

Meeting minutes



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

Date & time: 04.02.2025 9:30 – 11:30 hrs.

Location: online

Attendance (44): Faisal Ahmed, Natasha Appelman-Dijkstra, Beate Bartès, Charlotte van Beuzekom, Nienke Biermasz, Esther Bloem, Lexi Breen, Tessa de Bruin, Petra Brügmann, Aimee Casey, Frederic Castinetti, Evangelia Charmandari, Olaf Dekkers, Ulla Doehner, Thomas Eggermann, Jadranka Elezovic, Nathalie Ferard, Charlotte Gaasterland, Greta Ginski, Johan de Graaf, Corinna Grasmann, Claus Højbjerg Gravholt, Olaf Hiort, Violeta Iotova, Andrea Isidori, Eva Kassi, Martha Kirchhoff, Pietro Maffei, Mohamad Maghnie, Kamelia Markovska, Giorgio Dal Maso, Marek Niedziela, Anna Nordenström, Susan O'Connell, Lynette Pasman, Alberto Pereira, Dirk Prawitt, Nicole Reisch, Bernd Rosenbichler, Arlene Smyth, Gerlof Valk, Edward Visser, Emily White, Sevim Zekeries.

DISCUSSION TOPICS

Introduction

Alberto Pereira and Olaf Hiort opened the meeting and extended a warm welcome to all present Endo-ERN Steering Committee and Advisory Board members. Charlotte van Beuzekom proceeded with introducing the agenda of the meeting.

WP1 Management & Coordination

Management & Coordination – presented by Charlotte van Beuzekom

Replacement/new (chair) positions – Marta Baranski from the Pituitary Gland Association in Poland applied for ePAG membership. Her application was approved by all ePAGs, MTG6 chairs, Alberto Pereira and Olaf Hiort. She could not attend the SCAB meeting due to hospitalization, but the SCAB officially welcomed her. Corinna Grasmann from the Katholisches Klinikum Bochum has replaced Heiko Krude as Paediatric National Coordinator for Germany.

Endocrine Connections – special issue - SCAB members were invited to submit proposals focusing on rare diseases and transition in care. Eleven proposals were approved by Alberto Pereira, Olaf Hiort and the guest editors. Manuscript submissions are planned throughout the year, with initial submissions targeting publications at the Joint Congress in May 2025. Promotion will be in close partnership with our communication manager Aimee Casey and the marketing manager of Endocrine Connections, and may include webinars around the publication topics. Additionally, Endocrine Oncology Editors-in-Chief approached Endo-ERN for a potential collaboration in 2026 on 'Translation of care between paediatric and adulthood in patients with endocrine tumors'.

Meeting minutes



MTG HCP meetings- All MTGs must hold three meetings annually (two online, one in-person at GA). Attendance rates need improvement, as only 10% of invited individuals (25% of endorsed HCPs) attended. Suggestions are needed to increase participation and engagement. A survey will be sent to members to identify barriers to attendance, and possible incentives for participation will be explored, such as certification for professional development credits.

GA and Joint Congress Preparations- GA will be held in Copenhagen on May 9 and 10, 2025. Starting with the SCAB meeting at 12hrs, followed by plenary presentations from 13:30-19 hrs. The MTG specific sessions will be on Saturday morning from 9-12 hrs. A (self-paid) social dinner on Friday evening is being explored but is not yet confirmed. Endo-ERN will have a booth during the 3-day joint congress. This year for the first time it has been approved to share a double size booth with our Endo-ERN ePAGs, aimed at promoting activities and engaging with members. The Endo-ERN symposium program at the Joint congress was presented.

