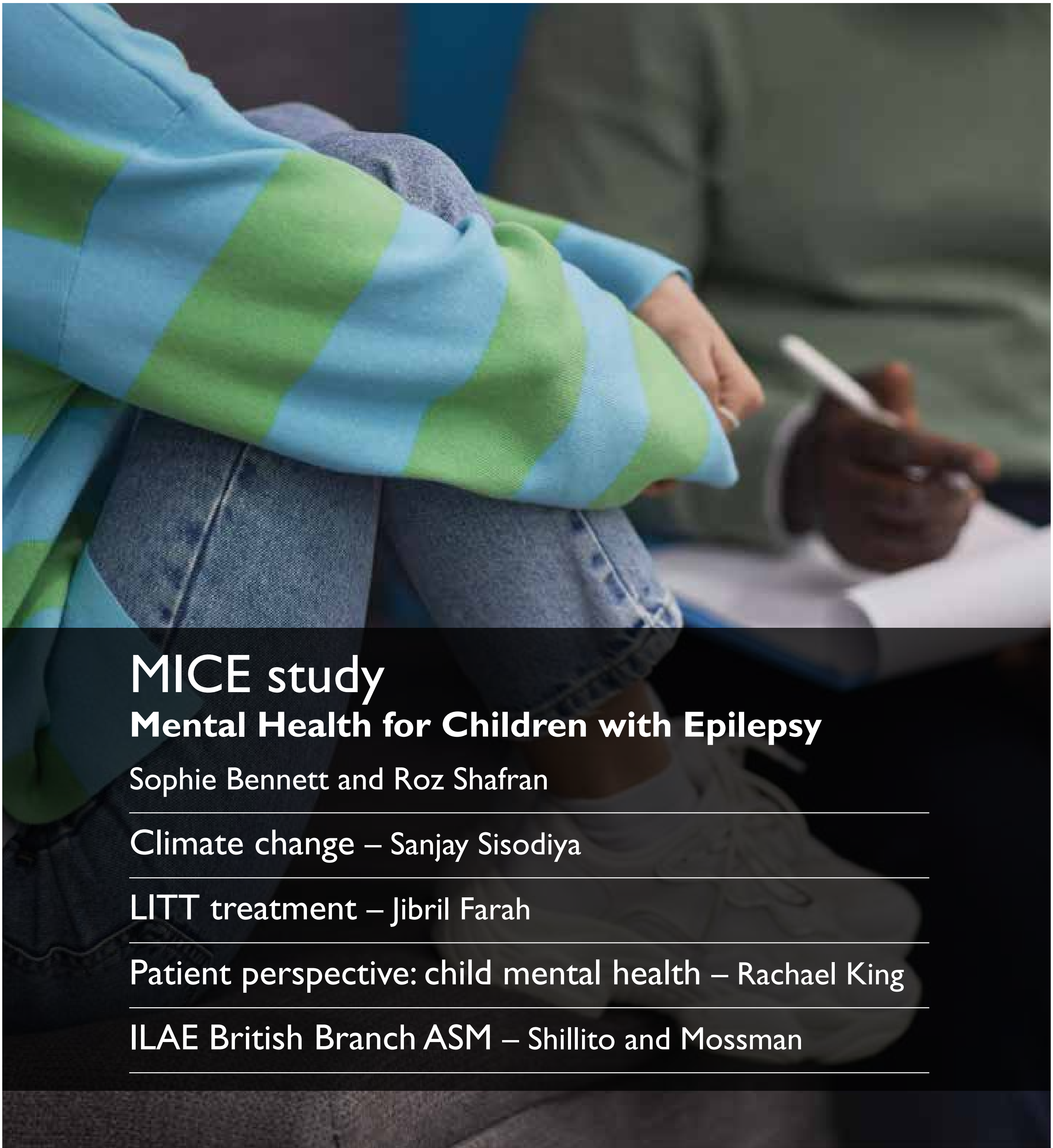
EPILEPSY ACTION

issue seventy six / Spring 2025
(Free to Epilepsy Action professional members)

epilepsy professional



EPILEPSY
ACTION

EPILEPSY SAYS STOP.

WE SAY GO.

Support your patients:

- **Helpline –** phone, webchat or email
- **Talk and Support Groups –** online & in-person
- **Befriending –** online or phone
- **Counselling** – Wales
- **Family support –** NI & Wales
- **Website –** high quality information about all things epilepsy
- **Epilepsy awareness courses**

scan for more

epilepsy.org.uk/referral

0808 800 5050

Trusted
Information
Creator
Patient Information Forum

Registered charity in England and Wales (No. 234343)

Welcome to the Spring 2025 Edition of Epilepsy Professional. The edition contains a range of articles of relevance to all healthcare professions who work with patients with epilepsy.

If you have any doubt about the reality of climate change then Sanjay M. Sisodiya (UCL Queen Square Institute of Neurology and Chalfont Centre for Epilepsy) will convince you that it is a reality and, more importantly, a reality for our patients. His article "Climate change: no longer to be ignored" explores how climate change is having an impact on our patients with epilepsy. He gives a call to action, both in terms of helping our patients, but also for more research on the impact of climate change. He also calls on us to personally reduce our own impact.

Have you heard the buzz about LITT? The NHS announced roll out of Laser Interstitial Thermal Therapy last year and the services are now up and running. In a question-and-answer format, Mr Jibril Farah, consultant neurosurgeon from The Walton Centre in Liverpool, discusses the service now offered in Liverpool, the potential of LITT for patients with focal epilepsy and a known seizure onset zone, and how he feels LITT treatment will develop in the UK in the future.

The mental health burden for people with epilepsy can be profound and the barriers to help can be exacerbated by their epilepsy diagnosis. Recognising these difficulties, Sophie D. Bennett and Roz Shafran from UCL Great Ormond Street Institute of Child Health in London discuss the background to and results of the MICE (Mental Health for Children with Epilepsy) trial. Importantly, this trial looked at how mental health issues can be managed from within the epilepsy team and the results showed improved mental health compared to standard care.

Did you miss the International League Against Epilepsy British Branch Annual Scientific Meeting that took place in Liverpool from 21-23 October last year? If so, Tom Shillito and Emily Mossman from the Epilepsy Action team have provided a round-up of what sounds like an informative and enjoyable event. This included several contributions from Epilepsy Action.

Finally, is the service you provide to your patients with learning disabilities and epilepsy as good as it could be? The Step Together toolkit can help to benchmark your service. The background to this toolkit, the benchmarking process and the potential benefits are described in an article by Epilepsy Action health improvement and research manager Tom Shillito.

I hope you enjoy this edition.

Sean J Slaght
Consultant neurologist
Medical adviser
Epilepsy Professional

contents

6
news
The latest in epilepsy care

This issue: Epilepsy Action chief executive steps down after 37 years, new Fetal Exposure to Medicines Service (FEMS) is piloted in the north of England and government launches new Neuro Forum

10
Behind the helpline
David Thornton

Epilepsy Action's award-winning helpline is a keystone resource for people with epilepsy. Helpline team leader David Thornton tells us more about the last year

12
Climate change
Sanjay Sisodiya

Prof Sanjay Sisodiya discusses the effects that climate change are having on patients already and why he can no longer ignore climate change and is imploring his peers not to either

18
MICE study
Bennett | Shafran

Dr Sophie Bennett and Prof Roz Shafran describe their study into integrating mental health services for children with epilepsy into their neurology pathway

28
Patient perspective
Rachael King

Rachael shares more about the mental and physical health challenges her three children face, what support would make a big difference to them and how they always manage to keep smiling

30
ILAE British Branch ASM
Shillito | Mossman

Epilepsy Action's Tom Shillito and Emily Mossman provide a summary of some of the highlights of last October's ILAE British Branch Annual Scientific Meeting

36
Epilepsy and learning disabilities
Tom Shillito

Tom Shillito discusses the Step Together guidance and toolkit and the importance of providing holistic care to people with epilepsy and learning disabilities

editorial

24

LITT treatment

Jibril Farah

Consultant neurosurgeon, Mr Jibril Farah, is delivering laser interstitial thermal therapy at the Walton Centre in Liverpool. He shares some insights about this exciting new treatment

Only a month into 2025, and I am fully committed to using it as a yardstick by which to assess societal progress. For example, it's 2025, how have we still not designed a fit-for-purpose dish rack where the glasses don't fall off? (Just me?) Or, it's 2025, why do people still call it ex-presso? Or, most pressingly it's 2025, how do we still sell loose glitter in art and crafts shops where children can see it?

But, all jokes aside, I'm actually really grateful to exist in 2025, when so much progress has been made in so many different areas. One of those is around considering, treating and talking about mental health. But there is still more we can do. On that note, Dr Bennett and Prof Shafran take us through their recent study showing how they successfully integrated mental health services for children with epilepsy into their neurology pathway (page 18). To know the importance and value of offering support with mental health in children, read Rachael King's experiences on page 28.

Also this issue, Prof Sisodiya shares why he can no longer ignore climate change in his practice and why he urges other health professionals not to either (page 12). Mr Jibril Farah shares more on the LITT treatment on page 24, calling for more referrals to be made. Meanwhile, from team Epilepsy Action, you can find out about our helpline as a source of support for your patients (page 10), our team's takeaways from the ILAE British Branch ASM (page 30) and our new guidance and toolkit for best care in patients with epilepsy and learning disabilities (page 36).

So, happy 2025! Let's be proud of all our progress and keep striving for more. (I'll start by vacuuming glitter from my carpets). I hope you enjoy this issue!

Kami Kountcheva
Editor

If you no longer wish to receive Epilepsy Professional *magazine, email us at kkountcheva@epilepsy.org.uk or call us on 0113 210 8800*

Editor/desktop publishing: Kami Kountcheva
(kkountcheva@epilepsy.org.uk)

Design: Jon Eaton
(jeaton@epilepsy.org.uk)

Publishers: Epilepsy Action
(Communications and Digital Engagement Department)

Advertising: Charlotte Stern
(cstern@epilepsy.org.uk)

The information contained in this magazine is intended for medical professionals

Epilepsy Professional is available on subscription to non-members – £13 a year to UK residents. Please send letters or articles to the editor. We are unable to acknowledge receipt of materials, due to cost. We cannot offer payment to authors. All income generated by *Epilepsy Professional* funds the Association's work.
Epilepsy Action is a working name of British Epilepsy Association. British Epilepsy Association is a Registered Charity in England and Wales (No. 234343) and a Company Limited by Guarantee (No. 797997).

ISSN 1750-2233
New Anstey House, Gate Way Drive, Yeadon,
Leeds LS19 7XY, UK
tel: 0113 210 8800 | **fax:** 0113 391 0300 | **Epilepsy Action Helpline freephone:** 0808 800 5050
email: epilepsy@epilepsy.org.uk **epilepsy.org.uk**

Epilepsy Action chief executive steps down after 37 years

Epilepsy Action chief executive, Philip Lee, has stepped down after more than 37 years at the organisation.

Rebekah Smith has been appointed as the new chief executive of Epilepsy Action.

Lee has led the organisation as its chief executive for more than 29 years. He left the organisation on Friday 29 November.

In a departing message, also posted to members on Facebook, Lee said: "After more than 37 years working for Epilepsy Action (British Epilepsy Association), and being the charity's chief executive for the past 29 years, it is time for me and the charity to move on to other things.

"Over so many years I have had the great fortune to know and work with thousands of truly wonderful, dedicated and inspiring people – be they staff, members, volunteers or trustees. Too many to name you all but you will know who you are, and to each and every one of you, I would like to say thank you for being such an essential and worthwhile part of my life. Together we have done amazing things.

"For me personally, it has always been a privilege to have been entrusted with the leadership of such a valuable and important organisation. I will always be proud of what the charity has achieved during my time and the contribution I have been able to make to improve the lives of people with epilepsy and their families.

"I take with me warm memories that will stay with me forever and I leave behind my very best wishes for the charity's future success."

Chair of Epilepsy Action's board of trustees, Jane Riley said: "After a highly successful first year of our strategy and as we progress with this new direction, Phil has decided that now is an ideal time for him to move on to a new personal challenge and pass the leadership on for the next phase of our journey.

"I want to thank Phil for his tireless dedication and long service at Epilepsy Action and to wish him all the very best for his future endeavours."

Ian Walker, a member of the Epilepsy Action board of trustees also resigned from his post in November. Walker was a trustee for 15 years, having joined in 2010, and serving as treasurer in 2012, vice chair between 2013-15 and chair between 2016-19.

Riley said: "Ian has been a pleasure to work alongside. He is well known for his sound knowledge, his commitment to Epilepsy Action, great enthusiasm to support those affected by epilepsy and his general good humour. On behalf of the trustees, we thank him very much for his relentless support and wish him well for the future."

New Fetal Exposure to Medicines Service piloted in north

People affected by epilepsy medications while they were in the womb can now seek support from a new Fetal Exposure to Medicines Service (FEMS), available in the north of England.

FEMS is being piloted at Saint Mary's Hospital in Manchester and Newcastle Hospitals NHS Foundation Trust. The service, funded by NHS England, will run until March 2026.

Children or adults living in the north of England who have problems that could be because of exposure to epilepsy medicines in the womb can be referred to the service by their doctor.

People will then be informed by the service whether a FEMS appointment would be of use to them.

Appointments will offer assessments and tests and offer detailed plans where needed to support people affected by medications.

Initially, people who have been exposed to the medications sodium valproate and topiramate will be eligible for a referral.

From April 2025, the pilot will extend to include a much wider range of medications, including cannabidiol, carbamazepine, phenobarbital and phenytoin, as well as medications considered safer in pregnancy, such as lamotrigine and levetiracetam.

Epilepsy Action welcomed the support, but warned that people in the rest of the UK need access to the service too, and that families are still waiting for redress.

Corridor care: vital investment needed to restore care

People are having seizures, medical procedures and nursing care in corridors, storerooms and even toilets in UK hospitals due to lack of government investment and reforms to the NHS and social care, a new report by the Royal College of Nursing (RCN) has revealed.

