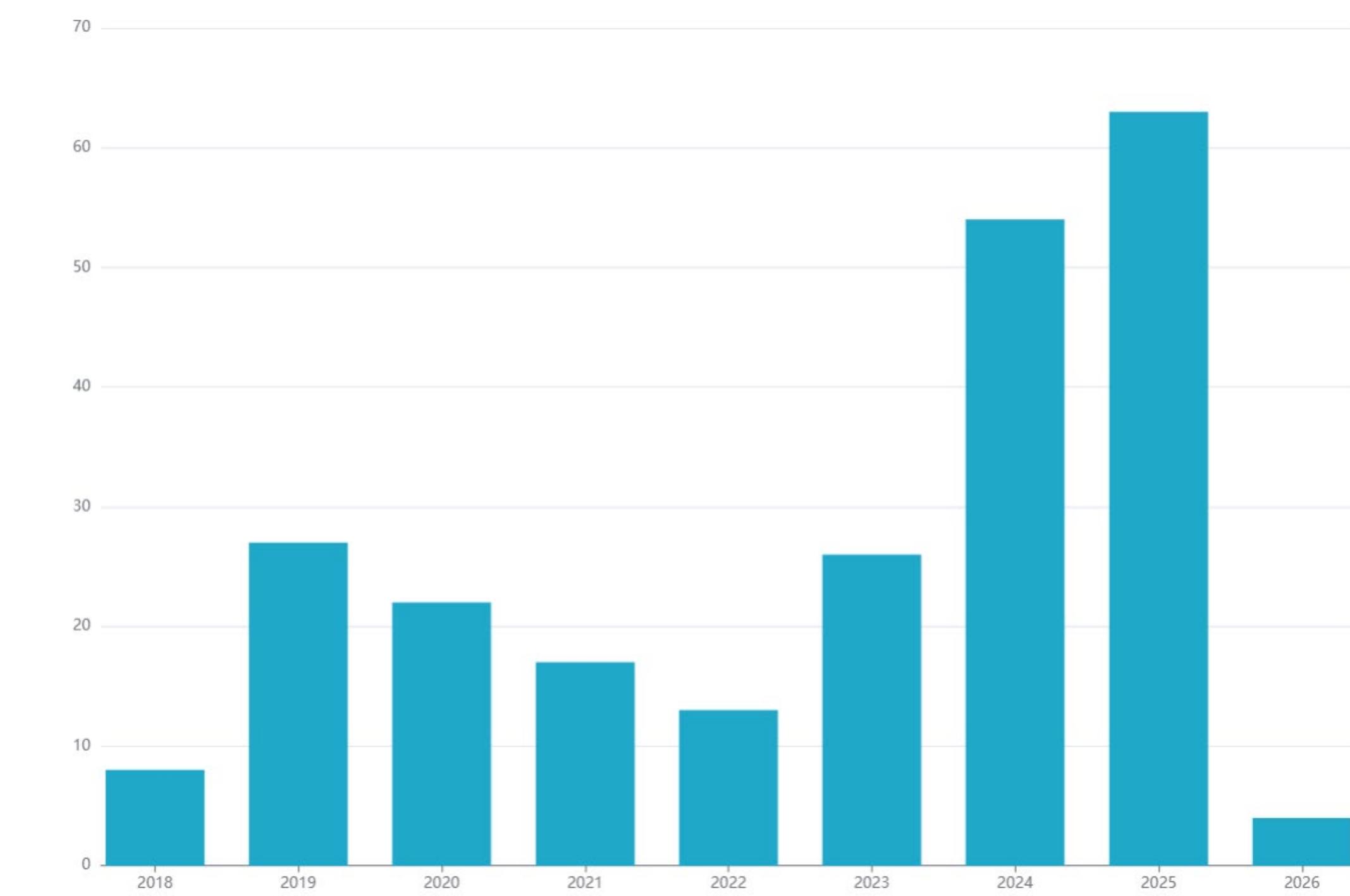
- 967 patients enrolled total

Urgent case discussion = 7

- 55 urgent cases total

Note:
Discussion = 'Panels'

Effective Meetings per year (since start)



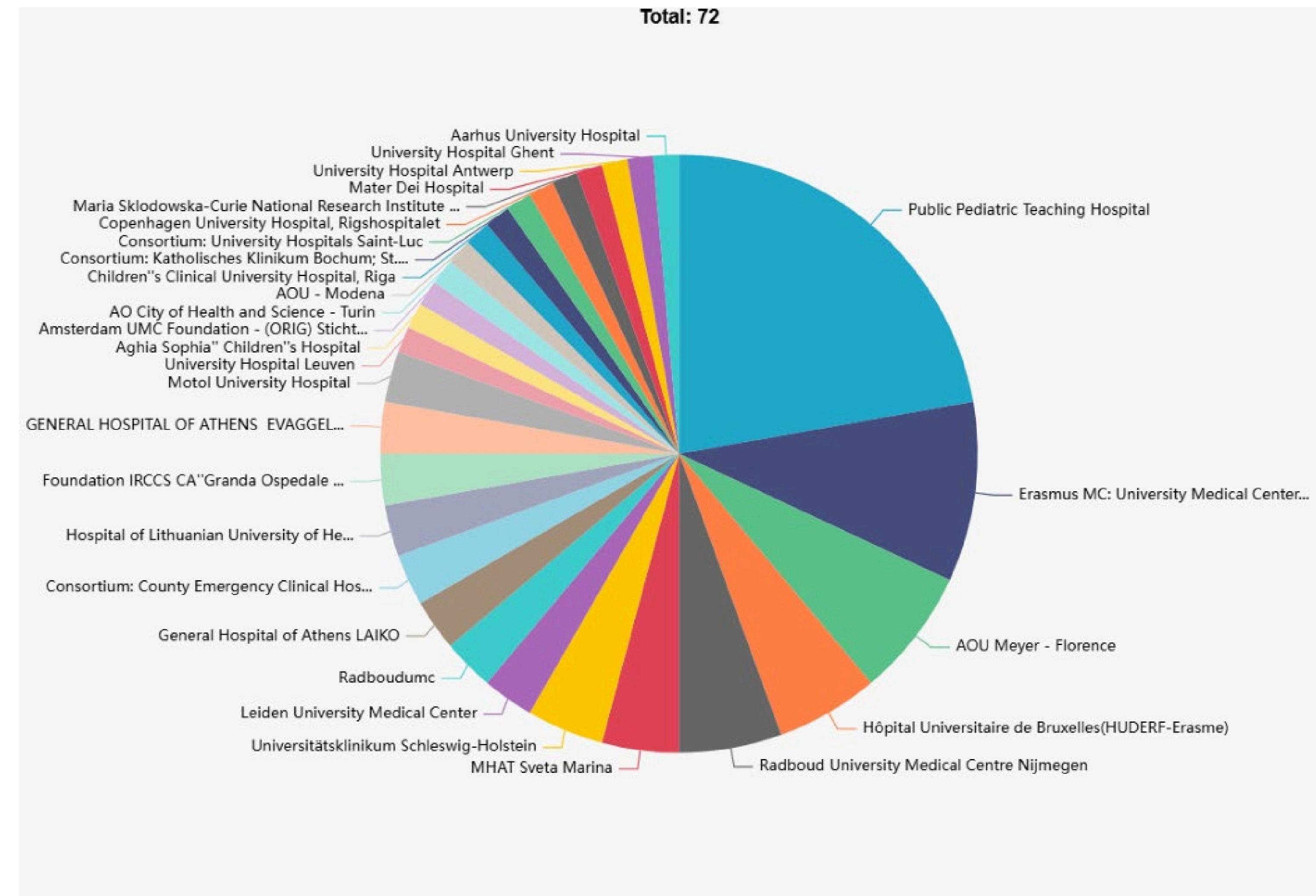
Count of patients per HCP in 2025



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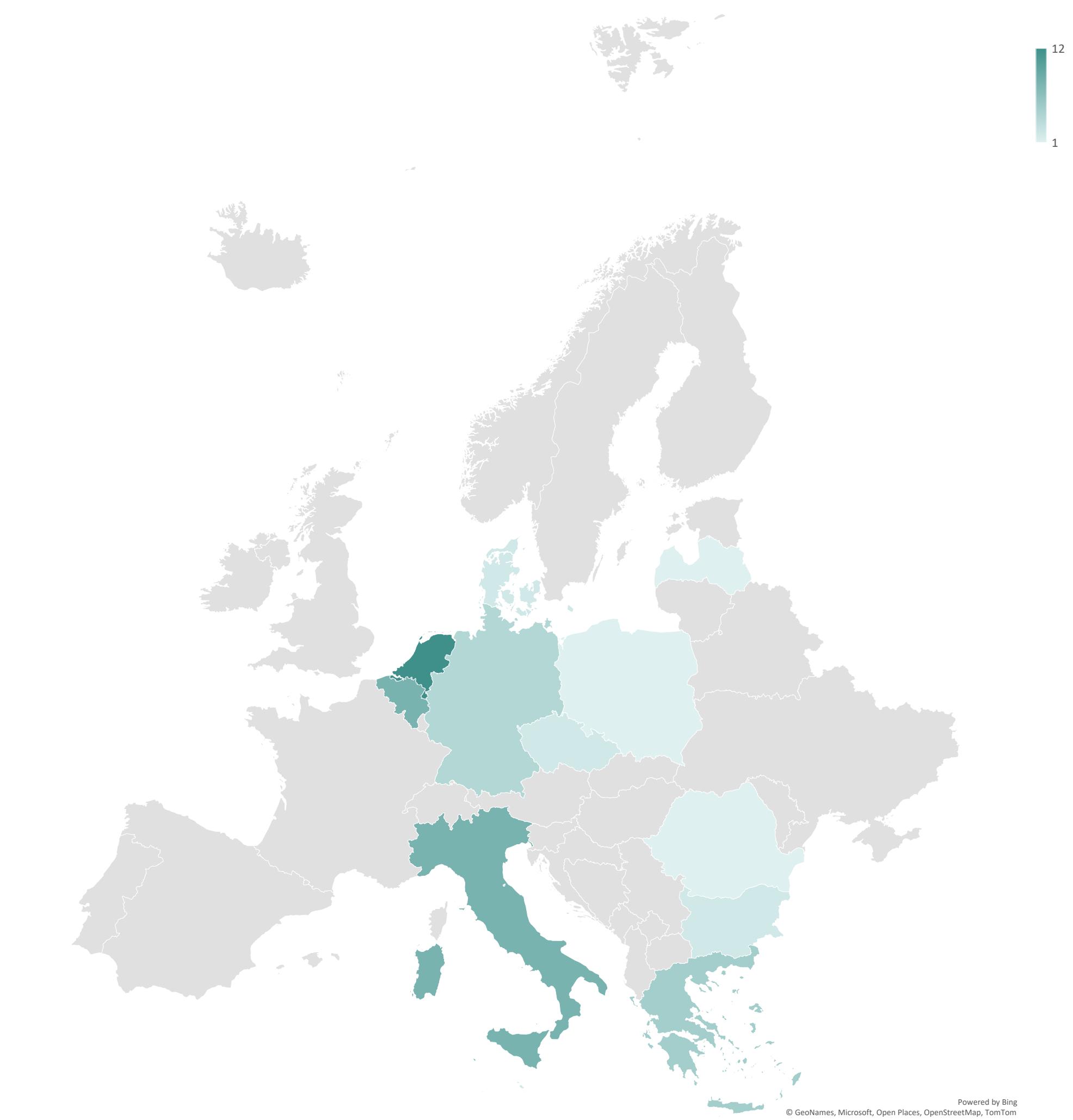


