

The ERN EpiCARE is a **network of medical teams** belonging to distinct HCPs or Consortia with global expertise in all domains related to care and research for rare and complex epilepsies.

Criteria for membership application, following the corresponding calls released by the European Commission, are defined by the EpiCARE ExCo and become available on the website of the ERN.

Each medical team/HCP or Consortium member or affiliated partner, **is represented at the BNM by one** health care professional with established expertise in the field of rare epilepsies.

He/She:

- represents the medical team and paramedics at all activities and missions of EpiCARE and is responsible for the dissemination of all information to the individual members of the local staff.
- establishes a regular liaison with the Coordinator and the Management team.
- is expected to regularly encourage individual members of the medical and paramedics staff to directly contribute to WGs and missions of ERN EpiCARE and ePAG activities.
- is expected to regularly encourage local patient associations and patient advocates to liaise with ERN EpiCARE and the ePAG group.

The full members and affiliated partners of EpiCARE commit to be actively involved in:

EpiCARE Registry: Include all consenting patients with rare and complex epilepsies followed by the team into the EpiCARE Registry in a timely manner. The aim of the ERN EpiCARE Registry is to create and maintain a comprehensive database of all patients in the EU with rare and complex epilepsies.

- The registry uses a dedicated platform, REDCap, and will utilize a pseudonymization tool to protect patient confidentiality and comply with GDPR regulations.
- Enrichment of the EpiCARE Registry is a major indicator of activity for both full members and Affiliated Partners, regularly reported to DG SANTE Europe. Non-compliance with regular contributions to the EpiCARE Registry is incompatible with ERN membership.

CPMS and Case Discussions: Health professionals, working for an ERN EpiCARE HCP have an obligation to participate in case discussions and the Clinical Patient Management System (CPMS), to provide expertise at the request of other HCPs, members or partners of the ERN.

- Each medical team, full Member or Affiliated Partner, is expected to **present a minimum of one case per year** at the case discussions and requested to **attend and contribute to at least three sessions annually**.
- Full members of EpiCARE also have the obligation to **chair or co-chair at least one case discussion** (surgical or non-surgical) in each period of 2 years, with the understanding that if no cases are to be brought for discussion by other HCPs, they must provide a case for discussion.
- Affiliated Partners can chair Case Discussion sessions on a voluntary basis.
- Contribution to CPMS is subject to monitoring and evaluation.
- It is mandatory that whoever presents a case for discussion, independently of the platform used, must enter the case into CPMS and ensure that there is a record of the case discussion and the outcome.
- Case Discussions are also considered **a major educational tool**. It is therefore expected from the leaders of the medical teams of EpiCARE to encourage active participation from all members of the staff, particularly of early-career epileptologists.

Contribution to WGs: The EpiCARE network is financed by the European Commission through the ERN health program. To obtain financing for its coordination activities and core missions the network and its members are expected to comply with the work program that was submitted to and validated by the European Commission.

- The above implies regular participation of members of the staff to the WGs of the network.

- Consequently, it is required that **at least 2 members of the medical team for full member and at least one member for Affiliated Partners actively contribute on a regular basis to one or more of the core WGs and/or Task Forces of the network in accordance with their level of expertise.**
- Contribution to WGs is subject to monitoring and evaluation. The absence of the HCP (either by the HCP expert team lead or by a recognized Healthcare Provider expert substitute representative providing expertise) to 4 of the WG meetings in a row leads to an alert/warning of the HCP Lead. After the absence to 12 monthly meetings (= not participating for one year), the HCP team may be excluded from EpiCARE.

Contribution to Research & Publications: Leading a clinical research project and/or regular contribution to projects related to rare and complex epilepsies are major expectations from both full members and affiliated partners.

Contribution to research is one of the indicators of activity, subject to monitoring and evaluation.

During a 5-year programme, EpiCARE medical teams are requested to:

- participate in a minimum of one research project, preferably a project endorsed by the EpiCARE network.
- have published, based on their own data, at least two scientific publications (one for Affiliated Partners) in peer reviewed journals, and contributed to at least 2 other publications.

Open Access publications are to be privileged.

All members, independently of their status, have the obligation to **mention in all publications** related to rare and complex epilepsies, “*Member or Affiliated partner or Collaborating partner of the ERN EpiCARE*”. Whenever possible it is preferable to mention the above as part of the affiliation. If due to local regulations this is not authorized the statement must appear in the Acknowledgments part.

For publications produced as part of a collaborative project of the Network (involving several members and usually considered before launching by the EpiCARE Scientific Committee) the leading author is requested to also mention in the acknowledgments “*This work is generated within the European Reference Network on Rare and Complex Epilepsies (EpiCARE)*”.

For projects, Guidelines, trials or publications having received financial and/or technical support from the coordination budget, the leading author is requested to acknowledge it by including the statement: “*This study/project/publication/Guidelines/survey has been supported by the European Reference Network on Rare and Complex Epilepsies (EpiCARE), which is partly co-funded by the European Union. The support to produce this publication does not constitute endorsement of the contents by the ERN EpiCARE or by the Commission, which reflects the views only of the authors, unless otherwise stated*”.

It is under the responsibility of the coordinator of the medical team leading the publication to transmit to the MT the PubMed link and a PDF of the publication. Open Access publications are to be privileged and will be made available on the website and promoted through social media.

Collaboration with patient associations: All members of EpiCARE are engaged to develop close and regular collaborations with patient groups and associations at National and EU levels, to support their actions and to contribute to the dissemination of all relevant information.

- The ePAG leadership must be regularly updated on ongoing and newly established collaborations.
- Collaboration with ePAG and support to patient associations are subject to monitoring and evaluation.
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NB: The HCPs, members or affiliated partners of an ERN, are regularly, and without previous notification, subject to audits from independent agencies missioned by the European Commission.

The above-mentioned indicators of activity are evaluated for accuracy and compliance.

Responsibility for non-compliance lies with each HCP.

An audit may conclude that the label of ERN should be withdrawn.

Use of the EpiCARE logo and Communications issues

The respect of the Graphic charter of the ERN is mandatory, as well as the presence of the EpiCARE logo together with the EU logo with the mention “co-funded by” when EpiCARE is mentioned.

When mentioning EpiCARE on social media, members are expected to tag the corresponding profile: “Epicare ERN” on **Facebook**; @EpiCARE_ERN on **Twitter**; and EpiCARE - European Reference Network for Rare and Complex Epilepsies on **LinkedIn**.

The Communication Manager should be notified when EpiCARE is mentioned in a publication, during a workshop, congress, or conference. Active participation to the global communication of EpiCARE is part of the responsibilities of all members: retweeting or sharing posts on social media, linking EpiCARE’s website on your own, disseminating information is strongly recommended.

The website (<https://epi-care.eu>) is the main tool of EpiCARE communication and information should be regularly updated. All health professionals working for EpiCARE medical teams and ePAG representatives are expected to communicate to the Management Team all relevant information

Disclaimer:

“The European Commission support for the production of this publication does not constitute endorsement of the contents which reflects the views only of the authors, and the Commission cannot be held responsible for any use which may be made of the information contained therein.”



<https://epi-care.eu/>

https://ec.europa.eu/health/ern_en



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