epilepsy action

issue sixty three / Winter 2021 £3.50
(Free to Epilepsy Action professional members)

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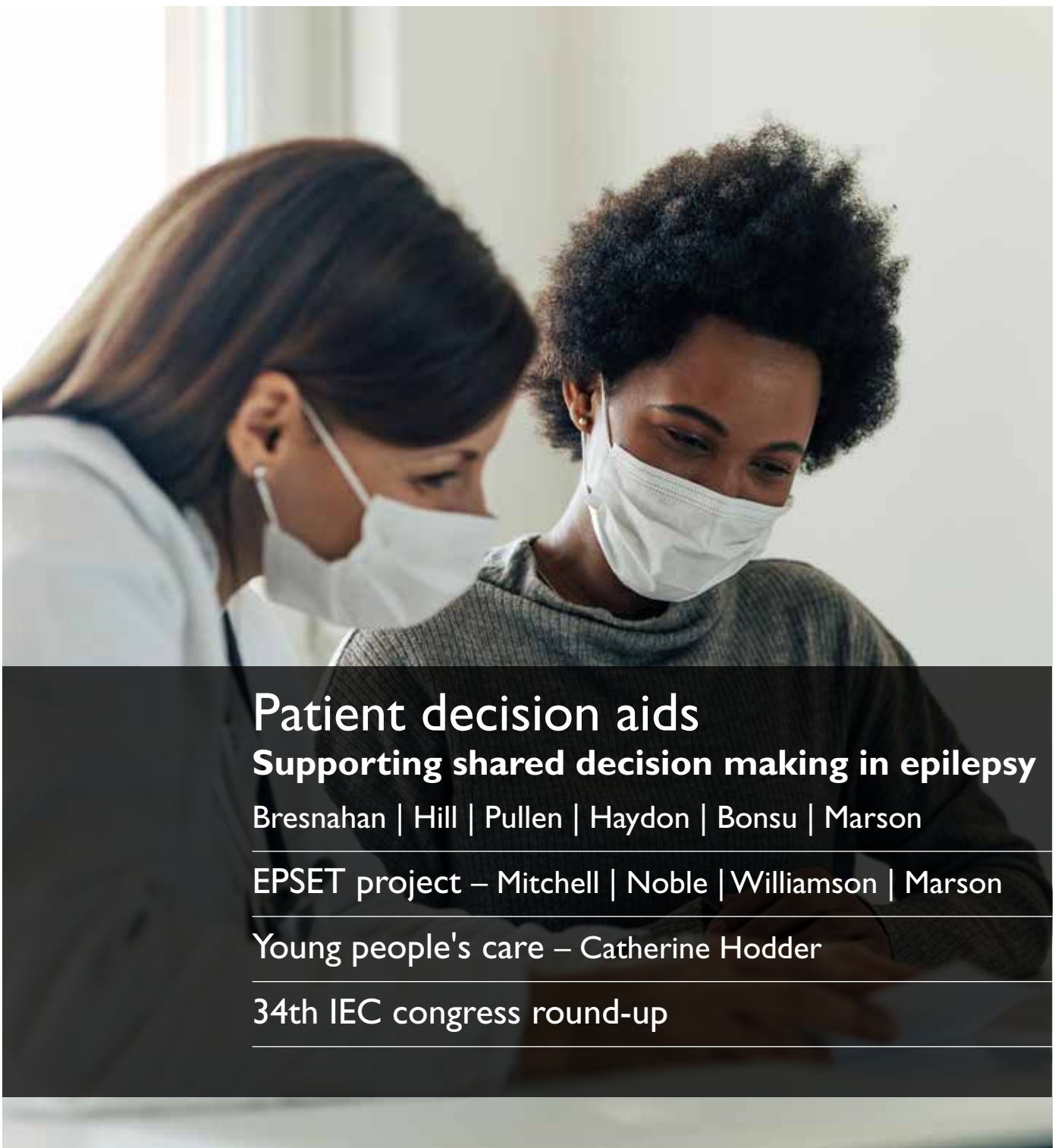

Patient decision aids
Supporting shared decision making in epilepsy

Bresnahan | Hill | Pullen | Haydon | Bonsu | Marson

EPSET project – Mitchell | Noble | Williamson | Marson

Young people's care – Catherine Hodder

34th IEC congress round-up

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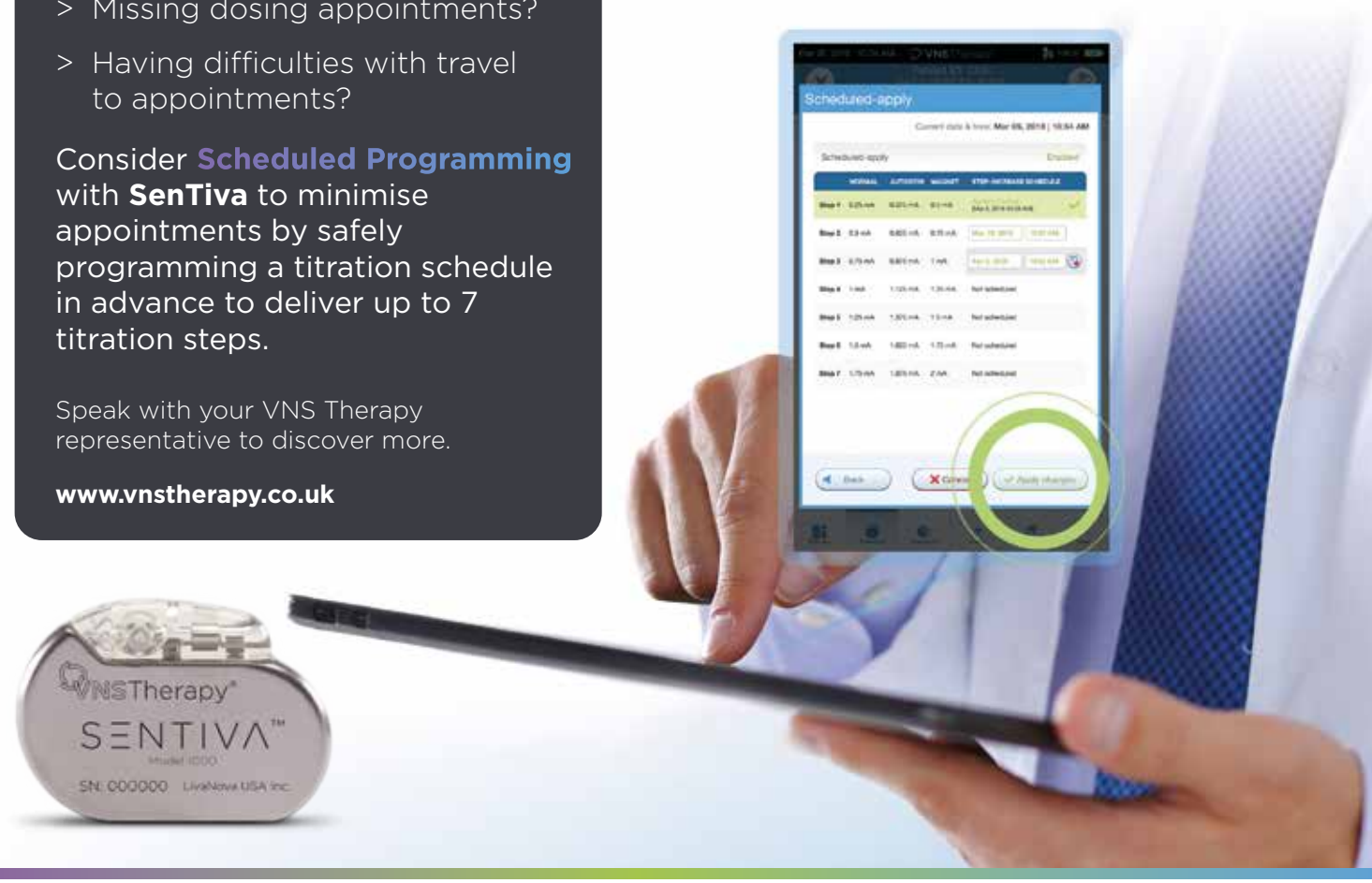

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LivaNova
Health innovation that matters

How are you? No really, how are you? Things are pretty grisly out there, aren't they?

As we prepare to enter the third year since the COVID-19 pandemic started, there has never been a better time to take stock, and think about our 'core business' – helping people with epilepsy. We are really fortunate in the UK to have a supportive and inspiring community. I thoroughly miss the coffee break chats and gossip that comes from bumping into people at meetings and conferences, but I get a sense of that comradery by reading *Epilepsy Professional* – a constant for us, the epilepsy tribe.

That's not to belittle the efforts of the educators who have been working like Trojans to create e-learning and hybrid events. Our very own Kami Kountcheva reports from the International Epilepsy Congress leading with a provocative thought – can machine learning produce insights that are impossible or invisible to us at a human level? I, for one, very much hope so and will welcome our new robot overlords, if they can help nudge the needle towards better treatment for people with epilepsy.

Management guru, Peter Drucker, is quoted as saying "you can't manage what you can't measure". But are we measuring what matters to people with epilepsy in clinical trials? Dr James Mitchell describes the COMET Initiative (The Core Outcome Measures in Effectiveness Trials) and the EPSET project team's plans to create a core outcome set for epilepsy studies. Is seizure freedom the main, essential objective? I often have parents of adults with learning difficulties tell me that predictability matters more to them than seizure frequency and that new side-effects can be more disconcerting than seizure burden.

Partnerships are more important than ever and our services are only as strong as the seams. Young Epilepsy remind us about the importance of transition arrangements for all young people with epilepsy. Their survey of 200 people ages 11 to 25 years are a stinging rebuke to any of us who offer transition care. The one big take-away for me? Young people recognise the need for better mental health and wellbeing services, and we need to identify how to support them.

And how about a 'blogshot'? This is a new one for me. Consider it the charmed offspring of a Cochrane review summary and an internet meme. But perhaps better than the sum of both of these parental parts? In all seriousness, how does one communicate benefits and risks of add-on treatments in people with drug-resistant epilepsy with nuance and clarity, when you boil down the message to its most integral and digestible parts? Rebecca Bresnahan and colleagues describe their journey towards creating the neatest accessible informative tools to support shared epilepsy treatment decision making. The final results – patient decision aids supported by Epilepsy Action and *Cochrane* – are a thing of true beauty. Do yourselves and your patients a favour and try them out in clinic.

So how are you? You could be better, I know. Well, why not indulge yourself with a cup of tea and a chocolatey biscuit of your choice (on me, send me the receipts) and read one or more of these treats above. Then try and tell me that you don't feel a whole lot better.

Rhys Thomas
Consultant neurologist
Chief medical adviser
Epilepsy Professional

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patient decision aids

Bresnahan | Hill | Pullen | Haydon | Bonsu | Marson

Rebecca Bresnahan and colleagues discuss developing patient decision aids for add-on therapies to support shared treatment decision making for people with drug-resistant epilepsy

We all know how important teamwork is. They teach us all the way back in nursery that working together achieves a lot. We've all heard 'teamwork makes the dream work', and 'two heads are better than one', and 'many hands make light work', and all the other proverbs that tell us the benefits of working together.

