epilepsy action

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(Free to Epilepsy Action professional members)

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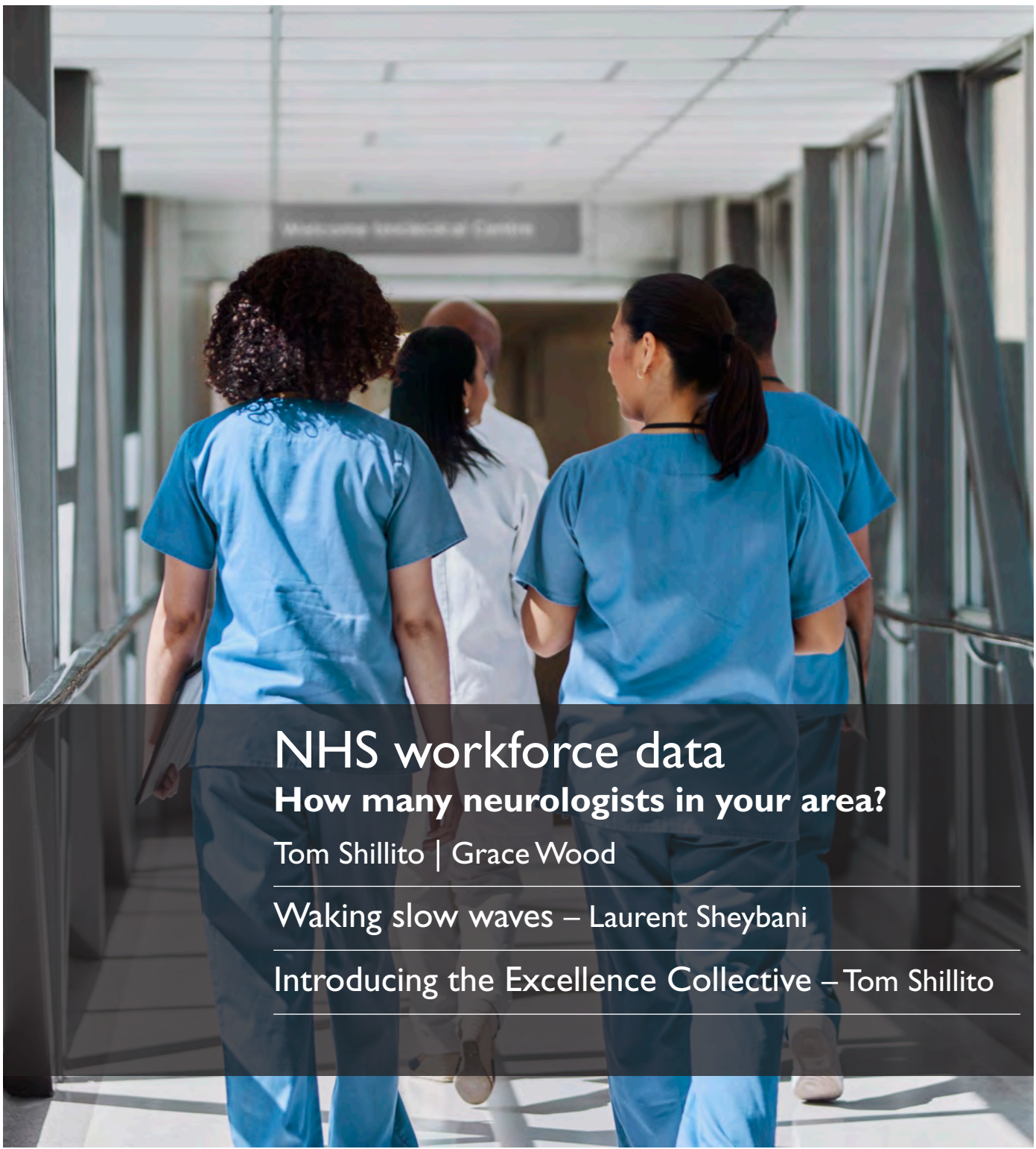

NHS workforce data

How many neurologists in your area?

Tom Shillito | Grace Wood

Waking slow waves – Laurent Sheybani

Introducing the Excellence Collective – Tom Shillito

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1. Elliott, RE., et al., (2011) Epilepsy & Behavior. 20; 478–483.
2. Patient's Guide for Epilepsy 2021, LivaNova USA, Inc.
3. Orosz, I., et al., (2014) Epilepsia 55(10):1576-84.
4. Helmers, et al., (2011) Epilepsy Behav; 22:370-5.
5. Spindler, et al., (2019) Seizure, 69:77-79.

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As the New Year rolled around it was easy to convince yourself that 2024 was going to be a great year. Even-numbered years feel luckier don't they? I had high hopes for 2020 – but it is nearly four years to the day since the UK went in to Covid lockdown…

So what will 2024 be remembered for? Well 64 countries – and approximately half of the world's population will be asked to vote in forthcoming elections. So, is 2024 the year of the great reset? Yes and probably in more than one way.

The Great Reset is the name of a think piece and initiative from the World Economic Forum, which, at a basic level, tries to extrapolate how we can use the chaos and change of COVID-19 as a lever for meaningful societal change. But it is also the centre piece of a series of interlinked conspiracy theories that were intelligently articulated by Jon Ronson on the new series of his podcast Things Fell Apart. So, if I was going to make predictions for 2024, some would be straightforward (it will be among the hottest years on record) but, with half of the world voting – and the context of ongoing geopolitical conflict – there are underlying opportunities for the twisting of facts.

Mr Rogers, who is as heartwarming and American as apple pie, is famous for the quote: "When I was a boy and I would see scary things in the news, my mother would say to me: 'Look for the helpers. You will always find people who are helping.'" So, how can you be a force for good in 2024?

Be inspired by the Epilepsy Action innovation described by Tom Shillito, the Excellence Collective (p24-26). We need more directed action, more concerted support and a range of diverse experience focused on a common goal. One of the project's aims is to narrow the gap between epilepsy research and the genuine impact seen in the clinics and people's lives.

Elsewhere, the study of the silent parts of our lives is so important. The study of mood, hope and emotion, the study of confidence and well-being, and the study of sleep. I remember the unconstrained joy I felt as a trainee when I realised that as a neurologist I was provided a curriculum of all the important and interesting brain diseases, but they also let us study and treat sleep. This responsibility felt humbling, because sleep is critical to all the aforementioned well-being states, as well as memory consolidation and seizure control. Dr Laurent Sheybani and colleagues from University College London report on the importance of slow wave activity and how this decreases network excitability – and the relative cost to the brain (p18-22).

And the final article, I find to be deeply rewarding. I am writing this introduction after another busy week at the metaphorical coalface. Are there really four times the number of neurologists per person with epilepsy in London, compared to the North East of England (p12-17)? It certainly feels like it. And if I am to get a quadrupling of my salary, with back pay, I promise to buy a bottle of bubbly each for our four brilliant epilepsy nurses up here – as everyone knows they are the ones who really do the work, and make the greatest difference – but I am still keeping the pay.

Rhys Thomas
Consultant neurologist
Chief medical adviser
Epilepsy Professional

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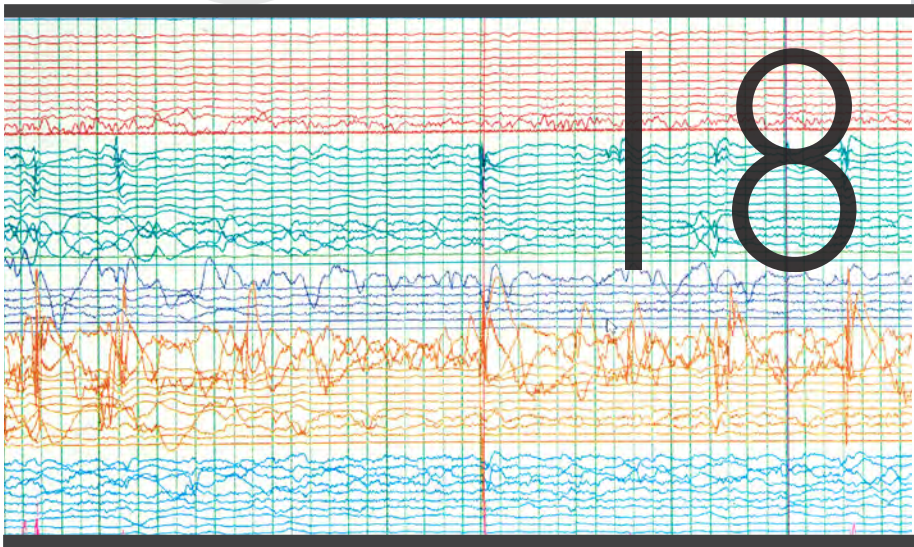

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Highlights include the International Training Course on Neuropsychology in Epilepsy in France; Congress of the European Academy of Neurology in Finland; and the ILAE British Branch Annual Scientific Meeting in Liverpool

With the news this week that the King has cancer, journalists, commentators and ordinary people across the UK will be discussing the condition: their experiences, their sympathies for the King and his family, and perhaps even asking the question – how would the King be treated in the NHS?

But what about epilepsy? What if the King had been diagnosed after a second seizure and an EEG? Well, if we take this unlikely hypothetical and run with it, it might depend where he lives – as our workforce data (p12-17) suggests.

The King's main residence is Clarence House in London. So, he would have access to 326 neurologists and 23 epilepsy specialist nurses (ESNs). In Sandringham, in the East of England that would be 77 neurologists and 20 ESNs. There's no royal residence in the North East of England but, if there was, he would have access to 39 neurologists and 11 ESNs. Of course those populations aren't equal, and so our study delves into what that means in greater detail.

As Rhys Thomas points out in his introduction, epilepsy specialists are overworked and doing their utmost. But, even so, it's safe to say the King – if treated for epilepsy on the NHS – would struggle to get regular appointments.

Some have suggested it is crass to compare the King's experience to others'. But, we know thousands of people treated in the NHS are declared cancer free every year and there's nothing to say the King wouldn't have the same experience.

As far as we know, the King does not have epilepsy – and, of course, we wouldn't wish it on him. But, however crass you think the question is, this is the situation many ordinary people in the UK face.

