

Endo-ERN

European Reference Network
on Rare Endocrine Conditions

General Assembly

Day 1

Virtual meeting

Tuesday 15 February 2022, 11:00 – 13:00 hrs



European
Commission

Endo-ERN is a European Reference Network co-funded by the
European Union's Health Programme under grant agreement No 739572



European
Reference
Network



programme: **Tuesday 15 February 2022**

09:30 – 10:30	Steering Committee & Advisory Board Meeting (for SC/AB members only)
11:00 – 11:05	Welcome and Opening <i>Alberto Pereira & Olaf Hiort (Endo-ERN coordinators)</i>
11:05 – 11:20	Endo-ERN: update Y5, plans and priorities for next period <i>Alberto Pereira (adult chair and coordinator) & Olaf Hiort (paediatric chair and deputy coordinator)</i>
11:20 – 11:35	Integration of new members <i>Olaf Hiort (paediatric chair, and deputy coordinator)</i>
11:35 – 11:50	Expansion of disease areas <i>Alberto Pereira (adult chair, and coordinator)</i>
11:50 – 12:00	Q&A and Online Voting
12:00 – 12:15	Coffee / Tea Break





12:15 – 12:30	Knowledge Generation Endo-ERN webinars, ERN Exchange Program, ERN Academy <i>Violeta Iotova</i> (WP1 chair)
12:30 – 12:45	e-Health, ICT & Monitoring CPMS, e-REC, EuRRECa, monitoring <i>Faisal Ahmed</i> (WP2 chair)
12:45 – 13:00	Research ERICA, EJP RD Research Mobility Fellowships and Research Workshop calls <i>Jérôme Bertherat</i> (WP3 chair)
13:00 – 13:30	Lunch Break
	Meet and interact with your MTG co-workers
13:30 – 14:00	MTG1 Adrenal
14:10 – 14:40	MTG2 Disorders of Calcium & Phosphate homeostasis
14:50 – 15:20	MTG3 Genetic disorders of Glucose & Insulin homeostasis
15:30 – 16:00	MTG4 Genetic Endocrine Tumour Syndromes





Welcome and Opening

Alberto Pereira & Olaf Hiort





Update Y5, plans and priorities for the next period

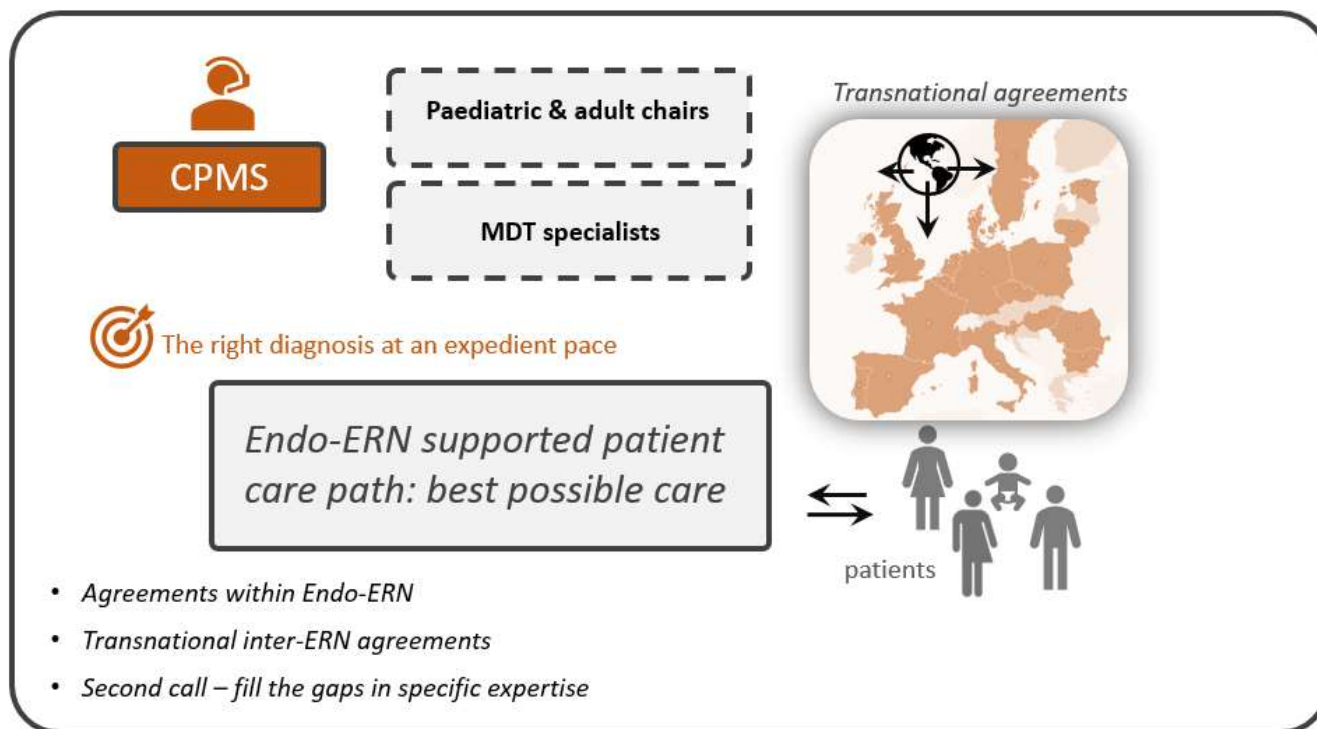
- Writing the new application
- Integration of WP activities

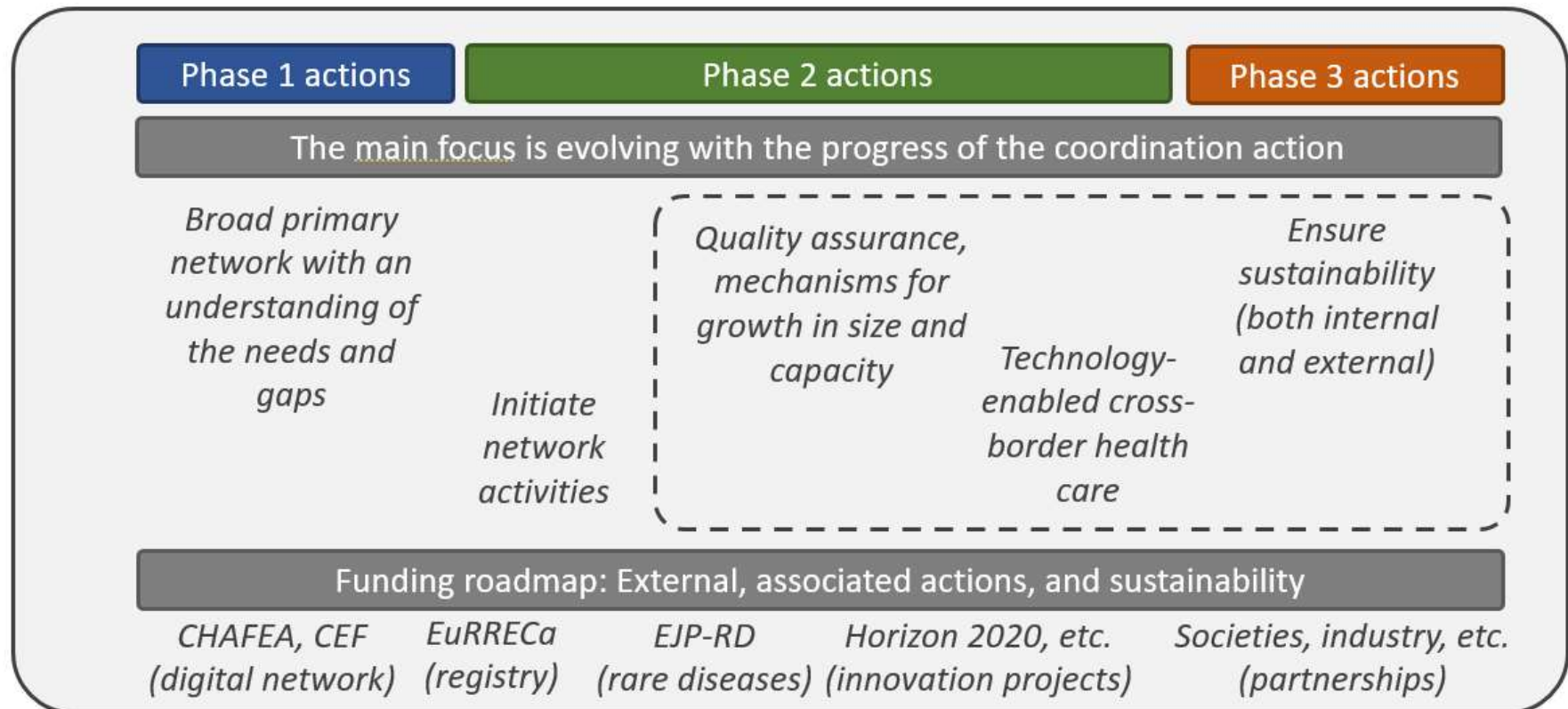
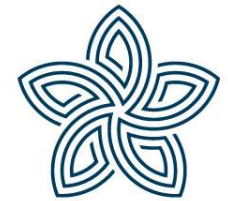
- ✓ **Objective 1:** To mitigate differences in awareness and knowledge regarding diagnosis and treatment.
- ✓ **Objective 2:** The reinforcement of research and epidemiological surveillance.
- ✓ **Objective 3:** Facilitating mobility of expertise to optimise communications between stakeholders.
- ✓ **Objective 4:** To create a single, easy-access platform containing all existing and future information.
- ✓ **Objective 5:** To setup agreements among the network for EU-wide access to the most fitting care.

