

MTG3 HCP meeting

Monday 20 October 2025
16:00 – 17:00 CEST

Pietro Maffei, Felix Reschke, Valeria Corradin, Bernd Rosenbichler, Nolwen le Floch

MTG3 chairs



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The representatives for **MTG3** [Genetic Disorders of Glucose & Insulin Homeostasis](#) are:

Pietro Maffei [Adult and Paediatric chair](#)

Azienda Ospedaliera di Padova (AOP) (Padova, Italy)



Pietro Maffei

Felix Reschke [Paediatric chair](#)

Hannoversche Kinderheilanstalt, Diabetes Centre for Children and
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Felix Reschke

Valeria Corradin [ePAG representative](#)

AILIP (Ass.ne Italiana Lipodistrofia) (Dossobuono, Italy)



Valeria Corradin

Nolwen LeFloch [ePAG representative](#)

Association du syndrome de Wolfram (ASW) (Grand-Champ, France)



Nolwen LeFloch

Bernd Rosenbichler [ePAG representative](#)

Alström Syndrom e.V. (Unterföhring, Germany)



Bernd Rosenbichler



European
Reference
Network



Endo-ERN

WP1

Management & Coordination



Endo-ERN General Assembly 2026

The **10th Endo-ERN General Assembly (GA)** is scheduled for Monday 20 April & Tuesday 21 April 2026 in Athens, Greece.

Meeting Venue: [Crowne Plaza Hotel](#), Michalecopoulou Street 50, Athens, 11528 Greece

Travel Arrangements: Please make your own travel arrangements at your earliest convenience. [This document](#) contains several options for transfer from the Athens Airport to the meeting venue.

Programme: Start: Monday, 20 April 2026 9:00 starting with SC/AB Meeting followed by general programme at 10:30.

End: Tuesday, 21 April 2026 at 13:45 ending with Farewell Lunch

Full programme is currently in development. Check back for updates.

Any questions in the meantime please contact the [project office](#).

#EndoGA2026



MTG 3 meetings for 2026

We are working to expand participation in these meetings and in our experience forward planning is an important component of greater attendance.

There will be an MTG 3 meeting at the GA in April and we would like to schedule 2 other on-line meetings for 2026 (before the GA and October 2026).

Topics to be discussed at the GA 2026 ??

WP1 Management & Coordination



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Upcoming Events

REGISTER: An update on primordial dwarfism conditions webinar

October 20th, 2025

Register now for this webinar on 20 October 15:00-16:00. Primordial dwarfism, comprises a group of rare disorders where normal human growth does not occur [...]

[Continue reading >](#)

REGISTRO: Gestione della iperplasia surrenalica congenita nelle diverse età (CAH management across the ages)

October 22nd, 2025

This event will be conducted in Italian. Webinars SIE-SIEDP sulle malattie endocrine rare: una serie di webinar rivolti agli specialisti italiani (Joint SIE-SIEDP webinars on [...])

[Continue reading >](#)

SAVE THE DATE: International Consortium for Fibrous Dysplasia and

WP1

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	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				
	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				
MTG1 MTG7	Gestione della iperplasia surrenalica congenita nelle diverse età (CAH management across the ages)	2025-10-22	17:00 – 18:30 hr				
MTG5	An update on primordial dwarfism conditions webinar	2025-10-20	15:00 – 16:00 hr				

WP1

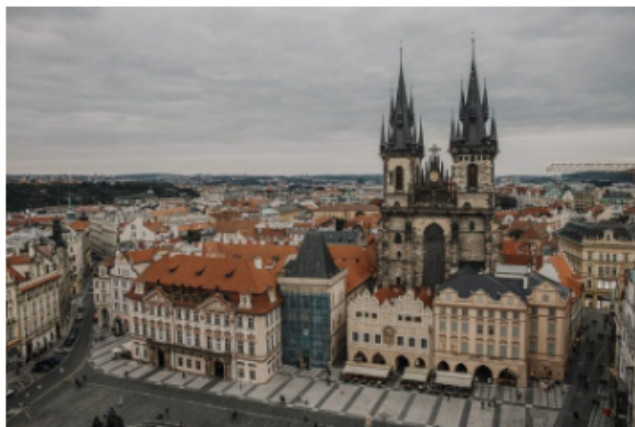
Management & Coordination

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

This event will be from May 9th to May 12th, 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 th – May 12 th , 2026
Location	Prague, Czechia
Organisation	European Society of Endocrinology (ECE)
Website	Visit event website
WP	WP6 Education and Training
	Add this event to your calendar



European
Reference
Network



Endo-ERN

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

This event will be from September 8th to September 10th, 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 th – September 10 th , 2026
Location	Marseilles, France
Organisation	European Society for Paediatric Endocrinology
	Add this event to your calendar