Grace Wood, editor

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Sodium valproate redress scheme proposed by Patient Safety Commissioner

A redress scheme for families who have suffered from exposure to valproate has been proposed by the Patient Safety Commissioner.

Sodium valproate is a commonly prescribed anti-seizure medication. It is also prescribed for bipolar disorder.

It has been linked to serious developmental issues in children exposed during pregnancy. However, for many people with epilepsy, it remains the most effective drug for their treatment.

Until this year, the rules around prescribing valproate were just for women and girls. The Valproate Pregnancy Prevention Programme ensures women taking valproate are aware of the risks in pregnancy and using highly effective contraception.

However, the rules changed on 31 January 2024, meaning no one under the age of 55 will be newly prescribed unless two specialists agree there is no other effective or tolerated treatment, or unless there are "compelling reasons that the reproductive risks do not apply".

According to the Patient Safety Commissioner, thousands of children have been exposed to valproate and suffered from learning and physical disabilities as result.

Dr Henrietta Hughes is the current Patient Safety Commissioner. The goals of the office are to influence government, advise on policy making and raise patient concerns to the Department of Health and Social Care.

The suggested redress scheme has two stages. The first identifies all those harmed and would "ensure patients receive long overdue financial redress quickly". The commissioner says this award would be about £25,000. This would be followed by a payout based on the individual needs of each patient.

The report also sets out non-financial redress to provide support for those affected. This includes a housing grant and improved access to education, benefits and support.

It suggests the redress agency would be independent of government or arms-length bodies.

Launching the report, Dr Hughes said: "My report could not be clearer – the case for redress has been made. It highlights in detail the daily problems that impact on those who have been harmed. We found that those exposed to valproate need specialist care but must battle with every part of the system – diagnosis, treatment and support services.

"This redress programme is a crucial step towards acknowledging the challenges faced by families impacted by valproate."

Exposure to valproate in pregnancy is linked to spina bifida, facial and skull malformations, malformations of the limbs and organs, and learning and development problems.

Rebekah Smith, Epilepsy Action deputy chief executive, said: "The 2020 Cumberlege review recommended a redress scheme should be set up to meet the cost of providing additional care and support to those who have experienced avoidable harm due to sodium valproate.

"Although the government stated on a number of occasions that it was 'carefully considering' a redress scheme, the recommendation wasn't taken on board at the time. It was instead advised that affected families could pursue clinical negligence claims. These would be costly, both financially and emotionally, and time consuming.

"Epilepsy Action has long supported the calls for compensation for the estimated 20,000 children who have been harmed by valproate. Some of these children require 24-hour care, the cost of which has been entirely on the families' shoulders for years.

"We welcome this latest call for compensation from the Patient Safety Commissioner. We hope the government listens to the calls of patients who have been harmed, providing the long-overdue financial support they need."

Clinical pathway for treating people with epilepsy launched

Epilepsy care should be more local, with people given an expert point of contact and decision making should be better shared between patients and doctors, according to the National Neurosciences Advisory Group (NNAG).

The NNAG's "optimal clinical care pathway" for adults with epilepsy has been developed by organisations including Epilepsy Action.

The pathway for people with epilepsy was developed by the NNAG – a collaboration of professionals and patient groups.

The pathways set out what good treatment, care and support should look like. It is part of a set of care guidelines for many neurological conditions.

Following a six-week public consultation, the NNAG emphasised the need for people with epilepsy to have a "first point of contact" with an expert.

According to the group, care should be local when possible. It said patients needed to be seen in a regional neuroscience centre rather than tertiary and secondary services, which could be far from their homes.

The group said the improved pathways would also create efficiency savings for the NHS while improving the quality of epilepsy services.

It added that another barrier the new pathways would overcome was the inability of centres to receive and store patient information, including video monitoring. It said an increased focus on data sharing or a national epilepsy register would facilitate communication between clinicians and improve care for people with epilepsy.

The document also outlines what good practice should look like. For instance, it says: "After a first suspected seizure, a patient should be referred to a first seizure service."

Among the useful resources to improve patient care, the document references a number of Epilepsy Action led-projects, including Step Together – Integrating care for children, young people and adults with epilepsy and learning disability, and the Step Together Benchmarking Toolkit – Service Evaluation.

Epilepsy Action director of health improvement and influencing Alison Fuller said: "We are delighted to be a part of such an ambitious project to improve the quality and delivery of epilepsy services. We're hoping the recommendations outlined in the new epilepsy pathway will be adopted widely, to improve the quality of care people with epilepsy receive and streamline processes for healthcare providers at the same time.

"We will continue to work closely with clinicians and other organisations to optimise the level of care patients receive and define 'what good looks like' for people with the condition."

Pathways have also been developed for multiple sclerosis, neurological autoimmune disorders and motor neurone disease.

Paula McGowan joins Epilepsy Action as ambassador

Paula McGowan OBE has become an ambassador for Epilepsy Action.

Paula is an award-winning activist who campaigns for the equality and equity of health and social care for intellectually disabled and/or autistic people.

Following the preventable death of her teenage son Oliver, Paula and her family set up Oliver's Campaign.

As part of the campaign, Paula successfully launched a parliamentary petition that meant health and social care staff in England now receive mandatory training in learning disability and autism awareness.

On 28 April 2022, learning disability and autism training became law. The Oliver McGowan Mandatory Training was designed, evaluated and is delivered alongside learning disabled and/or autistic people to meet this law.

"The family became aware of Epilepsy Action after Oliver died, which led to my husband and daughter running the half marathon in Bristol for Epilepsy Action. We felt we wanted to support a charity who can, and is, making a difference," said Paula.

Oliver had epilepsy, autism and a mild intellectual disability, which led to diagnostic overshadowing.

Paula said: "Oliver's seizures were poorly understood by health, care and education staff. Oliver would remain conscious, which caused him to be scared, anxious and confused. This led to hospital staff administering antipsychotic medication.

"Clinicians did not understand that Oliver's behaviours were typical of when he was having a seizure. This led to Oliver's avoidable death at just 18."

EU introduces valproate measures

The European Medicines Agency (EMA) has announced precautionary measures for prescribing valproate to men with epilepsy.

The measures follow those made by UK regulatory body the Medicines and Healthcare products Regulatory Agency (MHRA) last year.

The European regulations are less strict than those made by the MHRA. In the UK, no one under the age of 55 will be newly prescribed sodium valproate unless two specialists agree there is no other effective or tolerated treatment or reproductive risks do not apply.

In the EU, doctors will continue to be able to prescribe valproate following these recommendations:

- Valproate prescriptions for men should be supervised by a specialist
- Men should be informed of the potential risk of neurodevelopmental disorders for future children
- Doctors should discuss the need to consider effective contraception, including for female partners, while using valproate and for at least three months after stopping treatment
- Men should undergo regular reviews with doctors to assess if valproate remains the most appropriate treatment
- Men should be advised not to donate sperm while taking valproate
- Men should be given a patient card with their medicine, reminding them of the potential risks of using valproate.

The EMA is a European Union committee responsible for assessing medicines for humans. It said the recommendations were the result of a review by its Pharmacovigilance Risk Assessment Committee.

The review followed a study from Norway, Denmark and Sweden, which looked at the association between fathers' exposure to valproate and the risk of neurodevelopmental disorders, including autism and congenital malformations, in children.

According to the EMA, the study showed that 5 out of 100 children had a neurodevelopmental disorder when born to fathers treated with valproate, compared with 3 out of 100 when born to fathers treated with lamotrigine or levetiracetam.

However, the organisation said the study had some limitations, such as differences between patient groups and being too small. It said that as a result it was not possible to confirm that this increased risk was caused by valproate, but that it was implementing the recommendations as a precautionary measure.

The UK regulations come into effect on January 31.

Speaking when the MHRA announcement was made in November 2023, Epilepsy Action chief executive Philip Lee said: "We hope that all people with epilepsy affected by this policy will receive personalised information about their epilepsy and associated risks from their health professionals.

"Epilepsy Action will remain engaged with the MHRA and others on this issue for as long as we feel we can have a positive benefit for people with epilepsy and the wider community.

"We will continue to be alongside people and families and seek accountability and learning as needed. We will also continue to call for openness of evidence, positive opportunities for engagement and balanced messaging, so that people can make properly informed choices about their treatment and safety."

For more information about valproate medicines go to: www.epilepsy.org.uk/valproate

Epilepsy diagnosis tool gets MHRA approval

A new clinical decision tool, which can be used as additional evidence in diagnosis has been approved in the UK.

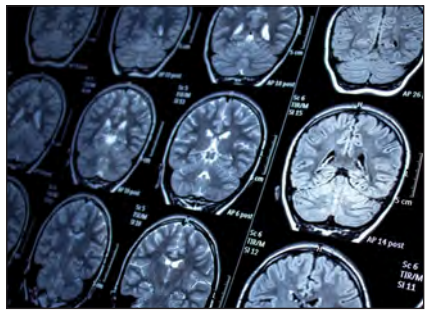
BioEP was awarded a UKCA mark in December 2023.

It has been developed by a firm called Neuronostics, which says results can be produced in 15 minutes. It is listed as a Class I medical device, meaning it is low-risk.

It speeds up the diagnosis by using background EEG results to identify the likelihood of future seizures.

According to Neuronostics, average clinical diagnosis of epilepsy currently takes more than a year.

BioEP was awarded the UKCA mark by the government's Medicines and Healthcare products Regulatory Agency (MHRA). The mark indicates that a product meets the



requirements to be sold in the UK.

The regulatory upgrade to UKCA included a thorough clinical evaluation, literature review and usability evaluations by clinicians.

Neuronostics managing director John Terry said: "I am delighted that we have been able to deliver this key regulatory milestone.

"Our entire team has worked collaboratively towards this achievement, ensuring that the Neuronostics Platform meets the robust standards laid out as part of a UKCA mark.

"This UKCA marking provides our partners, collaborators and clinicians with the confidence that we have developed a safe, effective and clinically valuable product."

The UKCA mark replaced the CE mark in the UK, which was the European Union equivalent. BioEP also has CE certification. This year, Neuronostics hopes to achieve FDA approval for BioEP, which will also allow it to be used in the USA.

The firm has also begun a prospective clinical trial of BioEP. The randomised study will measure time to diagnosis and accuracy. It will include 559 participants and conclude in February 2027.

