epilepsy action

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epilepsy professional

What's changed eight years on?
Findings from the third NASH audit

Pete Dixon | Mike Pearson | Claire Taylor | Tony Marson

Secure video sharing – Sameer Zuberi

Preconception care – Janine Winterbottom

Subtle seizures – Jacob Pellinen

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Welcome to the summer 2021 edition of *Epilepsy Professional*. I hope that life is returning to normal for all of you and the scars of the pandemic are starting to heal. Certainly with the success of the vaccination programme so far, we will be able to get back to improving the lives of our patients with epilepsy. To that end, this edition of *Epilepsy Professional* contains a number of excellent articles that will help us improve patient care.

Early recognition and treatment of epilepsy is very important in reducing morbidity and mortality. Dr Jacob Pellinen from the University of Colorado describes the impact of delayed diagnosis, particularly for non-motor seizures, and discusses how we might start to improve time to diagnosis for our patients.

The third National Audit of Seizure management in Hospitals (NASH3) is summarised by Pete Dixon *et al*. Disappointingly, it shows no real improvement in epilepsy care between 2011, when NASH1 took place, and 2018, when the data for NASH3 was collected. Their recommendations do help us to focus on areas of deficiency in the national and local service provision for our patients with epilepsy. Hopefully, this will help us all focus on improving our care pathways to ensure things do improve for NASH4.

One potential innovation that may help speed up care pathways and diagnosis is described in the article by Prof Sameer Zuberi. vCreate Neuro is a cloud based video sharing system developed by the team in Glasgow, that allows safe sharing of seizure videos with healthcare professionals to aid rapid diagnosis.

Managing the risks of sodium valproate in women with epilepsy is now embedded in our practice, but Dr Janine Winterbottom describes how variable our preconception care for women with epilepsy is. To help close this gap and establish best practice and a platform for improvement, she and her collaborators have set up a Delphi consensus study, which is further described in her article. Please, read the article, express interest and pass on information to your patients to take part in this important study.

Enjoy this edition and I wish you all a happy and (hopefully) COVID-free summer.

Seán Slaght
Consultant neurologist
Executive medical adviser
Epilepsy Professional

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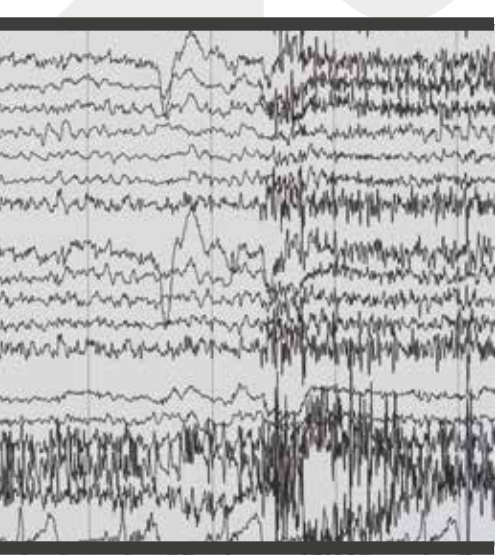
preconception care

Janine Winterbottom

Dr Janine Winterbottom describes the mixed-methods Delphi study to develop a preconception care pathway for women with epilepsy



As you are reading this, we are likely on the precipice of a UK with no restrictions. The government has set 21 June as the day all COVID-19 pandemic restrictions will be lifted – the final step in the Prime Minister's roadmap to the end of restrictions. But, with the new variant spreading and experts warning against lifting all restrictions too early, it's clear we're not our of the woods yet.

As we are still reeling from the repercussions of the pandemic, Prof Sameer Zuberi shines a hopeful light with his article on the vCreate Neuro system on page 14. This system allows secure video sharing, so patients can send potential seizure evens to specialists and have them reviewed quickly. With epilepsy services having been impacted by the panedmic, this new tool can help streamline and speed up patient care.

Delivering the best possible service to patients is always at the fore of our work – pandemic or no pandemic – and the rest of the articles in this issue of *Epilepsy Professional* aim directly at that. On page 10, you can read the findings of the latest NASH audit around seizure management in hospitals, and suggestions for next steps towards improvement. Dr Janine Winterbottom discusses a new mixed-methods Delphi study she is undertaking hoping to develop a preconception pathway for women with epilepsy – you can read more on page 20. And on page 28, Dr Jacob Pellinen describes reasons why subtle nonmotor seizures may result in missed diagnoses and ways to bridge this gap.

Whatever the next few months brings in terms of restrictions, we hope you have a restful and restorative summer.

Kami Kountcheva
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Registry finds pregnant women were prescribed valproate

Findings from a new registry of valproate use in pregnancy show 180 women were prescribed valproate in a month in which they were pregnant, between April 2018 and September 2020.

NHS Digital and the Medicines and Healthcare products Regulatory Agency (MHRA) are developing Medicines in Pregnancy Registries to monitor the use of medicines like valproate in pregnancy.

Valproate is a very effective epilepsy medicine, especially in genetic generalised epilepsies. However, it is well known to also have teratogenic effects if taken in pregnancy.

The Independent Medicines and Medical Devices Safety (IMMDS) Review carried out on three medical products concluded that a registry should be set up to monitor the effects of epilepsy medicines used during pregnancy.

The MHRA has said that valproate should not be prescribed to "any woman or girl able to have children unless she is supported by a Pregnancy Prevention Programme (PPP)". The Medicines in Pregnancy Registry on valproate is looking to monitor the changing use of valproate in women and the implementation of the PPP.

Within the reporting period, 47,532 women and girls were prescribed valproate for a health condition for one or more months. In September 2020, the majority (89%) prescribed valproate were aged 16-54 years.

Despite guidance from the MHRA around avoiding prescribing valproate to women or girls being published in 2018, 180 women were subsequently prescribed valproate while they were pregnant. This is out of 462 women or girls who had conceived over the reporting period.

However, the findings also showed that there was a general decrease in prescribing of valproate during the reporting period. From the start of the reporting period to the end, there were 5,353 fewer prescriptions for valproate in women and girls.

