WP3 Evaluation

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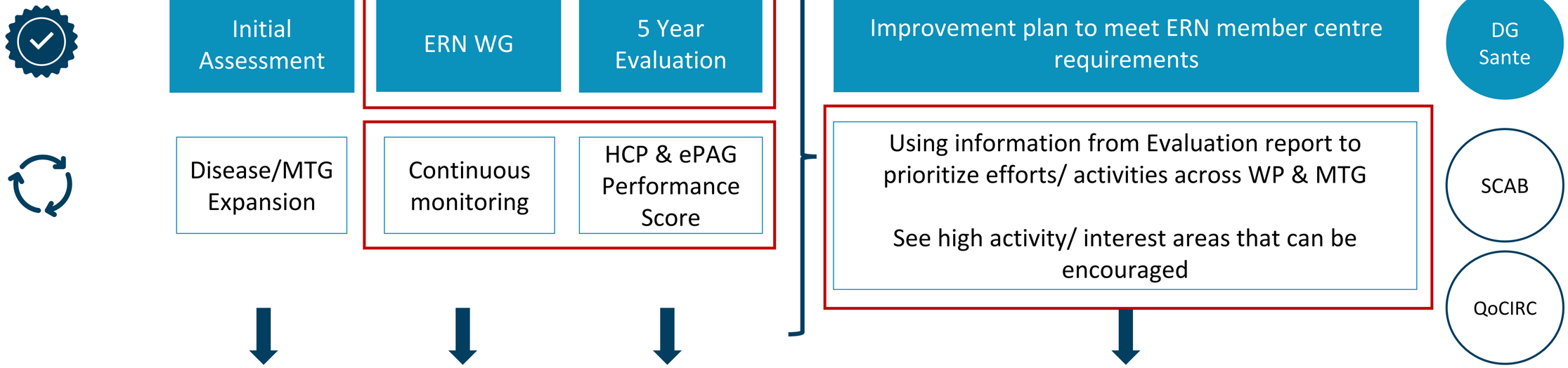
Funded by
the European Union

Evaluation in Endo-ERN – QI



Assessment **M**onitoring **E**valuation **&** **Q**uality **I**mprovement **S**ystem

AMEQUIS

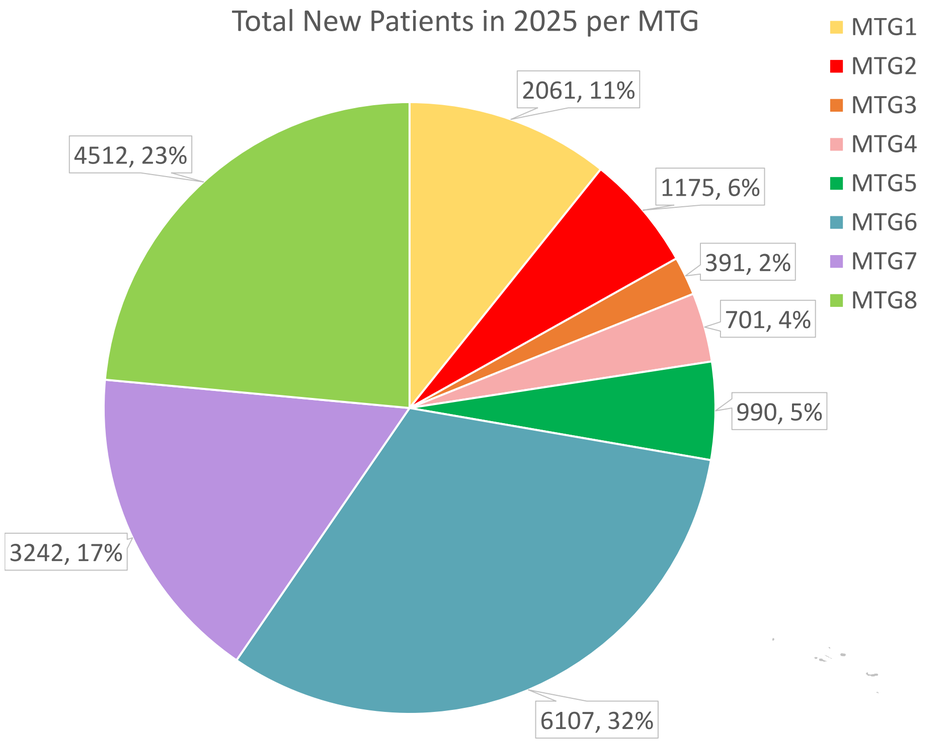
In 2025 Our Members Have....