Linkage to European Rare Disease Projects:

- [ERICA project](#) has been extended for six months - until September 2025. The first ERN research conference was recently held in Udine, where Endo-ERN representatives won awards for their work: [Edward Visser](#) from Erasmus MC Rotterdam was selected for an oral presentation on thyroid hormone, analogue therapy for resistance to thyroid hormone in children. He won the Best Presentation Award in the category CLINICAL TRIALS. ePAGs Johan de Graaf and Petra Brüggmann, together with Emily White and Dirk de Rijdt (ESE) won the award for the best poster entitled 'Multistakeholder Mapping of Endocrine Medicine availability and shortages in Europe: Endo-ERN expert centers'. The achievements and ongoing activities of ERICA will be as much as possible captured and continued in the ERDERA project.
- [ERDERA Project](#): Focused on research. Competitive funding opportunities are also available for non-partner organizations. Endo-ERN has not yet applied but is looking for collaboration research opportunities. Currently open: Joint Transnational Call 2025 for collaborative research projects.
- [JARDIN Project](#): Focused on integrating ERNs into national healthcare systems. Proposed collaboration areas with ERDERA include research, synergy activities, and information sharing. Endo-ERN's role will be developing a care pathway for DSD/AGS, led by Hedi Claahsen, Claus Gravholt and Manuel Brosamle, in collaboration with MTG1 and ERN eUROGEN.

Questions and Comments

Alberto Pereira emphasized the need for structured collaboration with ESE journals and suggested keeping an open mind for other partnerships. He also suggested forming a dedicated editorial advisory board. **Olaf Hiort** highlighted the need to extend endocrine oncology collaboration beyond tumors, incorporating endocrine conditions related to cancer, particularly for paediatric cancer survivors. He stressed the importance of multidisciplinary research in this area. **Alberto Pereira** supported this, stating that collaboration with other ERNs, including adult cancer ERNs, is a valuable opportunity. He proposed organizing a dedicated session at the next Joint Congress to discuss cross-ERN collaborations. **Olaf Hiort** proposed a stronger focus on integrating ERNs into national healthcare systems, emphasizing research on health system structures, transition care, and economic factors like CPMS reimbursement. **Alberto Pereira** agreed and emphasized that this integration is critical for long-term sustainability. He suggested a policy paper to highlight these challenges and propose solutions.

Meeting minutes



Quality of Care Improvement through Research Council, presented by Emily White.

The Council has held its first formal meeting and established its remit, outlining its function and key focus areas within the network. A first call for research grants is expected to be launched within the next six months, though minor practical delays may occur. The grant application process will be competitive, and the Principal Investigator must be affiliated with an Endo-ERN member, HCP, patient organization, or advocacy group. Additional criteria will define eligibility and highlight priority research areas.

Details, including the proposal submission guide and deadlines, will be available on the Endo-ERN website. The call will be open, including all MTG chairs, and young researchers are encouraged to stay informed about upcoming communications.

Transversal Working Group on Genomics presented by Thomas Eggermann and Dirk Prawitt

The WG currently consists of 23 participants from eight different countries. A virtual meeting was held in December 2024, and the next meeting is scheduled for the upcoming week. The group has been in discussions with the European Society of Human Genetics (ESHG) regarding collaboration on genetic topics across different ERNs. However, they are still waiting for the protocol from October.

The planned collaboration includes: Establishing a mutual link between ESHG and the ERNs. Creating a list of overlapping topics for education and training programs, including webinars on ethical aspects of genetic testing and testing methods and providing a directory of genetic experts on the ESHG website (currently under construction).

Current activities:

- Genetic Expertise Mapping – The working group is developing a matrix and overview of genetic expertise within the ERN. This will be discussed and structured in the next meeting. The focus is on expertise centers rather than general genetic testing providers.
- Joint Paper on Genetic Testing in Endocrinology – The group is preparing a summary paper addressing endocrinologists' expectations for genetic testing and reporting. This will not replace existing guidelines but rather summarize key aspects and link to relevant consensus papers. Topics include: When genetic testing is appropriate, standardized testing procedures (e.g., whole genome vs. exome sequencing), standardizing testing quality, handling variants of unknown significance and incidental findings and research considerations. The first draft is being compiled based on input from working group members.

Questions and Comments:

Alberto Pereira asked whether this initiative overlaps with [Solve-RD](#) or other activities related to genetic hubs.