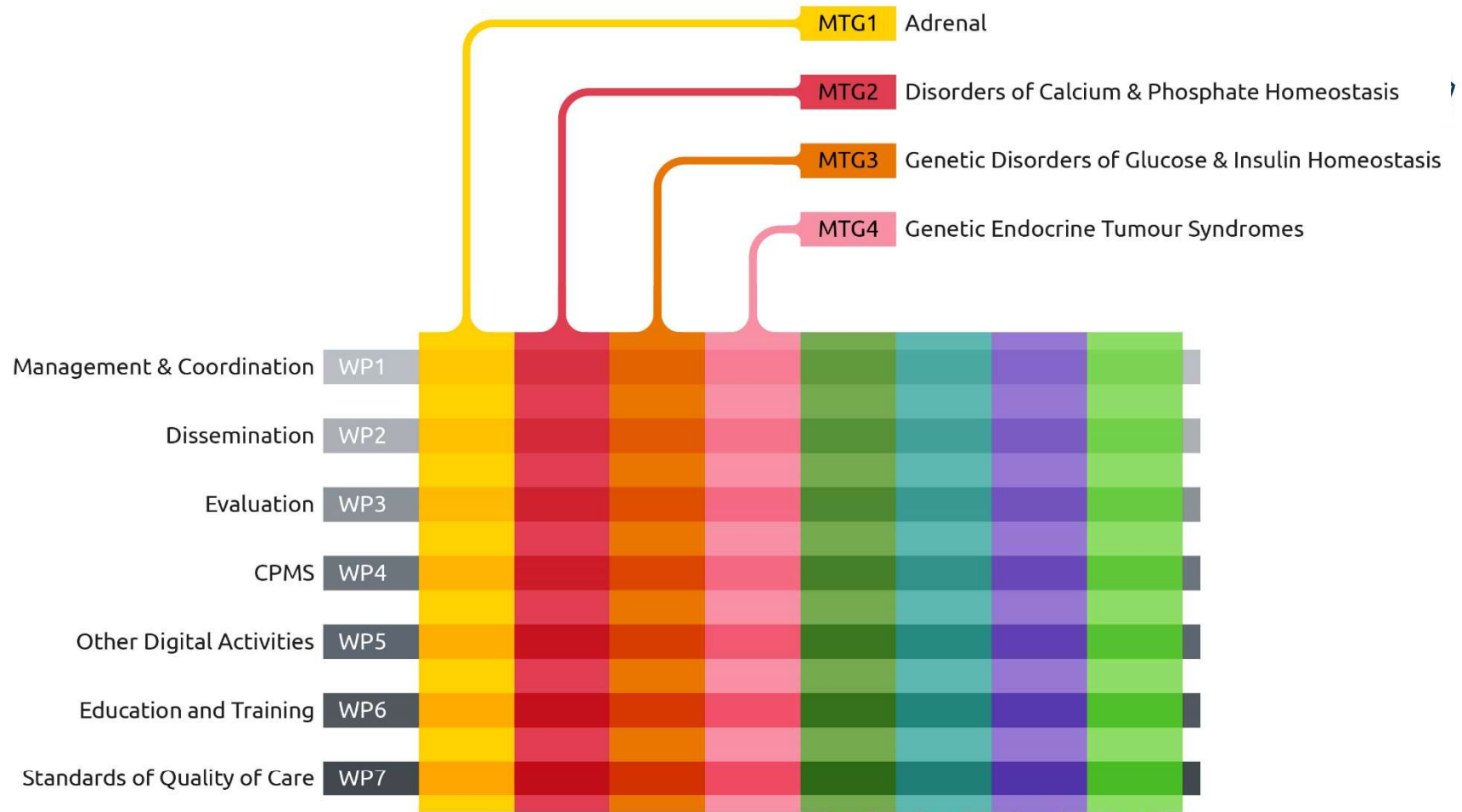




Associated ERNs:
EURACAN, eUROGEN,
MetabERN, GENTURIS







- Growth & Genetic Obesity Syndromes MTG5
- Hypothalamic and Pituitary Conditions MTG6
- Sex Development & Maturation MTG7
- Thyroid MTG8





Integration of new members

October – November 2019: Call open

- Call for new members to join existing ERNs

November 2019 – November 2021: Review process

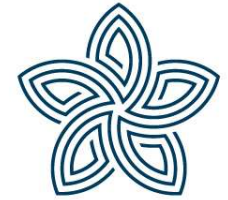
- By European Commission, Endo-ERN network board, Independent Assessment Body and Board of Member States

November 2021: Approval

- 34 new Endo-ERN members (in total 620 new members for 24 ERNs)

The new members started their membership on the 1st January 2022 and the ERNs will progressively on-board them (timeline is ERN dependent).





Currently, Endo-ERN has full coverage of all 27 EU member states plus Norway, and in specific the EU member states with a low gross domestic product (GDP) per capita.

MEMBERS | NEWSLETTER | ENGLISH

NEWS | EVENTS | CONTACT | ERN | FAQ

Endo-ERN About Specific Expertise Patients Activities Publications

ABOUT / REFERENCE CENTRES

Reference Centres (RCs)

Finland: 1 Reference Centres

Distribution of Reference Centres by country

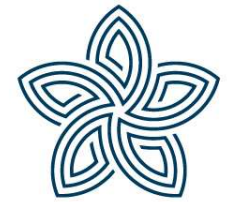
Participating Reference Centres (RCs)

Showing 111 RCs

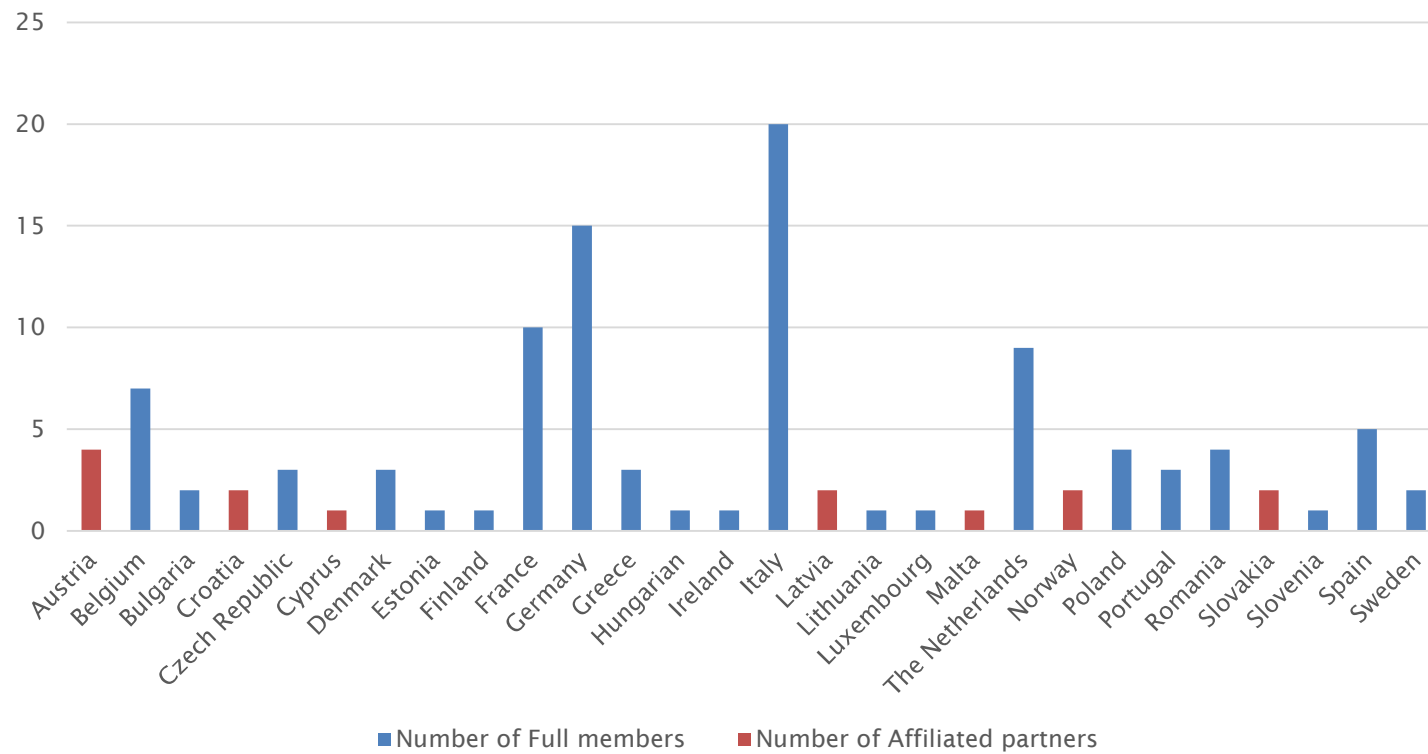
RC Name	Country	City	Member of MTGs	Representative(s)
Medical University of Vienna,Center for Disorders of Sex Development / Dpt. of Pediatrics ¹	Austria	Vienna	7	Stefan Riedl, Diana-Alexandra Ertl
Medical University of Vienna,Center for Rare Diabetes and Congenital Hyperinsulinism / Dpt. of Pediatrics ¹	Austria	Vienna	3	Birgit Rami-Merhar
Medical University of Vienna,Center for Rare Endocrinologic	Austria	Vienna	3 2 1	Greisa Vila, Sabina Baumgartner-Parzer