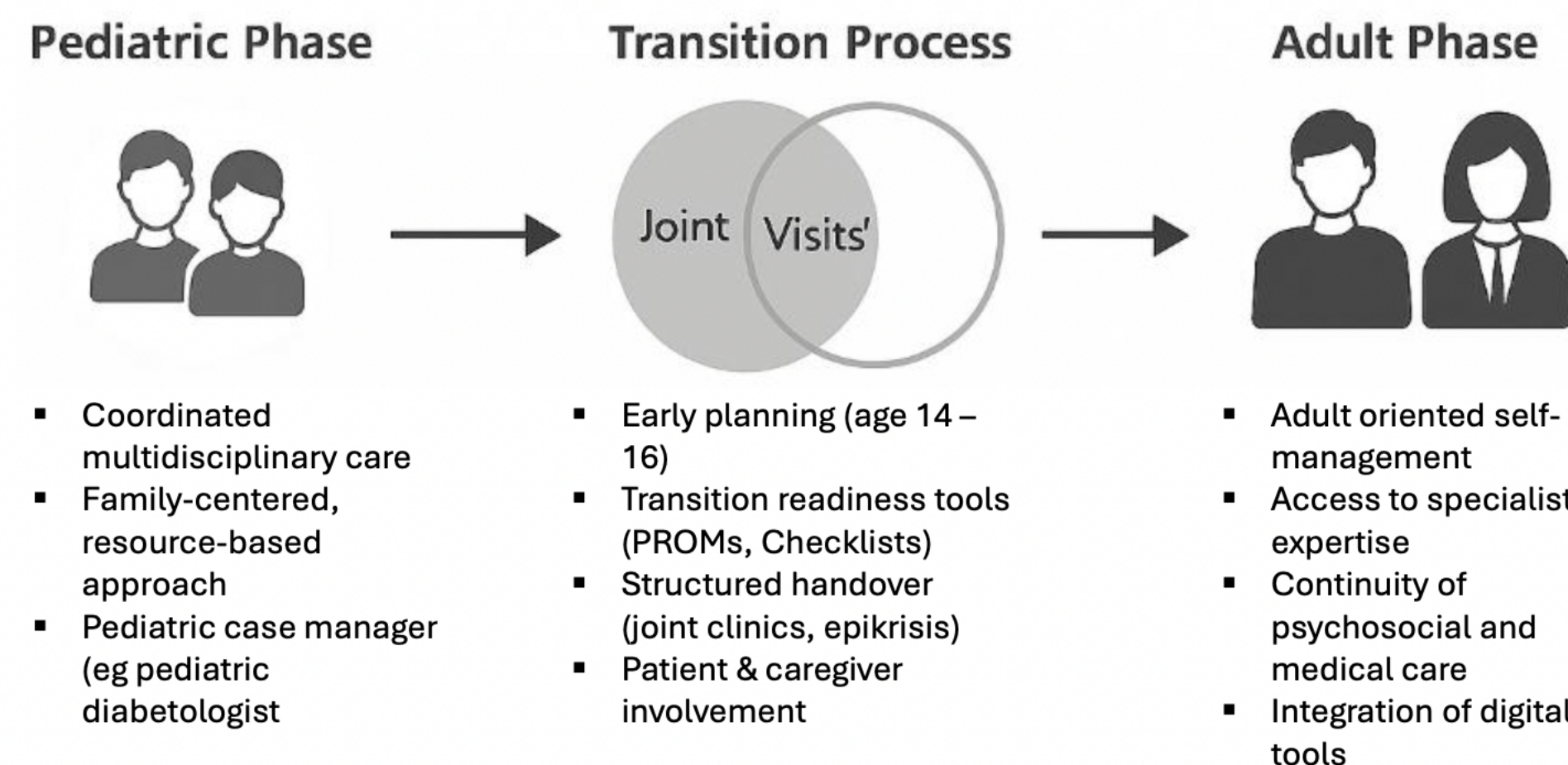
WP2

Communication & Dissemination



MTG 3 task

Structured Transition Pathways Improve Outcomes in Rare Diabetes Syndromes



Title:

Transitioning Adolescents with Rare Forms of Diabetes to Adult Care: Challenges and Perspectives

Felix Reschke ^{1,7*}, ^{***}, Gundula Ernst ², Olga Kordonouri ^{1***}, Sarah K Lyons ^{3**}, Barbara Piccini ^{4***}, Andrea Isidori ⁵, Ulla Döhnert ⁶, Rebecca Toenne ⁷, Francesca Dassie^{8, 14}, Evangelia Charmandari⁹, Violeta Iotova ¹⁰, Valeria Corradin¹¹, Nolwen LeFloch ¹², Bernd Rosenbichler¹³, Pietro Maffei ^{8*}, on behalf of the ENDO ERN Transition of Care group & TALENT Initiative

Endocrine Connections (in press)

New proposal to be discussed for the 2026 ??

WP2

Communication & Dissemination



- New publications, materials or events to be endorsed/updated/disseminated
- Please follow Endo-ERN web-page at our **socials**

<https://www.linkedin.com/company/rareendoern>

<https://www.facebook.com/rareendoern>

<https://www.youtube.com/@rareendoern>

www.endo-ern.eu



Clinical Patient Management System (CPMS)

- 250 CPMS case discussions since 2017



New experts are wellcome !

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Virtual Consultations with CPMS

The **Clinical Patient Management System (CPMS) 2.0** is a secure web-based application to support European Reference Networks in the diagnosis and treatment of rare or complex conditions across national borders.

CPMS 2.0 will realise one of the ERNs core tasks; ***bringing expert specialised care to all patients in Europe.***

The system will allow for virtual consultation across national borders, ensuring that the needed expertise can travel to the patient, instead of the other way around.

Are you seeking expert opinion?

ERNs are not directly accessible to individual patients. However, with the patients' consent and in accordance with the rules of their national health system, patient cases can be referred to the relevant ERN member in their country by their local physician.

