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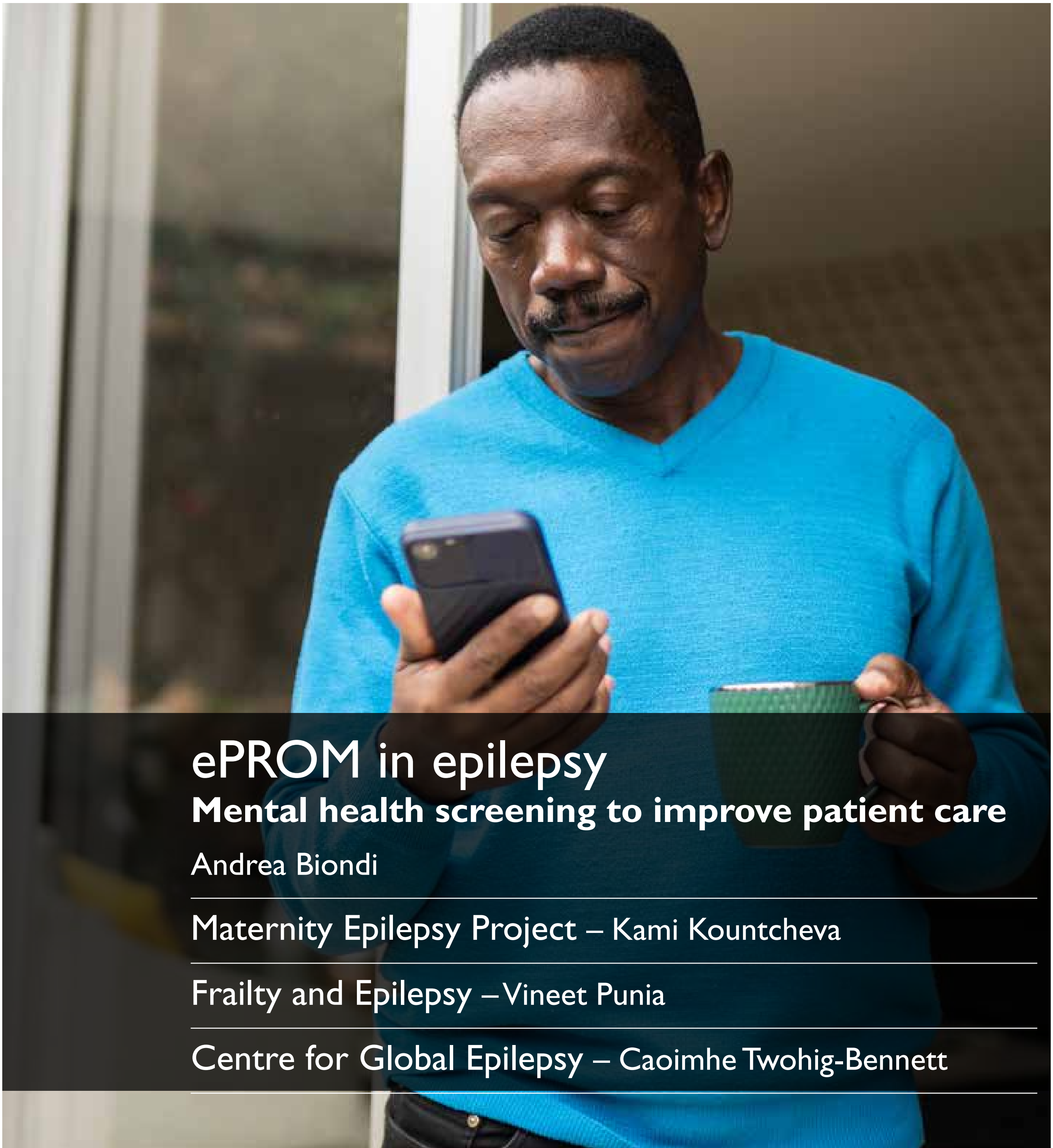

ePROM in epilepsy

Mental health screening to improve patient care

Andrea Biondi

Maternity Epilepsy Project – Kami Kountcheva

Frailty and Epilepsy – Vineet Punia

Centre for Global Epilepsy – Caoimhe Twohig-Bennett

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1. Elliott, RE., et al., (2011) Epilepsy & Behavior. 20; 478–483.
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LivaNova Epilepsy

Welcome to the summer 2025 edition of Epilepsy Professional. In this issue we have a selection of articles focusing on important clinical topics in epilepsy, such as mental health, maternity care and epilepsy in older people. There is also an exciting overview of the new centre for global research in epilepsy based at Wolfson College at the University of Oxford.

Andrea Biondi in his article pleas for a greater focus on the mental health and wellbeing of people with epilepsy. He highlights the frequency of mental health conditions such as anxiety, depression and also the co-occurrence of neurodevelopmental disorders which, in turn, affect mental health. He acknowledges the well-documented barriers to addressing these conditions in an epilepsy clinic, such as time, lack of assessment tools, training and expertise to manage the outcomes. Given this, he suggests the new promising tool of PROM (patient reported outcomes) could be employed to collect data in a timely way. In light of this, his team at Kings College performed a prospective study in which patients completed a digital mental health screening tool in advance of their epilepsy clinical appointment, whereupon the results were uploaded onto the patient electronic record, therefore allowing appropriate discussion, onwards referral or intervention as needed. In his article, he discusses the results, outlines the next steps and overall illustrates this use of patient collected data as a promising technique to address the comorbidity of mental health issues in a busy and multi-faceted epilepsy clinic.

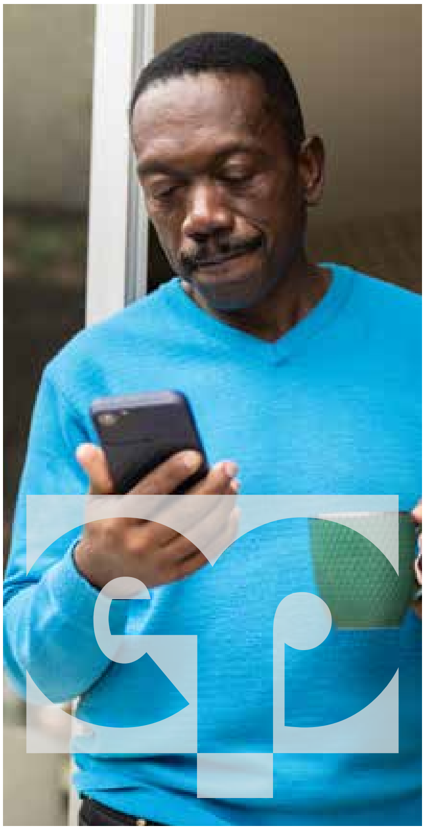
Frailty is currently a big topic in hospital and community medicine and I'd encourage you to read Dr Vineet Punia's article on frailty in older adults in the context of epilepsy. This article explores the relationship between these two conditions and outlines important clinical strategies for management in older adults. Dr Punia explores the bidirectional effect of epilepsy and frailty and focuses on the relevant themes of polypharmacy, comorbidities, physical inactivity, social isolation and tolerance of antiseizure mediations. Overall, Dr Punia suggests a multidisciplinary team approach and emphasises the opportunity to detect frailty early, to tailor medications appropriately, to encourage light physical activity and attempt to address social isolation and mental health, overall aiming to improve outcomes and quality of life in older adults with epilepsy.

Can I highlight Kami's overview of the Maternity Epilepsy Project in the North West of England? They have reacted to the MBRRACE outcomes from 2021 and 2023, which identified that women with epilepsy are 10 times more likely to die in pregnancy than women without epilepsy, alongside the worrying statistic that SUDEP had almost tripled in the last three years. A gap analysis of maternity care across the North West was performed which employed surveys and listening events across a range of care givers, people with epilepsy, and care settings. The results make interesting and sadly unsurprising reading but have served as a catalyst for change. The project team continues to produce further resources to support health professionals working with women with epilepsy before, during and after pregnancy, hoping to improve the services for and the safety of women with epilepsy in the area.

And, finally, Caoimhe Twohig-Bennett, director of research at the Centre for Global Epilepsy in Oxford, a world first, and a dedicated centre focusing on advancing epilepsy research and care on a global scale, lets us in on details of the launch event from 31st January, which included Professor Helen Cross, Professor Arjune Sen and Sir Tim Hitchens, president of Wolfson College. This novel centre aims to challenge stigma, foster international collaboration and provide opportunities for immersive research in Oxford and beyond, serving as a multidisciplinary hub for knowledge exchange in epilepsy.

I do hope you enjoy this varied summer edition and can reflect on your own service and practice in epilepsy in light of these articles.

Ann Johnston
Consultant neurologist
Executive medical adviser
Epilepsy Professional



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ePROM in epilepsy

Andrea Biondi

Dr Biondi discusses the role of digital mental health screening for people with epilepsy and its potential for future care

We all strive to deliver the best service that we can for people. That's when a job is at its most rewarding – when you can give the best support possible, everything you need in order to to do that is easy and works, and the person's life is improved as a result. The running theme of service improvement is evident throughout the articles in this issue, using new tools, better pathways, and learning from each other.

First up, on page 10, the Maternity Epilepsy Project by Epilepsy Action and the North West Regional Maternity team has worked to assess the maternity services for people with epilepsy in the region, developing resources to support health professionals working in those services. Meanwhile, on page 20, Dr Andrea Biondi suggests digital mental health screening prior to neurology appointments could improve the level of care for people with epilepsy.

On page 28, Ruby Hooper shares her epilepsy story. She also told her story to a class of trainee nurses in Liverpool, discussing medication side effects, struggling to question doctors' decisions and feeling both able and disabled at the same time. Understanding lived experience can really help build empathy in healthcare professionals working with epilepsy. Also in the spirit of information sharing, Dr Vineet Punia discusses frailty in older adults with epilepsy, suggesting multi-disciplinary and holistic approach to care is needed (page 14). On page 30, you can read about the Centre for Global Epilepsy, which has been launched to foster international collaboration in research and epilepsy care.

I hope there's some food for thought here, and that you enjoy this issue.

Kami Kountcheva
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Benefit cuts to PIP "damaging" for people with disabilities

Parliament TV

People will need to score at least four points in a category to qualify for daily living personal independence payments (PIP) support, Work and Pensions Secretary Liz Kendall announced on 18 March.

Speaking in Parliament, Liz Kendall announced the government's plans for "significant reform" to the welfare system and save £5 billion by 2029/30.

The planned changes mean people will need to score at least four points in any category in order to qualify for the daily living component of PIP. This will not affect the mobility component.

Disability charities have widely criticised the decision which will effectively tighten the eligibility for PIP, saying it is "immoral" and "devastating", and warning that it will push disabled people into poverty.

Epilepsy Action warned that cutting the benefit that helps disabled people manage daily life is "damaging" and counterproductive for getting people into work.

In the announcement, Liz Kendall added that there are no plans to means test or freeze PIP and that the government will launch a review of the assessment process for PIP.

Alison Fuller, director of Health Improvement and Influencing at Epilepsy Action, said: "If the government wants to get more people with disabilities into work, this just isn't the way to do it.

"For people with epilepsy, it's hard enough to get PIP as it is. We've heard too many stories over the years of people feeling really alienated by the process, and having to 'prove' they actually have a disability. Being made to feel 'they're not disabled enough'.

"And the assessment is one of the most difficult parts. We have said time and time again that this should change. But not in this way. We think that more weight should be given to the views of the individual's healthcare professionals about the impact of their health condition, not what the assessor says. Now, it sounds like people are going to have to fight even more to achieve a higher score when being assessed.