The 'On the frontline of the UK's corridor care crisis' report, published on 16 January 2025, featured 5,408 responses from nursing staff working in UK NHS hospitals from 18 December to 11 January 2025.

Nearly two-thirds of responders said they had to care for patients in places not designated for patient care on a daily basis. More than 90% of responders said this compromised patient care and safety.

Professor Nicola Ranger, general secretary and chief executive of the RCN, said: "Nursing staff trying to care for patients in corridors, storerooms, carparks, offices and even toilets. No access to safety critical facilities like oxygen, suction or monitoring equipment. Fire escapes blocked. Patients having diagnoses and discussions in public, and being treated, fed, washed and toileted – and sadly even dying – with no privacy.

"Staff across health and social care at breaking point as professionals and as people, knowing they cannot give patients and families the care and dignity they deserve.

"Most shocking is this situation now being accepted as the norm."

Examples of people having seizures in waiting rooms and corridors were reported across many regions covered by the report, including London, the North West, West Midlands, Northern Ireland and Scotland.

Many said the situation is "heart-breaking" and "stressful", and is leaving them unable to deliver the level of care they want to.

Ranger said: "Investment in our workforce is vital to deliver the reforms needed to recover patient care, otherwise the future of the NHS, already broken, becomes truly bleak."

Electronic health records track fall in sodium valproate use – study

A new study has used national level electronic health records to track use of sodium valproate in men and women across England and Wales.

Study authors Dr Caroline Dale and colleagues found that current and new use of sodium valproate has declined in women during and outside of pregnancy between 2019 and 2023.

The study was able to identify sodium valproate use trends through linking information from electronic health record data sources.

The authors write: "With improved access to electronic health data with coverage of the whole population, the effect of policy changes and their consequences can be more reliably tracked."

The researchers found that the new use of sodium valproate in men also decreased during the study period, but remained at much higher levels than for women.

The study concluded that "no clear evidence was found that deaths related to epilepsy increased in women aged 15-49 during 2015-22, but a slight increase was found in men during the later period between April 2018 and December 2022". It said further studies should focus on people who had switched away from sodium valproate.

Drugwatch update

Epilim
Sanofi, the manufacturer of Epilim have told Epilepsy Action that Epilim modified release granules 1000mg and 750mg are being discontinued. The expected end of supply is estimated to be September 2025. Epilim 50mg, 100mg, 250mg and 500mg modified release granules will continue to be available.

Tegretol
Novartis, manufacturer of Tegretol, have informed Epilepsy Action that Tegretol is in stock with them. They are looking into any supply chain problems with wholesalers they work with and any wider issues. Novartis are requesting pharmacies who are struggling to get supply to email or call their Customer Care team directly.

Government launches new Neuro Forum

The UK government has launched the first ever Neuro Forum to address gaps in treatment care in neurology.

Parliamentary Under-Secretary of State at the Department of Health and Social Care (DHSC), Andrew Gwynne announced the new UK-wide forum on 28 November 2024. He said it will work to improve care and support for people affected by neurological conditions.

The forum will hold formal biannual meetings, bringing together clinical leaders, organisations and people with lived experience of neurological conditions, such as epilepsy. The forum is expecting to hold its first meeting in early 2025.

The announcement follows the long-standing 'Back the 1 in 6' campaign by the Neurological Alliance organisations from the four UK nations.

The forum will "aim to drive real progress in areas where UK-wide collaboration is most impactful", the Neurological Alliance said. It added that the forum will drive person-centred care and "address unwarranted variation in access to care across the country".

Epilepsy Action said it's "glad" that this will strengthen the patient voice.

Optogenetics for treating seizures

Researchers from the University of California in the US have used optogenetics to find a new possible treatment for seizures.

In their research, published in November in Nature Neuroscience, the scientists used optogenetics in human brain tissue which had been removed from epilepsy patients during surgery as part of their epilepsy treatment.

The researchers say this was the first demonstration of the use of optogenetics in human brain tissue.

The team hope that, eventually, this technique could replace epilepsy surgery for people with refractory focal seizures.

Assistant professor of neurological surgery and study author, Dr Tomasz Nowakowski, said: "This represents a giant step toward a powerful new way of treating epilepsy and likely other conditions."

Dr Edward Chang, chair of neurological surgery at UCSF, said this could revolutionise care for people with epilepsy. "We'll be able to give people much more subtle, effective control over their seizures while saving them from such an invasive surgery."

Man who killed parents during postictal psychosis had 'significant time lapses' in mental health care

An inquest has found that there were "significant time lapses" in the mental health care of a man with epilepsy, who killed his parents during an episode of postictal psychosis following a seizure.

James Duncan Andrews killed his mother, Mary, 76, and father, Bryan, 79, in November 2022 at their home in Sheffield. He was believed to have been in a postictal psychotic episode, following several seizures two days earlier.

He was given an indefinite hospital order in July 2023, after pleading guilty of manslaughter on the grounds of diminished responsibility.

An inquest heard last October that a referral was made to specialist services in mid-2022 following Andrews experiencing episodes possibly linked to his seizures. The referral was denied.

According to senior coroner in the case, Tanyka Rawden: "Had there been a regular and appropriate interaction between services and had the early intervention service referral been accepted, it is possible that treatment could have been given."

A doctors' report from the unit where Andrews was staying said that he had had four seizures two days before he killed his parents. Consultant neurologist Prof Markus Reuber said that Andrews was likely to have been having postictal psychosis.

He had previously complained about post-ictal paranoia, psychotic episodes and suicidal thoughts.

Man dies after "missed opportunities" to issue medication

A London man died from a seizure after "a significant number of failings" from health services in the days before his death meant he was left without his epilepsy medication, an inquest has found.

Masters student Charlie Marriage, 32, died from sudden unexpected death in epilepsy (SUDEP) in his flat in Camberwell on 26 June 2021, assistant coroner for Inner South London, Xavier Mooyaart, ruled on Tuesday, 21 January 2025.

Mr Marriage had been isolating after being alerted to do so by NHS Test and Trace on 24 June 2021. This meant he could not go to his usual pharmacy at his university in Uxbridge, which had his prescription for the epilepsy medication Fycompa (perampanel) ready to collect.

He had made calls to his GP and NHS 111 to try to arrange emergency access to his medication at a local pharmacy in the days before his death.

Mr Mooyaart said there had been "a significant number of failings" and "many missed opportunities" that contributed to Mr Marriage's death. These occurred on the part of the NHS 111 service, the Superdrug pharmacy in Camberwell, and Mr Marriage's GP. Mr Mooyaart issued a Prevention of Future Deaths report to NHS England.

Man dies after pharmacy sends 'IOU' for epilepsy medication – inquest

A West Yorkshire senior coroner has warned that "future deaths will occur unless action is taken", following an inquest into the death of a 44-year-old man, who received an 'IOU' for his epilepsy medication from a Leeds pharmacy last December.

David Joseph Crompton, who had epilepsy, died following a fall down the stairs on 13 December, senior coroner Kevin McLoughlin concluded.

In the inquest report, McLoughlin stated the cause of death to be hypoxic ischaemic encephalopathy (a form of brain damage caused by lack of oxygen), cardiac arrest, a spine injury due to the fall and epilepsy.

Earlier in December, Crompton had received a manuscript 'IOU' for his epilepsy medication, Tegretol (carbamazepine), when his other medicines arrived from Midway Pharmacy in Pudsey.

He had previously been left without his medication in April 2024 for around 10 days, as the pharmacy could not supply it.

McLoughlin said that it was "questionable whether lessons were learnt from this potentially dangerous interval".

Epilepsy Action is asking for an urgent review of the medication supply chain.

Cannabis trials for refractory epilepsy to start in 2025

Two national NHS clinical trials will investigate the safety and effectiveness of cannabidiol (CBD) and tetrahydrocannabinol (THC) in adults and children with treatment-resistant epilepsy.

Prof Finbar O'Callaghan and Prof Helen Cross from University College London (UCL) and Great Ormond Street Hospitals (GOSH) will co-lead the trials, which are due to start in 2025.

The trials will randomly assign CBD, CBD with a small amount of THC or placebo to a total of 500 adults and children with medicine-resistant (refractory) early-onset and genetic generalised epilepsies for 24 weeks. People will be recruited into the trial from NHS sites around the UK. The trial will use formulations by the company Ananda Developments, known as MRX2 (CBD) and MRX2T (CBD+THC).

The researchers want to investigate whether these medicines are safe and effective in reducing seizure frequency and severity, and how they affect learning, sleep, behaviour, quality of life, stress and anxiety.

Epilepsy Action CEO Rebekah Smith said it's encouraging to see these long-awaited trials taking place. However, Matt Hughe, co-founder of the organisation Medcan warned that it should be noted that the trials don't include second generation, advanced cannabinoid medicines, which he says are used by most families seeing significant improvements in seizure control.

Behind the helpline

Epilepsy Action's award-winning helpline is a keystone resource for people with epilepsy. Helpline team leader David Thornton tells us more about the last year

No day is the same on the helpline. With epilepsy being such a wide-ranging condition, we cover a range of different topics. While many contact us about medicine or work, for example, some have also enquired about some less common topics, including thunderstorms, Ironman challenges and Mozart. We don't always have all the answers, but we do support and empower our service users with some information and options.

Besides the usual enquiries, sometimes a new, topical health issue, such as the COVID-19 global pandemic, will bring on a surge of new queries. At the start of 2024, widespread medication shortages affected many people with epilepsy. We saw a more than 300% increase in enquiries about this compared to the year before, which was deeply concerning. We worked to raise these issues with manufacturers and policymakers, as well as offering the best advice and solutions we could to concerned helpline callers.

While this issue has largely subsided, we know that getting medicine remains a worry for many. This is especially in the wake of cases in the media, such as that of Mr David Joseph Crompton, who died from a fall down the stairs, after receiving an IOU for Tegretol from his pharmacy. We will continue to raise medication shortage issues with manufacturers and lobbying the government for an urgent review of the medication supply chain. The latest information around medication availability known to us can be accessed on the Drugwatch section of the Epilepsy Action website.

The role of the helpline is more than just information and advice. It is also a gateway into Epilepsy Action's other support services, such as our one-to-one Befriending service and our Talk and Support groups. While we aim to get our users options and solutions through the helpline itself, we know that having ongoing support from these services and from others affected by epilepsy can be invaluable.

As well as this, the remit of the helpline is also going to expand in 2025, with the support of funding secured in 2024. It was clear that with 630,000 people with epilepsy in the UK and more than a million visits to our website every year, there was a need to do more.

We piloted a live chat function on the Epilepsy Action website, which has been very successful. The funding will help us improve and continue having this contact channel. We have also welcomed more staff to our team. This will help us to answer more questions from people with epilepsy and give us more resources to support people with more in-depth information.

This will enable us to provide a much more effective service for the growing number of people contacting us with mental health issues and queries around medication. We will look at how to expand this to other specialist topics in the future, and how we can support you and other professionals by providing more first-stage support.

We're working hard behind the scenes to deliver this exciting expansion, but day to day, we are still here for our community. If you or your patients have any questions, we'd love to hear from you.

If you would like to refer someone affected by epilepsy directly to our helpline, you can fill in our referral form here: Support for you form - Epilepsy Action

Clinicians and patients can also contact us on our freephone number 0808 800 5050 or via our standard webform. Our helpline is open Monday to Friday, 8:30am to 5pm and Saturdays 10am to 4pm.

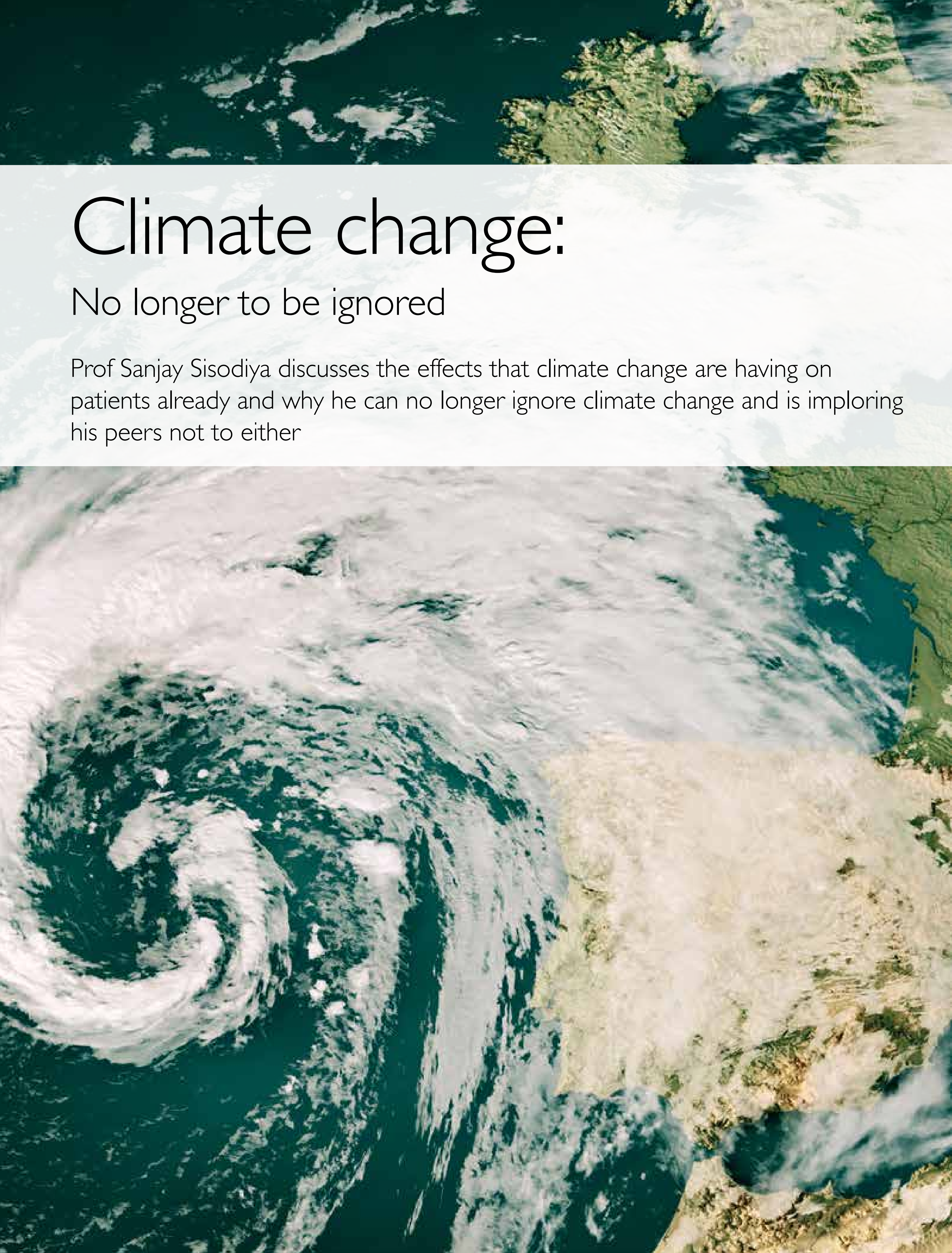
Throughout the year, our service users have told us the impact our service has had, and we're very thankful for those kind words. This wonderful feedback reminds us of the important work we are doing together with the epilepsy community. Together with you, it's brilliant to be able to help and empower people to change their lives for the better.

