PATIENT AND PUBLIC INVOLVEMENT AND ENGAGEMENT (PPIE) STRATEGY 2026–2029

Patients do not merely live with the outcomes of research — they should help shape it.

Encephalitis International
The brain inflammation non-profit
www.encephalitis.info

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Encephalitis International
The brain inflammation non-profit

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.

What is encephalitis?

Encephalitis is an inflammation of the brain. It is caused either by an infection invading the brain (infectious encephalitis) or through the immune system attacking the brain in error (post-infectious or autoimmune encephalitis).

The condition has a high mortality rate and can result in a range of sequelae. Encephalitis affects people of all ages, genders and ethnicities, wherever they live in the world. Global incidence data for encephalitis varies and is incomplete because of missing or inaccurate reporting systems; it is currently thought to be between 1 and 1.5 million people. In 2021, encephalitis was the fourth leading cause of neurological health loss in children under five and 13th across all age groups, and it is estimated that 100,000 people die annually from the condition.

As well as having the potential to be fatal, encephalitis often causes lifelong disability. This can include problems with memory and cognition, seizures, physical, emotional or behaviour changes. To learn more about the different causes of encephalitis and its effects, please visit our website: www.encephalitis.info. The effects of encephalitis can impact the patient, their family, their caregivers and their social network. These lived experiences of encephalitis therefore hold significant value for encephalitis research, to ensure that research is relevant and accessible to the patients to ensure that research is relevant and accessible to the patients researchers hope to help.

Defining key terms

What is Patient and Public Involvement and Engagement (PPIE)?

The National Institute for Health and Care Research (NIHR) defines PPIE as research being carried out 'with' or 'by' members of the public rather than 'to', 'about' or 'for' them. It is an active partnership between patients, caregivers and members of the public with researchers that influences and shapes research.

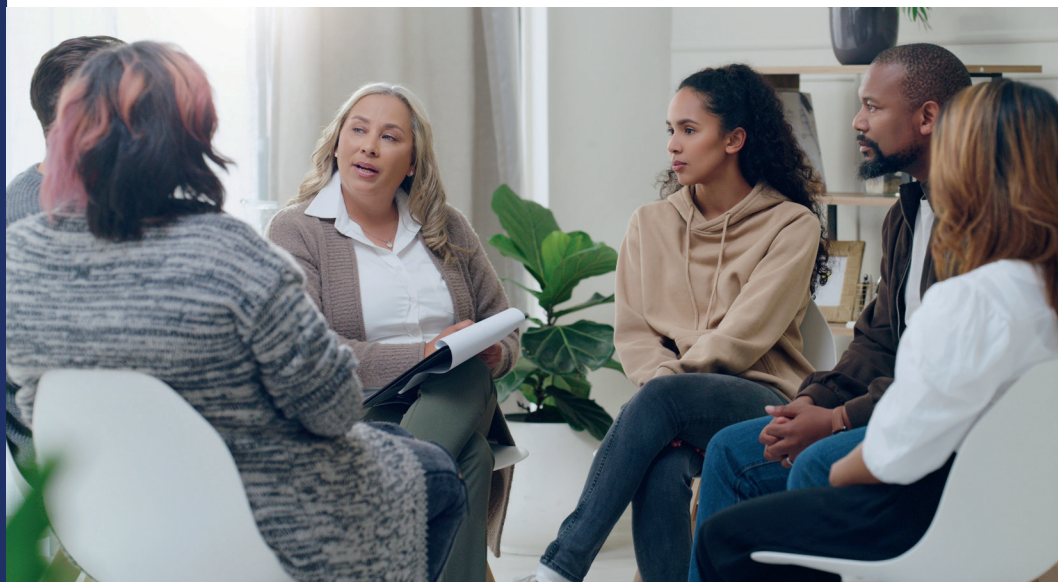
Key terms in this document	
Lay members	Members of the general public, often a member of our community who has personal experience of encephalitis. Lay members also include caregivers and family members of those affected.
Professionals	Members of our scientific, medical and academic communities. This can include for example clinicians, scientists, researchers, or allied professionals.
Stakeholders	Anyone who is invested in the research e.g. academics, clinicians, PPIE workers, service users, carers, patient advocates, community organisations or community leaders, funders.