<https://endo-ern.eu/about/reference-centres/>





Endo-ERN members as of 01-01-2022

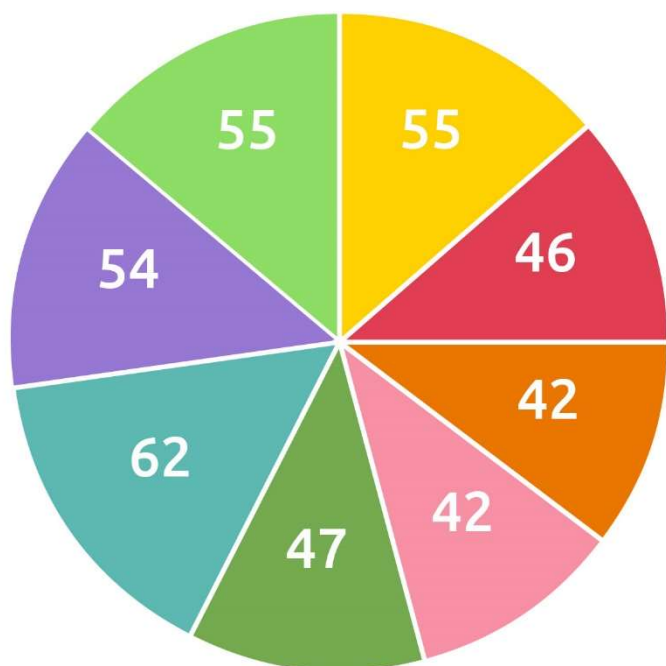


97 Full members + 14 Affiliated partners = **111 members**





Number of Reference Centers per MTG



- MTG1** Adrenal
- MTG2** Disorders of Calcium & Phosphate Homeostasis
- MTG3** Genetic Disorders of Glucose & Insulin Homeostasis
- MTG4** Genetic Endocrine Tumour Syndromes
- MTG5** Growth & Genetic Obesity Syndromes
- MTG6** Hypothalamic and Pituitary Conditions
- MTG7** Sex Development & Maturation
- MTG8** Thyroid





SOP for expansion of disease areas

- National endorsement
- Request to Endo-ERN coordinating center including completed application form
- Review by Endo-ERN specific main thematic group chairs and Endo-ERN board
- Advise to DG Sante
- Confirmation by Board of Member States
- Official letter for acceptance by Endo-ERN coordinating center

Until now, 10 members have requested disease expansion. Retrospectively completion of official template, which will also be used for future requests.





Q&A and Online Voting





Online voting

Do you agree with the fulfilled actions of Endo-ERN of year 5, and the proposed actions for the future grant?





Coffee / Tea Break





Knowledge Generation

Violeta Iotova





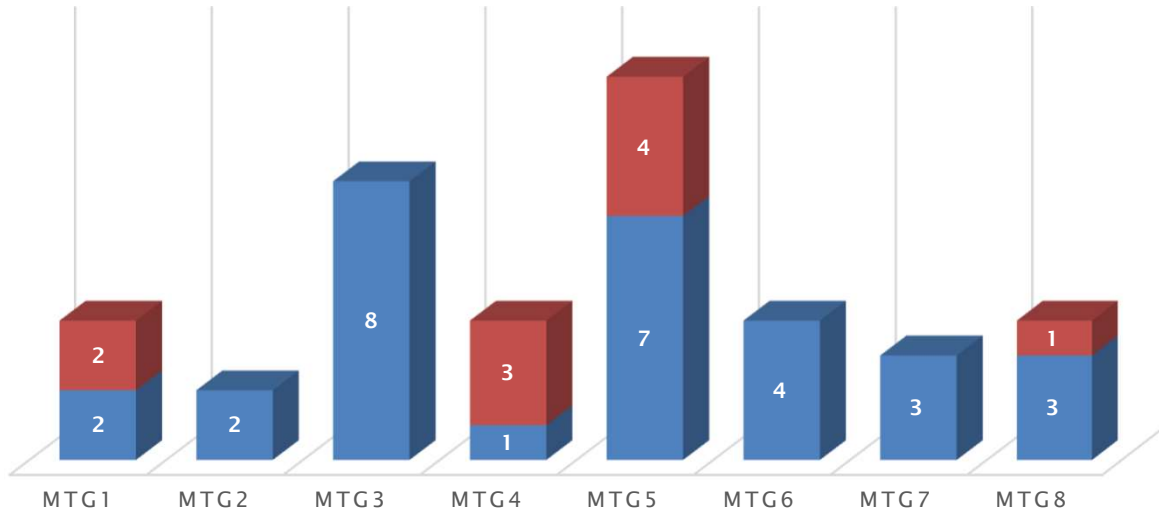
- Endo-ERN webinars
- ERN Clinical Exchange programme
- ERN Academy