David Thornton

"Was so lovely to speak to someone who listened and understood, I really needed that."

We're pleased we've been here for the epilepsy community this past 12 months – and for the past 30 years that the helpline has existed. And we aren't going anywhere.

David Thornton
Helpline team leader
Epilepsy Action



Climate change:

No longer to be ignored

Prof Sanjay Sisodiya discusses the effects that climate change are having on patients already and why he can no longer ignore climate change and is imploring his peers not to either

As a young trainee with ambition and bounce, I asked the late Dr Barry Hoffbrand, who taught me with common sense about the art and humanity, as well as its practice, of medicine, about a research post I had been offered at the Institute of Neurology to work on the science of epilepsy. He, in turn, asked me to reflect on whether I wanted to spend the rest of my life doing epilepsy clinics. I don't remember that I did reflect much, but 33 years later, I do not regret for one moment taking the opportunity. Over that time, I have learnt a huge amount about epilepsy. Most importantly, I have learnt the effect it has on people and about their resilience – humbling learning which drives those who work in epilepsy to keep trying harder to better understand epilepsy and improve its treatment. As technology has advanced, how epilepsy can be studied and our understanding of its nature has developed astonishingly: in my own small area, genomics has revolutionised understanding of epilepsy at individual and population levels. Genetic causes, for example, are emerging – and making a difference – for people I have seen for years in clinic without a known cause for their condition. Trials are now happening that use gene-based therapies and technologies to treat types of epilepsy that had not even been described when I started. It is such an exciting time in epilepsy that I wish I could have the privilege of another 33 years of research and clinical practice, because not only is there so much left to do, but also now so many ways of doing it. I wish I could focus just on what I thought was my work and my passion.

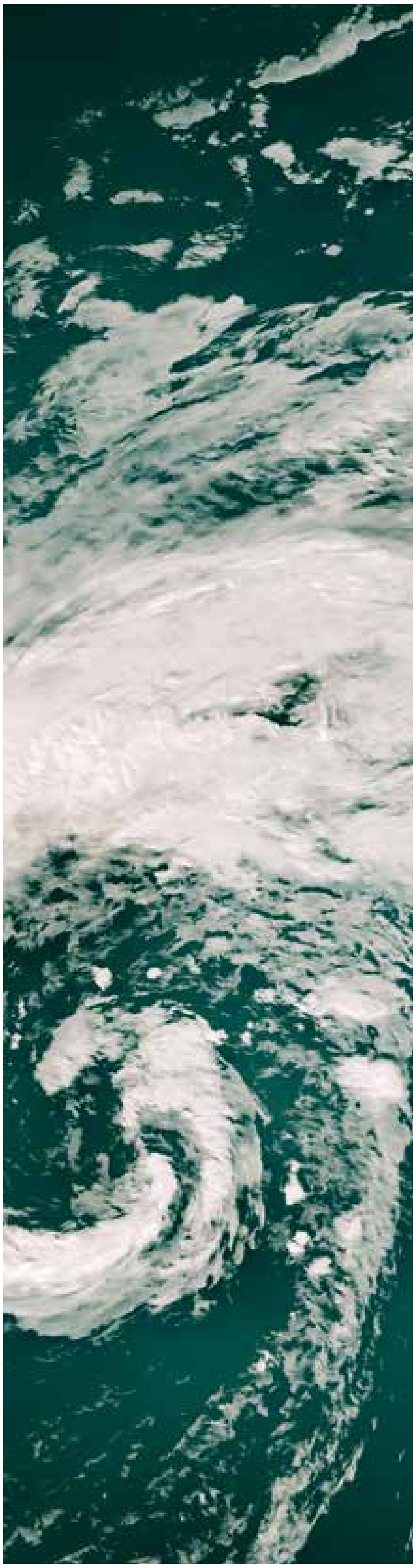
Should anyone still doubt that the global and local climate is changing around us now, for the worse, there are statistics galore about our changing climate

So, really, I would very much like climate change not to be happening, and that I did not have to think about it: but it is happening and I can't just not think about it. Should anyone still doubt that the global and local climate is changing around us now, for the worse, there are statistics galore about our changing climate.

- Atmospheric carbon dioxide levels are at highs not seen over geological timescales [NOAA, 2024];
- 2024 was the hottest year on record [World Meteorological Organization, 2024];
- heatwaves, wildfires and floods have devastated swathes of Europe in 2023 and again in 2024 [worldweatherattribution.org, 2024]; and
- each year, the Lancet Countdown documents and forecasts the crushing burden on human health posed by climate change, echoed by joint editorials published across leading health journals [Abbasi et al, 2024; Atwoli et al, 2021].

And, still, we do not pay enough attention, and, still, we do not act.

Sanjay Sisodiya



Climate change began to matter to me at a professional level when the families of people with some rare genetic epilepsies started to tell me about the difficulties their adult children were having during the unprecedented heatwaves we have experienced in the last decade in the UK. People were having more seizures, worse behavioural difficulties, greater lethargy: existing symptoms were worsening and families were having to take action. Surveys by the Epilepsy Society showed concern amongst people with epilepsy broadly across the community. Once you start asking people with epilepsy and their families and carers, more and more stories emerge, but often such information is not volunteered, because 'What can you do about the weather, doc?'

There are many reasons to think that the consequences of climate change matter in epilepsy. We are raising atmospheric carbon dioxide – climate change is anthropogenic. This is altering every aspect of the very environment in which we have to live and work. I struggle to express the fundamental nature of the experiment we are unwittingly unleashing on our own life support system. Imagine raising blood carbon dioxide levels to twice what they should be in short order, and then watching the resulting chaos. For climate change, amongst the consequential outcomes are more days with unseasonal and exceptional temperatures (with a record-breaking run of 116 such days at the end of 2023), higher night-time temperatures compromising the relief that should take place during the night, and more frequent and severe heatwaves, droughts, rainfall and floods.

These changes have health consequences that are now widely documented [Romanello et al, 2023]. For people with epilepsy, data are still limited, but accumulating [Gulcebi et al, 2021; Sisodiya et al, 2024]. Theoretical and laboratory studies raise concern because molecules, such as ion channels, that are fundamental to brain function, and inevitably involved in processes in epilepsy, are exquisitely sensitive to ambient temperature. Mutated ion channels, and other brain proteins, also malfunction with rising temperature. Thermoregulation provides some security by attempting to maintain the internal environment of the body within a narrow range of temperatures, but thermoregulation can be compromised under a variety of circumstances, including in genetic conditions and with particular drug treatments, such as some antiseizure medications and anticholinergics [Manivannan et al, 2021]. Cognitive dysfunction is common in epilepsy and could impair necessary behavioural responses to adverse weather events, such as heatwaves. Topiramate can impair sweating and lead to hyperthermia [Karachristianou et al, 2013]. Extreme environmental events can hamper delivery of healthcare and treatments. The thermal comfort of places where people with epilepsy live, at home or in residential accommodation, matters [McNicholas et al, 2024]: most people in high-income countries spend the majority of their lives

Infrastructural weaknesses can lead to unreliable medication supplies and inadequate healthcare

indoors and, for some people with epilepsy, that time indoors might be particularly high. Building fabric modulates the impacts of external weather, especially heat. In the UK, housing stock is designed largely to keep heat in, not for coolness in hot weather. Across the world, climate change is associated with a spread of the ranges of insect vectors of viruses that can infect the brain and lead acutely to seizures, or the development of epilepsy. In addition, infrastructural weaknesses can lead to unreliable medication supplies and inadequate healthcare: the existing global treatment gap is well documented in epilepsy, and likely to be aggravated by climate change. Collation of available evidence suggests that signals about the negative impacts of climate change on epilepsy are growing [Sisodiya et al, 2024].

We need to ask what people with epilepsy are experiencing and discuss the risks posed, for example, by acute manifestations of climate change, such as a heatwave

At the individual level, the impacts of climate change can be complicated; some consequences we probably do not yet even know about. Real-life individual experiences can be knitted into 'not improbable' or 'uncommon' scenarios [Sisodiya, 2023]. We need to document these outcomes at individual and population levels in order to better manage the new challenges – sets of challenges – resulting from the consequences of climate change.

For example, for someone living at the top of a block of flats – already not ideal for a person with epilepsy – a heatwave can lead to temperatures that become difficult to tolerate. Elevated night-time temperatures can disrupt sleep. If that person has, say, juvenile myoclonic epilepsy (JME), poor sleep may increase the risk of occurrence of seizures. In some cases, JME is associated with impaired functions of the frontal lobe, which may compromise planning in relation to healthy actions during, or in preparation for, a heatwave. Concerns about valproate usage may have led to treatment with topiramate, which can lead to reduced sweating, risking thermoregulatory compensation that may otherwise have been important. Severe flooding that may be associated with increased water vapour content in a hotter atmosphere due to climate change could disrupt an already precarious medication supply chain with interruptions that, irrespective of climate change, have been a feature of medical treatments recently [Letter to Wes Streeting, 2024]. Added to all this, anxiety about the heatwave, and maybe about climate change itself ('climate anxiety', a well recognised entity, especially amongst the young [Clayton, 2020]), could further increase seizure risk. The scene is set for a worsening of this person's seizure control.

What can and do we need to do? There are three areas of action to consider: awareness, research and action.

Health professionals are trusted people. We have a duty of care. As we warn about valproate risks to women of child-bearing potential, as we advise about obesity and smoking, so we need to bring climate change-related risks into our thinking. We need to ask

what people with epilepsy are experiencing, and discuss the risks posed, for example, by the acute manifestations of climate change, such as heatwaves. We also need to advise about longer-term objectives: for the family of a young adult with a developmental and epileptic encephalopathy, perhaps a south-facing extension with large windows is not necessarily the best option in a warming world. We need to raise awareness and preparedness, short and long term – for example, about actions to take during a heatwave, and medication storage options.

We may also want to think about our roles as guardians of the health of the population, including those with whom we have the closest association – people with epilepsy. How can we help raise awareness amongst those who provide healthcare services, how can we make those who are already acting, such as the UK Health Security Agency, aware of the particular needs of all people with epilepsy and their carers? How can we raise awareness of climate-related vulnerabilities of people with epilepsy, and other neurological diseases, amongst those with the levers of power, to encourage governmental action on climate change? Doctors have been jailed for their actions in this regard: we need to think what we can best do to help keep people with epilepsy safe in a changing world in the context of our professional lives and the service we provide daily [Sisodiya, 2024].

A more refined and nuanced understanding of climate change-related impacts is essential. We all recognise that different people not only can have different epilepsies, but also different and unique individual circumstances in their lives overall. Like the genomic risks of epilepsy, there may be common, shared risks from climate change across the epilepsies (such as the risk of sleep disturbance), and more particular risks for individual types of epilepsy (such as the risk of higher ambient temperature for someone with genetically- and pharmacologically-compromised thermoregulation). We need more research, at all levels: from the population to the molecular. It is no longer a case of working either on epilepsy research or working on climate change. The reality of climate change, the biology of the epilepsies, and the regulatory environments within which we operate (NHS, UKRI, institutional requirements) require us to do both: to work in our professional lives in the context of climate change.

