

Meeting minutes



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

Date & time: Tuesday 2 September 2025, 09:30-11:30

Location: Online

Attendance (38): Marta Barańska, Charlotte van Beuzekom, Esther Bloem, Petra Brüggmann, Marc Büdenbender, Patricia Carl-Innig, Aimee Casey, Frederic Castinetti, Evangelia Charmandari, Maria Cherenko, Natasha Appelman-Dijkstra, Ulla Doehnert, Thomas Eggermann, Jadranka Elezovic, Greta Ginski, Johan de Graaf, Corinna Grasemann, Claus Højbjerg Gravholt, Olaf Hiort, Andrea Isidori, Eva Kassi, Martha Kirchhoff, Laura Maag, Pietro Maffei, Kamelia Markovska, Giorgio dal Maso, Marek Niedziela, Anna Nordenström, Susan O'Connell, Alberto Pereira, Luca Persani, Dirk Prawitt, Antje Redlich, Felix Reschke, Athanasia Stoupa, Gerlof Valk, Emily White, Sevim Zekerie.

Agenda items

1. WP1 Management & Coordination (Charlotte van Beuzekom)

Coordination

- Charlotte van Beuzekom opened with updates on ePAGs: Jette Kristensen has fallen seriously ill, recent treatment appears to be effective, but she is currently unable to take on tasks and may attend only as an observer. Arlene Smith will step down as ePAG representative due to workload. The group welcomed new ePAGs: Laura Maag (Association Surrénales, FR) and Marc Büdenbender (Let's Cure ACC, DE).
- EU4Health grant: eight milestones and six deliverables submitted and accepted, eleven further deliverables due by end-November 2025.
- Interim report (first 27 months incl. finances) due end-February 2026, WP leads and MTG Chairs will be approached for inputs.
- Funding outlook: first draft of the EU Multiannual Financial Framework (2028–2034) lacks a stand-alone EU4Health successor, health sits within a competitive pillar (e.g., biotech, agriculture). Stakeholders are mobilizing, members to flag advocacy opportunities.
- Affiliated partners: a new call expected (focus on increase of geographical coverage). MTGs may be asked to review applications (limited nr. expected for Endo-ERN).
- GA2026: Mon 20 & Tue 21 April 2026, Crowne Plaza Athens (programme drafting underway, Tuesday finishes after lunch).
- MTG-specific HCP meetings: most Autumn 2025 dates set, MTGs 1 & 4 to add theirs, please also pre-schedule 2026 meetings ahead of GA.

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Research Working Group

- Open call launched for the composition of Endo-ERN Research Working Group. Main objective is to be “call-ready” (ERDERA and other schemes). To date: 2 member applications, no chair applications.
- Model proposed: dual chair (experienced paediatric + adult endocrinologist) with strong research track records, if possible involve younger researchers as members.
Olaf Hiort suggested identifying HCP colleagues who already hold ERC/EU grants, as they bring valuable grant-writing and administrative expertise.

2. Work Package 2 Communication & Dissemination (Aimee Casey)

- Social media update 2025: LinkedIn growth, Facebook engagement improving, YouTube steady, newsletter cca 2,500 subscribers with 35–40% open rates.
- Patient resources: more than 100 items now searchable on the website, AI-assisted English summaries with local-language versions for searchability, submissions via website form to be vetted through ePAGs/MTGs.
- Newsletters: moving to topic-based issues (Research/Registries, CPMS, Training & Education).
- New monthly “Digest” for all primary/sub representatives (first Friday of the month): classifies tasks & reminders to reduce number of emails.
- National associations outreach: database validated with national coordinators, a landing page is being prepared.
- Commission’s Continuous Monitoring Report: Expected end of September, will underpin ERN-wide awareness campaign, Phase 2 showcase Endo-ERN using performance data, Endo-ERN to follow up with its own highlights.

3. WP3 Evaluation (Emily White)

- Continuous Monitoring Report: DG Sante Report to be published in September of aggregated data for all ERNs (gathered 2023–24)
- HCP Performance Reports (2024): to be sent within a week, comment deadline foreseen: 19 Sept 2025.
- Continuous Monitoring (2025 data): opens Jan 2026. MTG Chairs to remind HCPs to update e-REC by year-end and request yearly totals in time.
- Short survey upcoming to map resources (genetic labs, urgent-case experts, rare-disease office contacts, Ukraine-related links).
- Evaluation Working Group: recommendations for streamlining the next 5-year evaluation/site visits submitted to DG SANTE.

