EPILEPSY RESEARCH INSTITUTE UK

ESTABLISHING AN EPILEPSY RESEARCH NETWORK: GOOD PRACTICE RECOMMENDATIONS

The Epilepsy Research Institute's mission is to radically advance research into the causes, prevention and treatment of epilepsy and its associated conditions.

One of our priority areas of work is to build capacity in epilepsy research.

In 2023, we asked the epilepsy research community about their experience as researchers in this area, and how the Institute could help. Support for collaborations between basic scientists and clinicians, and opportunities to develop epilepsy-specific research groups in areas where they are lacking were identified. Our advisory group of academics and clinicians also highlighted the value of local and regional epilepsy networks and supported efforts to help people build networks where they are needed.

In April 2025, we brought together people with experience of running successful epilepsy networks and those who would like to start a network. The aim was to share experience and identify key features of a successful and long-lived epilepsy research network. Discussions from this meeting have informed the development of this document.

Questions to ask when planning a network

1. What is your network's purpose?

What will your network be for? Will it be to build collaborations between researchers, or between basic and clinical researchers? Or do you want to support junior researchers' development? Or cascade excellent clinical practice? Is the network focused on a particular area of epilepsy or will it encompass all types? What is the benefit for network members?

Recommendation 1 Formulate a clear shared vision for the network, setting out what the network will look like or achieve when it is fully established. Schedule regular review and refinement.

> When a network first starts, it needs to have an idea of what it wants to achieve and how it is going to do that. Have a vision and ensure it's shared by colleagues
>
> Sameer Zuberi, Scottish Paediatric Epilepsy Managed Clinical Network

2. Who do you want to include?

Deciding on the purpose of the network will identify the network membership: clinicians, epilepsy specialist nurses, basic science researchers, students, postdocs, senior academics. Who else might be interested: pathologists, biochemists, statisticians, psychologists, neurophysiologists, general practitioners, public health professionals? How could you map out the skills and interests of your proposed network to help guide your programme?

As a biochemist working on rare epilepsies, it was difficult to find an epilepsy research network to join. Sometimes our scientific 'language' can be a barrier, but it can be overcome

David Sauer, Oxford

People affected by epilepsy The insight and experience of people affected by epilepsy is invaluable when discussing research. Some people may want to become full network members. Give thought to how to make best use of people's time and support non-specialists' involvement.

The Epilepsy Research Institute has a Shape Network of people affected by epilepsy and can advertise opportunities. There is also guidance about involving people in research and funding applications here:

www.nihr.ac.uk/research-funding/application-support/working-with-people-and-communities
www.hra.nhs.uk/planning-and-improving-research/best-practice/public-involvement/

Recommendation 2 Identify the groups of people needed to deliver the network's vision and set out the envisaged benefit(s) when inviting people to join. Consider geographical reach and local/regional expertise.

Other relationships Are there other organisations or networks that you could usefully buddy with, to share costs and expand your meeting agenda? Think about related networks where there may be overlapping research areas (for example, autism, dementia, sleep, mental health).

We held an annual 2-day meeting; on day 2, we joined with a neurostimulation network to widen collaborative opportunities

Peter Taylor, North East Epilepsy Network

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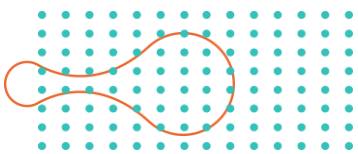
3. How will your network endure?

A successful network should be sustainable, and an approach to maintain the network and keep it fresh should be planned in from the start.



Administrative support is important as considerable time will be needed to book venues, advertise meetings, book speakers and organise papers. Some researchers build this administration time into funding applications, reflecting the value of the network meetings to their research activity. Others receive admin support from other networks or third-sector organisations.

Recommendation 3 Plan sufficient administration support for the network and set out how this will be supported financially.

Leadership/governance While a network may be started through one person's enthusiasm and drive, its longevity and success will depend on making everyone feel part of the network. A good idea is to rotate the chair/leadership roles every couple of years, to bring in new ideas and energy.

Recommendation 4 Set out how long the network chair/leadership team will hold the role(s) and the arrangements for identifying the next person or group. Consider the different interests of the network and how these will be represented in the decision-making roles.

To ensure ongoing inclusion and support throughout the network, it's vital for the lead academic or clinician to have a fixed term, with leadership rotating in terms of job role/area of interest and geographical base

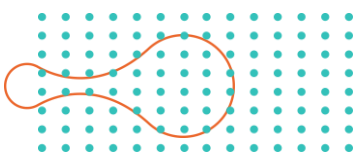
Sameer Zuberi

Maintaining membership is vital, but if you are running interesting and relevant meetings, people will want to be involved. How could you map out the skills and interests of your proposed network to help guide your programme and what will you do to ensure your meetings remain relevant (see Feedback, below)?

We have a half-day meeting that includes time for six or seven short presentations from junior researchers. Lots of young people attend

Tony Marson, North West Epilepsy Network

Funding is likely to be needed to cover venue costs and refreshments. Some networks receive a small amount of funding from pharmaceutical companies or other commercial organisations and, in return, allow them to have banners on show or leave print information near refreshments.