Patient discussions per country 2025

Many HCPs require support with
permission to use CPMS 2.0?

72 patients enrolled
47 discussions opened

Over 70 experts have joined calls
in CPMS and alternative video
calls (Webex) to consult on CPMS
cases





HCPs with permission to use CPMS 2.0 we know of

Currently updating via
Continuous Monitoring
survey



HCP	Permission obtained
University Medical Centre Ljubljana	DPIA completed
Radboud University Medical Centre Nijmegen	DPIA completed
AOU - Modena	DPIA completed
University Hospital and Faculty of Medicine Tübingen	DPIA completed
Helsinki University Hospital (HUS)	DPIA completed
Universitätsklinikum Schleswig-Holstein	DPIA completed
AOU Meyer - Florence	Case was uploaded, permission assumed
Foundation IRCCS CA'Granda Ospedale Maggiore polyclinic - Milan	Case was uploaded, permission assumed
General Hospital of Athens LAIKO	Case was uploaded, permission assumed
Leiden University Medical Center	DPIA approved, ICT pending
Children's Clinical University Hospital, Riga	Case was uploaded, permission assumed
Erasmus MC: University Medical Center Rotterdam	DPIA completed
Amsterdam University Medical Centers Location AMC	DPIA completed
Spitalul Clinic Judetean de Urgenta Cluj (Cluj County Emergency Clinical Hospital)	Case was uploaded, permission assumed
Hôpital Universitaire de Bruxelles(HUDERF-Erasme)	Case was uploaded, permission assumed
Aarhus University Hospital	DPIA completed
Maria Skłodowska-Curie National Research Institute of Oncology (MSCNRI)	Case was uploaded, permission assumed
AO City of Health and Science - Turin	Case was uploaded, permission assumed
Katholisches Klinikum Bochum	Case was uploaded, permission assumed
AO City of Health and Science – Turin	Case was uploaded, permission assumed
MHAT "Sveta Marina"	Case was uploaded, permission assumed



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CPMS 2.0 Goes Mobile

New CPMS 2.0 App Now Available for Download

- 📱 Consult & join meetings on the go
- 🔔 Real-time notifications for messages & updates
- 🔒 Secure communication with two-factor authentication
- ✓ Respond during rounds or while traveling – no desktop needed

Goal for GA – all attendees
download the CPMS 2.0 app &
check their EU login app
functionality



Google Play



App Store



CPMS 2.0 Goes Mobile!

Secure, efficient, and user-friendly
case discussions across the



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Available in



Google Play



Apple Store



← ⌛ ⌂ https://cpms2.ern-net.eu/screen/meetings

≡  CPMS 2.0 - CARE

Home Patient Record Add New Patient **Meetings** Supporting doc... Advanced search

From: 19/01/2026 To: Select a date Apply Reset

51 upcoming meetings

Title	Time	Date
Meeting on patient Poppet Jane 830	12:00 - 12:30 30 min	22 Jan 2026
MTG3 CPMS 2.0 Meeting Endo-ERN	13:30 - 14:30 1 hr	28 Jan 2026
MTG3 CPMS 2.0 Meeting Endo-ERN	13:30 - 14:30 1 hr	28 Jan 2026
MTG1 CPMS 2.0 Meeting Endo-ERN	15:00 - 16:00 1 hr	03 Feb 2026
MTG7 CPMS 2.0 Meeting Endo-ERN	16:00 - 17:00 1 hr	04 Feb 2026
MTG6 CPMS 2.0 Meeting Endo-ERN	13:00 - 14:00 1 hr	20 Feb 2026
MTG3 CPMS 2.0 Meeting Endo-ERN	13:30 - 14:30 1 hr	25 Feb 2026
regular DSD case-conference	16:00 - 17:00 1 hr	03 Mar 2026
MTG7 CPMS 2.0 Meeting Endo-ERN	16:00 - 17:00 1 hr	04 Mar 2026
MTG2 - CPMS meeting Endo-ERN	14:00 - 15:00 1 hr	11 Mar 2026
MTG6 CPMS 2.0 Meeting Endo-ERN	13:00 - 14:00 1 hr	20 Mar 2026

CPMS 2.0 - 1.72.3



Recurring MTG meeting in CPMS - status

[CPMS Recurring Meetings - Endo-ERN](#)

No MTG4 or MTG5 – please coordinate with heldesk for preferred meeting times

New Support Feature



1/1 Support

Running into issues or have questions on CPMS 2.0?

--> Use the [booking software](#) on our website to schedule a 15-min call with the Operational Helpdesk

[Index](#)

[Virtual Consultations](#)

[CPMS 2.0](#)

[Log-in](#)

[HCP Permission&Consent](#)

[Manuals&Guides](#)

[CPMS Recurring Meetings](#)

[Ukraine](#)

[1/1 Support](#)

Schedule a Meeting

[CPMS 2.0 helpdesk Endo-ERN](#)