4. WP4 Healthcare & CPMS (Greta Ginski)

- Adoption/use: active users across MTGs 96 (60 in CPMS 2.0 **only**), 942 patients enrolled, multiple HCPS attending CPMS meetings, some HCPs still not using the system.
- Mobile app: CPMS 2.0 app available on Android/iOS with EU-Login 2FA, feature parity with desktop, snippet videos and training planned.
- Meeting structure: re-framed recurring meetings to set a main agenda item plus slots for urgent cases, definitive calendar on CPMS/website.

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- Support: booking link for 1:1 help-desk (login/app/setup).
- Discussion: Anna Nordenström reported Karolinska's legal office has not yet approved CPMS 2.0, Emily White offered direct DPO-level support and info packs. Susan O'Connell highlighted DPO confusion (registry vs clinical tool) and administrative burden, Claus Gravholt-Højbjerg noted national MDTs using other platforms. Olaf Hiort advocated for EU-level promotion and national reimbursement recognition for teleconsultations to drive uptake. Alberto Pereira underlined safe public-Wi-Fi practices, Emily White confirmed 2FA encryption and general good-practice guidance.

5. Work Package 5 (Natasha Appelman-Dijkstra)

- e-REC: approx. 90% of centres active, more than 9,000 new cases in the reporting period (2025).
- Core registry: participation rising (from Dec 2024 to Aug 2025: +9 active centres, now approx. 38%), 630 new ERN-related cases entered in 2025.
- Proposed KPIs: (1) time-to-diagnosis in the expert centre, (2) e-REC-to-CORE ratio (for centers authorized to use CORE) to support prospective benchmarking.
- New modules: MEN1 (final testing), Women's Health (pregnancy, fertility, menopause, beta with patient testing), Hyperparathyroidism (kick-off, large WG, paediatric and treatment outcomes foreseen).
- Events: annual [EuRREB symposia](#) will take place on 12.09.2025, this year more aligned to bone/mineral and broader endocrine focus next year.
- Discussion: Alberto Pereira asked whether quorum had been reached for decisions and requested clarification of KPI 2 before moving to agreement. Charlotte van Beuzekom confirmed the reached quorum for decisions. Natasha Appelman-Dijkstra explained the rationale and prospective use for benchmarking and future grant applications.

6. WP6 Education and Training (Aimee Casey, on behalf of Violeta Iotova)

- Event endorsements continue (Endo-ERN among few ERNs offering this).
- Clinical Exchanges 2025: six approved, next call open from 1 Oct–30 Nov 2025 for 2026 exchanges, exploring longer stays, hosts page to be refreshed.
- Webinars: please pre-plan minimum 5 webinars early for 2026 (minimum 6 weeks lead time) to enable accreditation, MTG supporters available to help.
- Winter School: early March 2026 in Varna, funding secured, MTGs 5/6/7 & 3 to expect programme input, promotion from October.

7. WP7 Clinical Practice Guidelines & Clinical Decision Support Tools (Anna Nordenström)

- Develop Endo-ERN clinical guidelines with decision tools; include transition aspects; engage patients from the start; disseminate with WP2/WP6.
- Pubertal induction/transition (2022) and Familial Hyperaldosteronism (2024) completed; Transition in collab with MTG6 in progress; SOPs for endorsement in place and under further development; lay versions to be (re)started.

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- Survey outcome: Top new topics: (1) Hypothalamic obesity treatment and management (of craniopharyngioma) in children & adults (MTG5/6)); (2) Replacement treatment in hypoadrenalism: focus on monitoring target (MTG1).
- Discussion: Olaf Hiort supported partnering with ESPE/ESE to boost uptake; Anna confirmed society collaboration and lay versions are built into the plan.
- Decisions: (Quorum confirmed later in the meeting): Start two guideline projects in parallel: Hypothalamic obesity; Hypoadrenalism replacement therapy, monitoring focus (see pre-previous point for full titles).

8. Transversal Working Group on Genomic Testing (Thomas Eggermann & Dirk Prawitt)

- TWG includes 24 members across nine countries that meets bimonthly.
- Formalising collaboration with the European Society of Human Genetics (ESHG); liaison manager discussion/meeting scheduled.
- Preparing a matrix of genetics expertise across Endo-ERN HCPs (similar to endocrinological tests matrix) for internal use and potential web display.
- Publications plan: drafting a joint paper on the endocrinologist's perspective on genetic testing; Frederic Castinetti (ESE Clinical Committee) expressed interest in ESE endorsement once a draft/author list is available.
- Alberto Pereira thanked the group and encouraged clear Endo-ERN acknowledgement in outputs.

