



COLLABORATIONS & PARTNERSHIPS IN RESEARCH

A GUIDE (INCLUDING PATIENT & PUBLIC INVOLVEMENT)



**Encephalitis
International**
The brain inflammation non-profit

www.encephalitis.info

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Encephalitis International (EI) has a vision of a world without death and disability from encephalitis. This drives forward our mission of rebuilding futures around the world by saving lives, accelerating awareness, and driving research.

EI prioritises the support of research on encephalitis, to improve understanding of disease mechanisms, drive faster diagnosis, improve treatment, and enhance understanding of the sequelae of encephalitis and quality of life for those recovering from the condition. We are the leading international encephalitis non-profit, and our extensive 30-year expertise and experience with those affected and the professionals supporting them gives us the opportunity to make a meaningful and unique contribution to research projects.

We cannot meet our vision alone. To ensure that global change happens we are committed to seeking mutually beneficial partnerships, driven by our vision and the voice and needs of those affected by encephalitis, which will help to drive both the mission of EI and that of the scientific, academic, medical and research teams we work with. Partnerships will be tailored to the needs of the researchers and the priorities of the project, helping to enhance the impact of the research funding, including liaising with policy makers or industry where appropriate to drive impact. We will work with scientific, research, medical and academic institutions, other non-profit organisations, and research funders around the world to develop exciting partnerships.

To achieve these goals, it is our research policy that the organisation and those within it are adequately remunerated for their time, expertise, involvement, and outputs resulting from their expertise and contributions. Therefore, our Board of Trustees and Scientific Advisory Panel ask that any researcher or study requiring our involvement request our costings and include them in their study/grant applications in a timely manner (i.e. providing sufficient time to allow for a complete appraisal of how we can help and to allow for submission of costings). An ideal timeframe for these activities are in the table below:

Patient and Public Involvement and Engagement (PPIE)	Timeframe to respond
Review of lay summary	1 month
Budget costings	1 month
PPIE proposal for funding applications	2 months
Participant recruitment support	1 month
Letters of support	2 weeks
Co-author on dissemination materials	1 month
Review dissemination materials	2 months
Co-author on journal articles	1 month

To discuss how we can help, please email:
research@encephalitis.info

El is able to provide extensive support to researchers and offer highly valuable contributions to research through our expertise in encephalitis and the patient experience. Examples of this include, but are not limited to:

Pre-application

- **Identifying research priorities**, including what is important to those affected by encephalitis and their caregivers, to highlight unmet needs in research.
- **Knowledge sharing**, sharing our wealth of experience from supporting previous and ongoing research studies, including randomised control trials (RCTs) to help inform application design.
- **Supporting market research** e.g. recruiting for patient or caregiver focus groups or interviews as preliminary research for studies or clinical trials.
- **Lived experiences/expertise** on the impact of encephalitis, including perspectives from both patients and their carers or family members.
- **Funding application review** to assess study feasibility and appropriateness e.g. to ensure that the study will be accessible for participants affected by encephalitis or their family members.
- **Letters of support** for research projects, leveraging our 30 years of expertise within the research area of encephalitis.
- **Promoting equality, diversity, and inclusion** including facilitating and advising on patient and public involvement and engagement (PPIE) in research, e.g. advising on the accessibility of patient involvement in the study, particularly patients with acquired brain injuries and their carers.
- **Co-author dissemination and impact statements**

Ongoing study/trial support

- **Facilitate and manage PPIE work**, e.g. facilitate and recruit for PPIE panels, steering committees, co-design/advise on recruitment material and study design.
- **Support recruitment** of participants to studies through our communication channels and supporters' database, including targeted mailouts to specified demographics within our professional and lay community.
- **Act as a 'temperature check'** throughout studies and attend and feed into trial management and steering groups, including providing feedback between participants/PPIE members and researchers.
- **Social media coverage** of studies and clinical trials e.g. on the EI website and sharing study details with our lay and professional supports through our social media platforms.
- **Standards mapping** of studies against current best practice.
- **Contribute to initial analysis of findings.**
- **Assist with interpretation of research findings** and implications for the patient community.

For more information on our research impact and involvement, please see our **Research Impact Report**

"We're delighted to report that our two remaining Caregiver focus groups sessions have been filled. Thank you so much for all of your efforts and assistance with getting the word out – it has clearly made a massive impact."

"In total we have four patients with autoimmune encephalitis that came through your assistance, which is great and has meant there has been good representation from this patient group, so thank you ever so much"

"Encephalitis International were excellent in helping recruit for our study. They were thorough and professional in seeking to understand the study design and ethics. They were consistently friendly and helpful in aiding the recruitment process. Finding relevant participants can be difficult when researching. I am very grateful for their help!"

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Dissemination facilitation and support

- **Co-author manuscripts** for publication.
- **Organise and run events**, e.g. patient and professional seminars, podcasts, and webinars, sharing knowledge of encephalitis and the experience of those affected by encephalitis.
- **Review and produce dissemination documents, including patient research summaries and journal publications**, ensuring the accessibility of these materials. Our experience with patients and lay people affected by encephalitis means that we are best positioned to provide dissemination support and produce dissemination materials for lay people, ensuring that research findings are accessible to all.
- **Provide internationally renowned dissemination platforms** e.g. the Encephalitis Conference (we also offer bursaries and free places at the Encephalitis Conference for low-to-middle income countries (LMIC) research teams).

Other research-related support opportunities

- **Personalised participant support** to help participants to access research.
- **Contribute to clinical, medical and researcher training**, e.g. support LMIC training courses or encephalitis training webinars.
- **Facilitate introductions** and the meeting of professionals and key opinion leaders by email and at our events such as our annual Encephalitis Conference.
- **Resource provision** for organisations and clinicians to help shape research knowledge.
- **Corporate collaboration**: EI has extensive experience working with industry, corporates, diagnostic and pharmaceutical partners, e.g. corporate sponsors for the Encephalitis Conference.
- **Providing translated resources** on encephalitis for patients and professionals.

Examples of our research involvement

- We have been involved in the first randomised control trial (RCT) in herpes simplex virus encephalitis (HSVE) in more than 40 years (**DexEnceph study**). We supported the **ENCEPHUK** study which looked into the outcomes and clinical predictors of encephalitis.
- During the COVID-19 pandemic, we were involved in studies on COVID-19: **COVID-CNS** and **COVID NeuroGlobal**.
- We have worked in multi-country research studies such as **Brain Infections Global (BIGlobal)**.
- In 2024 alone, we have supported PPIE in more than 15 research studies, currently including the **ExTINGUISH** and **CIELO** clinical trials.
- We have two upcoming PPIE publications detailing our PPIE work in the **BIGlobal** and **COVID-CNS** projects.

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