[CPMS 2.0 Support Call](#) ▶

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Work Package 5

EuRREB Registries, Data Management and Analysis

Update on activities

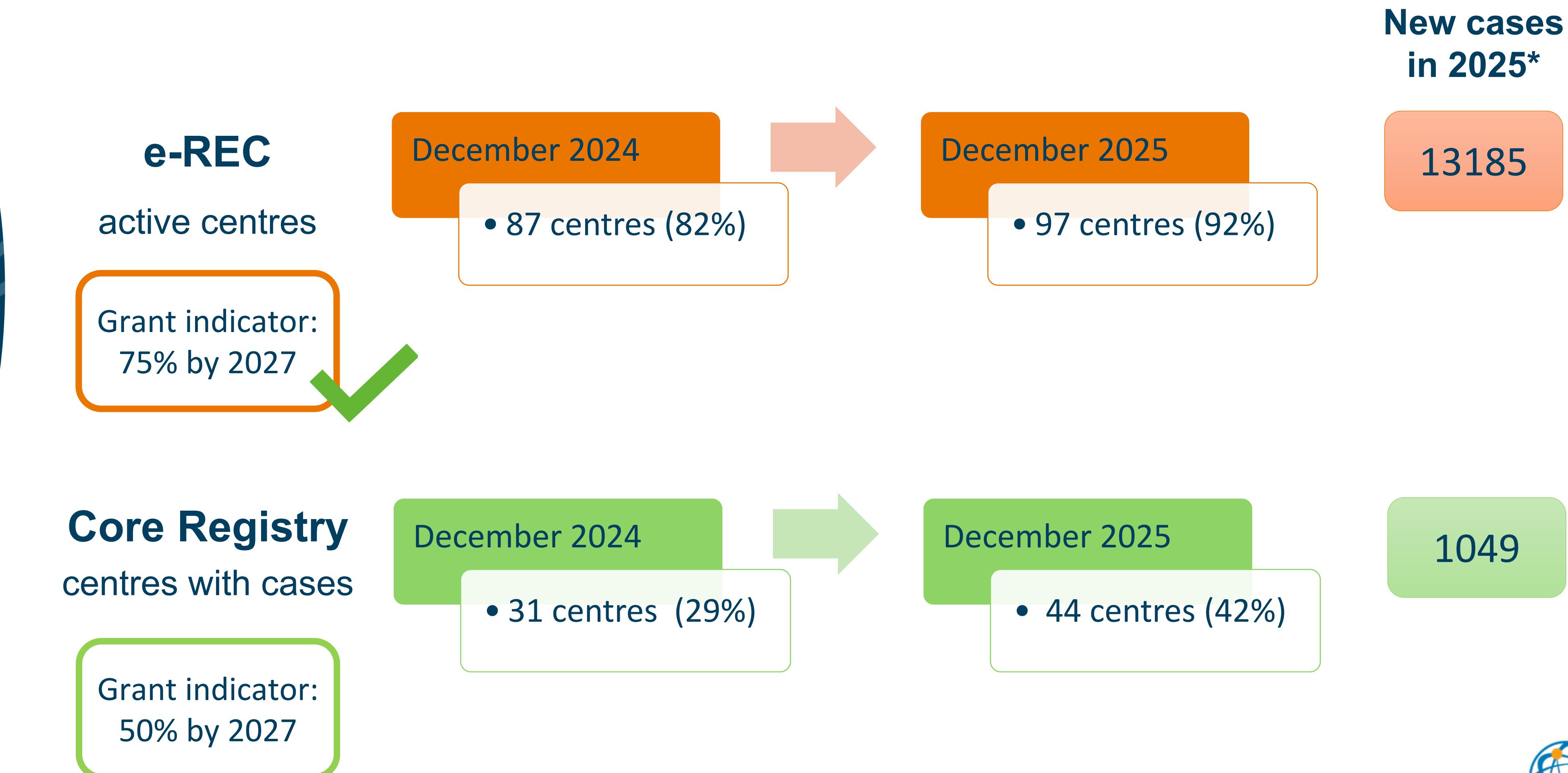
Natasha Appelman-Dijkstra

EuRREB Coordinator



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Endo-ERN members activity



e-REC changes 2026



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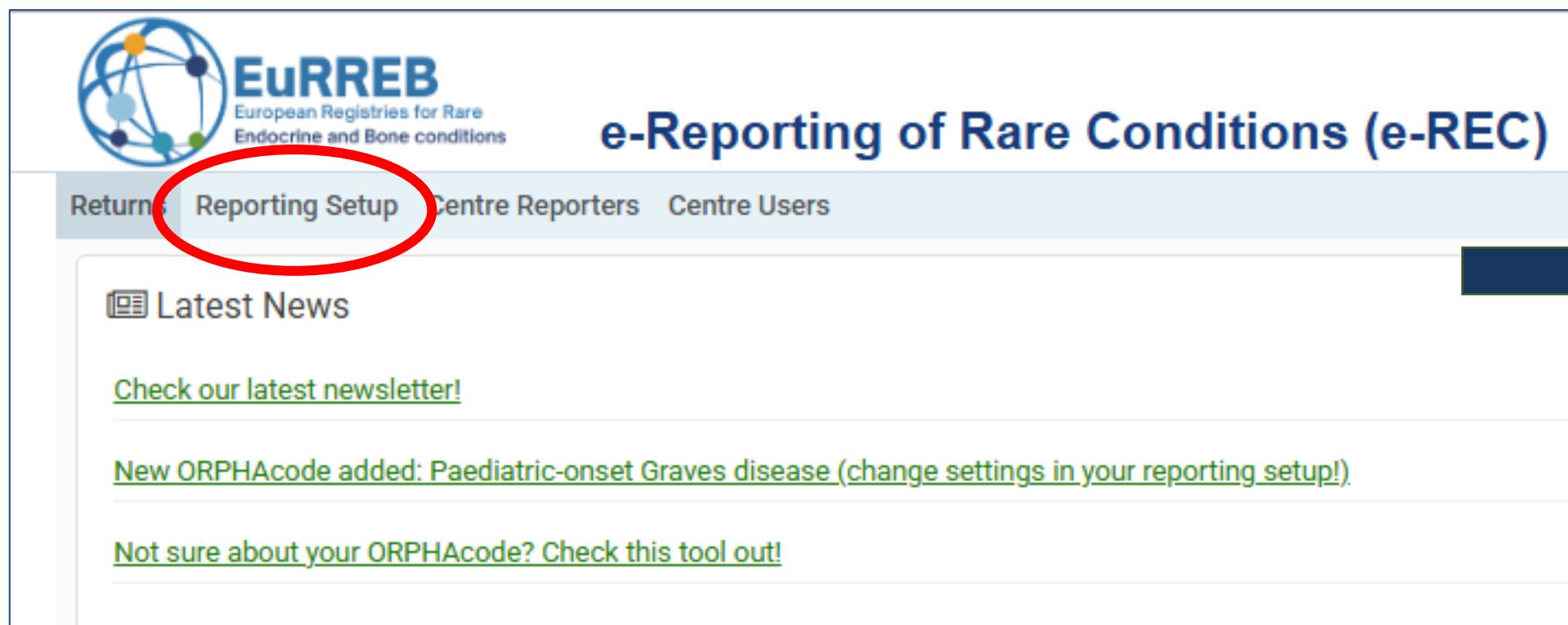
1) MTG6

- ↳ [Pituitary adenoma](#) ORPHA:99408 -
- ↳ [Functioning pituitary adenoma](#) ORPHA:314753 +
- ↳ [Cushing disease](#) ORPHA:96253
- ↳ [Functioning gonadotropic adenoma](#) ORPHA:91348
- ↳ [Mixed functioning pituitary adenoma](#) ORPHA:314759 +
- ↳ [Nelson syndrome](#) ORPHA:199244
- ↳ [Prolactinoma](#) ORPHA:2965
- ↳ [Somatotrophic adenoma](#) ORPHA:96256 +
- ↳ [TSH-secreting pituitary adenoma](#) ORPHA:91347

Other types
of pituitary
adenomas



e-REC changes 2026



e-Reporting of Rare Conditions (e-REC)

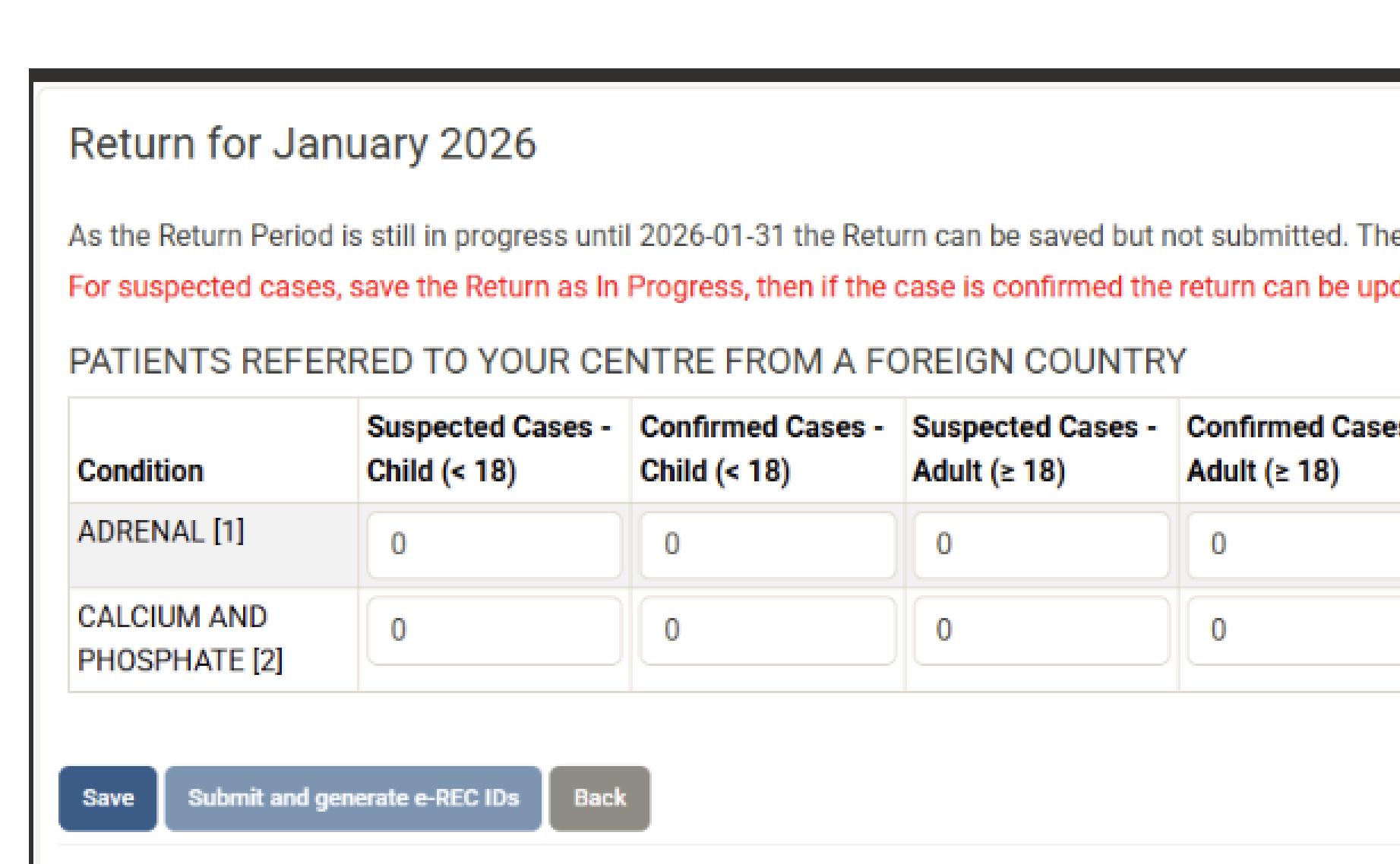
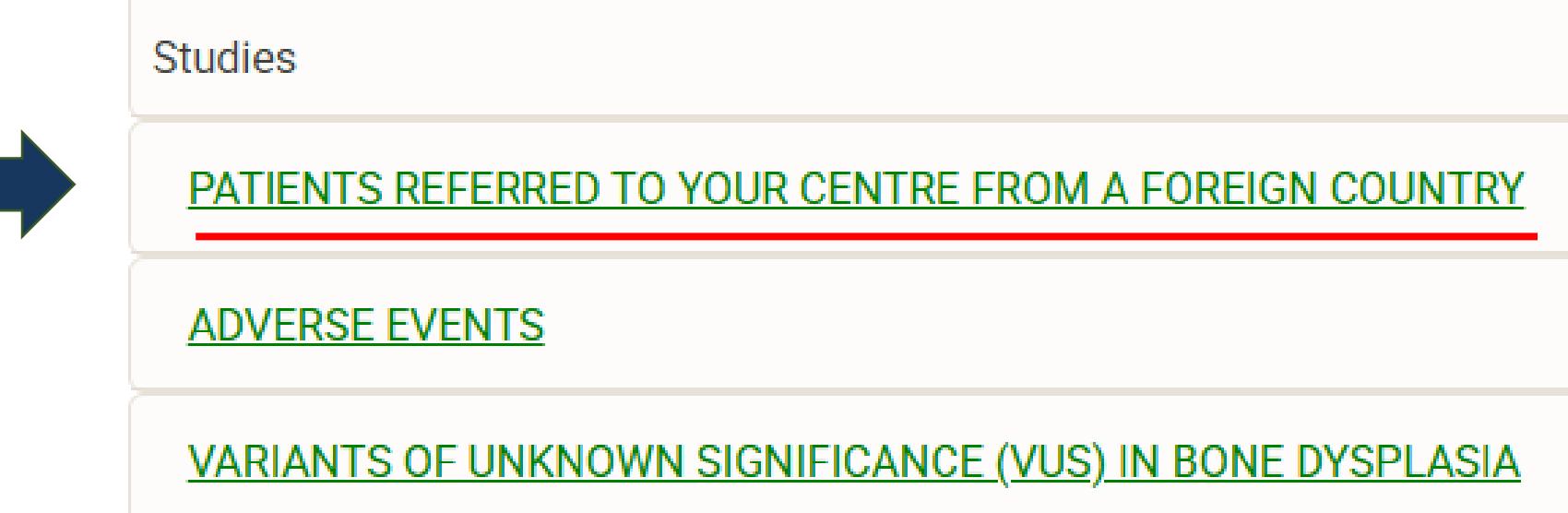
Return Reporting Setup Centre Reporters Centre Users

Latest News

Check our latest newsletter!