Thomas Eggermann clarified that while there may be some overlap, the goal is to avoid duplication and ensure coordination with other groups. Alberto Pereira also inquired about Endo-ERN's involvement in the Cross-ERN Working Group on Pregnancy and Genetic Disorders. Thomas and Dirk were unsure and agreed to follow up on their involvement.

Meeting minutes



Transversal Working Group on Transition in Care presented by Andrea Isidori and Ulla Doehnert

The working group on transition in rare endocrine disorders has been fully established, incorporating a diverse mix of adult and paediatric endocrinologists. A kick-off meeting has taken place, and a new visual identity for the group has been developed.

Key activities:

- **Resource Sharing:** A shared OneDrive folder has been created to store consensus documents and studies related to transition.
- **Survey on Transition:** A Europe-wide survey on transition processes has been launched and has already received over 90 responses, marking a significant step in mapping transition practices.
- **Cross-ERN Collaboration:** Meetings have been held with ERN- EuroBloodNet, EUROGEN and Euro-NMD to explore collaboration opportunities. The endocrinology community plays a crucial role in transition due to the significance of puberty as an endocrinological event.
- **Coordination with Scientific Societies:** Efforts have been made to align activities with the European Society of Endocrinology (ESE) to avoid duplication. Instead of overlap, a synergy has been observed between the two groups. Leaders from the parallel working group at ESE will attend the upcoming meeting in February.
- **Involvement of ePAG:** Diana Vitali has joined the working group, and an open call has been issued to encourage further participation from ePAG members. A second open call will follow.
- **Upcoming Deliverables:**
 - Presentation of survey results.
 - Drafting of a consultation document on transition of care for rare endocrine disorders.

The group is preparing for the **Rome TALENT meeting on February 12–13, 2025**, which will feature distinguished speakers and has received endorsements from multiple organizations, including Endo-ERN, the European Society of Endocrinology, and the European Academy of Andrology. The event will be recorded to serve as an educational resource. Additionally, the business subscription for the survey platform was personally covered by Andrea Isidori's research grant, and reimbursement options through Endo-ERN were briefly mentioned.

WP2 Communication & Dissemination - presented by Aimee Casey

Social Media Development - provided an update on the social media development for Endo ERN, reporting growth across all platforms, particularly YouTube, where subscriptions have doubled. Aimee Casey attributed this to the quality of educational content, noting that the increase in newsletter subscriptions was also linked to the webinar program. Aimee encouraged members who are not yet following Endo-ERN on LinkedIn to do so, emphasizing that it helps showcase the expertise within the network.

VuMedi – is a commercial platform similar to YouTube but focused on medical content. VuMedi had reached out to Endo-ERN after seeing a video by Hedi Claahsen, and they proposed creating an Endo-ERN channel on their platform. Aimee clarified that VuMedi would allow the content to reach a new audience, especially in North America, and that videos could still be accessed on Endo-ERN's website and YouTube.

Meeting minutes



The publications database - is now live, but it's not yet complete. More data will be added soon. Once it's finished, attention will shift to updating the patient pages and reviewing the members section, which contains valuable information. Members are encouraged to favour this section for easy access.

Showcase materials – the plans are in place to develop more materials, particularly related to endocrine connections. This will include background information about research papers to provide context on why the research is being done and its clinical impact.

Rare Disease Day – is on February 28th, and for the first time, ERNs will collectively promote awareness through communication materials and visuals. This will target both the public and non-member clinicians. Endo-ERN will feature relevant content in its newsletter.

European Hormone Day - organized by ESE, has expanded to World Hormone Day, and Endo-ERN will be actively involved, sharing information through its channels.