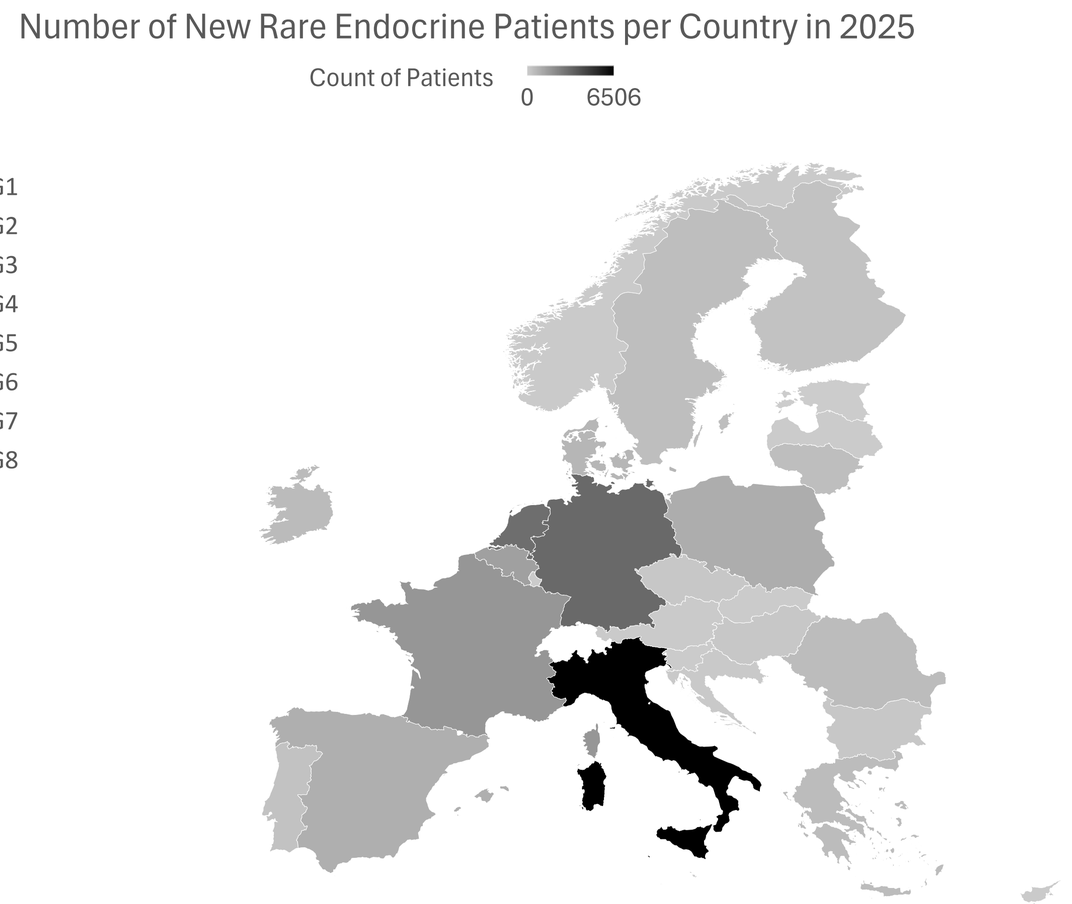
- Seen **22,421** confirmed new cases of rare endocrine patients
- Researcher with **over 70** active clinical trials and studies
- **Endorsed 15** rare disease specific training and educational activities, including the RED Winter School
- Used the **62 guidelines and CDSTs** endorsed by Endo-ERN and highlighted 50 more for review for endorsement
- Attended and contributed to **over 100 congresses**, conferences & meetings discussing rare endocrine disease/ care
- Worked alongside experts **from over 46 countries** worldwide

Thank you to the 102 members who completed this year's exercise!