Drug developed for rare genetic epilepsies

A new medication for rare epilepsies has reduced seizures by more than 50% in the latest clinical trials.

Bexicaserin has been developed to treat Dravet syndrome, Lennox-Gastaut syndrome and other developmental and epileptic encephalopathies (DEEs).

Bexicaserin has been created and tested by American company Longboard Pharmaceuticals.

Longboard's president and chief executive officer Kevin R Lind said: "We believe bexicaserin provides us with the cornerstone to build a world-class epilepsy franchise and to explore development paths that may offer novel options to DEE patients."

The company said bexicaserin achieved an average seizure reduction of 53.3%, compared to 20.8% in the placebo group.

The average seizure reduction for patients with Dravet syndrome was 72.1%, 48.1% in Lennox-Gastaut syndrome and 61.2% in other DEEs.

The results come from a small group of 52 people aged 12-65 years old. Nine dropped out. 43 participants took bexicaserin and nine took the placebo.

The drug was taken orally at measures of 6mg, 9mg and 12mg, three times daily.

The studies took place at 34 sites across the US and Australia.

Only three participants reported a serious adverse event during the trial, these were ankle fracture, constipation and increased seizures. No deaths were reported. No participants in the placebo group discontinued or experienced a side effect.

All of the participants who completed the study are now taking part in a 52-week extension study.

Longboard's chief medical officer Dr Randall Kaye said: "These exciting results underscore our belief that bexicaserin's differentiated profile will translate into a clinically and commercially best-in-class product and has the potential to redefine the standard of care in DEEs."

Stormont urged to support people with epilepsy as government returns

Epilepsy Action Northern Ireland is calling for parties to work together to support people with epilepsy, following the news that the DUP executive has endorsed a deal to restore government at Stormont.

The Assembly has been suspended for nearly two years due to disagreements about post-Brexit trade arrangements. This has led to a stall in decision making. During this time, Epilepsy Action Northern Ireland has continued campaigning for people with epilepsy – including meeting the mental health champion professor Siobhan O'Neill to raise concerns about young people's well-being.

Epilepsy Action Northern Ireland's policy and campaigns officer Jack Morgan said: "We welcome the news that the DUP executive has endorsed a deal to restore devolution at Stormont.

"Epilepsy Action Northern Ireland has repeatedly called for political parties to restore power sharing and work together to address the problems facing people with epilepsy.

"Over the last number of months, we have been engaging and briefing members of the legislative assembly on the life-changing issues that affect people with epilepsy in Northern Ireland. These include struggles getting a diagnosis, access to services and challenges with employment and benefits.

"It is now time for elected representatives to work on these issues and to improve the lives of people living with epilepsy in Northern Ireland."

Epilepsy Action Cymru meets Senedd members

Epilepsy Action Cymru met members of the Senedd, clinicians and patients in Cardiff Bay on 31 January to discuss the support available for people with epilepsy in Wales.

There are more than 30,000 people with epilepsy in Wales, some of whom are having to wait a year or more to see a neurologist.

Epilepsy Action is campaigning for more Epilepsy Specialist Nurses (ESNs) and has introduced a counselling service for people living with epilepsy and their loved ones.

Jan Paterson, Wales manager at Epilepsy Action Cymru, was joined by senior policy and campaigns officer Daniel Jennings and volunteer Becci Smart.

Luke Fletcher, member of the Senedd for South Wales West also supported the event. Luke, who has previously campaigned for people with epilepsy in the Senedd, said: "Epilepsy

Action Cymru's research reveals a distressing reality for those managing epilepsy in Wales.

"Wales has the highest rates of incidence of epilepsy in the UK, and the extremely low specialist availability, regional discrepancies in services, and lack of investment in epilepsy resources serves only to compound the situations of those living with epilepsy in Wales.

"While we acknowledge the Welsh Government is taking some positive steps to drive forward necessary improvements, things are still slow to change. People with epilepsy must get the urgent support they need."

Becci Smart, who is based in Swansea, was diagnosed with juvenile myoclonic epilepsy at the age of 18. She joined Jan and Daniel at the event.

Becci said: "I cannot stress enough how vital providing extra support to help people with epilepsy in Wales live safer, freer lives would be."

According to Epilepsy Action, 43% of patients aren't getting referred to any kind of specialist service following a seizure, while others wait a year or more to see a neurologist.

Wales manager Jan said: "NICE guidelines recommend a waiting time of no longer than two weeks for patients with a suspected first seizure, which are nowhere near being met by any of the seven health boards operating across Wales. We are therefore calling on the Welsh Department for Health to actively support the provision of more ESNs across Wales."

Sleep study shows potential treatments for epilepsy

Slow brain waves may reduce the impact of seizures and could provide potential avenues for future therapies, according to a group of researchers at University College London (UCL).

The researchers found that people with epilepsy have slow brain waves – which are usually seen during sleep – while they are awake.

The study, titled 'Wake slow waves in focal human epilepsy impact network activity and cognition', was featured in the journal *Nature Communications* last month.

Speaking to Epilepsy Action, lead author Dr Laurent Sheybani explained the results of the work.

"During sleep, slow waves of nerve cell activity decrease the excitability that has accumulated during the day, allowing the brain to reset, ready for the next day.

"We found that these slow waves, which usually occur only during sleep, also occur during wakefulness in people with epilepsy," he said.

The team made the discovery by analysing the EEGs of patients with focal epilepsy who were undergoing assessment for surgery.

The study included 25 patients, 11 female and 14 male, with an average age of 39, who were being treated at the National Hospital for Neurology and Neurosurgery in London.

Dr Sheybani added: "These slow waves slowed people's reaction times but did not affect how accurately people did on memory tasks. This contrasts with epileptic activity, which affected memory performance.

"We propose that enhancing these slow waves could open up avenues for future therapies in epilepsy for reducing seizures and improving memory."

For more information about the study go to page 18.

Drugwatch

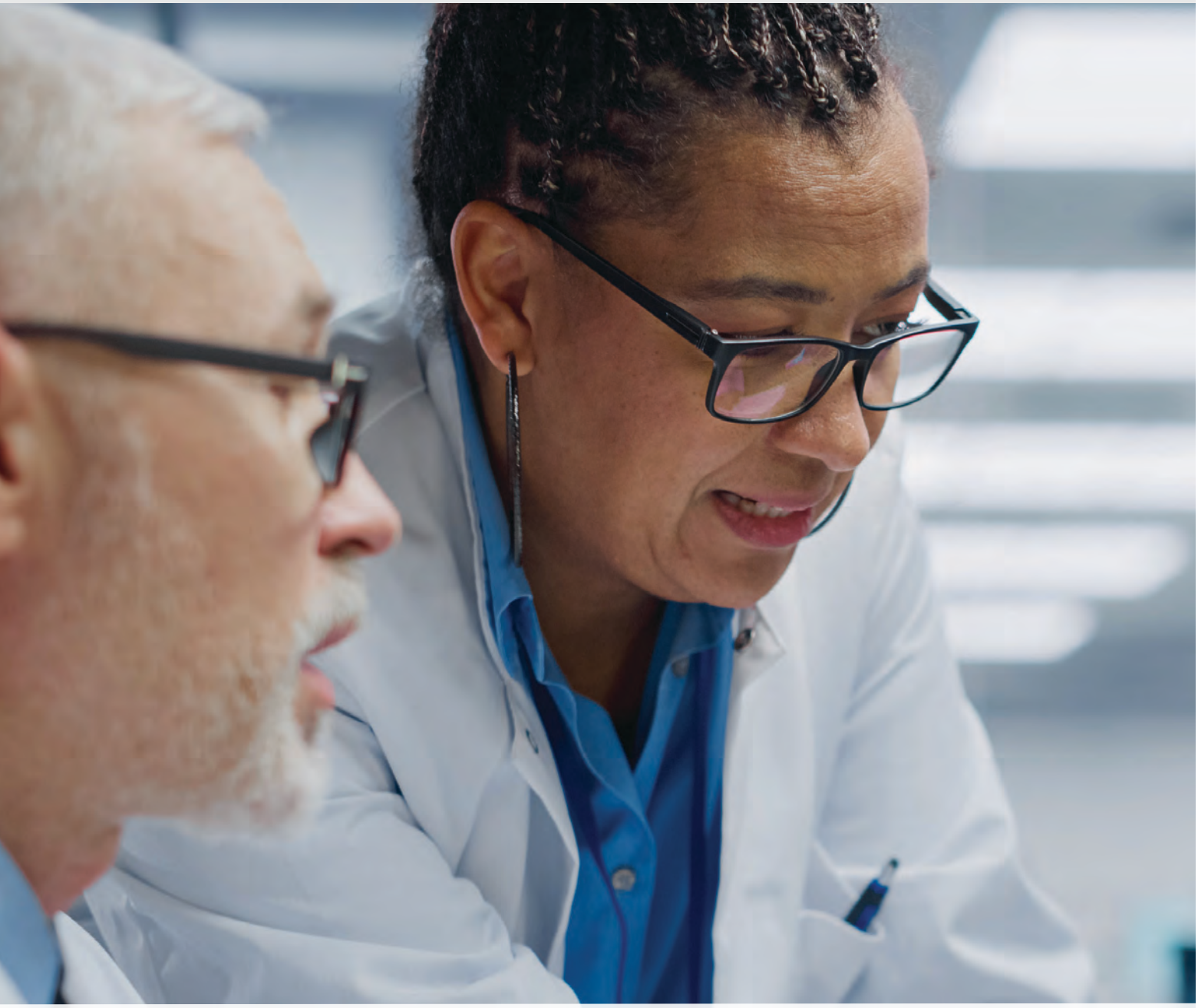
Oxcarbazepine 150mg and 300mg tablets made by Mylan (Viatris) are out of stock. Mylan have told us when each strength is expected to be back in stock: 150mg – week commencing 25th March 2024; 300mg – week commencing 19th February 2024.

Pharmacists may offer patients a different version of oxcarbazepine.

There have been reports of people struggling to get supply of **Tegretol**. Novartis have said 200mg and 400mg Tegretol prolonged release tablets are in stock with them and going out to wholesalers. 200mg and 400mg Tegretol standard release tablets are in stock as normal. 200mg standard release tablets have been in higher demand, but Novartis can meet this demand. There are no plans to discontinue any form of Tegretol.