[Find out more about cross-border healthcare](#)

Are you a member and do you need help with the CPMS?

The Endo-ERN Operational Helpdesk has [created short manuals for the use of the CPMS 2.0](#). In addition, videos are available to help you with the new system including: [Welcome Webinar for Clinicians](#), [Sign Up to CPMS 2.0](#) and [Brief Presentation of CPMS 2.0](#).

If you need further support please contact the [Endo-ERN CPMS helpdesk](#).

[Login Clinical Patient Management System](#)

WP4 CPMS

Useful links

[CPMS - Endo-ERN](#)

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

A recent example of really helpful virtual consultation !



← → ↻ cpms2.ern-net.eu/screen/patients/P0010253

CPMS 2.0

Pietro MAFFEI
ERN Clinician

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

Search for a record > Camille Heath 422

Camille Heath 422

P0010253 Under Discussion

Details Files Participants History

More	File category	Date	Actions
>	Other		👁️ ⋮
>	Other		👁️ ⋮

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Expand all Pedigree Upload

Discussion topic i

This boy has diabetes mellitus diagnosed in February 2024 , asymptomatic, for now mild and treated only by insulin glargine in th...

View more ▾

**4 cases of Italian paediatric patients (6, 8, 11, 16 yr)
with WFS1 spectrum disorder have been discussed (May 2025)
with Prof. Tim Barrett**

WP3 Evaluation

- Ensure that HCP members are entering data into e-REC for the continuous monitoring process
- Please feedback any challenges you are having

e-REC

e-REC is an electronic reporting (e-reporting) programme that captures new clinical encounters. This allows for a better understanding of the occurrence of the rare endocrine and bone conditions covered by European Reference Networks (ERN) such as [Endo-ERN](#) and [ERN BOND](#).

Compared to the [Core Registry](#), where more detailed and longitudinal data is collected, e-REC only captures the number of new cases, suspected or confirmed, seen monthly at the participating expert centres. Because e-REC does not collect any personal data, there is no informed consent needed from the patient. It is a clinician-only platform designed to support the ERN's in their continuous monitoring program.

e-REC is open to all centres that look after people with rare endocrine and bone conditions. It allows continuous reporting of core indicators of activity and enables clinical networks to objectively map the conditions and related activities. e-REC assists Endo-ERN and ERN BOND and its members in the continuous monitoring programme.