To that end, this issue, we have a focus on patient participation in their own healthcare, encouraging us to work together for the best possible outcome. On page 10, you can read about the EPSET project from Dr James Mitchell and colleagues. The project is looking to establish key core outcome sets for randomised controlled trials, by getting the opinions of people with epilepsy, caregivers, clinicians and researchers. On page 14, you can read the findings from a Young Epilepsy survey, looking at the experiences of young people with changing epilepsy care as they grow. Catherine Hodder's article amplifies the voices of young people with epilepsy and helps us better understand what services and support they need at different stages in their lives.

On page 20, Rebecca Bresnahan and colleagues discuss the patient decision aids they have created to support shared decision making between healthcare professionals and people with drug-resistant epilepsy. The decision aids help people understand their options of potential add-on anti-seizure medicines, so they can make an informed decision with their doctor. Finally, on page 28 we summarise some of the many brilliant presentations from this year's International Epilepsy Congress held in August 2021.

Please enjoy this issue and we wish you a restful festive season.

Kami Kountcheva
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Epilepsy Professional is available on subscription to non-members – £13 a year to UK residents. Please send letters or articles to the editor. We are unable to acknowledge receipt of materials, due to cost. We cannot offer payment to authors. All income generated by *Epilepsy Professional* funds the Association's work.
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 ISSN 1750-2233
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Partnership aims to establish research priorities for epilepsy

A group of epilepsy charities, clinicians, researchers and people with epilepsy have joined forces to identify which areas of epilepsy need to be prioritised for research.

The group is part of Epilepsy Research UK's (ERUK) James Lind Alliance (JLA) Priority Setting Partnership (PSP) which was launched this week. It includes Epilepsy Action, Young Epilepsy, SUDEP Action and Epilepsy Society, as well as ERUK.

The process that the JLA PSP will use will identify the most important themes around epilepsy for people with the condition and reach a top 10 of research questions for epilepsy. Researchers and funders will then devise the most meaningful research projects within those areas, aiming for them to support those who need it most.

The JLA PSP will consider causes and prevention of other related conditions, access to health services for diagnosis, and treatments for epilepsy, drug-resistant epilepsy, side-effects and related conditions. They will also look at risk of epilepsy-related deaths, social and psychological factors, epilepsy in older people, medical education and pathways to improved medical care.

A similar JLA priority setting activity was done 12 years ago by consultant neurologist Dr Rhys Thomas, who will also lead the current group.

Dr Thomas said: "A new study is long overdue, the outcomes for which would benefit people living with epilepsy by providing the evidence of need and priorities to support research development. We know that PSPs can lead to increased funding from NIHR [National Institute for Health Research], which is so urgently needed for epilepsy, given the shocking inequalities in research funding."

Angie Pullen, research and healthcare projects programme lead at Epilepsy Action, said: "We are really pleased to be encouraging people participation in agreeing priorities for the future of epilepsy research. Knowing directly from people with epilepsy and their loved ones about what is really important to them is key to helping us to drive forward positive change.

"When the priorities have been agreed we will be able to make the case for more research funding for epilepsy and how care can be improved for people affected by the condition."

ERUK will fund and provide the resources for the programme to establish research priorities.

Cenobamate expected to be approved for use by NICE

The National Institute for health and Care Excellence (NICE) is expected to approve the use of cenobamate for treating focal onset seizure in adults with hard-to-treat epilepsy in England.

NICE has put together its final appraisal document, recommending its use when at least two other epilepsy medicines have not worked. The document adds that cenobamate is recommended as an add-on treatment after at least one other add-on medicine has not worked, and says this treatment should be prescribed by an epilepsy specialist.

The recommendation is based on evidence from two medical trials, showing the effectiveness of cenobamate. The larger of the two trials showed that cenobamate reduced focal seizures by at least half in nearly two-thirds (65.2%) of people taking the largest dose in the study (400mg). This is compared to a similar reduction in just a quarter of people (25.5%) in the placebo group. The most commonly seen side-effects with cenobamate were sleepiness, dizziness and tiredness.

NICE's final appraisal document has been sent to groups involved in the appraisal process, who have until 26 November 2021 to raise any issues with it. If there are no issues, it is likely that NICE will approve the use of cenobamate in the NHS in England, and Wales and Northern Ireland will follow. It is not yet clear if it will be approved in Scotland.

New MEG imaging technology improves accessibility to children

New technology to make magnetoencephalography (MEG) brain imaging more accessible in children has been developed by UK scientists and Young Epilepsy.

The charity unveiled the brain scanning system for children at their Neville Childhood Epilepsy Centre in Surrey at the end of September.

MEG brain scans look at brain activity and offer high spatial and temporal resolution when identifying seizure activity or focus and essential brain regions. This can help with diagnosis and surgical evaluations. However, up until now, MEG imaging has been difficult to use. It has required the use of large and expensive machinery used in a specifically designed and expensive room, and for the person being scanned to remain still.

This has made the technology difficult to access in many epilepsy centres and not suitable for use in children.

The new optically pumped magnetometers (OPM) technology allows the MEG scanner to be worn like a helmet and for the person being scanned to move freely. The room the scan needs to take place in is also less expensive and children can bring toys and have family in with them.

The improved accessibility and cost could mean a wider use of MEG imaging around things like diagnosis and surgery, and more MEG facilities could become available around the UK in the future.

Young Epilepsy says the helmet can fit the head of any child and also helps to make MEG more accessible to children with complex needs.

The technology was developed in partnership with the University of Nottingham and University College London, as well as companies Cerca Magnetics Ltd and Megnetic Shields Ltd. It is currently being used at Young Epilepsy's research centre in Surrey.

There is more information at: *epilepsy.org.uk/youngepilepsymeg*

Addendum to Epilepsy Professional issue 62

The research around the article in issue 62 of *Epilepsy Professional* entitled 'Levetiracetam and mood', by Melissa Young, was carried out under the supervision of Dr Khalid Hamandi at the Cardiff and Vale University Health Board.

Epilepsy Action certified 'trusted information creator'

Epilepsy Action has gained a Patient Information Forum (PIF) TICK certifying the organisation as a 'trusted information creator'.

This is the UK's only quality mark for print and online health information. To gain the accreditation, Epilepsy Action underwent an assessment to show its information met 10 key criteria.

The PIF TICK means PIF was satisfied that Epilepsy Action's information is evidence-based, understandable, jargon-free, up-to-date and produced to the best possible standard.

The PIF TICK was launched in May 2020. In June 2021, the organisation also launched a website to help people find trusted health information and spot false health information.

PIF TICK manager Dan Willis said: "We are thrilled to welcome Epilepsy Action to our ever-growing community of accredited PIF TICK members. Accurate, accessible, evidence-based information is key to increasing patient empowerment and improving health outcomes."

Previously, Epilepsy Action's advice and information had received the Information Standard logo from a scheme run by NHS England, until the scheme ended in 2019.

For more information about the PIF TICK, visit *piftick.org.uk*

Levetiracetam improves cognition in people with Alzheimer's disease and epilepsy

Levetiracetam has been found to improve cognitive functions, like learning and memory, in people diagnosed with Alzheimer's disease who also have epileptic brain activity, a study in *Journal of the American Medical Association (JAMA) Neurology* has found.

There are around 850,000 people with dementia in the UK. Alzheimer's disease affects between 50-75% of people with dementia, according to the Alzheimer's Society.

According to the study, among people with Alzheimer's disease, up to around 60% have seizures or silent epileptic activity.

Lead study author Dr Keith Vossel called Alzheimer's disease with epileptic activity an "epileptic variant" of the disease.

The study analysed 34 people with Alzheimer's disease, 40% of whom had epileptic activity. People were split up into two groups, and received treatment with a placebo or a low dose of levetiracetam for four weeks. This was alongside their current Alzheimer's disease treatment. Then, the groups had a four-week break and swapped over to receive the opposite treatment.

The researchers assessed people's abilities to problem solve, reason, remember words and navigate during treatment. People treated with levetiracetam showed a tendency towards improvement in these kinds of skills. People with silent epileptic activity were seen to have a clear benefit of this medicine to their cognitive functions.

The researchers concluded that these findings showed the importance of extended neurological assessments in Alzheimer's disease patients, to identify people with epileptic activity who may benefit from levetiracetam.

The full study is available at *epilepsy.org.uk/jamasep21*

Dogs can smell seizures, study says

Dogs can detect a specific odour associated with seizures, a new study published in *MDPI Animals* has found.

The research, led by Dr Neil Powell, looked at how a group of 19 untrained pet dogs reacted to seizure-related and non seizure-related odours. The seizure-related odours reflected pre-ictal, ictal and post-ictal phases of a seizure. All 19 dogs showed a change in behaviour to try to connect with their owner with the seizure-related odours, compared with the non seizure-related ones.

Dr Powell concluded that this research could be used to train dogs to detect oncoming seizures.

The full study is available at *epilepsy.org.uk/mdpijun21*

Hypertension may double epilepsy risk

Hypertension could double the risk of developing late-onset epilepsy, according to a new *Epilepsia* study.

The US study by Dr Maria Stefanidou and colleagues looked at vascular risk factors that may predict late-onset epilepsy in people aged 45 years and older.

Participants from the Framing Heart Study (1991-95), who were at least 45 years old at the time, were included in the study. They also needed to have available modifiable vascular risk factor data and an epilepsy follow-up. Modifiable vascular risk factors included hypertension, diabetes mellitus, smoking and hyperlipidemia.

The team found that out of the 2,986 people included in the study, 55 had epilepsy at the follow-up. High blood pressure appeared to double the risk of developing late-onset epilepsy. The team did a second analysis, where they excluded people with normal blood pressure who were receiving anti-hypertensive treatment. This changed the total number of people in this group to 2,613 and those who had epilepsy to 50. In this analysis, hypertension increased the risk by nearly two-and-a-half times.

The study authors concluded that their study added to evidence that hypertension increases the risk of developing late-onset epilepsy. They stressed that this is a modifiable risk factor that can be reduced in the general population, through things like lifestyle changes and medication.

The full study is available at *epilepsy.org.uk/epilepsianov21*

Lower depression levels during the COVID pandemic, study from India finds

Depression levels have reduced during the COVID-19 pandemic in a group of 449 people with epilepsy, a new study from India has found.

The research, published in *Epilepsy & Behavior* journal, aimed to assess the impact of the pandemic on seizure control, depression status and medicine adherence, given that healthcare services have been disrupted.

The study evaluated 449 people with epilepsy, who had previously been assessed for depression in New Delhi, India, over the phone. They were asked about their epilepsy medicines, seizures, depression and suicidal thoughts in the last six months.

The results showed that 19.9% had symptoms of depression, compared to 40.1% before the pandemic. Suicidal ideation was reported in 5.4%. Just over 23.9% reported seizures during the pandemic.

The study authors, Prof Jatinder Katyal and colleagues, found that seizures during the pandemic, increased seizure frequency, previous history of depression and changes to medicine regime were significantly linked with depression during the pandemic. Needing multiple anti-seizure medications, having seizures during the pandemic and a previous history of depression and suicidal thoughts were linked with people experiencing suicidal thoughts during the pandemic.

The researchers concluded that depression levels dropped significantly during the pandemic in their study group, despite other reports mostly finding an increase in anxiety and depression during this time. The reason for this isn't clear, but the study authors suggested that lockdown may have provided a better support structure with things like taking medicines regularly, which may have contributed to lower depression levels. However, the researchers warned that conducting the follow-up interviews over the phone may have resulted in missed cases of depression.