Teva has told us that Clonazepam 500 microgram tablets are expected back in stock at the end of January, following supply issues in December, and will be available from the first week of February.

Desitin Pharma, the manufacturers of **Desitrend** (levetiracetam granules sachets), has advised that there is another version of levetiracetam granules available through a different manufacturer. They have said the other version has some differences. Prescriptions many need to be written as 'Desitrend' to ensure patients receive the right medication, particularly if they have swallowing difficulties, are on a ketogenic diet or are using a feeding tube.



The epilepsy workforce

How many neurologists and epilepsy specialist nurses are there in England? And where are they?

Epilepsy Action's health improvement and research manager Tom Shillito and Epilepsy Professional editor Grace Wood present the charity's research into England's workforce

London has almost four times more neurologists per person with epilepsy than the north east of England.

There is just one neurologist to every 755 people with epilepsy (PWE) in the north east of England (39 in total), but one to every 191 in London (326 in total).

These figures come from an Epilepsy Action report into NHS workforce data across England. The charity sent freedom of information requests to 193 trusts across England (of which 174 responded) and then compiled the data. It shows there are significant variations in the number of healthcare professionals available across the country.

NICE recommends that for a population of 500,000 people, nine ESNs should be available [Christodoulou et al, 2012]. Our investigation shows there are about 230 ESNs in England, this equates to two ESNs for 500,000 people – with or without epilepsy (according to the ONS, England has a population of 56,536,000) [Office for National Statistics 2024].

People living in the most deprived areas are nearly three times as likely to die with epilepsy than those living in the least deprived areas [The Neurological Alliance, 2024].

ESN ratios

London has the best neurologist to PWE ratio, but a low ratio of ESNs. There are 326 neurologists in London but just 23 ESNs. This is one ESN for every 2,714 PWE.

There are 11 ESNs in the North East of England. This is one ESN for every 2,678 PWE. Elsewhere, the Midlands also has a low ratio of ESNs, with one nurse to every 2,718 PWE. Ratios are better in the South West of England where there are 1,600 PWE for every ESN, and best in Yorkshire and the Humber, where for every PWE there are 1,137 ESNs.

This is a total of 45 ESNs across Yorkshire and the Humber – four times more than in the North East and twice as many as in London. There are 51,000 PWE in Yorkshire and the Humber.

In the North West there is one ESN to every 2,617 PWE. In the East of England there is one to every 2,506 and in the South East there is one to every 2,159. This equates to 28 nurses in the North West, 20 in the East of England, 36 in the South East, 35 in the Midlands and 33 in the South West.

A previous report by Epilepsy Action, published in October 2019, said many UK epilepsy specialists agree that effective epilepsy services depend on ESNs. [Epilepsy Action, 2018]. The report also said there was strong evidence from the UK to suggest the ESN role is cost-effective and valued among other health professionals. ESNs are the only professionals who work across the boundaries that patients navigate.

London has the best neurologist to PWE ratio, but a low ratio of ESNs

General NHS workforce

In January 2024, the latest general practice workforce data that was available was for November 2023. According to the NHS, there are 46,879 GPs in England, of which 37,014 are fully qualified. Across the UK, there are 44 GPs for every 100,000 patients. The NHS estimates that there are 9,977 patients per GP practice. However, these figures vary depending on location and practice.

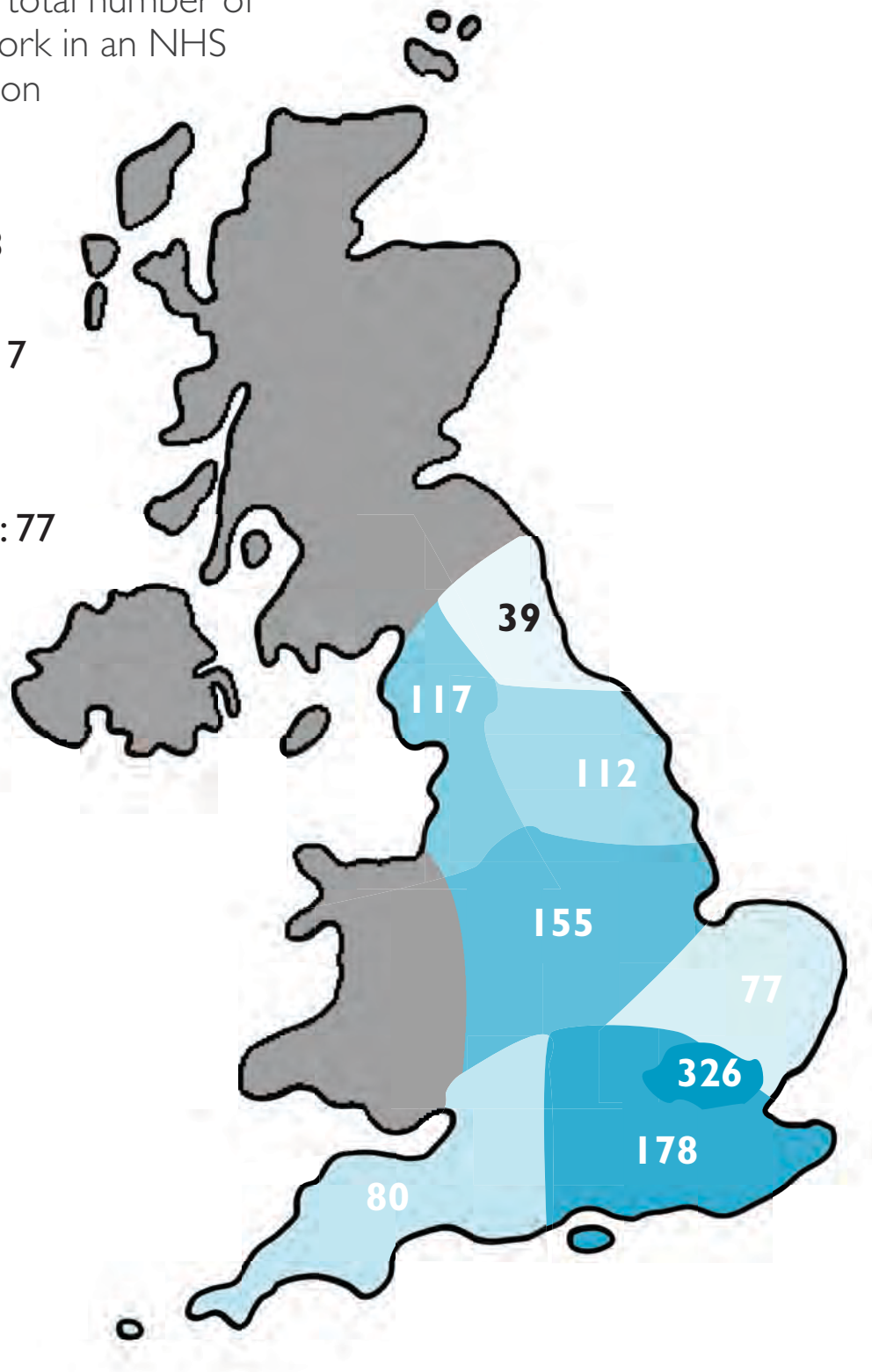
Geographical breakdown details

There are 29,500 people with epilepsy in the North East – one of the smallest population figures. However, it has the highest prevalence rate of any area at 1.1% and the lowest number of neurologists. It has significantly fewer than any other location at just 39. In this area, 42 people out of 100,000 will be diagnosed with epilepsy every year.

The largest population of PWE is in the Midlands, which has 95,000 PWE, but it has a lower prevalence

Neurologists: the total number of neurologists who work in an NHS hospital in each region

- London: 326
- South East: 178
- Midlands: 155
- North West: 117
- Yorkshire: 112
- South West: 80
- East of England: 77
- North East: 39



rate of 0.9%. It has 155 neurologists, which is one for every 614 PWE.

The North West also has a large number of PWE (73,000) and a prevalence of 1%. The area includes cities such as Liverpool, Manchester and Wigan. It has 117 neurologists, which is one for every 623 PWE.

Yorkshire and the Humber (51,000 PWE), the South East (78,000 PWE) and the South West (53,000 PWE) also have a prevalence rate of 0.9%. The East of England (50,000 PWE) has an incidence rate of 0.8% and 77 neurologists.

London has the lowest prevalence rate of 0.7% (62,500 PWE) but the most neurologists at 326. In London, 29 people in every 100,000 are diagnosed with epilepsy every year.

Comparing adult to paediatric

When it comes to the breakdown of nurses, the North East, North West, Yorkshire and the Humber, the East of England and the South East have a fairly even split of adult and paediatric ESNs. The Midlands has more than twice as many adult ESNs as paediatric ESNs (32:11), as does London (14:6). The South West has 25 adult ESNs and 19 paediatric ones.

Averages across centres

We also calculated the average number of neurologists and ESNs per trust in each area and broke this down to adult and paediatric care. The South West has the lowest average neurologist scores whereas London has the highest. ESN averages do not back the trend, with Yorkshire and the Humber averaging the highest number of ESNs.

We contacted 194 trusts in total and 18 did not respond. These included: Royal Free London NHSFT, London North West University NHS Trust, Imperial College NHS Trust, Guy's and St Thomas's NHS Foundation Trust, Barts Health NHS Trust, and Manchester University NHS Foundation Trust.

The South West has the lowest average of neurologists per trust at 5.3. 19 trusts were contacted and 18 responded to our requests. However, it has a comparatively high number of ESNs at 1.9 per trust.

London has the highest average per trust by a significant margin at 16.3 neurologists per trust, but it has the lowest average number of ESNs per trust at 1.

The North East has the fewest trusts. Six trusts were contacted. These cover cities such as Durham, Newcastle, Gateshead, Sunderland and Middlesborough. All six trusts responded to our FOI requests. There are an average of 9.8 neurologists in every trust in the North East. There is an average of 1.8 ESNs across trusts in the North East.

While four trusts did not respond in the North West, 29 did. There is an average of 6.2 neurologists across the trusts that provided results and 1.2 ESNs in each trust.

In Yorkshire and the Humber, all 20 trusts that were contacted provided results. This includes areas such as Leeds, Bradford, York and Hull. There is an average of 8.6 neurologists across these trusts. Each trust has 2.8 ESNs on average – this is the highest result of all the areas.

