Encephalitis International
The brain inflammation non-profit

Research Strategy
2023-2026

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Our Vision

A world without death and disability from encephalitis

Our Mission

Rebuilding futures around the world by saving lives, accelerating awareness and driving research

Background to encephalitis research

We know that prompt diagnosis and treatment in all types of encephalitis is critically important, both in saving lives and limiting brain injury, as is rehabilitation for those suffering sequelae which is an area with limited evidence. We are also aware that facilities for diagnosis, treatment and rehabilitation vary greatly depending on location.

Priority Areas

Diagnosis

Increasingly we recognise the additional challenges of emerging infections, with specific geographical variation. Therefore, we are keen to support research which makes diagnosis quicker and more specific, particularly with relevance to these emerging and future challenges, and to disseminate new knowledge effectively. We are also interested in research that explores correlations between delays in diagnosis, treatment and outcome/levels of disability.

Treatment

Treatments are often limited in infectious aetiologies of encephalitis and we know from experience with COVID-19 that sometimes widely available treatments (for example dexamethasone), can be very effective in reducing symptoms, although we know little about the longer term benefits. We are interested in supporting research that explores the use of repurposing existing medications or the identification of targets for novel immunomodulatory agents in both infectious and autoimmune causes of encephalitis, along with their effects, not only during the acute stages but thereafter during rehabilitation. These aims will require the establishment of fuller registries and clinical trial platforms/networks in encephalitis to support specific studies and trials in the future.

Recovery and rehabilitation

There is currently very little good quality research on outcomes from encephalitis. Research into the recovery and rehabilitation of patients who have had encephalitis has been limited. We know little about patient recovery pathways, which forms of rehabilitation are more effective, what rehabilitation services are being offered to patients following encephalitis, what are the most effective interventions in maximising people's clinical outcomes and quality of life and when should rehabilitation begin.

In addition to cognitive and physical outcomes, research that explores behavioural, mental health and social outcomes are much needed. This should include-patient-derived input to inform outcome metrics.

Approaches to engagement in clinical research

Encephalitis International has a strong track record of supporting both clinical and academic trainees through doctoral fellowships including in collaboration with external professional partners, such as the Association of British Neurologists. Future doctoral fellowships for our organisation should continue to engage with professional bodies, and also with governmental research departments, such as the Medical Research Council and National Institute for Health Research.

Encephalitis International has enabled early career researchers, especially in resource-limited settings, through the Seed Funding Programme which has provided £59,914 over three years to six researchers in five countries (at August 2022). Ongoing Seed Funding grants awarded can be partnered with a high-income country partner to provide support and mentorship opportunities where there is need for added value.

Encephalitis International has always engaged clinical trainees across the spectrum, including those in neurology, psychiatry, psychology, intensive care, rehabilitation, pain, immunology, and sociology, amongst many others. Going forwards, we hope to develop partnerships with academic institutions supporting Academic Clinical Fellowships (ACF) for clinical trainees across the neuroscience spectrum. ACFs are traditionally funded by the NHS institution, with the programme integrated within the national structure and overseen by the Dean of the Integrated Clinical Academic Training Pathway. ACFs are given three months a year for three years, or one period of nine months to obtain research experience, with the expectation that they will be successful in acquiring subsequent independent funding leading to a PhD. Encephalitis International will approach the Deans in the hope of developing a matched funding scheme to expand the number of ACFs. These would provide the successful ACFs a springboard towards a clinical academic career in encephalitis.

In addition to engagment with acaemic organisations, professional societies and organisations that provide clinical services, our Scientific Advisors will make every effort to help able, enthusiastic young scientists and clinicians acquire their own external funding. Potential joint funding between us and the Medical Research Council has already been established as an exciting example of one form of external collaboration with substantial benefits to the trainee and our organisations aims.

International engagement

Recognising the global burden of encephalitis, as outlined most recently in the Global Impact Report, (www.encephalitis.info/global-impact-report) our Scientific Advisory Panel encourage engagement throughout the world. Beyond the engagement activities of Encephalitis International, such as World Encephalitis Day, we aim to support investigators conducting research which addresses our organisation's strategic objectives.

The Scientific Advisory Panel consider that, in addition to the Seed Funding Programme, these aims would be best served by short (three to six months) research exchanges between low-middle income countries (LMIC) and UK centres of excellence. We anticipate bidirectional educational benefit with exchanges that see LMICs coming to UK, and vice versa.

"Today's empirical treatment based on non-specific signs and symptoms is a "blind" treatment strategy contributing to mortality. Therefore, there is an urgent need to identify the etiological agents of encephalitis in LMIC."
(Dr Alain Kenfak, Cameroon)

"The seed funding was essential to start my career as a young scientist and made me able to dedicate myself to my main topic of interest – neurological manifestations of emergent and re-emergent viruses in encephalitis."
(Dr Aline Matos, Brazil)

How we fund research

What does Encephalitis International fund?