The study authors called for restoring epilepsy services to pre-COVID levels, as well as putting in place continuity plans to help make this kind of care for people with epilepsy a priority.

Read the full research at: *epilepsy.org.uk/epilepsybehaviorsep21*

Epilepsy diagnosis after one seizure

Epilepsy resulting from certain causes could be diagnosed after only one seizure, a new *Epilepsy & Behavior* study suggests.

Dr Salvador Vergara-López and colleagues aimed to assess what epilepsy aetiologies could allow for a diagnosis to be made after only one unprovoked seizure.

The International League Against Epilepsy (ILAE) classifies epilepsy as at least two unprovoked seizures more than 24 hours apart. However, it says that one unprovoked seizure could also be classified as epilepsy, if there is more than a 60% chance that there will be a second within the next 10 years.

The study authors explain that the second definition is challenging, as the risk of a second seizure is different depending on the aetiology. They explained that it is difficult to find the risks among the current literature.

The researchers reviewed the studies done to date on this topic, and found only two that were relevant. These studies concluded that there was around 66% chance of a second seizure to occur within eight years in aetiologies such as stroke, traumatic brain injury, cavernous or arteriovenous malformations and neuroinfections.

The researchers concluded that for these aetiologies, epilepsy could be diagnosed after only one seizure. However, they warned that the strength of the evidence is low and more studies are needed in the future.

The full study is available at *epilepsy.org.uk/epilepsybehaviournov21*

EPSET project

Developing a core outcome set for adult epilepsy clinical trials

Dr James Mitchell, Dr Adam Noble, Prof Paula Williamson and Prof Tony Marson outline the background and scope for the EPSET project and how you can contribute

Introduction

Randomised controlled trials (RCTs) are the gold standard source of evidence informing treatment decisions for people with epilepsy. RCTs evaluate the effect of an intervention on outcome measures, which should be predefined by the research team. In epilepsy, the choice of outcome measures varies widely among studies [Nolan *et al*, 2013], and may not reflect what is important to people with epilepsy. This diminishes opportunities for informed decision making, contributes to research waste and is a barrier to integrating findings from multiple RCTs in systematic reviews and meta-analyses.

For other chronic diseases, there has been increasing international effort to identify Core Outcome Sets (COS) using well-established methods developed by The Core Outcome Measures in Effectiveness Trials (COMET) Initiative (comet-initiative.org). COS derive consensus among people affected by that condition and relevant key stakeholders (caregivers, clinicians and researchers) as to which outcomes should be reported as a minimum [Williamson *et al*, 2017]. COS facilitate the undertaking of trials that are relevant to patients and health services, and help standardise trial methodology, so more meaningful results can be obtained from systematic reviews and meta-analyses [Clarke, 2007]. The importance of the use of outcome sets is increasingly recognised by research funders and regulatory bodies. The National Institute for Health Research's (NIHR) Health Technology Assessment programme in the UK and the European Medicines Agency are both encouraging outcome sets in new studies.

This project is being led by Dr James W. Mitchell, Association of British Neurologists Fellow, and Professor Tony Marson from the University of Liverpool. Methodological support is being provided by the COMET Initiative, and international collaboration is being facilitated by an international working group of epilepsy researchers and representatives, patient organisations and charities. The team at Liverpool have a strong track record for interventional drug trials for adults with epilepsy, with Professor Marson having led on some of the largest RCTs in epilepsy to date (MESS Study, SANAD and SANAD-II). This project will build on this existing work, to help improve the methods used in future epilepsy drug trials.

The EPSET project

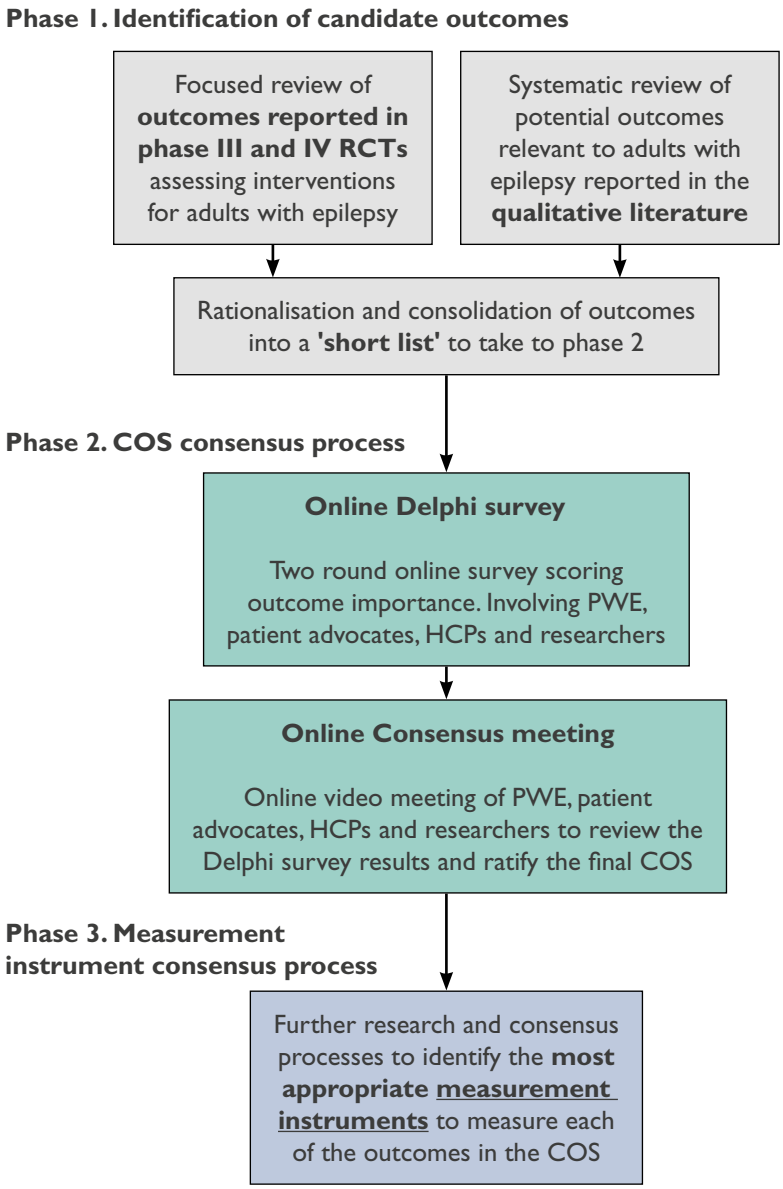
The development of the adult epilepsy COS is following three phases (see *Figure 1*.)

Phase 1 – Identification of candidate outcomes

The first phase of this study has already been completed, and the results are currently being prepared for peer review publication. Our review of the most recent 50 clinical trials with results, investigating drug treatments for adults with epilepsy from the clinicaltrials.gov database, has demonstrated marked outcome heterogeneity. In total, 115 unique outcomes were measured across the trials, including specific measures of seizure frequency and severity, and broader outcome domains, such as health-related quality of life. Where the same outcome was measured across multiple trials, this was commonly measured differently. For example, the outcome 'seizure frequency', was measured in 13 different ways across the selected trials.

Our review of the qualitative literature describing the views of adults with epilepsy and their caregivers, identified 75 relevant papers, where verbatim views were expressed in the paper or associated paper supplements. In total, the views of over 2,000 people with epilepsy and over 600 caregivers were included from six continents. Most studies included people with a wide range of epilepsy subtypes, using purposive

Figure 1. The three phases of developing the adult epilepsy COS



sampling to ensure that views represented a broad range of people with epilepsy. In total, 180 unique outcomes were interpreted from the included studies.

After removing duplicate outcomes, the unique outcomes from both reviews were categorised, and rationalised into a more manageable 'short list' to aid conceptualisation of the outcomes.

Phase 2 – Consensus process

The outcomes in the 'short list' will be taken to an international, multistakeholder consensus process involving a two-round, online modified Delphi survey and online video consensus meeting. This will decide which outcomes should be prioritised and classified as core outcomes.

The modified Delphi method allows for participants to consecutively score the importance of outcomes in multiple rounds, as a means of obtaining consensus on what should be included in the final COS. The Delphi method allows anonymous review and scoring of outcomes in a way that gives equal influence to all who participate. It avoids an individual participant being overly influenced by the opinions of any other participant, facilitates international contribution and provides a mechanism for reconciling different opinions [Sinha, Smyth & Williamson, 2011]. Outcomes will be included or excluded from the COS based on predefined consensus criteria.

The following stakeholder groups will be invited to participate in both the Delphi surveys and the online video consensus meeting:

1. Adults with epilepsy
2. Family members and caregivers of adults with epilepsy
3. Other patient advocates for example representatives from patient charities and advocacy groups
4. Healthcare professionals who regularly assess and treat adults with epilepsy (neurologists, epileptologists, epilepsy specialist nurses and allied healthcare practitioners)
5. Researchers involved in epilepsy treatment trials

Phase 3 – Selecting the measurement instruments for the COS

Often, researchers use different measurement instruments to measure the same construct, and it can therefore be difficult to compare and contrast results from different studies, further contributing to research waste. The final Core Outcome Set (COS) represents **what** outcomes should be measured as a minimum in future research. Further research will then be undertaken to obtain consensus on **how** to best measure each outcome from the COS, meaning which measurement instruments should be used. Similar consensus methods to phase 2 of this project will be used.

Get involved

If you are an epilepsy researcher working in clinical trials, or healthcare professional regularly treating adults with epilepsy, we invite you to share your expertise and views to help shape the final COS.

Those who take part will be asked to complete two online surveys, voting for which outcomes they think are the most important to measure. Some participants will also be invited to an online consensus meeting at a later date. The online surveys will take 10-15 minutes to complete.

To register your interest, please visit the study website ***www.epsetproject.org*** or email ***epset@liverpool.ac.uk***. You will soon be contacted by a member of the EPSET team with more detailed information about the surveys and meetings that will take please in Spring and Summer 2022.

You can also scan the QR code to register your interest in taking part.