In the Midlands, 33 of the 36 trusts contacted responded. There is an average of 6.7 neurologists for each trust and 1.6 ESNs. The Midlands included areas such as Birmingham, Wolverhampton, Shropshire and Nottingham.

In the East of England, there is an average of 6.4 neurologists across the 18 trusts that responded. One trust did not respond. The average number of ESNs per trust is 1.3 Lincolnshire and Norfolk were among the areas included in the East of England.

The results are similar in the South East of England, where there is an average of 8.1 neurologists per trust. The South East has the second highest number of trusts at 28. Two trusts did not respond. There are an average of 1.3 ESNs per trust.

Comparing England to other nations

The UK's workforce data does not compare favourably to other similar countries. Our study found there are 1.94 neurologists to every 100,000 people living in England. Both France and Germany had one consultant for every 25,000 people or fewer [Nitkunan et al, 2020].

According to the World Health Organisation, in 2004, high-income countries had 2.96 neurologists per 100,000, high middle had 3.10, low middle had 0.74 and low income countries had 0.03 [World Health Organisation, 2004]. The World Bank lists the UK as a high-income country, meaning our workforce average (1.94) is falling behind by a long way. According to the MS Society, France and Germany have more than seven neurologists for every two the UK has [MS Society, 2024].

In May 2022, the European Academy of Neurology released its Brain Health Strategy. The results of this study also suggest the UK is falling far behind its European neighbours, with only Ireland and Uzbekistan having fewer neurologists per person [Bassetti et al, 2022].

A briefing paper produced by the Neurological Alliance in February 2022 said that in December 2021, 51,195 people were waiting for neurosurgery. Of these, 7% (3,584) had been waiting for surgery for more than 12 months [The Neurological Alliance 2021]. It added that 174,243 people were waiting for a neurology appointment.

Of these, 3,485 (2%) had waited more than 12 months [Bassetti et al, 2022].

Conclusion

The results of this workforce study show a huge variation across England. Unsurprisingly, people in London are generally better served than the rest of the country. However, ESN numbers remain low even in the capital. The North East consistently comes off worse than other areas.

This suggests that where a patient lives will impact the level of care available to them, but comparisons with the rest of Europe show that even the better-served areas of England have less access to neurologists than other similar countries. However, this does not take into account the model of UK public healthcare.

There is little doubt that neurologists across the NHS are overworked and their departments are under-resourced. Despite this, the government left epilepsy out of its Major Conditions Strategy last summer [gov.uk, 2023] and the NHS Long Term Workforce plan made no mention of measures to address shortages in condition-specific workforces [NHS England, 2023].

Methodology

A list of all NHS Trusts in England and their contact details was compiled. This list was reviewed and ambulance trusts were removed, as were any trusts that were not relevant to the neurology, learning disability or maternity workforce (e.g. ear nose and throat hospitals, thoracic surgery trusts, etc). The 193 trusts that remained were contacted under the Freedom of Information Act.
The Freedom of Information Act states that public authorities should provide access to information within 20 days of valid requests.

Non-responders were asked for a response every four weeks for 24 weeks. Clarifying questions were asked when response data was inconsistent.

Responses were gained from 174 of the 193 trusts – a 90% response rate. The total and mean number of each healthcare professional were calculated for England and each constituent region. The total number of people with epilepsy per healthcare professional was calculated in England and each constituent region based on epilepsy prevalence data from Wigglesworth et al (GOLD database data was used) [Wigglesworth et al, 2023].

The analysis of this data has used the total number of healthcare professionals and not the average full-time-equivalent number. This may affect some comparisons with other data studies.

Elsewhere around the UK

The data only includes figures for England – and not Scotland, Wales or Northern Ireland. Figures that are available show that in Northern Ireland there are five epilepsy specialist neurologists and 14 ESNs, with a resulting ratio of one ESN to every 1,947 people with epilepsy. In Wales there are about 32,000 people with epilepsy, and 22.5 ESNs and 12 epilepsy specialist neurologists. That's one epilepsy specialist neurologist to every 2,996 people with epilepsy and one ESN to every 1,598 people with epilepsy.

Tom Shillito
Health improvement and research manager, Epilepsy Action

Grace Wood
Editor

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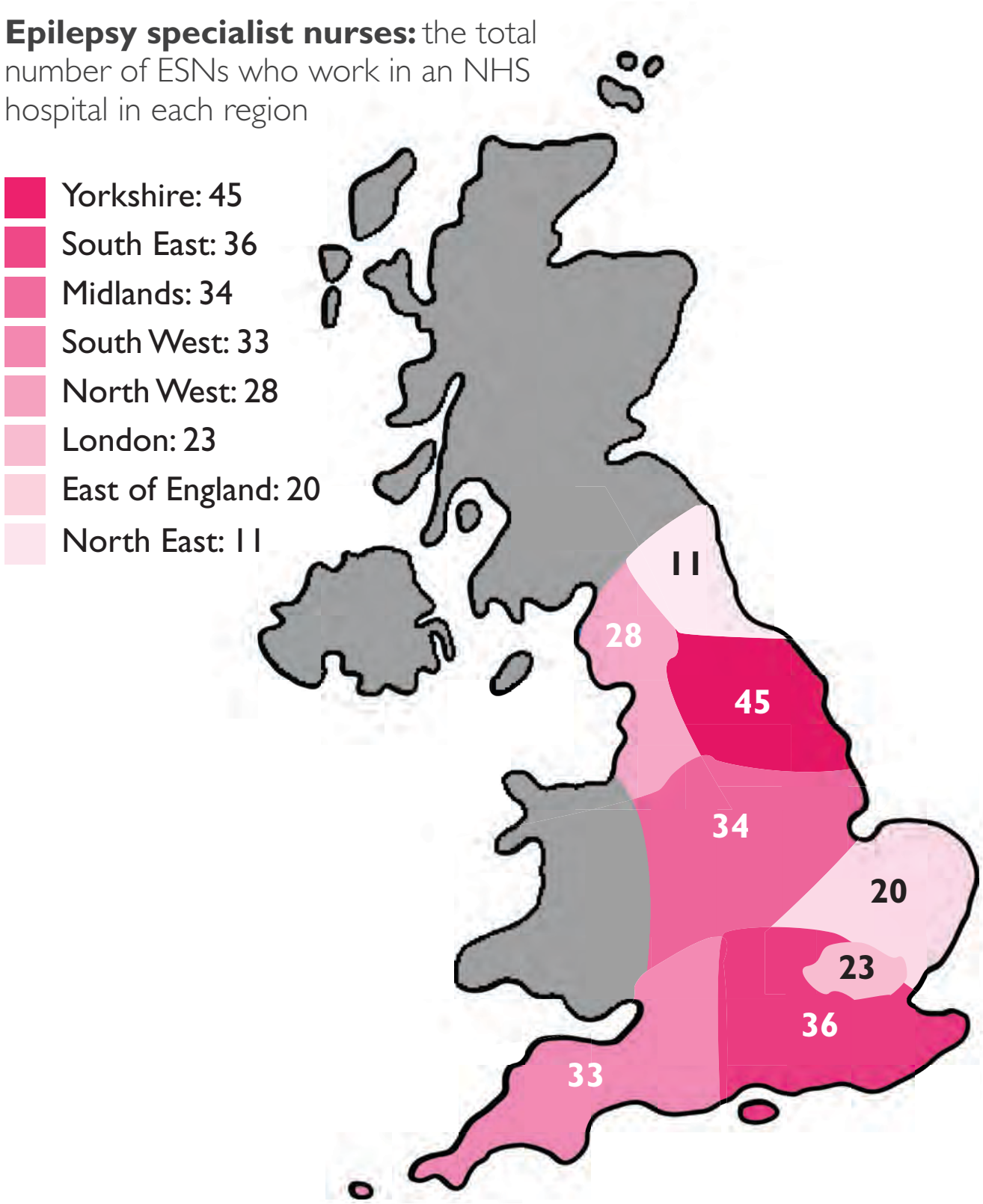
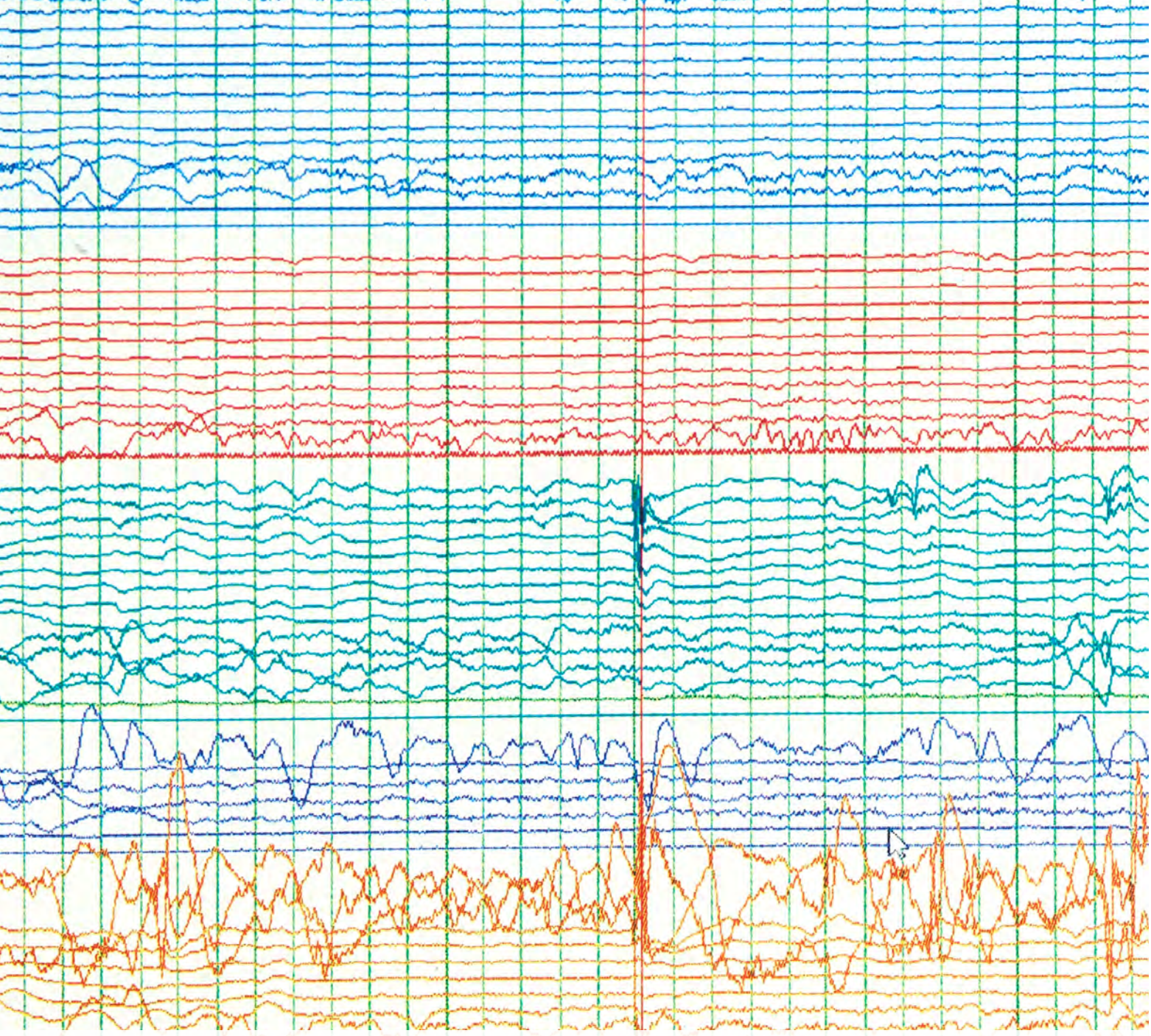
Epilepsy specialist nurses: the total number of ESNs who work in an NHS hospital in each region