Questions and Comments

Anna Nordenström expressed confusion about why Endo-ERN should partner with VuMedi when we had been successful in developing our own webinar series and social media presence. She questioned the value of sharing content on another platform, especially one with commercial intentions. **Aimee Casey** responded, explaining that it was an opportunity to expand their reach, especially to North American audiences, without incurring significant costs, noting that this was not a mandate but an option for the group to consider. **Violeta Iotova** expressed concerns about advertising on VuMedi. She expressed a preference for keeping Endo-ERN's communication to high scientific standards and questioned whether VuMedi's platform would expose their content to disruptive advertising, which could be problematic. **Aimee** clarified that, based on her understanding, ads would not be embedded in the videos themselves but would appear around the content on the platform. **Anna** again raised concerns, noting that Endo-ERN had put a lot of effort into developing our own website and content, and feared that partnering with VuMedi could diminish our own platform. She emphasized that VuMedi was much larger and had commercial interests, and she did not want our work to be overshadowed by such a platform. She felt that the potential risk of losing their own identity on a larger, commercial platform like VuMedi was too high. **Aimee** acknowledged Anna's concerns, explaining that it was about reaching a new audience and offering their content on a platform with a different audience, similar to how Google Scholar differs from PubMed. **Ulla Doehnert** asked whether VuMedi targeted a European audience, to which Casey replied that VuMedi's primary focus was North America but they were expanding into Europe. **Olaf Hiort** also expressed caution about using American platforms, especially given the current uncertainty in the USA. He advised waiting a few months before committing to anything related to the USA. **Gerlof Valk** agreed with Anna and Olaf, expressing his concern about Endo-ERN's content being overshadowed by the larger VuMedi platform and its commercial focus. He suggested focusing on driving more traffic to Endo-ERN's own website. **Arlene Smyth** raised the concern that some patients with rare conditions could unintentionally be identified through content shared on VuMedi, which could lead to issues with insurance and other concerns. She, too, expressed hesitation given the uncertainty about the situation in the USA. In conclusion, **Aimee** acknowledged all the feedback, clarifying that this opportunity came to Endo-ERN, not the other way around, and reiterated that the group would ultimately decide whether to move forward. She suggested putting the discussion on hold and revisiting it later in the year.

Meeting minutes



WP3 Evaluation – presented by Emily White

Continuous monitoring- The first step of the continuous monitoring is complete as of January 31st, with the deadline passed for updating the e-REC data for 2024. If this wasn't completed at the centre, local figures should be reported when submitting to the European Commission platform. The Endo-ERN survey completion is an ongoing task, with the deadline for submission set for February 28th. A Q&A session is scheduled for February 14th, and some common queries, like those related to ORPHA codes, will be addressed. If an HCP does not use ORPHA codes, an overview of ICD 10/11 and Snomed codes linking to ORPHA codes will be provided to assist in the survey.

Evaluation Working Group- The Evaluation Working Group, composed of project managers and coordinators from the ERNs, is working with the European Commission and evaluation bodies to review the five-year evaluation process. The group aims to improve the efficiency and relevance of the evaluation. A proposed redraft of measurable evaluation elements for the ERN and hospital evaluations was reviewed by the coordinators and ePAGs. The next ePAG&Coordinators meeting will take place on February 18th, focusing on patient involvement in evaluations and the recording of patient evaluation measures. The upcoming five-year evaluation will assess the period from 2022-2027 and will involve all ERNs, including those starting in 2022.

Work Package 4 Healthcare and CPMS – presented by Greta Ginski

CPMS 2.0 Migration - CPMS 2.0 is now live, and all users have been migrated to the new system. The new CPMS 2.0 system is more user-friendly and easier to work with. The previous CPMS is now in read-only mode. The patient data and file migration is still in progress, so users don't need to re-enter data, but previously entered cases aren't visible yet. Users should log into CPMS 2.0 to verify the settings are accurate and update their profile settings (profession, clinical focus, patient age group). The two-factor authentication method has changed. SMS authentication is no longer supported; users need the EU login app for authentication. [A guide](#) is available for setting up the app.

Recurring meeting schedule - The regular meetings, paused during January due to migration, will resume in February, with changes to the schedule for MTG2 and MTG7. MTG2 will have alternating meetings on Monday or Wednesday at 1:00 PM, and MTG7 has moved to Wednesday at 4:00 PM. Hospitals must obtain permission to use CPMS 2.0 by checking with their Data Protection Officer. A status update was requested from the MTG chairs regarding their hospital's approval status for using CPMS 2.0.