There were also fewer 'new starters' – women and girls who had not been prescribed valproate in the previous 12 months – in September 2020, compared with September 2019. Also, 238 women and girls had their valproate prescription changed to another treatment before they became pregnant.

Louise Cousins, director of external affairs at Epilepsy Action, said: "This new register, while very welcome, has highlighted that some women are still being prescribed valproate while they are pregnant. This is extremely concerning.

"Women with epilepsy face complicated decisions if they become pregnant or wish to start a family. They need access to pre-conception counselling, as well as more support with family planning, so that they are supported and able to make informed decisions about their care."

Recent findings suggest that more epilepsy medicines than just valproate can cause teratogenic effects. The Department of Health and Social Care has said it will extend the registry to include women prescribed all epilepsy medicines in the next phase of its development.

NICE updates cannabis medicine guidelines

The National Institute for Health and Care Excellence (NICE) has made a clarification to guidelines around clinicians prescribing cannabis-based medicines.

The clarification has come after the parents of three-year old Charlie Hughes, who has severe epilepsy, made a legal challenge over the guidelines.

The amended guidance includes a section called 'Interpretation of the guideline'. This says that at the time the guideline was published, NICE did not believe there was enough evidence to support a "population-wide practice recommendation".

"The fact that NICE made no such population-wide recommendation should not, however, be interpreted by healthcare professionals as meaning that they are prevented from considering the use of unlicensed cannabis-based medicinal products where that is clinically appropriate in an individual case," the update says.

"Patients in this population can be prescribed cannabis based medicinal products if the healthcare professional considers that that would be appropriate on a balance of benefit and risk, and in consultation with the patient, and their families and carers or guardian.

"There is no recommendation against the use of cannabis-based medicinal products."

Further recall of neurology patients in NI reveals more cases of misdiagnosis

About one-fifth of patients recalled by the Belfast Trust in Northern Ireland, as part of a second group, have needed a change in diagnosis and treatment, a review published on 20 April has shown.

Around 2,500 patients treated by Dr Michael Watt were recalled in May 2018 after concerns were raised by other doctors about his treatment plans and diagnoses.

A second group of 1,044 people, treated by Dr Watt between 2012 and 2017, was recalled for review in October 2018. This group of patients had either been discharged back into the care of their GPs, or had been discharged and then referred back to neurology services by their GPs. It includes people prescribed epilepsy medicines.

The recall intended to review whether these people had been given a correct diagnosis and whether their treatment and care plans were appropriate. The review found that out of 927 patients, 181 (19.5%) did not have a 'secure diagnosis' and review clinicians were 'uncertain' about the diagnosis of a further 44 people (just under 5%).

While a 'not secure' diagnosis did not automatically mean misdiagnosis, the majority of people in this category received a new diagnosis. Also, for the majority, the original prescribed treatment was not deemed appropriate.

Northern Ireland Health Minister Robin Swann made a statement to the assembly to deliver the findings. He made an apology to the people affected by the situation, adding: "I know that many [people] will have had their confidence in our health service shaken and I remain committed to helping to restore it."

Carla Smyth, Northern Ireland manager at Epilepsy Action, said: "This announcement highlights that three years on from the first patient recall, even more people have been impacted by unsecure diagnoses. While epilepsy is a difficult condition to diagnose and misdiagnosis does occur, the nature of these misdiagnoses and the ongoing uncertainty for many people is particularly concerning.

"It is right and proper that others who were previously under the care of Dr Watt have now also been recalled. Both recall groups 2 and 3 include people who have been living with an incorrect epilepsy diagnosis for many years. They will have been taking epilepsy medicines that were of no benefit to their health but that could have had potentially damaging side-effects.

"Epilepsy Action Northern Ireland has heard first-hand about the impact of the recall on those affected. It is vital that appropriate support, including mental health support, is made available to those who have been caught up in this process.

"While this is a seemingly isolated case relating to a particular neurologist, it is hard to ignore the context of overstretched and under pressure epilepsy services in Northern Ireland. It is vital that the various inquiries and reviews associated with the recall are completed as a matter of urgency and that recommendations for improvements are fully implemented and funded.

"Lessons must be learnt, and services must be appropriately supported so that people with suspected and diagnosed neurological conditions receive the care and support they deserve. A situation like this must never happen again."

A third group will be reviewed next, which includes people treated by Dr Watt between 1996 and 2012 and young stroke patients who had not been reviewed as part of the previous groups. People affected have already been contacted. Initial review consultations will be held virtually and clinicians will then decide if a face-to-face appointment is needed. A patient helpline has been set up for those affected, and can be reached at 0800 980 1100.

Mr Swann added that a redress scheme was set up in 2018 to provide compensation to people affected by the "negligent care" of Dr Watt. While its development was paused in 2020 due to the pandemic, work on it is restarting again.

Other reviews will also be carried out on patients of Dr Watt who had died in the 10 years before the recall and more generally on neurology services in Northern Ireland.

MPs hear about maternal deaths and epilepsy medicines in pregnancy

Maternal deaths in epilepsy and the effects of epilepsy medicines when taken during pregnancy were the focus points of the latest All-Party Parliamentary Group (APPG) hosted by Epilepsy Action.

The Zoom meeting, held on Monday 22 March, was chaired by Valerie Vaz MP and Yasmin Qureshi MP. Together with SUDEP Action, Epilepsy Action is co-secretariat of the APPG on Epilepsy.

Professor Marian Knight presented the findings of the MBRRACE report into maternal deaths in epilepsy. MBRRACE (Mothers and Babies: Reducing Risk through Audits and Confidential Enquiries in UK) published the report 'Saving Lives, Improving Mothers' Care 2020' in January this year.

The report examines the care received by UK women who died during or up to a year after pregnancy.

The national inquiry investigated 547 maternal deaths, finding that 22 women with epilepsy died during pregnancy, or up to a year after, during 2016-18, compared with 13 women with epilepsy in 2013-15.

