

## MTG6 HCP meeting

Friday 14 November 2025

11:00 – 12:00 CET

**MTG6 chairs:**

Nienke Biermasz, Evangelia Charmandari, Marta Baranska, Johan de Graaf, Diana Vitali



Funded by  
the European Union

## WP1 Management & Coordination

### Endo-ERN General Assembly 2026

- 10th Endo-ERN GA: 20–21 Apr 2026, Athens (Crowne Plaza). Invitations sent in Oct to main/sub reps. Details [here](#).

### MTG6 meetings for 2026

- We are working to expand participation in these meetings, and careful planning will be important to increase attendance.
- There will be an MTG6 meeting at the GA 2026, where the MTG6 chairs will inform attendees of the dates of the next two online meetings in 2026.
- Topics to be discussed at the GA2026?

# WP1 Management & Coordination

## Upcoming Events:

- Visit [Endo-ERN](#) › Upcoming events for all dates



## Upcoming Events

### FUNCTIONING NEUROENDOCRINE TUMOUR SYNDROMES: BIOCHEMICAL, GENETIC, IMAGING WORKUP AND THERAPEUTIC MANAGEMENT

November 6<sup>th</sup> – November 8<sup>th</sup>, 2025

Recordati Rare Diseases Foundation is hosting a European Society of Endocrinology (ESE) endorsed course that is suitable for endocrinologists, nuclear medicine, physicians, pathologists, and oncologists. [...]

[Continue reading >](#)



### REGISTRO: Aggiornamento in tema di ipopituitarismo (Update on hypopituitarism)

December 2<sup>nd</sup>, 2025

This event will be conducted in Italian. Serie di Webinars SIE-SIEDP sulle malattie endocrine rare per specialisti italiani (Joint SIE-SIEDP webinars in rare endocrine diseases: [...])

[Continue reading >](#)

### SAVE THE DATE: European Neuroendocrine Association

December 3<sup>rd</sup> – December 5<sup>th</sup>, 2025

Check out the programme of this 9th workshop organised by the European NeuroEndocrine Association. The theme of the event is Changing the Paradigms Over 20 [...]

[Continue reading >](#)

### REGISTER: International Conference on Clinical Research Networks for Rare Diseases

December 9<sup>th</sup> – December 10<sup>th</sup>, 2025

Reigster now for the 2nd International Conference on Clinical Research Networks for Rare Diseases, organised by IRDiRC, ERDERA, and Rare Diseases International. This event will [...]

[Continue reading >](#)

# WP1 Management & Coordination



## REGISTER: Joint-ERN Information Webinar for Ukrainian Physicians

February 18<sup>th</sup>, 2026

👉 Endo-ERN & ERN eUROGEN Collaborative Event Improving Rare Disease Care in Ukraine: Access to European Reference Networks (ERNs) and Expert Resources ⓘ Wednesday 18 [...]

[Continue reading >](#)



## SAVE THE DATE: Rare Endocrine Diseases Winter School, Varna, Bulgaria

February 28<sup>th</sup> – March 3<sup>rd</sup>, 2026

Save the date and look out for more information in the coming weeks. This Winter School will feature international speakers from Endo-ERN. A small group [...]

[Continue reading >](#)

## REGISTER: Corticotroph tumors and Postoperative Quality of Life – Perspectives from a Neurosurgeon, an Endocrinologist and a Patient

March 24<sup>th</sup>, 2026

Register now for a webinar from MTG6 planned for Tuesday, 24 March 16:00–18:00 CET. Webinar Chair: Prof. Nienke R. Biermasz Endo-ERN MTG6 Adult Chair Agenda [...]

[Continue reading >](#)

## SAVE THE DATE: Endo-ERN General Assembly (GA)

April 20<sup>th</sup> – April 21<sup>st</sup>, 2026

Dates: Monday 20 and Tuesday 21 April 2026 Location: Athens, Greece Programme: Start: Monday, 20 April 2026 9:00 starting with SC/AB Meeting followed by general [...]

[Continue reading >](#)



# WP1 Management & Coordination



## SAVE THE DATE: European Congress of Endocrinology (ECE) 2026

This event will be from May 9<sup>th</sup> to May 12<sup>th</sup>, 2026

The European Congress of Endocrinology (ECE) will take place in **Prague, Czech Republic, from 9 – 12 May 2026.**

Save the Date! Further details will be announced in due course.



### Event summary

Event	European Congress of Endocrinology (ECE) 2026
Date	May 9 <sup>th</sup> – May 12 <sup>th</sup> , 2026
Location	Prague, Czechia
Organisation	European Society of Endocrinology (ECE)
Website	<a href="#">Visit event website</a>
WP	<b>WP6</b> Education and Training
	<a href="#">Add this event to your calendar</a>

## SAVE THE DATE: European Society of Paediatric Endocrinology (ESPE) 2026

This event will be from September 8<sup>th</sup> to September 10<sup>th</sup>, 2026

Save the date for the 64th ESPE 8-10 September, 2026 to be held in Marseilles, France.



More information will be available closer to the event.

### Event summary

Event	European Society of Paediatric Endocrinology (ESPE) 2026
Date	September 8 <sup>th</sup> – September 10 <sup>th</sup> , 2026
Location	Marseilles, France
Organisation	European Society for Paediatric Endocrinology
	<a href="#">Add this event to your calendar</a>

## WP2 Communication & Dissemination

- A Monthly Digest has been launched by Endo-ERN, where all relevant network updates from the past month can be found.
- New publications, materials or events to be endorsed/updated/disseminated
- Please follow Endo-ERN at our socials:

<https://www.linkedin.com/company/rareendoern>  
<https://www.facebook.com/rareendoern>  
<https://www.youtube.com/@rareendoern>  
[www.endo-ern.eu](http://www.endo-ern.eu)

## WP3 Evaluation



- Evaluation allows for continuous improvement and sharing of best practices across the network. For Endo-ERN members there is self-evaluation annually, and an external review as part of the AMEQUIS cycle, every 5 years.
- Attendance at MTG-specific meetings is expected for all HCPs and counts toward performance scoring. If you cannot attend, please forward the invite to a colleague to attend on behalf of your HCP.
- Ensure that HCP members are entering data into e\_REC for the continuous monitoring process
- Please feedback any challenges you are having

## WP4 CPMS

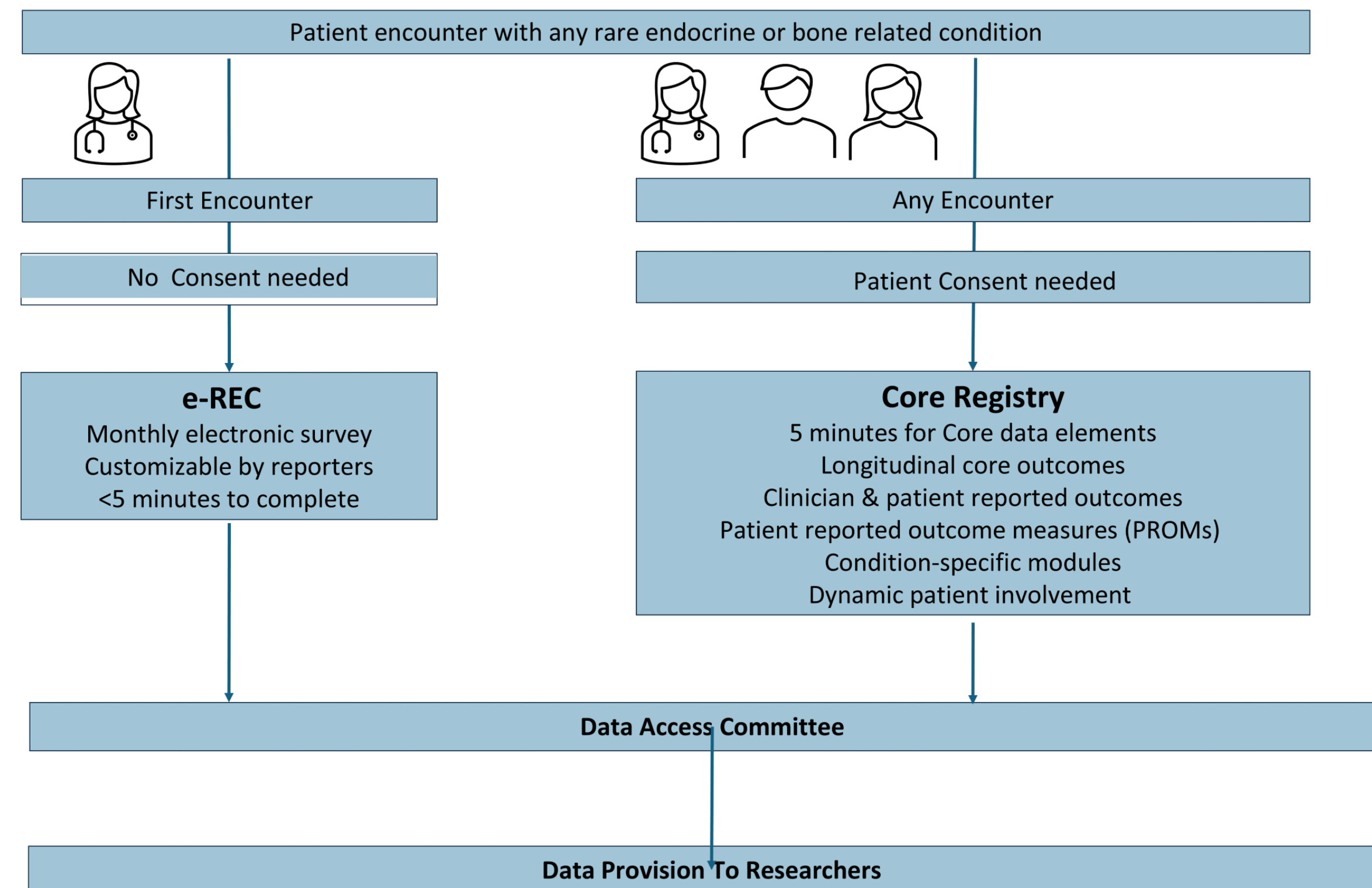
- Pediatric case of Cushing Syndrome (by Sophia Sakka) planned for next MTG6 meeting