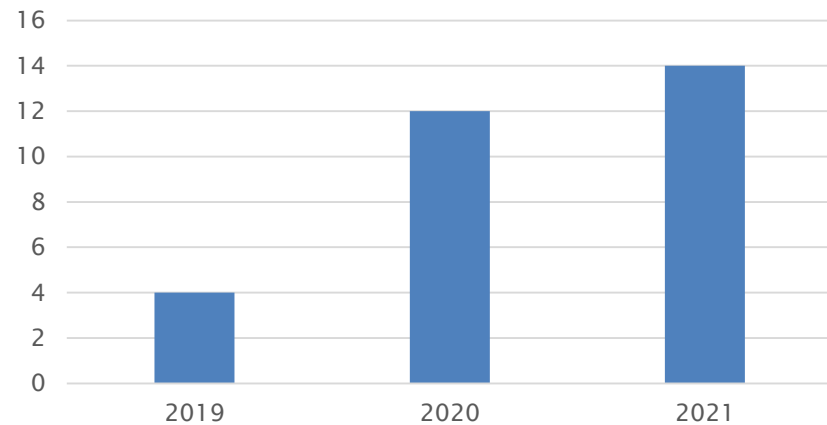
Endo-ERN webinars 2019-2022

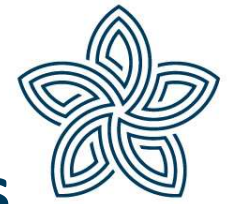


■ Previous webinars ■ Upcoming webinars



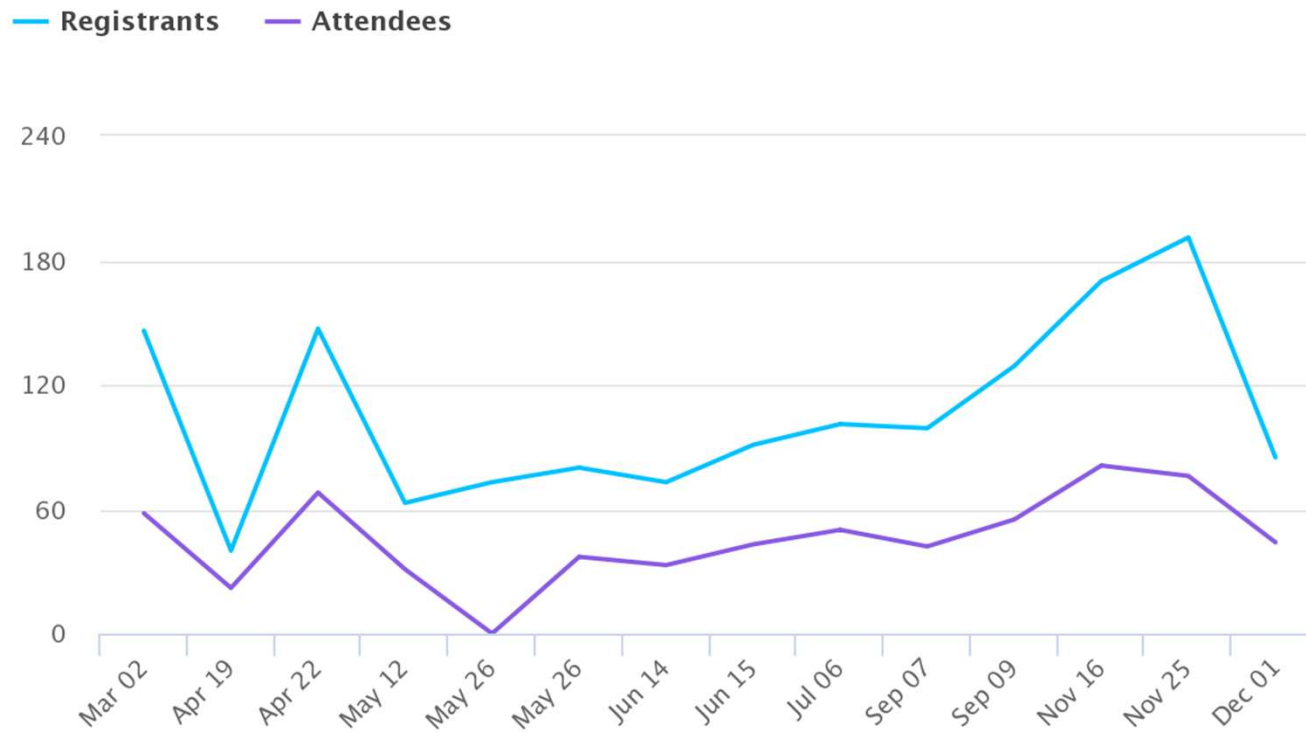
Numbers of webinars 2019-2021





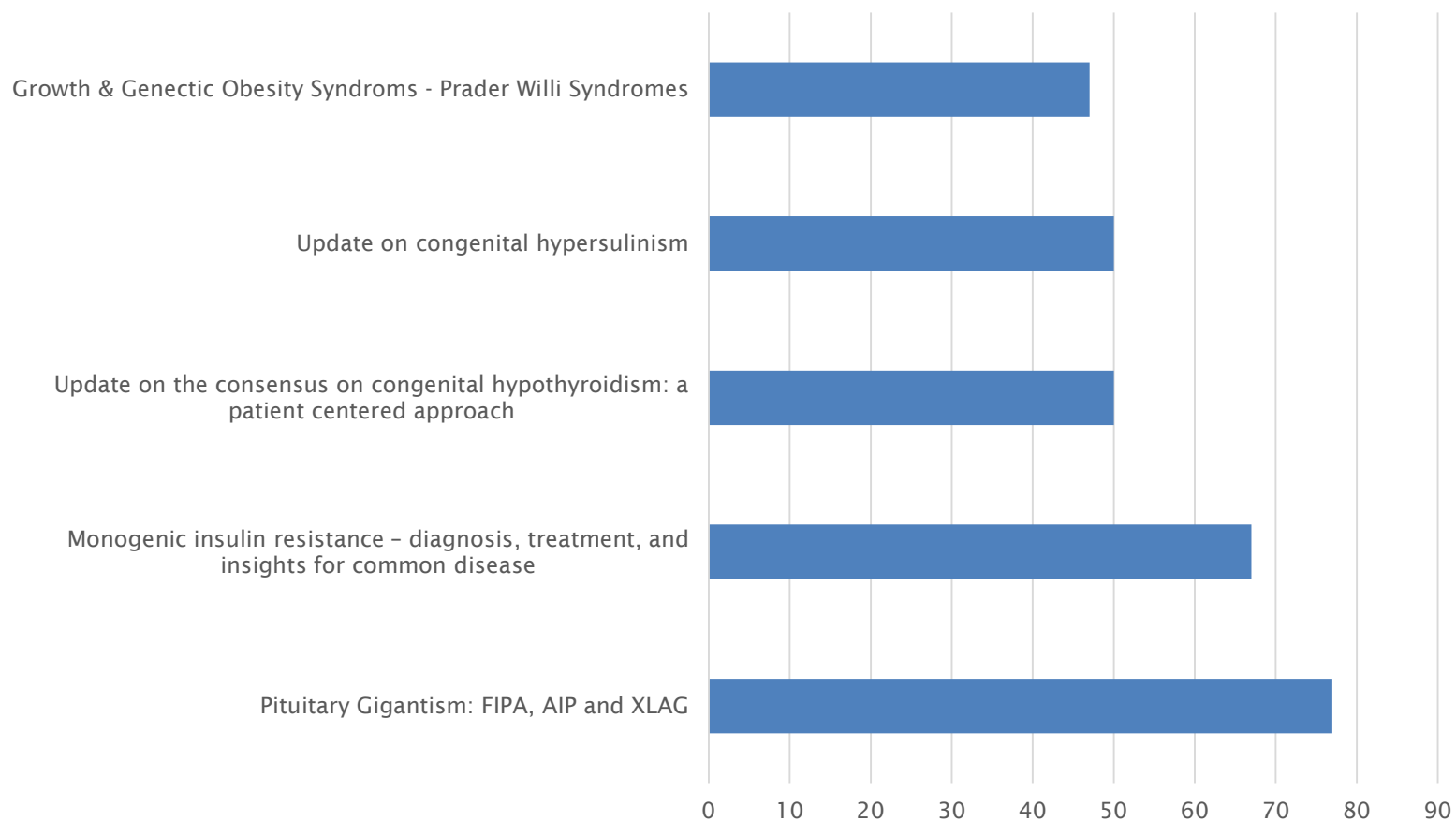
Registrant & attendees of Endo-ERN webinars

March – Dec 2021





Top 5 Viewed Recordings Published between Feb 03, 2021 - Feb 02, 2022





How to subscribe and view?

www.endo-ern.eu/webinars



Endo-ERN Webinars

On a regular base Endo-ERN will organise an interesting webinar.

[Overview of webinars](#)

MTG	Theme / Title	Date	Time CET	Speaker(s)	Register	View	CPMS
MTG2	Hypoparathyroidism in adults, diagnosis and therapeutic challenges	2019-02-28	14:00-14:30	Lars Rejnmark	🔒	👁	
MTG3	Hyperinsulinism	2019-07-01	10:00-11:00	Klaus Mohnike and Indi Banerjee		👁	
MTG3	Alström Syndrome	2019-11-25	15:00-16:00	Pietro Maffei	🔒	👁	
MTG7	Turner Syndrome Guideline & the patient perspective	2020-02-13	18:00-19:00	Claus H. Gravholt and Arlene Smyth	🔒	👁	
MTG4	Prophylactic thyroidectomy in Children with MEN2	2020-02-21	18:00-19:00	Tom Kurzwinski	🔒	👁	
MTG1	Update on congenital adrenal hyperplasia	2020-03-23	18:00-19:00	Nicole Reisch	🔒	👁	
	COVID-19 Endocrine conditions with increased risk - Endo-ERN	2020-05-12	18:00-19:00	Alberto Pereira, Eelco de Koning and Wiebke Artl	🔒	👁	
MTG8	Update on the consensus on congenital hypothyroidism a patient centered approach	2020-07-01	18:00-19:00	Michel Polak	🔒	👁	
MTG5	Genetic Obesity Disorders caused by Leptin-melanocortin Pathway Defects	2020-07-07	18:00-19:00	Erica van den Akker	🔒	👁	
MTG3	Understanding Lipodystrophy	2020-07-08	15:00-16:00	Giovanni Ceccarini and Rebecca Sanders	🔒	👁	
MTG3	Monogenic insulin resistance - diagnosis, treatment, and insights for common disease	2020-09-16	15:00-16:00	Robert K. Semple	🔒	👁	
MTG5	Prader-willi syndrome	2020-09-29	17:00-18:00	Anita Hokken	🔒	👁	
MTG3	Wolfram syndrome	2020-10-07	15:00-16:00	Timothy Barrett	🔒	👁	



European
Reference
Networks

*Exchange Programme
2021-2022*



ERN Clinical Exchange Programme

The ERN Clinical Exchange Programme, funded by the European Commission, has been launched as per March 1, 2021 and is a great opportunity for **clinical exchanges** in ERNs.

The programme is designed to strengthen the clinical capacities and organisation of the ERN, and to stimulate knowledge sharing regarding expert clinical care between network (affiliated) members.

This can be achieved either by hosting HCPs or by visiting an HCP that wants to be supported in the development and implementation of the specific aims. For example, by onsite teaching of staff, share SOPs and see in- and outpatients together with the local physicians.





Specific aims

1. Encouraging the development and implementation of value-based health care
2. Investing in outcome measurements and aligning in registries
3. Further professionalization the MDT's and its integration in specific patient care pathways
4. Stimulating the development and implementation of clearly defined transition from childhood to adulthood





Exchange packages

34x



for small-sized ERNs

44x



for medium-sized ERNs

55x



for large-sized ERNs

A single package provides compensation for



The standard duration of the visits is 5 working days for 1 person



Travel arrangements



Travel insurance



Daily Allowance (200 euro per working day)

- ✓ it includes: the cost of accommodation, food, local transport and travel insurance
- ✗ it doesn't include: insurance for professional liability for visitors and any costs incurred by the hosting health care professionals (HCP's)



Previous and upcoming exchanges

Endo-ERN Exchanges

Name	Institute	Hosting Institute	Exchange Information
Savi Shishkov	UMHAT "Sveta Marina" (Varna)	Leiden University Medical Center	Pituitary Center of Excellence: Insight in shared decision making, treatment, and outcome evaluation From 2021-10-04 to 2021-10-29 over 20 working days.
Anna Strandqvist	Karolinska University Hospital	Erasmus MC: University Medical Center Rotterdam	Clinic work for psychosocial support in DSD patient groups From 2021-10-19 to 2021-10-23 over 5 working days.
Sandra Wessmann	Karolinska University Hospital	Ghent University Hospital	Examination and diagnostic work on surgically removed gonads from patients with DSD Started on - postponed (new data not clear yet).





European
Reference
Networks

Exchange Programme
2021-2022



First Endo-ERN Clinical Exchange program participant has arrived!

The first Endo-ERN participant of this exchange program is Savi Shishkov, an endocrinologist in training at the the "St. Marina" University Hospital, and a assistant in the Department of Internal Medicine of the Medical University in Varna, Bulgaria. He was motivated to apply for this fellowship because of his interest in rare endocrine disease, and expanding the international cooperation between ERN HCPs. He has started his exchange to the Leiden University Medical Center under the supervision of Endo-ERN coordinator prof.dr. A.M. Pereira Arias, and pituitary MTG leader prof.dr. N.R. Biermasz on October 5th. During the four-week program, an insight into the tertiary referral center's outpatient clinic, including the way of shared decision making, treatment, and outcome evaluation will be offered.





How to apply?

- 45 packages left for Endo-ERN members
- Apply as a trainee
if you would like expand or share your knowledge by visiting another ERN member center

OR

- Apply as a hosting center
if you can provide an interesting program for the visiting health care professional(s)

More information and application forms

<https://endo-ern.eu/activities/exchange-programme/>





Future perspectives

Endo-ERN Academy:

- Continuation Endo-ERN webinar programme
- Continuation Clinical Exchange Program
- Implementation ERN Academy





ERN Academy

EUROPEAN REFERENCE NETWORKS

ERN ACADEMY

The ERN Academy is a tool which will facilitate the activity of the ERN Knowledge Generation activity

The ERN Academy will involve the following components:

- e-training/e-learning Moodle-based environment and support to the content generators (the ERNs) to produce the deliverables and manage the system
- Repository-library of all the “products” of the ERNs (the ones included under the agreed taxonomy and any other produced by the ERNs) with a powerful search engine and structure
- Integrated web conferencing system for the training and learning activities
- A central IT and development support and helpdesk for all the activities and needs of the ERN Academy.