<https://eurreb.eu/registries/e-rec>

European Registries for Rare Endocrine and Bone conditions

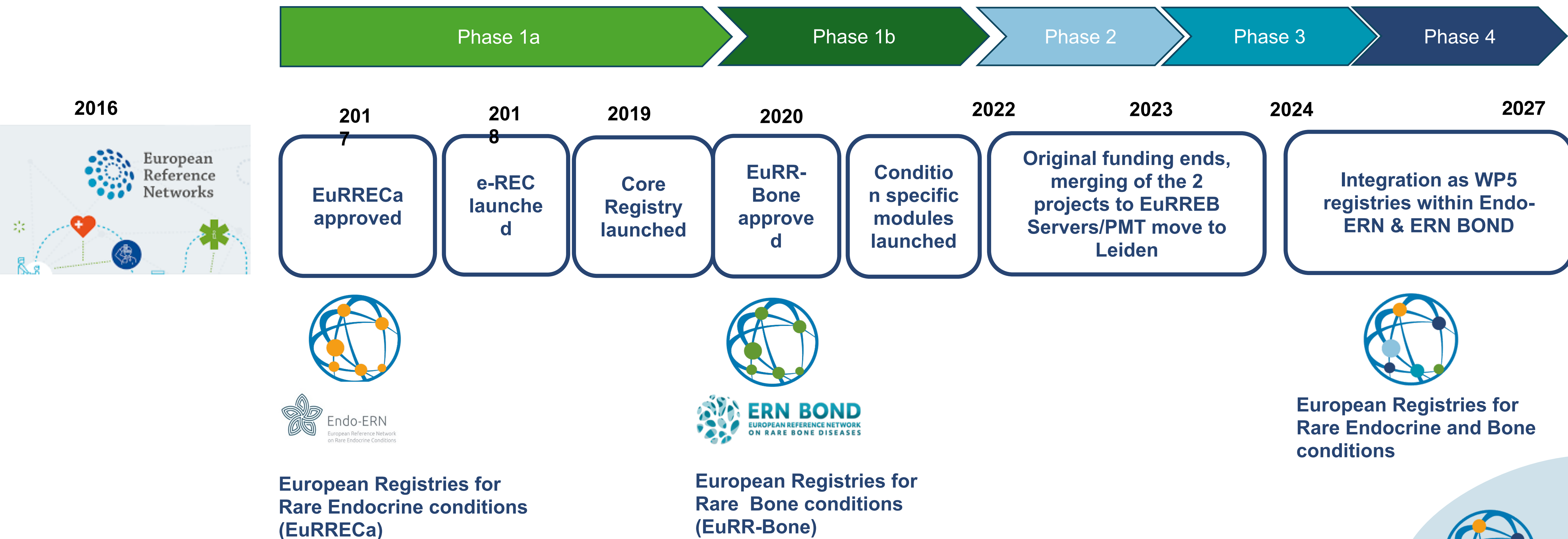
WP5 Registries

www.eurreb.eu

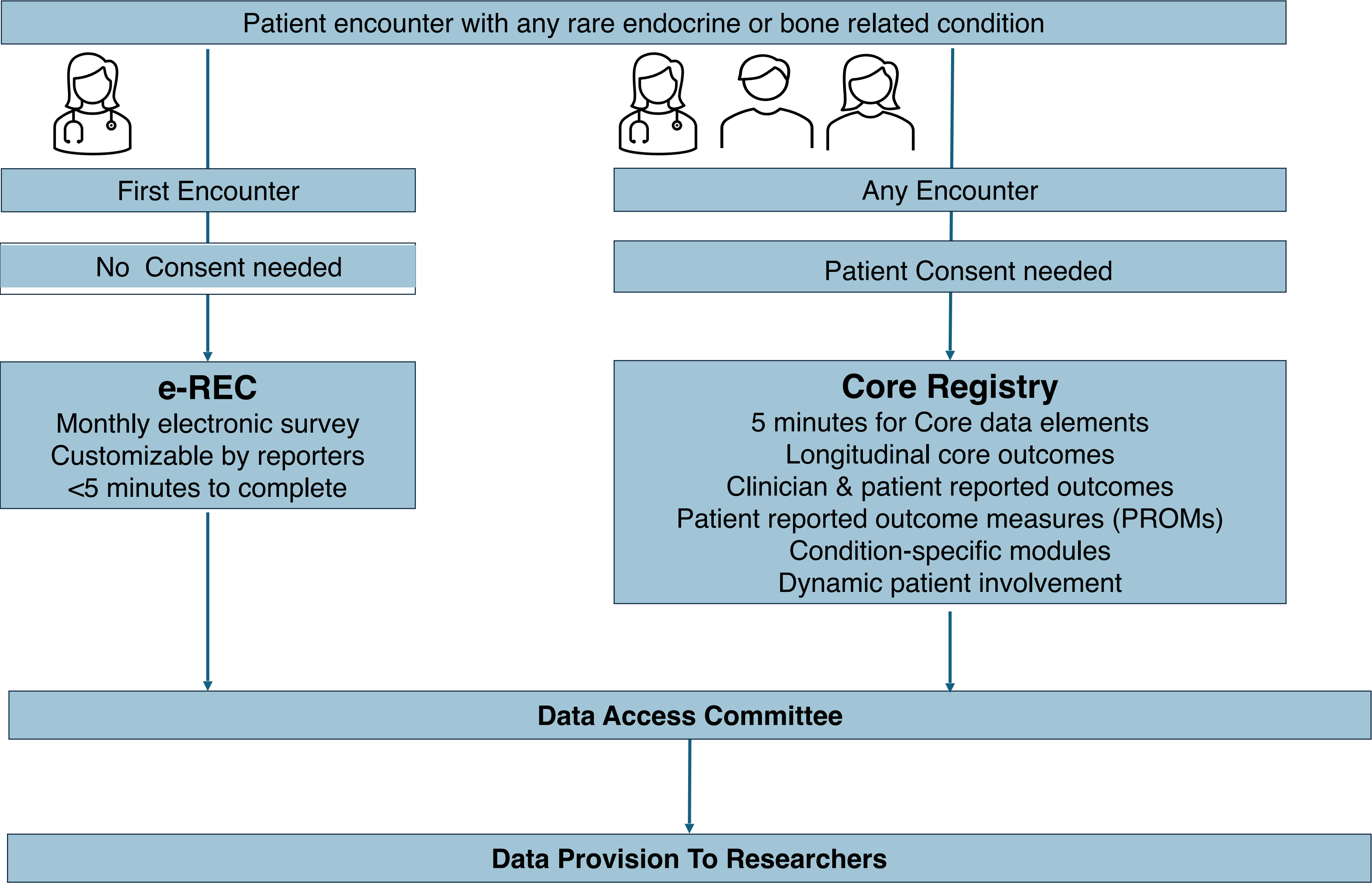
- Any issues or barriers to using the EuRREB Core registry and the affiliated registries