## WP5 Registries

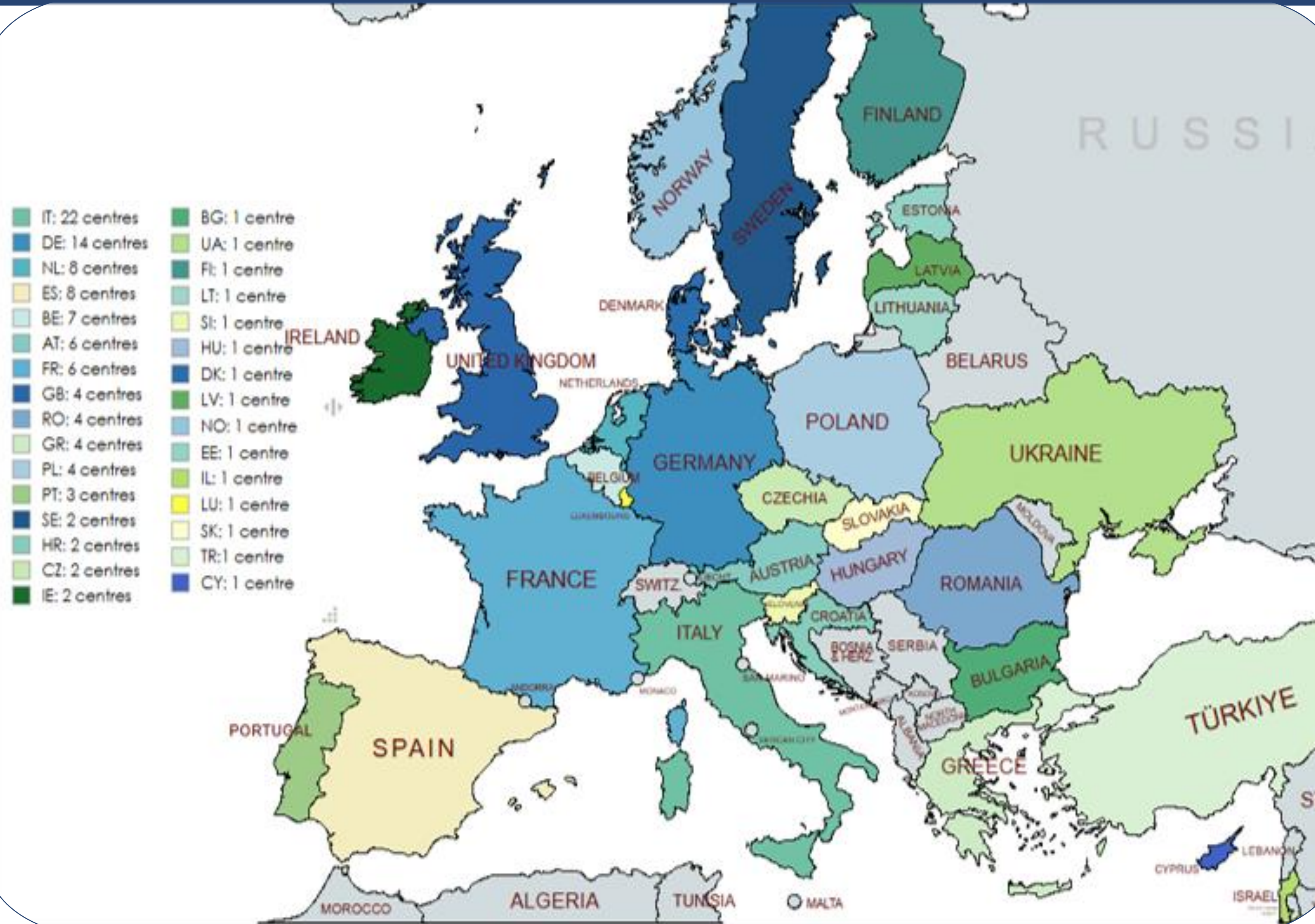
### EuRREB registry

- There are several disease specific modules under construction.

## The Registries in a Nutshell



# Centres Reporting in e-REC



**July 2018 – December 2024**

**Active reporters:**

113 centres from 32 countries  
(5 non-EU)

**HCPs ERN affiliation**

Endo-ERN only - **62**

Endo-ERN and ERN-BOND - **29**

ERN-BOND only - **3**

Not affiliated to either – **19**

**Number of patients in e-Rec:**

56573 cases




(41933 in adults, 14640 in children)

Full report at [eureb.eu](http://eureb.eu)



## WP6 Education & Training

- Current Clinical exchange Program call open until 30 November
- Have a webinar topic for 2026? Send your suggestions to [pituitary@endo-ern.eu](mailto:pituitary@endo-ern.eu)
- The following MTG6 webinars are already scheduled:

MTG	Theme / Title	Date	Time CET	Speaker(s)	Register	View	CPMS
MTG6	Corticotroph tumors and Postoperative Quality of Life – Perspectives from a Neurosurgeon, an Endocrinologist and a Patient	2026-03-24	16:00 – 18:00 hr				
	Joint-ERN Information Webinar for Ukrainian Physicians	2026-02-18	16:00 – 17:45 hr				
MTG6	Aggiornamento in tema di ipopituitarismo (Update on hypopituitarism)	2025-12-02	17:00 – 18:30 hr				

# WP6 Education & Training



- MTG6 involvement in Winter School, Varna, Bulgaria

## SAVE THE DATE: Rare Endocrine Diseases Winter School, Varna, Bulgaria

This event will be from February 28<sup>th</sup> to March 3<sup>rd</sup>, 2026

Save the date and look out for more information in the coming weeks. This Winter School will feature international speakers from Endo-ERN. A small group of a maximum of 30 participants will be treated to a diverse sessions including lecturers, case presentations, roundtable discussions and plenty of time to interface with international experts.

### Event summary

Event	Rare Endocrine Diseases Winter School, Varna, Bulgaria
Date	February 28 <sup>th</sup> - March 3 <sup>rd</sup> , 2026
Time	13:30 – 11:30 hr
Location	Varna, Bulgaria
Contact	
WP	<div>WP6</div> Education and Training
	<a href="#">Add this event to your calendar</a>

## **WP7 Clinical Practice Guidelines & Clinical Decision Support Tools**

### Topics for next guidelines chosen:

- Primary hypoadrenalism, focus on treatment and monitoring target
- Hypothalamic obesity treatment and management (of craniopharyngioma) in children and adults  
ESE have initiated same topic, have responded positively to collaboration with Endo-ERN and ESPE
- Update on the 3<sup>rd</sup> CPG on transition

## WP8/9 Capacity building and best practice sharing for Ukraine



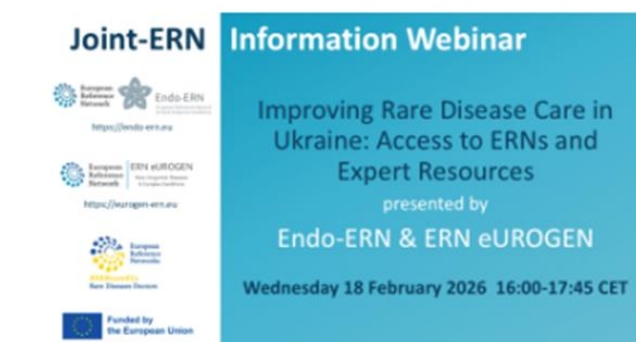
Any contacts with Ukrainian endocrinologists?