"Also, PIP is paid to help people with a disability offset the extra costs of living with the condition. Claimants don't have to be out of work to receive it. The rhetoric that cutting disability benefits is going to help more people into work is just damaging. Plus, lots of people with epilepsy need PIP precisely to manage all aspects of life, which includes getting to work."

Surveys conducted by Epilepsy Action have shown that people with epilepsy face a number of pressing challenges when it comes to employment. For example, in an Epilepsy Action survey, 42% of employers admitted that they would be inclined not to hire someone with epilepsy to save their company potential challenges, even though they know this is discrimination.

Among surveys of people with epilepsy, 40% said their employers refused to provide reasonable adjustments, 60% said they'd faced discrimination at work because of their epilepsy and 28% had been given disciplinaries because of seizures.

Alison Fuller continued: "Epilepsy has the second-highest disability pay gap, at 26.9%. People with epilepsy still get discriminated against when trying to find or stay in a job. Too many employers are not willing to give people with epilepsy reasonable adjustments – 40% of people with epilepsy have told us this is the case. These are the issues to address.

"People shouldn't be punished for having a condition, or being made to feel like their quality of life can be sacrificed to make 'savings'. For people with epilepsy, anxiety and stress are major seizure triggers. This could potentially make this worse for so many people, not knowing if their independence, the very thing this benefit should be supporting, could be stripped away.

"We will respond to the consultation, and urge everyone who could be affected to do the same, as well as sharing the issue with their MP."

Starmer plans to abolish NHS England must not leave people with epilepsy "in limbo"

Sir Keir Starmer announced on 14 March that he will abolish NHS England to bring the NHS into "democratic control".

In an address at British consumer goods company Reckitt, the prime minister said there is too much regulation. He said he wants to "cut bureaucracy across the state" and "shift money to the frontline".

He said management of the NHS should be "at the heart of the government, where it belongs".

He added: "I don't see why decisions about £200bn of taxpayer money, on something as fundamental to our security as the NHS, should be taken my arms-length body NHS England.

"I can't, in all honesty, explain to the British people why they should spend their money on two layers of bureaucracy [NHS England and the Department of Health and Social Care (DHSC)].

"That money could and should be spent on nurses, doctors, operations, GP appointments."

However, organisations like Epilepsy Action are concerned over the practicalities of the restructure and warn that people with conditions like epilepsy can't be "left in limbo" while it is carried out.

NHS England was established in 2013, to function as an arm's-length body responsible for delivering safe and high-quality care, supporting NHS staff and deliver value for money.

The government plans to bring in NHS England's work into the DHSC, which Health Secretary Wes Streeting said, in an address to Parliament following the prime minister's announcement, would take around two years.

He said hundreds of thousands that would be saved a year will flow down to frontline workers, help cut waiting times and deliver better care.

A transformation period of bringing NHS England into the DHSC is beginning immediately.

Tom Shillito, health improvement and research manager at Epilepsy Action, said: "Such a massive restructure poses the risk of slowing down quality improvement work, when it was starting to gain momentum. Shifting more power to local commissioners could make the current service postcode lottery even worse. With epilepsy often being low on the priority list at best, and completely forgotten at worst, this is clearly worrying.

"There could be some potential for process improvement, but it's unclear if we will able to see much progress in the short-term. But there are 80 new people being diagnosed with epilepsy every day. They can't be left in limbo in the meantime."

The prime minister added that more "tough choices" will be made.

45 MPs call for review of medication supply chain

Forty-five MPs have signed a letter calling on Health Secretary Wes Streeting to review and address the cause of medication shortages and help safeguard people's health.

Lead signatory, Cat Smith MP, said recent news around the death of 44-year-old David Crompton, who died after getting an IOU for his medicine from his pharmacy, has added real urgency to their call.

She said: "Medication shortages have been a crucial issue over the last year and in our letter, we warned the Health Secretary that the shortages of epilepsy medications could result in fatal seizures.

"It is vital that the Health Secretary takes action now before there is another tragedy. One death is a death too many. Our hearts go out to the family and friends of David."

The MPs worked with Epilepsy Action, Epilepsy Society and SUDEP Action on the letter. In it, they warned that a review into the shortage of medication is urgently needed to prevent an increased risk of sometimes fatal seizures.

Ketamine trialled for status epilepticus in adults and children

Scientists in the US have received an initial $9.3 million from the National Institutes of Health for a $30 million clinical trial into the use of ketamine for status epilepticus in adults and children.

Dr Jaideep Kapur (pictured), neurologist at the UVA Brain Institute and study lead said the trial is due to start in the summer. Additional funding will be provided based on the study's progress and the team expect it to last around 4.5 years.

Previous studies have looked into the use of the powerful anaesthetic ketamine for the prolonged epileptic seizures. A study from 2022 found that ketamine had a 60% success rate, while a 2024 study from Spain found a "good response" in 57% of patients.

In the latter, study authors concluded that the presence of super-refractory status epilepticus (SRSE) and how quickly ketamine was administered was linked to its effectiveness.

Now, University of Virginia (UVA) Brain Institute and School of Medicine researchers are looking to investigate whether adding ketamine to existing status epilepticus treatment would stop these seizures in more patients than current treatment alone.

The trial is looking to initiate ketamine as second-line therapy alongside levetiracetam.

UVA said the trial will particularly focus on the outcomes in children aged over one year, expecting around a third of participants to be aged 1-17 years. Dr Kapur said: "Ketamine has been used in children with refractory or super refractory status epilepticus. We plan to use it in established status epilepticus.

"Our hope is that this trial can improve treatment guidelines for patients suffering from these dangerous seizures."

The trial will be randomised and double blinded, and will evaluate the effectiveness of adding 1mg or 3mg of ketamine to patients' status epilepticus treatment. It is expecting to enrol "hundreds of participants" and run over the next "several years" across around 60 sites.

Fenfluramine for Lennox-Gastaut available on NHS

Epilepsy medication fenfluramine is now funded for NHS patients with Lennox-Gastaut syndrome (LGS).

The National Institute for Health and Care Excellence (NICE) has recommended it as a treatment for seizures in LGS for people aged two years and over.

Clinical trials have shown that fenfluramine can reduce the frequency of drop seizures by more than a quarter on average.

Fenfluramine can also reduce the risk of hospitalisations and needing emergency care. It has previously been recommended for Dravet syndrome.

Men already taking valproate don't need two specialists' sign-off, MHRA says

Men currently taking sodium valproate will not need sign off from two independent specialists to continue their treatment, the Medicines and Healthcare products Regulatory Agency has confirmed today.

The update means they will also not need to sign a Risk Acknowledgement Form.

However, any new valproate prescriptions for men or for women under the age of 55 will still need two specialists to independently agree that "there is no other effective or tolerated treatment, or there are compelling reasons that the reproductive risks do not apply", the MHRA said.

After a new prescription of valproate, women will then need to sign an Annual Risk Acknowledgement Form, while men will only need to sign a Risk Acknowledgement Form once.

These changes to the prescription guidance were introduced in January 2024, affecting men and boys for the first time. The MHRA has been tightening prescription rules around valproate for women since 2018. This followed decades of problems in babies born to mothers taking valproate without women being made aware of the risks, which became a "medical scandal".

AI detects FCDs missed by eye

An AI-powered tool can detect 64% of brain abnormalities linked to epilepsy that radiologists miss, according to a new study.

Scientists from King's College London and University College London developed the MELD Graph, which helps detect focal cortical dysplasia (FCD).

Researchers say the tool will speed up diagnosis times, get people surgical treatment quicker and reduce costs to the NHS by up to £55,000 per patient.

According to the team, FCDs are a common cause of refractory epilepsy, but surgery can be effective.

However, FCDs can be difficult to see with the human eye and up to half of these are missed by radiologists.

The study used MRI data from 1,185 patients from 23 epilepsy centres around the world who took part in the Multicentre Epilepsy Lesion Detection project (MELD). Of the participants, half were children, and 703 had FCD and 482 did not.

The researchers used the data to train the AI tool to detect subtle brain abnormalities that might not be seen by a doctor.

Study author and project lead Dr Konrad Wagstyl said radiologists are inundated with images for review. "Using an AI-powered tool like MELD Graph can support them with their decisions, making the NHS more efficient, speeding time to treatment for patients and relieving them of unnecessary and costly tests and procedures."

Tool predicts epilepsy after stroke

A new tool that can help predict the risk of epilepsy developing after venous stroke has been created by an international team of researchers.

Cerebral venous thrombosis can cause a stroke, and people can experience a seizure as part of this.

The team of researchers, from 15 centres across three continents, wanted to develop a tool to help identify the risk of this turning into epilepsy. In a paper in JAMA Neurology, Dr Erik Lindgren Bogdanoff and colleagues presented the DIAS3 tool, freely available online to clinicians. In their research of 1,128 people, 11% developed epilepsy after a blood clot in the brain. The researchers found that the tool could adequately predict the risk of epilepsy developing. The researchers said that with this tool, preventative treatment can be considered between patients and their doctors.

Dr Lindgren Bogdanoff, from the University of Gothenburg said: "The calculator predicts the risk of epilepsy based on factors that are already available in clinical routine when the person is hospitalised, there is therefore no need for additional tests or investigations."

He said that people with a blood clot in the brain need to know what the aftermath would be.

Wales epilepsy open access service reopens

The Aneurin Bevan University Health Board's (ABUHB) epilepsy open access service in Newport, Wales, has reopened after an unexpected closure in November last year.