Just as COVID was, climate change is part of our professional lives: we have to engage and act

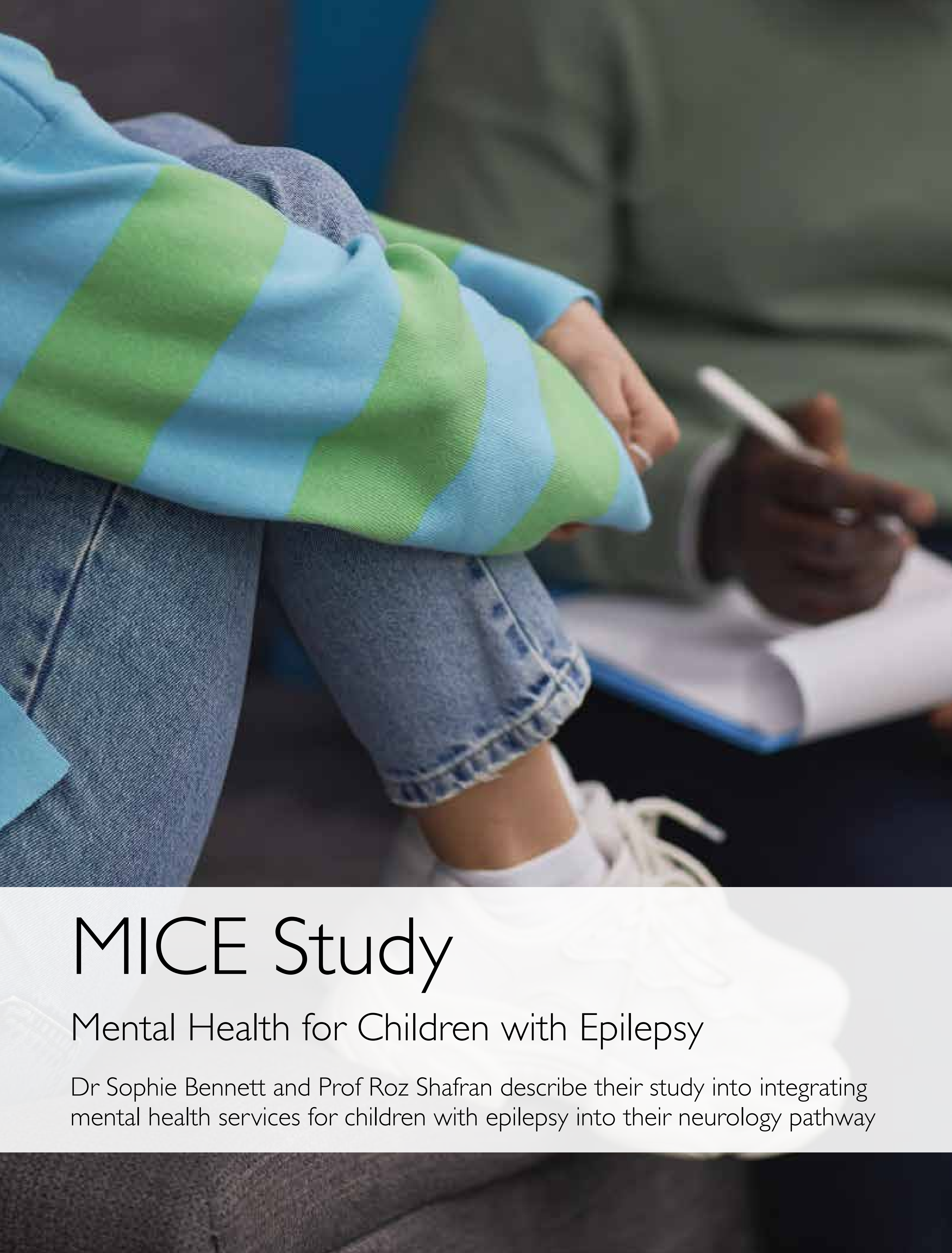
And finally, we need to take action. The UK NHS has boldly declared ambitious targets to reduce its carbon emissions: it has already, for example, decommissioned the anaesthetic gas desflurane, in favour of equally safe and effective, but less potent in terms of greenhouse gas-effect, alternatives. For the NHS to achieve its aim, we will all need to take action. The healthcare sector in the UK accounts for some 4% of the UK's greenhouse gas emissions. Across the world, the healthcare sector, if it were a country, would be the world's fifth greatest greenhouse gas emitter. We ban smoking in hospitals, partly because it would be nonsensical to allow it. By the same token, climate change is the biggest threat to human health, and healthcare services face increased demand during heatwaves – we have to reduce our own contributions to the problem. This principle applies to all our professional behaviours – for example, is it necessary to fly to every conference, or could some be attended virtually? Healthcare professionals in the UK have had their own challenges in recent years, including pay and their own mental health. But it is also sobering to note that the world's richest 10% produce as much greenhouse gas emissions as the rest of the world's population put together. There are many actions we can take at individual, professional and institutional levels.

For the people whose health we work to improve – people with epilepsy – we need to think about climate change. I would rather not have to think about climate change, and just think about what causes drug resistance in epilepsy, or how best to help the patient with a complex genetic epilepsy on ITU get better and get home. I would rather spend the rest of my career focused on epilepsy alone. But I can no longer do that, ignoring the context within which we work. The world has changed. Just as COVID was, climate change is part of our professional lives: we have to engage and act.

Prof Sanjay M. Sisodiya
Department of Clinical and Experimental Epilepsy
UCL Queen Square Institute of Neurology
Chalfont Centre for Epilepsy
s.sisodiya@ucl.ac.uk

Further reading

Abbasi K, Ali P, Barbour V, Benfield T, Bibbins-Domingo K, Hancocks S, Horton R, Laybourn-Langton L, Mash R, Sahni P, Sharief WM, Yonga P and Zielinski C. (2024). Editorial: Time to Treat the Climate and Nature Crisis as One Indivisible Global Health Emergency. Journal of General Internal Medicine, 39(8), pp.1283–1285. doi:https://doi.org/10.1007/s11606-024-08634-9.
Atwoli L, Baqui AH, Benfield T, Bosurgi R, Godlee F, Hancocks S, Horton R, Laybourn-Langton L, Monteiro CA, Norman I, Patrick K, Praities N, Rikkert MGMO, Rubin EJ, Sahni P, Smith R, Talley NJ, Turale S and Vázquez D. (2021). Call for emergency action to limit global temperature increases, restore biodiversity, and protect health. BMJ, [online] 374, p.n1734. doi:https://doi.org/10.1136/bmj.n1734. NOAA (2024). Global Monitoring Laboratory - Carbon Cycle Greenhouse Gases. [online] gml.noaa.gov. Available at: https://gml.noaa.gov/ccgg/trends/. Accessed 23 September 2024.
Clayton S. (2020) Climate anxiety: Psychological responses to climate change. J Anxiety Disord 74: 102263.
Gulcebi MI, Bartolini E, Lee O, et al. (2021). Climate change and epilepsy: Insights from clinical and basic science studies. Epilepsy & Behavior: E&B, [online] 116, p.107791. doi:https://doi.org/10.1016/j.yebeh.2021.107791.
Karachristianou S, Papamichalis E, Sarantopoulos A, Boura P, Georgiadis G. (2013) Hypohidrosis induced by topiramate in an adult patient. Epileptic Disord. 15(2):203-6.
Letter to Wes Streeting. (2024) [online] https://epilepsysociety.org.uk/sites/default/files/2024-08/Health%20Secretary%20letter%20-%20medicines%20supply_%20Aug%202024.pdf Accessed 23 September 2024.
Manivannan A, Kabbani D, Levine D. (2021) Use of multiple anticholinergic medications can predispose patients to severe non-exertional hyperthermia. BMJ Case Rep. 14(3):e239873.
McNicholas OC, Jiménez-Jiménez D, Oliveira JFA, et al. (2024) The influence of temperature and genomic variation on intracranial EEG measures in people with epilepsy. Brain Commun. Sep 10;6(5):fcae269.
Romanello M, Napoli CD, Green C, et al. (2023) The 2023 report of the Lancet Countdown on health and climate change: the imperative for a health-centred response in a world facing irreversible harms. The Lancet, 402(10419). doi:https://doi.org/10.1016/s0140-6736(23)01859-7.
Sisodiya SM. (2023) Climate change and the brain. Brain 146(5):1731-1733.
Sisodiya SM. (2024) Hot brain: practical climate change advice for neurologists. Pract Neurol. 24(1):28-36.
Sisodiya SM, Gulcebi MI, Fortunato F et al. (2024). Climate change and disorders of the nervous system. Lancet neurology, 23(6), pp.636–648. doi:https://doi.org/10.1016/s1474-4422(24)00087-5. World Meteorological Organization (2024). Climate Change Indicators Reached Record Levels in 2023: WMO. [online] World Meteorological Organization. Available at: https://wmo.int/news/media-centre/climate-change-indicators-reached-record-levels-2023-wmo Accessed 23 September 2024.
Worldweatherattribution.org. (2024). Europe – World Weather Attribution. [online] Available at: https://www.worldweatherattribution.org/location/europe/ [Accessed 23 Sep. 2024].



MICE Study

Mental Health for Children with Epilepsy

Dr Sophie Bennett and Prof Roz Shafran describe their study into integrating mental health services for children with epilepsy into their neurology pathway

Epilepsy is a neurological disorder that involves more than seizures. Around two in five children or young people with epilepsy also have a common mental health condition, like anxiety or depression [Davies et al, 2003; Russ et al, 2012], compared to around one in five for children and young people who do not have a chronic illness [NHS England, 2023]. There are many possible reasons for this; for example, it can be hard to live with the unpredictability of seizures, seizures can affect activities we associate with transition to adulthood like driving, and some anti-seizure medications can affect mood and behaviour [Dunn et al, 2016]. In addition, people with neurological conditions are more likely to have mental health difficulties than people with other chronic physical health conditions, and people with epilepsy have higher rates of mental health difficulties even before seizures develop [Kanner et al, 2012]. This suggests that there may be some shared neurological factors that may increase the risk of developing both seizures and mental health difficulties. The mental health conditions can affect the quality of life of young people and their families more than physical health factors such as seizure status [Baca et al, 2011].

Until now, services for mental health have typically been separated from services for physical health for children and young people with epilepsy and this results in children 'falling through the gap'. As most services do not have co-located mental health professionals, such as psychologists or psychiatrists [RCPCH, 2021], children may be referred to external children and young people's mental health services (CYPMH). However, clinicians in CYPMH may reject these referrals because the addition of epilepsy is perceived as complex and needing specialist support/intervention [Byrne et al, 2023]. This means that many children and young people are not able to get the mental health support they need [Welch et al, 2020], even though we know that treating mental health problems can improve children's quality of life and future outcomes like educational qualifications [Knapp and Wong, 2020].

The mental health conditions can affect the quality of life of young people and their families more than physical health factors such as seizure status

Our research programme set out to address this gap. Thousands of papers demonstrate the efficacy of standard evidence-based intervention for mental health intervention in children [Weisz et al, 2012] and research showed that they are effective for a wide range of children and young people, including neurodivergent young people [Weston et al, 2016]. However, we did not know if such evidence-based mental health treatments were safe and efficacious in children with epilepsy. There was reason to think that these treatments would also work in children with epilepsy, however, particularly since we know that the underlying causes of mental health difficulties in children and young people with epilepsy may not be directly related to seizures. Healthtalk explains: "The relationship between epilepsy and anxiety or depression was complex for young people; it wasn't just feeling down about their diagnosis. Most people who had had anxiety or depression said it was connected to their life situations, such

as problems in the family or losing a relative" [Health Talk, 2016]. We therefore thought it was most cost effective to trial a modified version of an existing evidence-based intervention for mental health difficulties in children and young people, as recommended by the National Institute for Health and Care Excellence (NICE) and other international bodies. Families we spoke with said they would find it most helpful if the therapist could be someone in their epilepsy team who understood what it was like to have epilepsy ["Obviously they don't need to know the ins and outs of epilepsy and the medical terms, but I think someone's got to understand that having epilepsy must be like you're walking on a frozen lake, waiting for it to crack"; Bennett et al, 2018]. The MICE programme therefore aimed to transform the mental healthcare of children and young people with epilepsy through integrating mental healthcare with physical healthcare in epilepsy services.

An assistant in the epilepsy clinic invited all parents of children and young people aged 3-18 to complete a short screening questionnaire (the Strengths and Difficulties Questionnaire; SDQ) [Goodman, 1997] on a tablet in the waiting room [Bennett et al, 2019]. We chose the SDQ because it covers a wide range of difficulties, is relatively short (it can be completed in five minutes in clinic) and can be used for the full age-range we could include in our study. This is the same measure that is used across child mental health services in England, which allows us to benchmark against the outcomes from these services. We included children with intellectual disabilities and autism spectrum disorder diagnoses because we know children who have these additional diagnoses may be even less likely to have their mental health needs met and we did not want them to be excluded from receiving potentially helpful treatment. We also wanted our findings to be as relevant to routine clinical services as possible so that the intervention could be easily implemented if found to be effective.

Once the SDQ was completed, it was scored automatically. An inbuilt algorithm meant that those who did not report that their child had significant emotional and/or behavioural difficulties that interfered with their day-to-day life would finish at that point. Those who did have difficulties were asked to complete a longer package of interviews, questionnaires and rating techniques designed to generate ICD-10 and DSM-IV or DSM-5 psychiatric diagnoses on 2-17-year-olds (the Development and Wellbeing Assessment; DAWBA) [Goodman et al, 2000]. The DAWBA could be completed in families' own homes and did not have to be completed in one sitting. It took about an hour depending on how many difficulties were noted. The completed DAWBA was then automatically sent to a clinician from the MICE team who

The MICE programme aimed to transform the mental healthcare of children and young people with epilepsy through integrating mental healthcare with physical healthcare in epilepsy services

read all of the information to understand whether there was a mental health difficulty that could be treated using the MICE treatment (i.e. anxiety, low mood and/or behavioural difficulties).

The MICE intervention was developed in close collaboration with young people with epilepsy and their families, charities such as Epilepsy Action and Young Epilepsy, and clinicians. We took an existing evidence-based intervention, the Modular Approach to Therapy for Children with Anxiety, Depression, Trauma and Conduct (MATCH-ADTC) [Chorpita and Weisz, 2009] and modified it for children and young people with epilepsy. We chose this intervention because it is modular, which allows a therapist to address more than one area of difficulty with a single treatment protocol (e.g. anxiety and depression) rather than having separate treatments for each. It also meant that we could add a module specifically for epilepsy. We developed this 'Epilepsy Specific Module for Youth' (ESMY) through literature reviews to inform us of factors that might uniquely affect mental health in children and young people with epilepsy, focus groups of families and clinicians, and iterative testing with patients [Shafran et al, 2020]. The final epilepsy module included education about the relationship between epilepsy and mental health. Many families we spoke with felt that they had been blamed for their child's mental health difficulties, or otherwise stigmatised. They had never been told that there were higher rates of mental health difficulties in children with epilepsy. The new module allowed us to provide information to normalise mental health difficulties in epilepsy and explain some of the reasons for the higher rates, with the aim of reducing the guilt and perceived blame felt by some parents. It also clarified that whilst many children with epilepsy may have mental health difficulties, and that these may be affected by anti-seizure medications, that did not mean that we could not improve those difficulties in some way.

