

Meeting minutes



Endo-ERN Steering Committee & Advisory Board (SCAB) meeting

Date & time: Friday 9th May, 12:00-13:00 CEST

Location: Bella Center Copenhagen, Denmark, MEETING ROOM 18/19

Attendance: See page 3 - All WPs were represented and MTGs **except for MTG4**

Agenda items

1. Endo-ERN grant
 - Interim grant report
 - Sustainability (FfS, EU4Health, Life Sciences)
 - Next ECG with EC meeting 20/21 May in Rome
2. Endocrine Connections special issue
3. Affiliated Registries – Endo-ERN's affiliation requirements
4. Topic change 3rd CPG, topic choice 4th CPG, guideline endorsement procedure
5. Quality of Care Improvement through Research Council
6. (potential need for) Extra Transversal Working Group on Research
7. EndoCompass project
8. ERN working groups and other EU RD projects
9. GA 2026
10. Program for the next 2 days
11. Other

Tasks / decisions / information

#	Description	Responsible	Target date	Task (T) Decisions (D) Information (I) <i>select what is appropriate</i>
1	Recognition Affiliate registries	Official Endo-ERN recognition of affiliated registries listed at EuRREB website Affiliate Registries EuRREB	2025	T
2	Update citation guidelines	Update Endo-ERN publication/citation guideline with affiliation requirements of work by Endo-ERN members from affiliated registries	2025	T
3	Review MTG web pages	Critically review MTG specific 'existing networks' pages and adjust accordingly	2025	T

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4	CPG topics in WP7	The 3 rd Endo-ERN CPG topic 'Congenital Hypopituitarism' was formally approved with no objections during the meeting. - Writing committee prepared to begin shortly	2025	D
5	4 th Endo-ERN CPG topic	The 4 th Endo-ERN CPG topic selection process has already been begun and will be finalized asap.	2025	T
6	Guideline endorsement procedure	Further develop and implement based on survey results	2025	T
7	Transversal Research WG	Create the 3 rd transversal WG on Research, similar to those of Genetic Testing and Transition of Care. Alignment with QoCIRC.	2025	D & T
8	ERN overarching WGs	Circulate updated overview of ERN overarching WGs and Endo-ERN representation	2025	T
9	Endo-ERN GA2026	Mark your calendar: 20-21 April 2026, Athens	2025	T

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Introduction by Alberto Pereira

1. Endo-ERN grant

Multi-beneficiary grant (half way) report is mandatory. The grant runs from 1 Oct 2023-1 October 2027.

- a. Interim grant report – Start of writing Q4 2025 (submission early 2026)
 - All WPs will be contacted first
 - Then MTGs for contribution
- b. Sustainability (FFS, EU4Health, Life Sciences)
 - Grant efforts already underway with all ERNs for after 2027
 - Any input/ advice is welcome
- c. Next ERN Coordinators Group with European Commission meeting 20/21 May in Rome
 - Agenda available upon request
 - Meeting will be physically attended by Alberto Pereira and Charlotte van Beuzekom

2. Endocrine Connections special issue – Theme: Rare Disease and Transition in Care

- Introduction + 9 papers confirmed, 1 additional to be confirmed
- 2 papers under review (already submitted) (thank you Corinna Grasemann & Judith Toke!)
- Plans for promotion of all of these papers and topics
- Using previous issue as promotion at booth
- Endocrine Oncology will be next special issue (they invited us)
 - Q Hedi Claahsen – is there a set journal for Endo-ERN?
 - No, but there are several journals that we can link to based on topic/ relevance
 - Society journals due to our formal memorandum of understanding have some preference but this is not set in stone
 - Q Hedi Claahsen – price for publication is still an outstanding barrier to publishing
 - Alberto Pereira agrees the 'netto' outreach should be balanced
 - Use of university discounts
 - Current special issue APC is 50% discounted: 1,050 pound
 - Embed funding of such research in our future strategies
 - Information from Marek Niedziela - Bioscientifica journals also has lower price for publications (euro 2,000 or so without discount)
 - We need to engage first in what spaces we want to be known as
 - Liaise with societies on these matters so it's top down
 - Discussion is pending – perhaps in the space of the research WG as an objective
 - a. Suggestion from Nienke Biermasz: Map university discounts