Slow brain waves

Study presents potential future epilepsy treatments

Dr Laurent Sheybani and the researchers at University College London discuss their study into wake slow waves in focal epilepsy

Sleep serves a restorative function during which toxins are removed [Xie *et al*, 2013] and the excitability of neurons is normalised [Miyawaki *et al*, 2019]. A critical form of brain activity that is known to contribute to this restorative function is "sleep slow waves".

Sleep slow waves are recorded mainly in the deepest stage of sleep called non-rapid eye movement sleep stage [Massimini et al, 2004]. These slow waves last a maximum of one second and travel from the anterior to the posterior parts of the brain [Massimini et a*l*, 2004]. At a given time, they can also be generated as an isolated event in one part of the sleeping brain, while other cerebral regions do not express them – in other words, they can be temporally and spatially isolated. On a functional basis, that makes sense: these restorative waves increase where they are needed, i.e. in brain regions that were particularly active during the preceding day [Huber et al, 2004].

Up until now, such slow waves were believed to be strictly specific to sleep and absent during the wake state. Again, this makes sense on a functional perspective: it is known that sleep slow waves modulate the activity of neurons. During a slow wave, neurons go from a hyperexcitable state of depolarisation to a hypoexcitable state of hyperpolarisation. The former is called an up-state and the latter a down-state. It is assumed that these states, which are associated with profound modulation of neuronal activity, are not compatible with normal brain activity that characterises wakefulness, explaining why they would be restricted to sleep.

What if slow waves were able to decrease neuronal excitability associated with epileptic activity?

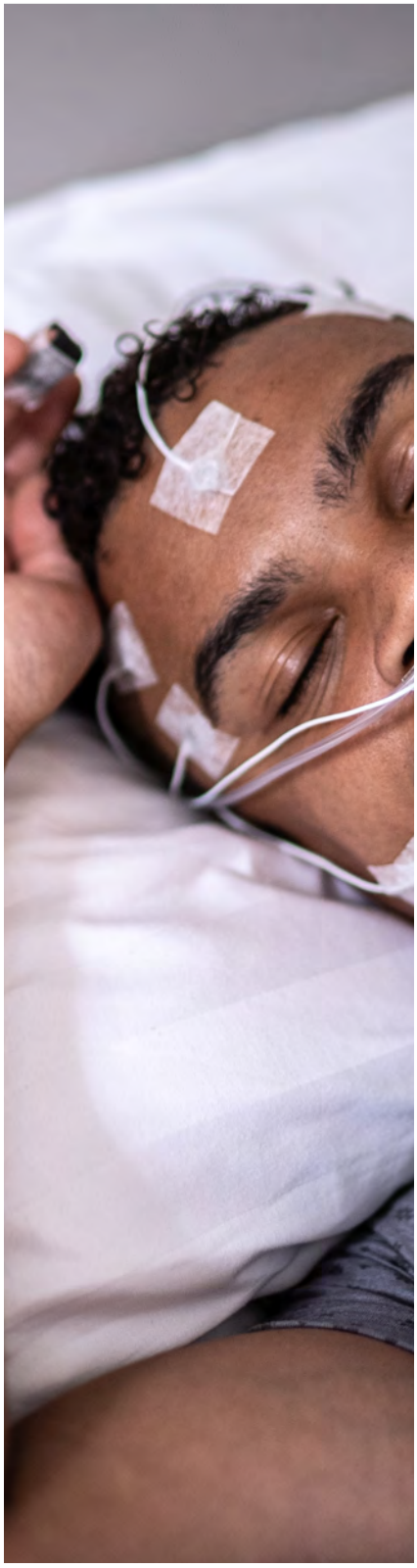
However, recent evidence has suggested that in particular circumstances, such as after sleep deprivation, they could occur in an awake brain [Vyazovskiy et al, 2015; Andrillon et al, 2021]. What could be the function of these "wake slow waves" if they do indeed exist during wakefulness? Are they also involved in restoring brain excitability, similar to their function during sleep?

Epilepsy is the prototypical neurological disorder in which neuronal excitability is abnormally high. In fact, it has been shown that targeting neurons that are too excitable can reduce seizure-related activity [Qiu et al, 2022]. What if slow waves also showed an anti-epileptic effect? What if slow waves were able to decrease neuronal excitability associated with epileptic activity?

Study questions

In this study [Sheybani et al, 2023], we asked three interdependent questions. First, we wished to establish whether slow waves occur during wakefulness. Second, we tested whether these wake slow waves are associated with a decrease in epileptic activity. Third, we assessed whether wake slow waves impact on normal cognitive processing, as anticipated from their strong modulation of neuronal excitability.

To answer these questions, we retrospectively enrolled 25 patients with focal, drug-resistant epilepsy who benefitted from intracranial evaluation of their epilepsy. Eight of these had microelectrodes, i.e., electrodes that can record the activity of single neurons. During the recordings patients performed an associated memory task. Recordings during resting-state activity were also



available. Visually, we identified slow waves during wakefulness that were clearly different from interictal epileptiform discharges (IEDs). Slow waves were slower and less sharp than IEDs. IEDs are often immediately followed by a slow wave, and we thus discarded any slow waves that occurred within one second after a detected IED. Visual identification of slow waves can be extremely time consuming. We thus designed an automatic detector based on the sleep literature [Massimini et al, 2004; Frauscher et al, 2015] and, using this detector, we identified slow waves in all patients. As expected, they were much rarer during wakefulness than during sleep. To test how similar to typical sleep slow waves these wake slow waves were, we measured neuronal activity using microelectrodes during slow waves and identified a typical down-state, i.e., a significant decrease of neuronal action potentials during the trough of individual waves. Hence, slow waves detected during wakefulness reproduce a core feature of sleep slow waves.

The fact that we were able to detect slow waves during wakefulness, although others reported their absence during this state of vigilance, [Massimini et al, 2004] led us to verify whether they were specific to our recordings or if we could also identify them in independent recordings, i.e., in intracranial recordings obtained from other centres. We took advantage of two publicly available data sets from the University of Zürich in Switzerland and the Montreal Neurological Institute in Canada [Boran et al, 2020; Boran et al, 2019; Frauscher et al, Brain, 2018; Frauscher et al, 2018; Von Ellenrieder et al, 2020] and, again, we were able to detect such waves in these recordings.

Based on the finding that slow waves can occur during wakefulness, we then tested their interaction with IEDs. During sleep slow waves provide a restorative function. Furthermore, they operate as a homeostatic regulator and are more frequent after a long period of wakefulness. Other markers such as the slope and amplitude of slow waves also indicate that sleep homeostatic pressure is high. Hence, at the beginning of the night, when sleep homeostatic pressure is high, the rate, the slope and the amplitude of sleep slow waves are high as well, and then progressively decrease during the sleep period. In our recordings, we wanted to test whether these parameters also changed during the build-up of activity before IEDs. Our hypothesis was based on the observation that network excitability increases before IEDs [Ren et al, 2015; Thomas et al, 2023]: this increase could trigger a change in the rate, slope and/or amplitude of slow waves, which would then operate a negative feedback on IEDs, decreasing their excitability.

Slow waves detected during wakefulness reproduce a core feature of sleep slow waves

We first measured network excitability before IEDs and confirmed that we could reproduce previous results from other groups [Ren et al, 2015; Thomas et al, 2023] in the build-up of IEDs, there is a progressive increase in markers of neuronal excitability. Based on this observed increase in excitability before IEDs, we then measured the rate, slope and amplitude of slow waves before IEDs.