A full report is being prepared with **final** figures in summer...

Patient numbers





New: Cross Border Patients Estimates – now in e-REC

31 HCPs didn’t respond

22 HCPs said no cross border patients were received with rare endocrine disease (HCPs from different 13 countries)

Total approximate: 1,444 from 19 different countries

Range: 0 - 523 patients

Median = **2** (*IQR* 0-10)

67 patients were enrolled in CPMS:

- *Did CPMS mean less travel for these patients?*
- *How many of these 1,444 could have benefitted from CPMS?*


European Commission

Accessing treatment abroad

Governing legislation at a glance

FEBRUARY 2024

*As a resident in the **EU, Iceland, Liechtenstein, or Norway (EU/EEA)** with healthcare coverage, you have the right to medical treatment in any other EU/EEA country. Your country of residence will cover part or all of your medical costs. Contact your country's National Contact Point to find out about your patient rights and get all the information on the documents and the procedures to be followed.*

For more information, see Frequently Asked Questions for outgoing patients. Information about rules for social security coordination with the UK can be found here.

TREATMENT ABROAD

OPTION 1		OPTION 2
Regulations (EC) Nos 883/2004 and 987/2009 that coordinate social security systems	GOVERNING LEGISLATION	Directive 2011/24/EU on patients' rights in cross-border healthcare
Public or contracted private healthcare providers	PROVIDER	Any public or private healthcare providers
Planned treatment: Prior authorisation (form S2) **Unplanned necessary treatment:** European Health Insurance Card (EHIC)	CONDITIONS OF USE	Applies **only to treatments covered** by the national insurance plan of the home country. **Planned treatment:** May need prior authorisation with a country-specific form (not the S2). **Unplanned necessary treatment:** No EHIC requirement
Mostly covered directly by national health insurance providers. Payment might be requested if this is the normal practice for patients in the treatment country.	PAYMENT	**Patient pays, full payment upfront**
According to the **treatment country's coverage plan** (tariffs, procedures, etc.)	REIMBURSEMENT	According to the **home country's coverage plan** (tariffs, procedures, etc Potential partial or full reimbursement after filing for reimbursement in home country. Estimated expenses (prior notification) provided prior to treatment in some countries
Any EU/EEA Member State and **Switzerland** Different rules in place for the UK	TREATMENT COUNTRIES	Any EU/EEA Member State **(excluding Switzerland)**

See 'Section 1.2. Who is entitled to cross-border healthcare? Which countries are covered?' in the Frequently Asked Questions for outgoing patients for more information on exceptions, or contact your National Contact Point.