Sudden unexpected death in epilepsy (SUDEP) was the main cause of death in 15 of the 22 women, and four of the women were not taking epilepsy medicines. Very few of the women had documented pre-pregnancy counselling. Epilepsy Action has called for all women with epilepsy to receive pre-conception counselling and family planning advice so that they can make an informed decision about their medicine, and will continue to do so.

Professor Knight's presentation was followed by Jane Hanna, CEO at SUDEP Action. Jane Hanna also discussed the MBRRACE report, and concerns that the risk of SUDEP are not properly communicated to women with epilepsy.

Sarah Mee, the senior medical assessor at the Medicines and Healthcare Products Regulatory Agency (MHRA), shared the work the MHRA is doing to communicate the risks of taking certain epilepsy medicines in pregnancy. This included communicating the findings of the recent CHM review on epilepsy medicines, and work to establish the valproate registry.

Following these two presentations, the APPG heard from a number of leading clinicians about what next steps need to happen to ensure that the issues raised are addressed. This included further research into epilepsy medicines, more epilepsy nurses and more funding for epilepsy services.

There was also a powerful and important story from Joanne Doody about her son Peter who died due to SUDEP at the age of 21.

APPG chair Valerie Vaz has written to the Department of Health and Social Care to outline the key points raised during the meeting. She has asked Health Secretary Matt Hancock to attend a future APPG meeting to address these points.

Almost 50 representatives attended, including patient groups, clinicians, researchers, MPs and Peers.

Broader effect of epilepsy

One in four (23%) members of the general public believe epilepsy has no impact on a person's life aside from having seizures, a new poll by Epilepsy Action has revealed.

The poll was carried out to mark Purple Day, the international epilepsy awareness day celebrated on 26 March. It showed more evidence of a disconnect between the reality of living with epilepsy for many people and the perception of it by the general public, Epilepsy Action explained.

Side-effects of epilepsy medicines, memory problems and impacted mental health are just some of the things that can affect people, the organisation said.

One third of people surveyed said they believe epilepsy does not impact a person's mental health. In addition, two-thirds of people agreed with the suggestion that people "just need to be more positive when living with health conditions".

As well as this, two-thirds of respondents said they would be afraid to even witness someone having a seizure. These findings are in contrast to a second Epilepsy Action poll, asking people with epilepsy for the one thing they wish people knew about the condition. The results show that nearly half of the respondents wanted wider understanding of the fact that epilepsy is about more than seizures. One in five people (20%) said their biggest wish was for better awareness that there are many different types of seizures. People also said they wanted more understanding that not all seizures are triggered by flashing lights and that epilepsy is a fluctuating condition.

Employment and pay gap raised at Select Committee

Only a third (34%) of people with epilepsy are in employment and those in work are paid on average 11.8% less than non-disabled people, the Work and Pensions Select Committee heard yesterday.

The Select Committee, held on 28 April, involved 11 MPs speaking to a number of organisations, including Epilepsy Action, about the disability employment gap. Select Committees consider policy issues and government work, and look at proposals for new legislation. The Work and Pensions Select Committee is currently carrying out an inquiry into the disability employment gap, and will publish a report with its conclusions.

Epilepsy Action shared findings from research conducted by the Institute of Employment Studies on employment support for people with epilepsy. The charity also gave evidence on the first-hand experiences of people with epilepsy.

The organisation raised the need for specific targeted support to help people with epilepsy find and stay in work. Current support schemes have fallen short, Epilepsy Action explained, as employment rates for people with epilepsy have fallen from around four in 10 people (42%) in employment in 2008 to around three in 10 (34%) in 2021. The disability employment gap has also remained at around 30% since 2013, with around half of disabled people in employment (52.3%) compared to over four in five non-disabled people (81.1%).

Epilepsy Action said this shows a need to reform existing employment schemes and introduce mandatory reporting on the disability employment and disability pay gaps. The barriers for people with epilepsy getting and staying in work, including a lack of understanding of the condition among employers, were also raised with MPs. The effects of the pandemic were also shared with the committee.

Daniel Jennings, senior policy and campaigns officer at Epilepsy Action, who spoke at the Select Committee, said: "We can see that not only are people with epilepsy less likely to have a paid job than their non-disabled peers, but when they do, they earn less. From previous surveys, we know that more than one in four employees in the UK would be wary of working with a colleague who has epilepsy. We also know that a majority of UK employers would not know how to help a co-worker having a seizure.

"Many of the existing employment support schemes, especially those launched during the COVID-19 pandemic, are far too generic. They don't include specific support for people with epilepsy and those with other disabilities. Mandatory reporting on the disability employment gap is needed, including reporting for specific conditions to help identify where there are specific employment problems.

"As well as reforming the current support available, it is also vital that the government better communicates the support available. More support is also needed to help people stay in work once they are in employment."

Epilepsy Action offers online and face-to-face training around seizure first-aid, and has recently launched an employer toolkit to help employers support employees with epilepsy.

Employer Toolkit launched

A new Employer Toolkit has been launched by Epilepsy Action to better support people with epilepsy in the workplace. This follows what the charity calls "a dire need for more understanding of the condition" at work.

The Office of National Statistics reports that only a third of people with epilepsy of a working age are in employment, and are paid on average around 10% less than their peers.

One major barrier for people with epilepsy to get and stay in work is a lack of understanding around the condition, Epilepsy Action said. A 2016 YouGov survey showed that 26% of respondents were concerned about working with someone with epilepsy. Of those, 63% said it was because they didn't know how to help a colleague having a seizure.

