



FREQUENTLY ASKED QUESTIONS

What is a James Lind Alliance Priority Setting Partnership?

Established in 2004, the [James Lind Alliance \(JLA\)](#) is a non-profit initiative that provides a platform for the research priorities of patients, carers, and clinicians. They facilitate Priority Setting Partnerships (PSPs), which strive to:

- **Unite** patients, families, friends, carers and clinicians, by encouraging them to work together to identify unanswered research priorities – whether they are questions, interests or concerns about the causes, symptoms, treatments, diagnosis or impact of the condition – that, if answered, would reduce risk and improve their lives, and the lives of others affected by the healthcare concern in question, driving positive change
- **Collate** research priorities from all patients, carers and clinicians affected by the healthcare area in question
- **Publicise** the methods and results of the PSP to ensure complete transparency of the process.
- **Communicate** the results of the PSP with researchers, research funders, pharmaceutical companies, and other organisations to drive change

Through the JLA's reliable and rigorous process, the PSP results in a list of Top 10 unanswered research priorities. These are the most important uncertainties for the condition in question, as identified by those affected – either personally or professionally.

While the JLA facilitates these partnerships, the funding and organising are done by the PSP itself – which, in the case of the UK Epilepsy PSP, is coordinated and funded by Epilepsy Research UK.

To find more about the James Lind Alliance watch “An Introduction to the James Lind Alliance Priority Setting Partnerships” [here](#).

You can read about the broad range of JLA PSPs [here](#).

What is the UK Epilepsy Priority Setting Partnership?

The UK Epilepsy Priority Setting Partnership (PSP) is a national survey collating the views of the entire UK epilepsy community. We are seeking the input of all those working in epilepsy and all those affected by epilepsy including families, friends and carers. This is a unique opportunity for you to have your say in driving and shaping the future of research.

Have you ever wondered why research on an area of epilepsy that affects you has not been a priority? Have you ever wondered how you could draw attention to this? Have you ever wondered how your opinion could make a difference?

If any of the above has occurred to you (or even if it hasn't) then we want to hear from you. This national survey will collate the views of the entire epilepsy community – healthcare professionals, epilepsy charities, people affected by epilepsy, their families, friends and carers, and those bereaved by epilepsy. The

information gathered will help identify and prioritise areas of healthcare that can be improved by research and result in higher quality studies and increased investment.

The rigorous JLA PSP process reveals the Top 10 research questions for a particular condition, in our case epilepsy. The responses to the survey will highlight areas that are important to those affected by the condition in question, but it does not require individuals to come up with specific research questions.

The Top 10 may include broader areas of interest, where patients, carers and health professionals have agreed a need for research exists. Researchers and funders can then prioritise the most meaningful research for those who need it most.

The scope of the UK Epilepsy PSP will be defined by the health research priorities of people affected by epilepsy:

- **Causes:** to include prevention and co-morbidities
- **Diagnosis:** to include access to health services
- **Treatments:** to include anti-epileptic drugs, surgery, treatment side effects, co-morbidities (including those as a consequence of treatment), and epilepsy that does not respond to treatment
- **Clinical management of epilepsy:** to include risk of epilepsy-related deaths (including Sudden Unexpected Death in Epilepsy – SUDEP), service access, neurodevelopment, co-morbidities, social and psychological factors, and emerging areas such as epilepsy in older people
- **Dissemination of research breakthroughs to influence epilepsy care, practice and policy:** to include medical education and pathways to improve care

Epilepsy Research UK has committed the funds and resources to undertake this programme and recruit a Steering Group, which is comprised of stakeholders from leading, UK-wide epilepsy charities, clinicians from the four nations and people living with, and affected by, epilepsy.

Has a JLA Priority Setting Partnership for epilepsy been previously performed?

The last UK JLA priority setting exercise in this area was undertaken over 12 years ago by Dr Rhys Thomas, Consultant Neurologist and Neuroscientist, with the Wales Epilepsy Research Network. Dr Thomas will lead the Steering Group for this 2021 initiative.

“A new study is long overdue, the outcomes of which would benefit people living with epilepsy by providing the evidence of need and priorities to support research development. We know that PSPs can lead to increased funding from NIHR, which is so urgently needed for epilepsy, given the shocking inequalities in research funding.” - Dr Rhys Thomas

Recently, the Top 10 priorities of [the Canadian Epilepsy PSP](#) were published, and we will utilise the learnings from the Canadian Epilepsy PSP to accelerate and inform our own efforts.