> *"Thank you so much for organising the PPIE session. I wanted to say how much I appreciated and enjoyed it. Beyond finding it useful, I just felt really lucky to have the opportunity to meet and hear the stories from patients about their experiences. As a lab scientist I don't often get the chance to do this...the group went really well, and I think that you did a brilliant job organising it. I was very pleasantly surprised at the number of participants and those who wished to share their experiences with us."*
>
> Dr Claire Hetherington, University of Liverpool, 2025 (feedback received following an online Patient and Public group facilitated by EI).

Why is PPIE a priority for Encephalitis International (EI)?

Our PPIE work enables us to contribute our expertise as a patient organisation, alongside our in-depth understanding of the condition and people's lived experience, to researchers and their teams. At the same time, it strengthens our ongoing commitment to listening carefully and respectfully to those affected.

We are in a privileged position. We place the highest priority on listening directly to individuals impacted by encephalitis, and, having established the largest database of patients with encephalitis, we have also developed strong, trusted relationships with researchers, academics and clinicians.



PPIE is an increasingly vital element of any research project and associated funding proposals. There are several reasons why PPIE must be a priority in research:

It makes research more relevant to patients and caregivers

- Researchers and clinicians may prioritise scientific or clinical outcomes, which can differ from the priorities of patients and caregivers.
- A lack of patient involvement research may mean that research only measures outcomes that are important to academics, and misses patient-reported outcomes.

It improves study design and feasibility

- Patients and carers can identify practical barriers to research, including accessibility issues and emotional burden.
- PPIE is increasingly seen as an indication of high-quality research from major research funders.
- PPI encourages researchers to include Encephalitis International and our community from the beginning of their research projects.

It helps to strengthen ethics and trust between participants and researchers

- Patients are treated less as passive subjects and have more of a collaborative role.
- Meaningful engagement with patients can increase trust, transparency and accountability.
- PPIE promotes democracy in research (listening to the public).
- Involving patient organisations such as EI can help share current challenges faced by researchers with patients to facilitate a stronger and shared understanding.

It improves dissemination and impact

- Patients and patient organisations can help communicate findings to the general public and policy makers to demonstrate the impact that research can have on patient care.

Helps to increase diversity and reduce health inequality

- A diverse patient representation can increase involvement and engagement from groups of people that might otherwise be hesitant to participate in or be excluded from research.
- Hearing from a diverse group of people in research helps to maintain the relevance of global studies.

With encephalitis research, the voices and experiences of patients and caregivers provide vital information and details often missing from the research landscape. Meaningfully involving patients and caregivers helps to demonstrate the everyday real impact of encephalitis on their lives.

> *"Your collaboration with us has been excellent. You were consistently prompt in your responses and in carrying out the outreach as needed, effectively engaging individuals throughout the process. Your proactive suggestions during the setup phase, particularly around incentives, were very insightful and truly appreciated. We also valued how open you were about your strategy from the outset, which allowed us to align early on and jointly agree on the best approach. This study would not have been successful without your participation; we sincerely appreciate all the work that you do."*
>
> Industry PPIE lead feedback, following EI recruitment support for international clinical trial market research, 2026

> *"absolutely thank you, your work is invaluable truly... I really appreciate how much you help."*
>
> PPIE volunteer, female, affected by NMDAR encephalitis, 2026

Who is involved in PPIE?

Our PPIE work involves those with lived experience of encephalitis, their families and their caregivers. We also work with volunteers, researchers, clinicians and academics worldwide. The professionals we work with span students, early career researchers, senior and global experts in the field of encephalitis. Our relationships expand globally as we continue to support the development of medical and social provision for those affected by encephalitis, especially in low- and middle-income countries (LMIC).

Why might members of our community wish to get involved in PPIE?