Dr James W Mitchell
Association of British Neurologists clinical research fellow
University of Liverpool

Dr Adam Noble
Senior lecturer in Health Services Research
University of Liverpool

Prof Paula Williamson
Professor of Medical Statistics
University of Liverpool

Prof Tony Marson
Professor of Neurology
University of Liverpool

Further reading

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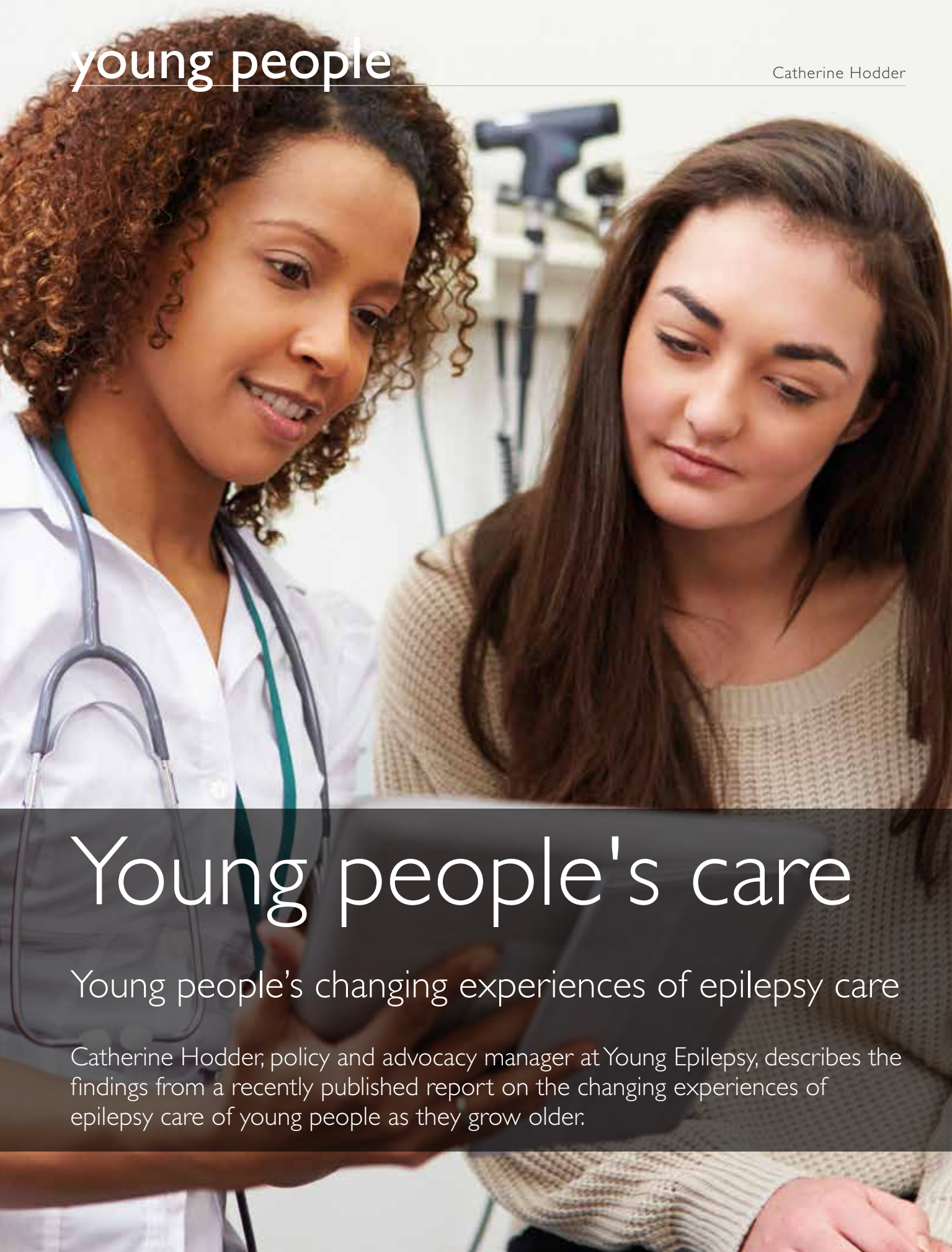
Catherine Hodder



Young people's care

Young people's changing experiences of epilepsy care

Catherine Hodder, policy and advocacy manager at Young Epilepsy, describes the findings from a recently published report on the changing experiences of epilepsy care of young people as they grow older.

The charity Young Epilepsy has published a report on young people's experiences of epilepsy care and how this has changed as they have grown older. The report reflects survey responses from over 200 young people with epilepsy (aged 11 to 25) in the UK, looking at both paediatric and adult epilepsy care.

Key findings include:

- 40% of young people had no joint appointments as part of their transition to adult epilepsy care, while 27% had more than three
- Nearly a third of young people said their experience of transitioning to adult epilepsy care had a negative impact on their mental health
- Only half of young people said their epilepsy doctor or epilepsy specialist nurse (ESN) helped them to understand and self-manage their epilepsy more as they got older
- Nearly a third of young people said their paediatric epilepsy doctor or ESN did not speak to them about how epilepsy might impact on a range of life issues, including mental health

Young Epilepsy is sharing its survey findings with healthcare professionals in order to improve young people's experiences of epilepsy care. The charity is calling for mental health screening and support to be integrated into children's epilepsy care.

Transition from paediatric to adult epilepsy care

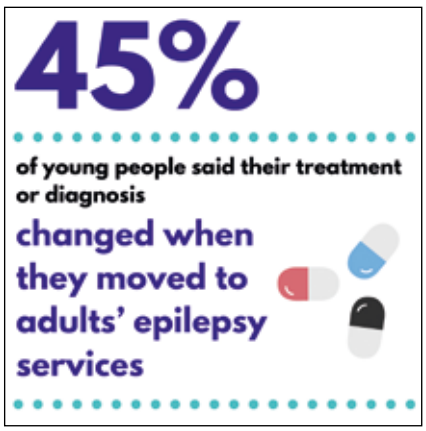
Most young people (77.5%) said they transitioned to adult epilepsy care at age 16, 17 or 18.

More young people transferred at 16 than any other age (34.8%). Of these, less than half said their epilepsy doctor or ESN spoke to them about their move to adult epilepsy care before they turned 16 (45.1%).

The largest proportion of young people who had transitioned to adult epilepsy care – 39.5% – said they had no joint appointments with children's and adults' epilepsy services. However, 26.7% had more than three joint appointments. Much fewer young people said they had one (9.3%) or two (3.5%) joint appointments.

"Paediatric care was amazing but there wasn't a transition period. One day

Catherine Hodder



I was just handed off to a new service with no idea who I was seeing or what these people were like."

Several young people highlighted the need for more targeted services for young adults.

"I think there could be a transition period for young people turning 18 where if they feel they need to or want to talk with a specialist after they have been discharged from paediatrics this can be offered no matter how controlled their epilepsy is."

In the survey, 32.3% of young people said their experience of moving from children's to adult epilepsy services had a negative impact on their mental health. However, 52.1% said that the process had no impact on their mental health.

"I feel forgotten within the system and very much alone."

"I feel that I have been abandoned by the hospital after years of support as a child."

"It wasn't a successful transition, which caused a lot of anxiety and stress."

Of the respondents, 45.3% said their treatment or diagnosis changed when they moved to adult epilepsy services. Some of this appeared to be due to different medication or an increased dosage being suitable in adulthood. Other changes appeared to mark a different approach to diagnosis or care.

Access to epilepsy professionals

Slightly more young people had contact with an ESN in children's services (79.4%) than in adult epilepsy care (73.1%).

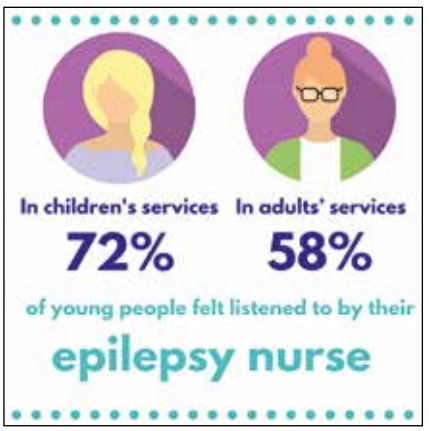
Several young people said they had less support in adult services, in comparison to their experience of paediatric epilepsy care.

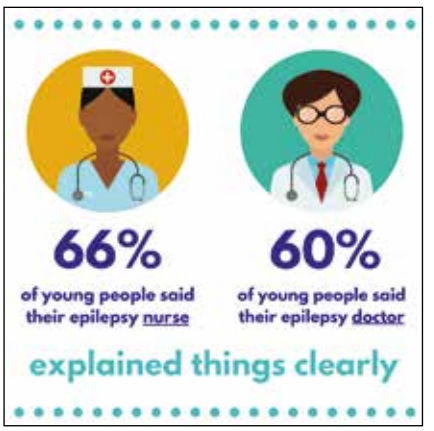
"My appointments have become less frequent and are now only brief 10-15 minute chats. My seizures are not controlled and my medication is just increasing."

"I no longer have as much support. If needed, I'm told I can talk to my GP, but I feel they don't know as much and that they also don't really care."

A significant number of young people suggested that more frequent contact from their ESN or epilepsy doctor would help them manage their epilepsy as they got older. Their recommendations included:

"Easier ways to contact epilepsy nurses or doctors."





"Regular mini appointments just to check up and more help on how I can manage epilepsy in everyday life."

Several young people mentioned the importance of having a healthcare professional who is the same sex, for discussing personal issues.

Conversations with epilepsy professionals

More young people felt listened to by their ESN in paediatric care (72.3%) than by their ESN in adult epilepsy services (57.8%). Overall, 57.6% of the young people felt listened to by their epilepsy doctor.

"As a child, I was listened to, as an adult, they try and tell me what to do."

Young people commented on what would help them manage their epilepsy as they got older:

"To have my concerns listened to."
"Longer appointments! I have so many questions that just don't fit into the time!"
"My appointments on time and me being listened to better. I struggle to understand things and what [medication] I am taking."

In the survey, 66.4% of young people said their ESN explained things clearly, while 59.9% said the same of their epilepsy doctor.

Several young people commented on how important this was to help them better understand their condition.

"Tell me in more details, and maybe, for me, use pictures to help."
"I just feel since my diagnoses, I've been seen by many different doctors who all tell me different things and have never been clear."

Only 39.4% of young people said their paediatric epilepsy doctor or ESN spent more time talking to them directly as they got older. This can support young people's transition to adult care, increasing their involvement and confidence in managing their condition.

Young people commented on the difference in this area after moving from children's to adult epilepsy care.

"They're more direct and listen to me a lot more!"
"It suddenly changed to the doctor only speaking to me and not my mum."

Only 29% of young people said they had more opportunities to speak with their paediatric epilepsy doctor or ESN on their own as they got older.

Table 1. Has your epilepsy doctor / nurse spoken to you about how your epilepsy might impact on any of the following (now or in the future)?

	Children's epilepsy care	Adults' epilepsy care
Mental health (e.g. worries and anxieties)	41.9%	48.5%
Exams	31.6%	20.9%
Studying at college or university	26.5%	30.6%
Moving away from home	12.9%	27.6%
Working	23.2%	34.3%
Alcohol	40.0%	50.7%
Driving	51.0%	67.9%
Travelling	12.9%	20.1%
Relationships	16.8%	30.6%
Your own life goals	16.8%	23.9%
None of these things	29.7%	19.4%

These opportunities provide a valuable space for young people to discuss issues in confidence, without their parents present.

Support with epilepsy self-management

Only 51% of young people said their epilepsy doctor or ESN helped them to understand and self-manage their epilepsy more as they got older.

"I have the freedom to choose my treatment! … I feel like I'm in control."

A significant number of young people commented on how support with self-management could be improved. This included help to manage seizure triggers such as stress and tiredness, as well as support to manage medication routines and side-effects.

"More interaction and support from people who know and understand epilepsy. Doctors or specialists teaching me more about what epilepsy affects etc."

"Start talking one to one about getting older and wanting to get more independence, so I can be taken more seriously as a young adult."

Several young people commented on how they would like better access to support as they get older because they are unable to live independently. Others spoke about the need for more epilepsy research and better treatments.