The MICE intervention was developed in close collaboration with young people with epilepsy and their families, charities such as Epilepsy Action and Young Epilepsy, and clinicians

Families helped us to develop 'Frequently Asked Questions' about mental health difficulties in epilepsy, together with a list of useful resources, like websites or support groups. These were provided to families at the beginning of the treatment. We also developed optional modules for difficulties that might frequently occur for children and young people with epilepsy. These included modules on: stigma (around both epilepsy and mental health difficulties); parental mental health, as we know that many parents of children with epilepsy may have anxiety or depression [Lv et al, 2009]; and transition to adulthood, as we know that can be a particularly challenging time for both young people and their parents [Thomson et al, 2014]. These were added to the existing MATCH-ADTC intervention. The existing intervention was also modified by including epilepsy specific examples throughout the modules for

anxiety, depression and behavioural difficulties. It was delivered remotely to either parents, or to young people directly, depending on the main presenting difficulty, the age of the child/young person and the ability of the child/young person. We also developed training so that clinicians in the epilepsy services, such as epilepsy specialist nurses, would be able to deliver the intervention. We ensured that the intervention was effective and that the therapists we trained could deliver it to an appropriate standard before we proceeded to the full trial [Bennett et al, 2021; Coughtrey et al, 2021].

In the trial, 334 children and young people were randomised to receive either the MICE intervention in addition to usual care for their mental health difficulties, or usual care alone. We assessed their progress at baseline and six and 12 months later. Children in the MICE arm received up to 20 sessions within the first six-month period. We assessed mental health outcomes and quality of life for the child/young person with epilepsy as well as the mental health of the parents. Our results showed that children and young people who were in the 'MICE' arm of the study had significantly better mental health at the six-month timepoint compared to those who received usual care alone

> **"Seeing how far we have all come in a year was astonishing and that was all down to our 'Key Worker' and the MICE project"**

Further reading

Baca CB, Vickrey BG, Caplan R, Vassar SD and Berg AT. 2011. Psychiatric and medical comorbidity and quality of life outcomes in childhood-onset epilepsy. Pediatrics, 128(6), pp.e1532-e1543.

Bennett SD, Coughtrey AE, Heyman I, Greally S, Clarkson H, Bhattacharyya T, Lewis C, Varadkar S and Shafran R. 2018. Guided self-help for mental health disorders in children and young people with chronic neurological conditions: A qualitative evaluation. European Journal of Paediatric Neurology, 22(4), pp.620-631.

Bennett SD, Au C, Byford S, Chorpita B, Coughtrey AE, Cross JH, Dalrymple E, Fonagy P, Ford T, Heyman I and Lewins A. 2021. Feasibility of telephone-delivered therapy for common mental health difficulties embedded in pediatric epilepsy clinics. Epilepsy & Behavior, 116, p.107743.

Bennett SD, Cross JH, Chowdhury K, Ford T, Heyman I, Coughtrey AE, Dalrymple E, Byford S, Chorpita B, Fonagy P and Moss-Morris R. 2024. Clinical effectiveness of the psychological therapy Mental Health Intervention for Children with Epilepsy in addition to usual care compared with assessment-enhanced usual care alone: a multicentre, randomised controlled clinical trial in the UK. The Lancet, 403(10433), pp.1254-1266.

Bennett SD, Heyman I, Coughtrey AE, Buszewicz M, Byford S, Dore CJ, Fonagy P, Ford T, Moss-Morris R, Stephenson T, Varadkar S and Shafran R. 2019. Assessing feasibility of routine identification tools for mental health disorder in neurology clinics. Archives of disease in childhood, 104(12), pp.1161-1166.

Byrne GR, Shafran R, Whadcock K and Bennett SD. 2023. The influence of comorbidity and perceived complexity on outcomes of referrals to Children and Young Person Mental Health Services (UK): a mixed methods vignette study. Clinical child psychology and psychiatry, 28(4), pp.1393-1407.

Chorpita BF and Weisz JR. 2009. MATCH-ADTC: Modular Approach to Therapy for Children with Anxiety. Depression, Trauma, or Conduct Problems.

Coughtrey AE, Bennett SD, Sibelli A, Chorpita B, Dalrymple E, Fonagy P, Ford T, Heyman I, Moss-Morris R, Ching BC and Shafran R. 2021. "A greatest hits compilation of mental health support": A qualitative study of health professionals' perceptions of modular CBT in pediatric epilepsy services. Epilepsy & Behavior, 123, p.108249.

Davies S, Heyman I and Goodman R. 2003. A population survey of mental health problems in children with epilepsy. Developmental medicine and child neurology, 45(5), pp.292-295.

Dunn DW, Besag F, Caplan R, Aldenkamp A, Gobbi G and Sillanpää M. 2016. Psychiatric and behavioural disorders in children with epilepsy (ILAE Task Force Report): anxiety, depression and childhood epilepsy. Epileptic Disorders, 18(s1), pp.S24-S30.

Gandy M, Michaelis R, Acraman J, Donald KA, Fitzpatrick M, LaFrance Jr WC, Margolis SA, Modi AC, Reuber M, Tang V and Thayer Z. 2023. Integrated psychological care services within seizure settings: key components and implementation factors

for their mental health difficulties. Their mental health also remained better six months after the treatment had finished (the 12-month timepoint). The quality of life of the children and young people, and mental health of the parents, was also better in the MICE group following the intervention compared to those in the usual care group [Bennett et al, 2024].

Importantly, parents and young people found the intervention highly acceptable. One told us: "Seeing how far we all had come on in a year was astonishing and that was all thanks to our 'Key Worker' and the MICE project. I'm not saying every day is easy – that would be lying – but to have more good days than bad is a massive improvement… I think if I had one wish it would be that this trial will lead onto the MICE project being a permanent fixture for children with epilepsy and struggling with their mental health. They MICE Project definitely had a different outlook and understanding that other health care professionals didn't have, those that had tried to help in the past or the ones we had been turned away from."

We are now a step closer to that being a possibility. NHS England are piloting models of integrating mental health care within epilepsy services in several Integrated Care Boards. This will enable an evidence base to be generated for effective models of mental health support for children and young people with epilepsy. The pilots are also screening for mental health difficulties using the SDQ. The results of these SDQs are sent directly to physical health clinicians, and the clinicians are then able to offer a suite of interventions depending on the level of need, following a model piloted in NHS Lothian (The Psychology Adding Value – Epilepsy Screening (PAVES) and early intervention for children and young people with epilepsy at risk of mental health problems) [see Gandy et al, 2003 for further description]. In several sites, MICE is being offered to those with the greatest level of mental health need. The pilots are now being independently evaluated and the results will inform the next steps of integrating mental healthcare within physical healthcare for children and young people with epilepsy.

Sophie D Bennett
Clinical psychologist
King's College London

Roz Shafran
Professor of Translational Psychology
UCL Great Ormond Street Institute of Child Health

among example services in four ILAE regions: a report by the ILAE Psychiatry Commission. Epilepsia, 64(7), pp.1766-1784.

Goodman R. 1997. The Strengths and Difficulties Questionnaire: a research note. Journal of child psychology and psychiatry, 38(5), pp.581-586.

Goodman R, Ford T, Richards H, Gatward R and Meltzer H. 2000. The development and well-being assessment: Description and initial validation of an integrated assessment of child and adolescent psychopathology. Journal of child psychology and psychiatry, 41(5), pp.645-655.

Healthtalk (2016) Anxiety, depression and epilepsy. Available at: https://healthtalk.org/experiences/epilepsy-in-young-people/anxiety-and-depression-and-epilepsy/ (Accessed: 21 January 2025).

Kanner AM, Schachter SC, Barry JJ, Hersdorffer DC, Mula M, Trimble M, Hermann B, Ettinger AE, Dunn D, Caplan R and Ryvlin P. 2012. Depression and epilepsy: epidemiologic and neurobiologic perspectives that may explain their high comorbid occurrence. Epilepsy & Behavior, 24(2), pp.156-168.

Knapp M and Wong G. 2020. Economics and mental health: the current scenario. World Psychiatry, 19(1), pp.3-14.

Lv R, Wu L, Jin L, Lu Q, Wang M, Qu Y and Liu H. 2009. Depression, anxiety and quality of life in parents of children with epilepsy. Acta Neurologica Scandinavica, 120(5), pp.335-341.

NHS England, 2023. One in five children and young people had a probable mental disorder in 2023. NHS England. Available at: https://www.england.nhs.uk/2023/11/one-in-five-children-and-young-people-had-a-probable-mental-disorder-in-2023/ [Accessed 22 Jan. 2025].

Royal College of Paediatrics and Child Health (2021) Epilepsy12: Combined organisational and clinical audits: Report for England and Wales, Round 3 Cohort 2 (2019-20). Available at: https://www.rcpch.ac.uk/sites/default/files/2021-07/Epilepsy12%20summary%20report%203.3_0.pdf (Accessed: 21 January 2025).

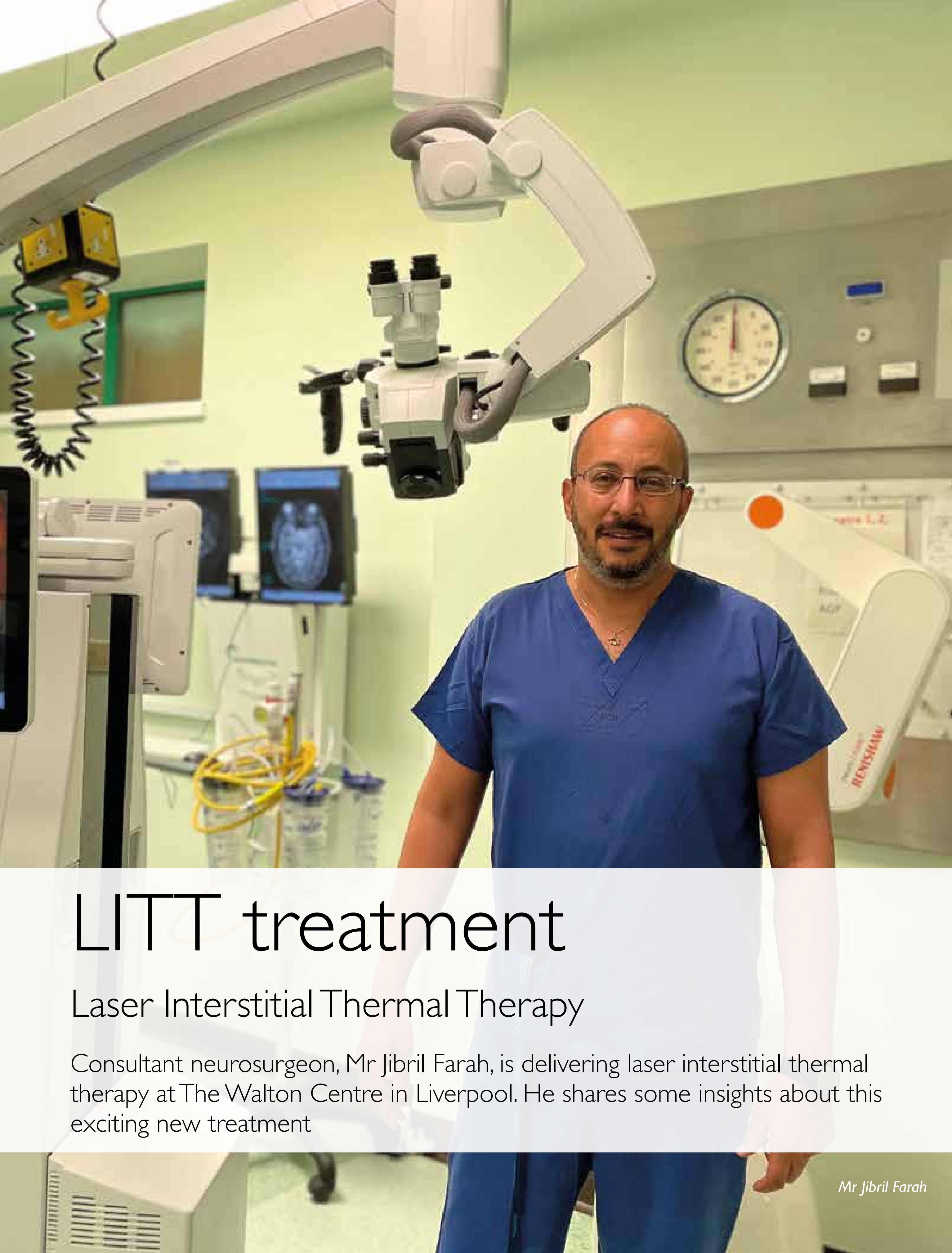
Russ SA, Larson K and Halfon N. 2012. A national profile of childhood epilepsy and seizure disorder. Pediatrics, 129(2), pp.256-264.

Shafran R, Bennett S, Coughtrey A, Welch A, Walji F, Cross JH, Heyman I, Sibelli A, Smith J, Ross J, Dalrymple E, Vardkar S, MICE Study Team and Moss-Morris R. 2020. Optimising evidence-based psychological treatment for the mental health needs of children with epilepsy: principles and methods. Clinical Child and Family Psychology Review, 23, pp.284-295.

Thomson L, Fayed N, Sedarous F and Ronen GM. 2014. Life quality and health in adolescents and emerging adults with epilepsy during the years of transition: a scoping review. Developmental Medicine & Child Neurology, 56(5), pp.421-433.

Welch A, Shafran R, Heyman I, Coughtrey A and Bennett S. 2020. Usual care for mental health problems in children with epilepsy: a cohort study. F1000Research, 7, p.1907.

Weston L, Hodgekins J and Langdon PE. 2016. Effectiveness of cognitive behavioural therapy with people who have autistic spectrum disorders: A systematic review and meta-analysis. Clinical psychology review, 49, pp.41-54.



Mr Jibril Farah

LITT treatment

Laser Interstitial Thermal Therapy

Consultant neurosurgeon, Mr Jibril Farah, is delivering laser interstitial thermal therapy at The Walton Centre in Liverpool. He shares some insights about this exciting new treatment

Laser interstitial thermal therapy – known as LITT, is a treatment for epilepsy that uses heat from a laser beam to destroy damaged areas of the brain that cause seizures.