- To reduce the divide between researchers, lay people and those with lived experience.
- To be heard and understood.
- To give back and to reduce the impact of encephalitis on others in the future.
- To access new diagnostics, treatments and vaccines in clinical trials.
- To improve rehabilitation services post-hospital discharge.
- To champion their own voice or those of their caregivers and highlight the value in patient-reported outcome measures.

> *"The SAPIENCE project cooperates closely with national and international patient organizations, including Encephalitis International... this collaboration enables access to a larger and internationally diverse patient sample, including patients from low- and middle-income countries (LMICs). This not only increases the validity and generalizability of the results but also strengthens the impact of the active patient involvement, as the perspectives of diverse groups of affected individuals are included and the findings can support globally relevant practical recommendations."*
>
> SAPIENCE research team

How we fund PPIE work

As a non-profit, EI relies on external funding, such as trusts and foundations, corporate funding, fundraising and donations from our members, to be able to carry out our vital work and provide our unique support to patients and their caregivers. We have been able to form strong partnerships with academic institutions and research groups to enable us to offer our support and expertise in PPIE. In return we do ask that our time, expertise and resources are adequately costed into applications and our time and resources compensated as per other costings of research studies.

Partnerships are central to EI being able to support encephalitis research and ultimately see improvements in the lives of those affected by encephalitis. Our Collaborations & Partnerships in Research document (see *Related documents and publications* below) outlines the way in which such partnerships can be formed. Our support is adapted to suit the requirements of the study and the research team.

30 years of PPIE and research activities

EI has over 30 years of experience carrying out PPIE activities and funding and supporting projects to drive forward encephalitis research and improve patient outcomes. Below is a timeline of activities and key achievements giving an overview of our work and achievements:

We co-funded (supported by the Big Lottery Fund) the first study to investigate the after-effects and social consequences of encephalitis.

We have funded 13 seed projects, many in LMIC.

We established the global, annual go-to Encephalitis Conference. In 2025, we welcomed over 500 delegates from over 80 countries with representatives from across the industry.

We have provided 15 travel bursaries to our Encephalitis Conference attendees in LMICs.

We were involved in the first randomised control trial (RCT) in herpes simplex virus encephalitis (HSVE) in more than 40 years (DexEnceph study).

During the COVID-19 pandemic, we were involved in significant studies on COVID-19: www.encephalitis.info/news/covid-cns-blog/

We have over 3200+ professional members.

At the time of writing, our CEO has authored on 69 PubMed indexed publications (alongside over 150 other publications and book chapters) as well as publishing L*ife After Encephalitis: a narrative approach* (Easton, 2016) .

We have 28 members on our scientific advisory panel, which includes highly regarded experts from neurological, neuropsychological, neuropsychiatric, neuro-immunological, paediatric and other relevant fields.

In 2021, we published our *Global Impact Report (Encephalitis: an in-depth review and gap analysis of key variables affecting global disease burden),* which directly led to the development of a WHO Technical Brief on Encephalitis, supported by EI.

We currently have over 530 people affected, their family members and caregivers on our Research Panel across 46 countries - our first point of contact when recruiting for PPIE activities and 13,000 lived experience community members on our mailing list.

Alongside these achievements, we continue to organise masterclass webinars for patients and professionals and support patient participation and recruitment for research projects. We have ambitious plans for the future, which are outlined in our *Objectives* below. They build on our past achievements to ensure that we can continue to improve the lives of those affected by encephalitis.