Trainings for CPMS 2.0 - Training sessions are available from DG SANTE, with an upcoming tour of the system for MTG chairs and webinars for Endo ERN members. Additional role-specific trainings are planned for March.

CPMS 2.0 and Ukraine - The process for handling Ukrainian patient cases is coordinated via the Ukrainian hub in Kiev. Ukrainian doctors will contact the hub, which evaluates the case and routes it to the appropriate ERN help desk for expert consultation.

Questions and Comments

Meeting minutes



Alberto pointed out that many Health Expert Panellists (HEPs) are also active in other ERNs, so it might be useful to ask colleagues in those ERNs about their approval status for using CPMS 2.0. He also suggested that not all centers may have a rare disease institutional office.

Work Package 5 Registries, data management and analysis - presented by Natasha Appelman-Dijkstra

Endo-ERN members activity – Natasha Appelman provided an update on the participation of Endo-ERN members in the registry, noting a 10% increase in the number of centres actively participating in e-REC over the past year. However, certain countries and centres are still unable to share data due to ethical committee restrictions. The target is to have 75% of centres active by 2027, which is on track. Natasha shared that while progress has been made, there is still work to do in terms of core registry participation. The target for 2027 is to have 50% of eligible centres participating. There has been an 11% increase in participation over the last year, primarily driven by condition-specific modules. The condition-specific modules are seen as particularly valuable as they make participation more practical for both clinicians and patients.

Study Groups and Working Groups - Several new working groups have been initiated, including a collaboration with ERN BOND, ERN EuroBloodNet and Endo-ERN on Langerhans cell histiocytosis (LCH), focusing on endocrine and bone complications. Another new module is being developed for CNO (Chronic Non-Bacterial Osteomyelitis) in collaboration with the ERNs for bone and rheumatological diseases. Both modules are expected to launch in spring 2025.

International Collaboration for Registry Connections - There is ongoing collaboration with BaMaRa, the French national registry, to improve communication between national and international registries. This project aims to allow clinicians to upload data once to BaMaRa, which will then feed into the various ERN registries. This requires careful planning around data safety measures and communication between developers and data managers.

Rebranding - The new logo for the joint registry (combining EuRRECa and EuRR-Bone) is being finalized. It will incorporate a globe and colours from both entities, reflecting their collaboration under a unified brand. Natasha mentioned the recent update to the registry website, which now includes a drop-down menu to help users find participating centres in their countries, making it easier to connect with others who have received ethical approval for participation.

Questions and Comments

Alberto asked about the capacity restrictions for new condition-specific modules, and whether any specific modules were already in the pipeline for prioritization. **Natasha** explained that the registry team can develop up to two new modules each year. If additional modules are proposed, they are reviewed by the coordination team and Steering Committee to determine priority. She also highlighted the possibility of expanding existing modules by adding new tabs for specific studies or additional data. She gave the example of a pregnancy-specific module currently under development. Natasha clarified that when a new condition-specific study is needed within an existing module, a new tab or section may be added to the module. For example, the pituitary module is large and might require additional data for new studies. However, if a completely new condition-specific module is needed, the process begins with forming a working group to develop it.

Meeting minutes



Work Package 6 Education and Training – presented by Violeta Iotova

Endorsements, Accreditation & Clinical Exchange - Violeta began by outlining the importance of Work Package 6, emphasizing that education and training are the foundation of most activities. She noted that everything done in the network ties into education, training, and dissemination. She briefly explained the goals and processes involved in endorsing events, accrediting webinars, and the clinical exchange program. The **endorsement of events** is progressing well, with more events being organized and endorsed, reflecting increased interest. There have already been 8 endorsed events in 2024 (up from 6 in the previous year). Future events are expected to follow this trend. Events must meet certain requirements, such as incorporating both adult and childhood perspectives, patient involvement, and addressing transitions. These guidelines are aimed at improving the quality and inclusivity of events. Violeta emphasized the importance of follow-up information from events, especially regarding participant numbers and the countries they represent. Violeta highlighted the **accreditation of webinars** as an area of growing interest. A total of 32 certificate requests were received for the 5 accredited webinars held so far in 2024. Violeta discussed the **clinical exchange program**, pointing out that while it has faced some challenges, it is progressing well. Only three networks have maintained clinical exchanges in their project presentations for the next period. However, many other networks expressed regret for not continuing this option.