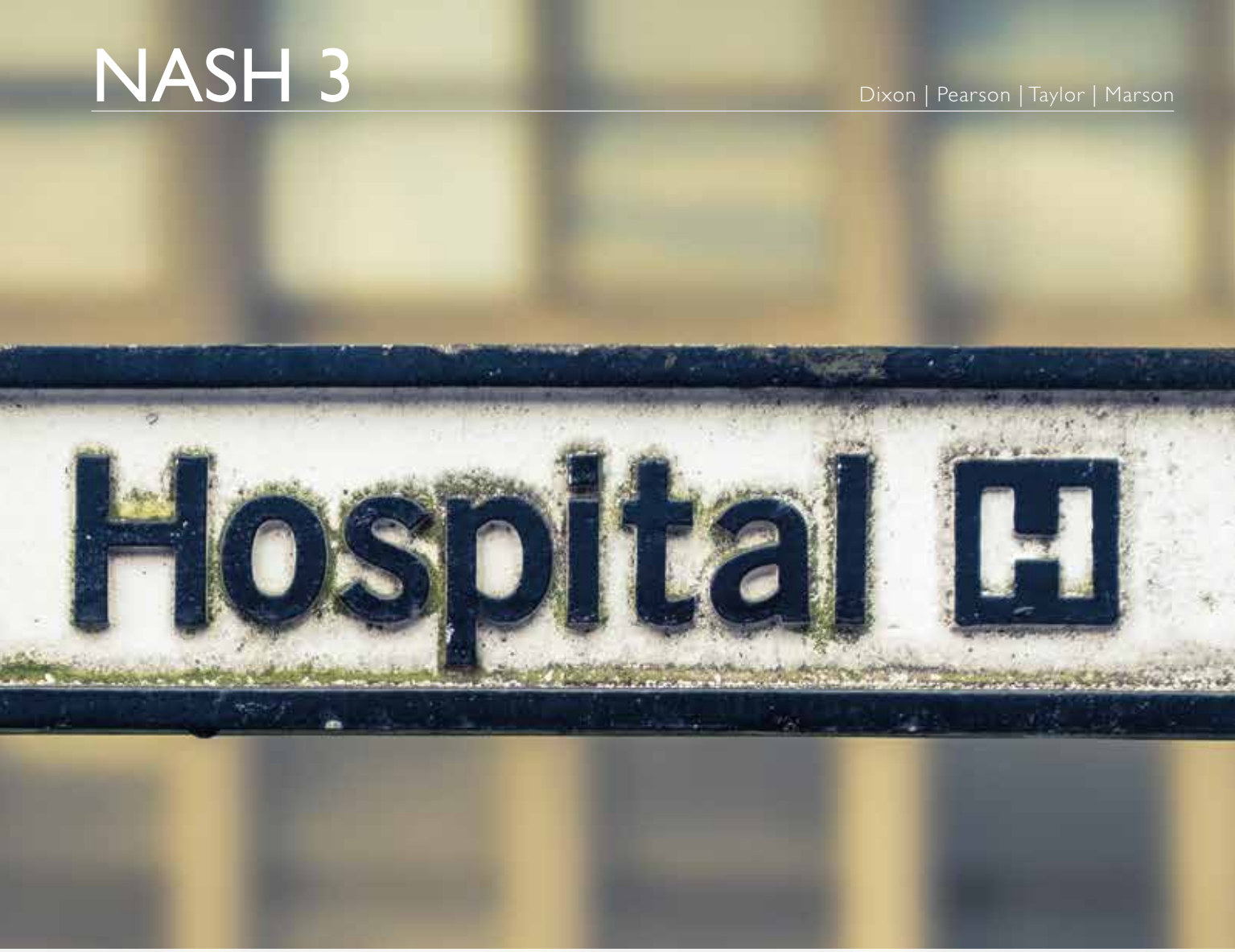
People with epilepsy report being humiliated in front of colleagues, demoted, redeployed or even made redundant because of their epilepsy.

The new toolkit is designed to give employers the confidence to help staff with epilepsy. It includes templates to provide support, assess risks and talk about epilepsy. It also offers descriptions of a range of different seizure types, as well as access to detailed first-aid videos.

The toolkit aims to encourage better communication between employees and employers to allow better support and reasonable adjustments to be made.

The toolkit is available at: ***employers.epilepsy.org.uk***

Dixon | Pearson | Taylor | Marson



What's changed eight years on?

Findings from the third National Audit of Seizure management in Hospitals (NASH)

Dr Pete Dixon, Prof Mike Pearson, Claire Taylor and Prof Tony Marson, on behalf of the NASH Steering Committee, discuss the findings from the third NASH audit.

The National Audit of Seizure management in Hospitals (NASH) was established in 2010 by two professors based at the University of Liverpool. Prof Tony Marson and Prof Mike Pearson proposed collecting data that could evaluate whether the care given to people with epilepsy was good enough. Despite being the most common serious, long-term neurological condition (with around 600,000 people in the UK having the diagnosis), epilepsy is not high on the commissioning agenda for the NHS. That means it can often be ignored for funding, left behind higher profile conditions such as cancer, heart disease, diabetes and stroke. Epilepsy is a very worrying condition for patients and the public, but with good care, it can be better controlled and the risks minimised – benefitting both patients and the NHS.

Attending an emergency department (ED) with a seizure is a clearly identifiable point in a person's clinical pathway, and one where epilepsy control has failed (or is yet to begin). Lessons learned from national audits in other conditions showed the need to define the population of interest and identify some very simple, specific objectives. With this in mind, NASH identified adults who had attended an ED with a seizure as the entry point to the audit. Guided by a Steering Committee comprised of healthcare professionals and patient groups, a suite of data items were collected to assess the process and outcomes of care prior, during and after the ED attendance.

While NASH uses an ED attendance as the starting point, it is important to note that the audit covered the whole care pathway, as we were able to assess previous and onward care. When someone with epilepsy attends an ED with a seizure, there is an opportunity to put a plan in place to ensure specialist intervention and follow-up. This will most commonly require out-patient appointments in neurology services. It is neurologists and epilepsy specialists that have the expertise to ensure that treatments and strategies are put in place to maximise seizure control. This, in turn, can help to reduce the need for ED attendance due to seizures. For almost a fifth of those attending the ED with a seizure, it is their first episode. They need timely assessment to identify a possible cause and to get advice about any treatment that might be required, as well as the risk of future seizures, driving and employment.