> *Dear Team at Encephalitis International,*
>
> *I am writing to express my sincere gratitude for the incredibly detailed and thoughtful feedback you provided on the O-MEG-A-MIND study materials. The insights gathered from your network of parents and young people have been brilliant and will be instrumental in shaping the future of this research. We are so grateful for the enthusiasm for research, time taken and thoughtful insights provided.*
>
> *This collaborative process has highlighted the importance of positioning parents, children and young people as partners, and the honesty of the families involved—including those who felt the study was too big a commitment—has given us a much deeper understanding of the daily challenges they face.*
>
> *Thank you again for your incredible support and for connecting us with such a dedicated community. This feedback will ensure the O-MEG-A-MIND study is as family-friendly and impactful as possible.*
>
> Prof Sukhvir Wright (Aston University)

Objectives

Objective 1: Strive for Encephalitis International to become the 'go-to' organisation for PPIE in encephalitis research.	
Key results	• 10% annual increase in research partnerships (with academic and research institutions). • 10% increase in peer-reviewed publications naming EI as a contributor to research projects. • 10% increase of partnerships with LMIC research and academic institutions. • Maintain membership with Association of Medical Research Charities (AMRC), which supports, represents and raises the profile of medical research charities in the UK.
Example initiatives	• Seek annual increase in professional membership. • Continue to provide seed funding grants and conference bursaries to researchers in LMICs to increase EI's reach within the field of research. • Develop PPIE resources to guide and support our professional community to engage with PPIE.

Objective 2: Motivate the encephalitis community to take part in and engage with research studies and patient involvement activities.	
Key results	• 20% annual increase in the EI lived experience Research Panel membership. • 20% annual increase of participants in research from LMICs.
Example initiatives	• Continue seeking to support researchers to consider the diversity and inclusion of research opportunities. • Increase engagement with research and PPIE-related assets, including mailings and advertising materials. • Diversify EI lay membership. • Assess the success of mailings to people on the Research Panel, including open rates.

Objective 3: Engage funders to financially support PPIE work carried out at EI.	
Key results	• 10% increase of research studies costing EI PPIE support into project budgets over the next three years. • 10% increase of research funding provided to EI, outside of researchers' funding.
Example initiatives	• Increase and diversify the range of funding sources for research. • Widely disseminate the impact that EI has had on research studies through PPIE support. • Collect feedback from professionals for use in funding applications as a means to demonstrate the value EI brings to a research project.

Challenges

EI recognises that there are significant challenges that currently limit the degree to which PPIE can be carried out within research projects. These challenges centre around:

- **Lack of consistent awareness and understanding of PPIE, for both lay people and researchers,** including what PPIE is and the value it can hold in research.
- **Barriers to engagement with PPIE** including unequal access to Wi-Fi and socio-economic priorities that compete with engaging with PPIE.
- **Limited finances for PPIE,** often due to a lack of funding for PPIE in funding applications.
- **Lack of PPIE diversity;** limited access to communities can make it difficult to engage with people who are not already part of our community e.g. due to cultural barriers, health stigma or further challenges as a result of language barriers.

With continued collaboration between EI, researchers and patients and their caregivers, we foresee PPIE being further integrated into encephalitis research.

Measuring impact, governance and review

We recognise the importance of being accountable for the way in which we conduct PPIE work and the way in which we are involved in research.

Leadership and accountability for PPIE activities is allocated as such:

- Overall leadership of PPIE activities and publications - CEO.
- Day-to-day and ongoing management of PPIE activities, Patient and Public Involvement Manager.

Our research work is also governed by and thus adheres to organisational policies of: Data Protection, Privacy Notice, Safeguarding Policy.