Potential Risks & Priority Issues

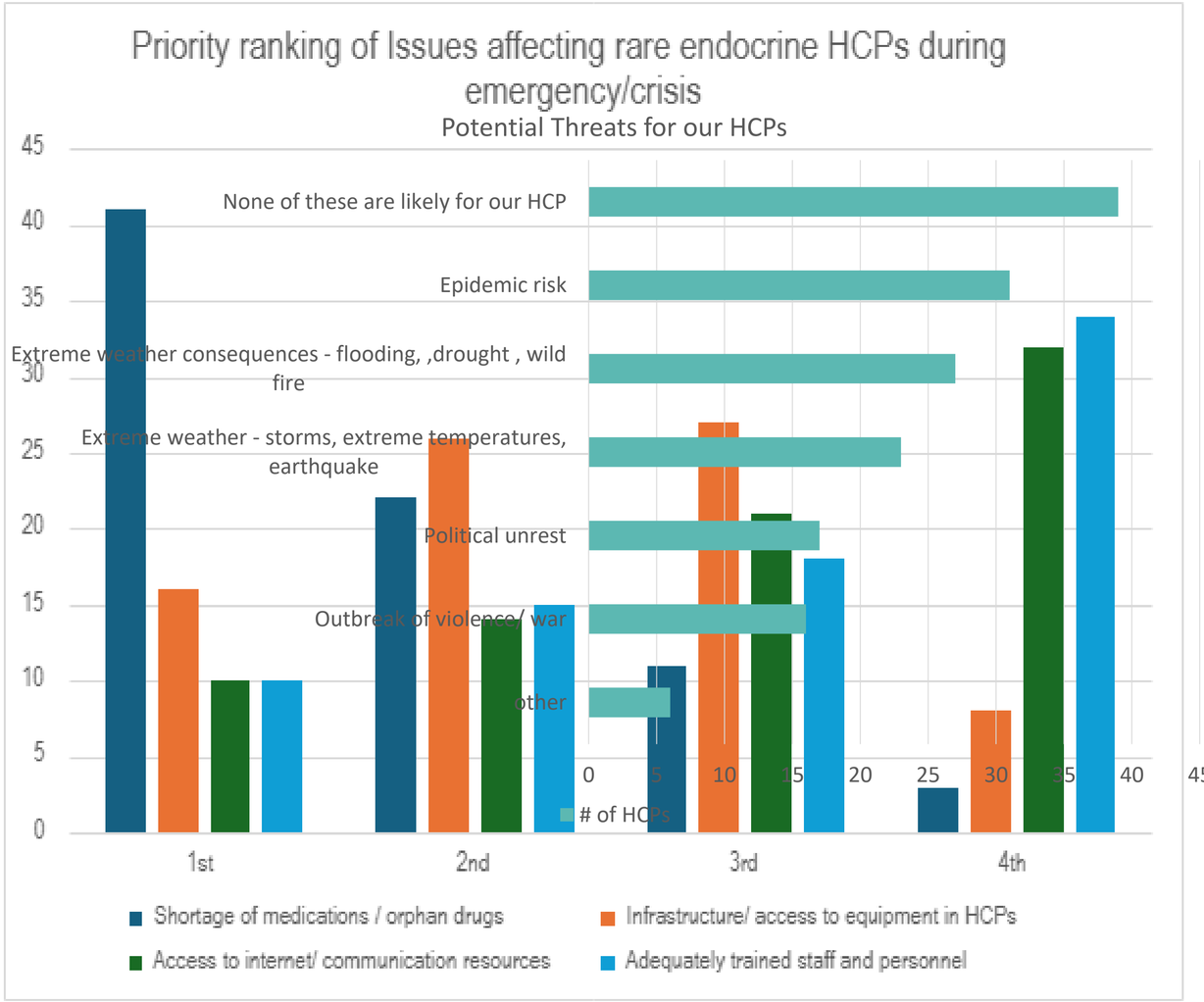
77 responses from 74 different HCPs from 20 countries.
(66 = FM, 8 = AP)

3 HCPs had multiple responses so they were all taken into account

Majority ranked 1st: Shortage of medications / orphan drugs

What's being done?

- *Discussions with ESE about ongoing work*
- *Clarifying essential medicines for rare endocrine disease*



Continuous Monitoring Process

34 HCPs reported same figures in EC Platform and e-REC