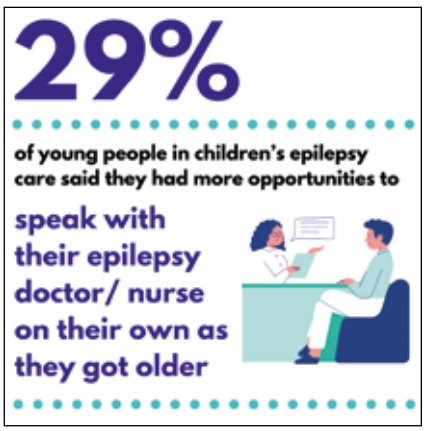
One young person spoke about withdrawing themselves from medical care, describing the side-effects of medication as worse than the seizures:

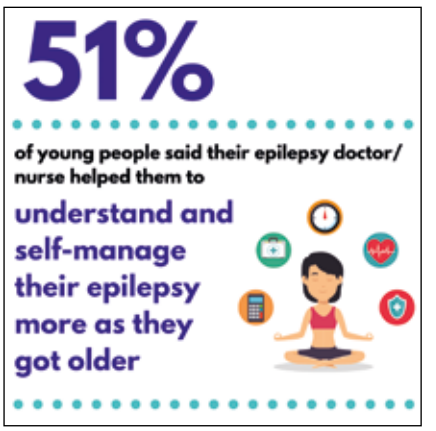
"I discharged myself and lied about seizures stopping as I felt medical care no longer helped me."

Epilepsy's broader impact on life

Of the young people, 29.7% said their paediatric epilepsy doctor or ESN did not speak to them about how epilepsy might impact on a range of life issues. For adult care, this was only 19.4% (*Table 1*).

The most likely topics mentioned by epilepsy professionals were the condition's impact on driving, mental





health and alcohol. Many young people said there should be more support on how epilepsy impacts on different areas of their lives as they get older. This could be support provided by their epilepsy team or signposting to other information sources or support groups.

"I have been given lots of useful information about different issues as I've gone through university and into employment."

"I don't think there is much support as I would like to talk to someone as I get upset as I am not the same as my friends."

"I hate it. I can't drive, I messed up my GCSEs, I won't be able to get a job, I can't even shower without telling someone."

Many young people highlighted the need for more support with epilepsy's impact on mental health and suggested how this could be improved.

"Quicker access to mental health services."

"Discussion of effect of diagnosis on mental health and regular mental health and general wellbeing check-up through later teen years."

"Offering mental health support, because the stigma and misconceptions surrounding epilepsy are strong enough for people to leave you out of things in fear you'll have a seizure which can be really damaging mentally."

For more on the survey findings, visit: *bit.ly/3p83DFV*.

Catherine Hodder
Policy and advocacy manager
Young Epilepsy

Further reading

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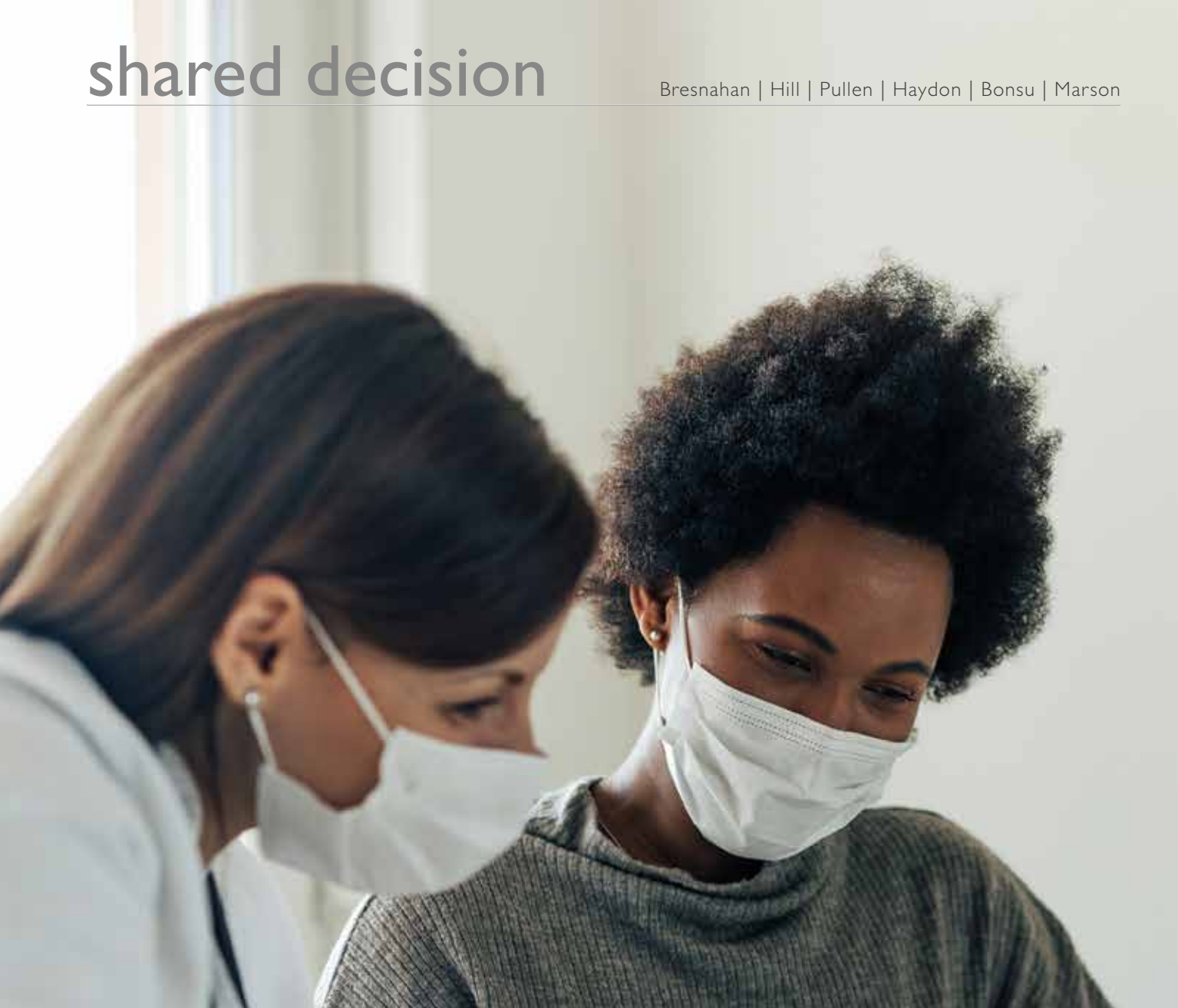

Patient decision aids

Supporting shared decision making in epilepsy

Rebecca Bresnahan, Dr Ruaraidh Hill, Angie Pullen, Grace Haydon, Angela Bonsu and Prof Tony Marson discuss developing patient decision aids for add-on therapies to support shared decision making for people with drug-resistant epilepsy.

Research dissemination is recognised as an important and essential aspect of research. It ensures that a target audience is aware of the research and can appropriately implement its findings. Effective research dissemination should engage a target audience and plainly describe and explain the research findings. For clinical research, the target audience includes patients, clinicians and caregivers, who will use the information to guide clinical decisions.

As part of a National Institute for Health Research (NIHR) Cochrane Programme Grant (NIHR 16/114/26), the Cochrane Epilepsy Group collaborated with Epilepsy Action on a research dissemination project. Through collaboration, we produced Patient Decision Aids (PDAs) to facilitate and support shared decision making. The PDAs are based on Cochrane systematic reviews that collated evidence to assess the effectiveness and tolerability of anti-seizure medicines (ASMs) as add-on therapies for people with drug-resistant epilepsy (DRE).

Effective research dissemination should engage a target audience and plainly describe and explain the research findings

The development process

We first aimed to produce 'blogshots' as recommended by the Cochrane Knowledge Translation Group. A blogshot is a single infographic that summarises the results of a Cochrane systematic review and is well-suited for sharing on social media. While blogshots are effective at initially engaging users, they provide limited information and rely on users seeking further information.

We were mindful that decision-making for epilepsy therapies requires people to consider a range of outcomes to gauge benefits and harms. The blogshot was not informative enough for our purpose because we were unable to present all outcomes in the single infographic. Despite reducing the content, our blogshot was dominated by text and became overwhelming for readers due to the lack of white space. We were unable to include any imagery in the blogshot, although it is recommended by the Cochrane Knowledge Translation Group, due to the restricted size. This made the blogshot unappealing and unengaging. Our development team decided that the blogshot format was not suited to our objectives or our target audience and agreed that a more detailed and self-contained dissemination format was needed.

We researched alternative formats, designs and recommended contents for PDAs. From our research, we decided to develop our PDAs primarily based on the National Institute for Health and Care Excellence (NICE) decision aid

template. Our PDAs also incorporated guidance from the International Patient Decision Aid Standards (IPDAS) Collaboration guidelines, Cochrane brand guidelines, and other available resources, including webinars.

We used plain language in our PDAs to ensure that the content was accessible to all users. We employed a graphic designer and, with input from the Cochrane Knowledge Translation Group, we designed imagery to convey the introductory information where we explain:

- WHAT a PDA is
- WHO the PDA is intended for
- HOW it should be used
- WHERE the evidence was extracted from
- WHEN it was collected

In the PDAs, we included information about the probability of benefits, such as seizure freedom, and harms, such as adverse events. We communicated absolute risk (how many people are expected to experience an outcome when a certain number of people take an ASM) using icon arrays that illustrate the estimated risk of an outcome per 100 people. We also provided the relative risk (how likely a person is to experience an outcome if they take ASM 'x' compared to a placebo) and described the certainty of the evidence for the efficacy outcomes. We used emoticons to visually represent the certainty grading, ranging from a 'sad face' to illustrate very low-certainty evidence to a 'happy face' to illustrate high-certainty evidence.

When necessary, we clearly and transparently informed the user which information had not been gained from a Cochrane systematic review, for example, adverse event data extracted from the Summary of Product Characteristics. We provided external links to the Epilepsy Action website for additional information that was not covered in the PDAs, such as advice for women of child-bearing age and women planning pregnancy. We added stock photographs to further engage readers and represent diversity.

Challenges and identified learning

Our first challenge was to minimise the amount of text without losing the information necessary for understanding. We made the text concise by avoiding excessive wordiness and specialist terms. This also helped us to maintain our use of plain language.

Our first challenge was to minimise the amount of text without losing the information necessary for understanding

We also experienced issues when finding suitable graphics. Following guidance from a Cochrane webinar, 'Visualising Cochrane Evidence in practice', we collaborated with a graphic designer to design our own graphics. We ensured that the graphics were representative, engaging and inoffensive. We kept the graphics simple so that they were suitable for printing in black and white. We accessed stock images provided by the Cochrane Knowledge Translation Group to visualise and emphasise shared decision making at the end of the PDA. Designing our own graphics and using stock photos was necessary to avoid copyright infringement.

User testing for PDAs

We organised user testing to evaluate the usability and functionality of the

PDAs for our target audience and to identify any improvements required. For our first round of user testing, we sent a mock PDA and a questionnaire to a sample of 10 Epilepsy Action Information Reviewers (EAIRs). EAIRs are people with epilepsy or family members and caregivers of people with epilepsy who volunteer to test and review information resources for Epilepsy Action. We received responses from six EAIRs.

All six responders:

- Rated the PDA as either 'useful' or 'extremely useful' in helping them to make a decision about whether or not to take a medicine
- Reported that the diagrams were 'mostly' or 'very' clear and easy to understand
- Reported that the language was 'mostly' or 'very' clear and easy to understand

We also included four content knowledge questions that required the EAIRs to search through the PDA to find the relevant answer. All responders answered the four questions correctly. This showed that users could navigate the PDAs and understand the content.