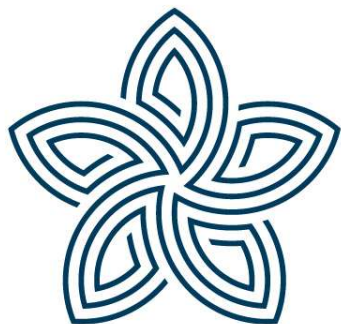




e-Health, ICT & Monitoring

Faisal Ahmed





Endo-ERN

European Reference Network
on Rare Endocrine Conditions

Endo-ERN WP2 – EuRRECa update

S Faisal Ahmed, Natasha Appelman-Dijkstra, Salma Ali, Johan Beun, Jillian Bryce, Shannon Mullen, Ana Luisa Priego, Chris Smythe, Domenica Taruscio



European
Commission

Endo-ERN is a European Reference Network co-funded by the
European Union's Health Programme under grant agreement No 739572





<https://eurreca.net/>, <https://eur-bone.com/>

- End of current funding Mar 2022 - aligned with Endo-ERN
- EuRR-Bone Registry funding till 2023
- Common steering Committee and Data Access Committee
- Transfer of database to LUMC from UofG (by q1 2022)
- e-REC report available at <https://eurreca.net/e-rec-reports/>
 - Since July 2018, 60 centres from 22 countries have reported reported over 12,250 cases
 - Assisting ESE RD COVID19 taskforce
- Core Registry report available at <https://eurreca.net/reports/>
 - Since July 2019, 14 centres from 9 countries have entered almost 500 cases
 - Developing condition specific modules (eg thyroid, iPPSD, pituitary adenoma)
 - In over 10% of the cases, patients have also been provided access
 - Work on outcomes and affiliate registries continues

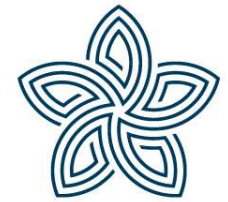




<https://eurreca.net/>, <https://eur-bone.com/>

- Kodra Y, Weinbach J, Posada-de-la-Paz M, Coi A, Lemonnier L, van Enkevort D, Roos M, Jacobsen A, Cornet R, Ahmed SF, Bros-Facer V, Popa V, van Meel M, Renault D, von Gizycki R, Santoro SM, Landais P, Torreri P, Carta C, Mascalconi D, Gainotti S, Lopez E, Ambrosini A, Müller H, Reis R, Bianchi F, Rubinstein YR, Lochmüller H, Taruscio D. Recommendations for improving the quality of rare disease registries. *Int J Environ Res Public Health* 2018, 15(8), 1644
- Ali SR, Bryce J, Cools M, Korbonits M, Beun JG, Taruscio D, Danne T, Dattani M, Dekkers OM, Linglart A, Netchine I, Nordenstrom A, Patocs A, Persani L, Reisch N, Smyth A, Sumnik Z, Visser WE, Hiort O, Pereira AM, Ahmed SF. The current landscape of European registries for rare endocrine conditions. *Eur J Endocrinol*. 2019;180:89-98.
- Ali SR, Bryce J, Tan LE, Hiort O, Pereira AM, van den Akker ELT, Appelman-Dijkstra NM, Bertherat J, Cools M, Dekkers OM, Kodra Y, Persani L, Smyth A, Smythe C, Taruscio D, Ahmed SF. The EuRRECa project as a model for data access and governance policies for rare disease registries that collect clinical outcomes. *Int J Environ Res Public Health*. 2020;17:8743.
- de Vries F, Bruin M, Cersosimo A, van Beuzekom CN, Ahmed SF, Peeters RP, Biermasz NR, Hiort O, Pereira AM. An overview of clinical activities in Endo-ERN: the need for alignment of future network criteria. *Eur J Endocrinol*. 2020;183:141-148.
- Ali SR, Bryce J, Smythe C, Hytiris M, Priego AL, Appelman-Dijkstra NM, Ahmed SF. Supporting international networks through platforms for standardised data collection - the European Registries for Rare Endocrine Conditions (EuRRECa) model. *Endocrine*. 2021;71:555-560
- Mönig I, Steenvoorden D, de Graaf JP, Ahmed SF, Taruscio D, Beun JG, Johannsen TH, Juul A, Hiort O, Pereira AM. CPMS-improving patient care in Europe via virtual case discussions. *Endocrine*. 2021;71:549-554.
- Ali SR, Bryce J, Kodra Y, Taruscio D, Persani L, Ahmed SF. The quality evaluation of rare disease registries- an assessment of the essential features of a disease registry. *Int J Environ Res Public Health*. In Press, subject to minor revision.





Pituitary Tumour Module

Pituitary tumour study group

Objective: to collect longitudinal data on pituitary tumours; identify tumours with aggressive behaviour



Core Registry



Add Diagnosis-specific Outcome



Core Registry

Dashboard Patients Centres Centre Users Patient Users

ID	Date of Birth	Uploader	Responsible Clinician	Specific Diagnosis	Patient Conditions	Outcomes	Audit
537	2000-03-01	Dr. Ana Priego	Dr. Ana Priego	Pituitary adenoma	HYPOTHAL & PITUITARY	Generic Diagnosis-specific	Audit

Who is the clinical lead for the pituitary tumour care?

Adult endocrinologist

Has the patient started a transition process?

Yes





Monitoring & Clinical Patient Management System

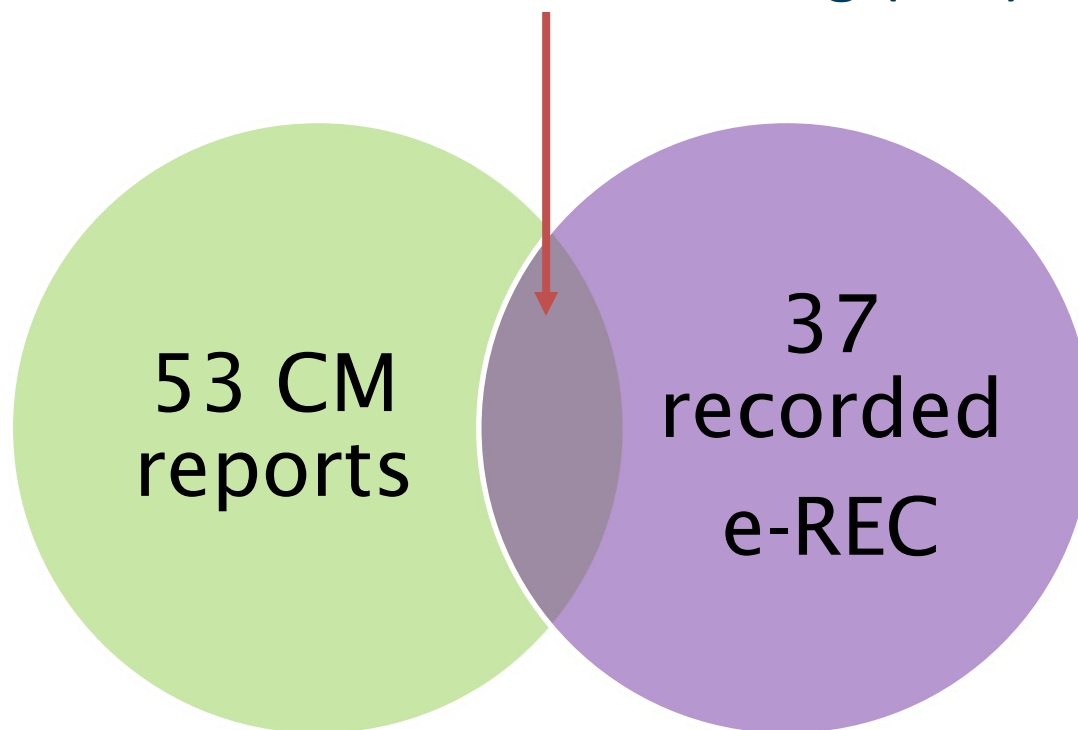
Emily White





Monitoring & E-REC

- **24 HCPs** Indicated they had completed the e-REC reports in their continuous monitoring (CM) survey





Indicators

18 ERN Core Indicators

1. Nr of Member States within an ERN
2. Nr of full member HCPs
3. Nr of affiliated partners
4. Nr of patient organisations
5. Nr of new patients referred to HCPs
6. Nr of patients entered into CPMS
7. Nr of panels reviewed by the ERN (incl. outcome document)
8. Time taken to provide MDT clinical advise
9. Nr. education activities (not accruing higher education credits)
10. Nr. formal education activities (accruing higher educational credits)
11. Nr. of clinical trials (involving ERN members in at least 2 MS)
Nr. of observational prospective studies
12. Nr. of accepted peer-reviewed publications in scientific journals
which acknowledge the ERN
13. Number of adopted Clinical Practice Guidelines and other CDMTs
14. Nr. of new CPGs written by the ERN
Nr. of other types of CDMTs written by the ERN
15. Nr. of congresses at which the ERN activities/results were presented
16. Nr. of individual ERN website hits
17. Level of patient satisfaction
18. HCP compliance to clinical guidelines





Updates to Continuous Monitoring

- The continuous monitoring program will now be based on AMEQUIS protocols
 - A short video explaining this will be shown following our CPMS update
- Mandatory submission of data by HCPS will now occur on an **Annual** basis for KPIs
- Data submitted will be published on our Endo-ERN website & contribute to:
 - ERICA clinical trial database
 - EURRECA registry

Data to be published online

Clinical Trials

Observational, cohort, case control, retrospective studies

Peer Reviewed Publications

Clinical Practice Guidelines

Clinical Decision Support Tools





Clinical Trials

Filter list of Clinical Trials

Topic

Clinical Trial ID(s)

Status

Link

Trial Name

MTG(s)

OrphaCode

Q

Showing 125 Clinical Trials

Topic	Trial name of investigational drug	Clinical Trial ID(s)	MTG(s)	Status	OrphaCode	Link
Growth Hormone Deficiency	Investigating Efficacy and Safety of Once-weekly NNC0195-0092 (Somapacitan) Treatment Compared to Daily Growth Hormone Treatment (Norditropin® FlexPro®) in Growth Hormone Treatment naive Pre-pubertal Children With Growth Hormone Deficiency	NCT02616562	6	Ongoing Recruiting	ORPHA95488	Info
Type 1 Diabetes Mellitus	LA Study Comparing LY900014 to Insulin Lispro (Humalog) in Adults With Type 1 Diabetes Using Insulin Pump Therapy (PRONTO-Pump-2)	NCT03830281	3	Completed	ORPHA181371	Info
Thyroid Carcinoma	Phase 1/2 Study of the Highly-selective RET Inhibitor, Pralsetinib (BLU-667), in Patients With Thyroid Cancer, Non-Small Cell Lung Cancer, and Other Advanced Solid Tumors (ARROW)	NCT03037385	8	Ongoing	ORPHA1332	Info



EuRRECa
European Registries for
Rare Endocrine Conditions



ERICA
European Rare Disease Research
Coordination and Support Action





Clinical Patient Management System





What is the Clinical Patient Management System?