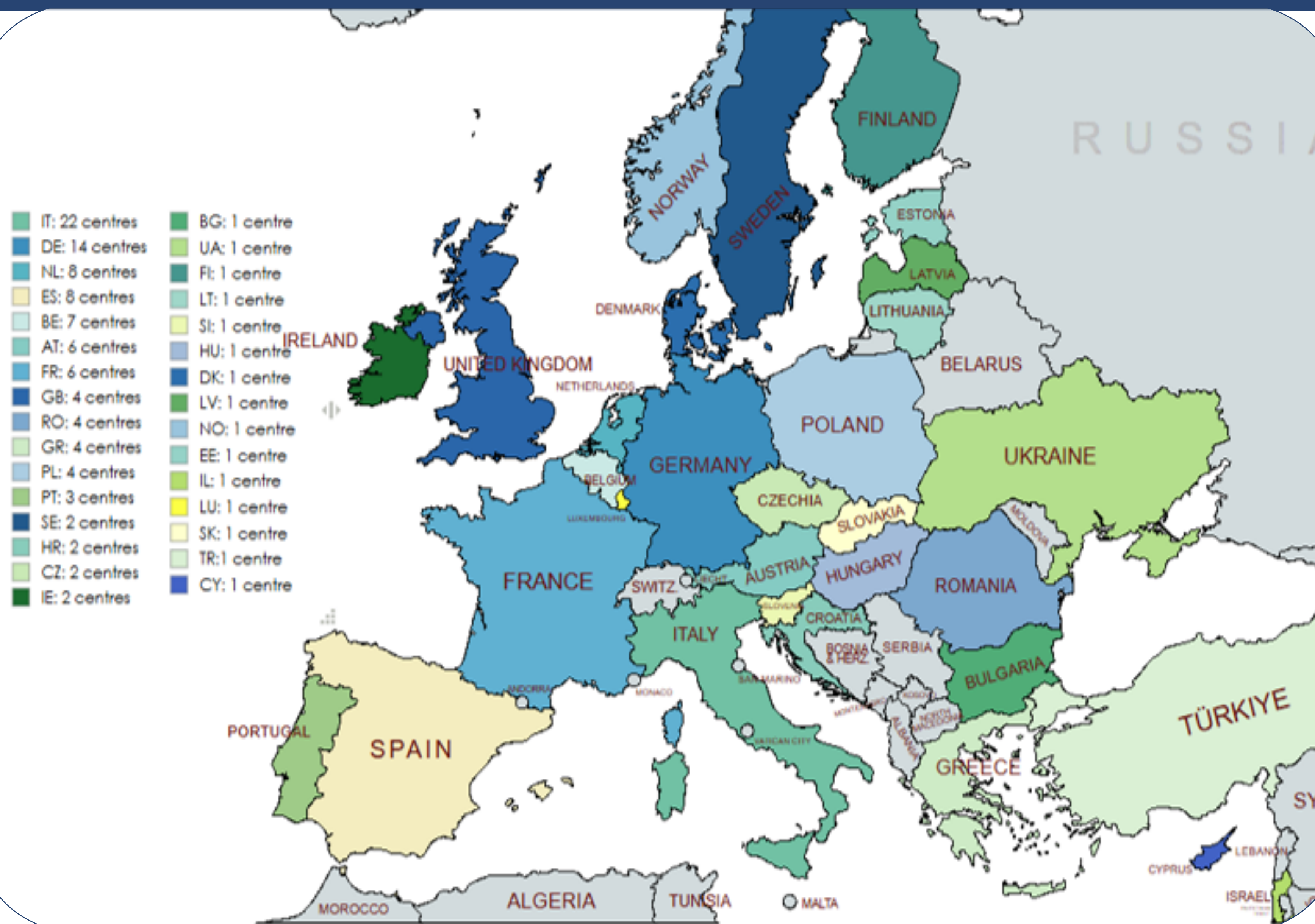
The Evolution of EuRRECa and EuRR-Bone to EuRREB