The results of the first two rounds of NASH in 2011 and 2013 clearly showed sub-optimal levels in many aspects of care, as well as wide variability across sites

The first two rounds of NASH took place in 2011 and 2013, collecting data on almost 8,300 ED presentations across the UK. The results from these initial two rounds clearly showed sub-optimal levels in many aspects of care, as well as wide variability across sites. Bespoke reports were provided for all participating sites and overall reports published. Moreover, the findings of NASH directly informed the NICE quality standards for epilepsy in adults and in children. They were also presented at both the All Party Parliamentary Working Group on epilepsy and the Northern Ireland Assembly. At more local levels, the results of NASH helped sites develop new care pathways and identified the need for epilepsy nurses.

It was against that background that a third round of the audit, NASH3, took place in 2018, hoping to be able to demonstrate that there had been

improvement since the first two audits. This again audited the care and onward referral of seizure-related ED presentations. Over 85% (137) of eligible EDs in hospitals across the UK took part, recording data on over 4,100 presentations. While there were slight improvements in some care items, the overall message was disappointing in that very little had changed over the eight years between NASH1 and NASH3. Epilepsy care remains inadequate.

Key findings

The findings pinpoint issues and variability in epilepsy services, hospital care provision and resource use.

- Access to, and the coordination of, epilepsy services in the UK is inadequate
- At hospital level, there is wide variation in performance concerning the ED, acute medicine and ward care between sites
- Use of CT scans is often excessive
- Fewer than a third of people were given advice and information about future seizures

Some of our key findings also showed that many of these episodes could have been prevented if opportunities to improve treatment hadn't been missed.

- Two-thirds of patients were on inadequate epilepsy medication that might be improved upon
- Half of people with known epilepsy had not seen an epilepsy specialist in the previous year

The audit also showed that ongoing care was a particular concern.

- A third of patients with a suspected first seizure were not referred onwards to any neurological or specialist clinic. Those that were referred waited, on average, twice as long as the NICE recommendation of two weeks for their appointment
- 60% of those with established epilepsy were not referred onwards
- People aged over 60 were significantly less likely to be referred to neurology than younger people. This is a particular concern when considering the fact that around one in every four people who are newly diagnosed with epilepsy is in this age group

A number of issues were identified in the first two NASH audits which had significant impacts on quality of care and service provision guidance. It is concerning that, a decade on from the first audit, there has been little improvement in the care of people with seizures. Failings remain both within the emergency setting and in the wider care pathway. There is a pressing need to remove the revolving door that sees patients going back to their local hospital with seizures, in some cases, many times. We need to reconfigure how we manage these patients. Better clinical pathways are needed between hospitals and community services to

It is concerning that, a decade on from the first audit, there has been little improvement in the care of people with seizures – failings remain both within the emergency setting and in the wider care pathway

enable referrals to the appropriate neurological support available. This can be done but requires re-educating staff, underpinned by reconfiguration of services to provide a systematic approach across the health service to

ensure continuity for patients. Some initiatives are underway and should help. One is the NHS England initiated work on 'Optimum Pathways', supported by the Neurological Alliance, Epilepsy Action and SUDEP Action. Another is the NHS Getting it Right First Time (GiRFT) Neurology programme, although this focusses heavily on neurology services rather than integration of care across services.

With the treatments currently available and with good care, epilepsy can be better controlled and the risks minimised, allowing people to get on with their lives. But when control breaks down, the health system needs to have a co-ordinated response that controls the acute episode and, just as importantly, gets the person to the specialists who can help them.

Our key recommendations to improve the clinical service provided to patients by the NHS are:

- Develop improved clinical pathways to join up services between neurology, emergency and primary care
- Ensure primary care identifies frequent emergency department attenders and seeks advice from neurology or refers patients on appropriately
- Increase local neurology clinics and community services so they can offer help and act as a service hospitals and GPs can refer patients to, post the emergency presentation
- Increase education of ED staff, general practitioners and paramedic staff in management of patients experiencing a seizure, and in ways to coordinate care
- Fund further research to investigate and help put in place the best treatment pathways for seizure patients during their ED attendance. This should include more information on when to and when not to use brain scans (eg CT)
- Ensure useful information is provided about epilepsy and how the person and family can safely manage the condition. This will help enable them to gain maximum benefits from these coordinated systems

We hope our recommendations will be considered and appropriately resourced so they can be adopted by the NHS and its staff. The recommendations are wide-ranging and, if the needs of people attending an ED with a seizure are to be met, care must be coordinated across the health service. This includes ambulance services, EDs, hospitals, primary care and epilepsy specialists. These recommendations cannot be done overnight and will take time. But this report is evidence that the journey to improved treatment for those with epilepsy needs to start now.

We are very grateful to all the sites that took part in the audit and for the high quality of data submitted. Our thanks also to UCB, who funded the audit (through an educational grant) without requesting any input into the content or analysis.

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Further reading

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Sameer Zuberi

Secure video sharing

Experience from a multi-centre UK pilot

Prof Sameer Zuberi reviews vCreate Neuro – a secure, cloud-based, video sharing, storage and classification service for epilepsy diagnosis and management

As readers of *Epilepsy Professional* know, the diagnosis of epilepsy is challenging. It has been long accepted that diagnosis should be made by an individual with training, experience and expertise not only in epilepsy but in all the paroxysmal disorders which can mimic epilepsy. In the United Kingdom, there are relatively few neurologists, paediatric and adult, per head of population and even fewer of those would claim to be epilepsy experts. This is one of the reasons that misdiagnosis rates reported in the literature are worryingly high, varying between 25-50% [Dobson, 2006].

The paroxysmal and unpredictable nature of seizures means that the mainstay of diagnosis has been the taking of an oral history from the person affected and a witness. History taking is a skill acquired with training and experience but even a senior clinician can struggle to make the correct diagnosis from a history alone.

Only one in four of the 40 million people with epilepsy living in low and middle-income countries receive treatment as their access to clinicians with knowledge of the condition is even more limited. A diagnostic and treatment gap exists for people with epilepsy wherever they live.