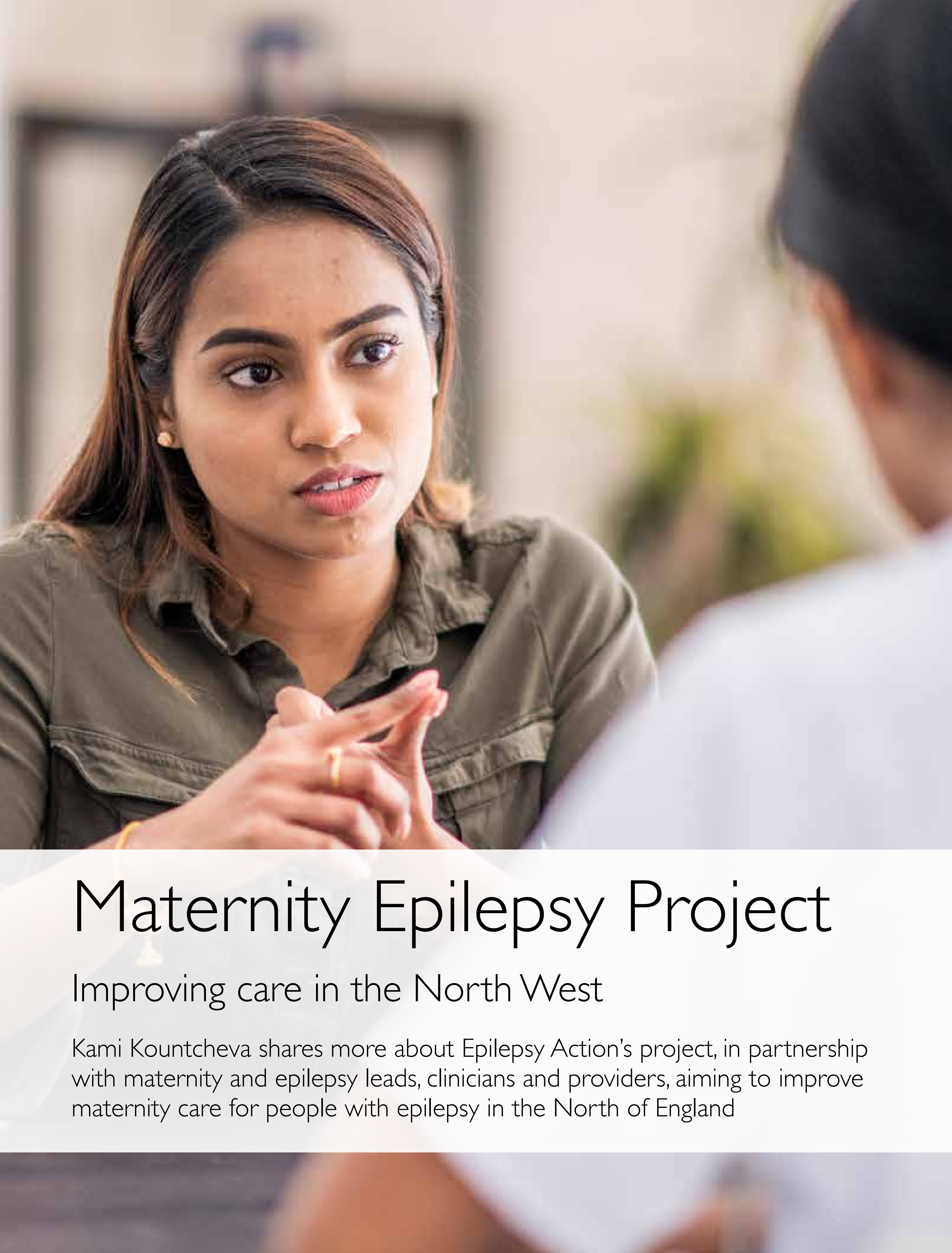
The service closed without notice around mid-November, and Epilepsy Action understood this was due to staffing problems and sick leave.

The open access service was set up to offer timely support, specialist care and ongoing management for people with epilepsy.

The service has now resumed with improved staffing in the health board. People from the area have called the helpline service "excellent" and something that patients are "reliant" on.

Epilepsy Action Wales manager, Janet Paterson, said: "It's certainly positive news to hear the service is back up and running. As many people with epilepsy in the area rely on it, it's absolutely crucial that any future fluctuations are communicated in a timely and complete manner. Patients need to be fully aware of the options available to them. We're hoping this will be taken on board in the future, should there be any more changes to service provision."

Epilepsy affects around 36,000 people in Wales, with around 1,500 new diagnoses each year. ABUHB provides specialised epilepsy services and the use of open access for people across Wales, with 6,700 people with epilepsy living in the ABUHB area.



Maternity Epilepsy Project

Improving care in the North West

Kami Kountcheva shares more about Epilepsy Action's project, in partnership with maternity and epilepsy leads, clinicians and providers, aiming to improve maternity care for people with epilepsy in the North of England

Kami Kountcheva

Epilepsy Action and the North West Regional Maternity Team have developed a new and innovative maternity pathway, supported by a range of resources to improve the clinical outcomes and experiences of birthing people with epilepsy across the North West Region in England.

The Maternity Epilepsy Project began in January 2024 and, through extensive partnership working with maternity and epilepsy leads, clinicians and providers, Epilepsy Action co-developed a maternity pathway which included preconception, pregnancy and postnatal care.

As a result of this project, a North West clinical guideline, minimum service specification and a self-assessment tool for local providers to benchmark their service against national best practice and safe standards was co-developed.

'We need to do things differently'

The team set up the Maternity Epilepsy Project to address the findings of the Mothers and Babies: Reducing Risk through Audits and Confidential Enquiries across the UK report (MBRRACE 2021 and 2023) which identified women with epilepsy are 10 times more likely to die in

> **The team set up the Maternity Epilepsy Project to address the findings of the MBRRACE report which identified women with epilepsy are 10 times more likely to die in pregnancy than women without epilepsy**

Kami Kountcheva

pregnancy than women without epilepsy. Sudden Unexplained Death in Epilepsy (SUDEP) also reported maternal epilepsy-related deaths had almost tripled in the last three years – and that many of these deaths were preventable; risk factors were identified but not acted on.

According to Catherine Owens, Midwifery and Epilepsy Coordinator at Epilepsy Action, one of the biggest challenges during the project was the limited availability of local and national data, as epilepsy-related information is not part of the national maternity reporting database (maternity safety data sheets (MSDS)).

What we do know is that people with epilepsy have an increased risk of developing mental health issues during pregnancy, increased associated learning difficulties and increased likelihood of living in areas of deprivation which brings additional health inequalities and co-morbidities. We also know that around 73,000 people are living with epilepsy in the North West region, equating to around 1% of the population. Local data populated by Cheshire and Merseyside Local Maternity and Neonatal System (LMNS) identified 51% of Birthing People with epilepsy in this area live in the most deprived areas in England.

Owens questioned: "Why has epilepsy care not got a higher profile across the maternity agenda? The information we do have is alarming and we need to do things differently."

Project findings

The Maternity Epilepsy Project team wanted to make sure that all birthing people have all the information they need to make the right choices for them and their family when considering and going through pregnancy. They also wanted to capture young voices, as this represents an inclusive cohort of current and future maternity service users.

As part of the project, the team undertook a gap analysis to assess the currently available services and found huge variation in service provisions and resources.

> **"The elephant in the room is that there is no clearly identifiable pathway for preconception care and no direction as to who will own this"**

"The elephant in the room is that there is no clearly identifiable pathway for preconception care and no direction as to who will own this," Owens said. This is despite preconception counselling being referenced to in many national guidelines.

Alongside this, the gap analysis found that some providers did not have a maternity specific guideline and some of the guidelines were not fit for purpose due to limited/no details and signposting to appropriate services. In some cases, links to comorbidities, such as mental health problems or learning disabilities were omitted, and some guidelines lacked guidance relating to a person experiencing a first seizure during pregnancy. There were inconsistencies in terms of language, such as anti-epileptic drugs (AEDs) versus anti-seizure medication (ASMs), as well as limited data availability due to variances in digital databases and epilepsy data submissions being non mandatory.

The project team also held multiple listening events with adult and young people, as well as clinical listening events attended by a diverse range of health professionals, including midwives, obstetricians, epilepsy specialist nurses, transitional care nurses, neurologists and GPs.

Learning from these events included that people with epilepsy in pregnancy often felt very isolated, under pressure and repeatedly felt they were not listened to, exampled by one woman who shared that she wasn't believed when she said she'd had a seizure. People with epilepsy reported lack of support, experienced poor communication between epilepsy and maternity services and noted some staff as lacking knowledge. However, good care was reportedly provided by epilepsy specialist nurses (ESNs) and care received at the Maternal Medicine Centres.

People with epilepsy reported lack of support, experienced poor communication between epilepsy and maternity services and noted some staff as lacking knowledge

Issues shared in the clinical listening events included the variation and inequity in joint services. These were compared to diabetes services, where the local teams within local providers were considered robust. In smaller units, lack of staffing, lack of access to information, education and knowledge and lack of time were raised as current problems.

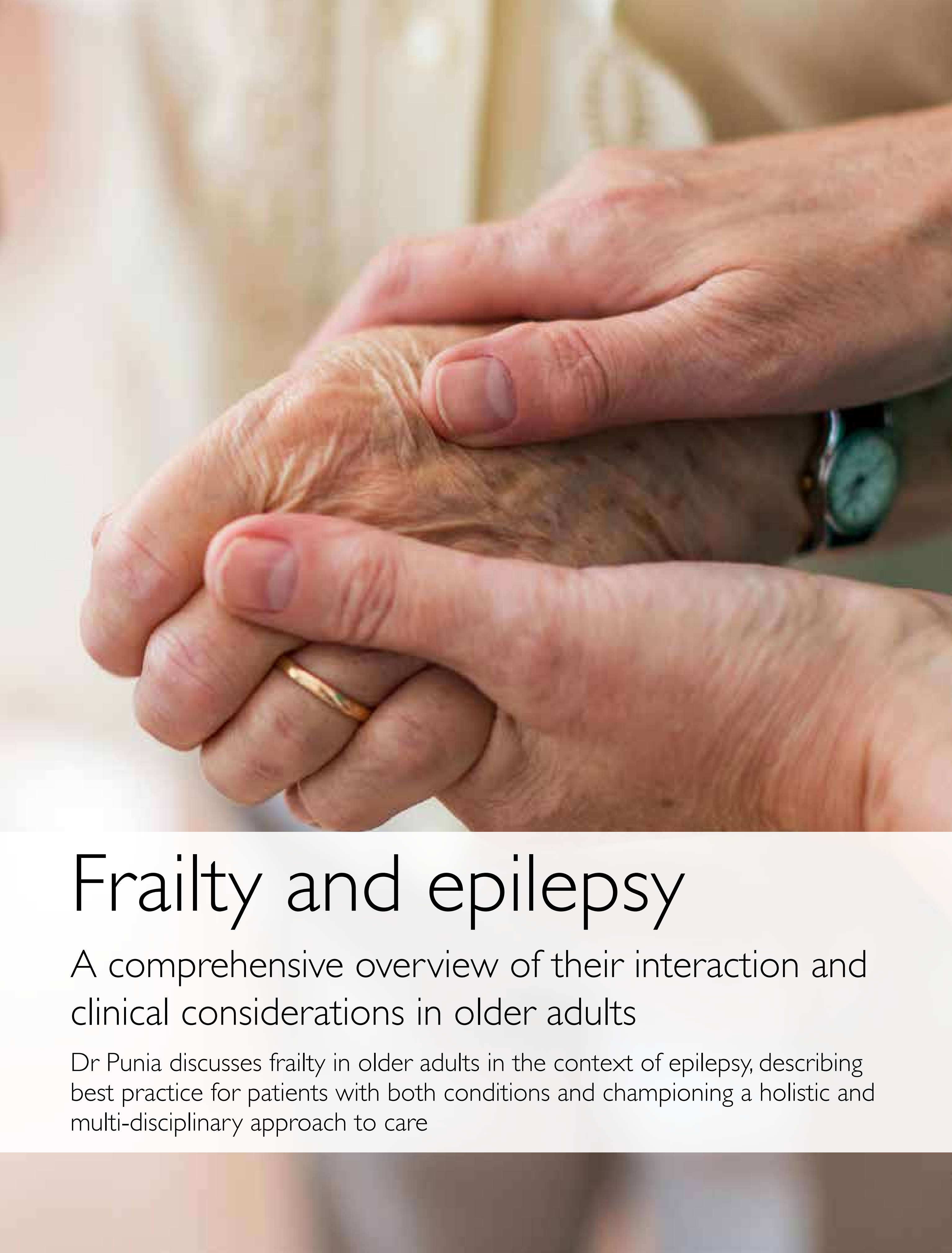
Several surveys were also completed by the project team. A survey of young people found that out of 28 responders, two-thirds had been given contraceptive advice, but only seven had been given information on planning a pregnancy. While around two thirds (67%) of young people preferred to receive information digitally, more than four-fifths (85.7%) preferred appointments to be face-to-face with a midwife or a doctor. The care considered most important among responders was around taking ASMs.

A survey of midwives was also conducted to capture how midwives assessed their knowledge and confidence in caring for people with epilepsy. Of the 60 responses, the years of midwifery experience ranged from 4-38. There were no midwives working in preconception care, and the majority reported feeling that they had no or very little knowledge about epilepsy.