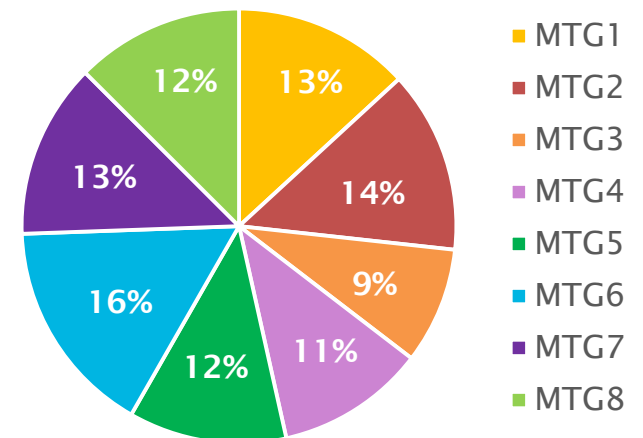
- The Clinical Patient Management System (CPMS) is a secure web-based application to support European Reference Networks in the diagnosis and treatment of rare or complex conditions across national borders.

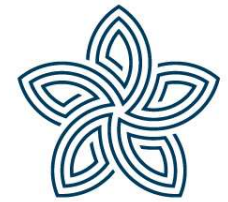
CPMS patient path

- ❖ Via the CPMS any doctor can ask for virtual consultation of Endo-ERN reference centres / HCPs
- ❖ This IT platform will enable a multidisciplinary team (MDT) from relevant reference centres to discuss highly specialised patient cases in a secure closed-off environment.
- ❖ The resulting advice can then be directly referred back to the patient by their own treating physician, via the reference centre/HCP leading the discussion

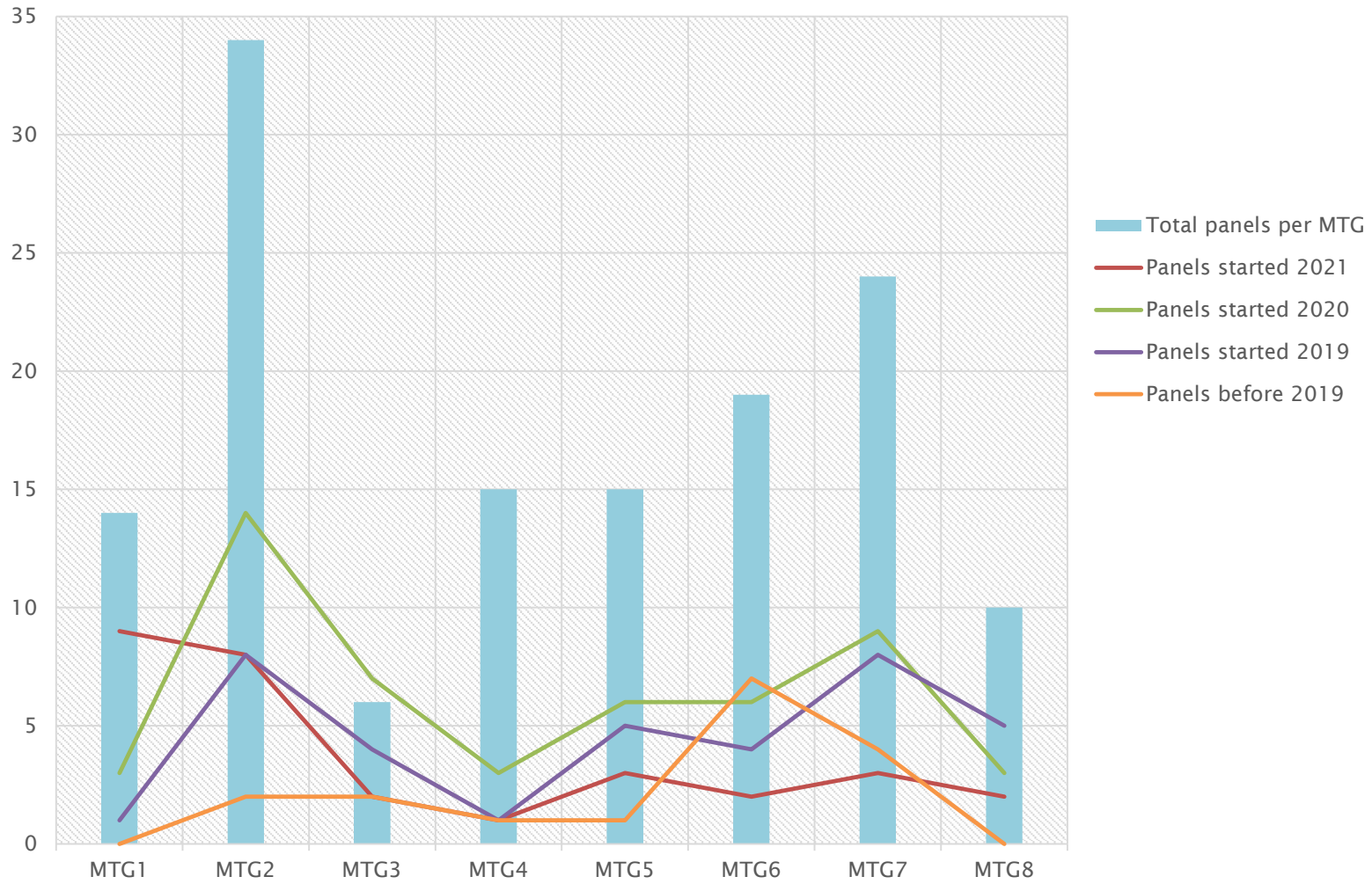
Registered Users: 305 Total Panels: 137

Expertise of Users





CPMS Panels Overview



Changes & current updates



- Welcome Isabel Wagner working with CPMS from the Paediatric office for Endo-ERN!
- The most recent updates to the CPMS include an updated user manual with further instructions on changes in:
 - Rights & Roles
 - Video meeting settings
 - File upload capacity

Note: Currently we are updating our [website resources](#) to reflect these changes
- Operational Helpdesk managers from all the ERNs are combining resources to ensure the most up-to-date information on CPMS is offered in our website resources.
- DG Santé are starting workshops to further develop the CPMS to meet the needs of clinicians in their daily work. Discussions on:
 - What systems are used in different HCPs
 - The compatibilities required
- Customized datasets for MTG 6 & 7 on CPMS
 - Implemented by **April 30th 2022**





Training for CPMS

- For new Endo-ERN HCPs and members:
 - You will be notified when your members will be able register in the CPMS
 - The Operational Helpdesk managers from all the ERNs are combining resources to ensure the most up-to-date information on CPMS is relayed to new members in a welcome folder and using resources on our own website.
- There will be a 2 hour CPMS training workshop for members, both new and existing
 - **Provisional date: 25th of February 2022***
 - This will include a walkthrough of the system, where to find guidance on specific tasks and a sample account registration/panel set up

*Date dependent on processing of details for new HCPs. Separate notice sent to all HCPs for training when confirmed





AMEQUIS





Research

Jérôme Bertherat





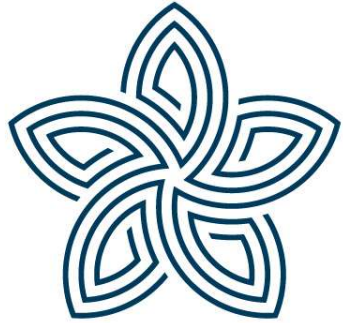
Collaboration in EU Rare Disease Research Consortia

➤ ERICA



➤ EJP RD





Endo-ERN

European Reference Network
on Rare Endocrine Conditions

ERICA : the European Rare disease research Coordination and support Action

<https://erica-rd.eu/> Coordinator: Alberto Pereira (Endo-ERN)



European
Commission

Endo-ERN is a European Reference Network co-funded by the
European Union's Health Programme under grant agreement No 739572

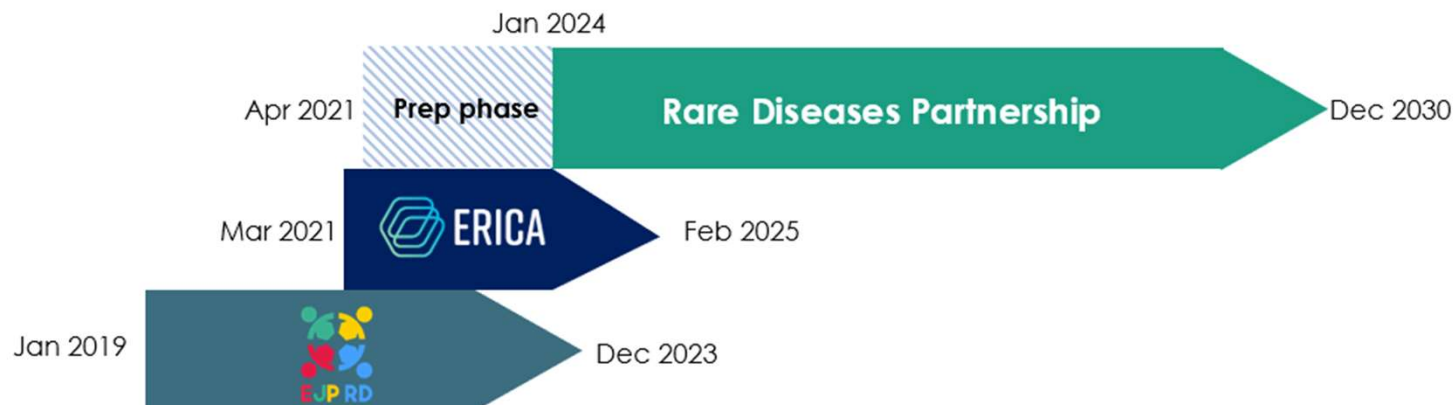


European
Reference
Network

Objectives



- The aim of ERICA, in which all 24 ERN's take part, is to strengthening ERN's research and innovation capacity of, through:
 - **facilitating inter-ERN collaboration**
 - **increase the visibility and impact of ERNs**
(outreach and collaboration with multiple stakeholders)
 - To align the strategy of ERICA and **to integrate the results into the new RD Partnership** to further stimulate the international collaboration and interoperability in RD Research and Clinical Network.