New ORPHAcode added: Paediatric-onset Graves disease (change settings in your reporting setup!)

Not sure about your ORPHAcode? Check this tool out!



Return for January 2026

As the Return Period is still in progress until 2026-01-31 the Return can be saved but not submitted. The Return can be submitted and e-REC IDs can be generated after 2026-01-31.

For suspected cases, save the Return as In Progress, then if the case is confirmed the return can be updated before submission

PATIENTS REFERRED TO YOUR CENTRE FROM A FOREIGN COUNTRY

Condition	Suspected Cases - Child (< 18)	Confirmed Cases - Child (< 18)	Suspected Cases - Adult (≥ 18)	Confirmed Cases - Adult (≥ 18)
ADRENAL [1]	0	0	0	0
CALCIUM AND PHOSPHATE [2]	0	0	0	0

Save Submit and generate e-REC IDs Back



The CR Platform updates

- 1) Autosave functionality (CSMs)
- 2) Direct links from the condition-specific modules to generic PROMs

- 3) New category – Life-course outcomes



The screenshot shows the EuRREB Core Registry interface. The top navigation bar includes links for Dashboard, Patients, Centres, Users, Centre Users, Patient Users, Reference Data, Emails, Reporting, and a user profile for Mariya Cherenko - Leiden University Medical Center. The main content area is titled 'Life-course Outcomes' and shows a patient ID of 4291 and a date of birth of 2011-11-11. A note indicates that condition sections marked with an asterisk (*) are mandatory. The 'BONE DYSPLASIA' tab is selected. Below the tabs, there are filters for 'Created Date', 'Latest Assessment Date', 'Completed By', 'Questionnaire', and 'Actions'. A search bar and a '10 entries per page' dropdown are also present. The message 'No Outcomes found' is displayed at the bottom.



Diagnosis-specific Outcome Details

Patient ID - 427 Date of Birth - 1959-10-27 Condition Group - Bone Dysplasia

[Supplemental material to complete this module](#)

Questionnaire: Fibrous dysplasia/McCune Albright module - V4_Apr_2024

Created Date: 2024-06-21

Completed By: Sophie Huisman

Linked Generic Outcomes

[WHO-ICF Mobility](#) [MSK-HQ](#) [BPI-SF](#) [NPSI](#)



New PROMs

- 1) **Cancer worry scale (MEN-1 oriented)**
- 2) **HPQ-28 (Hypoparathyroidism)**
- 3) **HPES-Impact and HPES-symptoms (Hypoparathyroidism) - WIP**





Other activities:

- With WP7: KPIs from guidelines
- Genetic testing in hypoparathyroidism (cross-country project)
- Case study, EuRREB/EC Discussion Paper on ERN Registries
- January EuRREB Newsletter



WP6 Education and Training

**Violeta Iotova, Kami Markovska, Sevim Zekeries,
Manuela Brösamle, Petra Bruegmann**



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Endorsements

- 4 endorsed events for 2026 so far
- **NOTE** for those interested in receiving an Endorsement:
 - General requirements of the Network
 - Follow-up info required

Members can apply for endorsement for their locally organised educational events

Endorsed events are promoted on the Endo-ERN channels

Application should be received at least 6 weeks before the event

All criteria can be found on the website: <https://endo-ern.eu/members/endorsement/>



Clinical Exchange

- 8 exchanges/1 week were available for 2026
- 4 approved exchanges- 6 weeks
- First Exchange is in April
- Longer exchange periods- 2 participants are going for 2 weeks

Webinars & Accreditation



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Webinars

- **REMINDER:** MTGs need to provide a minimum of 2 webinars per year-omitting summer months (July-August)
- Organizing a webinar needs to be reported to WP6 **at least 6 weeks in advance**
- **NOTE:** A webinar will be processed after the Webinar Planning Form is submitted

Organized Webinars

- **MTG5-** An update on genetics and clinical management of tall stature
- **MTG6-** Corticotroph tumors and Postoperative Quality of Life – Perspectives from a Neurosurgeon, an Endocrinologist and a Patient
- **Joint EYE/Endo - Genetic basis of BPES (Blepharophimosis, Ptosis, and Epicanthus Inversus Syndrome) and implications for genetic counseling**

Accreditation

- Accreditation means more registrants and attendees
- Minimum 5 webinars per accreditation pack

https://endo-ern.eu/webinars/

European Reference Network Endo-ERN

Rare Endocrine Conditions About Us For Professionals For Members For Patients

Index Upcoming events Webinars Registration Previous events

Overview of Webinars

Showing 106 entries

MTG	Theme / Title	Date	Time CET	Speaker(s)	Register	View	CPMS
	ESE Talks Webinar...Recent therapeutic perspectives for rare endocrine diseases (multiple examples)	2025-11-04	17:00 – 18:30 hr				
MTG2	Webinar on the Clinical Practice recommendations for the diagnosis and management of XLH	2025-10-29	17:00 – 18:00 hr				
MTG5	An update on primordial dwarfism conditions webinar	2025-10-20	15:00 – 16:00 hr				
MTG8	Diagnosis and management of TSH resistance	2025-10-07	17:00 – 18:00 hr	Edward Visser and Luca Persani			
MTG1	Genotype-phenotype correlations in CAH	2025-09-24	16:00 – 17:00 hr				
MTG7	Advances in the diagnosis and management of Congenital Hypogonadotropic Hypogonadism (CHH) webinar	2025-09-22	17:00 – 18:15 hr				
	ESE Talks Webinar...CAH: diagnostic and therapeutic challenges across the lifespan	2025-09-02	17:00 – 18:30 hr				
	Rare disease research and the value of registries	2025-06-27	16:00 – 17:00 hr				
MTG6	Congenital combined pituitary hormone deficiency in Europe webinar	2025-06-25	16:00 – 17:00 hr				
MTG6	Cushing's Syndrome Webinar	2025-06-10	16:00 – 18:00 hr	Jérôme Bertherat, Marta Baranska and			



RED Winter School

- Program built on MTG3; MTG5; MTG6 and MTG7
- We are expecting 36 highly qualified students in Varna for the Winter School dedicated to Rare Endocrine Diseases (RED)
- 30/36 are from ERN
- 20/36 are from The Netherlands, Italy, Ireland, France, Czech Republic, Latvia, Lithuania, Belgium, Turkey
- 16/36 are Bulgarians
- 24 distinguished teachers



**RARE ENDOCRINE DISEASE
WINTER SCHOOL VARNA**

RED Winter School

28.02 - 3.03.2026

Sts. Constantine and Helena Resort, Varna, Bulgaria
Ensana Aquahouse Hotel

Financed by the European Union - NextGenerationEU, through the National Recovery and Resilience Plan of the Republic of Bulgaria, project № BG-RRP-2.004-0009 "Medical University - Varna: Enhancement of Translational Excellence Achievement in Medicine (MUVE-TEAM)"



WP7 Clinical Practice Guidelines & Clinical Decision Support Tools

Olaf Dekkers, Anna Nordenström, Charlotte Gaasterland, Alessandro Lazzarini, Diana Vitali



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the European Union



In memoriam: Jette Kristensen





Points to discuss

- 3 ongoing CPG's
- Endorsement strategy



3 ongoing CPGs

- **Congenital hypopituitarism:** First working group meeting in February
 - Survey to find out the most controversial topics
- **Hypoadrenalinism replacement therapy:** First meeting with chairs in January
- **Hypothalamic obesity:** Chairs are assigned





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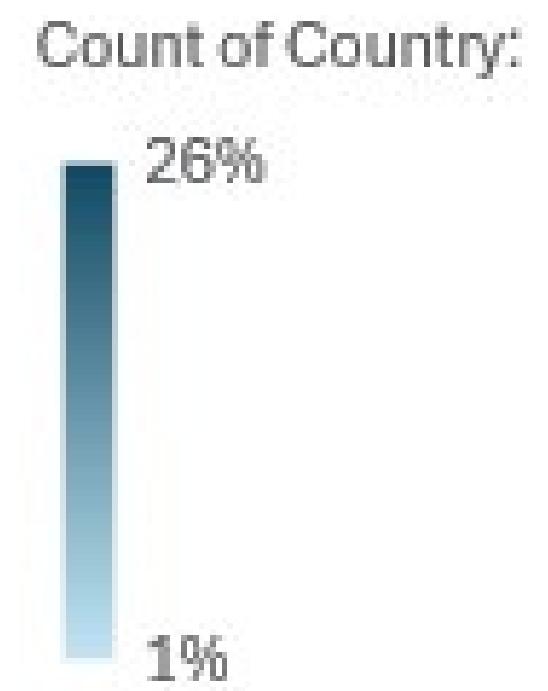
Endorsement strategy