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 eurreb.eu



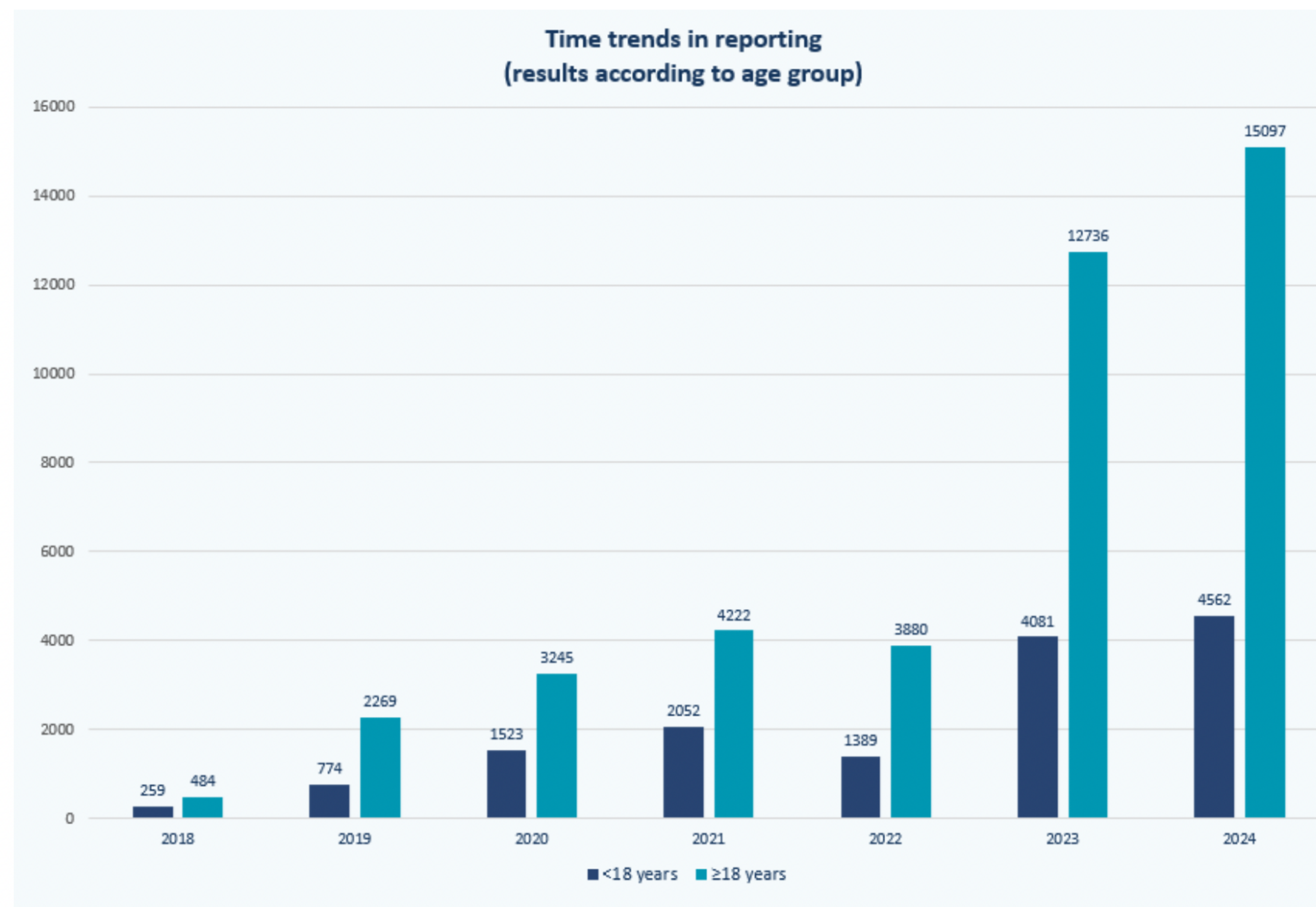
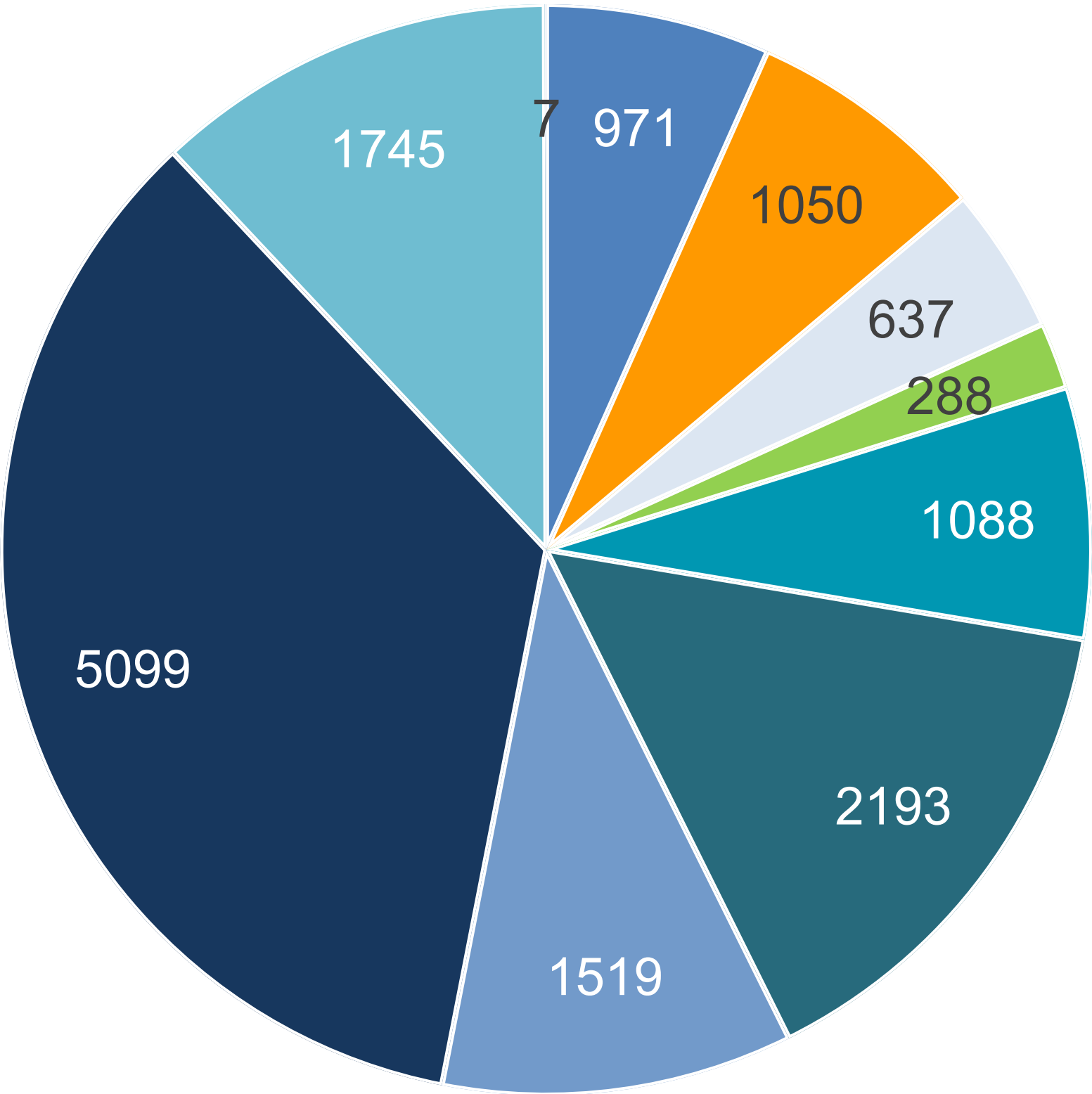