Work Packages



The priorities set by ERNs are divided into following WPs:

<https://erica-rd.eu/work-packages/>

Engagement of all ERN Members in all activities of the project through participation in the different WP specific Expert Working Groups (EWGs) – nominations via ENDO-ERN coordinating office or directly via [ERICA office](#)

Examples of activities. WP2:

Series of workshops on ERN Data Strategy



2-day
Multistakeholder
Workshop on
ERN Data
Strategy in
May/June 2022



WP5 Translation and Innovation

Catalogue of Services: <https://erica-rd.eu/work-packages/translation-and-innovation/expert-working-groups/>



The graphic is a promotional poster for an educational webinar. It features the ERICA logo and name at the top left, and the full name of the support action at the top right. The main title of the webinar is 'Educational Webinar 1: Current research services available for the rare diseases community'. A portrait of Anton Ussi, identified as being from EATRI, is shown on the left. At the bottom, the date 'November 8th, 2021' and the time '15:00-16:00 CET' are displayed with corresponding icons.

ERICA
European Rare Disease Research Coordination and Support Action

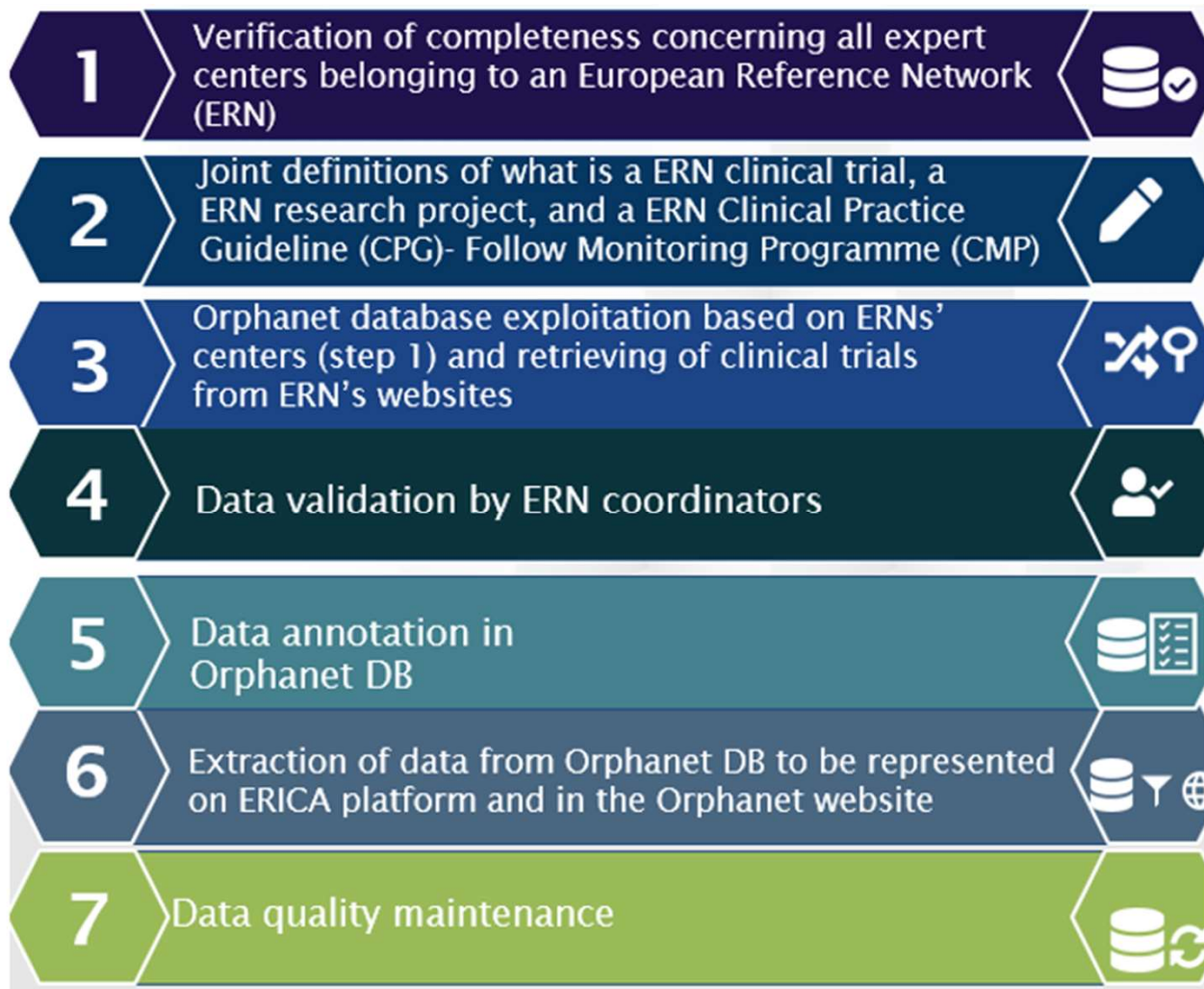
Educational Webinar 1
**Current research services
available for the rare
diseases community**

Anton Ussi
EATRI

November 8th, 2021 15:00-16:00 CET

<https://erica-rd.eu/event/educational-webinar-1-current-research-services-available-for-the-rare-diseases-community/>

WP6: T.6.2 Design of an interactive ERN research web-based platform with [Orphanet](#)



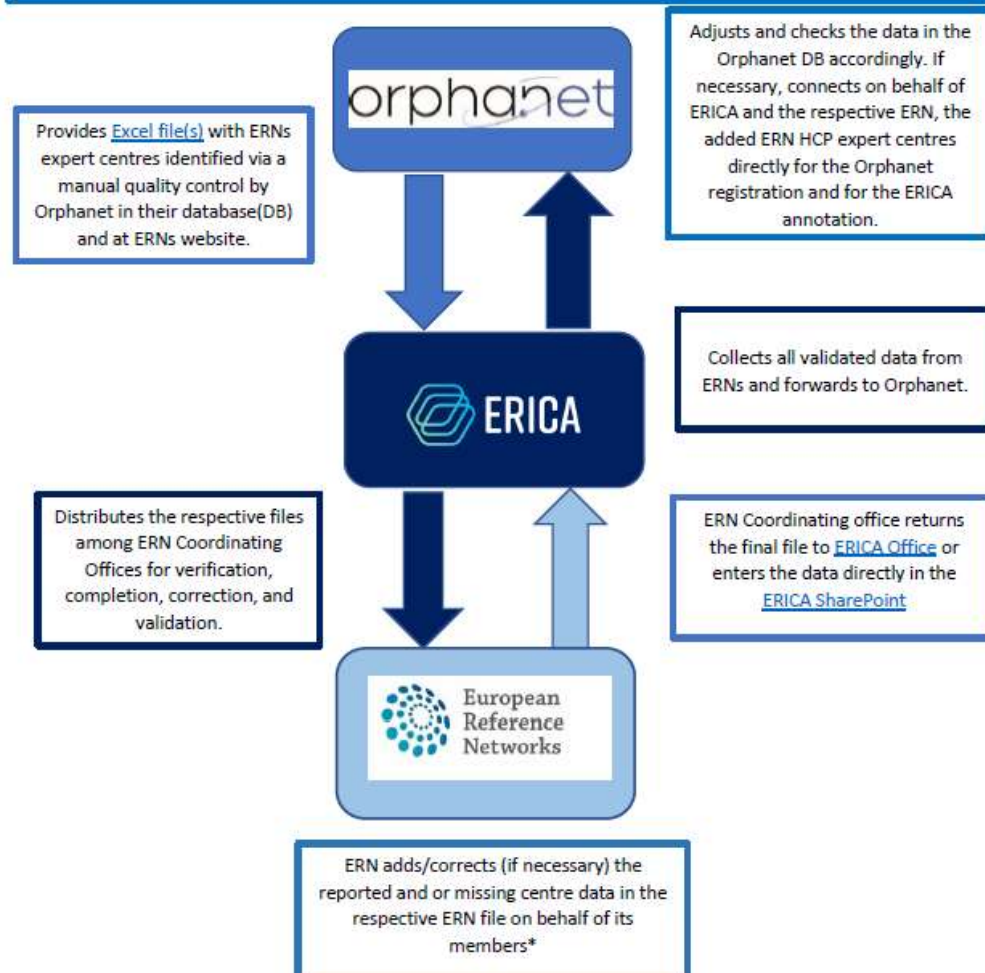
ENDO-ERN example

T.6.2 Design of an interactive ERN research web-based platform

<https://erica-rd.eu/>

SOP for the collection, verification and validation of completeness of all expert centers belonging to an ERNs

In all processes the GDPR will be considered.