Why is this the most important survey you will ever complete?

In October 2020, Epilepsy Research UK released a report highlighting the alarming inequalities in research funding for one of the most prevalent, serious neurological conditions. The stark figures in the [#ALifeInterrupted – Shaping the Future of Research into Epilepsy](#) report demonstrate that epilepsy research funding is disproportionately less than other neurological conditions.

Research into epilepsy is chronically underfunded, receiving only 7% of total neurological research funding and 0.3% of the £4.8 billion spent on health-related research in the UK. To combat this inequality, we need your help.

If we want to drive more investment in research into epilepsy, we must do as other health conditions have done, and provide clearly evidenced priorities and a focus that will affect change. Your priorities will enable us to:

- Carry out clinical research that matters most to people affected by epilepsy
- Fund research based on evidenced priorities
- Drive collaborations with associated condition charities
- Generate the evidence needed to influence government and institutional funders to give us our fair share

It is time for change. The inequalities in research funding of epilepsy have meant progress has been slow. If we don't act now, innovations in the diagnosis and treatment of epilepsy will continue to lag behind. **And that is why this is the most important survey you'll ever complete.**

Who should participate in the survey?

We want to hear from:

- People with epilepsy
- Parents of someone with epilepsy
- Carers, family members and friends of someone with epilepsy
- Bereaved carers, family members and friends of someone who had epilepsy
- Healthcare professionals consulting, treating, and caring for people with epilepsy
- Organisations representing people affected by epilepsy

Historically, health research has been driven by pharmaceutical companies and researchers, whose priorities often do not reflect those of people affected by epilepsy. For this reason, the JLA excludes the priorities of pharmaceutical companies and researchers.

What do you mean by 'research priority'?

A research priority is a question, interest or concern you have about the causes, symptoms, treatments, diagnosis or impact of epilepsy that is 1) not currently answered by research, but 2) if addressed and fully answered by research, would be valuable, reduce risk and have a positive impact on your life and the lives of other people affected epilepsy.

What will happen to my information?

By participating in the survey, you are agreeing to have your priorities included in the UK Epilepsy Priority Setting Partnership. All submissions will be anonymous and any personal information will be kept confidential. Your research priorities will be analysed and published, but not linked to you or your organisation. You can read our Privacy Policy [here](#).

To stay in touch and updated with the Priority Setting Partnership and participate in the second stage of the process – the interim survey, where the long list of unanswered priorities are shortlisted – please go to the 'What happens next?' page and enter your email address.

Who is involved in the UK Epilepsy PSP?

PSP Team

The PSP Team comprises of:

- JLA Advisor – Katherine Cowan (Senior Advisor, James Lind Alliance)
- PSP Leader – Rhys Thomas (Neurologist and Neuroscientist, Newcastle University)
- PSP Sponsor – Maxine Smeaton (Chief Executive, Epilepsy Research UK)
- PSP Coordinator – Anna Norton (Research & Involvement Officer, Epilepsy Research UK)

Steering Group

Epilepsy Research UK has brought together a steering committee of 22 individuals, including clinicians from across the UK, key epilepsy charities and people with a personal connection to epilepsy. The committee supervises the PSP, convening at regular intervals along the JLA PSP timeline to guide the partnership using their unique knowledge and backgrounds (see PSP timeline [here](#)). You can read more about the members of the UK Epilepsy PSP Steering Group [here](#).

Partner Organisations

Once the survey is live, we will be contacting all the major patient groups covering associated conditions and rare epilepsies. We want to reach as many people as possible, from every walk of life, and every corner of the country to ensure we receive representative responses from the entire epilepsy community. Several organisations have partnered with the UK Epilepsy PSP to help promote the priorities identified by this partnership to the individuals they represent, researchers they fund, industry they know and the wider public.

People affected by epilepsy: people with epilepsy, their parents, families, friends, carers, and clinicians, and those bereaved by epilepsy.

The involvement of people affected by epilepsy is essential for the success of the UK Epilepsy PSP. To identify the Top 10 research priorities for epilepsy, we are relying on responses from across the UK and from all members of the epilepsy community - including clinicians, carers, organisations representing the interests of people affected by epilepsy, people with epilepsy, as well as their parents, families, friends, and those bereaved by epilepsy. We need your help to drive change and make a positive impact on the lives of people affected by epilepsy.