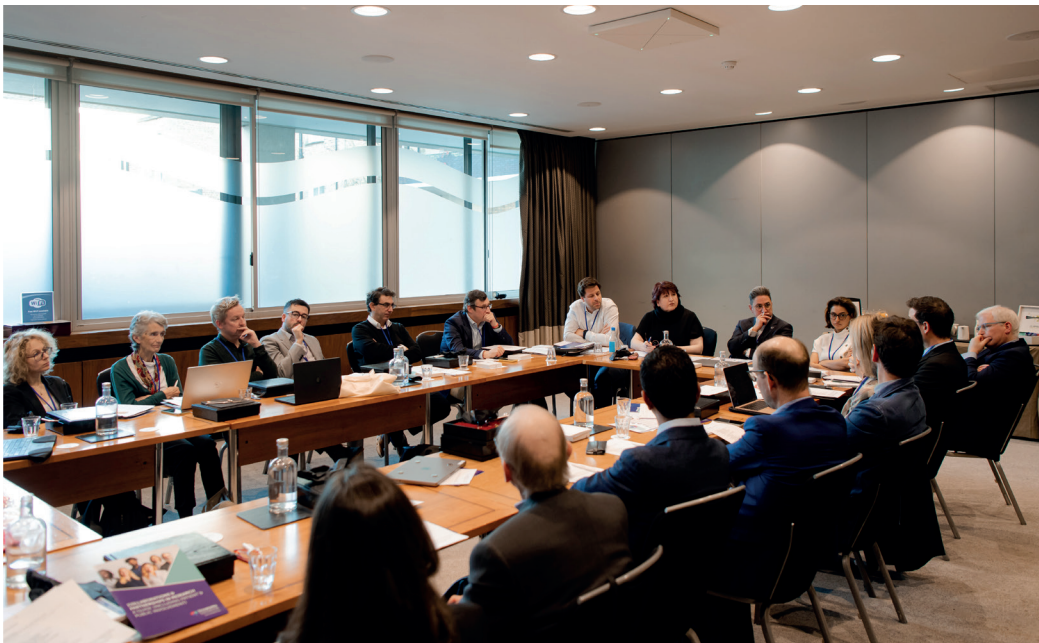
As a member of the Association of Medical Research Charities (AMRC), EI follows AMRC guidance and policy on the use of animals in research, hence, the research projects that we engage with are also considered against this policy.

Clear feedback mechanisms will help to ensure transparency and public trust, visible accountability for PPIE in EI and clear and deliberate opportunities for public feedback. Importantly, it also provides further opportunity to listen to the patient voice on PPIE matters and allows for our organisational processes around research to be reviewed regularly.

We aim to encourage and support researchers to collect and provide feedback on the PPIE support that we provide.

Examples of how we gather feedback includes:

- Providing a diverse range of opportunities for patient feedback, for example, through polls, verbal feedback or surveys.
- Liaising between researchers and patients to ensure that researchers share the contributions and impact that patients have had on research.



Measuring the outcomes of our PPIE work helps us to communicate the impact of our work more clearly, as well as being able to use this evidence to further support the inclusion of PPIE in research.

Examples of how we measure PPIE impact includes:

- Using measurable goals for EI's PPIE work to record progress, using the Objectives and Key Results (OKR) goal-setting framework to drive focus, engagement and accountability.
- Encouraging researchers to consider how they have involved patients and the public, beyond patient recruitment.
- Communicating research impact and outcomes through the publication of our *Research Impact Report*, as well as through our webpages and other resources, such as blogs and podcasts.

Strategy summary

Encephalitis International has over 30 years of expertise supporting encephalitis research. This document has outlined our key objectives for PPIE development within our global organisation for 2026–2029.

PPIE is a growing area of research. Although it faces challenges that should be recognised and addressed, there is an opportunity to expand on our PPIE work which ultimately helps us achieve our vision of a world without death and disability from encephalitis. The encephalitis research community values the support that we have been able to provide, and we feel confident to be able to build upon and expand on this success.

We have identified the following key objectives to work towards achieving this:

STRIVE to become the 'go-to' organisation for PPIE in encephalitis research.

MOTIVATE the encephalitis community to take part in encephalitis research.

ENGAGE funders for our PPIE work.

We envisage that strategies will not only help to overcome the current challenges facing PPIE stakeholders but also be adaptable to the changes that this field will inevitably face in the future. By keeping patients at the heart of research through PPIE, we acknowledge the power of the patient voice and recognise patients and their caregivers as experts by experience.

Related documents and publications

The following documents can be found on the Encephalitis International website: www.encephalitis.info/

- **Collaborations & Partnerships In Research A Guide (Including Patient and Public Involvement)**
- **Encephalitis: Global Threats, Trends and Public Health Implications: A Technical Brief**
- **EI Research Strategy**
- **Global Impact Report**
- **EI Research Impact Report**

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