This treatment is also sometimes known as laser ablation surgery, and can be used as a less invasive alternative to open skull surgery.

The treatment promises a speedier and less painful recovery, and offers fewer cognitive problems afterwards compared to more typical epilepsy surgery.

We spoke to Mr Farah to learn more about this treatment.

KK: Can you tell me a bit about the LITT treatment?

JF: The operation is a form of ablation. Once brain tissue has been identified as a focus of epilepsy, it is possible to burn it away with a laser probe.

The probe is delivered through a twist drill and then is inserted into the focus. The laser ablation can be used in cases such as hypothalamic hamartoma in the UK. In the US, it can be used for temporal lobe epilepsy or extratemporal lobe epilepsy.

KK: Who is eligible for this treatment?

JF: This treatment is only available for people with focal seizures, and the maximum seizure focus size that can be ablated is 3cm. It is not used for generalised epilepsy at the moment, although there is a new way of doing a corpus callosotomy (where a band of fibres connecting the two halves of the brain are cut), but I would say that this is still experimental.

In the US, the model for treatment has changed, and now LITT is considered the first-line treatment and those who fail it are considered for surgery.

I may not agree completely with a change of the model of this level in the UK. Here, LITT is limited to those cases in which open surgery is not an option, and I think that is a better option while we are building the experience in this country.

KK: How effective is this treatment?

JF: It has been proven to be as effective as surgery in suitable cases. A meta-analysis of data from 16 studies that included 269 patients with treatment-resistant epilepsy showed that MRI-guided LITT significantly reduced the frequency of seizures and reduced postoperative complications, supporting the safety and effectiveness of MRI-guided LITT in the treatment of drug-resistant epilepsy. The reported average figure was 61%, ranging between 41-88% depending on the indication (seizure cause).

KK: What further research do we need in the UK on it?

JF: In the UK, research is limited at the moment. In the US, LITT is well researched.

Practically, in the UK, you need to build up the experience and so our experience is mainly on hypothalamic hamartoma, which is only one indication. But looking at temporal lobe and extratemporal lobe epilepsies, our experience is limited, I would say.

We can utilise the research that is in the US. I wouldn't personally consider LITT an alternative to surgery in this moment in time, because the evidence that there is from the US is not strong enough in certain aspects. There are no specific restrictions on what can be treated with LITT in the UK. At The Walton Centre we decided to treat focal epilepsies related to conditions difficult to treat with open surgery, or linked with higher surgical risks of complication. I think that's a more appropriate approach to it.

KK: Where is the treatment currently available?

JF: This treatment is available on the NHS in Liverpool at The Walton Centre, and in London at Kings College Hospital for adult epilepsy.

For paediatric epilepsy, it's available in four centres, including Alder Hey,

Bristol Royal Hospital for Children and Great Ormond Street Hospital.

However, everyone can be referred within the country, it is very much open. I encourage a referral system from epilepsy services. In other words, it's important to identify the seizure focus, and the work up to surgery in epilepsy is quite long. I think this should be done at the local unit, and any appropriate cases can be referred to us and I would be very happy to provide the treatment.

What we cannot do is become a centre that investigates the types of epilepsy for the whole of the north of the UK. So, generally, the referral should be from let's say Newcastle area. Newcastle should investigate the patient and then refer the patient to us. Manchester should investigate the patient and then refer them to us.

We aren't in a position to investigate all the patients with epilepsy covering such a widespread area.

What has been a bit disappointing is that since the service has started, I haven't received a single referral outside of our catchment area of region. All the referrals and all the treatments have been from within our catchment area, which is basically Merseyside and Cheshire. So, we cover the northwest of England, Merseyside and North Wales. That has been the catchment area from where we received referrals.

Theoretically, we should have received patients from Manchester, Newcastle, Sheffield, because we are covering the whole of the north of the UK up to Birmingham.

I don't know why this is the case, but I would have expected that each one of these areas will have at least hypothalamic hamartoma patients on their books. There will be hypothalamic hamartoma patients in Sheffield, in Newcastle, in Manchester. But none of them have been referred for laser and this is an appropriate treatment for them.

I have also offered to my colleagues the possibility of utilising our machine. So, I would be very happy, if the patient is worked up correctly, to discuss the patient that they want to refer and then they themselves can actually physically come here and utilise the machine and perform the treatment.

KK: What is the cost of this procedure?

JF: The cost per capita is £10,000. For a resection for epilepsy, it would cost the NHS £9,000. So, with laser, a single probe will be more expensive than the open surgery procedure.

KK: For a patient, what does a day look like coming in for this treatment?

JF: This is a minimally invasive treatment, in the sense that it will substitute a full craniotomy. These cases are sometimes done as day cases, or possibly with a 24-hour hospital stay. The patient signs a consent form and undergoes general anaesthesia. I then place a static frame, I do a registration and then will place the laser probe using a robotic arm for precision. Then I will verify the position of the laser probe and after I verify the position, we go into the MRI scanner and the treatment is delivered within the MRI scanner with the patient asleep.

The ablation and the treatment probably lasts about half an hour. Then the patient has a scan to verify the ablation and then we remove the laser probe and the patient is woken up.

At the moment, we're keeping patients for 24 hours after the procedure. In the future, I think we'll go down the route of a day case and therefore we will discharge the patient on the same day.

KK: What's the aftercare and recovery like for patients?
JF: There isn't really any sort of scar and there is no hair shaving. The only thing is just a small entry point where a single suture is applied.

People are observed in recovery for a few hours and then the patient goes to the ward or goes home.

The only problem could be oedema (a build up of fluid) and swelling. The swelling is the biggest issue, and will occur post operatively within a week. Generally, this is controlled with steroids, so we send the patient home with steroids to take. It lasts between six and eight days and resolves progressively.

KK: Can you have the procedure done more than once?
JF: It can be repeated and it can be staged. There are a lot of openings on that. For example, if you want to treat a 3cm area and then you realise that you've actually only ablated 2cm, you can retreat the patient. Or, if you want to treat a 6cm area, you can stage the treatment over two LITT procedures, so you can treat a 3cm area first and then a second 3cm area next time. This is possible as well.

KK: Can patients be weaned off their epilepsy medicines after having the treatment?
JF: The same applies to patients getting LITT as with patients undergoing open surgery. On other words, you can get seizure freedom on and off medication. The best success and outcome would be seizure freedom off medication. But you can also be seizure free and stay on medication.

That means it's the choice of the patient whether to stop the medication. Several patients will not want to stop their medication, particularly adults, due to the potential risk of losing their driving licence.

The normal procedure is that we would attempt to stop the medication within one year from the treatment, because if a patient has been seizure free for one year, they would be reluctant to stop their medication and risk losing their driving licence.

From my experience, about 50% of my patients who are completely seizure free would say that they prefer to stay on medication, but the target would be to make patients seizure free off medication.

KK: Are there waiting lists for this treatment at the moment?
JF: On my books, I have about five patients waiting, so the list is not particularly long. There is a longer wait for the investigations within the epilepsy surgical programme. You need to identify a focus where seizures are coming from and all those investigations, and the epilepsy programme itself will have a longer wait time.

KK: What are the next steps for this treatment?
JF: In the longer term, possibly in the next three to five years, I would expect that each major epilepsy service within the UK will offer this treatment and I wouldn't expect that the whole of the North of England would be covered by one single centre. But I would not expect that every single new surgery unit would have this as a treatment option, I think this will depend on how big the epilepsy programme is.

Mr Jibril Farah
Consultant neurosurgeon
The Walton Centre

Jenson, Darcie and William

Patient perspective

The impact of mental health problems in children can be really significant. It can affect their wellbeing, challenge the whole family and can take its toll physically – including increasing seizures. Rachael shares more about the mental and physical health challenges her three children face, what support would make a big difference to them and how they always manage to keep smiling

I have three amazing children who I am extremely proud of. Jenson is my eldest, 13. He had his first seizure when he was eight months old. He started having tonic-clonic seizures, and then, as time went on, he began to have absence seizures, focal impaired awareness seizures (complex partial at the time) and atonic seizures. Jenson also has diagnoses of autism, attention deficit hyperactivity disorder (ADHD) and dyslexia.

William, 11, started having his seizures at eight weeks old, where he had 113 seizures over 10 days. William has tonic-clonic seizures, absence seizures, focal aware seizures and can be prone to having tonic seizures, particularly when he's unwell. William also has tics, Pica, ADHD and autism.

Darcie, nine, started having seizures when she was about 10 months old. She has absence seizures, tonic-clonic seizures and focal seizures. Her longest focal seizure was 26 minutes when she was little. Darcie has been referred and is currently on the autism spectrum disorder (ASD) pathway.

Growing up, it has been challenging for them having a lot more to deal with from such a young age compared to their peers. We have always wanted the children to be able to be as included as possible with school life and playing with their friends, but it hasn't always been possible with the many hospital admissions and appointments over the years.

However, I feel that out positive attitude as parents has really encouraged the children to realise how capable and able they are to be able to do things like their friends, being included and involved, even if it means having to have extra supervision.

I have always been extremely conscious of the children feeling 'different' and how this may make them feel. I have been unable to let them play out with their friends independently and allow them on their bikes in the village or to be in a pool unattended, and, as they've got older, they have asked me about it and realised there are reasons why they can't do things exactly like their peers. I think this does affect their confidence and mental health.

The children are becoming more self-aware, and this is something which becomes more apparent as they get older, realising that their friends don't have to take medicines twice a day or don't have to go to lots of appointments, for example.

Jenson, in particular, is extremely anxious, which also links with his autism. He struggles to socialise the most out of the children. When Jenson was at primary school, a child once made a nasty remark about his seizures, and I think he has always remembered this, knocking his confidence.

Also, William's tics look very similar to focal seizures and again, this definitely affects his self-confidence, mental health and self-esteem.

One of the biggest challenges so far this year has been the children being off school poorly for the first two weeks of term after Christmas. They had high temperatures and William had to go to hospital. It doesn't sound like a very big deal, but, for my kids, this has a huge impact on the children when they do return to school. They have to get back into routine, they have to catch up on the work that they missed and all the homework they have to do. This then causes them great anxiety, exhaustion and stress, which can then affect them physically with stomach pains, headaches and increased seizures. Jenson has recently developed a tic and I think this is linked to the stress of everything going on for him at the moment.

I would definitely say that there is a link between the children's epilepsy and their mental health. I think that stress can definitely make seizures worse for them, which, as the children have got older, they are becoming more aware of. Missing school when they are poorly or have appointments can cause them stress, which can present physically, as with the start of this year, or mentally, with anxiety, panic and worry.

Over the years, I have had many people tell me they don't know how we manage with everything. But, to be honest, you always find a way, especially when you don't have a choice. I have autism myself, which I think has played a positive role when looking after the children. I'm very organised with things like their medication, appointment and recording seizures.

When Jenson first started having seizures, I felt scared and isolated, which is why I reached out to Epilepsy Action. After William was diagnosed with epilepsy, I decidede to try to help others become more aware of what to do if you saw someone having a seizure. That's when I became a media volunteer for Epilepsy Action. This made me feel much more positive, knowing I wasn't in this alone.

We have to plan ahead with things like days out, and we always have an emergency plan in case of a seizure. With the children also having autism and ADHD, we also have to tailor days out to cover these needs and challenges too. I've always found that having a hospital bag packed ready in case of an emergency has been extremely useful.

For us as parents, the biggest challenges are making sure the children all feel included, valued, understood and are happy – all whilst keeping them safe. As they get older and move to high school, you have to find the right balance of giving them more independence but making sure that they will be safe if they have a seizure. Thankfully, the high school my children attend is very accommodating. It is essential that professionals, schools and parents work together to insure the best possible outcome for the children.

The children have good support within school, particularly from the special educational needs (SEN) department, but my husband Ben and I have spoken about reaching out to a local counselling/mental health service. We have recently joined the cheshire autism practical support (CHAPS), which we are also hoping will have a positive impact on the children's mental health.

I think there needs to be more inclusive mental health support for children with epilepsy and also with SEN, autism and ADHD. It would be great if this could be done in school and built into the children's school timetable. I would like to see a more positive representation of epilepsy, autism and ADHD taught within schools to make all children and teachers aware that some children may have additional needs, but it doesn't mean they should be any less valued. If anything, they should realise they are all amazing, as most people don't have to go through half of the worries that some children have to go through. Even then, it doesn't stop them smiling!

Ben and Rachael with kids Jenson, William and Darcie

ILAE British Branch:

Annual Scientific Meeting 2024

Epilepsy Action's Tom Shillito and Emily Mossman provide a summary of some of the highlights of last October's ILAE British Branch Annual Scientific Meeting, covering ASMs, mental health and technology

The International League Against Epilepsy British Branch Annual Scientific Meeting took place in Liverpool from 21-23 October last year. This annual conference covers the treatment of, and science behind, epilepsy, and is attended by researchers and healthcare professionals from across the UK.

Epilepsy Action was pleased to present two posters at the meeting. The first outlined our work benchmarking care for people with epilepsy and a learning disability using the Step Together toolkit (see page 30 for more information). The second covered the process we used to coproduce a new service specification and clinical guidance for the management of preconception and maternity care for people with epilepsy. For more information you can visit [Epilepsy Action Maternity Project, 2025].

We were also co-authors on posters about risk prediction tools for conveyance to hospital after a seizure and managing seizures in care homes [Noble et al, 2024a; Noble et al 2024b; Morris et al, 2024].

There were 43 different talks and symposia across the three days of the conference. Here are some of the highlights.

Drug safety in pregnancy

The first day of the conference concluded with an interesting session on epilepsy and pregnancy. This session focussed on anti-seizure medication (ASM) safety during pregnancy.

The first talk in this session was given by Dr Graeme Sills, who discussed the safety profiles of different ASMs when used during pregnancy. He gave an overview of the drugs with the best safety profiles, and highlighted where there is a lack of information.