### REGISTER: Joint-ERN Information Webinar for Ukrainian Physicians

This webinar will be on February 18<sup>th</sup>, 2026

👉 Endo-ERN & ERN eUROGEN Collaborative Event

#### Improving Rare Disease Care in Ukraine: Access to European Reference Networks (ERNs) and Expert Resources



📅 Wednesday 18 February, 16:00–17:45 CET / 17:00–18:45 EET

📍 Online (Zoom, English with Ukrainian live captions)

This joint webinar will explore how Ukrainian clinicians and patient representatives can collaborate with European Reference Networks (ERNs) to strengthen rare disease care. The programme will introduce the ERN system, feature insights from **Endo-ERN** and **ERN eUROGEN**, and outline how to engage through the **Clinical Patient Management System (CPMS)**.

Speakers include **Tetiana Kulesha**, ePAG representative from **Orphan Diseases of Ukraine**, with additional speakers to be confirmed. A case example and Q&A are planned to illustrate how ERNs connect expertise across Europe to benefit patients in Ukraine.



# What are ‘patient journeys’?

1980s-90s: A shift to greater focus on **patient experience** as an indicator of healthcare quality

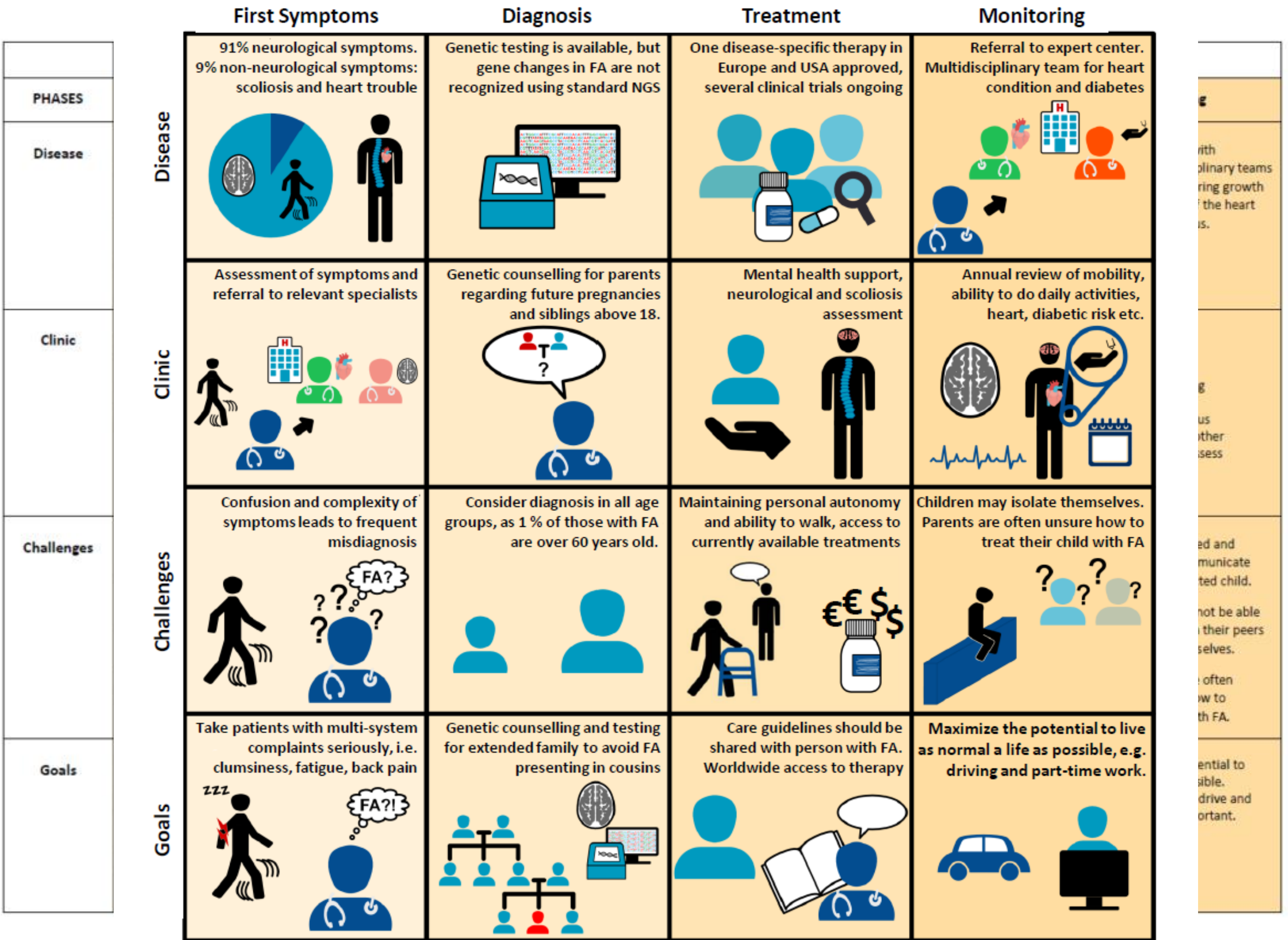
**Journey maps** = research methods originally in marketing/ service fields → used to highlight areas of improvement based on experience of customers

Great **variation** in how term ‘patient journey’ is used in research





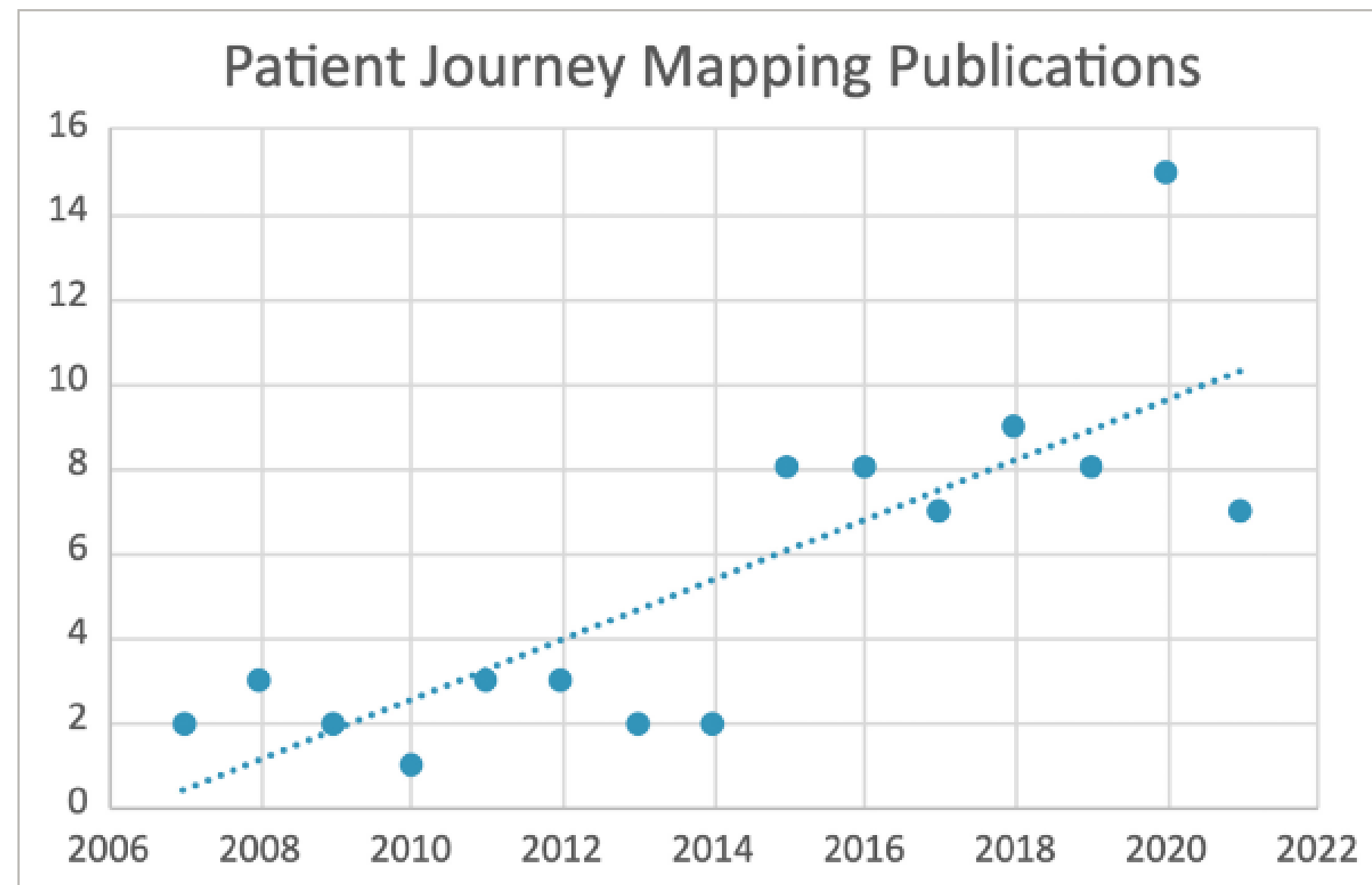
# What are ‘patient journeys’?