20 HCPs requested us to report correct figures to EC during validation

14 HCPs did not request but we reported e-REC on their behalf

General Reflections	Key Take Aways
Stricter indicators than other years	Focus on how ERN is impacting/ creating activities
More late submissions than usual	*More reminders preferred?*
More main & sub representatives that had changed/ updated since last year	Make sure to keep us informed when your contact details need updating

HCP Performance System

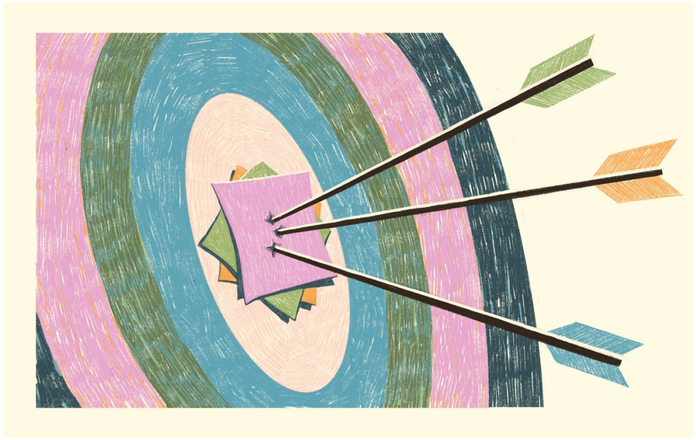
Updates this year:

