

TERMS OF ENGAGEMENT V1.3

ERN EpiCARE Research Council and ePAG Associations

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1. Role/Purpose

The role of ERN EpiCARE 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. The collaboration with Patient Organisations is essential and this includes having representatives on the Research Council Committee as well as involvement of the appropriate Patient Organisations and ePAG representatives in the studies supported by the ERN EpiCARE and the Research Council.

2. Term

These Terms of Engagement are effective from **(insert start date)** and will be ongoing until terminated by agreement of ERN EpiCARE Coordinator and the Research Council Committee.

3. Membership

Within the research council committee there will be two representatives from ePAG EpiCARE who will be appointed from within the group every two years.

4. Level of Engagement

- Sitting on management committees
 - Ensuring the dissemination of the upcoming studies to the appropriate Patient Organisations
 - Inform the management committee of gaps in research from a patient perspective
 - Collaborating with ECET, the research council and industry
- Facilitate the input of patients' perspectives in study designs: e.g., disorder-specific symptoms/treatment goals/comorbidities
- Coordinate participation in the development of protocols as required e.g., PROMs
- Advice on participation leaflets
- Providing support to Patient Organisations participating in research for the first time in collaboration with members of the ERC

5. Responsibilities of Researchers re: ePAG engagement

- Early engagement of Patient Organisations/representatives
- Have a clear and concise plan of the level of engagement required by the Patient Organisation(s), as appropriate to each research study proposal.
- Ensure appropriate costing is included in applications for resources, travel, other expenses related to Patient Organisation involvement
- Be aware of any conflicts of interest
- Ensure that Patient Organisations are appropriately recognised in any publication/dissemination of results resulting from the study

6. Meetings

At least one of the two designated ePAG representatives will be present at each of the Research Council meetings. If neither representative is available, then the role should be temporarily allocated to an appropriate member of the ePAG trained and aware of their role/responsibilities within this meeting. The Research Council meetings will initially be every three months with the possibility of this increasing in 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 and it would be desirable for at least one ePAG representative to be present.

7. 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.

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