Patient Journey for Friedreich's Ataxia (FA) , ERN RND



# What are they used for?



Timeline of patient journey mapping publications, 2007–2021  
(Joseph, Kushniruk & Borycki, 2020)

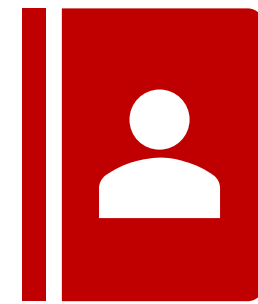
Increased use of ‘Patient Journeys’ in multitude of healthcare/ HTA fields

Tool/ concept used by multiple professionals to easily understand:

- Barriers/ delays in care delivery
- Facilitators of improved care quality
- Experiences impacting health outcomes
- Examining how health system is navigated



# How can they impact quality of care?



- Patient experience & satisfaction act as strong measures of quality of healthcare
- Identifies gaps in care delivered via current/ traditional pathways



- Enhanced communication
- Support decision making
- Personalize approach to patient care

Webb et al., 2022  
Baker et al., 2018



# Patient Journey Definition

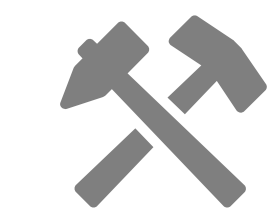
‘Patient Journeys’ map the **common needs** of a **specific** patient community along the **different stages** of their journey, from first symptoms, diagnosis, to treatment and follow-up. These needs are **identified and described** through the **eyes of the patients** or caregivers” (Bolz-Johnson et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



# Patient Journey VS Care Pathway

## Patient journey

## Care pathways



Tool



Experiences & Needs



Created by Patients  
& Experts

Clinical stage

What is needed



When



Who's responsible

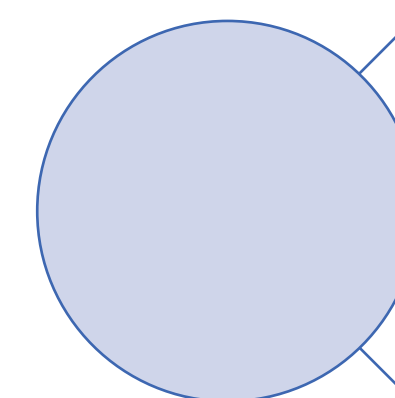
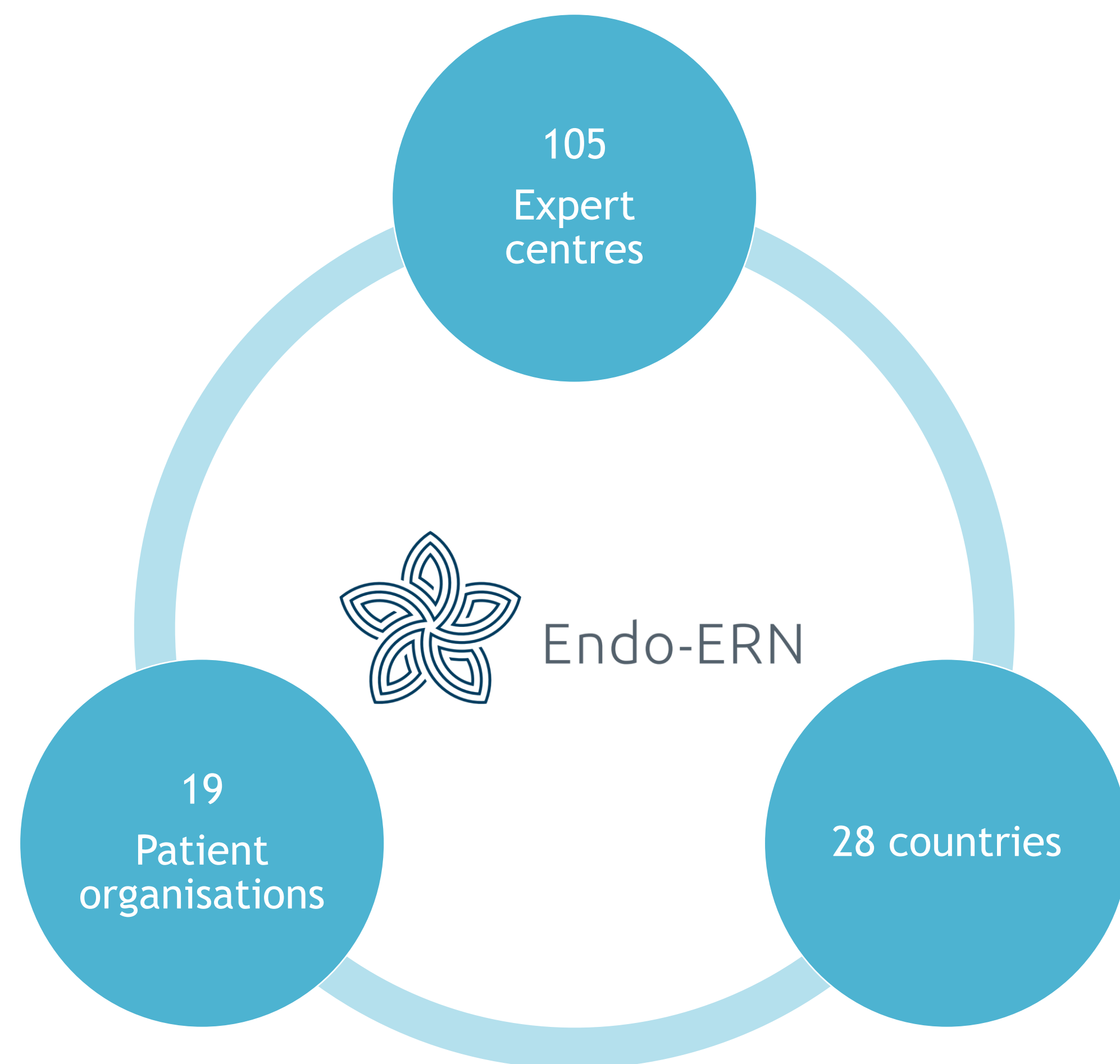


Created by Hospitals &  
MDt

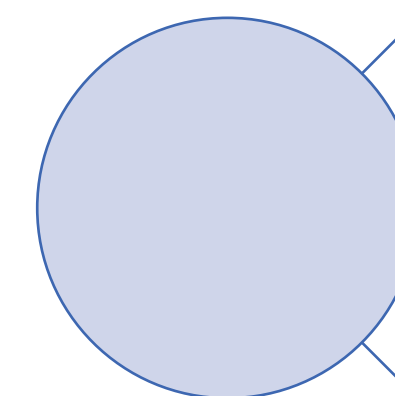




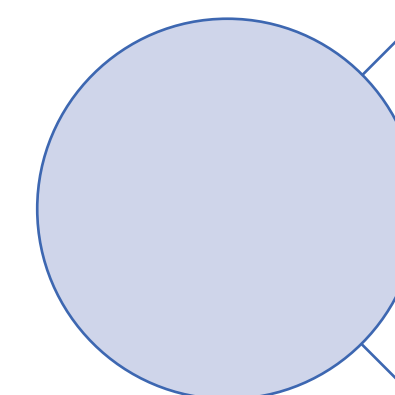
# Endo-ERN Role in Creating Patient Journeys



To demonstrate added value of virtual multidisciplinary expert boards (CPMS)



Standardization of care for rare endocrine conditions (transparency, guidelines, patient involvement)