The project team is working in partnership with North West Local Providers and the North West Maternal Medicine Network to co-produce further resources to support health professionals working with people with epilepsy before, during and after pregnancy to improve the outcomes and lived experience of people with epilepsy.

Catherine Owens appeared alongside Alison Fuller, Director of Health Improvement and Influencing at Epilepsy Action, on the Maternity and Midwifery Forum, during Epilepsy Awareness week, to discuss this project. This is available online at: youtube.com/watch?v=0-6M9qSy2uI

For more information about the project, you can speak to Catherine Owens (cowens@epilepsy.org.uk) or Tom Shillito (tshillito@epilepsy.org.uk) or visit the Epilepsy Action website: epilepsy.org.uk/professional/maternity



Frailty and epilepsy

A comprehensive overview of their interaction and clinical considerations in older adults

Dr Punia discusses frailty in older adults in the context of epilepsy, describing best practice for patients with both conditions and championing a holistic and multi-disciplinary approach to care

Vineet Punia

As populations across the globe grow older, the occurrence of conditions like frailty and epilepsy is on the rise. Both present substantial challenges for clinicians, particularly in older adults where the two conditions often coexist. Epilepsy, characterised by recurring unprovoked seizures, becomes increasingly common with advancing age, particularly after the age of 60. Meanwhile, frailty, a state of reduced physiological resilience, leaves individuals more vulnerable to health-related stressors. Understanding the intricate relationship between frailty and epilepsy is critical for clinicians to optimise treatment and improve outcomes in older adults with epilepsy. This article explores the relationship between these two conditions and outlines important clinical strategies for managing them in older adults.

What is frailty?

All of us have a nebulous sense of frailty and may likely recognise a frail individual but precisely defining it can be challenging. Frailty refers to a condition where multiple physiological systems decline, leading to increased vulnerability to everyday and acute stressors. It differs from normal aging in that it involves more profound functional deterioration.

Unlike chronological aging, frailty is considered more representative of biological aging and can be reversible, particularly if detected early

The World Health Organization defines frailty as a state in which the body's ability to maintain stability and cope with stressors diminishes due to age-related declines in various organ systems [WHO, n.d.]. Individuals with frailty often exhibit symptoms such as muscle weakness, fatigue, slow walking speed, and weight loss. Frailty can also affect cognitive and psychological functioning, adding to the complexity of its management in older adults.

Unlike chronological aging, frailty is considered more representative of biological aging and can be reversible, particularly if detected early. People who are frail are at greater risk of negative health outcomes, including disability, falls, hospitalisation, and mortality. Identifying frailty early allows for interventions that can slow its progression or, in some cases, reverse it altogether. In recent years, various frailty subtypes, including physical frailty, social frailty, psychological frailty and cognitive frailty have been proposed and being actively investigated [Syeda Amrah Hashmi, Seerat Sachdeva, Carolyn Tsai, Kalyanchakradhar Bonda, Mark Keezer, Ifrah Zawar, Vineet Punia, n.d.].

Vineet Punia

Epilepsy in older adults

Epilepsy affects people of all ages, but its incidence increases in older adults and is highest in individuals over the age of 75 years [Cloyd et al, n.d.]. This increase is partly due to the higher incidence of conditions such as stroke, neurodegenerative diseases, and other age-related comorbidities, which can trigger seizures later in life. Late-onset epilepsy (LOE), defined as epilepsy that begins after the age of 60, is a growing concern in older populations [Punia et al, 2024]. By default, LOE is a focal epilepsy and it is extremely rare for generalised epilepsy to emerge de novo in older adults [Alzahrany and Punia, 2023].

The seizure types seen in older adults tend to differ from those in younger populations. The seizures are more subtle in presentation, including brief confusional events and less often whole-body convulsion. Additionally, seizure control in older adults with epilepsy may be complicated by factors such as polypharmacy and reduced drug metabolism, making treatment more challenging.

How frailty and epilepsy interact?

Frailty and epilepsy often coexist in older adults, and their interaction presents significant challenges in clinical practice [Syeda Amrah Hashmi, Seerat Sachdeva, Carolyn Tsai, Kalyanchakradhar Bonda, Mark Keezer, Ifrah Zawar, Vineet Punia, n.d.]. Frailty can worsen the outcomes of epilepsy, while epilepsy itself may exacerbate frailty. The prevalence of frailty in people with epilepsy, depending on the study population and measuring instrument used, ranges from 7.4% in all adults undergoing epilepsy surgery to 55% in LOE. Several key factors contribute to the close relationship between these two conditions:

Polypharmacy: Older adults with epilepsy frequently take multiple medications to manage not only seizures but also comorbidities such as hypertension, diabetes, and cardiovascular diseases. The use of multiple medications increases the risk of drug interactions and side effects, which can lead to dizziness, balance issues, cognitive decline, and falls—all of which contribute to frailty.

Comorbidities: Conditions like osteoporosis, cardiovascular disease, and neurodegenerative disorders, which are common in older adults, can lead to frailty. These conditions may also complicate the management of epilepsy. Coexisting osteoporosis can increase the likelihood of fractures from seizure-related falls. Cognitive status may worsen in individuals who have epilepsy along with neurodegenerative disorder. Additionally, individuals with LOE and cardiovascular disease could have increased risk of developing stroke.

While no specific biomarkers for frailty have been established, clinical assessments can help identify individuals who may benefit from interventions

Physical Inactivity: Frailty often leads to reduced physical activity, and conversely, inactivity can exacerbate frailty. For older adults with epilepsy, fear of having a seizure or injury during physical activity may further limit their engagement in exercise, compounding the problem of frailty.

Social Isolation: Many older adults with epilepsy experience social isolation due to the stigma associated with seizures, mobility limitations, or the loss of caregivers. This isolation can contribute to frailty by negatively affecting mental health and reducing physical and social activity.

The interaction between frailty and epilepsy extends to the tolerance of antiseizure medications (ASMs). Frail individuals are more likely to experience side effects such as dizziness, fatigue, and cognitive decline when taking ASMs. These side effects can increase the risk of falls and injuries, which in turn can exacerbate frailty. Moreover, frailty has been associated with poorer outcomes following epilepsy surgery, further emphasising the need for a comprehensive, multidisciplinary approach to managing these conditions [Estes et al, 2023].

Key considerations for clinicians

Given the complex interaction between frailty and epilepsy, managing these conditions in older adults requires a thoughtful and holistic approach. Some key areas of focus are listed below.

Early detection of frailty

Screening for frailty is essential in older adults with epilepsy. Various frailty assessment tools are available, including the Frailty Index (FI) [Rockwood and Mitnitski, 2007], which evaluates the accumulation of health deficits, and the Edmonton Frail Scale (EFS) [Rolfson et al, 2006], which assesses multiple domains such as physical, psychological, and social functioning. EFS has been evaluated in older adults with epilepsy and shown to have good convergence validity [Vary-O'Neal et al, 2023]. Additionally, an epilepsy-specific frailty measuring instrument was proposed, but this needs external validation [Cerulli Irelli et al, 2024]. Using these tools during routine clinical evaluations can help detect frailty in its early stages, allowing for timely interventions that may prevent or slow its progression.

While no specific biomarkers for frailty have been established, clinical assessments can help identify individuals who may benefit from interventions such as physical therapy, social support, and medication adjustments. Early identification and management of frailty can improve the overall health outcomes of older adults with epilepsy.

Tailoring medication management

Older adults with epilepsy are particularly vulnerable to the adverse effects of ASMs, and this risk is heightened in frail individuals. Age-related changes in liver and kidney function, combined with alterations in fat distribution and protein binding, can affect how medications are processed in the body. This means that frail individuals are more likely to experience side effects such as dizziness, fatigue, and cognitive impairment, even at lower doses of medication. A recent study found that ASM adverse effects were significantly higher among older adults who were diagnosed as frail based on the EFS [Vary-O'Neal et al, 2023]. Therefore, use of frailty measuring tools for screening older adults at higher risk of frailty should be considered in outpatient clinical practice.

To minimise the risk of adverse effects, clinicians should adopt a "start low and go slow" approach when prescribing ASMs [Punia, 2023]. Polypharmacy should be avoided whenever possible, and medications that are known to worsen frailty, such as enzyme-inducing ASMs like carbamazepine or phenytoin, should be used cautiously. Alternatives that have fewer side effects, like lamotrigine, and a lower risk of drug

interactions, like levetiracetam, should be considered whenever possible.

Encouraging physical activity
Physical inactivity is a major contributor to frailty, and it can also exacerbate epilepsy by increasing the risk of falls and injuries. Encouraging older adults with epilepsy to engage in regular physical activity is one of the most effective ways to prevent and manage frailty. Even light activities such as walking, stretching, or balance exercises can help improve strength, coordination, and overall well-being.

Clinicians can work with physical therapists to develop individualised exercise programs tailored to the needs and limitations of frail older adults with epilepsy. These programs should prioritise improving mobility, balance, and muscle strength while also addressing any fears related to seizures or injuries. By promoting regular physical activity, clinicians can help reduce the impact of frailty on their patients' quality of life.

Addressing social isolation and mental health
Social isolation is a significant risk factor for both frailty and epilepsy. In addition, it is a modifiable risk for dementia. Older adults with epilepsy may experience social withdrawal due to mobility limitations, fear of seizures, or the loss of social support networks. This isolation can negatively affect both their mental and physical health, increasing the risk of depression, anxiety, and further frailty.

Clinicians should assess the social support systems of their older patients with epilepsy and encourage them to stay connected with family, friends, and community groups. In some cases, referral to social workers or support organisations may be necessary to help patients overcome social isolation and improve their mental health.

Addressing mental health concerns such as depression and anxiety is also important, as these conditions can contribute to both epilepsy and frailty.

Implementing multidisciplinary care
Managing frailty and epilepsy in older adults requires a team-based approach. In addition to neurologists, the care team should include geriatricians, physical therapists, social workers, and, when necessary, dietitians, pharmacologists, and psychologists.

Although research on frailty and epilepsy has only started to emerge, it is clear that these two conditions are closely related and that their management requires careful consideration

This multidisciplinary approach ensures that all aspects of the patient's health are addressed, from medication management to physical rehabilitation and social support.

By involving multiple specialists in the care of older adults with epilepsy, clinicians can develop comprehensive care plans that address the unique needs of each patient. For instance, while a neurologist may focus on optimising seizure control, a geriatrician can address comorbidities and medication interactions, and a physical therapist can work on improving mobility and reducing the risk of falls. This holistic approach can lead to better health outcomes and improved quality of life for frail older adults with epilepsy.

Looking ahead: future research and clinical practice

Although research on frailty and epilepsy has only started to emerge, it is clear that these two conditions are closely related and that their management requires careful consideration. As the population of older adults with epilepsy continues to grow, more research is needed to understand the long-term impact of frailty on seizure control, medication tolerance, and quality of life.

Developing epilepsy-specific frailty assessment tools that account for the unique challenges faced by older adults with epilepsy is also a priority. These tools would help clinicians better understand the relationship between frailty and epilepsy, allowing for more targeted interventions. Additionally, future studies should explore the potential benefits of interventions aimed at reducing frailty, such as exercise programmes, medication adjustments, and social support, in improving epilepsy outcomes.