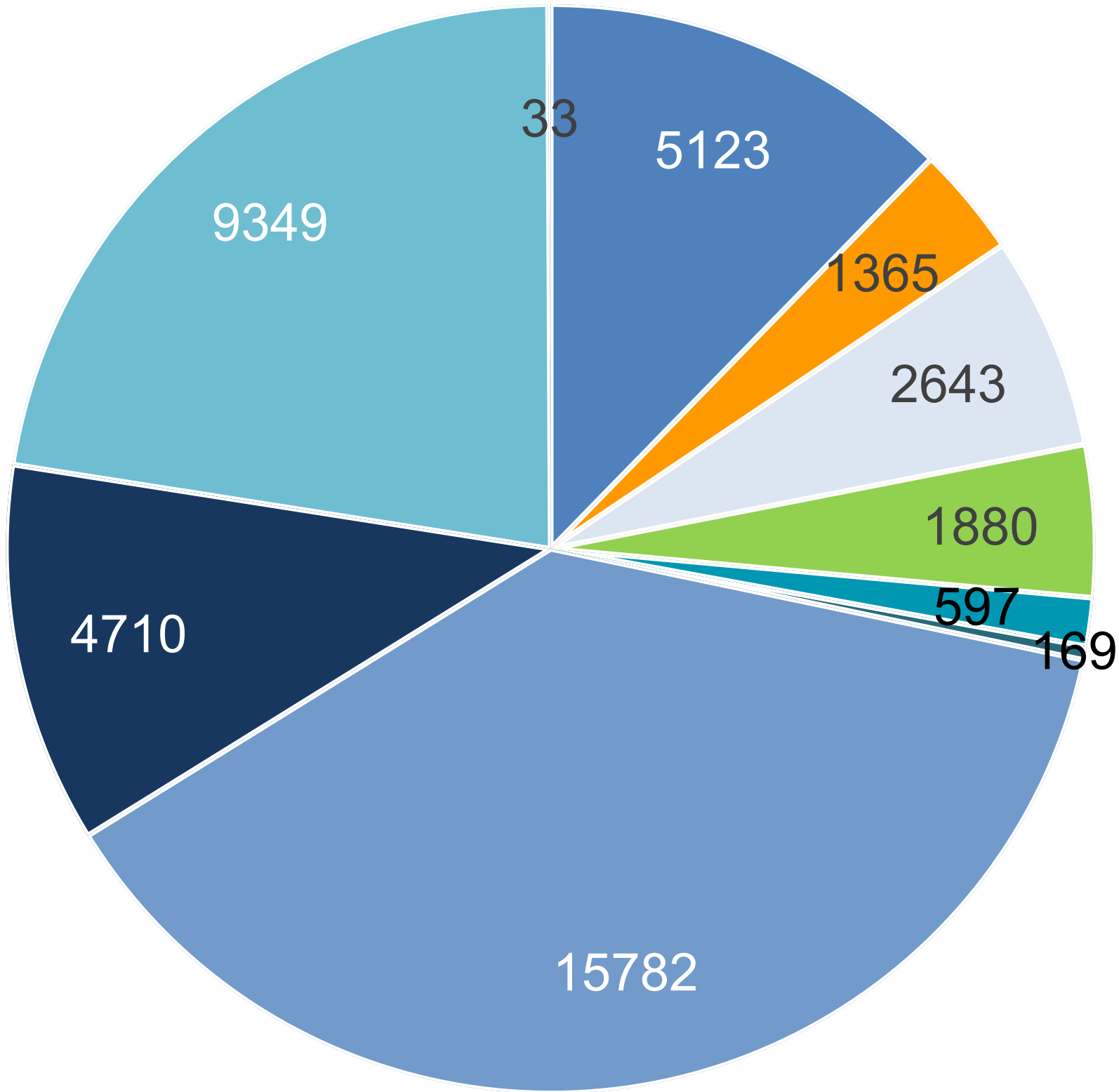
Fig. 2 – The trends in cases reported between July 2018 and December 2024