- Current strategy drafted by Charlotte G
- Survey for input sent out early May, deadline 20 June 2025
- Updated strategy to be discussed in Athens



Submissions – 77 total

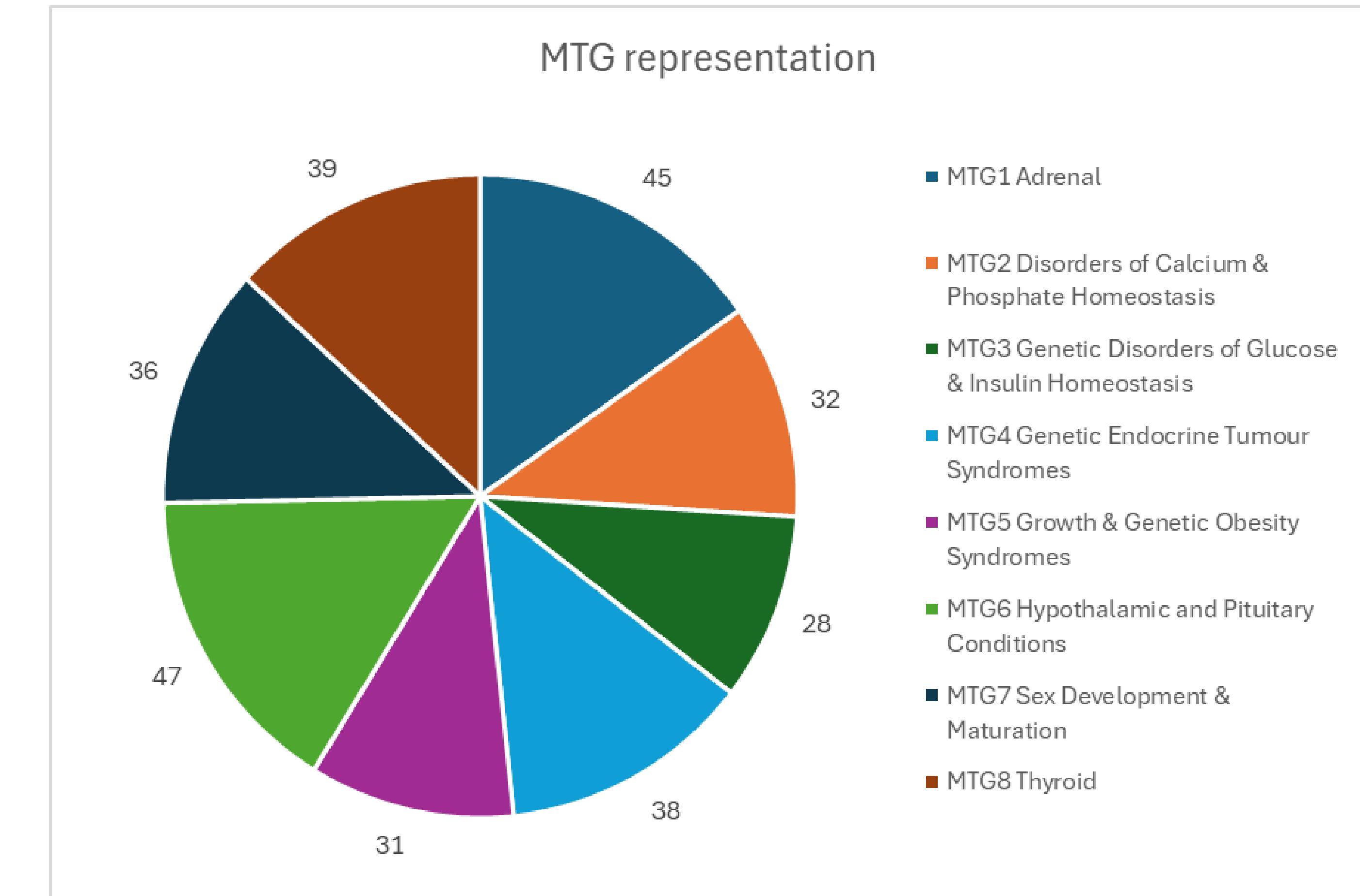
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Belgium	6%
Bulgaria	3%
Cyprus	3%
Czech Republic	3%
Denmark	5%
Finland	3%
France	5%
Germany	9%
Greece	6%
Hungary	1%
Republic of Ireland	1%
Italy	26%
Luxembourg	4%
Malta, Montana	1%
Netherlands	6%
Norway	1%
Poland	3%
Portugal	3%
Slovakia	3%
Spain	4%
Sweden	1%
United Kingdom	1%



Results demographics



- Majority main or sub representatives
- 1 patient association (from Italy)





What do you think endorsement of a document by Endo-ERN should mean?



The document's recommendations should be followed by Endo-ERN members	29%
The document's recommendations should be known by Endo-ERN members	51%
The Endo-ERN members should be aware of the document	20%

*My understanding of endorsement of a document by EndoERN should mean, is that the document/meeting should be **supported or approved** by EndoERN. Therefore EndoERN should know about the document's **recommendations** and approve its publication.*

that the document has been reviewed by recognized experts within the network and reflects a consensus or broad agreement among specialists in the field.

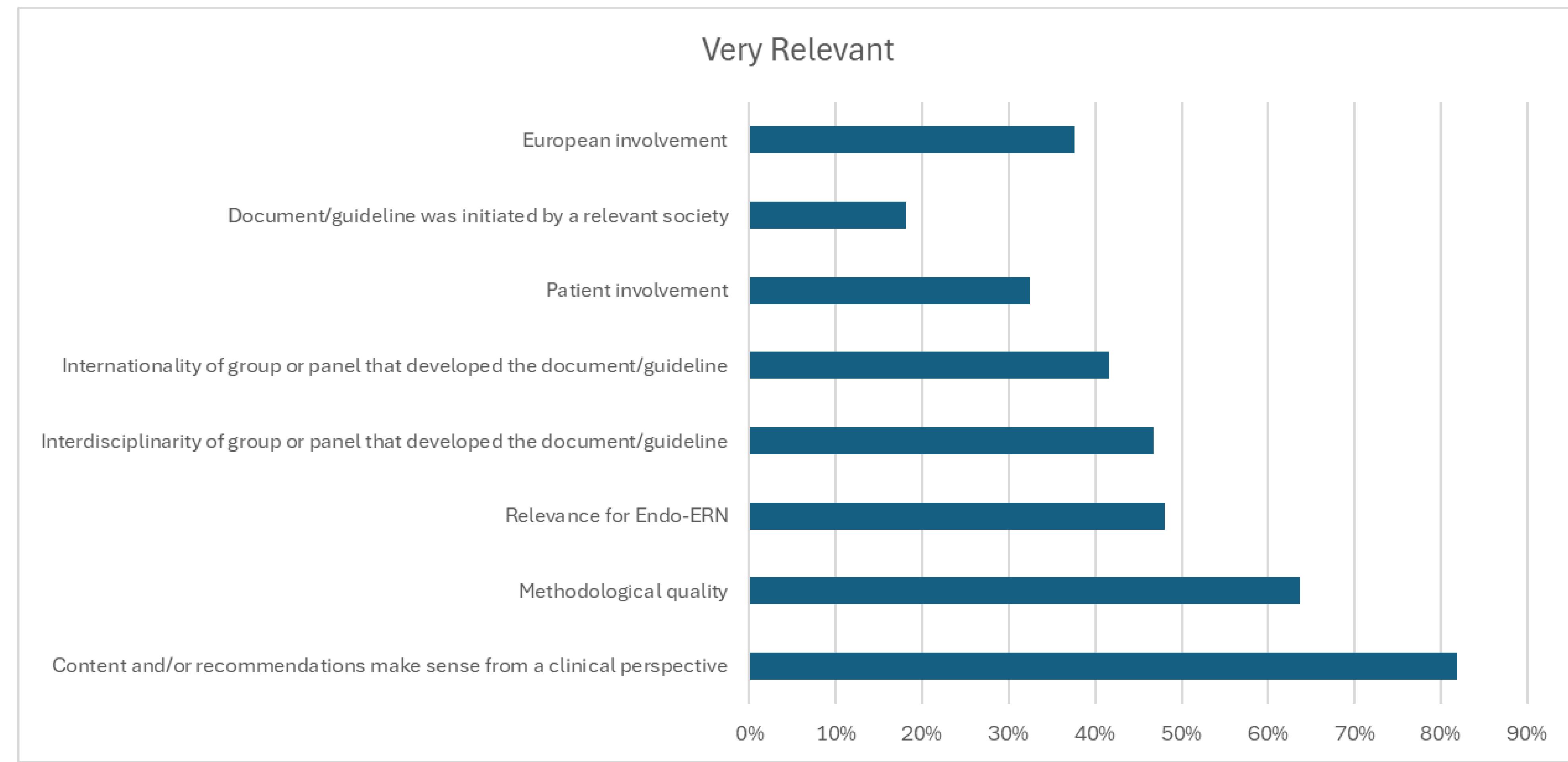
Endorsement should be given after consultation and possible comments/feedback from Endo-ern members

Endorsement means that EndoErn recommend it because 1) the methodology is correct or 2) the topic covered is consistent with the EndoERN mission

"ENDO-ERN endorsement enhances the document's importance. It means that the ENDO-ERN supports such a document. (support/acceptance AND compliance/adherence)"



Please rate how relevant you find these criteria for the endorsement of consensus documents/guidelines:



