

Endo-ERN position statement on interaction with Commercial Partners

The mission of the European Reference Network for Rare Endocrine Conditions (Endo-ERN) is to improve access to high-quality healthcare for patients with hormonal disorders and promote health through research, sharing of knowledge, through support of patients and patient organizations, and through medical and public education. Endo-ERN raises funds in order to execute this mission via publishing, application for external grants, hosting of events (offering promotional opportunities therein) and provision of educational courses and tools. In many instances this requires interaction with commercial partners, such as the pharmaceutical and medical device industry. The purpose of this document is to set out clear principles to be followed for such interaction to prevent any possibility of commercial influence on the content of Endo-ERN materials, to ensure fairness to all commercial partners, to avoid any confusion regarding the authorship of materials, and to protect the integrity of Endo-ERN and its officers.

Importantly, however, conditions such as orphan and rare endocrine conditions represent small marketing opportunities for pharmaceutical industry. Therefore, few companies if any claim registration and reimbursement of treatment so that there is few or no competition among commercial partners. Moreover, they necessarily develop collaboration with HCPs to include patients in trials and often continue supply of treatment after the study without knowing whether reimbursement will be obtained. In this context, potential conflicts of interest are limited. Instead, collaboration between HCP and industry is important for the quality of care and service to patients. The marketing status (registration, reimbursement and cost) is likely to vary among the network countries. The data obtained in the network will provide authorities with possible arguments towards reimbursement of new established treatment in countries where this is not the case. Also, the network existence and activities will contribute to the likelihood of involvement of more countries in studies with new promising treatment.

Policy for Interaction with Industry

The independence and integrity of the Endo-ERN is highly valued; healthcare professionals can use our tools, materials and participate at our events with the certain knowledge that they are free of commercial influence. In addition, patients can trust that the information provided by the Endo-ERN on rare endocrine conditions is independent of Industry messages and that our calls to government are those of the members and officers of the Endo-ERN. It is vitally important to protect this reputation from actual or perceived commercial bias. The policy of the Endo-ERN is to lead its own initiatives in support of its mission statement, seeking financial support where it is deemed necessary and appropriate. All commercial interactions are managed by the Endo-ERN Steering Committee reporting to the Endo-ERN Advisory Board which supervises and audits the implementation of this policy.

Annual Conflict of Interest 2025



In all of these interactions including seeking funding the basis of agreements made with the private sector will:

- Ensure that all Endo-ERN activities remain free of commercial influence
- Ensure that Endo-ERN scientific and educational materials remain clearly separated from the private sector's promotional and commercial activities.
- Ensure that the private sector's content/materials are clearly identified and there is no suggestion of endorsement by Endo-ERN.
- Ensure that, where funding is sought, all reasonable effort has been made to give equal opportunity to all potential commercial partners.
- Ensure that the agreement does not constitute a partnership with an individual commercial organization from the private sector.
- Ensure the best and long-term interests of the Endo-ERN, its representatives and its members are considered.
- Respect the national laws and guidelines of the country where the funded activity is considered to take place.

Endo-ERN will follow the above guiding principles in all interactions with sponsors and these principles will be the basis of any agreement with Industry.

In the interests of supporting the above position all members of Endo-ERN must sign an annual Conflict of Interest declaration in support of this Code of Practice.

This statement has been adapted from the Statement of the ERN Board of Member States on European Reference Networks (ERNs) & industry as published on their website

https://ec.europa.eu/health/sites/health/files/ern/docs/statement_industry_conflictinterest_en.pdf (last assessed 25 June 2019)

Herewith I declare that I have read and consent the Annual Conflict of Interest declaration form for the Endo-ERN.

In [place] _____, on [date] _____,

HCP _____

Signature _____ Name _____

Please tick below the appropriate box(es)

HCP representative ePAG patient representative

ESE or ESPE representative National Coordinator

MTG / WP chair

Representative of other European (paediatric) endocrine society