Webinars - Violeta thanked everyone involved in organizing webinars, highlighting that 16 webinars were organized in 2024. The increasing registrant numbers demonstrate the growing popularity of these events. The webinars are well-organized, and their content is high-quality. She also pointed out that the accreditation process remains a key obstacle, especially if announcement for webinars are delayed.

Further initiatives - Violeta discussed the proposal for summer schools for rare diseases, which was initially suggested through the Erasmus+ program. However, it was concluded that Erasmus+ was not suitable for this initiative, and the team is now looking for alternative resources. Violeta emphasized that **patient involvement in educational activities** is still underrepresented and needs better organization. Patient representatives interested in organizing webinars are welcome to apply, and the network will accommodate these requests. Violeta mentioned the ongoing development of the ERN Academy, which aims to be a platform for all educational activities within the networks. However, she noted that the platform is still in its early stages and may not be very useful in its current form.

Questions and Comments:

Alberto asked about the advance notice required for accreditation, asking if three months would be sufficient. **Violeta** confirmed that at least three months' notice is required to allow for the administrative process, including payments.. She also suggested that earlier notice would be even better. **Alberto** mentioned that he presumed specific webinars with ESPE/ESE would still be organized several times a year, which was confirmed by Violeta. She explained that these events are more aligned with the network management package rather than the education and training package. **Alberto** suggested that patient representatives should be involved in webinars not only as participants but also as chairs. **Violeta** fully agreed, highlighting that patient comments at the beginning of webinars would bring the network closer to its goals.

Meeting minutes



Work Package 7 Clinical Practice Guidelines and CDST – presented by Charlotte Gaasterland

Charlotte Gaasterland introduced herself as a new member of the team, emphasizing her background in guideline methodology. She is based at the LUMC in the Department of Epidemiology and has previously worked as a guideline methodologist for the ERN-ITHACA. Charlotte shared her enthusiasm for contributing her experience to the team and mentioned that she is about to go on maternity leave but will still attend the upcoming meeting in Copenhagen.

3rd Endo-ERN CPG: Transition (MTG6) - Charlotte presented the ongoing development of the working group for the Endo ERN transition guideline, with chairs Nienke Biermasz and Evangelia Charmandari. The group will attend the upcoming Talent Conference in Rome to align with existing initiatives and build on available knowledge. Charlotte emphasized that the group will also ask all MTGs for suggestions on the next clinical practice guidelines, and she discussed the importance of refining the list of proposed topics by adding or removing items based on their relevance.

Next CPG topic - Charlotte proposed a procedure where MTGs are asked to suggest themes, followed by reviewing and prioritizing them based on feasibility and relevance, and creating a shortlist for decision-making by the Steering Committee. She noted that this procedure may involve requesting additional information about the literature on each topic. **Alberto** agreed with the procedure but suggested a slight update to the process for ensuring relevance of existing topics. He stressed the importance of allowing the Steering Committee to make the final decision on prioritization. **Olaf Dekkers** recommended a standardized format for submitting topics, which would include a brief explanation of why the topic is important, what existing literature exists, and whether other societies already have guidelines on the subject. This would facilitate easier decision-making for the Steering Committee.

Standard Operating Procedures - Charlotte G. discussed the creation of lay versions for clinical decision support tools and guidelines. She mentioned exploring examples from the ESE and suggested that feedback from the group could be valuable in shaping these versions.