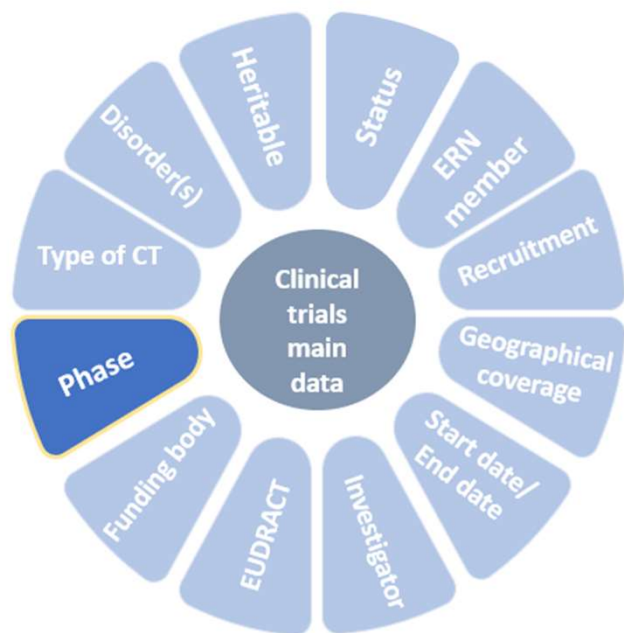
Verifying the ERN Expert Centres forms a foundation to enable further mapping of ERN research activities (e.g. on Clinical Trials)

Data workflow to be streamlined so as data is collected once: WIP

T.6.2 Design of an interactive ERN research web-based platform

<https://erica-rd.eu/>

Clinical trial (CT) main data



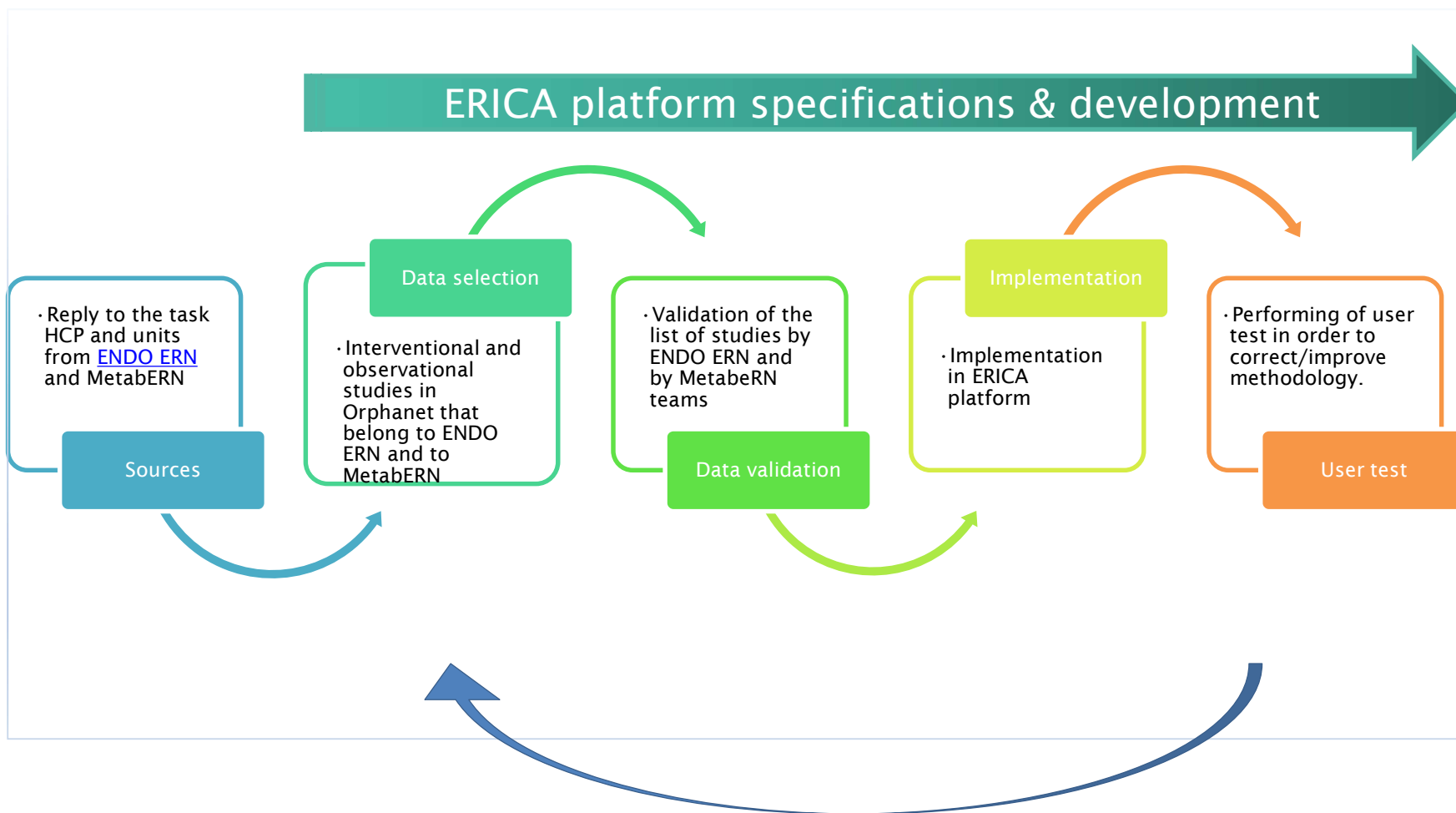
Phase

- I
- I-II
- II
- II-III
- III
- IV
- bioequivalence

- Candidate clinical research (observational, natural history) and CTs to be submitted to all ERN coordinators for validation

- Overview of Phase I CTs

Proof of concept





European Joint Program on Rare Diseases (EJP RD)

Concrete possibilities for ERN members

- ERN Research Mobility Fellowships
- ERN Research Workshops

<https://www.ejprarediseases.org/>





ERN Research Mobility Fellowships

The ERN

Research Mobility Fellowship funding opportunity

What can be funded?
Visits of junior clinical or lab researchers aimed to acquire scientific skills and advance rare disease research performed by the ERNs

Who can be funded?
PhD students, post-Docs and medical doctors from ERN Member/Affiliated Partner centers or other European research institutions

Where can you go?
- To another ERN Member/Affiliated Partner center
- To any research institution in Europe
Either home or host institution must be a Full Member or Affiliated Partner of an ERN

For how long can you go?
1 to 6 months

Aim

To support PhD students, Postdocs and medical doctors in training to undertake **scientific** visits fostering specialist research training outside their countries of residence.

The exchange can be carried out either:

- within the same ERN (Full Members and Affiliated Partners), OR
- between different ERNs (Full Members and Affiliated Partners), OR
- between ERN Full Members / Affiliated Partners and non-ERN institutions.

Either home or host (secondment) institution must be a Full Member or Affiliated Partner of an ERN at the time when the application is submitted, as well as during the proposed period of the training stay.

Successful applicants should acquire new competences and knowledge related to their research on rare diseases, with a defined research plan and demonstrable benefit to the ERN of the home and/or host institution.

Next call: fall 2022

(will be announced via Endo-ERN website, newsletter, social media)





Endo-ERN Fellowships

Applicant	Call	HCP	Visiting HCP	Project title
Oana-Ofelia Dănilă	3rd call	Carol Davila" University of Medicine and Pharmacy Bucharest, Romania (non ERN)	LUMC, NL	The influence of Growth Hormone excess secretion on the evolution of Fibrous Dysplasia in patients
Eva Coopmans	3 rd call	LUMC, NL	Barts Cancer Institute London and The William Harvey Research Institute (WHRI) London, UK (non-ERN)	GH-secreting pituitary tumours: nip therapy resistance in the bud (pilot-study)

<https://endo-ern.eu/prestigious-ejprd-ern-research-mobility-fellowship-for-drs-eva-coopmans-and-drs-oana-danila/>





ERN Research Workshops

The ERN
Research Training Workshops
funding opportunity

- Identify the most suitable topics for the organization of research training workshops with a cross-ERN added value
- Training topics include (but are not limited to): innovative research methodologies, diagnostic research topics, interdisciplinary treatment approaches (e.g. gene therapy, transplantation)
- Financing of 25,000€ covers the organization of a 2 day workshop (e.g. venue, catering & travel and accommodation of speakers and participants)
- Organizer's profile:
 - Affiliated to an EJP RD beneficiary institution OR
 - Affiliated to an ERN-Full Member or ERN-Affiliated Partner institution

Aim

To train researchers and clinicians affiliated to ERN-Full Members or – Affiliated Partners in relevant topics on research in rare diseases.

Training themes may include innovative research methodologies, diagnostic research methodologies, interdisciplinary treatment approaches, such as gene therapy and transplantation, etc. Moreover, the workshops will be aiming to provide a cross-ERN added value.

The workshops will be delivered as two-day events. Topics can be proposed by clinicians/investigators affiliated to ERN-institutions or EJP RD beneficiaries.

Next call: spring 2022

(will be announced via Endo-ERN website, newsletter, social media)





Endo-ERN Workshops

Organizer	Call	HCP	Country	Title workshop	Date	www	Status
Olaf Dekkers	1 st call	LUMC	The Netherlands	Clinical Research: The Basics & Beyond Workshop in clinical epidemiological research for ERNs	30 Sept / 1 Oct 2021		Closed
Barbara Jarzab	2 nd call	M. Sklodowska-Curie National Research Institute	Poland	ENDOCRINE CANCER: A challenge for children and adults	4 May 2022	https://endo-ern.eu/ern-workshop-on-endocrine-cancer-a-challenge-in-adults-and-children-4-may-2022/	Call for participants open until 7 March
Ana Caroline Pereira Neves	4 th call	Associação Protetora dos Diabéticos de Portugal (APDP), Lisbon	Portugal	GENETICS AND PRECISION MEDICINE IN RARE DISEASES	Autumn 2022		Call for participants to be opened in Spring 2022





Lunch Break





Meet and interact with your MTG co-workers

13:30 – 14:00	MTG1 Adrenal
14:10 – 14:40	MTG2 Disorders of Calcium & Phosphate homeostasis
14:50 – 15:20	MTG3 Genetic disorders of Glucose & Insulin homeostasis
15:30 – 16:00	MTG4 Genetic Endocrine Tumour Syndromes

See the handouts for the meeting links