Everyday technology, harnessed in an innovative way, provides an opportunity to close the diagnostic and treatment gap

Everyday technology, harnessed in an innovative way, provides an opportunity to close this gap. There are 3.5 billion smartphones in the world, all with video capability. People with epilepsy and their carers have been using this technology for years to help their clinical teams, and there is evidence from published small series of the clinical utility of patient/carer recordings [Dash *et al*, 2016; Tatum *et al*, 2020].

Videos are brought into clinic on the phone and on USB sticks, patients and families set up private video sharing platforms and try to email videos. Hospitals have not been equipped or willing to deal with the clinical governance and security around transfer and storage of parent/carer recorded clinical videos. This has proven a frustration to our team in Glasgow and many others around the country, but a confluence of circumstances has allowed us to finally – and successfully – overcome these challenges.

vCreate Neuro pilot

In 2016, a service was developed by the neonatal service in Glasgow, in partnership with technology company vCreate Ltd. This was created to send videos of babies in the hospital to their parents when they could not be with their child. Nurses take videos on secure tablets and these are uploaded to the vCreate cloud server where they can be accessed by families. These are videos highlighting positive experiences; the first feed, a

baby off the ventilator, a nappy change, all serving to promote family integrated care.

This vCreate Diaries system has been very successful and is now in over 200 neonatal, paediatric and adult ICUs. Critically for the development of vCreate Neuro, the Diaries service fulfilled all security and governance protocols required by UK and EU legislation. NHS services considered and approved this use-case for video transfer and storage perhaps because the videos were not considered 'clinical' in the same way a video being used for diagnostic purposes would be.

In 2019, the neuroscience and neonatology teams in Glasgow began to discuss whether we could use the same secure platform to send videos the opposite way. That is, into the hospital from the family, for diagnostic purposes and clinical management. At an early stage, we engaged directly with families and colleagues in Epilepsy Scotland, who were very supportive.

The COVID-19 pandemic from early 2020 provided challenges to regular clinic review and an opportunity to develop new ways of working. There was a 'can do' attitude from colleagues in management and Information Governance, not to minimise or compromise processes but to assess innovations rapidly and efficiently.

vCreate Neuro was developed and designed by the Paediatric Neurosciences Service at the Royal Hospital for Children, Glasgow, in partnership with vCreate Ltd. and supported by the West of Scotland NHS Innovation Hub and clinical colleagues elsewhere in the UK, notably Edinburgh Paediatric Neurosciences. Pilot funding for the project, from COVID-19 mitigation funds, was awarded by Scottish Government Technology Enabled Care in March 2020. The system was rapidly implemented and rolled-out to all paediatric and adult neurology services in Scotland, with the first patient registered and video uploaded in Glasgow on 1 May 2020.

Users are securely invited to register and can upload videos with structured data linked to pre-determined questions related to modifiable pathways, for example, epilepsy and paroxysmal disorders or movement disorders. Clinicians can log in to the cloud-based service from any device, and view the video and metadata. They can classify the events using modifiable dropdown and free text options. Data can link directly to the electronic patient record.

Users of vCreate Neuro are invited to register and upload videos with structured data linked to pre-determined questions related to modifiable pathways, for example epilepsy

Communication with users is also possible directly through the service with the ability to translate text to multiple languages. Clinicians can invite second opinions through the system and, in Scotland, tertiary clinicians can access systems in district hospitals to provide rapid opinions.

A clinician-to-clinician service will allow videos to be taken by clinicians in newborn intensive care units (NICU), paediatric ICUs (PICU), adult ICUs, the emergency room (ER) and wards, and shared with colleagues. A screen capture service allows easy transfer of video-EEG clips. Other

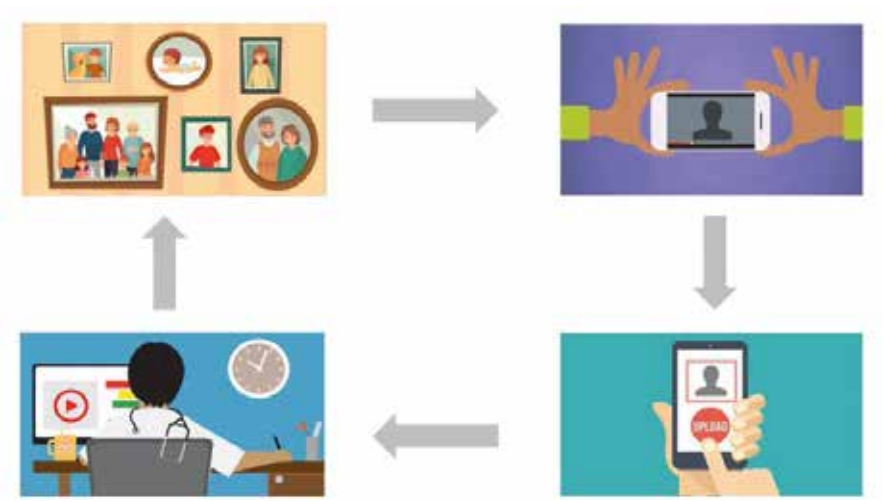

Figure 1. The vCreate Neuro pathway, allowing secure video sharing

features, including a seizure diary, will be added in 2021. The system has evolved significantly in the last year. vCreate has added features and pathways as suggested by clinicians. This agile design from the bottom up as suggested by users has been an important contributor to the rapid engagement from clinicians, patients and carers.

Future funding is secured in NHS Scotland for teaching and district general hospitals. The service has extended to many adult and paediatric teaching hospitals in England including Great Ormond Street, London Evelina Children's Hospital, Oxford University Hospitals, Sheffield, Newcastle and many more. Full local language localisation will be available by end of Summer 2021 and several international pilots are planned.

Since 1 May 2020, more than 2,200 patients have used the service, uploading over 5,500 videos, with over 350 clinicians registered to use the system in the UK. Health Improvement Scotland is undertaking an evaluation of the service. Preliminary data suggest that more than 95% of users are highly satisfied with the service. More than 95% of clinicians report that the system speeds up the diagnostic process, makes it more accurate, and prevents unnecessary clinic visits and investigations, as well as helping prioritise relevant investigations. It is likely that this new way of working will provide clinical benefits, economic benefits and other impacts, including reducing the carbon footprint of health services. The ability to search for videos of particular seizure types and non-epileptic events with consent for teaching has significantly benefitted epilepsy training.