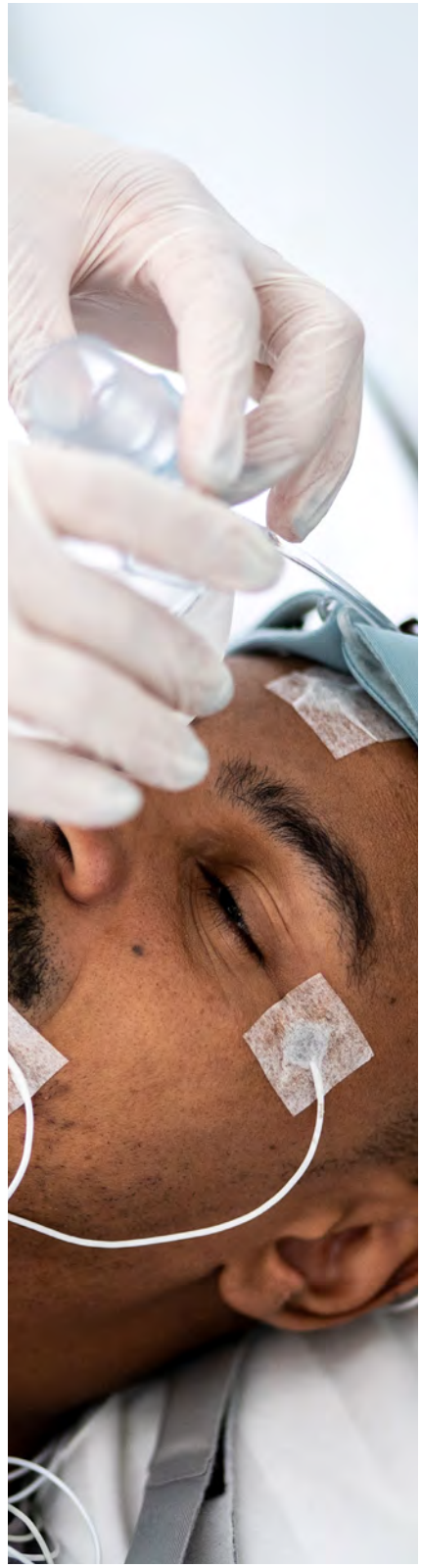
We found no change in the rate of slow waves before IEDs. However, we observed that the slope and amplitude of slow waves increased before IEDs, similar to their increase in conditions of high sleep homeostatic pressure, such as after a period of wakefulness. Hence, in parallel to increases in excitability in the build-up of IEDs, we observed changes in the shape of slow waves that recapitulate the changes expected from sleep slow waves at the beginning of a sleep period. We then wanted to test whether these wake slow waves feedback on IEDs. In our first analysis, we measured the rate of IEDs after slow waves but we found no change. We then tested whether slow waves had an impact on the network excitability associated with IEDs. To test this, we measured the correlation between the delay since the last slow wave and network excitability during an IED. We found a positive correlation: the longer the delay, the higher the excitability, so that any beneficial effect of slow waves dissipates with time. Thus, we were able to identify a signature of a protective function of wake slow waves on epileptic activity.

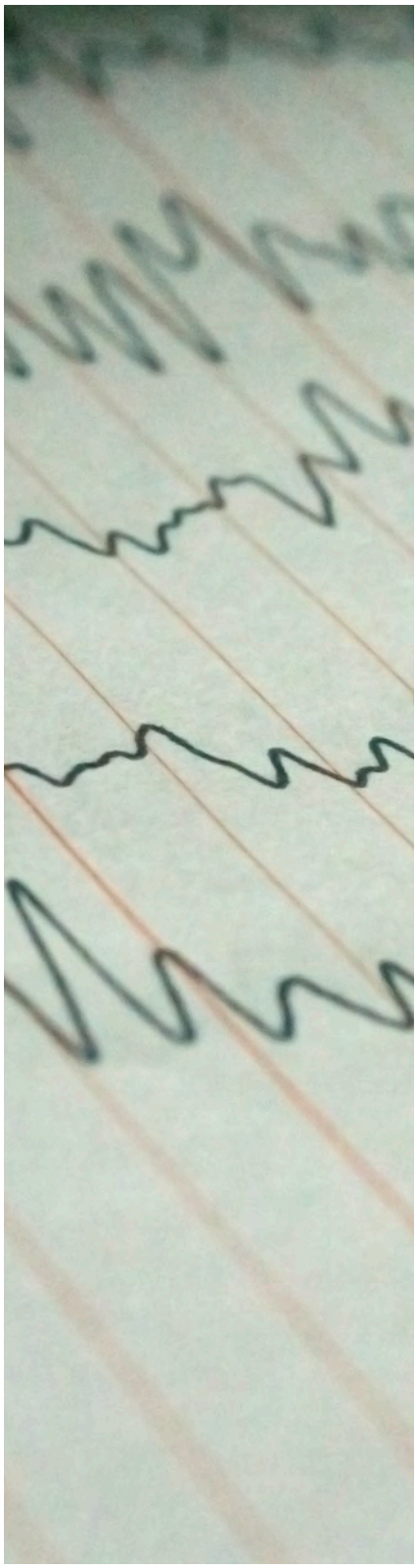
If wake slow waves are beneficial, why are they so rare? One potential explanation, as introduced earlier, is that they are not compatible with normal cognitive processing [Vyazovskiy et al, 2013], because of their profound modulation of neuronal activity. We were able to address this question by studying the impact of slow waves on memory processing. We observed that the more frequent slow waves are during retrieval of the memory task, the slower the reaction time: for each step increase of one wake slow waves per second, the reaction time increased markedly by more than half a second. Although slow waves slowed reaction time, they were not associated with a negative impact on accuracy in response to the memory task. We found the opposite result for IEDs: their presence negatively impacted accuracy, but not reaction time. It might be that the impact of IEDs on neuronal activity is so disruptive that the brain stops working reliably during the period of an IED – less than 200 milliseconds. Conversely, the impact of slow waves is to slow down brain processing but not to decrease overall accuracy.

We were able to identify a signature of a protective function of wake slow waves on epileptic activity

Overall, our study revealed that slow waves, previously believed to be specific to sleep, can also be recorded during wakefulness. Their rarity during wakefulness might explain, at least in part, why they were not previously identified during wakefulness. The second observation is an "epileptic homeostatic loop" provided by slow waves: in parallel to increases in network excitability, their slope and amplitude increase, and the delay since the last slow wave is positively correlated with increases in IEDs excitability. Slow waves might provide a restorative function against IED-associated hyperexcitability, but this dissipates with time, explaining this positive correlation. Last, slow waves slow down memory processing but not accuracy, in contrast to the impact of IEDs.

These findings open avenues to develop closed-loop neurostimulation devices that could enhance these protective slow waves. This concept would take advantage of an intrinsic





protective mechanism of the brain and enhance it to provide potential protection against epileptic activities. These results are encouraging but further research is needed. Indeed, while our observations suggest a protective function of slow waves, the evidence remains associative: we need to test the causal relationship between slow waves and IEDs and/or seizures. The second caveat is that we do not want to impact negatively on memory processing. Based on our observations, accuracy in memory would not be impacted, which is encouraging. Furthermore, if slow waves decrease IEDs and since IEDs are associated with decreased accuracy, then boosting slow waves might have a positive effect on memory processing, but this remains to be tested. Overall, we need to determine the right balance between the impact on brain function and on the epileptic load.

Summary

Our study demonstrates that an intrinsic brain activity, slow waves, decreases network excitability associated with IEDs at the price of slower reaction time in an associative memory task. Future works should test the causal relationship and test whether enhancing these slow waves can have a beneficial effect on epilepsy.

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Reliance Technology Care Solutions

My Medic Watch

Reliance Technology Care Solutions is proud to be partnering with My Medic Watch to provide innovative smartwatch apps that can detect movement associated with seizures and general falls. Users can set up key contacts who are notified when the smartwatch detects an incident or when the user raises the alarm themselves. If a contact does not respond, then support is only seconds away with our 24/7/365 in-house monitoring centre and we can escalate all alarms through the emergency services if required.*

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*Reliance Technology Care monitoring service and website will be live mid January 2024

Tom Shillito

Research update

Epilepsy Action health improvement and research manager Tom Shillito shares updates from Epilepsy Action's research work

Epilepsy Action Excellence Collective

An innovative new project to create change and connect the epilepsy community, called the Epilepsy Action Excellence Collective, was launched in February. The Excellence Collective will drive change and improvement in all aspects of epilepsy care by bringing together people with epilepsy, health and social care professionals, researchers and policy makers.

The Excellence Collective will create and facilitate improvements through a variety of diverse mechanisms. These include funding and supporting quality improvement projects within health and social care organisations, creating an information repository, mapping epilepsy services and support across the UK, bridging the gap between research and practice, and supporting other organisations to improve their services for people with epilepsy.

Who is involved?

The Excellence Collective brings together everyone with an interest in epilepsy. As with all of our work, this starts with people affected by epilepsy. These are our members, supporters, volunteers and followers. We will gather information from them through our services, helpline, social media, surveys and consultations, and this will set the direction for the work we do. This will show us their priority topics, the problems they face and whether there are differences in priorities across the regions of the UK. We can communicate their needs to the other stakeholders within the collective, ensuring that research and care reflects the desires of people with epilepsy. We will also use the information we collect from the other stakeholders in the collective to create resources that people affected by epilepsy can use. For example, we will map epilepsy services across the UK, provide conversation guides for appointments, deliver up-to-date information on treatments and investigations, and inform them of the latest research.

We will also work very closely with health and social care professionals. This includes any and all professionals who may come into contact with people with epilepsy, from neurologists and epilepsy specialist nurses, to paramedics, occupational therapists, social workers, professional carers and everyone in between. We will have a constant open

dialogue with these professionals to find out what is happening in practice, what their priorities are, what support they need, what problems they face and what they hear from their patients. We will share examples of best practice, toolkits and guidance that can enhance care and bring people together to share ideas and solutions. The information we collect will also inform the quality improvement projects that we fund and support, and our campaigns and lobbying with policy makers within the NHS and government.

Epilepsy researchers are a key part of the collective. There is a disconnect between what is found in research and what is done in practice when it comes to epilepsy care. We want to bridge that gap and ensure that all aspects of care are based on the most up to date and relevant information. We will create communication channels between researchers and healthcare professionals to allow new discoveries to be shared quickly and easily. We will also develop tools to assist with putting research findings into practice. Alongside disseminating information about current findings, we will work closely with research institutions and funders to highlight knowledge gaps and prioritise these areas for research attention. To support this future research, we will lobby decision makers to ensure that research funding, resources and attention are available from both funders and the NHS, as well as other organisations, to support research in priority areas.

Policy makers within the NHS, local and national governments have an important role to play within the Excellence Collective. They will make us aware of the priorities and constraints within their organisations, which can help us to target our campaigns. We will make sure the

needs and wants of the other stakeholders are communicated to policy and decision makers, and lobby for change on our key priorities. We will also use the information gathered from policy makers to provide support for people wanting to create change, for example by providing business cases, support with commissioning, information on key priorities and targets within the NHS/local ICB and guides on speaking to politicians.

What will the Excellence Collective do?

The purpose of the Excellence Collective is to create improvements for people with epilepsy. There are no limits on what this improvement should involve. It is improvement across the board, for every person affected by epilepsy and for every aspect of life with epilepsy. People with epilepsy deserve to live normal lives without restrictions or barriers to good quality of life and the Excellence Collective will bring together the whole epilepsy community to break down the barriers they face.