- Performance Scores 2025 reported by Endo-ERN as part of Continuous Monitoring
- Only based on *Mandatory* activities

Excellent (100%) = 31 HCPs

Good (60%>) = 56 HCPs

Needs improvement (<60%) = 18 HCPs



Full reports to be released for comments by August 1st

ePAG Evaluation

We wanted to complement the HCP performance system implemented in 2024. As different activities are assessed for our member hospitals, in parallel we propose to check the activity level of our ePAGs.

Objectives:

- To identify the key areas of contribution for our ePAGs
- Measuring contribution concretely
- Using this gathered information to inform on the role demands and goals of being an international ePAG for our ERN

Activities	Details
	Mandatory – points per event/ meeting
1	Attendance at the Endo ERN general assembly
2	Attendance at the SCAB meetings
3	Complete necessary governance documents
4	Attend ePAG regular meeting with coordinator
5	Give input on relevant questions addressed to MTG chairs
6	Include Endo-ERN information/ link/logo at their organisation website
	Expected
7	Participation in patient notebook (submit notebook)
8	Co Chair MTG specific meetings
9	Active contributions WP co-chair role
	Bonus
10	Performed role as rotating Chair for Endo-ERN ePAGs
11	Participated in ePAG Buddy System
12	Endo-ERN representative for other projects/ initiatives/ committees or collaborating with other ERNs
13	Involved in writing/ creating of Endo-ERN resource (CPG, patient material, PJ etc.)
14	Contribute/ present during Endo-ERN webinars
15	Other independent initiatives by ePAGs

Our Initial Findings

10 countries represented

Continued efforts need to be made to include input from under represented countries in Europe

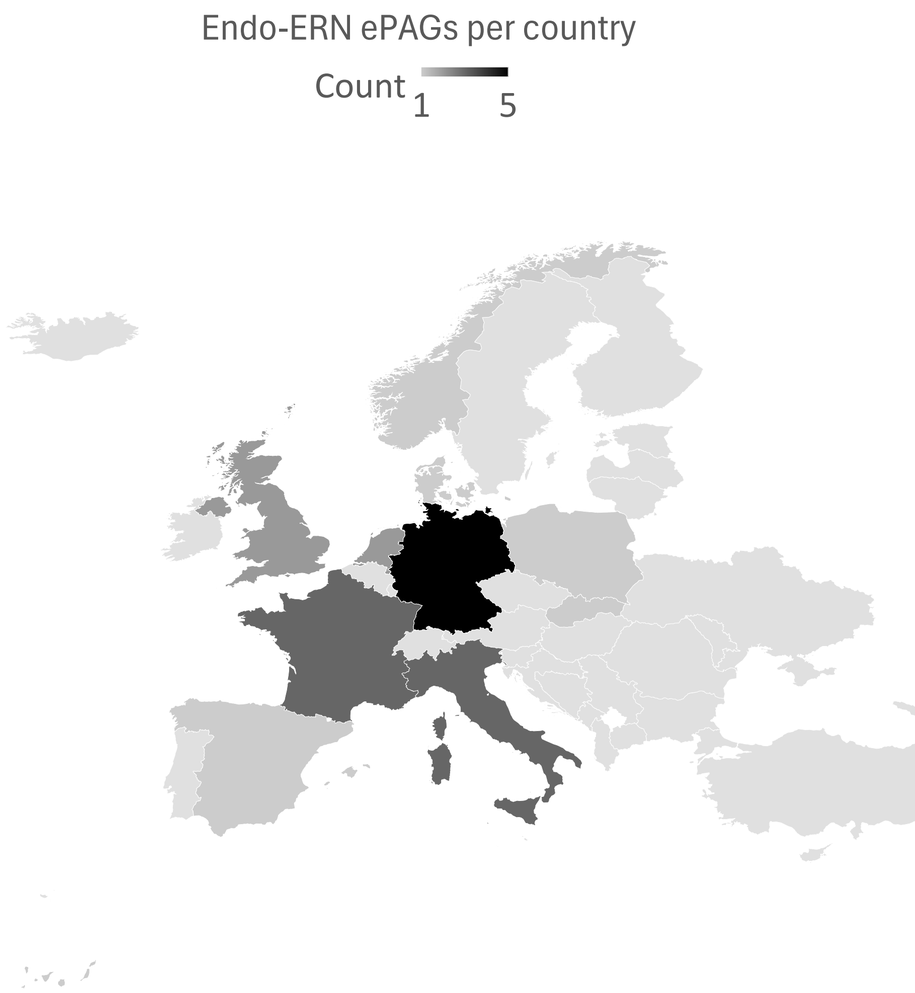
Attendance at the Endo-ERN GA is likely difficult for 100% completion