A clinician-to-clinician service will allow videos to be taken by clinicians in NICU, PICU, adult ICUs, the ER and wards, and shared with colleagues

A linked neurology video research database has received National

Research Ethics Service approval in the UK. Epilepsy Research UK has awarded an Innovations in Healthcare Grant to support a detailed health economic and clinical benefit evaluation. With the video database growing by 600-800 uploads a month, we plan to assess if carer-recorded videos can be used to develop machine learning algorithms for seizure types and non-epileptic events.

vCreate Neuro has received national media interest related to clinical benefit in the UK and internationally, with pieces on BBC Breakfast News and BBC World Service Radio (vcreate.tv/media).

vCreate Ltd and the clinical team aim to offer the system without cost to low and middle income settings as it has the potential to facilitate access to specialist clinicians and to promote teaching and research. In Scotland, the system is used equitably across all socio-economic groups and in urban and remote areas.

Following on from video transfer for the Diaries service, neurology has been at the vanguard of the development of secure clinical video management. This is now likely to extend to many other fields of clinical practice.

Illustrative case study

During the first lockdown in May 2020, a GP from a rural location 100 miles from Glasgow contacted the department with concerns about abnormal movements in an eight-month-old infant. The baby appeared well in between episodes. Only emergency patients were being admitted to hospital and seen in clinic.

The family were rapidly registered for vCreate Neuro. That same day, they uploaded videos which were viewed by the neurology team. The unknown movements were diagnosed as infantile spasms, a feature of a potentially severe developmental and epileptic encephalopathy. Within 24 hours, the child had an EEG, which was severely abnormal and was commenced on steroids and vigabatrin.

The infant responded well to the treatment with resolution of EEG abnormalities and spasms. Subsequent development has been normal.

Delayed diagnosis and treatment of infantile spasms can lead to lifelong learning disability. Over the next few months, the family uploaded other videos to the system of movements which were worrying them. The clinical team were able to reassure them that these were normal infantile behaviours therefore saving the family the 200 mile round trip to Glasgow and unnecessary tests.

NHS Greater Glasgow & Clyde as the clinical service in which vCreate Neuro was developed receive a discounted cost from the technology provider.

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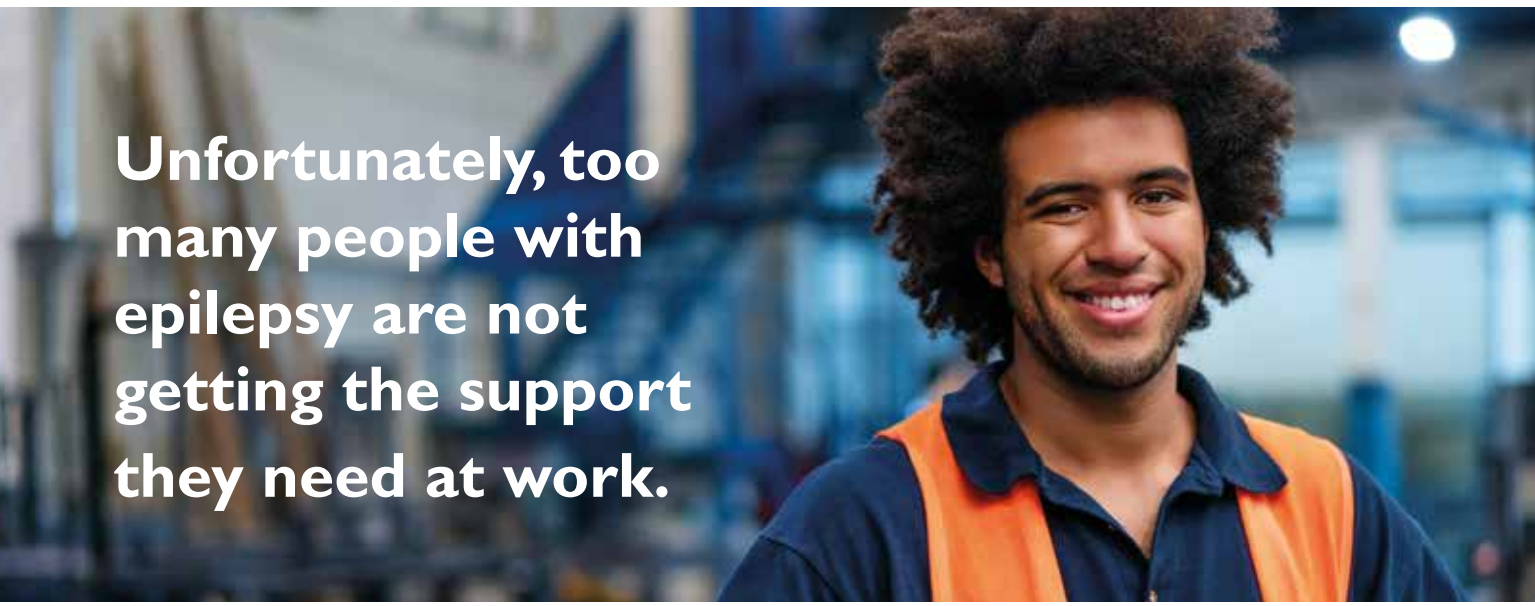
epilepsy action

employers.epilepsy.org.uk

Employer toolkit

Supporting employees with epilepsy in the workplace



That's why we've launched our new Employer toolkit, an online resource to help employers confidently support their employees with epilepsy. With helpful information, videos and printable resources, the toolkit helps employers to:

- Understand that there are many different types of epilepsy and seizures
- Know how to help in the event of a seizure
- Confidently approach the topic of epilepsy with their employee
- Offer any support that might be necessary
- Understand that many people with epilepsy need little to no extra support

Leaflets about the Employer toolkit can be requested from **nurseorders@epilepsy.org.uk** (Order code **FL66.01**).