This improvement will be created in a variety of different ways. Our priorities will be based on everything we hear from our stakeholders, and will evolve over time and as our work progresses. We will encourage information sharing between stakeholders and develop tools to encourage and facilitate change.

The following priorities have been chosen for our first year of operation.

Funding and supporting quality improvement projects

The collective will fund and support quality improvement projects within the NHS, social care and other organisations that support people with epilepsy. We will use the input from all of our stakeholders to identify key priority areas for improvement, which may be around a particular topic (e.g. transition to adult services, learning disability and epilepsy, epilepsy and sport, etc), a geographical area or both. We will then ask for project proposals to tackle those priorities and use stakeholder representatives to decide which projects receive funding. We will also provide non-financial support to projects. This will include access to our volunteers and PPI representatives, helping to run focus groups, creating and disseminating surveys, and sharing information with other stakeholders.

In 2024 we are supporting two projects, one of which we are funding entirely and the other we are part-funding and project managing. The first of these projects will map care for pregnant people with epilepsy and create a toolkit to ensure care is safe, holistic and effective. The second project will create self-management training for people with epilepsy and a learning disability. We have chosen these projects based on the feedback we have received both from people with epilepsy and from healthcare professionals who highlighted serious gaps in care for both pregnant people and people with learning disabilities. The outcomes of these projects will help to fill those gaps and improve patient safety.

Information repository and epilepsy map

We will create an information repository, combining information from all of the stakeholders. This will include examples of best practice from our healthcare professionals, new research findings, available services, commissioning resources, prevalence statistics and more. Where applicable, this will be broken down by region.

We will also host an epilepsy map on our website. This will include all the information relevant to someone affected by epilepsy, broken down by region. It will list the prevalence and incidence, regional tertiary centres, epilepsy workforce numbers (see p12), our support services (such as local talk and support groups), other support resources and useful links.

Translating research into practice

There is a wide gap between what research suggests would be helpful for people with epilepsy and what is done in practice. It can be very difficult for healthcare professionals to keep up to date with current findings alongside their clinical roles, and even when they do find new ideas, policies may prevent them from making changes. We want to help bridge that gap by sharing information between researchers and health and social care professionals, and influencing policy makers to update policies in line with the latest research. We will create open lines of communication between these groups and allow them to share findings, barriers to change and ways to overcome those barriers. We will create resources to support the implementation of findings and tools that can be used to make the case for change.

How can you help?

If you're interested in being part of the collective, you can sign up for free at www. epilepsy.org.uk/ExCo. We are interested in hearing from everyone with an interest in epilepsy, whether you're a healthcare professional, researcher, policy maker, carer or some affected by epilepsy.

If you have any ideas you would like to share with us, you can contact Tom Shillito by emailing tshillito@epilepsy.org.uk.

epilepsy action

Epilepsy Action is here for you

helpline

Epilepsy can be very confusing. Our Helpline team are ready to answer any questions you might have on the phone, via live chat or email.

talk and support

If you want to talk to other people about life with epilepsy, you're welcome to come to one of our Talk and support groups to meet and share your experiences either on line or face-to-face.

befriending

Not everyone's ready for a group, though – one-to-one support through Befriending might be better for you. We'll connect you to a volunteer who will offer you a friendly listening ear either on the phone or online.

counselling

Counselling can be really helpful when things get tough – we're ready to help in Wales and Northern Ireland. Our professional Counselling team can provide the support you need online or over the phone.

family support Northern Ireland

Epilepsy doesn't just affect the person with the diagnosis – that's why our Family support service is there for family members and carers in Northern Ireland.

"Epilepsy Action has made such a big difference in my life... they have helped me learn to live with my condition"

epilepsy.org.uk/support

Epilepsy Action Helpline: freephone 0808 800 5050
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Highlights

Top picks from *Seizure*

Editor of the journal *Seizure*, Professor Markus Reuber highlights his key papers from the latest editions

Normalization and cross-sectional validation of an extended adverse event profile in a large cohort of patients with epilepsy.

In 2005 the International League Against Epilepsy and International Bureau for Epilepsy jointly produced a conceptual definition of epilepsy as "a disorder of the brain characterised by an enduring predisposition to generate epileptic seizures, and by the neurobiologic, cognitive, psychological and social consequences of this condition" [Fisher et al, 2005]. While this definition was further refined with a "practical clinical definition" in 2014, it has not been revoked [Fisher et al, 2014]. As seizures are not the only manifestation of epilepsy, the abolishment of seizures cannot be the sole aim of treatment. Especially when seizures cannot be fully controlled with treatment, it often becomes apparent that a balance needs to be struck between the impact of seizures and of the side effects of treatment. Indeed, among patients with epilepsy who are continuing to experience seizures, health-related quality of life is more closely related to mental and cognitive well-being as well as other non-seizure physical symptoms than with the frequency or severity of seizures [Rawlings et al, 2014].

If the possible "off-target" effects of epilepsy treatment (chiefly anti-seizure medications, ASMs) are so important for how well people feel and function – how should they be detected and monitored? To capture the broad range of potential side effects (including symptoms such as fatigue, mood change, problems with balance and vision, slowness of thinking, insomnia, autonomic changes and skin rashes) a number of inventories such as the Neurological and Systemic Adverse Event Rating Scales [Cramer et al, 2011] and the Adverse Event Profile (AEP) [Baker et al, 1995] have been developed.

But what actions should patients and clinicians take when a particular symptom has been reported? In order to make appropriate choices about medication changes or dose adjustments, patients and clinicians need to make judgements about the cause of these symptoms. Many potential ASM side effects are common in the "healthy" general population. They may also be manifestations of the brain disorder causing epileptic seizures or of comorbid conditions. In all of these cases it may not be necessary or helpful to change an ASM that is making a useful contribution to a patient's seizure control. While randomised placebo-controlled studies teach us about the side effect profiles of drugs at group level, the

information gained from such trials about side effects does not tell us much about whether the symptom reported by a particular patient in clinic is related to their ASM or not.

My editor's choice from volume 114 of *Seizure* is a retrospective comparison by Helmstaedter et al of a large clinical data set collected from patients with treatment-resistant epilepsy using an extended version of the AEP (E AEP) with E AEP data provided by a large general population sample [Helmstaedter et al, 2023]. The normalisation of the E AEP suggests that between one and two thirds of patient-reported symptoms on the E AEP scale are unlikely to be related to ASM. While future analysis of longitudinal E AEP changes associated with specific medication alterations may provide additional

information about the likely relationships between ASMs and patient-reported symptoms, this paper takes an important step forward in the analysis of potential patient-reported ASM side effects. The use of the normalised analysis of reported symptoms should help clinicians and patients to make better decisions when they contemplate whether or not to make changes to ASMs because of possible side effects.

Utilisation of specialist epilepsy services and anti-seizure medication adherence rates in a cohort of people with epilepsy accessing emergency care.

Some stories are not new but need to be told repeatedly before they have the effect they deserve. My editor's choice from volume 115 of *Seizure* is one such story. The study by Mohamed Taha et al, describes the management and outcome of 266 consecutive seizure-related Emergency Department (ED) attendances in hospitals in a large urban area in Scotland [Taha et al, 2023]. A history of mental health disorder (recorded in 35% of ED attendances) and excessive alcohol and/or recreational drug use (observed in 25% of attendances) were identified as risk factors for seizures in emergency presentations. ED attendances were an indicator of poor outcome. One in 20 of the patients seen in ED with a seizure emergency were dead in a year of their attendance. Almost half of the deaths identified (42.3%) were associated with poor ASM adherence. Neurology staff (most likely neurology doctors in training) only became involved in more than a quarter of emergency attendances. When they did, they proposed treatment changes in 60% of cases.

These observations are not new. Previous research in the UK has demonstrated that seizures are the most common neurological emergency leading to ED attendances (making up 0.7% of unscheduled hospital admissions) [Dickson et al, 2018]. Despite the fact seizures are a clear marker of acute neurological pathology, other studies have shown that neurologists only become involved in the assessment or treatment of a minority of cases [Dickson et al, 2017]. It is also well recognised that, in those with pre-existing epilepsy, poor medication adherence is one of the most common contributors to seizure-related ED attendances, and that ASM nonadherence is associated with a threefold increase in mortality [Faught et al, 2008].

The reason this story needs to be told again is that alternative care pathways – intended to reconnect patients experiencing seizure emergencies to appropriate specialist services rather than simply transporting them to an ED – have been described but rarely implemented [Dickson et al, 2017]. The opportunity to improve the management of seizures, seizure disorders and underlying pathologies is still too often missed by neurological service providers. Of course, input from neurologists alone will not be sufficient to address all of the medical, social and mental health needs of patients presenting with seizures in EDs, but it could make a significant contribution to better care and outcomes.

Further reading

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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

Dates for the diary

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

3-8 March
4th International Training Course on Neuropsychology in Epilepsy
Lyon, France
bit.ly/3gLFWD4

25-28 March
ILAE teaching course:
EEG in the First Year of Life
Cambridge, UK & Online
bit.ly/3uvZZM9

5-8 May
Seventeenth Eilat Conference on new Antiepileptic Drugs and Devices (EILAT XVII)
Madrid, Spain
bit.ly/3u7Mzm6

11-12 May 2024
ILAE British Branch 19th Epilepsy SPR Teaching Weekend.
Birmingham University, UK
bit.ly/47ysQy4

15-18 May
ILAE School on Neuroimaging
Potsdam, Berlin and online
bit.ly/3Hrzkn3

29 June-2 July
10th Congress of the European Academy of Neurology
Helsinki, Finland
bit.ly/47LSi3L

7-15 September
15th European Epilepsy Congress
Rome, Italy
bit.ly/45p17Pg

23 September
ILAE British Branch Annual Scientific Meeting
Liverpool, UK
bit.ly/3Gjx8gO

2025

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

Next issues:

Dr Louise Spiers

Dr Spiers discusses her research into people with epilepsy who might have what could be considered exceptional, anomalous and spiritual experiences.

Neuro Event Labs

The company talks about its NELLI video technology for diagnosis and monitoring epilepsy

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

gwood@epilepsy.org.uk

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