To demonstrate structural pathways into science

Amsterdam Gastroenterology Endocrinology Metabolism



# Research Aim & Goals

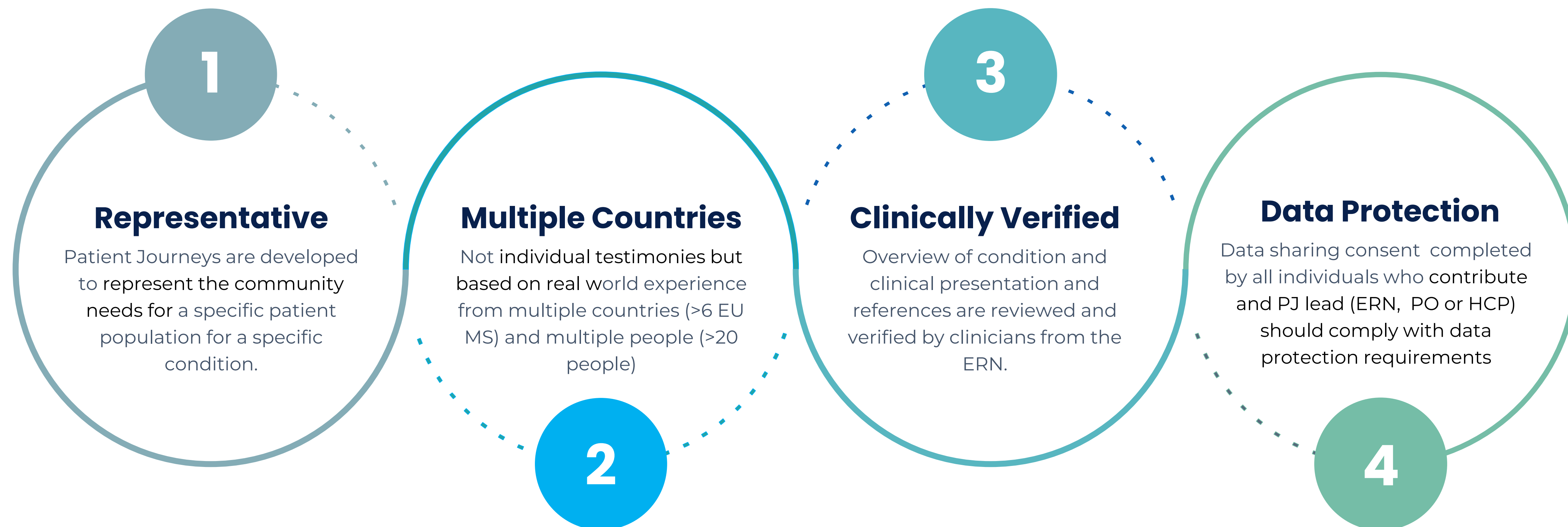
Our aim is to create rare endocrine disease specific patient journey tools based on a specific framework (developed by EURORDIS & Solve-RD) to inform quality of care improvement plans for European expert centres.

Our goal:

1. To identify gaps in the current care pathways for rare endocrine diseases.
2. To create patient journeys for ultra-rare endocrine conditions
3. To generate data-driven recommendations for quality of care improvements in European expert centres.



# Methodology





# Methodology - Stages

1

Select Topic &  
Define Scope



2

Define  
Stages of  
the Journey



3

Engage with  
your  
Community



4

Draft final  
Patient Journey



5

Clinical  
Review &  
Approval

6

Put Your  
Journey into  
Action

GA 2024 in  
Milan

PJ review of  
paper from  
2021

Discussion  
during ePAGs  
meetings

Currently  
ongoing

Next steps to  
form a clinical  
review team  
in MTG6

# Patient Journeys - Update

June-September 2025: Endo-ERN adapted protocol for creating patient journeys piloted for first journey **Acromegaly**

Initial protocol from EURORDIS methodology requires specification to rare endocrine and our ERN needs.

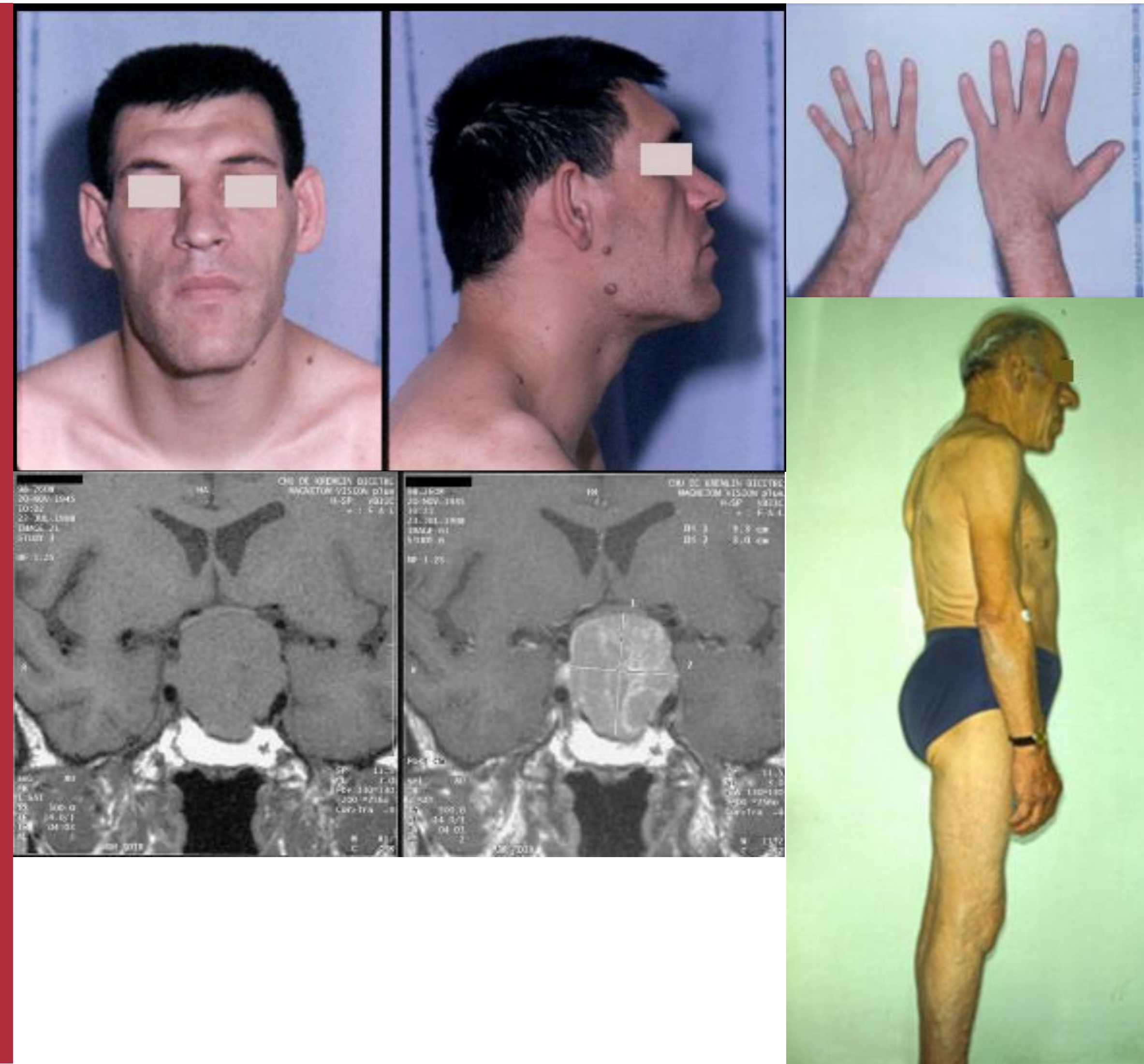
Next slides go through the initial adapted protocol and lessons learned from our pilot





# 1. Select Topic & Define Scope

First Proposed PJ: Acromegaly  
(based on previous mapping):