Dr Sills began by explaining the lack of evidence regarding the use of newer ASMs during pregnancy. This is due to patients being discouraged from using them during pregnancy, as there is little information about their effects on a foetus. ASMs that have not been tested for their safety and efficacy during pregnancy should not be used during pregnancy, but evidence can't be generated without their use, so there is a stalemate in the advancement of our understanding in this area.

He went on to mention that lamotrigine and levetiracetam are considered the safest ASMs to use during pregnancy, and this seems to be backed up by the evidence. He did mention that many of the deaths from recent MBRRACE reports have been of women taking lamotrigine. However, these deaths are often due to poor epilepsy management, rather than due to the drug itself.

Dr Sills mentioned oxcarbazepine, zonasamide and lacosamide as ASMs that seem to have promising safety profiles for use during pregnancy, based on the current, limited, evidence.

The evidence around the safety of topiramate is less clear. This drug has now been added to the Pregnancy Prevention Programme in the UK. The evidence on how safe it is during pregnancy is mixed, but there is some evidence of it having teratogenic effects.

Sodium valproate is well established to have significant teratogenic effects, and its prescription is subject to strict restrictions in the UK. However, it is a very effective ASM. Dr Sills briefly mentioned the changes to valproate prescribing for men. He said that the fertility impacts valproate may have for men seem to be reversible. There is little human data on the potential transgenerational effects valproate may have for children of fathers who are taking it. The human data that does exist is not robust enough to be taken as proof of those impacts in isolation.

The second talk in the pregnancy session was given by Dr Rebecca Bromley. She explained why we know so little about ASM safety during pregnancy, and suggested ways this could be remedied.

Dr Bromley began by giving the history of ASM use in pregnancy, to create the context for current discussions. She used the example of sodium valproate, giving a timeline showing that it took 41 years from sodium valproate first being licensed, before patients began to be counselled about the risks it can pose during pregnancy.

Valproate first came to market in 1973, and the first case reports of potential pregnancy risks emerged in the 1980s, with high-quality evidence appearing in the early 2000s. The pregnancy prevention programme began in 2018, and the guidance for men began in 2024. It took over 40 years for the risks to be taken seriously, despite evidence being available much sooner.

Similarly, topiramate first came to market in 1995, and evidence of risks were first reported in 2008. The Pregnancy Prevention Programme for topiramate was not implemented until 2024- 29 years after it was first used, and 16 years after the first suggestion of risks.

When all ASMs are considered together, it takes a mean of 27 years for a risk profile to be developed for a new ASM

When all ASMs are considered together, it takes a mean of 27 years for a risk profile to be developed for a new ASM.

A 2021 review [Eadie] showed that the evidence of safety during pregnancy for all ASMs is very limited, including for lamotrigine and levetiracetam. Of 21 ASMs reviewed in an MHRA public assessment report [MHRA, 2021], only seven had risks assessed, and only two of those showed low risk (lamotrigine and levetiracetam).

One of the reasons it is so difficult to create a risk profile is because of the complexity of the task. Each ASM has different dosages, and there are many different types of malformation and neurodevelopmental impact that need to be assessed, as well as a myriad of other factors that can impact the risk and need to be evaluated.

Dr Bromley highlighted that in the UK we have a passive pharmacovigilance system, which is ineffective at generating risk profiles for drugs during pregnancy. The current reporting requirements only cover preclinical data and adverse events. There is no reporting of research outcomes or secondary health reporting, and adverse events seen in children are not linked to ASM use by their mother.

She also highlighted some historical and current biases that have contributed to our lack of knowledge. Historically, there was a higher tolerance for risk from ASMs. This is now changing, and we no longer accept that people with epilepsy either shouldn't become pregnant, or should accept the risk that their children may be impacted by their ASM. In a modern context, there are other biases in play. Dr Bromley highlighted many of these, the chief of which is the acceptance of the slow accumulation of data. The epilepsy community currently does not expect there to be safety data about ASM use during pregnancy, and accepts that data will be very slow to be gathered. In some circumstances an absence of evidence is treated as proof of the safety of the drug, as there is not any evidence showing that it isn't safe. This clearly is a serious risk to patients.

There is limited workforce and funding available to rectify this absence of data. However, Dr Bromley did present two projects which are working to generate evidence. The UK Epilepsy Pregnancy Register follows pregnant people through their

pregnancy and for many years after birth. It collects data about the child's neurodevelopment and can be used to assess the impacts that ASMs may have had during pregnancy.

Dr Bromley also presented the ConcePTION project, which is a Europe-wide initiative to develop better ways to assess the safety of medication during pregnancy and while breastfeeding. It will use routine healthcare data, pharmacovigilance data, information from pregnant people and their children, and modelling methods to generate evidence-based information about the effects of medication use during pregnancy. Both of these projects will gather data on medication use and outcomes, and offer new ways to gather data and evaluate safety.

Dr Bromley ended her talk by stating that there is a need for a mandated and well-funded approach to discovering the safest ASMs to use during pregnancy.

The final talk in this session was given by Dr John Craig, who spoke about monitoring ASM levels during pregnancy. He explained that monitoring ASM levels has become less common now that newer ASMs are not considered to have therapeutic ranges, however it is still an important part of keeping pregnant people with epilepsy safe. He also highlighted the need for proactive, not reactive monitoring – monitoring should be done to identify problems before they appear, and not left until after problems have manifested.

As everyone working within epilepsy will know, there is a delicate balance to be struck during pregnancy, between the risks associated with taking an ASM, and the risks of having a seizure while pregnant. The risks of a seizure to the mother are well understood. There are also well-known risks to the foetus posed by some ASMs, however maternal seizures can also be dangerous for the foetus, for example through hypoxia. Monitoring ASM blood levels can help to ensure seizures are kept to a minimum, without exposing the foetus to an excessive dose of ASM.

It is important to monitor blood levels, not just medication adherence, during pregnancy, as pregnancy affects the ability of ASMs to enter the blood in many ways. For example, lamotrigine and zonisamide levels have been observed to decrease throughout pregnancy. This can lead to an increase in seizures. Similar reductions are seen in many ASMs, with the only exceptions being sodium valproate and certain older ASMs. There are many reasons for the changes in ASM levels during pregnancy, including increased blood volume, increased renal clearance, changes in metabolism, and a reduction in absorption. The impact of these factors on ASM blood levels varies for each person, which is why regular monitoring is so important.

Dr Craig suggested that everyone should have annual ASM levels taken, so that if a pregnancy occurs there is a baseline to work from. Levels should then ideally be taken monthly during pregnancy and four weeks post-partum.

Epilepsy and Mental Health

The second day of the conference started with a session exploring mental health in epilepsy. It is well-established that epilepsy is associated with a high rate of co-occurring mental health issues, and the scope of these three talks spanned a range of topics relating to mental health. This included mental health in children with epilepsy, anxiety and depression in people with epilepsy, and alcohol related seizures.

Dr Sophie Bennett kick started the

session with the findings of the Mental Health Intervention for Children with Epilepsy (MICE) study [Bennett et al, 2024], published in March 2024. The study was a randomised controlled trial, aiming to evaluate the clinical effectiveness of integrated mental health treatment for children and young people with epilepsy.

A selection of 3–18-year-olds with epilepsy and a common mental health disorder received either the Mental Health Intervention for Children with Epilepsy (MICE), or the usual care pathway. The usual care pathway mostly consisted of referral to appropriate services, whereas children under MICE received interventions such as cognitive behaviour therapy. These interventions were integrated into epilepsy services and delivered by professionals that weren't mental health specialists.

A seizure is more likely to be due to alcohol withdrawal if there is no warning and it is within 48 hours of alcohol withdrawal

The results of the study demonstrated the advantages of integrating mental health care within physical healthcare. Strengths and Difficulties Questionnaires (SDQ) scores showed that children receiving the MICE intervention performed better, including those with intellectual disabilities and those who were neurodivergent.

You can read more about the MICE study in this issue of Epilepsy Professional on page 18.

The next talk was given by Dr Thomas Cope, a neurologist specialising in epilepsy and neuropsychiatry. Dr Cope talked about the complex relationship of anxiety and depression in people with epilepsy, and the various aspects that surround this area. He highlighted the bidirectional relationship between these mental health issues and seizures, as well as the intrinsic links between mood, memory and sleep.

He also explored the issues that surround selective serotonin reuptake inhibitors (SSRIs) for people with epilepsy. While people with epilepsy generally respond well to these treatments, they can cause sleep disturbances, which is an issue as lack of sleep can be a common seizure trigger. However, this risk may be mitigated by taking SSRIs earlier in the day.

It is difficult to talk about these mental health conditions without mentioning suicide. Dr Cope explained that people with epilepsy had higher rates of suicide if they had higher a frequency of seizures or unpredictable seizures. He also addressed the risk of suicide when taking levetiracetam and cautioned against its use in people with existing mental health conditions. The takeaway message of this talk was the importance of providing people with epilepsy the support and treatment to manage their mental health.

The final talk of this session was from Dr Craig Heath about supporting people with alcohol related seizures. He first addressed the challenges of differentiating alcohol withdrawal seizures from underlying epilepsy. A seizure is more likely to be due to alcohol withdrawal if there is no warning and it is within 48 hours of alcohol withdrawal. This type of seizure is less likely in younger people.

Dr Heath talked about the link between epilepsy and addiction, and

that substance misuse is much higher in people with epilepsy. The 2023 study by Marshall et al. found that 14% of people with epilepsy had a comorbid addiction. In another study (Taha et al in 2024), 25% of people with epilepsy had alcohol or substance misuse, and a third of those also had poor ASM adherence.

The talk also featured a study about the NHS Greater Glasgow and Clyde live integrated epilepsy Dashboard. Using Dashboards as a way to monitor people with epilepsy was a recurrent topic across the conference. In this instance, the data was used to retrospectively identify people with epilepsy who had an unscheduled epilepsy-related admission or A&E attendance. Ultimately, using dashboards like this to capture data, might help to identify patients who need intervention and support.

Medical technology- prediction tools and information sharing

Throughout the conference, there were a number of interesting talks about the use of technology to help support epilepsy research and treatment. The types of technology, and how they were being used, were very varied, and covered many important aspects of epilepsy care. Here are some highlights, covering how seizures can be predicted, and how to gather and best use electronic health record data.

Dr Laura Bonnet began the first session with a talk about epilepsy prediction models. She mentioned some common pitfalls found in the literature, and suggested ways that they could be avoided.

Dr Bonnet began by discussing some common issues with epilepsy prediction models, including that they can be difficult to understand, use very complex maths or machine learning, focus on fixed outcomes such as time to first seizure only, and, most worryingly, sometimes lack accuracy.

In light of these issues, she made suggestions of ways prediction models could be improved. She highlighted the importance of creating models that are useful in practice. They should be able to be used to inform treatment choice and guide patient counselling. If the models are not useful in clinic and easy to understand they won't be used. Models could be used to map patient journeys and the track impact of treatment and lifestyle changes.

Using correct and robust methodology is important, as is model validation. Dr Bonnett mentioned the TRIPOD reporting guidelines as a good structure to follow (G.S. Collins).

It is also important that models can be understood by the people using them, and the patients whose treatment may be guided by them. One way to make them easier to understand is to make them visual. For example, a checklist with associated scores can be an easy way to enter data into a model and get a quick result. Nomograms and graphic score charts are also good options, depending on the model and its function.

Dr Phil Tittensor spoke about the ATMOSPHERE project [Stuart et al, 2024], which is using AI to give patients a 'weather forecast' for their seizures. The forecast is created based on risk factor data input by the patient as well as data collected by a smartwatch, and uses AI to predict the seizure risk in a set time window. This project is based in the knowledge that many people with epilepsy struggle with the unpredictable nature of seizures. This can hold them back from living a full life, as they are never sure when a seizure might occur. By giving a forecast of predicted seizures, Dr Tittensor and colleagues hope to reduce risk by allowing patients to plan their activities based on the probability of a seizure occurring. This will also increase patients' ability to take part in activities currently limited by their seizures, and gives them more control over their lives.

Dr Sameer Zuberi spoke about the vCreate Neuro app. This is a cloud-based video sharing app that can be used by patients to share videos of seizures with clinicians. It is currently in use in Scotland. Dr Zuberi discussed the benefits seen by using this app. It has reduced costs, as videos can be screened quickly to identify any events that are clearly not epileptic seizures. This allows patients to be taken off the epilepsy pathway without the need for an EEG and before other scans and investigations have taken place. This also has a knock-on effect on waiting times, as only patients who need investigations are on the waiting lists, and those who need to be seen outside of neurology can be quickly moved to the correct service without waiting for unnecessary investigations. The vCreate Neuro app can be integrated into electronic health records, allowing for easy sharing of videos and information with all relevant healthcare professionals.

Tom Shillito
Health improvement and research manager
Epilepsy Action

Emily Mossman
Health information and research officer
Epilepsy Action

Further reading

Bennett, SD, Cross JH, Chowdhury K, Ford T, Heyman I, Coughtrey AE et al. (2024) Clinical effectiveness of the psychological therapy Mental Health Intervention for Children with Epilepsy in addition to usual care compared with assessment-enhanced usual care alone: a multicentre, randomised controlled clinical trial in the UK. The Lancet. 403(10433): 1254-1266. Available at: https://www.thelancet.com/journals/lancet/article/PIIS0140-6736(23)02791-5/fulltext

www.imi-conception.eu. (n.d.). ConcePTION. [online] Available at: https://www.imi-conception.eu/.

Eadie M. (2021) Pregnancy and the Control of Epileptic Seizures: A Review. Neurology and Therapy 10: 455-468. Available at: https://link.springer.com/article/10.1007/s40120-021-00252-5

Epilepsy Action. (2025). Maternity Project - Epilepsy Action. [online] Available at: https://www.epilepsy.org.uk/professional/maternity [Accessed 20 Jan. 2025].

www.epilepsyandpregnancy.co.uk. (n.d.). UK Epilepsy & Pregnancy. [online] Available at: https://www.epilepsyandpregnancy.co.uk/.