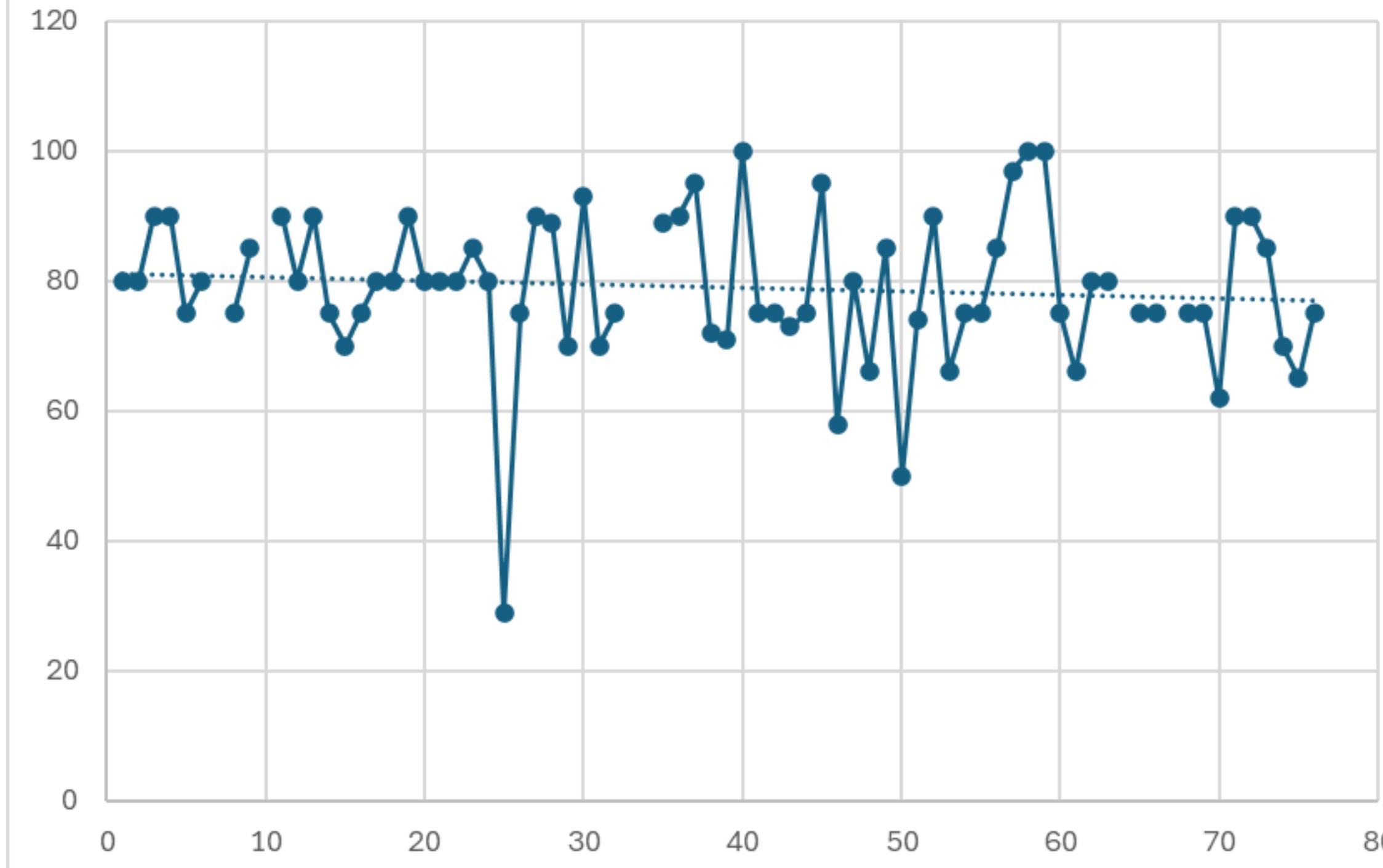


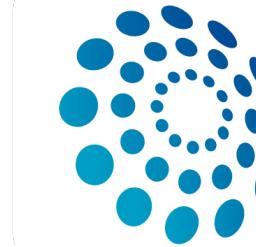
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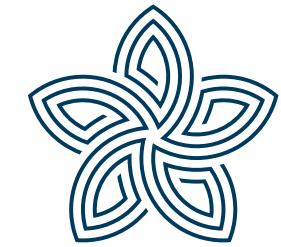
Endo-ERN

When a document provides recommendations, how much/many of the recommendations would you have to agree with from a clinical point of view before you would consider the document good enough for endorsement by Endo-ERN?





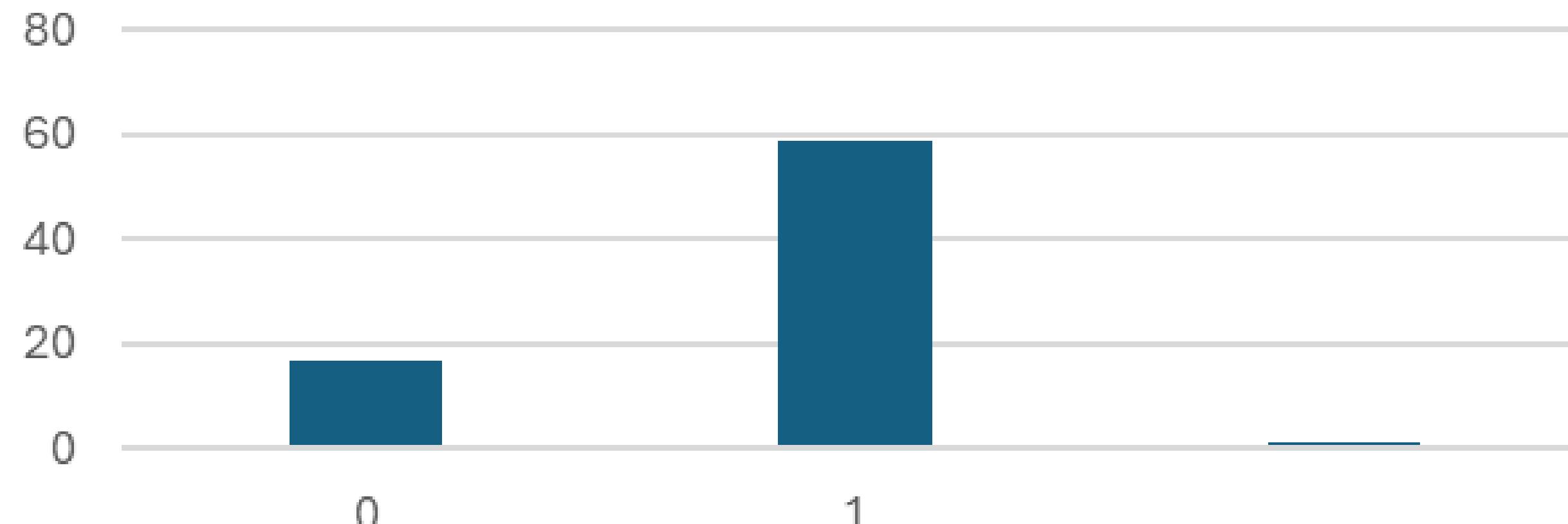
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Do you think that the endorsement strategy for clinical practice guidelines should be made in alignment with all ERNs?

Yes = 1
No = 0





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Delphi on minimum set of quality criteria

- Representation from many ERN's
- Consensus meeting only yesterday
- CPGs versus consensus statements



WP8/9 Capacity building, best practice sharing & other activities for Ukraine

Charlotte van Beuzekom, Project Manager Endo-ERN



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Joint-ERN



Information Webinar

Improving Rare Disease Care in
Ukraine: Access to ERNs and
Expert Resources

presented by

Endo-ERN & ERN eUROGEN

Wednesday 18 February 2026 16:00-17:45 CET

- Dedicated page for Ukrainian clinicians – and we are developing a database of contacts
- Upcoming joint webinar with eUROGEN
- Clinical Exchange has a Ukrainian participant in 2026
- 2026 AI translations of the existing webinar library and potentially other assets



Підтримка українських лікарів за допомогою Endo-ERN

Endo-ERN працює допомогти українським лікарям зв'язатися з провідними європейськими експертами з рідкісних ендокринних захворювань. За допомогою Endo-ERN ви можете запросити віртуальні консультації з експертними центрами по всій Європі, отримати доступ до клінічних рекомендацій, заснованих на спільному європейському досвіді, та взяти участь в освітніх та тренінгових програмах, розроблених для клініцистів.

Ваш досвід як лікаря залишається ключовим – Endo-ERN лише сприяє тому, щоб європейські знання та підтримка безпосередньо допомагали вашим пацієнтам. Процес відбувається за допомогою спеціального хабу, розташованому у лікарні «ОХМАТДИТ» у Києві.

Знайти експерта

Розкажіть нам про себе



Transversal Working Group on Genomic Testing

Thomas Eggermann (University Hospital Aachen, Germany)

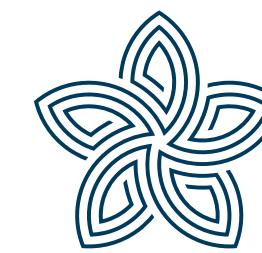
Dirk Prawitt (Center for Paediatrics and Adolescent Medicine, University Medical Center, Mainz, Germany)



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Status

Currently 31 participants from 10 different countries

Virtual meetings: every 2-3 months, with the current focus on the joint paper

ESHG – ERN collaboration

- communication managers (E. White) and liaison managers (TE, DP)
- Virtual meetings every 3 months

Teaching & Masterclass

- ESHG becomes part of the ERNs course portfolios and vice versa
- Germline genetics needs to be part of the educational program of ERNs
- ESHG is willing to engage in education if the part of genetics is part of the ERNs educational programmes
- ERN may request collaboration from ESHG to support genetics-related educational contents (“not related to Industrial interests”).
- Developing ESHG-ERN Courses endorsed by ESHG and ERN.

Cross-referencing in ESHG and ERNs websites regarding collaborative actions, joint-educational initiates and liaison members.

Visibility & Communication

- **Visibility : ERN visible on the ESHG website and vice versa**

How to make ERNs visible on the ESHG website?

