TERMS OF REFERENCE V1.5

ERN EpiCARE Research Council

16th February 2022, Lyon

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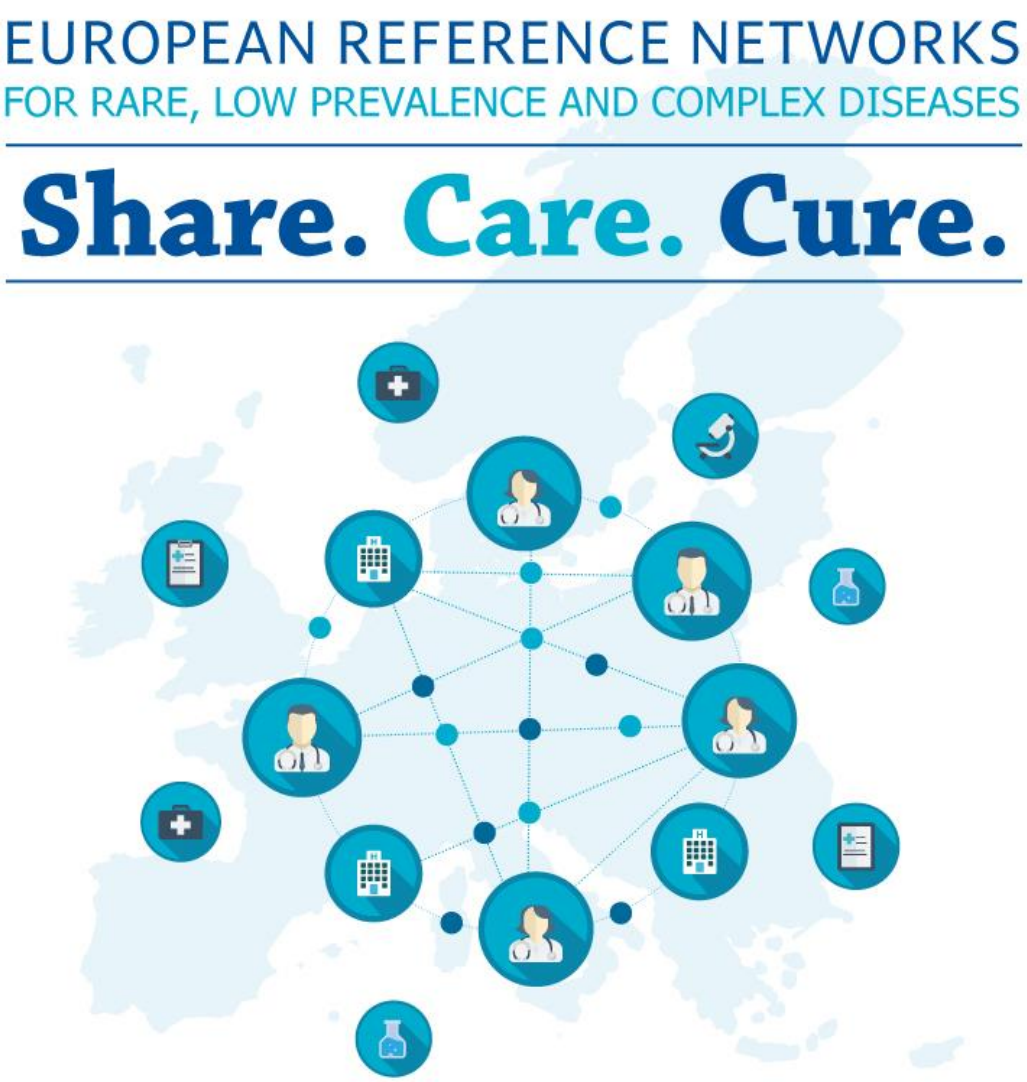

Publications Office

TERMS OF REFERENCE

1. Role/Purpose

The role of ERN EpiCAR Research Council is to support research conducted by EpiCARE members, with an aim to improve the quality and quantity of research within the network. This will include collaboration with other ERNs where applicable.

Specific goals include

- stimulating multi center studies,
- optimizing ethical, methodological, and statistical approaches
- to improve and optimize trial feasibility and reliability.

2. Term

These Terms of Reference are effective from 18th February 2022 and will be applicable until terminated by agreement of ERN EpiCARE Coordinator and the Research Council Committee.