Marshall AD, Mackay D and Heath CA. (2023). Specialist epilepsy service input following an epilepsy related unscheduled care episode. Seizure, [online] 112, pp.15–17. doi:https://doi.org/10.1016/j.seizure.2023.09.009.

Medicines & Healthcare products Regulatory Agency. Gov.UK. (2021). Antiepileptic drugs: review of safety of use during pregnancy. [online]. Available at: https://www.gov.uk/government/publications/public-assesment-report-of-antiepileptic-drugs-review-of-safety-of-use-during-pregnancy/antiepileptic-drugs-review-of-safety-of-use-during-pregnancy

Morris B, Morris B, Morris B, Morris B, Morris B, Morris B and Morris B. (2024). 'In the wilderness…dealing with difficult situations': Knowledge exchange with care home staff in England on managing seizures and epilepsy – An initial exploration. Epilepsy & behavior, 158, pp.109936–109936. doi:https://doi.org/10.1016/j.yebeh.2024.109936.

Noble AJ, Lane S, Lloyd P, Morris B, Bell S, Shillito T, Dixon P and Marson AG. (2024a) 'Blue-lighting' seizure-related needs in care homes: a retrospective analysis of ambulance call-outs for seizures in North West England (2014-2021), their management and costs, with community comparisons. BMJ Open 14:e089126. doi: 10.1136/bmjopen-2024-089126

Noble AJ, Morris B, Bonnett LJ, Reuber M, Mason S, Wright J, Pilbery R, Bell F, Shillito T, Marson AG and Dickson JM. (2024b). 'Knowledge exchange' workshops to optimise development of a risk prediction tool to assist conveyance decisions for suspected seizures - Part of the Risk of ADverse Outcomes after a Suspected Seizure (RADOSS) project. Epilepsy & Behavior: E&B, [online] 151, p.109611. doi:https://doi.org/10.1016/j.yebeh.2023.109611.

Stuart L, Tittensor P, Junges L, Deighan MT, Charles R, Kissack P, Qureshi Y, Kamaraj A, Privett S, Woldman W and Brigden ALC. (2024). A 'weather forecast' for seizures. Artificial intelligence To Optimise Seizure Prediction to Empower people with Epilepsy (ATMOSPHERE): Proof-of-concept mixed-methods research. University of Bristol. [online] doi:https://hdl.handle.net/1983/2a1ff491-c107-4394-97f9-69d06d4803b1.

Taha M, Hanif S, Dickson G, Todd J, Fyfe D, MacBride-Stewart S, Hassett R, Marshall A and Heath C. (2024). Utilisation of specialist epilepsy services and antiseizure medication adherence rates in a cohort of people with epilepsy (PWE) accessing emergency care. Seizure: European Journal of Epilepsy, [online] 115, pp.59–61. doi:https://doi.org/10.1016/j.seizure.2023.12.019.

Epilepsy and learning disabilities:

Benchmarking services to keep patients safe

Health improvement and research manager at Epilepsy Action, Tom Shillito, discusses the Step Together guidance and toolkit and the importance of providing holistic care to people with epilepsy and learning disabilities

Tom Shillito

It is vital that people with epilepsy and a learning disability are able to access high quality holistic care. There are 630,000 people with epilepsy in the UK, and around a quarter of them will also have a learning disability. About two thirds of people with both conditions will have treatment-resistant seizures. They are also at a much higher risk of mortality than those with only one of the conditions. SUDEP is up to nine times more common in people with learning disabilities, and epilepsy is one of the most common causes of avoidable deaths in this group.

The risks that come with having both epilepsy and a learning disability are often caused or exacerbated by a lack of access to appropriate and holistic care. Information is often not shared between services, and treatment is done in a siloed way, with no one taking responsibility for the overall wellbeing of the patient.

The Step Together guidance was created to overcome those problems. It lays out what a holistic and well-connected health service would look like for this group of vulnerable patients. The Step Together toolkit turns that guidance into a list of 56 quantitative questions. These cover every aspect of care needed to guarantee the wellbeing of people with epilepsy and a learning disability. These questions cover eight key domains:

- Workforce
- Local planning
- Key service provision
- Diversity of provision and third sector involvement
- Care planning
- Transition
- Information sharing
- Patient and carer participation

The risks that come with having both epilepsy and a learning disability are often caused or exacerbated by a lack of access to appropriate and holistic care

It is a self-assessment tool that benchmarks the services provided to people with epilepsy and a learning disability across the whole of the healthcare landscape. It can be used at any scale, from a single clinic to a whole region.

A new paper in the British Journal of Psychiatry explains how the toolkit was used by the 11 ICS in the Midlands region [Shillito et al, 2024]. It has also been used by Cornwall ICS, and the seven ICS across the North East, North West and Yorkshire regions are undertaking the benchmarking exercise at the moment.

The first step to complete the toolkit at a system level is to identify the key stakeholders. Input is needed from neurology and psychiatry services, primary care, social care, service users and carers, the local voluntary sector, and anyone else who may be offering support to this group of patients. This sounds like a daunting task, but the ask of each stakeholder is quite small – often only a short conversation or a couple of emails are needed. The systems who have undertaken it so far have reported that their colleagues understand the need for this work, and are often very happy to give up half an hour of their time to have a discussion about the toolkit questions. This consultation process also has hidden benefits- it creates an environment where people from across the healthcare landscape can discuss their work with colleagues they would not usually have contact with. This, in itself, has led to positive changes for many of the systems, as gaps were quickly and organically identified through those discussions.

Tom Shillito

Once the responses from all stakeholders have been collated, they can be entered into the toolkit. The toolkit then gives an overall score for the system and individual scores for each of the eight domains. The toolkit easily identifies areas of best practice which should be maintained, and potential areas for improvement. This is done both through the scoring system as well as through the specific questions themselves. It is very easy to scan through the list of questions and identify which specific aspects of care could be changed, based on the responses to the agree/disagree style questions.

The data is then sent to a researcher from Epilepsy Action who incorporates it into the UK-wide database. In the Midlands, and in the North East, North West and Yorkshire regions, a region-wide analysis has also been undertaken. Reports have been created to highlight areas of best practice, and to give specific improvement suggestions for each ICS and the region as a whole. These are then presented to the region at a feedback event, where each system can share their experiences and learn from each other.

For the systems who have completed the toolkit so far, there has been a great deal of variation in results. Each system has its own strengths and weaknesses, and the feedback events organised have focussed on the sharing of best practice between systems.

While there are very few findings that are true across all systems, some common themes emerging from the toolkit responses are:

- Very poor or non-existent sharing of information between services, often relying on patients to tell clinicians what has been said in appointments with other providers. This is especially true of information sharing between healthcare providers and social care.
- A lack of service user input into their care. While some systems have mechanisms for service users to provide feedback, it is rarely sought, and service users and carers have little to no input into how services are designed and delivered.
- It is often difficult to recruit and retain staff in roles within neurology and learning disability. However, despite these difficulties, most systems do provide access to all of the clinicians, nurses and allied healthcare professionals that this group of patients would need to access.
- Many systems did not know how many people with epilepsy and a learning disability were on their caseloads, and in some cases there were large discrepancies between how many were reported on a caseload and how many we would expect there to be based on local prevalence data.
- Very few areas use joint care plans to cover both epilepsy and learning disability
- Very few systems had ways to monitor the consistency of care across the services they provide, and across their geographical area
- Transition from children's to

The reports have been vital to make the case for change and to secure the funding needed to maintain current services and develop new pathways

adults' services was often an area of difficulty, with few systems able to offer patients a cohesive and supported journey through transition

- Each System has reported ongoing improvement plans that have been developed based on their Step Together toolkit feedback. Some examples of changes are:
- Epilepsy became a distinct workstream within learning disability and autism commissioning
- Creation of a forum with strategic oversight of pathway development and commissioning for this group of patients
- Regular webinars focussed on learning about the needs of this population, and how to best serve them
- Discussion forums to build upon the new relationships created during the information gathering process, enabling colleagues from across services to discuss the needs of this group
- Creation of new epilepsy specialist nurse posts

The feedback received from systems who have completed the toolkit has been very positive. They reported that the questions within the toolkit are clear and easy to understand, and they felt well supported to collect and collate the data and enter it into the toolkit. The toolkit gave them clear recommendations for change, as well as highlighting areas of best practice. The reports have been vital to make the case for change and to secure the funding needed to maintain current services and develop new pathways. The process of completing the toolkit has also fostered ownership of these issues within the systems and created a feeling of community and collaboration around the issues. Most importantly, the toolkit results have highlighted what is already going well, and recognition has been given to the teams who have created examples of best practice. This best practice has also been shared with their neighbouring systems, so that it can be built upon in other areas.

If you'd like to begin the quality improvement journey in this area, here are some suggestions of best practice that you could adopt:

- Complete the Step Together benchmarking toolkit every 3-5 years, to find your baseline and track ongoing progress in each domain
- Adopt single joint care plans that are shared between epilepsy and learning disability services
- Use primary care records to identify the number of people with epilepsy and a learning disability in your area
- Set up regular listening events where service users and carers can provide input into the services they access
- Implement shared care agreements between epilepsy, learning disability and primary care providers, to ensure each party understands their roles and responsibilities for this group of patients
- Commission care for people with epilepsy and a learning disability separately from general epilepsy services

If you would like to learn more, or to undertake the toolkit yourself, please visit Step Together - Epilepsy Action

Further reading

Shillito T, Watkins L, Ali H, Page G, Pullen A, Mitchell S, Roy A, Sen A, Kinney M, Thomas R, Tittensor P, Bagary M, Subramanium A, Kent B and Shankar R. Evidencing the Challenges of care delivery for people with intellectual disability and epilepsy in England by usin the Step Together toolkit. BJPsych Open. 2024;10(6):e186. doi:10.1192/bjo.2024.749

Multidisciplinary team potential

Increasingly, with complexity of modern medicine and emerging new and expensive treatments, we work and make decisions through multidisciplinary teams (MDTs). This is also true in epilepsy and so I thought it useful to look at some aspects of the wider MDT that we work in our unit and how we can harness further potential from all multiprofessional staff within our departments.

Epilepsy nurses are the core and mainstay of the epilepsy MDT; they essentially run the place and know the patients best. The only problem is that there are not enough of them for the patient need, especially given the increasing complexity of disease and social constructs. A strategy of dividing workloads or having nurses with individual specialist area of interests, such as antenatal, mental health, and acute seizures/front door working, can help streamline activities and can also help the nurses develop further professionally.

Medical secretaries also play a pivotal role in our MDT, from booking patients into clinics to even identifying at-risk patients from savvy letters. I am sure most will agree that the secretaries are also at the hub of most epilepsy units. They keep an eye on free clinic slots and cancellations, and, in our unit, they even managed the first seizure clinic lists for a time. After a bit of service mapping, we changed this, as, although it was highly efficient, we discovered the urgent cases weren't being triaging appropriately.

Some units around the country have employed prescribing pharmacists to help navigate some of the newer drug treatments in epilepsy and also the changes in sodium valproate prescribing. Maybe a point worthy of further discussion is that pharmacists might be able to play a role in prescribing for stable patients who fulfil the PREVENT programme. This may help alleviate some of the increasing workload on epilepsy specialist nurses and further develop the multiprofessional epilepsy unit.

Recently we have also had some nursing axillary staff redeployed from other clinical areas due to ill health. These staff have slotted into the department, learned new skills and their flexibility has assisted the administrative staff.

It's also that time of year when we see medical students appearing in the unit on student selected component of study projects. These are usually enthusiastic students who are interested in neurology and epilepsy and are keen to take on short projects, evaluate services and look at unmet and developing needs within the service. It's also an opportunity to harness a future workforce and cultivate young minds for the future. Often students come with a vast array of IT skills which are transferrable to other members of the MDT. We have also found roles for post graduate individuals who also have excellent IT skills and have worked well in data management and coordinator posts. Sadly, for us this is usually a stepping stone to other jobs.

We were also very fortunate to have the epilepsy charities attend our clinics and mingle in the waiting rooms, often ready and eager to help patients with some of the allied social issues that epilepsy poses.

As I conclude (and I type this slightly in jest), is there a role for people, patients and cares to make tea or even just be there and sit amongst us and grow the community? I know times have changed and, well, would infection control and health and safety even allow it?

Dates for the diary

Dates and events may be subject to change – please check on the relevant websites.

2025

20-22 March
19th World Congress on Controversies in Neurology
Prague, Czech Republic
cony.comtecmed.com

2-4 April
International Congress on Structural Epilepsy & Symptomatic Seizures 2025
Gothenburg, Sweden
bit.ly/3X8FlOt

11-27 May
12th International Residential Course on Drug Resistant Epilepsies
Tagliacozzo, Italy
epilepsytagliacozzo.com

15-17 May
ILAE School on Neuroimaging 2025
Potsdam, Germany
ilae.org/congresses/ilae-school-on-neuroimaging-2025

21-24 June
11th Congress of the European Academy of Neurology
Helsinki, Finland
ean.org/congress2025

30 August-3 September
36th International Epilepsy Congress
Lisbon, Portugal
bit.ly/3uz1ARq

2026

3-6 May
18th Eilat Conference on New Antiepileptic Drugs and Devices
Madrid, Spain
bit.ly/3Wq6dcc

5-9 September
16th European Epilepsy Congress
Athens, Greece
ilae.org/eec2026

Next issues:

Dr Andrea Biondi

Dr Biondi discusses mental health screening as an opportunity to improve patient care

Dr Vineet Punia

Dr Punia gives an overview of frailty in older adults in the context of epilepsy and describes best practice

If you are interested in submitting a research paper for inclusion in *Epilepsy Professional,* please contact the Editor:

kkountcheva@epilepsy.org.uk

Epilepsy Professional's advisory panel

We need more experts to join our forces!

Our health information needs professional feedback to continue to be PIF tick accredited.

If you can lend your professional skills to review information on an occasional basis, send an email to **health@epilepsy.org.uk** with the area you specialise in.

This is a great opportunity for your CPD portfolio as well as making a huge difference to people affected by epilepsy.

Trusted
Information
Creator
Patient Information Forum