Questions and Comments

Violeta Iotova suggested exploring the use of artificial intelligence tools, such as plain language summaries, which are increasingly used by journals to create simplified, accessible versions of research papers. She noted that these tools may offer a graphical representation, which could be beneficial for creating lay versions. **Petra Brüggmann** mentioned that the Patient Advocacy Group is working on lay versions and translations for MEN 1 guidelines. She suggested collaborating with other groups to avoid working in isolation and requested support from all involved parties. **Anna Nordenström** agreed that translations are challenging and suggested that AI could assist with this task, though emphasizing the need for quality validation. **Arlene Smyth** shared that the Turner Syndrome Support Society recently published patient-friendly versions of their guidelines. She provided [a link](#) to these versions and encouraged others to review them as an example. **Natasha Appelman-Dijkstra** mentioned that some patient associations have received funding to assist with translations and highlighted a checklist approach that was used in the past to guide patients in discussions with doctors about their diagnosis and long-term treatments. **Charlotte Gaasterland** agreed with the need for AI assistance in translations, while acknowledging that these tools must be validated. She expressed gratitude for the input from everyone and emphasized the importance of collaboration.

Meeting minutes



Work Package 8&9 Activities for Ukraine – presented by Charlotte van Beuzekom

A [specific page at the Endo-ERN website](#) has been launched to map the needs of Ukrainian healthcare providers, and a survey has been created to gather information on their areas of interest and needs. This data will help tailor communication efforts. Endo-ERN network representatives are encouraged to share the survey with their Ukrainian contacts. The survey will also be included in newsletters.

Other topics and important dates – presented by Charlotte van Beuzekom

Legal merger of Amsterdam University Medical Centers – It was formally announced that on January 1st, 2024, the Academic Medical Center (AMC) and VU Medical Center (VUMC) have merged and continued under the name Stichting Amsterdam UMC as a single legal entity. As a result thereof, Stichting Amsterdam UMC now acts as coordinating member of the Endo-ERN network, to which all SCAB members agreed. It was proposed and agreed that – if needed - the merger will be included as an agenda item for voting during the upcoming General Assembly. After the vote, the results could be submitted to the European Commission for their official records.

Meeting conclusion

Alberto Pereira and Olaf Hiort expressed gratitude for the productive and engaging steering committee meeting. They thanked everyone for their active participation and looked forward to seeing them again soon.

Action Items:

#	Description	Responsible	Target date	Task (T) Decisions (D) Information (I) <i>select what is appropriate</i>
1	Develop strategies to increase attendance at MTG meetings, including a survey to identify barriers to attendance	Endo-ERN team MTG chairs	ASAP	T
2	Finalize GA dinner arrangements and communicate updates	Endo-ERN team	March 2025	T
3	Continue drafting the joint paper on genetic testing and reporting,	Thomas Eggermann & Dirk Prawitt		T

Meeting minutes



	incorporating input from endocrinologists			
4	Clarify Endo-ERN's role in the Cross-ERN Working Group on pregnancy and genetic disorders and establish contact if necessary.	Thomas Eggermann & Dirk Prawitt		T
6	Evaluate potential risks related to VuMedi and revisit the topic	Aimee Casey		T
7	Enhance visibility of existing Endo-ERN channels	Aimee Casey		T
8	Follow-up on social media engagement	Aimee Casey		T
9	Reporting to the European commission portal (continuous monitoring 2024)	Endo-ERN members		T
10	Submit the Endo-ERN survey (continuous monitoring 2024)	Endo-ERN members	28.02.2025	T
11	Evaluate the performance and progress of the Evaluation working group	Emily White	11.02.2025	T
13	Check the updated CPMS meeting schedules on the website, and notify if further changes are needed.	MTG chairs		T
14	Provide updates on their hospital's permission to use CPMS 2.0 and report any difficulties in obtaining approval.	MTG chairs		T
15	Registries Logo Finalization and Implementation	WP5 chairs		
16	Clinical Exchange Program next call to be timely launched	WP6 chairs	01.06.2025	
17	Coordinate the process for next topic selection for clinical practice guidelines	WP7 chairs		
18	Provide a standardized format for submitting proposed topics	WP7 chairs		
19	Include the approval of the Amsterdam UMC merger in the voting agenda	Endo-ERN team		

Meeting minutes



	during the next General Assembly (if needed).			
--	---	--	--	--