We will fund salary costs, consumables and travel costs but not overheads of any affiliated institutions. We will fund staff and students of academic institutions, in the UK and overseas. We will also fund research students at postgraduate level (i.e. MSc and PhD) who must have an undergraduate degree.

Every three years Encephalitis International will aim to fund:

- One Academic Clinical Fellowship (three years).
- One PhD student (three years).
- One Research Exchange project (one to three years).
- Six Seed funding (9-18 months).

We have no regional or institutional priorities, but if the research takes place outside UK it must meet UK standards of research ethics and scientific integrity. If the research involves using animals we only fund research conducted in the UK. Grants will be awarded through targeted funding research calls. Encephalitis International may also commission a specific researcher or research group to investigate a topic of interest. These applications will also be peer reviewed and discussed by our Scientific Advisory Panel Research Subcommittee who will advise the Chief Executive Officer.

How will Encephalitis International support researchers beyond the award of the grant?

Encephalitis International has gradually increased the active participation of patients and the public in their research projects and remains committed to continually improving public involvement in research.

Encephalitis International will endeavour to support the research community beyond the award of the grant by using its newsletters, blogs, podcasts, webinars, website, annual conference, and social media channels to provide clear information on all research projects run and supported by us. We are committed to disseminating the outcomes of our funded research in peer-reviewed journals, among the wider research community and our audience irrespective of the research outcomes. We are co-respondents on most encephalitis research applications as primary investigators and funders believe this ensures patient representation and benefit.

In addition, information about other research projects, which are not conducted or funded by us, will be displayed on our website, and sent to our members, inviting them to take part in the specific research projects. Statistical data gathered over the years by us can be made available to the researchers when appropriate ensuring our support of research beyond the grant offer. Annually, Encephalitis International hosts a Conference to help promote and assist research into encephalitis. www.encephalitis.info/conference

Using animals in research

Encephalitis International supports the position of the Association of Medical Research Charities (AMRC) on the issue of using animals in research. www.amrc.org.uk/position-statement-on-the-use-of-animals-in-research

We will only consider funding applications for research that tests on animals on a case-by-case basis, where there is evidence of no other model or known alternative, and only for studies being conducted in the UK.

Encephalitis International uses expert peer-review to ensure that we fund only high-quality research where the benefits to people and animal health outweigh any harms to animals. We fund research which complies with UK regulation and supporst the principle of the AMRC of 3Rs to refine, reduce and replace the use of animals in research.

Encephalitis International wishes to actively support research which is working toward eradicating the need for animal testing and will always choose to fund studies that do not test on animals over and above equivalent studies that do.

Partnerships

As already mentioned above, Encephalitis International will seek partnerships with other funding institutions, scientists and universities that have similar objectives and aims, maximising the value of the research expenditure. We are open to collaborations with the wider research environment. But especially we are looking to strengthen our relationships with our members, who are people affected by encephalitis, facilitating direct involvement in research projects and effective communication with the researchers. We have regular articles in our newsletters about the research we fund or support and invite the researchers to present their findings at our members' meetings.

Providing feedback & measuring impact

We will endeavour to provide feedback to all those involved in the research process: applicants, staff, peer-reviewers and user-group. We are committed to measuring the outcomes and impact of our research activities, and communicate the results to all those involved in the encephalitis community.

Challenges we face

Encephalitis International does not receive any statutory funds and we rely heavily on the generosity of our donors: individuals, organisations, corporations and trusts whose efforts are greatly appreciated. There are limited financial resources for research. Thus, we will have to select those proposals that make the greatest difference to people's life.

Governance and Review

Encephalitis International has restructured its governance of research by appointing a Research Subcommittee whose members are chosen from the Scientific Advisory Panel for a three-year period with the possibility of renewal of their appointment for a further three-year period. The members have clear roles and responsibilities and will include lay members. They provide advice and make recommendations to the Chief Executive regarding the applications received. Members of the Research Subcommittee manage the peer-review process ensuring transparency, accountability, fairness and impartiality when assessing the quality of the research.

Encephalitis International will review this research strategy and the priorities therein annually with advice from our Scientific Advisory Panel. The research strategy will receive a full strategic review every three years taking into consideration advice from the Scientific Advisory Panel on new developments in the research field that could have an impact on encephalitis, the organisation's strategic goals, and adhering to the best practice, advances and current developments of other funders and charities, including the AMRC.

The approved budget for 2023-2026 to achieve this Research Strategy is £940,662.

This current research strategy was compiled in August 2022 by the Research Subcommittee consisting of advisors from the organisation's Scientific Advisory Panel:

Emeritus Professor Angela Vincent (Chair)

Dr. Nicolas Davies
Professor Benedict Michael

Dr Thomas Pollak

Asst. Professor Omar Siddiqi

It will be reviewed in August 2025.

Encephalitis International Scientific Advisory Panel

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