Commercial organisations have no role in setting the agendas or governance arrangements for the network.

If relying on external funding from commercial organisations, consider approaching multiple organisations for small amounts, to reduce the risk of a single sponsor dropping out.

Recommendation 5 Identify funding sources to cover network-related expenses. If seeking external funding, ensure the limits of the arrangements are agreed.

4. What will your meetings look like?

Timing Although some networks hold their meetings in the early evening, people are more likely to attend if the network meets during the working day. If clinicians are attending, give thought to how meetings will fit into their clinical commitments and whether they can organise protected time to attend. Give adequate notice of meetings (usually at least 6 weeks). When planning meeting schedules, check for clashes with conferences and other popular meetings.

Venue Considerations for your meeting venue include accessibility for all network members and the availability of funding.

Holding hybrid meetings, with some attending online, can make the network more accessible. This has to be weighed against many people's preference for face-to-face meetings, which present much better opportunities for networking and initiating collaborations. If going down the hybrid route, ensure the IT will allow the online attendees to participate fully. Conferencing equipment that incorporates a camera, microphone and speaker facilitates online involvement but is expensive.

Our meetings aim to bring together clinicians and researchers with an interest in epilepsy – we use a convenient and neutral venue and focus the meetings on topics that are interesting to our community

Andy Bagshaw, Birmingham Epilepsy Research Network

Frequency How often you hold network meetings will depend on what you want to achieve. Some networks hold annual awaydays or 2-day meetings. Some have monthly meetings and an annual research meeting. Others have 6-monthly meetings.

Agenda Your agenda will reflect your vision, but the topics should be of interest to the majority of attendees. Will you offer opportunities for researchers to present their research or ideas? Will there be developmental opportunities for junior researchers or clinicians? You may want to convene a steering group to plan the programme for the next couple of years or find other ways to seek the views of the wider network membership. Some networks have a theme for each meeting, alternating

Recommendation 6 Plan times and use a venue that will mean most people can attend.

between research and clinical as that reflects their membership. Inviting an external speaker adds value for attendees – having an online presentation opens up the possibility of inviting high-profile researchers or clinicians from around the world.

We have a residential meeting, with an overnight stay. As well as the intellectual contact, attendees appreciate the social event – usually a quiz
Torsten Baldeweg, Young Epilepsy Research Retreat

CPD accreditation may be possible for your meeting, to support clinical members' attendance. More information on CPD for clinicians is available here:

CPD approval FAQs | The Federation

Accreditation | Royal College of Nursing

Personalised certificates of attendance that show the duration of the meeting are helpful for people's CPD files.

Feedback is helpful both for shaping your agendas and future programme, and also for demonstrating the value of your meetings and network to potential members, partners or sponsors. A paper feedback form completed at the end of the meeting will have the highest response rate, but an online form is time efficient for the organisers/admin. Alternatively, set some time aside at the end of the meeting for people to share their thoughts.

Our meetings always end with Any Other Business, which gives people an opportunity to give feedback and share ideas
Phil Tittensor Epilepsy Specialist Nurses Association

Recommendation 7 Seek feedback on every meeting to help shape the programme and demonstrate the benefit of the network.

5. How will you let people know about your Network's activities and achievements?

Communicating the value of your network will help you bring new people in, build collaborations with other networks and organisations and engage sponsors and/or funders. As well as minutes or summary reports, some networks produce an annual report with metrics for activities.

How the Epilepsy Research Institute can support your network

The Epilepsy Research Institute has listened to its community of epilepsy researchers and understands the value of networks of people interested in epilepsy research and how it impacts on clinical care. We also know supportive networks have a role in bringing people into epilepsy research and keeping them there. As a result, we are pleased to offer three mechanisms of support for epilepsy networks.

Kickstart funding

We will consider applications for kickstarter grants to establish new networks where there are geographic gaps. Successful applications will receive two-step funding to establish a network, with the intention that the network will quickly become self-supporting. We expect plans for a new network to follow the recommendations set out in this guidance.

For more information, please contact themes@epilepsy-institute.org.uk.

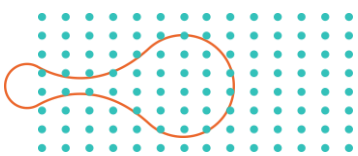
Shape Network

The Epilepsy Research Institute has convened the Shape Network of people affected by epilepsy who are interested in supporting research. We can advertise opportunities to join a network or provide thoughts about research proposals.

See our website for more information or contact our Head of Research and Involvement Annee Amjad: A.amjad@epilepsy-institute.org.uk

Institute accreditation

The Institute will formally recognise networks that demonstrate alignment with the recommendations set out here, and Epilepsy Research Institute-accredited networks will be able to use an Epilepsy Research Institute Network logo. For more information, please contact themes@epilepsy-institute.org.uk.

A well-supported epilepsy research network fosters the development of innovative treatments, enhances clinical care pathways, and advances public understanding. By centring on collaboration and community engagement, it builds a research ecosystem that delivers meaningful impact for people living with epilepsy

Vishnu Pratap Singh Kirar, PhD student