Cases Distribution in e-REC by MTG and Age Group

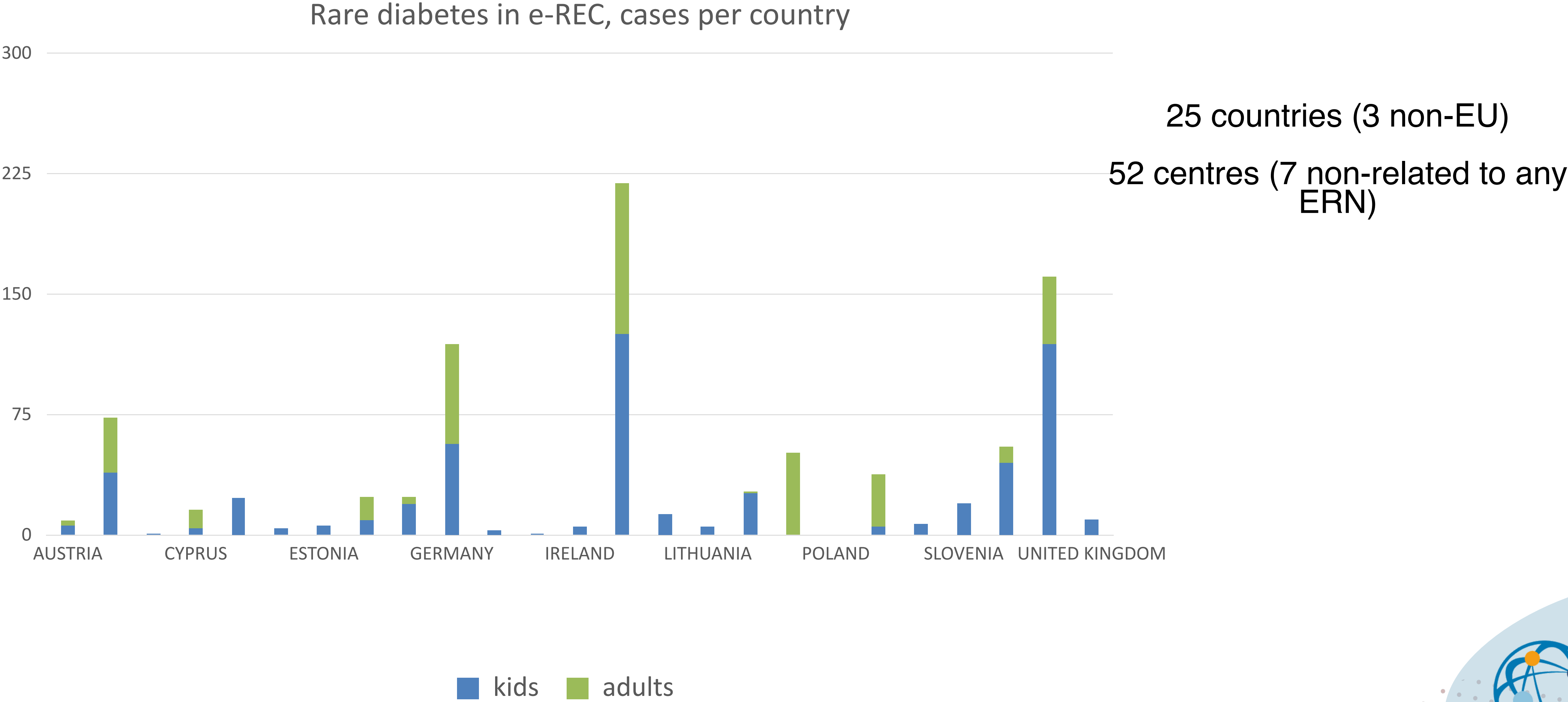
Total Number of Cases by MTG
(<18 years old)



Total Number of Cases by MTG
(≥18 years old)



Rare Diabetes in the EuRREB Registries





Overview of Webinars

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MTG3

MTG	Theme / Title	Date	Time CET	Speaker(s)	Register	View	CPMS
MTG3	SWEET-the role of a worldwide registry to investigate rare diabetes	2024-10-09	16:00 – 17:00 hr				
MTG3	The mysterious links among cilia, centrosomes and insulin resistance: What have we learned from human genetics?	2024-04-02	15:00 – 16:00 hr				
MTG3	Endo-ERN webinar HNF1B diabetes	2023-12-13	15:30 – 16:30 hr	Jarno Kettunen, Helka Parviainen, Tiinamaija Tuomi and Päivi Miettinen			
MTG3	Update on congenital hyperinsulinism	2021-07-06	16:00 – 17:00 hr	Oliver Blankenstein, Peter Kühnen, Sebastian Kummer, Thomas Meissner and Alena Welters			
MTG3	Rare diabetes caused by endoplasmic reticulum stress – clinical features and novel patients’ stem cell-based models	2021-05-26	16:00 – 17:00 hr	Miriam Cnop			

WP6 Education & Training



2026 MTG3 Plans for webinars:

- **Alstrom syndrome ePAGs:** AS-Germany, AS-UK, AS-Italy, AS-International
- **Congenital Hyperinsulinism in Europe:** Advances and care disparities (led by Henrik Christesen, Odense, DK)
- **Wolfram syndrome** webinars: T. Barrett (Birmingham); F. Urano (Washington)
- **Other topics ?**



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

This event will be from February 28th to March 3rd, 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.

MTG3 involvement to be discussed...

Event summary

Event	Rare Endocrine Diseases Winter School, Varna, Bulgaria
Date	February 28 th - March 3 rd , 2026
Time	13:30 – 11:30 hr
Location	Varna, Bulgaria
Contact	
WP	WP6 Education and Training
	Add this event to your calendar



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WP7 Clinical Practice Guidelines & Clinical Decision Support Tools

- Updates local guidelines
 - Update treatment options
 - Research/information you want to share
 - Any other business from your reference center / HCP
-
- We are working to set-up a survey on: **Medication for Rare Diabetes Treatment - For Medical Professionals of END-ERN (all MTGs)**
 - **Is anyone willing to join us and finalize the document ?**
-
- **Are you willing to submit a new survey ? Topic to be discussed....**



Title: Survey on Medication for Rare Diabetes Treatment - For Medical Professionals of END-ERN (all MTGs)

What is your medical specialty?

- ☐ Endocrinology
- ☐ Internal Medicine
- ☐ Family Medicine
- ☐ Other (please specify): _____

In which European country do you primarily practice?

[Dropdown list of European countries]

How would you rate the overall accessibility of medications for rare diabetes in your country?

- ☐ Very accessible
- ☐ Somewhat accessible
- ☐ Neutral
- ☐ Somewhat inaccessible
- ☐ Very inaccessible

Are there any specific medications for rare diabetes that are approved in other European countries but not available in your country?

- ☐ Yes (please specify): _____
- ☐ No
- ☐ Unsure

.....

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 18th, 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.



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