The three healthcare professionals agreed that providing both absolute and relative risk was beneficial for shared decision making

For our second round of user testing, we sent an example PDA and a questionnaire to a sample of three healthcare professionals. The questionnaire sent to healthcare professionals consisted of open-ended questions to encourage more detailed feedback. We specifically wanted their opinion on two issues in the PDAs: the presentation of both absolute and relative risk and the presentation of adverse event data from the systematic review and from the Summary of Product Characteristics (SmPC).

The three healthcare professionals agreed that providing both absolute and relative risk was beneficial for shared decision making. Two healthcare professionals reported that they supported adverse event data from both the systematic review and the SmPC being included in the PDA. One healthcare professional expressed that they would prefer that only data from the systematic review be included.

Overall, the user feedback from both EAIRs and healthcare professionals was very positive. All users expressed that they thought that the PDAs would be useful for shared decision making.

User feedback that required actions

A comment from one EAIR showed that we needed to clarify why there might be disparities between the absolute risk and relative risk for a single outcome:

"I had to double check the numbers (65 per 100 people vs 60 per 100 people), underneath the text says "people taking X were no more likely to experience side effects…", so that confused me a bit, I had to assume that although the numbers were different, the margin was insignificant."

A comment from another EAIR highlighted that users wanted more information about how the certainty of evidence was graded:

"I would like to know more about the grading process used to determine confidence in the findings. For me, an explanation is more useful than a label like low certainty."

As a team, we had been concerned that including adverse event data from

both the systematic review and the SmPC might cause confusion for users. The systematic review only includes data from people with DRE who took part in clinical trials and is current to the last search date, whereas the SmPC collects data for all licensed uses of a medicine and is regularly updated. The adverse events and incidence rates reported may therefore differ between the systematic review and the SmPC.

Our user testing prompted us to develop 'A Guide to using a Patient Decision Aid'. We designed the guide as a separate, standalone document to provide the additional information that our users had requested without adding extensive text to each PDA. The guide includes:

- A description of shared decision making
- Information about who produced the PDAs
- A description of where evidence for a PDA and a systematic review comes from, including a graphic to explain the format of a randomised controlled trial
- An explanation of absolute risk and relative risk, including an example of when it is important to be given both
- An explanation of why the adverse events from the systematic review may differ from those from the SmPC
- An explanation of how evidence is graded for certainty and what domains are considered
- Links to further information

Creating the guide allowed us to remain transparent, explain technical terms and expand on concepts first introduced in the PDAs without increasing the content in each PDA. The guide provides additional information to users who want to access it to increase their understanding while not risking overwhelming other users.

User testing for 'A Guide to using a Patient Decision Aid'

For the user testing of 'A Guide to using a Patient Decision Aid', we sent the guide, a mock PDA and a questionnaire to a sample of 10 EAIRs. We received eight responses.

Five responders rated the PDA as 'useful' in helping them to make a decision about whether or not to take a medicine while two responders rated it as 'quite useful' and one responder rated it as 'extremely useful'. All responders reported that the language was 'mostly' or 'very' clear and easy to understand. Five responders reported that the diagrams were 'very' clear and easy to understand while two voted that they were 'mostly' clear to understand and one voted that they were 'fairly' clear to understand. Again, the feedback was very positive overall.

Five responders rated the PDA as 'useful' in helping them to make a decision about whether or not to take a medicine, while two responders rated it as 'quite useful' and one responder rated it as 'extremely useful'

Finalisation and publication

Prior to publication, the PDA template and 'A Guide to using a Patient Decision Aid' were reviewed and quality assessed by the External Affairs team at Epilepsy Action. The PDAs are now available via the

Cochrane Epilepsy Group website (epilepsy.cochrane.org/evidence/patient-decision-aids and the Epilepsy Action website (***epilepsy.org.uk/decisions***).

Promoting our PDAs

We are now in the process of publicising and promoting the PDAs and the guide. The link to the PDAs will be signposted on relevant pages throughout the Cochrane Epilepsy Group and Epilepsy Action websites. We will use communication channels to engage with, and bring awareness to, our target audience. For example, we will be using animated Twitter posts (@CochraneEpileps) to generate interest in the PDAs and to encourage users to access them. We will also focus engagement on healthcare professionals, specifically epilepsy specialist nurses, who we anticipate will use these resources in consultations with patients. We will continue to conduct surveys to assess how useful the PDAs are and whether they do impact shared decision making.

Conclusions

Patient decision aids facilitate research dissemination to enhance patient autonomy. We strongly encourage researchers to develop research dissemination resources but planning is required to manage time, cost and staff resources. Challenges encountered during the development process included: maintaining concise text, communicating technical terms and concepts in plain language and selecting appropriate imagery. Initial user feedback highlights that the PDAs are useful for shared decision making. Continued follow-up with users will assess the effectiveness of our resources in community and healthcare settings.

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Markus Reuber

Highlights

Top picks from *Seizure*

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

Tuberous Sclerosis Complex (TSC) is an autosomal dominant disorder in which most patients carry one abnormal copy of their *TSC1* or *TSC2* genes in all their cells. TSC is characterised by abnormal tissue formation – the development of hamartomas – most commonly in the brain, kidney, skin, heart, liver or lungs. Although hamartomas are benign in principle, they can affect the functioning of the organs in which they grow. For instance, up to 90% of patients with TSC develop epilepsy. Other neuropsychiatric disorders, including intellectual disability, autism, anxiety and attention problems, are also common. The clinical picture caused by hamartomas can be complicated by the effects of second hit mutations which may be implicated in the development of benign tumours associated with TSC (including giant cell astrocytomas) [Zöllner *et al*, 2020].

Conventional ASM treatment fails to control seizures in about 50% of patients with TSC. However, the discovery that hyperactivation of the mTOR pathway due to loss of function of the TSC proteins is the cause of focal cortical dysplasia and intractable epilepsy in this condition has caused considerable excitement. We know that the mTOR pathway can be inhibited with everolimus or sirilimus, drugs previously used as immunosuppressants. This raised the possibility that patients with TSC might be the first people with epilepsy to benefit from truly anti-epileptic drug treatment, rather than medicines blocking seizures without tackling their underlying cause [Overwater *et al*, 2019].

The hyperactivation of the mTOR pathways has different effects at different stages of development. It can lead to abnormal migration and differentiation in neuronal precursors during prenatal brain development, resulting in giant cells, dysmorphic neurons, abnormal layering of the cortex of the brain and interrupted migration. During subsequent brain maturation, mTOR hyperactivation interferes with the interconnection of neurons. Encouragingly, mTOR-inhibiting drugs, have been shown to be effective in the treatment of TSC-related renal angiomyolipoma and subependymal giant cell astrocytoma. Several studies in TSC patients also showed a reduction in seizure frequency due to mTOR inhibition [Overwater *et al*, 2019]. In the EXIST-3 trial a 50% seizure reduction was observed in 15% of patients in the placebo group, 28% in a low-exposure and 40% in a high-exposure everolimus group [French *et al*, 2016]. In addition to everolimus, the ketogenic diet and highly concentrated cannabidiol may also have modulatory effects on the mTOR pathway [Schubert-Bast and Strzelczyk, 2021]. However, to date, most of our knowledge of the effects of mTOR inhibition relates to children above the age of two. At this age, some of the developmental problems associated with hyperactivation of the mTOR pathway may already be irreversible.

There is still, therefore, much to learn about the optimal treatment of the symptoms of TSC and their causes. But, there is a ray of hope in our understanding of what is likely to be the key disease mechanism in TSC (and our ability to manipulate it). This means that we urgently need to learn as much about this disorder and the causes of the great variability of its clinical presentations. My editor's choice from issue 91 of *Seizure* is a study exploring links between TSC genotypes and phenotypes in 297 unrelated individuals by Yifeng Ding *et al*. This research will make an important contribution to this process [Ding *et al*, 2021]. In this large cohort, abnormal copies of the *TSC1* or *TSC2* genes were found in 89.6% of children (in 266 out of 297 individuals). Epilepsy was more common in the *TSC1* group and among those in whom no mutation had been identified. Carriers of abnormal *TSC2* genes more commonly presented with infantile spasms and had a younger age at epilepsy onset. The age at epilepsy onset was also lower in abnormal *TSC1* carriers with truncated variants than among those with non-truncated variants.

So far, this genetic and clinical information has not been linked to treatment information. If the hyperactivation of the mTOR pathway

causes a progressive epileptogenic process, earlier treatment of TSC patients may be key. Disease modifying drugs may well have different effects in *TSC1* or *TSC2* carriers or among those with truncated and non-truncated variants. Hopefully we will know more soon!

Healthcare in forcibly displaced people

Over the last 30 years, the number of forcibly displaced people (FDP) has more than doubled to around 80 million worldwide. This development has coincided with increasing efforts by economically developed countries to close their borders to refugees. Two thirds of FDP come from one of five countries: Syria, Venezuela, Afghanistan, South Sudan and Myanmar [UNHRC, 2020].

All of these individuals will have to cope with the trauma of leaving their homes, the disruption of their sociocultural support networks and life in an alien environment. Many will also have to live with hostility from their host societies, and inadequate access to clean water, sanitation, sufficient nutrition and medical services. Those with nominal responsibilities for their well-being (like the United Nations High Commissioner for Refugees, UNHCR) are far away, have constrained resources and limited direct influence.

Many of the experiences FDPs are exposed to would be expected to increase the risk of both epilepsy and Psychogenic Non-Epileptic Seizures (PNES). Poor obstetric and emergency medical care, and a lack of access to neurological expertise, investigations, antiseizure medicines, antibiotics, antimalarials and antihelmintic drugs will all lead to higher rates of epilepsy. The deficiencies of medical services may be aggravated by a lack of interest in the fate of FDPs among developed nations. These deficiencies mean that information about the prevalence of important disabling neurological disorders, such as epilepsy and PNES, is scarce. Presumably, this is the reason why seizure disorders do not feature in the WHO's 2019 global action plan, 'Promoting the health of refugees and migrants 2019-2023' [World Health Organization, 2019].

My editor's choice from issue 92 of Seizure is a scoping review of studies about seizure disorders among FDPs by Asma Hallab and Arjune Sen. It strives to characterise the gaps in our knowledge and to answer questions about the prevalence, aetiology and consequences of epilepsy and PNES among refugees to the extent we can [Hallab and Sen, 2021]. This excellent synthesis of 56 research publications demonstrates that seizure disorders cause most medical emergencies among FDPs. It also suggests that the prevalence of epilepsy among FDPs is dramatically increased, although there a is considerable variability of the quoted prevalence figures. One study reported that 43.7% of female refugees with a history of sexual violence and 16.7% of women without this history had experienced PNES [Kizilhan *et al*, 2020]. Another study demonstrated that PNES generated even more medical emergencies than epilepsy among FDPs [Brinckmann *et al*, 2018].

Hopefully, this review will help to bring the neglect of FDPs with seizures out of the shadows. At the very least, it should alert its readers to the importance and urgency of exploring the great epileptological needs among refugee populations.

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34th IEC congress round-up

A round-up of some presentations from the 34th IEC

Kami Kountcheva summarises some presentations from the congress, discussing machine learning, mental health and suicidality.