Conclusion

Frailty and epilepsy often coexist in older adults, creating a complex and challenging clinical scenario. The increased vulnerability associated with frailty can make managing epilepsy more difficult, while epilepsy itself may contribute to the progression of frailty. By screening for frailty, carefully managing medications, encouraging physical activity, addressing social isolation, and adopting a multidisciplinary approach, clinicians can improve the outcomes and quality of life for older adults with epilepsy.

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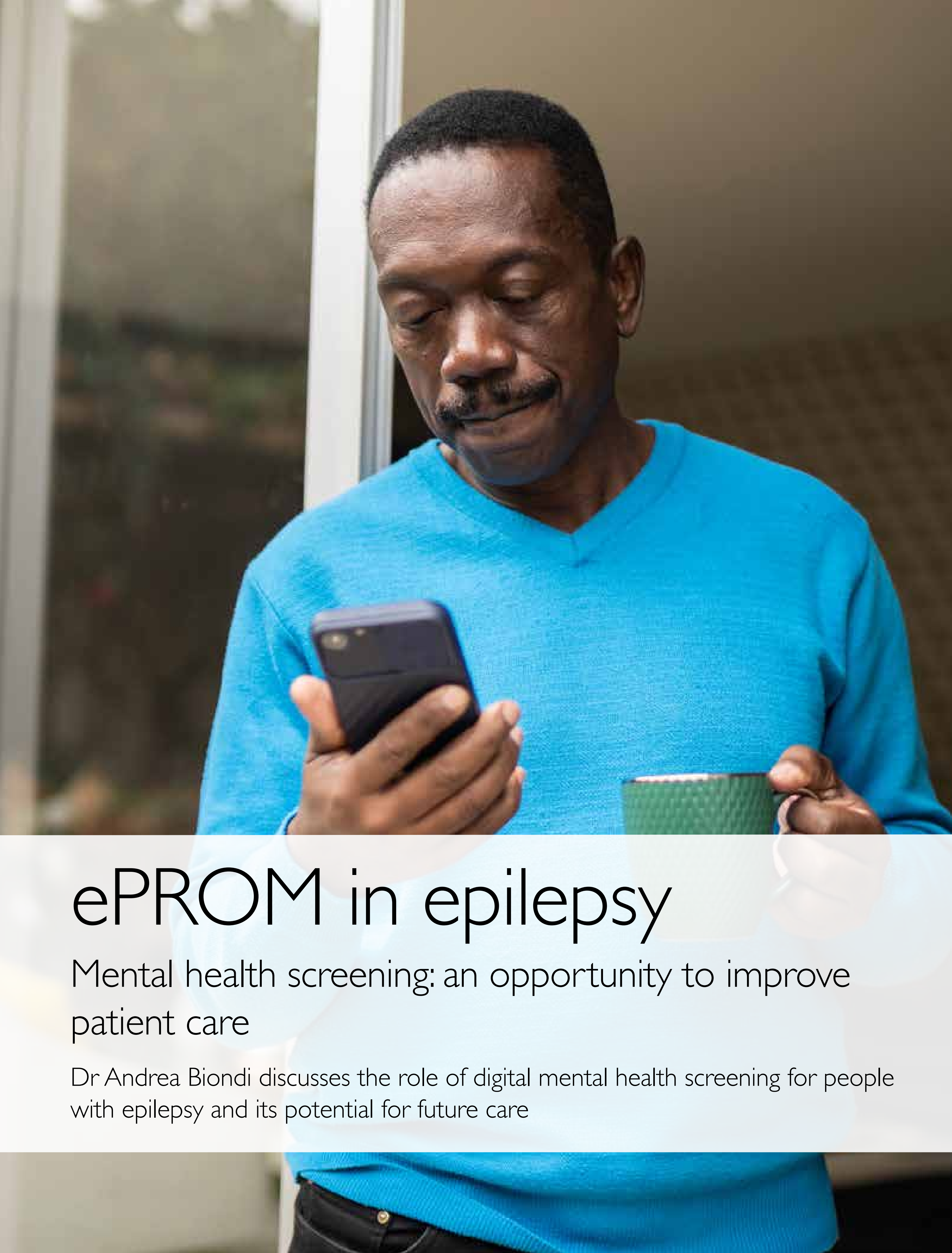


ePROM in epilepsy

Mental health screening: an opportunity to improve patient care

Dr Andrea Biondi discusses the role of digital mental health screening for people with epilepsy and its potential for future care

Andrea Biondi

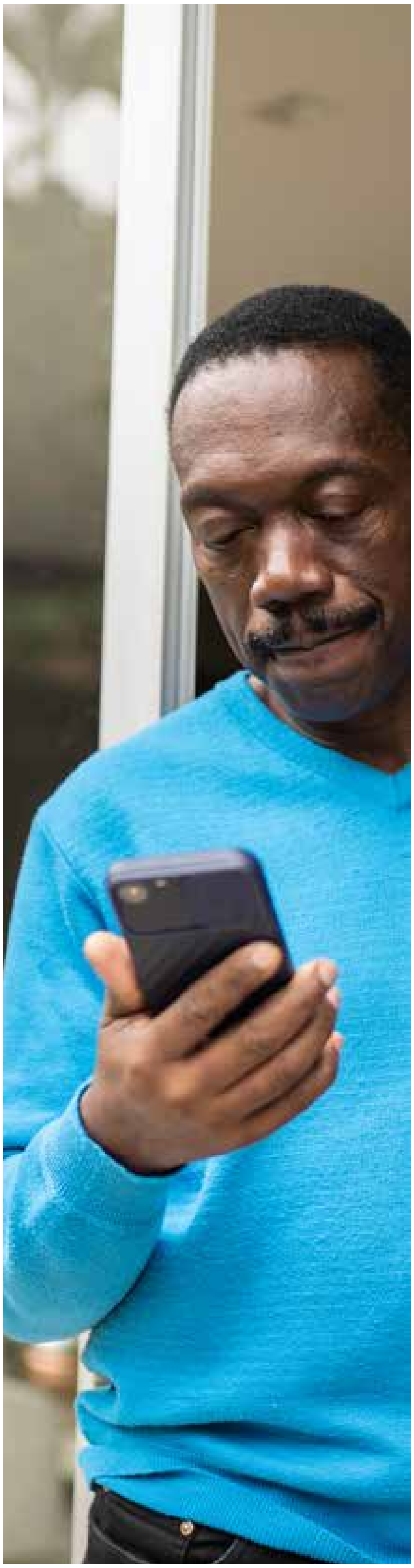
Here we aim to raise awareness about the mental health conditions of people with epilepsy, which are often overlooked, and demonstrate how new solutions can help address this issue.

Epilepsy and mental health: current situation

Mental health difficulties, particularly depression and anxiety, are common among people with epilepsy (PWE). Research shows that depression affects approximately 17-22% of PWE, with the prevalence increasing to 55% among those with drug-resistant epilepsy [Mula et al, 2021]. Anxiety is also widespread, emphasising the bidirectional relationship between epilepsy and mental health, where psychiatric symptoms can be aggravated by both the condition and its treatments [Goel et al., 2022]. Furthermore, individuals with epilepsy are at higher risk for neurodevelopmental disorders such as attention-deficit hyperactivity disorder (ADHD) and autism spectrum disorder (ASD), with ADHD affecting 11-46% of adults and ASD found in 18-30% of children with epilepsy [Shimizu et al, 2022]. These factors often exacerbate emotional and psychological difficulties, making it harder for individuals to access appropriate care. Risk factors such as sleep disturbances, low self-esteem, poor social support, and unhealthy lifestyle behaviours further aggravate mental health outcomes, lowering quality of life, increasing suicide risk, and complicating the management of epilepsy and related mental health conditions.

Despite the considerable mental health burden that epilepsy places on affected individuals, mental health concerns are often under-recognised in clinical settings

The International League Against Epilepsy's (ILAE) psychology task force surveyed over 60 countries, revealing that while healthcare professionals acknowledge the importance of addressing mental health in PWE, several barriers to screening exist. Barriers include a shortage of mental health specialists, lack of standardised protocols, and limited time during



appointments. Epilepsy care primarily focuses on seizure management, sometimes neglecting psychological symptoms, and is further hindered by the absence of mental health specialists in epilepsy services [Gandy et al, 2021].

To improve the care of individuals with epilepsy, routine mental health screening is crucial. Given the multifactorial relationship between epilepsy and mental health, integrating new tools such as electronic health technologies could help healthcare providers assess and monitor both mental health and seizure management. One promising tool is patient-reported outcome measures (PROMs), which are self-report questionnaires capturing a patient's experience with both physical and mental health conditions. PROMs have shown effectiveness in collecting data on quality of life and mental health status, aiding in the identification of individuals requiring further mental health intervention. Some studies have tested these tools using paper-based questionnaires or electronic portals linked to electronic health records (EHRs) [Michaelis et al, 2021; George et al, 2021], but more research is needed to evaluate their feasibility and effectiveness in both adult and paediatric epilepsy populations.

Our research aimed to reduce this gap by exploring the integration of a mental health screening tool within epilepsy clinics, offering a model for future implementation.

What we did

A prospective cohort study was conducted at King's College Hospital NHS Foundation Trust, London, UK, from February to October 2023. The study included individuals aged 18 and older who attended outpatient epilepsy services and met the following criteria: a confirmed diagnosis of epilepsy, ability to provide informed consent, and proficiency in English. Participants with intellectual disabilities or those unable to complete the digital surveys independently were excluded. Participants completed a digital mental health screening tool online before their clinic appointment, which they could access via SMS or QR code. Participants provided informed consent digitally, and caregivers assisted as needed. Clinicians involved in the study were trained on the use of the tool, which included technical aspects, the clinical importance of mental health screening, and appropriate care pathways for patients with identified mental health concerns.

Only 13% of participants were receiving mental health support, and 21% of those with self-reported mental health symptoms were already receiving support

The digital tool, developed on an established platform and framework (IMPARTS – Integrating Mental and Physical Healthcare: Research Training and Services), featured several patient-reported outcome measures assessing various health domains, including psychiatric symptoms, neurodevelopmental traits, and psychosocial risk factors (Table1). A patient public involvement (PPI) group, consisting of eight adults and young PWE, helped select the outcome measures [Winsor et al, 2023]. After completing the surveys, results were uploaded to patients'

Table 1 – List of digital tools used [Biondi et al, 2024] (reviewed from Bush et al, 1998; NICE, 2012; Adler et al, 2006; Spitzer et al, 2006; Bastien et al, 2001; Zimet et al, 1988; Kroenke et al, 2009; Rosenberg, 2015; Patton et al, 1995; Cramer et al, 1996).