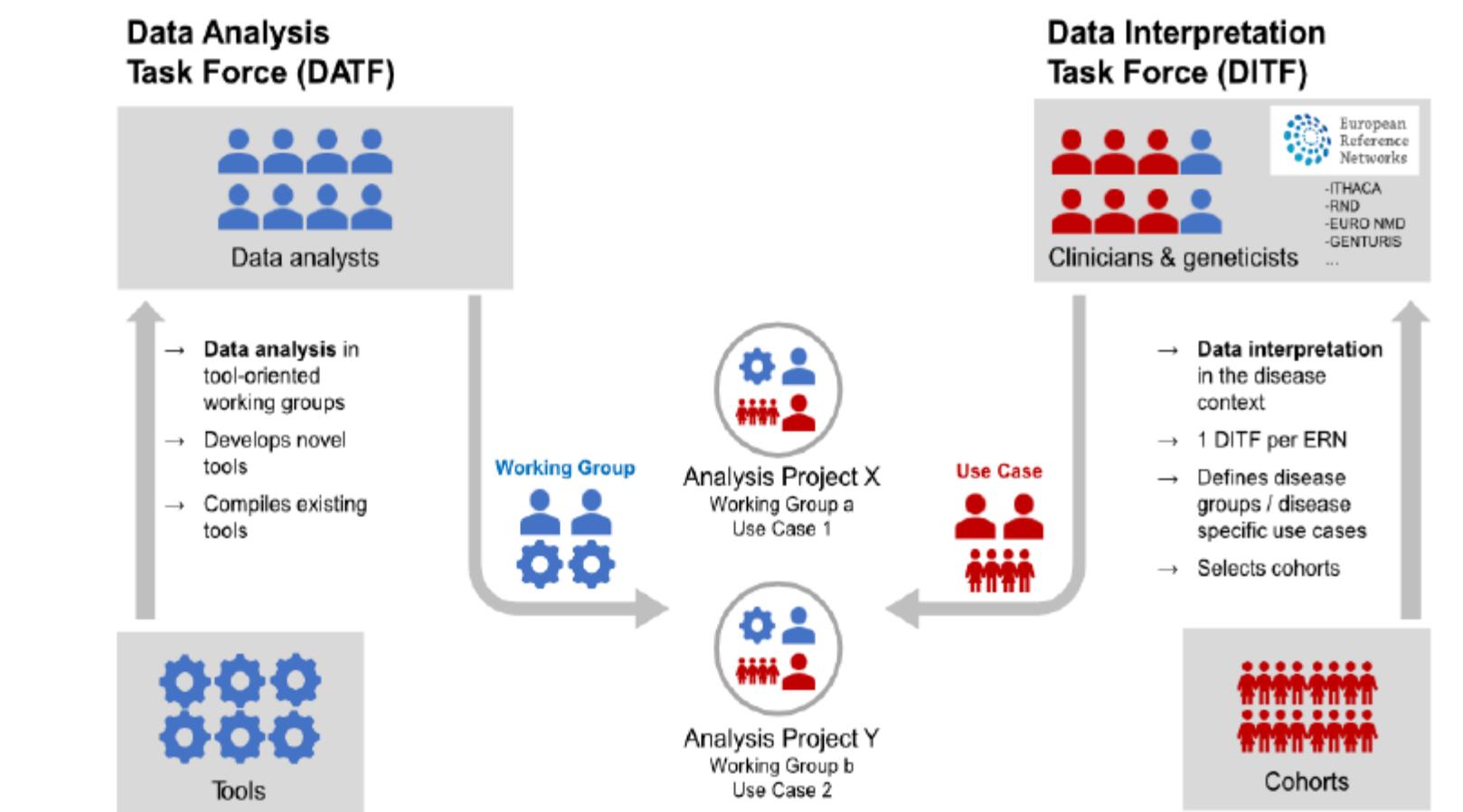
How to make ESHG visible on the ERN Websites?

Visibility of ERN-ESHG liaison members on both websites?

Communication managers (for ERN-ESHG information flux) and inform the ESHG Office (Jerome del Pichia) ?

Update ERDERA Diagnostic Research Workstream

Joint expert re-analysis



WHAT CAN YOU DO AS ERN TO CONTRIBUTE TO THE DRW?

- Inform your HCPs to contribute samples to the DRW
- Have HCPs sign up to contribute to the ERN-specific DITF if they have expert knowledge on:
 - ✓ Data interpretation for (non-)coding variants
 - ✓ Specific genes or phenotypes of relevance to your ERN
 - ✓ Novel gene/mechanism/paradigm discovery
 - ✓ (Data analysis to join DATF working groups)
- Nominate a candidate for the position ERN-specific DITF lead and provide the information to **Holm Graessner and Lisenka Vissers**



The WG Genetic Testing aims to moderate the cooperation between the HCPs of our network and the ERDERA Diagnostic workstream group, e.g. by bringing them in contact with ERDERA, and by exchanging information and experiences on national level in respect to the legal issues (e.g. data protection).

In addition to these individual cooperations between our HCPs and ERDERA Diagnostic Workstream, our ENDO-ERN has to assign colleagues for the Data Interpretation Task Force (DIFT).

We have been advised to encourage the MTG chairs to promote this in the network. If all agree, the follow up dissemination to HCPs and identification of Endo-ERN representation for the Data Interpretation Task Force, can be done afterwards by our coordination office.

Is it possible to ask each MTG to nominate at least one representative to discuss further steps with the WG (deadline: Feb. 15th 2026).



ERDERA2026 call

Conceptual phase of Calls for Proposals 2026

“Resolving unsolved cases in rare genetic and non-genetic diseases”

Submission deadline for pre-proposals: February 12th, 2026
at 2 PM (CET)

Currently pre-proposal discussions on
CHH (Marco Bonomi)
RTH (Luca Persani)

TWG on genomic testing tries to support these
(DSD (Martin Kircher))



Joint paper (in preparation): „What the endocrinologist expects from genetic testing and reporting“



Contents:

	Topic
1	When is a genetic test appropriate, including regulatory aspects, when is it allowed?
2	Standardised genetic testing procedures (cytogenetics, molecular cytogenetics/array, single gene analysis vs targeted panel vs WES vs WGS) What is optimal?
3	How to achieve a standardized genetic testing quality?
4	Standardized reports addressing the needs of the clinicians
5	Germline and somatic genetic testing have to be considered
6	How to deal with VUSs, Recall of VUS
7	Incidental/Secondary findings
8	Common research activities
9	How is genetic testing reimbursed across Europe

- First versions of sections 1-3, 5 finished; final versions of sections 4, 6, 7; sections 8 and 9 in preparation.
- Deadline: April 2026, submission in discussion

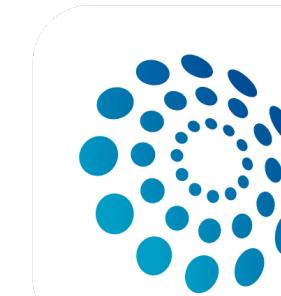
Status



In preparation:

Matrix overview about the genetic expertise available in the ENDO-ERN: a survey is in preparation

HCP	Country	City	Representative(s)	Accreditation methods	disease 1	disease 2	disease 3	disease 4	disease 5	relevant papers	Involvement in Guidelines	Testing for research possible
Department of Cyprus	Cyprus	Nicosia	Leonidas Phylactou, Vassos Neocleous	ISO 15189	NGS, Sanger, CAH	MEN2	MODY	Hypogonadotropic Hypogonadism	38637882; 31505704; 29396	Yes		
University Hospital Germany	Germany	Aachen	Thomas Eggermann, Miriam Elbracht	ISO 15189	(MS)MLPA, MFSRS	BWS	upd(20)mat	PWS	TNDM		PMID: 275859	yes
University Mainz Germany	Germany	Mainz	Dirk Prawitt, Joachim Pohlenz	ISO 15189	RT-PCR (rearr Heritable thyroid diseases)	Endocrine tumours	Abnormal growth, Imprinting Defects	(BWS 32462478, 35)	PMID: 332720	yes		



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Feel free to contact us at any time!

Ideas/Suggestions/Contacts are welcome,
preferably from every MTG

Contact:

Thomas Eggermann
(tegermann@ukaachen.de)

Dirk Prawitt
(dprawitt@uni-mainz.de)

Transversal Working Group on Transition in Care

Andrea Isidori (Azienda Ospedaliero-Universitaria Policlinico Umberto I, Rome, Italy)
Ulla Doechnert (Universitätsklinikum Schleswig-Holstein, Luebeck, Germany)



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Checklists for transition of patients with specific conditions



Final / in review:

- MTG 1: Congenital Adrenal Hyperplasia
- MTG 2: X-linked Hypophosphatemia
- MTG 4: MEN 1
- MTG 7: Congenital Hypogonadotropic Hypogonadism
- MTG 8: Congenital Hypothyroidism

In preparation:

- MTG 5: Prader-Willi Syndrome
- MTG 6: AVP Deficiency
- MTG 7: Turner Syndrome

8th TALENT Conference meeting



ENDORSED BY

European Reference Network Endo-ERN

eoA EUROPEAN ACADEMY OF ANDROLOGY

SAPIENZA UNIVERSITÀ DI ROMA

Endo-ERN TALENT
TRANSITION OF CARE WORKING GROUP

8-TALENT:
Transition Adolescence and young aduLts -Endocrine diseases management

An Endo-European Reference Network event

8th Conference Meeting

ROME
FEBRUARY 11.12.13 2026

FRIDAY FEBRUARY 13th

"VOICES IN TRANSITION": ROUNDTABLE BETWEEN PHYSICIANS AND PATIENT ASSOCIATIONS
Moderators: M.L. Jaffrain; M. Spaziani; F. Carlonagno
12:00-14:00 Panel Discussion

MTG 1: Discussant: **Rosa Maria Paragiola**
Patient Association Representative: Associazione Italiana Pazienti Addison - AIPAd (Simone Genovese, Roma)

MTG 2: Discussant: **Stefano Frara**
Patient Association Representative: Associazione Italiana dei Pazienti con Disordini Rari del Metabolismo del Fosfato - AIFOSF (Nicoletta Schio, Vicenza)