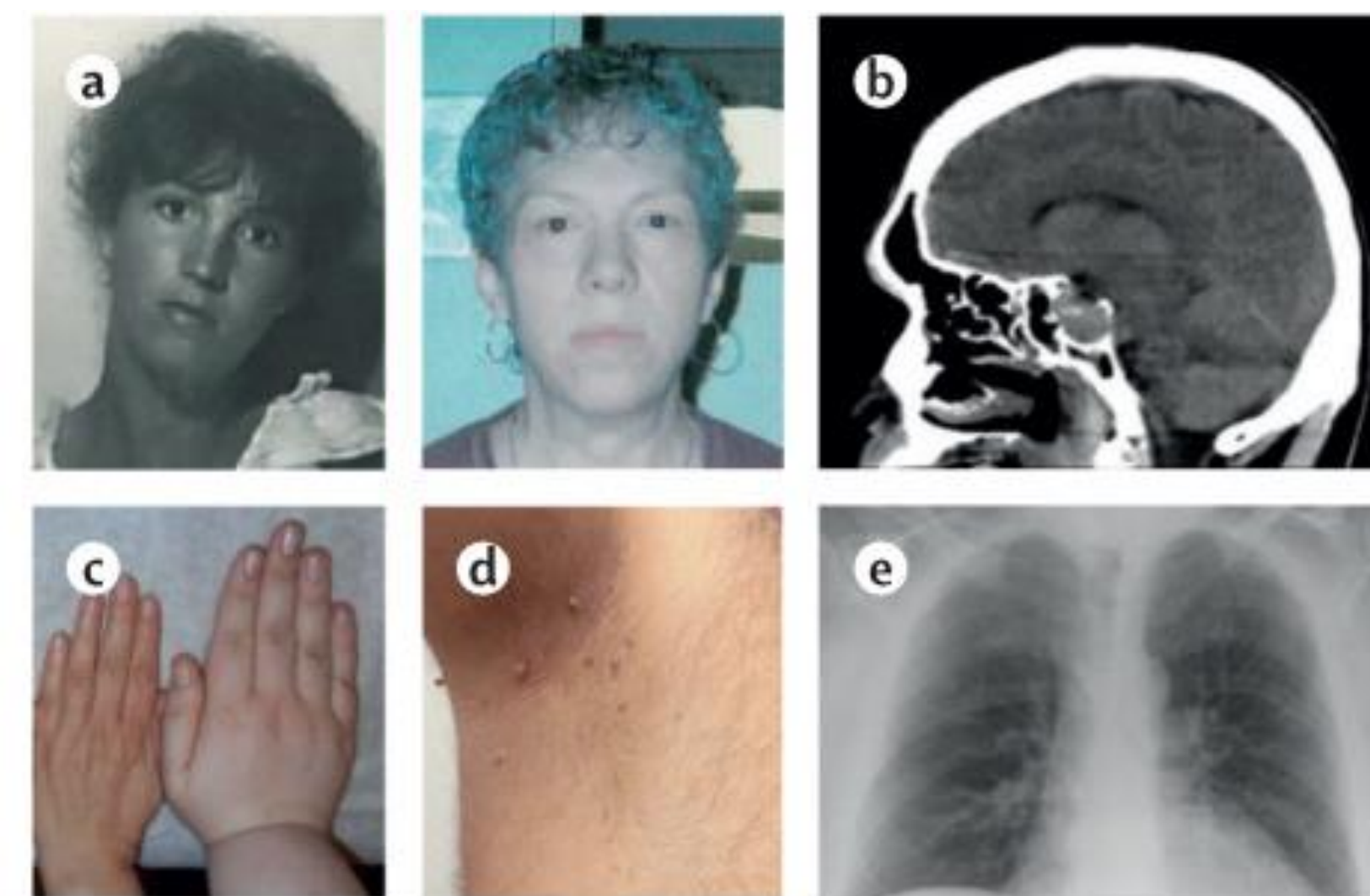
# 1. Why first patient journey

Lesson 1: Defining scope of Patient Journey needs additional engagement with MTG chairs ePAG & clinical - this PJ was an exception due to existing data gathered by our network

- Relevant:
  - Rare acquired endocrine disease
  - Average time to diagnosis: 4 -10+ years
- 79 patient cases identified in Endo-ERN centres in 2023
- 63 expert centres in 23 MS in MTG6
- Guidelines and experts exist within the Endo-ERN covering 24

## Clinical features and comorbidities

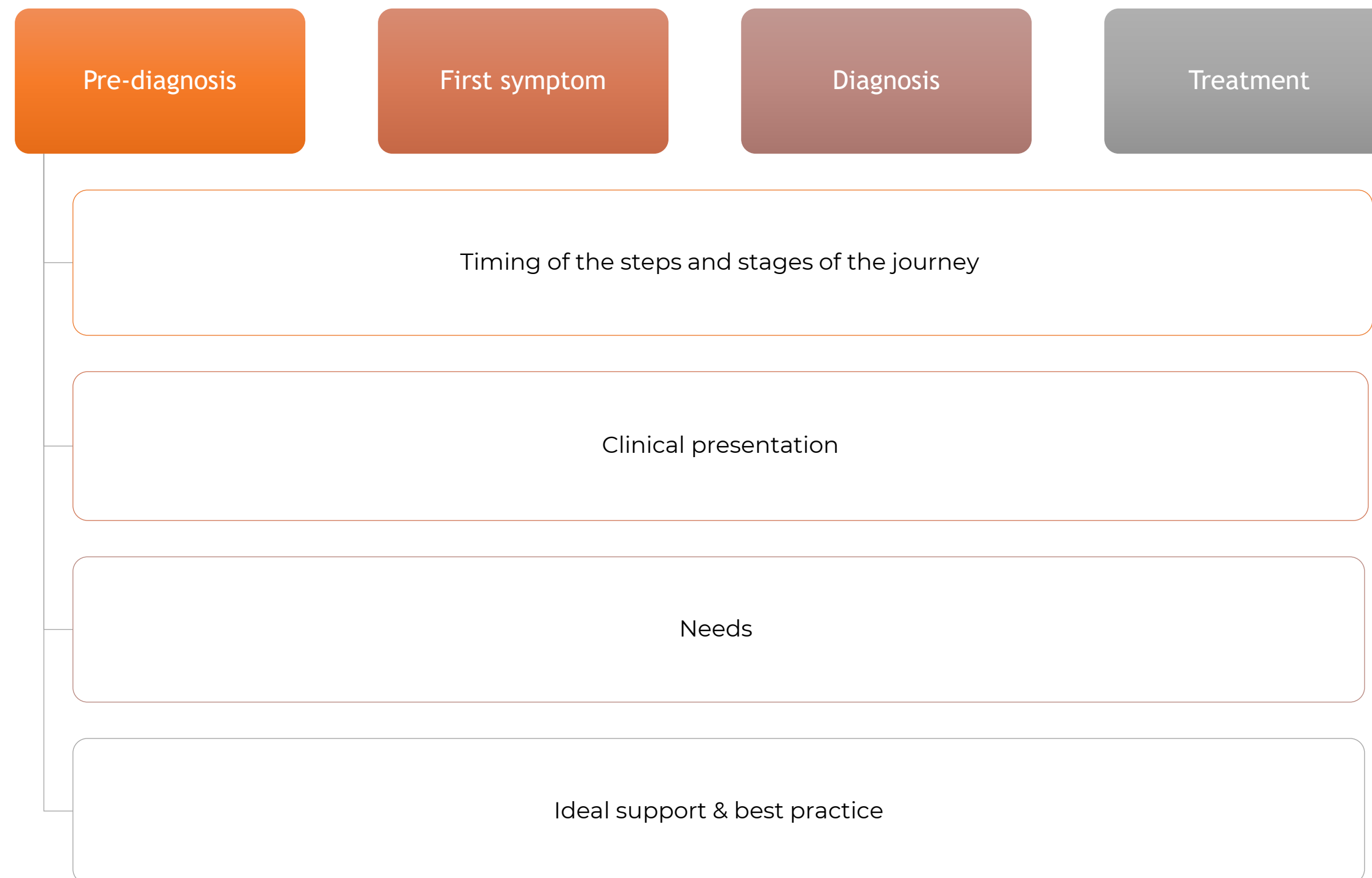
- Acral enlargement
- Prognathism
- Prominent supraorbital ridges
- Tongue enlargement
- Cardiac hypertrophy and failure
- Hypertension
- Skin tags
- Hyperhidrosis
- Headache
- Diabetes
- Sleep apnoea
- Osteoarthritis





## 2. Define Stage of Journey

Min.= 20 patients , 6 EU countries (stratified sampling strategy)



Lesson 2: Minimum of 6 EU countries may not be possible for baseline creation - to achieve this for Final PJ, the timeline needs translation steps included for 6 languages

Mixed methods analysis

Inclusion criteria:

- 18 + years
- Residing in Europe
- Able to provide informed consent
- Able to communicate answers to questions themselves or through a trusted third party such as personal carer or legal guardian

Exclusion Criteria:

- Patients unable to communicate in one of the study languages.
- U18 yrs / current gigantism diagnosis