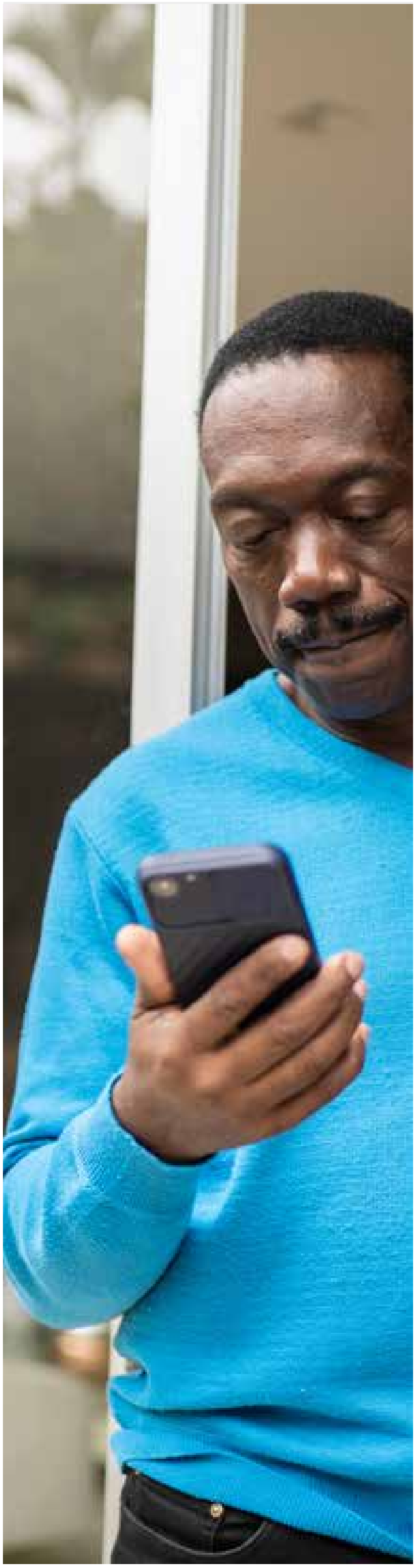
Domain	**Measures all instruments must be referenced**	**Topic**
Mental health symptoms	Generalised Anxiety Disorder - 7 (GAD-7)	Anxiety
	Patient Health Questionnaire - 8 (PHQ-8)	Depression
	Psychosis Screening Questionnaire (PSQ) (IMPARTS specific)	Psychosis
Neurodevelopmental traits	Attention-Deficit Hyperactivity Disorder - Self Report Scale (ADHD-SRS)	ADHD traits
	Autism Spectrum Quotient - 10 (ASQ-10)	Autistic traits
Seizure severity	IMPARTS specific Seizure Questionnaire (IMPARTS specific)	Triggers, numbers, types, burden and severity of seizures
Psychosocial/Behavioural Risk Factors	Smoking use and abuse questions (IMPARTS specific)	Smoking use/abuse
	Alcohol Use Disorders Identification Test Consumption Screening Tool (AUDIT-C)	Alcohol use/abuse
	Insomnia Severity Scale (ISI)	Insomnia
	Multidimensional Scale of Perceived Social Support (MSPSS)	Perceived Social Support
	Rosenberg Self Esteem Scale (RSS)	Level of self-esteem and self-perception
	Brief Barratts Impulsivity Scale (BIS-Brief)	Impulsivity traits
Other factors	Quality of Life in Epilepsy Scale - 10 (QOLIE-10)	Quality of life

Electronic Health Records (EHR) for clinician review during consultations, allowing for referrals or interventions if necessary.

What we found

A total of 955 adults with epilepsy were contacted via SMS 24-48 hours prior their clinic appointment, with 38.3% (366) accessing the questionnaires and 15.1% (144) completing the entire survey. A total of 144 adults were included in the final analysis. Seizures had moderate impact on participants' lives, though 34% had incurred an injury during a seizure. Stress (69%) and sleep disturbances (64%) were the most common seizure triggers followed by menstrual cycle (31.5%), while fewer participants identified concentration (11.8%) or alcohol (17.4%) as triggers.

Participants reported mild level of anxiety on average, with 6.95% experiencing mild anxiety and 30.6% reporting significant anxiety. Additionally, 12.5% reported some



depressive symptoms and 16.7% met criteria for probable major depressive disorder, with 50% of those reporting significant depressive symptoms facing challenges with work, home responsibilities, or social relationships. Most participants did not report psychotic symptoms (88.9%), although 11.1% reported at least one such symptom, including strange experiences, with fewer reports of hallucinations or paranoia. Notably, 16% of adults scored highly on a screen for ASD, suggesting the need for further assessment. Similarly, 34.1% scored in a range indicating potential ADHD.

Regarding psychosocial factors, 6.2% reported severe insomnia, 17.2% moderate insomnia, and 38.6% minor insomnia. Alcohol abuse was reported by 2.1%, and 3.5% reported moderate alcohol use. Most participants reported moderate or high (positive) scores in perceived social support, while 34% had low self-esteem. Quality of life scores were generally low, with only 11.8% reporting a high quality of life.

The sub-group of patients who self-reported mental health symptoms (n=62) mentioned more frequent seizures and greater perceived burden from seizures when compared to the people who did not self-report mental health symptoms (n=82). They also reported higher levels of autism and ADHD symptoms, lower self-esteem, less social support, and poorer sleep quality. Finally, a significantly lower quality of life, highlighting the greater seizure burden and worse psychosocial outcomes were found in those with mental health symptoms [Biondi et al, 2024].

Next steps

The findings from this study underscore the promising potential of a digital mental health screening tool tailored for PWE and highlight areas that require further development for broader implementation. We successfully applied the IMPARTS framework to integrate mental health care into epilepsy services, addressing psychological symptoms alongside physical health. This approach includes patient-reported outcome measures, tailored care pathways, staff training, self-help materials, and research integration. We encourage others to adopt this framework to enhance holistic care in epilepsy and similar conditions, improving patient outcomes through better mental health support [Hotopf et al, 2015].

The results confirmed a significant unmet need, with 30.6% of adults with epilepsy reporting anxiety or depression above clinical thresholds.

> **By embracing digital innovation, we can bridge the gap between physical and mental health care, ensuring that individuals with epilepsy receive the comprehensive support they deserve**

These findings are consistent with previous studies, such as Gillespie et al [2020] and Michaelis et al [2021] in UK and Germany. This study also uncovered related psychosocial factors, such as sleep disturbances, low self-esteem, impulsivity, and neurodevelopmental traits. Moreover, the study revealed a critical care gap: 87% of participants with mental health symptoms were not receiving support. This highlights the need for routine mental health screening in epilepsy care. Early identification of symptoms using ePROMS can allow clinicians to intervene early, improving patient outcomes.

Moving forward, it would be important in the future to focus on optimising the digital platform to ensure seamless integration into clinical workflows. Key areas of development include enhancing patient engagement, improving survey completion rates, and refining screening protocols. Strategies to monitor and address disengagement during the screening process can significantly increase patient participation. Longitudinal studies will also be crucial for evaluating the long-term impact of early mental health identification on both seizure control and overall well-being. In addition to optimising digital platforms, the development of care pathways and the delivery of training for healthcare staff are vital next steps. Healthcare professionals must be equipped with the knowledge and tools to appropriately address mental health issues in PWE.

Self-help materials should be provided to patients, specifically focused on managing mental health symptoms in the context of epilepsy. These materials should be developed through collaboration with patients who have long-term conditions, as well as expert clinicians, ensuring they are relevant and practical. Tailored mental health interventions for both children, adults and caregivers also represent an important area for future work. Programmes like the Mental Health Intervention for Children with Epilepsy (MICE) and COMPASS, which address psychological distress in individuals with chronic conditions, provide promising models for integration [Bennet et al, 2024; Picariello et al, 2024]. Finally, incorporating digital mental health screening into EHRs can streamline referrals and facilitate the early recognition of mental health concerns, thus improving the efficiency of recruitment for mental health research. Anonymised data from screening platforms, alongside information from EHRs, could also contribute to ongoing research and improve clinical practices.

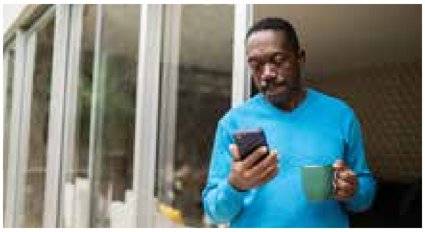
In conclusion, integrating digital screening tools into epilepsy clinics will represent a significant step forward in addressing the complex needs of PWE. Early identification of symptoms using tools like IMPARTS could allow clinicians to intervene early, improving patient outcomes.

Personal opinion

From my experience as a psychologist and neuroscientist, I strongly believe that integrating digital mental health tools into routine epilepsy care holds great promise. The gap in mental health care for individuals with epilepsy is substantial, and addressing it requires a multifaceted approach that includes digital tools, better communication between healthcare providers, and increased access to mental health services.

Electronic PROMs are particularly valuable as they enable continuous or repeated monitoring of mental health symptoms, ensuring that both physical and mental health are integrated into the management of epilepsy. Additionally, they help overcome barriers to mental health care, such as stigma and time constraints during clinical visits, while allowing for immediate decisions regarding a patient's future care path.

I'm optimistic that by focusing on enhancing the integration of these digital platforms into existing healthcare systems – ensuring they



are accessible, user-friendly, and aligned with tailored psychotherapy protocols – it will significantly enhance the quality of care for people with epilepsy and more effectively address the mental health challenges within this population.

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First licensed sulthiame oral liquid medicine available in the UK

The first licensed formulation of sulthiame in the UK, is now available from Desitin Pharma UK. Ospolot® 20mg/ml oral suspension (sulthiame) is indicated for the treatment of Self-Limited Epilepsy with Centrotemporal Spikes (SeLECTS) (please refer to SmPC for details).

Studies have shown that sulthiame reduces seizure frequency in SeLECTS. 91% of patients treated with sulthiame remained seizure free for 24 weeks [Borggraefe et al, 2013].

Sulthiame has demonstrated benefits compared to other ASMs (anti-seizure medications) in the treatment of SeLECTS. When compared to levetiracetam, sulthiame has a significantly lower withdrawal rate from treatment due to recurrence of seizure or adverse effects, but still shows the same efficacy rate [Borggraefe et al, 2013].

Sulthiame tablets have been used for many years in the UK on a "named patient" basis or through importation of an unlicensed medicine from Germany, and was listed by NICE in 2022 for the treatment of SeLECTS, even though it was not licensed at the time of publication [NICE, 2022]. However, there is considerable clinical use behind this new product. Sulthiame has been licensed for over 40 years in many European countries and is prescribed first line in Germany, Switzerland and Austria for SeLECTS. There have been 680,000 patient months of sulthiame prescribed in Germany alone in the last three years [IQVIA Data].

SeLECTS is one of the most common childhood epilepsies. The median age of onset is seven years and the incidence is approximately six per 100,000, [Borggraefe, 2024].

Although SeLECTS generally has a good prognosis and resolves during adolescence, some studies show that it is linked to neuropsychological impairment [Garcia 2015, Kirby 2017; Wickens 2017] and could potentially progress to more serious forms of epilepsy.

Desitin Pharma

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Ruby

Patient perspective

Ruby Hooper spoke at an event at Liverpool John Moores University for trainee nurses, sharing her experiences with epilepsy, medication and side effects to support their learning. She shares her story below, speaking on being perceived as both able and disabled, sudden appearance of medication side effects, the difficulty in questioning doctors' decisions and the value of learning from each other.

My name is Ruby Hooper. I am 38 years old, and I have focal epilepsy. I was diagnosed in Ireland at age 13 after having my second tonic-clonic seizure. Looking back, and after experiencing many more, mainly in the last five years, I believe I was having 'smaller' seizures before then. Being little, with no points of reference to create anxieties or fears around these experiences, which were few, I felt like they weren't bad. I just played with them, accepting that sometimes I may find myself in another part of the room. These sorts of experiences have interestingly been reflected in conversations I've had with others who've had similar experiences with childhood seizures. If or when my seizures choose to show, has been somewhat out of my control throughout my life. Taking anti-seizure medications (ASM) has often alleviated this unpredictability and given me long periods of independence. These medications have allowed me to work, travel, study, and have relationships but have, at different times, hampered all these things as well.

