EPILEPSY RESEARCH INSTITUTE UK

CAPACITY BUILDING SURVEY – **REPORT**

SURVEY BACKGROUND

What is holding back epilepsy research?

Not enough money goes towards epilepsy research, especially when compared with other conditions such as Parkinson's disease, dementia and motor neurone disease.[1] One of the Epilepsy Research Institute's aims is to boost funding for epilepsy research, but this will take time. While working towards this goal, we want to bring researchers together and build resources to maintain and strengthen the epilepsy research community.

The Epilepsy Research Institute has a Capacity Building group, led by three theme lead researchers —Professor Torsten Baldeweg, Dr Sukhvir Wright and Dr James Mitchell —and advised by a wider Task Force of researchers and people with lived experience of epilepsy. This group guides the Institute's work on bringing researchers into the epilepsy field and supporting those already working in this area.

To find out what UK epilepsy researchers think about the current state of epilepsy research and how we can help, the Capacity Building theme leads carried out a survey in March 2024. We are sharing some of the results here and, importantly, using them to shape the Institute's work to support epilepsy researchers over the next few years.

Who answered the survey?

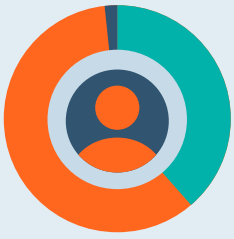
90 UK researchers responded to the survey

42 clinical researchers including specialist nurses, neurophysiologists, dieticians

43 with a non-clinical background including academia

5 unclear research background

Gender



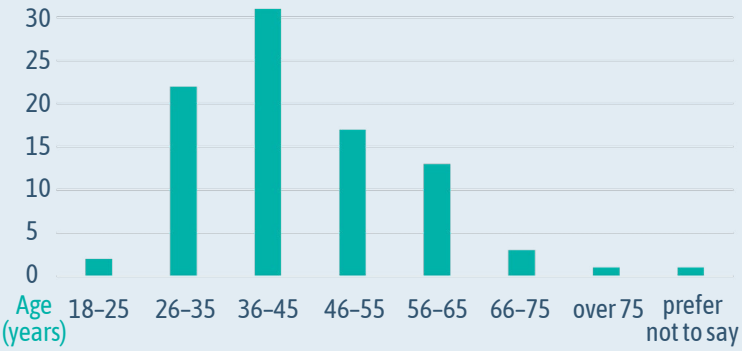
54 men
35 women
1 prefer not to say

Ethnicity

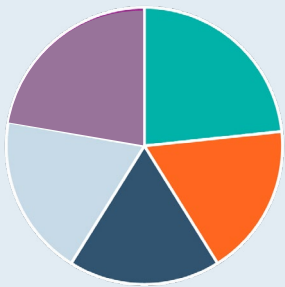


67 white
10 Asian/Asian British
1 Black/African/Caribbean/Black British
4 mixed/multiple ethnicities
6 other
2 prefer not to say

Age



Number of years in research



21 0–5 years
16 6–10 years
16 11–15 years
17 16+ years
20 not specified

1 Comparing funding allocations using UK Health Research Analysis 2022 (UK Clinical Research Collaboration, 2023) https://hrcsonline.net/reports/analysis-reports/uk-health-research-analysis-2022/

KEY FINDINGS



Equipment, staff and space are lacking

According to the survey, a lack of access to technology is one of the key factors holding back epilepsy research. With advanced imaging equipment only available to a limited number of research groups, many investigators are unable to use powerful tools such as MEG, 7T-MRI and PET-CT to understand what happens in the brain when a person has seizures (see explainer box). Other academic and clinical scientists can't carry out the laboratory research they want to because their university or research centre doesn't have the equipment, space or skilled technical staff needed.



Limited research funding

Researchers start their career by studying for a PhD before applying for postdoctoral positions with research groups. These fixed-term roles are usually funded through grants awarded to the senior researcher in the group. During this stage in their career, researchers are trying to build experience and expertise and publish their studies in academic journals. Unfortunately, early-career researchers told us that the lack of funding in epilepsy research means they can't always find these postdoctoral positions and have to move to other areas of research, away from epilepsy.



Clinical pressures

Health professionals, including doctors and specialist epilepsy nurses, who wish to carry out research face additional hurdles. Workload pressures and the need to keep clinical qualifications up to date can make it difficult to combine research with clinical care for patients.



A need for quality clinical data

Good-quality clinical data collected from large numbers of people with epilepsy can reveal new patterns and relationships between seizures and other symptoms. This can lead to recommendations and advice that helps people in their daily lives. However, epilepsy researchers told us that this data isn't currently available to them, and this is hampering their research.



Working together

Researchers told us they value the chance to share ideas and experience in local epilepsy research groups and other networks. Opportunities to mix people working in laboratories with the health professionals who care for people with epilepsy are particularly valuable. They also identified some areas where training and education would be helpful.

"These findings will guide our efforts for the coming years, with a focus on mentoring and funding initiatives to attract talented early-career researchers into our field."
Professor Torsten Baldeweg, Capacity Building Basic Science Theme Lead

OUR RESPONSE TO THE SURVEY

Over the coming years, the Capacity Building group will develop work programmes that answer the calls from the survey.

We have already provided:

- funding to support PhD students and early-career epilepsy researchers
- workshops and meetings to bring together researchers and clinicians to discuss how they can work together to answer some of the biggest questions in epilepsy
- an online space for researchers to share experience and make connections

We are planning to provide:

- financial support for early-career researchers to share their research findings at conferences and meetings on epilepsy
- training, learning and networking opportunities for everyone involved in epilepsy research, but particularly early-career researchers
- resources to help support epilepsy research

We are ambitious about building and maintaining a welcoming and supportive epilepsy research community. We need good researchers to radically advance epilepsy research.

EXPLAINER

Abbreviation	Short for	About
MEG	Magnetoencephalography	MEG creates images from magnetic fields produced inside the brain. These images help doctors pinpoint the areas of brain activity linked with epilepsy.
7T-MRI	7 Tesla magnetic resonance imaging	7T-MRI uses a strong magnetic field to give clearer and more detailed images of the brain's structure
PET-CT	Positron emission tomography/ computed tomography	PET and CT are ways of tracing the movement and final location of small amounts of a material that shows on an image. These methods can show what's happening in the brain. PET uses radioactive tracers while CT uses contrast fluid.

FULL SURVEY RESULTS

You can view the full results from the survey **here.**

For more information on the work of the Epilepsy Research Institute's research programme, please visit our website: **epilepsy-institute.org.uk/research-strategy.**