Focus instead on ensuring each MTG is represented

Mandatory activity lowest compliance *“Include Endo-ERN information/ link/logo at their organisation website ”*

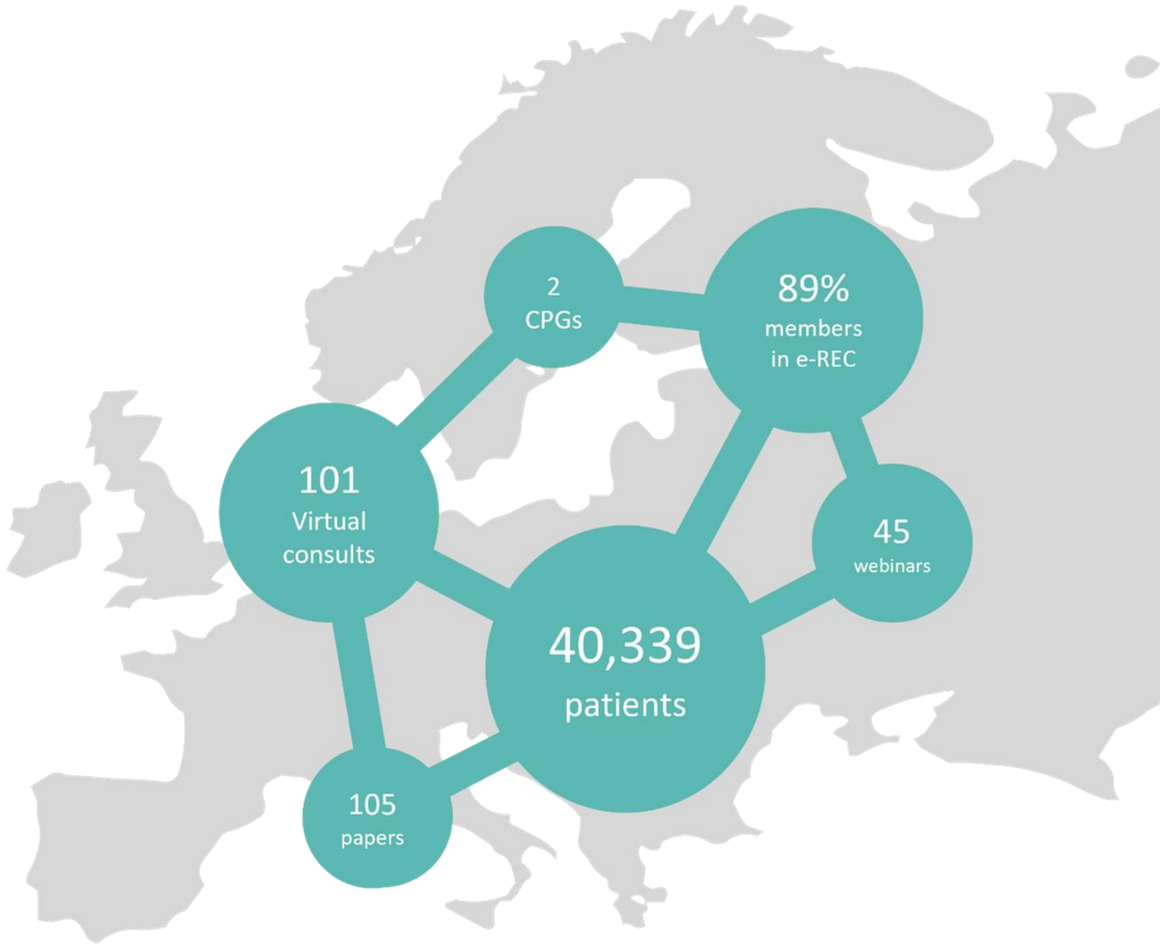
Target to improve this in 2025

Full report to be circulated after GA!



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
- Assessment of the 5-year evaluation for 1st call members of the European Reference Network on Rare Endocrine Conditions (Endo-ERN) in: Endocrine Connections Volume 15 Issue 3 (2026)



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

Areas of Improvement & Goals for 2026

European Reference Network

Endo-ERN

Formalization of improvement to **practically apply to care** via CDST, CPG and Patient Journeys

Affiliated Partner involvement in the network requires an engagement plan moving forward.

Highlight the efforts and achievements of our members

Use CPMS to work towards compatibility in all centers

Formalize clinical indicators of the network with WP5 and WP7

Create concrete patient **care pathways** and formal recommendations for the **cross border care access**

Highlight resources already available moving cross border as patient

All HCPs using e-REC by end of 2026

European Reference Network

Endo-ERN

Patient Journeys Update: Acromegaly

Funded by
the European Union

Patient Journey VS Care Pathway

Patient journey

- Tool
- Experiences & Needs
- Created by Patients & Experts

Clinical stage

Care pathways

- What is needed
- When
- Who’s responsible
- Created by Hospitals & MDt

Rationale – Why Acromegaly?

- Long average diagnostic odyssey
- Frequently chronic condition
- Treated by/ consult with multiple experts prior to and after diagnosis

Consequences of delayed diagnosis:

- ❑ Higher mortality risk
- ❑ Irreversible facial alteration
- ❑ Increased risk of comorbidities
- ❑ Higher costs in testing

High patient burden

*'Patient Journeys' map the **common needs** of a **specific** patient community along the **different stages** of their journey, from first symptoms, diagnosis, to treatment and follow-up. These needs are **identified and described** through the **eyes of the patients** or caregivers"*
(Bolz-Johnson et al. 2020)