The 34th International Epilepsy Congress was held virtually in August by the International League Against Epilepsy (ILAE) and the International Bureau for Epilepsy (IBE). The opening session saw outgoing ILAE President Prof Samuel Wiebe and outgoing IBE President Prof Martin Brodie welcome delegates to the congress. Their successors – Prof Helen Cross, ILAE President, and Dr Francesca Sofia, IBE President – also addressed the audience with their plans for their terms.

The congress spanned across five days and provided a forum for discussions on all aspects of epilepsy care and research. These included the value and challenges of telemedicine, progression in genetics research and understanding, treatment of status epilepticus, epilepsy surgery and much more. Despite not being able to meet in person, delegates and presenters were pleased to be able to share, network and discuss findings and ideas.

We summarise some of the many thought-provoking presentations from the sessions.

The machine learning era

Prof Margitta Seeck, professor in medicine, Geneva University Hospitals, Switzerland

Prof Seeck presented at the congress, looking at the future role of artificial

intelligence in drug treatment. She started off by saying that there is a big discrepancy between recorded and patient recorded seizures, and seizure diaries can be an unreliable record of seizure frequency. Prof Seeck posed the question: Can EEG spikes and electrical discharge biomarkers be used to assess anti-seizure medicine (ASM) effect?

Prof Kwan suggested the way to move from a trial and error method of prescribing ASMs would be through biological information, stem cell information and machine learning

Referencing a study by Baud *et al* 2018, Prof Seeck said there was evidence that seizures tend to occur at the onset or peak of rising electrical discharges. She said understanding people's specific seizure patterns could help us use ASMs more appropriately. She also referenced a De Stefano *et al* 2021 study, showing the role of spikes, or an increase in spikes, in an EEG in predicting seizures, and suggesting these could be an interesting feature to monitor ASM response.

Prof Seeck highlighted that machine learning is promising for utilising this data effectively and monitoring ASM response.

In conclusion, Prof Seeck said that preliminary work around using EEG features to monitor ASM response has been promising. She added that machine learning approaches are an exciting next step, using EEG and clinical data to train the models. However, she stressed that this preliminary work needs to be verified in early onset epilepsy patients and that good data will be needed for the machine learning models to be successful.

Prof Patrick Kwan, consultant neurologist, Monash University, Australia

Prof Kwan also spoke about machine learning's role in medicines. His focus was in a very similar vein to Prof Seeck, but rather than monitoring drug response specifically, he discussed moving from trial and error approaches of selecting an ASM for a patient, to personalised care.

We have developed many ASMs, especially in the last 20 or 30 years, but Prof Kwan noted that the treatment outcome hasn't improved, and the proportion of people with uncontrolled epilepsy hasn't changed. He suggested the way to move from a trial and error method of prescribing ASMs would be through biological information, stem cell information and machine learning.

Prof Kwan explained that machine learning models can be effective in predicting response to ASMs when using clinical information. When a combination of clinical and genetic information is integrated in a machine learning model, this gives the most effective predictions, but he said for resource-limited areas, clinical data alone is still useful. Prof Kwan added that in the future we could see neurons derived from a person's stem cells be used to screen for the most likely ASM to be effective from a library of ASMs, and prescribe this first.

Prof Kwan also warned that while machine learning holds a lot of potential to significantly improve the prediction of first ASM effectiveness, it needs to be properly studied and confirmed.

"The issue we have is of ASM selection rather than availability", Prof Kwan concluded, saying which to use still depends on "untested expert opinion" or trial and error. He reiterated that personalised models using machine learning for personalised ASM selection and stem cell-derived neurons for personalised screening of ASMs are still emerging. "We may be still yet to realise the full potential of the ASM options we currently have," he said.

Dr Carolina Ferreira Atuesta, clinical data manager, Icahn School of Medicine at Mount Sinai, US

The potential of machine learning doesn't end with predicting and selecting the best ASM for patients. Dr Ferreira Atuesta presented on the currently ongoing worldwide multi-centre project 'Withdrawal of Antiseizure Medication after epilepsy Surgery in adults' (WAMS).

There is no model currently for how and when to withdraw ASMs in adults after surgery, she explained. This means there is variability in the timing and strategies taken by healthcare professionals. Dr Ferreira Atuesta and the team have developed a prognostic model using data from 350 adults from nine epilepsy centres from six continents of the world. All

There is no model currently for how and when to withdraw ASMs in adults after epilepsy surgery, which means there is variability in the timing and strategies taken by healthcare professionals

participants had had resective epilepsy surgery, had been one year seizure free and had started ASM withdrawal after surgery.

Part of the team's project was to identify predictors for outcomes after ASM withdrawal following surgery, and they identified four:

- The presence of auras after surgery and before the beginning of ASM withdrawal
- Time to beginning of withdrawal
- Presence of generalised tonic-clonic seizures (GTCS) before surgery
- Number of ASMs at the time of surgery

The predictors informed the model the team developed, which showed good calibration and discrimination, as the predicted outcomes appeared very well matched with the real world outcomes. Dr Ferreira Atuesta explained that at two years after withdrawal, 20% of people had had a relapse in seizures and at four years this was 28%. At the end of follow up period studied, 32% had had a relapse.

The model is recalibrated with data from an individual patient on each of the four predictors. Estimates are developed based on the individual characteristics and then the model produces an overall number which gives a percentage chance predicted for remaining seizure free after withdrawal of ASMs.

The team wanted to increase the accessibility of the model, so they have made it available online at: *epilepsy.org.uk/predictepilepsy*

Dr Ferreira Atuesta concluded her talk, saying the team has provided an internationally validated tool to predict individualised seizure outcome following ASM withdrawal after epilepsy surgery in adults. She said that "this is the largest study on ASMs" and "it could inform people with epilepsy about the risk of seizure recurrence after ASM withdrawal and guide clinical decision-making on post-surgical ASM treatment".

Dr Christian Meisel, research group leader in Computational Neurology, Berlin

On top of providing new avenues for assessing and selecting epilepsy medicines, machine learning also holds a lot of promise for seizure forecasting and prediction. Dr Meisel, winner of the Epilepsia Clinical Science Prize, presented on his group's recent research. He discussed machine learning from wristband sensor data for wearable, non invasive seizure forecasting.

Dr Meisel concluded that his team's feasibility study shows that statistically significant seizure forecasting can be done with this machine learning model and that a non-invasive approach can work

Dr Meisel explained that seizure forecasting would be important for both people with epilepsy, and clinicians. The unpredictability of seizures is one of the biggest concerns for people with epilepsy, and an accurate record of seizures can be instrumental for appropriate treatment decisions. He added that currently, self reports have been found to be quite unreliable and yet treatment decisions and drug approval is still based on self reports of seizures.

Accurate forecasting of seizures could help people plan their daily activities around the likelihood of seizures, Dr Meisel said. Forecasting

could allow for treatment to be given when risk is high, minimising side-effects of high doses of ASMs. He added that a tool like this could also help with more objective diagnosis and getting a clearer picture of treatment response.

Seizure risk information can come from EEG data, but also other modalities, such as heart rate and heart rate variability, among others. Dr Meisel explained that data from other modalities, like ECG, can be explored to improve seizure forecasting.

The team's study aimed to find out whether wearable device data is feasible for use in machine learning to help forecast seizures. The modalities from wearable devices they looked at were electrodermal activity, temperature, blood volume pulse and accelerometry in 3D. Video EEG was recorded at the same time as the device was used, so that data could be identified and categorised into preictal (within an hour of a seizure) and ictal. The study included 452 seizures from 69 people.

The ILAE Psychology Task Force surveyed over 400 epilepsy healthcare professionals from 67 countries, and found that less than half of respondents felt they had adequate resources for screening for mental health and suicidality

An algorithm could be developed for a specific individual with this kind of data, with high accuracy for that person, Dr Meisel explained. But the team chose to develop an algorithm that could be applicable to new patients too, but which may not be as accurate. The effectiveness of the algorithm was significantly useful in about half of patients, with a 30 minute warning, which Dr Meisel said could be beneficial for administering fast-acting interventions. He added that the performance of the algorithm also increases with more data used in the training, so it has the potential to improve.

The researchers established that the algorithm used more than just the time of day to predict seizures, and that it was effective for focal as well as generalised seizures. Dr Meisel concluded that this feasibility study shows that statistically significant seizure forecasting can be done with this machine learning model and that a non-invasive approach can work. He said while it shows a lot of promise, more research is needed before it could be used in the clinic.

The full study can be found at *epilepsy.org.uk/epilepsiaoct20*

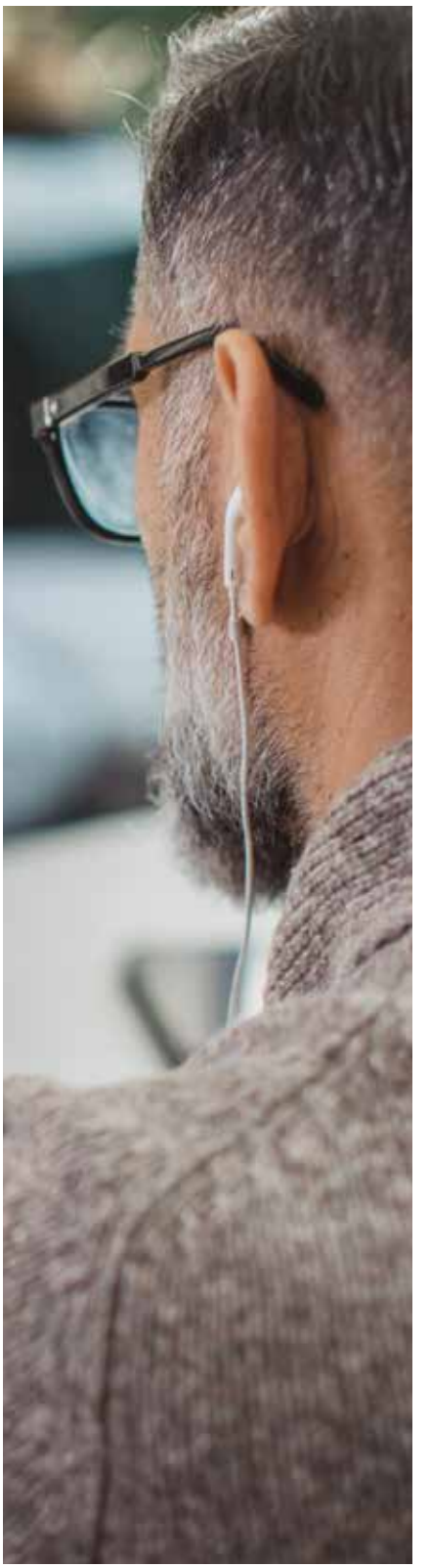
Suicide and seizures

Dr Milena Gandy, clinical psychologist, Macquarie University, Australia

The congress shone a light on suicide and seizures and its management in routine clinical care. Dr Gandy presented first in this session, discussing suicidality and mental health screening and management practices throughout the world.

Dr Gandy explained that the ILAE Psychology Task Force aimed at improving mental health outcomes for patients with epilepsy. The Task Force surveyed over 400 epilepsy healthcare professionals from 67 countries, with 89% of respondents being neurologists or epileptologists.

The survey revealed that less than half of respondents felt they had adequate resources for screening for mental health and suicidality, Dr Gandy



reported. She said 60% of respondents only screened for suicidality if a patient reported symptoms in relatives. She added that people weren't routinely screened, just those who bring it up, and research shows that the more depressed people are, the less likely they are to bring it up.