When my seizures occur, I become reliant on those around me, regardless of their relationship to me or their ability to cope with the situation, and I often feel very isolated. I have found epilepsy to be, only to some extent, a hidden disability, creating a fascinating example of the dichotomy between disability and societal expectations of normalcy or 'ability' within an individual. Being perceived as able, I have noticed that I am sometimes unconsciously judged by the same ideals as those around me. Few people have seen me have a seizure, so when they do, it can be somewhat jarring; also, many do not understand the impact of side effects. Although this can require a lot of explanation and can be a bit tiring, I always prefer that people ask me questions rather than react based on uninformed ideas. This is something I have encountered in the workplace.

Each ASM has different time frames and stories that come with them, and I am grateful for the time I have been seizure-free. I will stress that the negative experiences have been quite dramatic at times and left permanent marks on me and those around me. In general, medications have stopped working with little explanation, side effects have suddenly changed and become quite intense, and some medications made seizures worse (usually at higher doses). I've had allergic reactions and interactions with other prescription medications (this has happened more than once on different medications), and some side effects can induce high levels of depression and anxiety where there were none before. I have not found some of these easy drugs to take, although they may have controlled my seizures.

I understand that seizure control is an epilepsy team's priority, but I have, at times, argued that I would rather have an occasional seizure and want to get up in the morning than have total seizure control and have gone through some of the things I have been through taking these medications. There is an irregularity and unpredictability between these drugs, epilepsy and the psyche that is hard to navigate with minimal or nonexistent mental health support. That fact there are many under-recognised psychological challenges reflects my own experience of being epileptic, of being friends with and of working with those who have seizures.

Reading about others' experiences of epilepsy has been a vital source of information and support for me. My experience with my second drug, levetiracetam (or Keppra), which I took for two years, is a good example of this, but not the only one. I had excellent seizure control but horrible mental health side effects with no understanding of the negative potential of Keppra or what to do if anything like that happened. It wasn't until my mum sent me a link to a site where people discussed their experiences of epilepsy that I was able to relate mine to theirs. Up until then, I had believed the mental problems were mine, so I had not reached out, but the people close to me could see I was struggling. I wanted to come off levetiracetam but found that I did not know who or how to contact my epilepsy team or even knew I had one. I had had an okay experience with epilepsy care, being relatively seizure-free. Up until then, they had contacted me, but at the time I hadn't realised I needed them for these problems.

Questioning doctors or challenging their decisions is hard, and I certainly found it harder back then. It can be an intimidating situation where there is a lot of control over your wellbeing, and, as the patient, you feel vulnerable. I have continuously felt that, as epileptic patients, we have the ability, if supported, to communicate more about our experiences. There is a lot of condition-specific knowledge that would better support the self-management of our care that gets lost because the time is not taken to collect it or the weight given to it. Better health literacy could include healthcare professionals, including doctors, creating a space for their patients to educate them about what we know about our epilepsy.

That there are more than two kinds of seizures is not generally well known, and how these can present themselves even less so. The push for public awareness is helping. Having no predictable seizure pattern or triggers other than stress and tiredness, the times I have had reoccurring seizures have led me to live with a heightened sense of stressful anticipation as to when they may occur, making navigating my day-to-day life more difficult. I limit more normal behaviours like going to the shops or socialising. I have found that correlating the series of sensations experienced to relatable imagery, colours or feelings is a good way of communicating an experience that is difficult to describe to those who have never been through it. I use the metaphor of going over a bump in the road in a car or going over the top of a roller-coaster when relating the intensity of my 'smaller' seizures.

I feel sometimes we must be careful, as people with epilepsy, not to focus too much on epilepsy, as living life has its space, especially for us. I have found that an array of essential life things can get dismissed as less important than they may actually be, or epilepsy being confused with or even used as the root cause of something when the roots run much deeper. We walk a fine line, very well, between being able and disabled very quickly when epileptic. I have found that over the years, it is less my inability to cope with epilepsy itself but other people's reactions or potential professional inaction that can be the most distressing. More needs to be done to demystify the epileptic experience.

Prof Arjune Sen welcoming attendees to the Centre's launch

Centre for Global Epilepsy

Launch event at the University of Oxford

Dr Caoimhe Twohig-Bennett, Director of Research at the Centre for Global Epilepsy shares more on the launch event and discusses the global role and ambition of the centre

On 31st January, the Centre for Global Epilepsy launched at Wolfson College, University of Oxford. This is the world's first dedicated centre focused on advancing epilepsy research and care on a global scale. The event welcomed leading researchers and clinicians from Africa, South America, the United States and Europe, demonstrating a shared commitment to addressing the challenges of epilepsy worldwide.

More than 50 million people live with epilepsy, yet approximately 85% do not have access to accurate diagnosis or effective treatment. Key barriers include financial constraints, shortages of anti-seizure medications, and a lack of trained healthcare professionals. Additionally, epilepsy remains a heavily stigmatised condition in many parts of the world, contributing to discrimination in employment, personal relationships and social inclusion.

Generously supported by BAND Foundation, the Centre for Global Epilepsy's mission is to empower global epilepsy research and care together. The centre aims to capacity build epilepsy expertise and care in addition to challenging stigma, particularly in resource-limited settings. By fostering international collaboration, the centre will connect expertise from high-income countries with those working in resource limited healthcare environments, driving improvements in epilepsy research, diagnosis, treatment and care. Aligned with the World Health Organization's (WHO) Intersectoral Global Action Plan on Epilepsy and Other Neurological Disorders, the centre will provide opportunities for immersive research in Oxford and beyond, serving as a multidisciplinary hub for knowledge exchange.

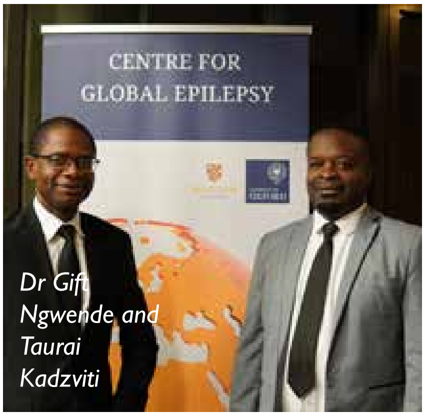
The launch event was opened by Sir Tim Hitchens, President of Wolfson College, who underscored the importance of tackling epilepsy as a global health priority. Professor Arjune Sen, Chief Executive of the centre and Professor of Global Epilepsy at the University of Oxford, formally opened the centre, outlining its mission to establish international networks of researchers and clinicians; curate and generate new data; offer capacity-building initiatives such as Visiting Fellowships; and develop innovative tools to enhance epilepsy diagnosis and treatment.

A distinctive aspect of the centre's work is its integration of humanities and historical research, particularly oral history, to understand better the lived experiences of those affected by epilepsy. At the heart of the centre's mission is a commitment to equitable partnerships with epilepsy-affected communities, challenging stigma and advocating for greater awareness and acceptance.

The launch event screened The Curse of Stigma, a thought-provoking film introduced by executive producer Gardiner Lapham of the BAND Foundation. The film set the stage for discussions on lived experiences of epilepsy, with personal insights then shared by Mr Taurai Kadzviti of the Epilepsy Support Foundation Zimbabwe and neurologist Dr Gift Ngwende from the University of Zimbabwe.

Professor Helen Cross, president of the International League Against Epilepsy, highlighted the transformative potential of the WHO's Global Action Plan. Researchers from the University of Oxford, including professors Kevin Marsh (Africa Oxford Initiative) and Trudie Lang (The Global Health Network), showcased pioneering initiatives taking place within Oxford's global health ecosystem. Professor Charles Newton (University of Oxford, KEMRI-Wellcome, Kenya) spoke about the groundbreaking Epilepsy Pathway Innovation in Africa (EPiNA) Project, which launched in 2019. Epilepsy is particularly prevalent in sub-Saharan Africa and this high incidence is, in at least a quarter of cases, because of preventable factors. Yet many people who may have had seizures are not diagnosed and even fewer receive appropriate treatments. These factors are compounded by enduring social stigma. The EPiNA project therefore aims to improve all aspects of the treatment pathway including prevention, diagnosis, treatment and awareness in regions in Ghana, Kenya and Tanzania.

Launching the centre represents a notable step towards reducing global disparities in epilepsy care, fostering innovation and improving the lives of millions affected by the condition worldwide. Initial key deliverables of the centre include building an international database of researchers and clinicians working in global epilepsy and the wider field of global mind brain health in addition to the centre's Visiting Fellowship Programme. Through the Visiting Fellows initiative, the centre will host clinicians, researchers and advocates from resource limited settings for up to eight weeks. The aim of the programme is to capacity build a cadre of collaborators across a diverse range of disciplines who will have an immersive experience and then translate their learning so that it embeds in their home country. This initiative is well underway, with the first Visiting Fellows being hosted in October 2024 and more fellows set to join the centre later in 2025.



Dr Gift Ngwende and Taurai Kadzviti

Professor Arjune Sen said: "It feels amazing to have launched the Centre for Global Epilepsy, something that we have been planning for the past several years. We are enormously grateful to BAND Foundation, Wolfson College and multiple worldwide partners who have helped this dream become reality. The launch is, though, only the first step. We now begin in earnest on our mission to empower global epilepsy research and care together. I hope that many of you will join us!"

You can follow the Centre for Global Epilepsy on LinkedIn and Bluesky or get in touch at: globalepilepsy@wolfson.ox.ac.uk.

Dr Caoimhe Twohig-Bennett
Director of research
Centre for Global Epilepsy

Highlights

Top picks from *Seizure*

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

A casual internet search for the question "can epilepsy be cured?" will provide numerous links to educational webpages and scientific documents explaining that "seizures can be controlled with medication but there is currently no cure for epilepsy". However, even leaving aside the rare scenarios in which epilepsy is caused by treatable metabolic deficiencies or by structural abnormalities amenable to epilepsy surgery, or the emerging potential of curing at least some genetic epilepsies, it is well recognised that, for many patients, epilepsy is not a lifelong affliction but a disorder which can pass. Benign (i.e. self-limiting) epilepsy syndromes are particularly common in childhood and adolescence, where over 20% of paediatric epilepsies fall into this category [Specchio et al, 2022]. Admittedly time and brain maturation rather than medical treatment are likely to be the healing factors in these cases, but patients could rightfully consider themselves 'cured' anyway, once they have discontinued treatment and not experienced seizures for a long time.

It is also well recognised that epilepsies starting in adulthood may not continue until the end of life and do not always require lifelong treatment. However, it continues to be difficult to predict which adults who have achieved long term seizure remission on antiseizure medication (ASM) still need to take their treatment and which patients may be able to stop it without experiencing a seizure recurrence. Decisions about this question do not only need to take account of the risk of seizure relapse if medication is discontinued but also of the risk of seizure recurrence if antiseizure medication is continued.

The risk of seizure relapse associated with stopping ASMs after a long period of successful seizure control has been described in a recent publication by Lamberink et al. [2017]. The 1,769 patients included in the studies contributing to this meta-analysis had been seizure free on ASM treatment for a median of 33 months before medication was withdrawn. After a median follow-up of 5.3 years (maximum 23 years) relapse occurred in 46% patients (although only 17% of the patients included in this study had adult-onset epilepsy and the risk of seizure relapse was found to be higher in older patients). Apart from age at onset, independent predictors of seizure recurrence included epilepsy duration before remission, seizure-free interval before antiepileptic drug withdrawal, history of febrile seizures, number of seizures before remission, absence of a self-limiting epilepsy syndrome, developmental delay, and epileptiform abnormality on electroencephalogram (EEG) before withdrawal.