**For Acromegaly**  
43 *patients joined project*  
31 *gave feedback*



- ❑ Data gathering via survey to fill gaps using Castor



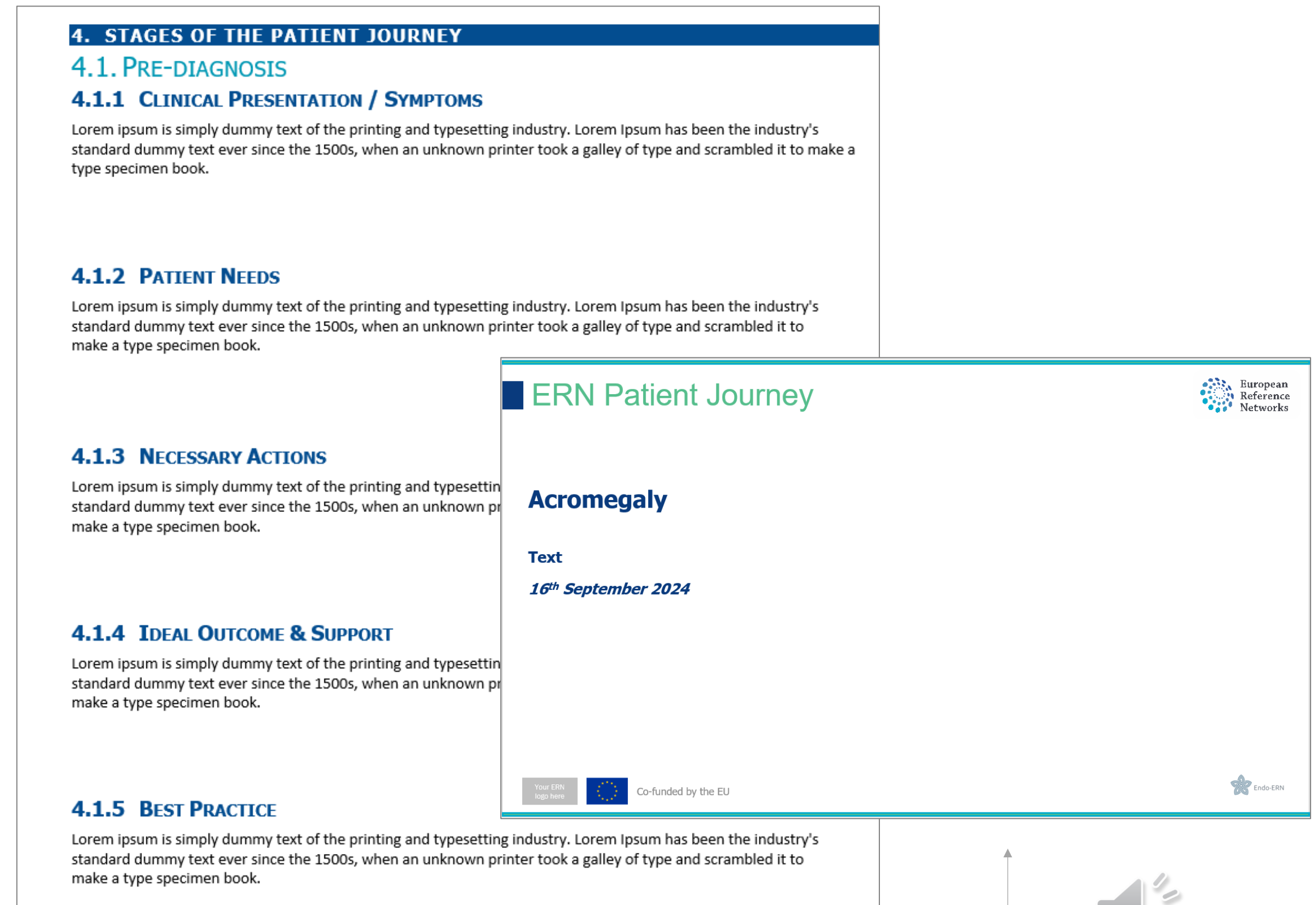


Lesson 4: This process should be part of maintenance over longer time span to allow for updated versions to be published yearly/ every 2 year basis

## 3. Engage with Community

Using Delphi method:

- Refine the key details using content analysis
- Highlight areas with lacking support/ gaps
- Min. of 10 reviewers per redraft



Create Baseline PJ

Circulate Baseline for review

Redraft based on comments

Repeat 2 -3 times with redrafts

Circulate for final consensus



Ongoing - multiple pages with  
dedicated page per stage

## 4. Draft Patient Journey

Discussions with MTG6 chairs & ePAGs on  
preferred format

Draft of data into graphical structure →  
PDF, handbook, video, webpage





# Sample of feedback

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



Consensus on acromegaly therapeutic outcomes: an update (2025)

Importance of QoL measures stressed (e.g. AcroQOL) but no direct recommendation to refer to a psychologist at start

# Sample of feedback

Ideal support during follow up care:

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*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



## 5. Clinical review & Approval

In parallel with step 4, Clinical group of experts review final PJ version

- Via **dedicated expert meeting**
- **At least 6 countries represented**

Task:

- Confirm medical data & clinical stage are accurate
- Check PJ is understandable
- Review gaps expressed by patients and how to incorporate into care



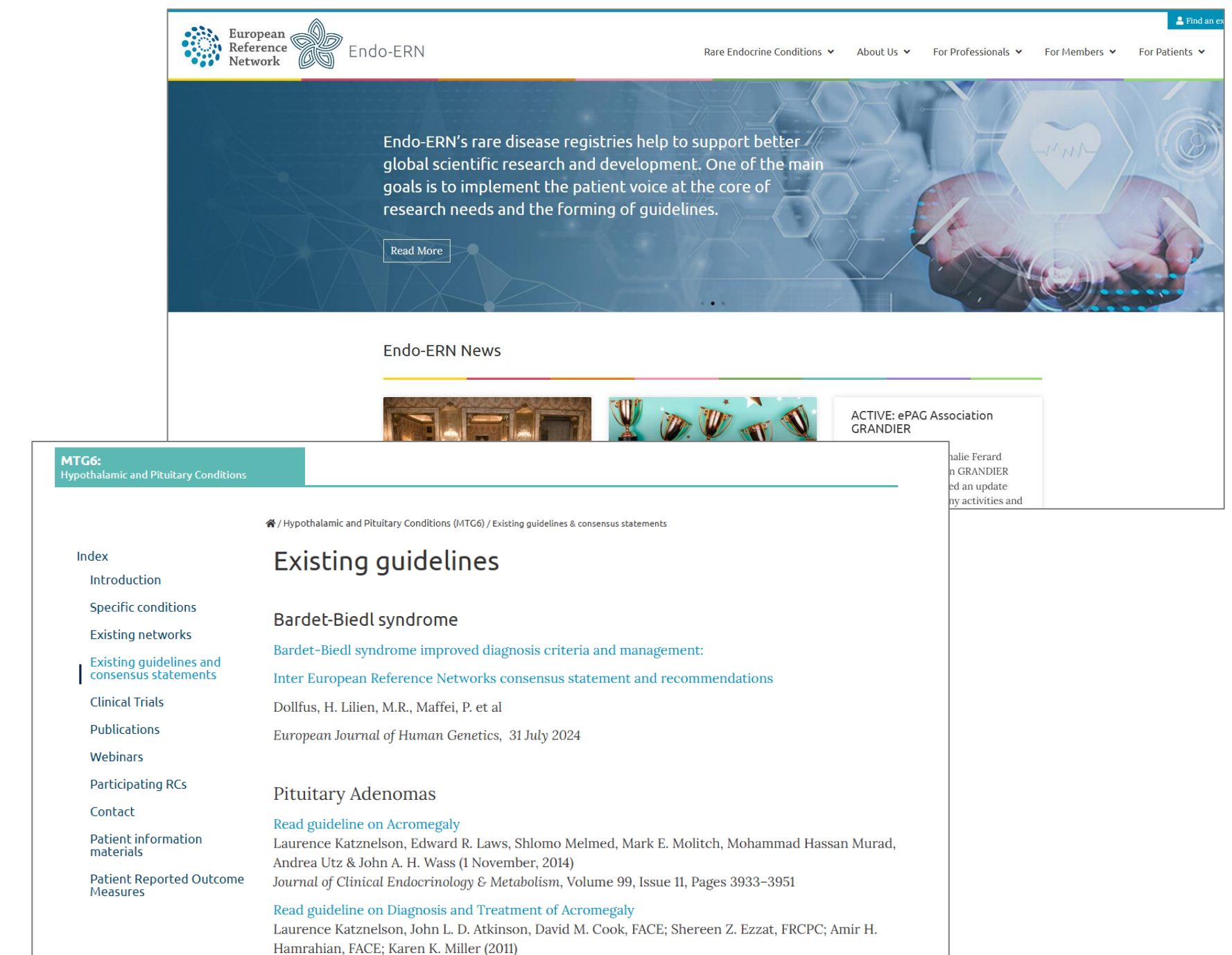


Lesson 5: Need input from ePAGs on most useful format this should take

## 6. Put Journey into Action

Implementing PJ via Clinical Practise Guideline group in Endo-ERN.

1. Perform comparative review of the existing CPG within Endo-ERN - *Are all needs addressed?*
2. Create printable version of PJ for each member HCP
3. Publish to Endo-ERN website & disseminate to all Patient Advocacy Groups involved
4. Complete an Endo-ERN webinar detailing PJ



## Amsterdam Gastroenterology Endocrinology Metabolism

Thanks to all engaging in the ongoing efforts for this project!