3. Membership

1. EpiCARE coordinator
2. Four further members as nominated by the steering committee and validated by the General Assembly
3. ECET Chair
4. One representative of the “Clinical trials and targeted medical therapies” (WP7)
5. One registry representative
6.. Representation from joint ERN/European research Initiatives (e.g. EJPRD, HBP)
7. Two ePAG representatives
8. Research projects manager of EpiCARE
9. EpiCARE data manager
10. One representative ILAE

Chair & deputy chair to be appointed from within the group every four years

4. Roles and Responsibilities

To enhance, promote and develop research across the EpiCARE network through

- Circulation of funding opportunities
- Helping to develop projects across EpiCARE
- Evaluation/facilitation of multicenter projects across EpiCARE
- Development of long-term research strategies and priorities
- Connecting and liaising between Members of EpiCARE
- Tracking EpiCARE projects
- Liaising with the ePAG groups/patient associations to identify areas of patients’ need
- Collaboration with the European Collaboration for Epilepsy Trials (ECET)

- Dissemination of outcomes of call submissions, results, and publications

5. Designation of an ERN EpiCARE project

An EpiCARE project will be defined as a project that is led by at least one HCP member of EpiCARE and involves two or more members (national or international) and

- Has undergone quality check/peer review by two members of the Research Council or external body
- Has received approval by the Research Council

6. Engagement with EpiCARE council by researchers

I. If an application is to be submitted from EpiCARE HCP utilising the network, contact with the Research Council is recommended early in the process, at least 6 weeks prior to any funding application or deadline.
II. If advice is sought on study design/development, contact will be made to the Research Contacts manager with an abstract, that will be circulated to relevant EpiCARE members to ask for immediate reply as to who would be interested to lead coordination for advice. Direct liaison will then be undertaken with the lead of the project.
III. For any project requesting ePAG involvement, a request should come to the Research Council for liaison at least 6 weeks in advance of the deadline.
IV. Letters of support may be provided for projects led by non-EpiCARE centres planning to engage members of EpiCARE, or those led by centres outside Europe. For such letters to be provided, the chair of the Research Council should be approached at least 2 weeks In advance of deadline with a synopsis of the project
V. EpiCARE Research Council will commit to feedback to researchers in a timely manner prior to the deadlines

7. Confidentiality

For each new research project proposed by a member of EpiCARE, each EpiCARE member undertakes to take the necessary measures to preserve the confidentiality of this project with the same level of protection that it uses to protect/safeguard its own confidential information against any disclosure to a third party, which may under no circumstances be below a strict due diligence. Each EpiCARE member undertakes to not disclose such confidential information to other persons than their employees or agents who have a need to know for the purposes of the execution of the Terms of Reference and undertakes not to use them for other purposes. Each EpiCARE member also undertakes to obtain from their employees or persons under their responsibility, who will have to know all or part of this confidential information, the full adherence to a confidentiality agreement at least identical in extent and provisions to the present stipulations, and will assume, vis-à-vis the other party, full responsibility for any violation of these obligations.

The following information is not subject to the confidentiality mentioned above:

· Information which would be in the public domain on the date of their communication or that would be made available to the public by a third party, or
· Information which would be known to EpiCARE members out of the context of EpiCare, or
· Information which would be subsequently received from a third party with the right of disposal, or
· Information which would be developed by the personnel of an EpiCARE members receiving this information without it having been sent to them.
· Information which by its nature must be communicated and published

Proof that information falls within one of the categories is the responsibility of the receiving party.

Notwithstanding the above, each EpiCARE member may disclose the confidential information to a public authority pursuant to a decision of a competent court, provided (i) that all public or judicial protective measures applicable to this type of information are implemented, (ii) that the other party be informed in advance within a reasonable timeframe, and (iii) that the disclosing party takes all reasonable steps to limit the extent of this disclosure.

8. Meetings of EpiCARE Research Council

Meetings will initially be every three months with the possibility of increasing this frequency dependent upon the number of research calls and applications being processed by the research council.

If a specific research call is launched between planned meetings, then an ad hoc meeting can be arranged with the relevant parties.

9. Amendment, modification, and variation

These Terms of Reference may be amended, varied, or modified in writing after consultation and agreement by the members of the Research Council.

Disclaimer:

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

https://epi-care.eu/