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3. Affiliate Registries

- 4 officially affiliated registries ([listed at EuRREB website](#))
- Officially recognize and update citation guidelines to reflect these other registries
 - Task for MTGs: Critically review the MTG sections of connected/ existing registries (to be started by project management)
- Core registry is the main comparative to these affiliated registries
 - Propose a data request to other registry, can always become a joint effort with EuRREB
- Q Hedi Claahsen : making the SDM registries just as visible at website - also as something to acknowledge with the CM

4. CPG Topic change

- 3rd CPG, topic choice (second voted topic did not cover pediatric component i.e. had an objection)
 - Has the new guideline topic been agreed upon with the societies in mind , specifically the clinical practice committee?
 - Both societies in the working group for writing already
 - Topic 'accepted' but not formally committee level endorsed
 - Evangelia Charmandari: Alert societies on topic choices Endo-ERN. Outreach to RD Committee comes first and then the guideline committees
 - Charlotte Gaasterland: Deadline of our guideline grant deliverable also to consider
 - Corinna Grasemann: Make a platform/ ongoing project record of the ongoing CPG efforts in the ERN
 - Edward Visser: Add meetings & negotiations on next CPGs fundings already to agenda of the named committees in interest of efficient timelines
- b. 4th CPG
 - Topic suggestions ongoing, final decision by SCAB
 - Opportunity to try involve the societies more
- c. Guideline endorsement procedure
 - Survey to all members on this topic
 - Results presented partly during the GA (preliminary)
 - Further development and implementation based on final results

5. Quality of Care Improvement through Research Council

- Financial barriers are being overcome by Charlotte & Emily
- The establishment of a Research WG would be beneficial and complementary of the core aims and task of the council

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6. (potential need for) Extra Transversal Working Group on Research

- Now ERNs are evolving and maturing, EC encourages ERNs to also create research initiatives
- Therefore need for creation of this transversal WG
- First step = survey on scientific contributions during joint congress Copenhagen. Aiming to identify by whom and where current operational RD research is being done. In addition to already existing repositories and Continuous Monitoring data. Results will serve as extra input for this WG.
- All agree, so we will further work on:
 - Composition
 - Dedicated email for WG
 - ERNICA research catalogue idea – make Endo version?
 - Guideline WP idea – research agendas following systematic reviews to show areas of needed research

7. EndoCompass project

- Major new research initiative, led by ESE and ESPE, that aims to give endocrine science the attention it deserves
- Two dedicated sessions at joint congress

8. ERN working groups and other EU RD projects

- DG Sante is working on an updated overview of active / needed transversal ERN WGs. Endo-ERN is well represented in almost all WGs, both as member and co-chair.

9. GA 2026

- GA in 2026 will be hosted by our Greek colleagues in Athens, chaired by Evangelia Charmandari
- Provisional dates are 20-21 April 2026; Please mark your calendar
- Preparations to find a suitable location and hotels are being made

10. Program for the next 2 days

11. Other

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Attendance

<i>First name</i>	Last name	Role
<i>Alberto</i>	Pereira Arias	Coordinator, WP1,2,3,8,9
<i>Olaf</i>	Hiort	Coordinator, WP4
<i>Charlotte</i>	van Beuzekom	WP1, WP2, WP8
<i>Emily</i>	White	WP3, WP4, WP9
<i>Natasha</i>	Appelman-Dijkstra	WP5
<i>Violeta</i>	Iotova	WP6
<i>Charlotte</i>	Gaasterland	WP7
<i>Giorgio</i>	Dal Maso	MTG1
<i>Jette</i>	Kristensen	MTG1
<i>Manuela</i>	Brösamle	MTG1, MTG7
<i>Corinna</i>	Grasemann	MTG2
<i>Bernd</i>	Rosenbichler	MTG3
<i>Pietro</i>	Maffei	MTG3
<i>Patricia</i>	Carl-Innig	MTG5
<i>Susan</i>	O'Connell	MTG5
<i>Diana</i>	Vitali	MTG6
<i>Nienke</i>	Biermasz	MTG6
<i>Hedi</i>	Claahsen	MTG7
<i>Lexi</i>	Breen	MTG7
<i>Arlene</i>	Smyth	MTG7
<i>Edward</i>	Visser	MTG8
<i>Beate</i>	Bartès	MTG8
<i>Esther</i>	Bloem	MTG8
<i>Judit</i>	Toke	AB
<i>Marek</i>	Niedziela	AB