My editor's choice from Seizure volume 124, a systematic review and meta-analysis by Tae-Wong Yang et al. [2024], focuses on the risk of seizure relapse in patients who have achieved long-term seizure control on ASM but choose to continue to take their treatment. This review is based on the analysis of seven datasets from six previous studies describing treatment outcomes in a total of 1,330 patients. In five of the studies patients had to be seizure free for a minimum of two years, in one study only one year of full seizure control was required for inclusion. After one year of follow up, a seizure had occurred in 12.8% of patients, and after two years the proportion of patients who had experienced was 21.5%. By the end of five years, 32.6% of patients had relapsed. Patients were more likely to relapse if they had required more than one ASM to achieve seizure control. Four datasets allowed the comparison of outcomes of patients who either continued or discontinued ASM. The relative risk of seizure recurrence with ASM discontinuation gradually declined from being 2.7 times that of patients

The question, 'which research should be prioritised?' when funds and research capacity are limited, continues to be a vexing one

still taking ASM after one year to 1.6 after five years.

While we are still unable to counsel individual patients who have achieved long-term seizure control with certainty about the risk of seizure relapse with continuing or stopping their ASM, this review and meta-analysis provides additional insights which patients and clinicians can consider when they decide whether or not to stop potentially unnecessary medication [Doerrfuss et al, 2024].

Research priorities

Although epilepsy is one of the commonest disabling neurological conditions [GBD, 2021], it has not attracted nearly as much research funding as it deserves in terms of its prevalence or the healthcare and social costs it generates. For instance, in the UK, epilepsy only received 0.3% of the £4.8 billion (5.9 billion USD, 5.8 billion Euros) funding spent on health-related research in 2018 [Epilepsy Research Institute, 2020].

While one would therefore expect universal agreement (at least among those with a clinical or research interest in epilepsy) that research funding for this area should increase, it is much more difficult to agree on the priorities any funds should be spent on. I have been a member of several committees – appointed by charities supporting members with epilepsy or by publicly funded organisations intended to facilitate research – which have grappled with this very issue. Traditionally, funding was mostly distributed by the GOBSAT method (i.e. an approach where "good old boys sitting around a table" would decide what should be funded). While the increasing involvement of women, external review processes and experts by personal experience (in this temporal order) has undoubtedly improved funding allocation processes, the question 'which research should be prioritised?' when funds and research capacity are limited, continues to be a vexing one.

There are a number of key problems: those with personal experience tend to have different priorities from researchers or clinicians. When choices have to be made, the priorities of patients are likely to lose out, perhaps because their questions are of a 'boring', practical nature, have been less well-formulated or have been answered by previous research already. The long-term outcomes of a previous project, in which patients and experts were asked separately about epilepsy research priorities without any attempt to address the perspectival differences and knowledge gradients between the two groups, is a good example [Thomas et al, 2010]. Six years after the publication of patient and clinical/research expert priorities, the latter were twice as likely as the former to have been picked up in public research policy documents [Hughes et al, 2017].

My editor's choice from Seizure volume 125, a report by Anna C. Norton et al. [2024] describes a much more serious approach to create a list of top ten priorities for epilepsy research and its outcome. While the consensus building process involving over 2,000 individuals was based in the United Kingdom (with experts by personal experience outnumbering 'professionals' with a 5/1 ratio), the findings may well influence researchers and research policy makers elsewhere. As a minimum, it is worth taking note of the methodology of the process.

Benefiting from the experience and support of the James Lindt Alliance [Partridge and Scadding, 2004], a non-profit initiative which designed and developed the Priority

Markus Reuber

Setting Partnership approach, this consensus-generating initiative was led by the Epilepsy Research Institute and supported by the National Institute for Health and Care Research, as well as over 100 partner organisations including the major UK epilepsy charities. The rigorous process involved an initial survey (identifying over 5,000 initial questions), an evidence review to remove questions with known answers, a further shortlisting survey of the most commonly asked remaining questions, and a final selection and ranking workshop. Readers wanting to know what ten questions future epilepsy research should prioritise are referred to the full text of my editor's choice articles. Any GOBSAT committees still in operation: please reflect and take note!

Mental health 'comorbidities'?

It will be well-known to anyone familiar with epilepsy that the manifestations of this disorder are not limited to the experience of recurrent unprovoked seizures. In percentage terms, seizures (even including pre-and postictal states) only occupy a tiny proportion of the lifetime of individuals with epilepsy. Unfortunately, most individuals with epilepsy also have to deal with other causes of disability or distress. Cognitive and mental health symptoms are very common and challenging for many people with epilepsy. In fact, mental health symptoms have a greater effect on the health-related quality of life of individuals with uncontrolled epilepsy than the frequency or severity of epileptic seizures [Rawlings et al, 2017]. In the current classification systems, these mental health symptoms are considered as 'comorbidities' of epilepsy. The commonest of these 'comorbid' mental health conditions are depression and anxiety (affecting about one in three patients) [Rai et al, 2012]. The presence of such 'comorbidities' does not only affect the quality of life of patients with epilepsy but also their chance of becoming seizure free and even their life expectancy [Hitiris et al, 2007; Fazel et al, 2013].

My editor's choice from Seizure volume 126 is a systematic review and meta-analysis of a type of 'comorbid' mental health problem usually more closely associated with functional/dissociative (nonepileptic) seizures than epilepsy [Diprose et al, 2016]: Posttraumatic Stress Disorder (PTSD). Based on their meta-analysis of 38 studies, involving 5,545 adults with epilepsy, Deniz Ertan et al. [2024] calculate a pooled prevalence of PTSD of 7.7% (95% confidence interval 5.2 to 11.2). Given that a previous study based on 26 population surveys from the World Health Organization's World Mental Health Surveys involving a total of 71,083 adult respondents revealed a cross-national lifetime prevalence of PTSD of 3.9 % [Koenen et al, 2017], epilepsy seems to double the risk of PTSD – similar to its effects on the lifetime risks of depression and anxiety [Tellez-Zenteno et al, 2007]. Like in the context of these mental health disorders, there is a bidirectional relationship between trauma/PTSD and epilepsy: a diagnosis

Cognitive and mental health symptoms are very common and challenging for many people with epilepsy

of PTSD increases the risk of the subsequent development of epilepsy [Chen et al, 2017], and individuals with epilepsy experience more trauma and are at greater risk of developing PTSD than those without [Nimmo-Smith, 2016]. What is more, a previous history of trauma increases the risk of a person with epilepsy experiencing their seizures as traumatic [Mariotti et al, 2021].

In the context of Parkinson's disease, clinicians now recognise 'non-motor features', including cognitive and mental health symptoms. Given the bidirectionality of the relationships described above, and the fact that the associations with mental health problems are much closer and more complex in individuals with epilepsy than in those with other chronic health conditions [Rai et al, 2012], is it not time to think of depression, anxiety and PTSD as 'non-seizure manifestations' of epilepsy rather than merely as more or less co-incidental comorbidities?

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The age of AI

"I didn't know what to say, so I asked ChatGPT" is the modern-day lazy opening for best man's speeches, state openings of Parliament, and Epilepsy Professional articles alike. AI is certainly making people more efficient and indolent. Automated summaries of meetings, clunkily abbreviated email headers abound in our increasingly chatbot-first society.

Even as I write this for you, I have an 'assistant' on my Uni computer that is nagging me with each word I write. "Would you like me to check your tone?" feels like the most passive aggressive question that I'll get asked today.

Marking the undergraduate students' essays this year was a very difficult task. Instead of asking 'did you use AI in the preparation of this essay?' the course now askes 'how much AI did you use and for what tasks'. It is the modern day equivalent of not using a word processor and sticking to the type-writer, or electing for Tippex over a spellchecker. All the essays were polished to within an inch of perfection, and it was so much harder to discern who had wisdom beyond the surface of the topic.

It is healthy to have writer's block. It is normal to be uncertain. It is rewarding to fail, sometimes to fail repeatedly. So, farewell, then, to the agonising emptiness of the blank page. Are we now destined to be a second set of eyes editing text first produced by our desk-based chum? I am reminded of the anecdote of the author Kurt Vonnegut as he relays the story of buying an envelope to his wife.

"'Oh,' she says, 'well, you're not a poor man. You know, why don't you go online and buy a hundred envelopes and put them in the closet?' And so I pretend not to hear her. And go out to get an envelope because I'm going to have a hell of a good time in the process of buying one envelope. I meet a lot of people. And, see some great looking babes. And a fire engine goes by. And I give them the thumbs up. And I'll ask a woman what kind of dog that is. And, and I don't know..." And I think he is right, you know. It may not be the case for everyone, but I find energy in the human reactions; I will always emotionally connect better in a face-to-face clinic than the cold distance of a phone interaction. The first feels mutual, and collaborative, the latter can be a passionless transaction once stripped of the nods and winks of an in-person consult.

For those of us who are noticing the specks of grey coalescing around our temples, it makes you pause to ponder the nature of creativity and inspiration. If large language models draw upon near infinite sources at a click of a button, they have to be less biased than our own ethnographic experiences. Equally, once amassing these data, they can be manipulated by a series of zeros and ones to produce authoritarian or counter-cultural outputs at the whim of the engineers.

There is a role for automation. Would I like a search function in my electronic patient record? Yes, please. Do I use the 'find my phone/my car keys/one of the twins' function on my smartphone at least once a week? Yes, I do. How often do I realise that I'm running this from that supposedly lost phone? I cannot possible divulge… So, as a peek in to the future of possibility, have a look at EpiPick - https://epipick.org/#/ International authors have tried to create an algorithm for anti-seizure medication choice that feels less random than pulling balls out of a bag for the FA Cup draw. The team have the ability to give feedback to the choices that the machine chose for you, but not the other way round; "we suggested lamotrigine first line, you gave felbamate – you animal!"

Having resisted the pull of automation for this column, I must end with a confession. I am a huge fan of the emotionless behemoth that is the large language model, ChatGPT. Like any relationship, the more you put in, the more you get out. "Ask me as many questions as you need to understand the task" is a favourite of mine, plus also, for fun, telling it what personality I'd like it to take on when responding. They may get more outlandish and playful, the more mundane the task I am asking it to perform. "Today you are an undocumented Ecuadorian migrant living in New York City as a seamstress, but you have dreams of signing on Broadway. But this will never happen because of chronic gout." But my point is, if there is a point, is that we think we are modifying the outputs of the machines; but they've won. They have already started to adapt our behaviour irrevocably. And I, for one, welcome our new robot overlords; but that is exactly what a drone would write for me, isn't it?

coming up

Dates for the diary

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

2025

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

25-29 August
XVIII Workshop on Neurobiology of Epilepsy (WONOEP 2025)
Cascais, Portugal
ilae.org/congresses/xviii-workshop-on-neurobiology-of-epilepsy-wonoep-2025

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

4-6 September
5th International Congress on Mobile Health and Digital Technology in Epilepsy
Copenhagen, Denmark
na.eventscloud.com/website/74027/home/

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:

Prof Ahmed and Prof Ghannam

A look at a new prototype lens with the potential to filter out 98% of wavelengths linked to photosensitive epilepsy.

Dr Syvertsen

A description of the Norwegian model of needs-based epilepsy follow-up.

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

kkountcheva@epilepsy.org.uk

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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.

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