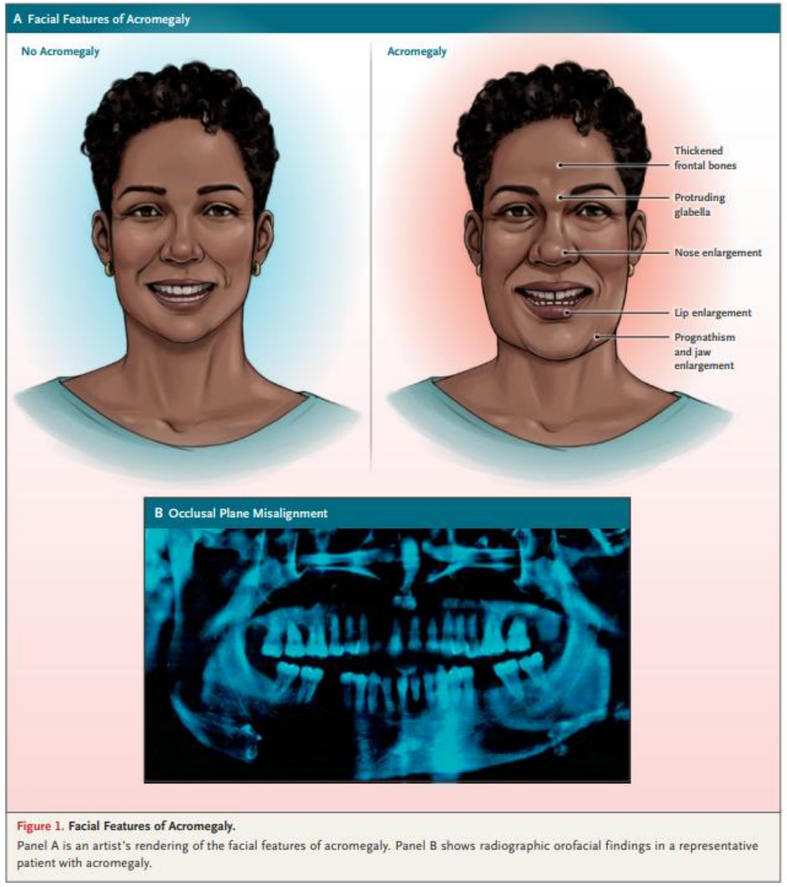


Figure 1. Facial Features of Acromegaly.
Panel A is an artist's rendering of the facial features of acromegaly. Panel B shows radiographic orofacial findings in a representative patient with acromegaly.

Giustina & Colao (2025)

Methods & Results

Mixed methods study
Min.= 20 patients from 6 EU countries (stratified sampling strategy)
Data gathering via eCastor
Ethical approval: Non-WMO from AUMC METC

Baseline journey:
Data from 2022 Patient Journey in Endo-ERN (Webb et al.) to the new EURORDIS baseline template in Stage 1 & 2

3 Engage with your Community

4 Draft final Patient Journey

5 Clinical Review & Approval

6 Put Your Journey into Action

Baseline disseminated to **63 expert centres in 23 countries** in MTG6

- Promoted by dedicated ePAGs internally in patient org.

52 patients enrolled in study

- 8 countries
- 50 patients, 2 caregivers

45 reviewed patient journey in ENG

- **30 confirmed baseline journey to be accurate**
- **15 gave additional comments**

Mean age: 58.13 years
Range in symptom onset to diagnosis (yrs): <1 – 10.5 years

Stage of diagnosis:
- 37 reported being in *Follow-up care/ Continued or maintained treatment*
- 5 were undergoing/awaiting *First Surgery*
- 3 were facing *Subsequent surgery*
- 0 were in *First symptom/ Diagnosis* stage

Sample of feedback

“It's the first time that i read such a exact definition of the symptoms of my illness”

Ideal support during follow up care:

Finding the right professionals with knowledge of Acromegaly (dietist, fysiotherapist, etc) ,psychological support, help finding good healthcare, information about disease and progress of the disease

Honesty by HCP if not familiar with the surgery/ LT treatment

Empathy – *Do not dismiss symptoms*

Holistic care – advice on pain management, how to inform dentist, gynecologist and workplace of diagnosis

Address fears – fears telling family, needles for treatment, fear of word ‘tumour’ / brain tumour

Key Unmet Needs expressed by EU patients

- ❑Information on surgery & radiation therapy
- ❑Clear explanation of terminology
- ❑Preemptive referral to psychologist, dietist, etc.
- ❑Referral or link to support group/ patient organization/community – others with condition
- ❑List of relevant specialists/ professionals to be consulted throughout

Next steps:

- ✓ Review of Patient Journey structure with patient volunteer
- ❑ Review with communication manager of Endo-ERN

- Baseline Acromegaly patient journey data has been validated and updated to better reflect current care experiences across Europe.
- Importance of QoL measures stressed (e.g. AcroQOL, ACROScore) in all literature but no direct recommendation/step to refer to a psychologist in most care pathways/ hospital protocols.
- Many facets of the unmet needs can be ameliorated in patient association tools, highlighting the value in connecting patients to patient associations/ organizations.

Lessons from Pilot of EURORDIS Methodology

1. Needs **additional engagement** with MTG chairs ePAG & clinical at earlier stage
2. Minimum of 6 EU countries **may not be possible for baseline** creation without translation support
3. Dissemination to all countries is possible for **English baseline- yielded good engagement**
4. Review process should be part of maintenance over longer time span i.e**. update every 2 years**
5. Present PJ wider MTG cohort expert cohort prior to public dissemination to **encourage maximum uptake**
6. Need **input from ePAGs on most useful format** this patient version should take