MTG 3: Discussant: **Tiziana Filardi**
Patient Association Representative: Federdiabete Lazio APS (Lina Delle Monache, Roma)

MTG 4: Discussant: **Franz Sesti**
Patient Association Representative: Associazione Italiana Tumori Neuroendocrini - AINET (Giovanni Guglielmi, Roma)

MTG 5: Discussant: **Marianna Minnetti**
Patient Association Representative: Associazione Sindrome di Bardet-Biedl Italia APS - ASBBI (Susanna Genova, Palermo; Arianna Foti, Monza)

MTG 6: Discussant: **Antonio Bianchi**
Patient Association Representative: Associazione Italiana Displasia Setto Ottica e altri Disordini Neuroendocrini - SOD ITALIA APS (Diana Vitali, Roma)

MTG 7: Discussant: **Marta Tenuta**
Patient Association Representative: Nascre Klinefelter APS (Pamela Pedretti, Firenze)

MTG 8: Discussant: **Carlotta Pozza**
Patient Association Representative: Comitato Associazioni Pazienti Endocrini & La Lumaca ODV (Anna Maria Biancifiori, Perugia)

Conclusion of the Conference

TALENT for SEX DEVELOP
Moderators: M. Cappa; U. Di

09:00-09:20 **LECTURE 19 :** I search for shar Holstein, Lubec

15:00-15:20 **LECTURE** hyperph Bambini

15:20-15:40 Discussion

15:40-16:10 Coffee b

TALENT for HYPOTHYROID DISEASE
Moderators: E. Charn

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12:00-13:00 L

16:10-16:30 **LECTURE** long-act Meiberg

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13:00-13:20 L a

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TALENT for GL
Moderators: S.

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16:50-17:10 **LECTURE** clinical i Switzerl

TALENT for ADRENAL DISEASE
Moderators: C. Scarpa

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17:20-17:40 **LECTURE** emergi Karolin

TALENT for GR
Moderators: P.

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17:40-18:00 D

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17:40-18:00 D

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Moderators: E. Kass

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15:20-15:40 **LECTURE** andr Bambi

15:40-16:00 **LECTURE** challenge Depart Milan, Italy

16:00-16:20 LI re U It

12:00-13:00 L

16:10-16:30 **LECTURE** long-act Meiberg

TALENT for DISORDERS
Moderators: E. Kass

16:20-16:40 D

13:00-13:20 L a

16:30-16:50 **LECTURE** Kinder u

MTG 2 Symposium

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Transition of Care Working Group research activity



**Mapping Transition of Care for Rare Endocrine Conditions:
Findings from a Cross-Sectional Survey by the Endo-ERN
ToC Working Group**

Journal:	<i>Endocrine Connections</i>
Manuscript ID	EC-25-0798
Manuscript Type:	Research Paper
Keywords:	transition, rare endocrine conditions (RECs), transitional care, Rare diseases/syndromes, Endo-ERN

SCHOLARONE™
Manuscripts

Under review in *Endocrine connections*



Co-operation – ESE-ESPE Transition of Care Working Group



**European Society for Paediatric Endocrinology (ESPE)
and European Society of Endocrinology (ESE)
Joint Clinical Practice Guidance for Healthcare
Transition from Paediatric to Adult Endocrine Care**
*(Accepted for publication by the European Journal of
Endocrinology (EJE) and Hormone Research in
Paediatrics (HRP))*

Next steps in discussion...:

- Joint educational activities?
- Research?

Co-operation – Overarching ERN Transition of Care Working Group

- Aim: to create a coordinating group for all transition-related work across ERNs
- Development of official structure and mandate as requested by EU
- Core group

Position	Name	ERN
Coordinator	Ruth De Bruyne	ERN RARE LIVER
Paediatric lead	Ramon Gorter	ERNICA
	Raffaella Colombatti and Anna Collado	ERN EuroBloodNet
Adult lead	Karolina Stepien	METAB ERN
	Katarzyna Nowomiejska	ERN EYE
Paramedic	Paloma Martinez	ERN transplant child
	Guillermo M. Sibón Sancho	ERN EYE
Geneticist	Liesbeth Wilder Van Wouwe	VASCERN
ePAG	Karsten Vanden Wyngaert	ERKNET
Youth panel member	Bent Hennersdorf	ERN RARE LIVER
	TBD	TBD
Junior researcher	Rebecca Pulvirenti	ERN ERNICA
	Janne Suykens	ERN RARE LIVER

- Recruitment of Youth panel
- Regular meetings of plenary working group

Co-operation – Overarching ERN Transition of Care Working Group



Endo-ERN Representatives

- Ulla Döhnert (paediatric endocrinology)
- Claudio Auteri (patient representative)

Transversal Working Group on Research

Alberto Pereira, Adult Chair Endo-ERN

Olaf Hiort, Paediatric Chair Endo-ERN

Charlotte van Beuzekom, Project Manager Endo-ERN



Funded by
the European Union



European Journal of Endocrinology, 2025, 193, ii128–ii131
<https://doi.org/10.1093/ejendo/lvaf072>

Review Article



EndoCompass project: rare diseases in endocrinology

Alberto M. Pereira^{1,2,*}  and Olaf Hiort^{2,3} 

¹Department of Endocrinology and Metabolism, Amsterdam University Medical Center, Meibergdreef 9, 1105AZ Amsterdam, the Netherlands

²European Reference Network on Rare Endocrine Conditions (Endo-ERN)

³Sektion für Pädiatrische Endokrinologie und Diabetologie, Klinik für Kinder- und Jugendmedizin, Universität zu Lübeck, Ratzeburger Allee 160, Lübeck 23562, Germany

*Corresponding author: Department of Endocrinology and Metabolism, Amsterdam University Medical Center, Meibergdreef 9, 1105AZ Amsterdam, the Netherlands. Email: a.m.pereira@amsterdamumc.nl

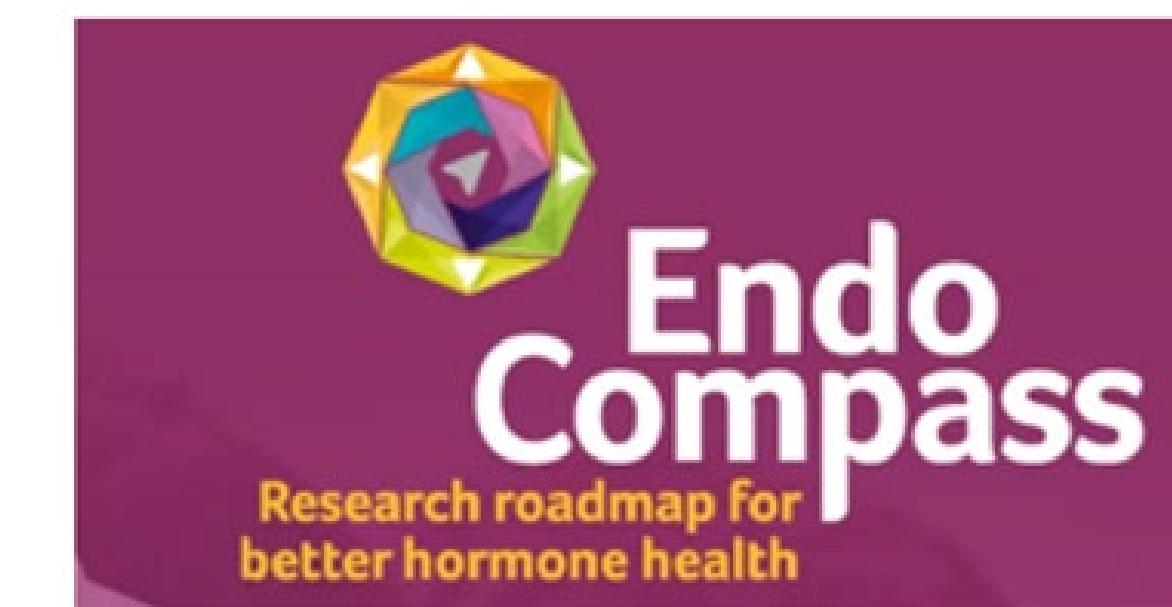
Focus areas for research into rare conditions

The following are examples of specific topics that should be considered when deciding on a research grant. They have been incorporated into the Endo-ERN Quality of Care Improvement and Research Counsel:

1. Diagnostic research readiness:
 - Assessment of data readiness, standardization, and harmonization
 - Genome re-analysis pipeline application, variant interpretation, and translation to endocrinology departments or clinics
 - Genomic innovation to shorten time to diagnosis
2. Clinical trial readiness:
 - Multinational patient inclusion and collaboration
 - Disease progression modelling
3. Clinical outcome assessment:
 - Estimating the socio-economic impact of rare endocrine diseases



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Research WG

Implement ***Focus areas for research into rare conditions***

- Map research landscape within Endo-ERN and the wider ERN ecosystem
- Raise awareness of persistent underfunding of endocrine research despite its major impact on the EU population
- Highlight patient impact and unmet needs in rare endocrine conditions





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Other RD Project updates

Charlotte van Beuzekom, Project Manager Endo-ERN



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Other RD project updates



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ERDERA

JTC 2026

- Resolving unsolved cases in rare genetic and non-genetic diseases through variant validation and new technological approaches
- Proposal initiatives:
 1. Martin Kircher (Luebeck): DSD
 2. Luca Persani (Milan): Rare Thyroid Disorders
 3. Pauline Romanet (Marseille): MEN1
 4. Marco Bonomi (Milan): CHH

Networking Support Scheme

- Funds for events that promote RD knowledge sharing
- Max Euro 30.000 per event
- Constant open call, next deadline 7 April 2026

www.erdera.org

RealiseD

- Factors influencing clinical trial enrolment in rare and ultra-rare diseases

👉 Open until 28 January 2026 <https://forms.office.com/e/nhaqB5gvN6>



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AOB & questions



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