### Thesis supervisors:

Alberto Pereira  
Dirk Jan Stenvers



Associazione Italiana SOD/ONH  
Displasia Setto Ottico e Ipoplasia del Nervo Ottico



### Endo-ERN patient representatives:

Johan de Graaf  
Jette Kristensen  
Diana Vitali  
Marta Baranska

### Project contributors:

Matt Bolz-Johnson  
Susan Webb  
Anna Nordenstrom



ADDISON FORENINGEN I DANMARK

# Citations



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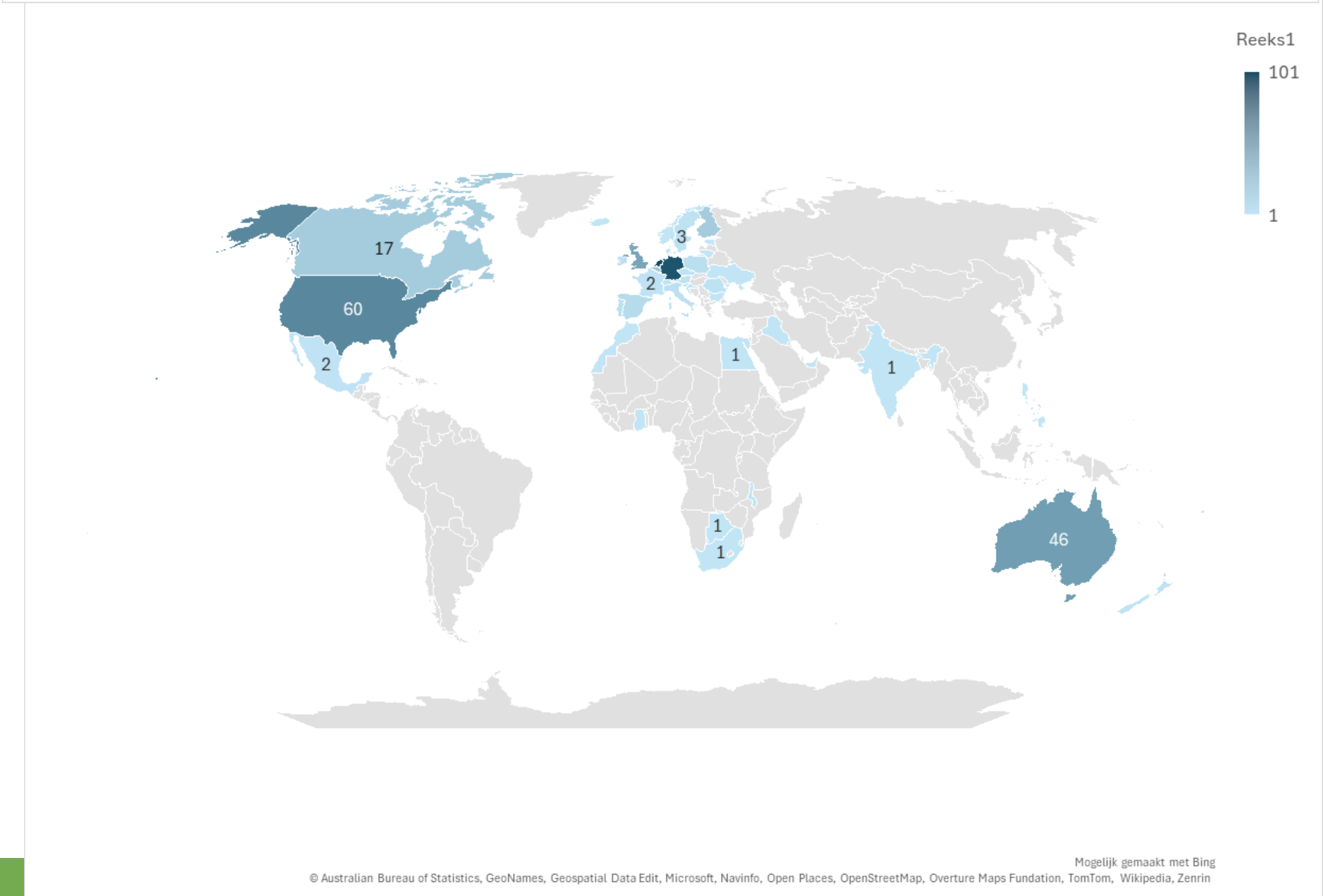
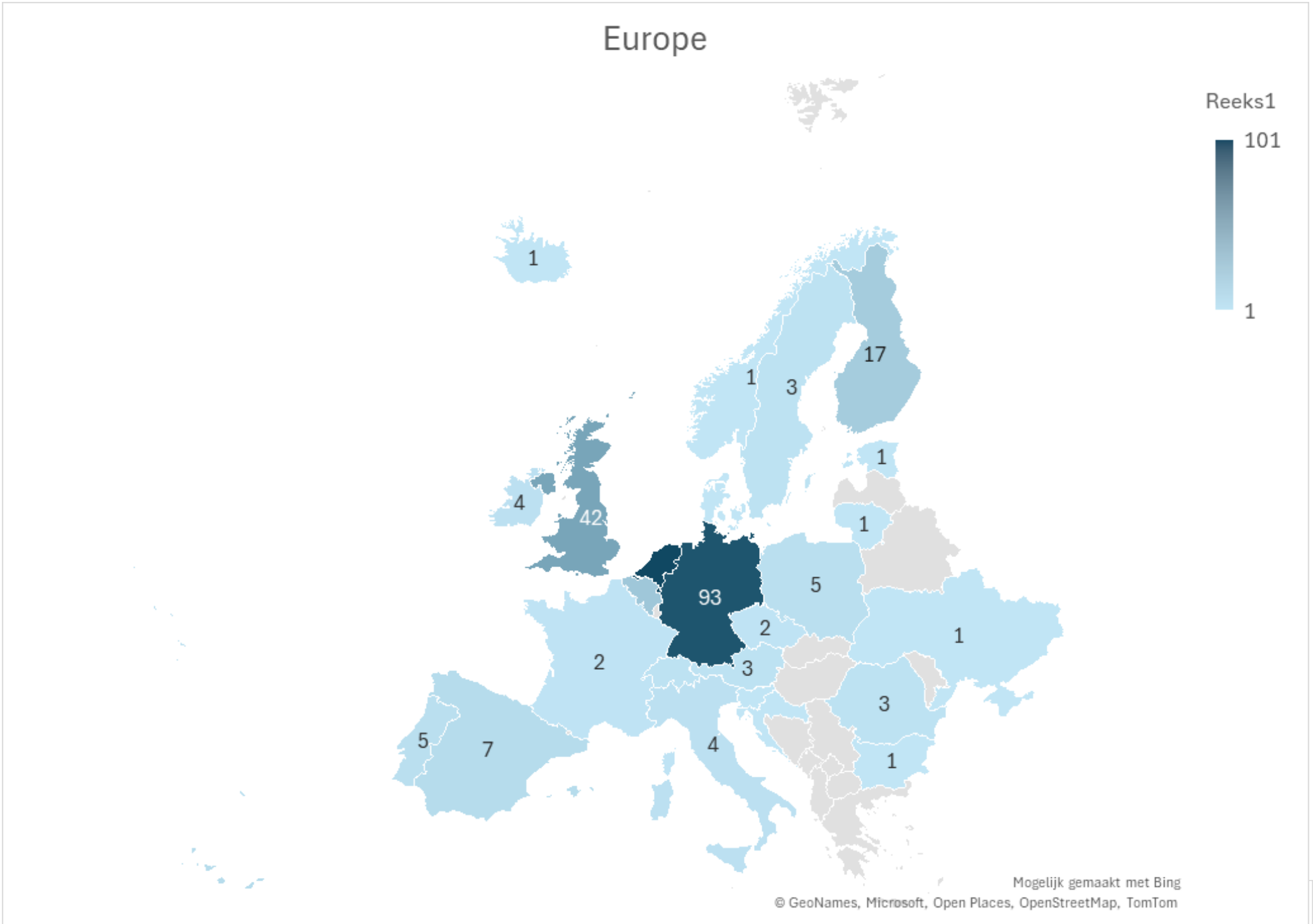
## Survey on psychosocial consequences of living with a pituitary condition



- What are the psychosocial consequences of people living with a pituitary condition?
- And answers the care available to the patient's needs and are there differences in the needs of care between the types of pituitary conditions?

- Launched at the end of October
  - Available in Arabic, Dutch, English, German, Italian, Polish, Portuguese, Spanish, Swedish, Bulgarian and Ukrainian
  - Greek, Slovakian and French in preparation
  - Suggestions for other languages welcome, but we need to identify patient groups first
  - Preliminary data until next week will be used for the ENEA Workshop in Marseille
  - Rest of the data will be collected until the end of February 2026 when the data is diverse enough
- 
- [https://ec.europa.eu/eusurvey/runner/Psychosocial\\_consequences](https://ec.europa.eu/eusurvey/runner/Psychosocial_consequences)

First glance:  
461 reactions  
Mainly Germany,  
Netherlands, the  
US, UK and  
Australia





**AOB**




European  
Reference  
Network



Endo-ERN









**INTERNATIONAL AWARENESS CALENDAR  
OF RARE ENDOCRINE DISEASES  
– PITUITARY DISORDERS**

**2026**

<b>28 February</b>	<b>Rare Disease Day</b>
<b>8 April</b>	<b>Cushing's Awareness Day</b>
<b>1–31 October</b>	<b>International Pituitary Awareness Month</b>
<b>1 November</b>	<b>Acromegaly Awareness Day</b>

 European  
Reference  
Network  Endo-ERN  European  
Patient  
Advocacy  
Group 

**Endo-ERN, MTG6: Hypothalamic and Pituitary Conditions**



European  
Reference  
Network



Endo-ERN