9. Transversal Working Group on Transition in Care (Andrea Isidori & Ulla Doehnert)

- Group expanding (including a new ePAG member); maintains a literature/guideline repository on transition.
- Network-wide transition e-survey completed; manuscript nearly ready and will be circulated for approval; considering journal submission (Journal of Endocrinology vs Endocrine Connections).
- Developing condition-specific transition checklists (drafts in progress, more to follow).
- Collaboration with the overarching ERN Transition initiative and with ESE/ESPE on transition guidance; expectation of two complementary documents endorsed by all three.
- Upcoming: All-ERN Transition workshop in Ghent (Feb 2026); Endo-ERN in-person transition meeting (TALENT) in Rome (11–13 Feb 2026).

10. Other RD Project updates (Charlotte van Beuzekom)

JARDIN

- Joint Action JARDIN:
 - WP6: care-pathway development for selected conditions (DSD/CAH) led by MTG7 chairs and with involvement from Endo-ERN MTG1 and rare urology (eUROGE) partners; aiming for completion by the end of the project (Dec 2026).
 - WP9: Survey #4 across ERNs led with survey development contributions from Alberto Pereira and Mari Murel; Endo-ERN response rate 38% (overall 34%). Results will inform recommendations to national authorities and ERN hospitals.
- JARDIN General Assembly: early October (Vilnius Park Plaza Hotel); online participation possible; details to follow.

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ERDERA

- [Networking Support Scheme - ERDERA](#) recently launched. Competitive funding instrument to support organization of transnational networking events that promote knowledge sharing on rare diseases and rare cancers, research uptake and collaborations among clinicians, researchers and patient advocacy organizations. Available funding up to 30.000 euros per networking event. Deadline for this round of funding is 7 October, but constant open call until April 2029 with six-monthly review rounds.
- General Assembly 29-31 October 2025, Amsterdam UMC, NL

Tasks / decisions / information

#	Description	Responsible	Target date	Task (T) Decisions (D) Information (I) <i>select what is appropriate</i>
1	Review ePAG task distribution given membership changes, report back at next SCAB.	ePAG Chairs/Endo-ERN team	Dec 2025	T
2	Circulate deliverable drafting guidance, prepare all deliverables due by end-Nov 2025, seek MTG inputs as needed.	Endo-ERN team, WP leads	Oct 2025	T
3	MTG1 & MTG4 chairs to schedule MTG specific HCP meeting for 2025	MTG1 and MTG4 chairs	Dec 2025	
4	Pre-plan 2026 MTG-specific HCP meetings (will be announce at GA2026);	All MTG Chairs	April 2026	T
5	Include the Continuous Monitoring overview slide in HCP meetings, remind HCPs to update e-REC by year-end and request 2025 totals in January 2026.	All MTG Chairs	Dec 2025	T
6	Research WG: continue recruitment (chairs & members), identify candidates with ERC/EU grants	Endo-ERN team	Dec 2025	T
7	Verify local permission to use CPMS 2.0, seek support from the help-desk for setup as needed, follow good practice for public-Wi-Fi use.	All HCPs		T
8	Expand patient resources, run topic-based newsletters and monthly Digest	WP2	Dec 2025	T

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9	Send HCP Performance Reports (2024) and collect comments by 19 Sept 2025, launch short resource survey (labs, urgent experts, RD offices, Ukraine links).	WP3	Sept 2025	T
10	Publish CPMS meeting calendar, provide DPO info packs, maintain 1:1 help-desk booking link, add short training videos, support centres with permissions.	WP4		T
11	Roll out MEN1 after final tests; launch Women's Health by year-end with beta feedback; kick off Hyperparathyroidism (variables + study groups); standardize modules on a core dataset with optional tabs; and report progress at the upcoming symposiums.	WP5		T
12	Pre-plan min 5 webinars for early 2026 accreditation, open Clinical Exchanges call (1 Oct–30 Nov 2025), refresh hosts page, Winter School planning (Varna).	WP6	Autumn 2025	T
13	Continue CPG on Transition, Kick off the two new guideline topics, approach ESPE/ESE and relevant societies per SOP, start planning for lay versions and decision tools	WP7	Autumn 2025	T