There is lack of clarity about whose responsibility it is to screen and manage mental health and suicidality in epilepsy, Dr Gandy continued. About 50% of respondents thought it was their responsibility to screen, but only a third felt responsible for the management and believed this should be the role of mental health professionals.

Dr Gandy said around three-quarters of patients had accessed mental health professionals or psychiatric medications, so this was a common issue for people with epilepsy. However, referral was only around 50%, and she added that there were "relatively high rates of watchful waiting, which is no longer considered good practice".

The barriers described in the presentation included lack of time for screening and referring, lack of standardised procedures and policies on this and not knowing who to contact. A lack of mental health professionals was also noted, especially ones who specialise in epilepsy. Dr Gandy said we need updated protocols, integrated supportive care models and trained mental health professionals in epilepsy settings. She championed the integration of mental health services in services for other conditions like cancer and HIV, and said we should be striving for something similar.

Dr Marco Mula, consultant neurologist, St George's University Hospitals, UK

Next, Dr Mula shared some practical advice about how to talk about suicide with adult patients in a busy epilepsy clinic. He started off reminding the audience that suicide is the 10th most common cause of death in all age groups. He stressed the importance of understanding the difference between the different terminology around suicide, as they represent a chain of events. He said

Dr Mula said that "suicide prevention should be everyone's job", adding that health professionals should know that suicide screening does not increase or induce suicidal thoughts in patients, but reduces them

35% of those with suicidal ideation make a suicide plan and 72% of those with a plan make a suicide attempt. Of those with suicidal ideation but without a plan, 25% make an unplanned suicide attempt. He highlighted that the majority of these transitions occur within the first year after onset of suicidal ideation (60% of planned and 90% of unplanned attempts).

Dr Mula explained that there are many challenges in screening for and tackling suicidality. These include stigma and discrimination, financial barriers, religious beliefs and cultural attitudes. There are also fragmented and poorly-integrated mental health services, lack of protocols and a lack of education for other health professionals.

Importantly, Dr Mula said that "suicide prevention should be everyone's job", adding that health professionals should know that suicide

screening does not increase or induce suicidal thoughts, but reduces them.

There are different instruments to assess suicidality, and Dr Mula explained that the PHD-9 and the NDDI-E tools both have a question (nine and four, respectively) which yields accurate results about suicide risk. He added that managing the risk when you get a positive screening result can be difficult for someone who is not trained, but there are steps which are useful:

- Caring – listen and attend to a person's distress
- Collaborating – identify existing coping strategies
- Connecting – have in place a clear clinical pathway

Dr Mula added that there is a guide at St George's University Hospital to managing people with epilepsy who have a high risk of suicide and there is a dedicated psychiatrist for this group of people.

Prof Modi and Dr Wagner suggested that yearly screening for mental health problems in all paediatric patients with epilepsy is important

Dr Mula acknowledged that this may not be the case everywhere, but said a pathway can still be developed with the resources that are available.

Prof Avani Modi, paediatric psychologist, Cincinnati Children's, US, and Dr Janelle Wagner, associate professor, Medical University of South Carolina, US

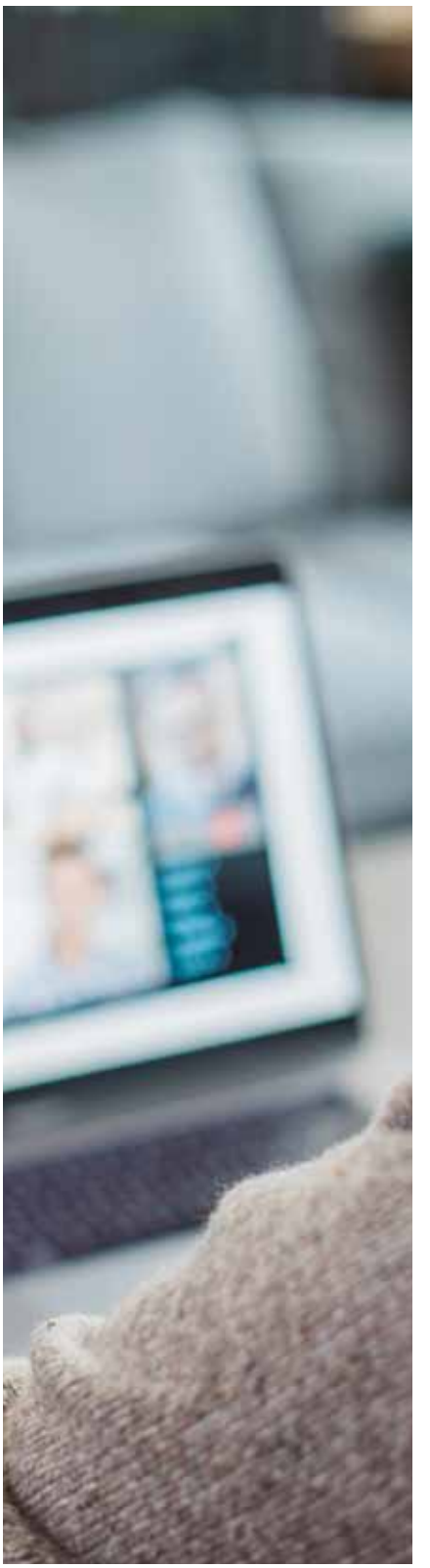
The final talk in the session came from Prof Modi and Dr Wagner. They presented on working with patients and families to recognise suicidal ideation in children with epilepsy. They began by saying that suicide is the second leading cause of death in young people. They added that evidence suggests that 14-27% of young people aged 7-17 years old with epilepsy had suicidal ideation, and that risk of suicidal ideation or attempt is 1.5x higher in those with epilepsy than those without.

They explained that adolescence is a vulnerable period, and that depression looks different in children. It might look like behavioural problems, irritability or talking about dying, for example. They added that risk factors of suicide attempts include comorbidities such as ADHD or anxiety, as well as substance abuse, previous attempts and past psychiatric hospitalisations, among others.

Prof Modi and Dr Wagner stressed that we need to adapt the language we use to be clear and easy to understand, and consider also adapting further for those with intellectual disability or developmental delays.

The speakers suggested that yearly screening for mental health problems in all paediatric patients with epilepsy is important. Those with risk factors, such as adolescents, patients with a mental health comorbidity, and patients with a long epilepsy duration, should be screened more often. Those who have had prior suicidal ideation or suicide attempts, or those with depression are considered very high risk patients. They said that protocol will depend on the particular healthcare setting, but it's key to identify who is responsible and use an appropriate method of screening.

The 14th European Epilepsy Congress is due to be held 9-13 July 2022 in Geneva, Switzerland.



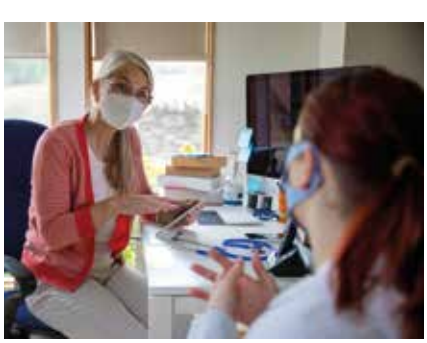
Discussion of side-effects: when, what and by whom?

The national issue of the adverse effects of sodium valproate on infant development and learning when taken furing pregnancy highlighted the importance of communication between doctors and patients. This has appropriately widened the discussion about when and how much to say about the potential adverse side-effects of anti-seizure (and in reality, all) medications, and who is responsible for these discussions.

During my medical training, I was taught that if I wrote a new prescription for a medication, I should discuss the reasons why I chose it and any possible side-effects (mild and serious). This discussion should be when the medication was prescribed, and it should be documented in the medical notes and in any correspondence. It is also my opinion that the patient or family should be given a written information sheet on the medication or a web address from where an information sheet could be downloaded. This sheet provides the relevant information in a more reader-friendly format than the Patient Information Leaflet (PIL) which is enclosed with each medication. The PIL is meant to be a 'patient-friendly' version of the medication Summary of Product Characteristics (SmPC). Both the PIL and the SmPC are written by the medication's manufacturer. Most PILs are long, often complicated and usually in small print. Information sheets for children are available at: www.*medicinesforchildren.org.uk*

A discussion about possible side-effects is important because it prepares the patient (or family in the case of a child) should one occur. Failure to do so might suggest to the patient that the medication is safe with no anticipated side-effects. In the event of a side-effect developing, this might have an adverse impact on the patient's or family's confidence in the doctor. It might also reduce patient concordance with not just that medication, but subsequent medications. Finally, failure to discuss the possibility of a serious side-effect might have medico-legal implications. In spite of these potential problems, a significant minority would argue that by proactively discussing even the most likely side-effects, it is to be expected that the patient will then report they have experienced them. This may lead to an unnecessary or premature discontinuation of the medication. However, the controversy over sodium valproate clearly illustrates the importance of clear and comprehensive communication. Consequently, there would seem to be no justification for withholding information on any anti-seizure medication's (ASM) potential side-effects.

I was also taught that if I prescribed a drug, then it was my responsibility to discuss its possible side-effects. Specifically, it was not the responsibility of any specialist nurse that might or might not be part of the hospital clinic team, the patient's general practitioner (GP) or the pharmacist. It is more likely that the consultant, rather than the nurse or pharmacist, would have the necessary information and knowledge about both the drug and the patient when writing the prescription. Pharmacists have a very important role in healthcare, but I would argue that this should not include a discussion of an ASM when it is first prescribed. This also applies to the GP. Predictably, some hospital doctors argue that such discussions are time-consuming and that they should more appropriately spend their time on seeing as many patients as possible. This may be short-sighted, because patients may refuse to take the medication after a discussion about possible side-effects with a pharmacist or GP. This may then require further time with the patient, or non-concordance with the medication, or both, which adds to the doctor's time. Finally, the use of a 'middle-man' to discuss possible side-effects increases the risk of mis-communication with all its inherent consequences. Clear and accurate communication is an important factor in good patient care.



Dates for the diary

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

2022

20-25 March
3rd International Training Course on Neuropsychology in Epilepsy
Bordeaux, France
bit.ly/3fae9rL

24-27 March
16th World Congress on Controversies in Neurology
London, UK
cony.comtecmed.com

10-13 April
EEG in the First Year of Life
Cambridge, UK and online
bit.ly/3oSA234

28 April - 2 May
14th European Paediatric Neurology Society Congress (EPNS)
Glasgow, UK
epns-congress.com/

14-15 May
ILAE British Branch 18th Specialist Registrar Epilepsy Teaching Weekend
Birmingham, UK
epilepsyteachingweekend.com

22-25 May
16th EILAT Conference on New Antiepileptic Drugs and Devices
Madrid, Spain
eilatxvi.com

25-28 June
8th Congress of the European Academy of Neurology (EAN)
Vienna, Austria and online
ean.org/congress2022

9-13 July
14th European Epilepsy Congress
Geneva, Switzerland
epilepsycongress.org/eec

2023

2-6 September
35th International Epilepsy Congress
Dublin, Ireland
bit.ly/30Spwk8

Next issue:

Dr Justin Strickland

Dr Strickland discusses managing artisanal CBD use in epilepsy care

Dr Helbig, Dr Lewis-Smith and Dr Thomas

Dr Helbig, Dr Lewis-Smith and Dr Thomas discuss the role of big data in supporting research and clinical care in epilepsy

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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