Take a look:
employers.epilepsy.org.uk

Get in touch: **helpline@epilepsy.org.uk**

Epilepsy Action
Information you can trust

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Janine Winterbottom

Preconception care

Mixed-methods Delphi consensus study

Dr Janine Winterbottom describes the mixed-methods Delphi study to develop a preconception care pathway for women with epilepsy

Introduction

The benefits of preconception care are widely recognised. However, the content of preconception care, how best to support women to plan pregnancy and the variability of service provision across the UK represent barriers to women receiving this care. This mixed-methods Delphi consensus study aims to meet these challenges by identifying the essential preconception interventions and key stages of support in development of a preconception care pathway. The study will further identify the content of patient-reported outcomes of importance, to be validated in future research.

Preconception care is defined by the World Health Organization (WHO) as a series of promotive, preventive and curative health interventions. These are able to benefit a wide range of stakeholder needs to maximise gains for maternal and child healthcare [WHO, 2013].

Preconception care includes:

- Interventions with the intention of improving maternal and child health **prior to conception** in a woman of childbearing potential
- Intervening in preparation for a first pregnancy, and peri-conception interventions (between pregnancies), to improve future outcomes
- Interventions involving a single or multiple health risk assessment, and educational and counselling sessions. This can be delivered as a single session or an intense programme involving multiple sessions over several weeks or months
- Interventions that are delivered in primary and secondary healthcare, by social care, education, religion and community providers including public health initiatives (such as family planning), and by the voluntary sector

Why is preconception care important for women with epilepsy?

Public Health England (PHE) highlights the opportunity for early intervention and identification of emerging risks with preconception care. This includes warnings to avoid the high-risk drug valproate for women with epilepsy of childbearing age [PHE, 2018A]. However, there is evidence of variance in preconception care provision for women with epilepsy in the UK. Findings from repeat surveys of 2,788 members of three UK epilepsy charities in 2016 and 2017 showed one in five did not know the risks of taking valproate during pregnancy. Also 27% could not recall a discussion with their healthcare professional about the risks of valproate in pregnancy [Sen and Nashef, 2018]. The Medicines and Healthcare products Regulatory Agency (MHRA) and European Medicines Agency (EMA) responded by stepping-up guidance. Mandatory completion of an Annual Risk Acknowledgement form is now required for women receiving prescriptions for valproate and a Pregnancy Prevention Programme (PPP) also needs to be in place. This aims to reduce the risk of valproate exposure in unplanned pregnancy. The challenge for some women is that valproate remains the most effective treatment for the genetic generalised epilepsies, which account for around a third of epilepsies [Mole, 2015]. While many women can achieve seizure control on other anti-seizure medications (ASMs), affording the opportunity for reduced pregnancy risks, others cannot.

For these women, avoiding valproate can result in having to manage the uncertainty of pregnancy risk with newer ASMs, or polytherapy regimens. However, both of these have little evidence of safety in pregnancy [MHRA 2021]. For women who need to continue valproate, this requires decisions for pregnancy to be balanced against the risks of inadequate seizure control with personal risks of injury, impact on employment and education opportunities, and, in extremis, death [Mole, 2015].

The requirement for women with epilepsy to access preconception epilepsy review gives them the opportunity for a review of their medication. It also provides the opportunity to complete treatment changes prior to pregnancy, and to be counselled about pregnancy related risks to support informed decision-making [NICE, 2012; 2019]. A key finding from the National Audit of Seizure management in Hospitals (NASH) showed half of those attending emergency services with seizures were not attending epilepsy services. Valproate was prescribed or taken by patients attending emergency services with seizures, with no significant change in prescribing practice between first 2011 and second audit 2013 (36% and 34% respectively)[Dixon, 2015]. This suggests missed opportunities and highlights the risk that women of childbearing age are not having access to support and monitoring in line with NICE guidelines.

Public Health England highlights the opportunity for early intervention and identification of emerging risks with preconception care

While the outcome of pregnancy for the majority of women with epilepsy is normal, these outcomes are dependent on a number of factors. Maternal age, aetiology and parental history of major congenital malformation need to be taken into account in the management of epilepsy in women of childbearing potential. The International League Against Epilepsy's (ILAE) Women and Pregnancy Task Force have recommended management strategies and discussion topics, blood tests and communication between professionals and the patient [Tomson, 2019A].

How preconception interventions might work

Preconception care brings together processes involving assessment, planning, treatment, education, decision support and counselling. This results in a wide range of potential health outcomes before, during and after pregnancy for both the woman and her future children [NICE, 2019]. Preconception care is based on a life course approach and aims to improve fitness for pregnancy by focusing on the 'four Ps': pregnancy planning, pregnancy prevention, pregnancy preparation and preparing for parenthood [Hanson, 2015; PHE, 2018B].

Promoting preconception healthcare in adolescence, this being a life stage when many behaviour patterns become established, is a key recommendation made by the UK Chief Medical Officer [PHE, 2018A]. This is a further challenge for adolescents with epilepsy – a potentially earlier sexual information debut for young women with epilepsy compared to their non-epilepsy population peers [Lossius, 2016]. Preconception is the ideal time to provide a targeted review of diagnosis and ASMs. This aims to ensure appropriate treatment before conception and to improve seizure control through rational ASM selection, including withdrawal of high risk drugs such as valproate [Leach, 2017].

Improving rates of a planned pregnancy for women with epilepsy will result in more women having

preconception epilepsy reviews and appropriate changes in prescribing [Leach, 2017]. Making changes from treatment with high-risk ASMs has the potential to prevent 31 children each year born to mothers with epilepsy being affected by major congenital malformation. An estimated cost saving of £1,746,000 (in 2011) can also be achieved by avoiding valproate alone, reducing the economic burden by preventing five cases of spina bifida per year [Kinney, 2011]. The European Epilepsy and Pregnancy register (EURAP) has reported a 27% reduction in rates of ASM-related major congenital malformations since 2000 due to changes in prescribing (reducing use of valproate and carbamazepine). This is without significant changes to rates of tonic-clonic seizures in pregnancy over the same time period [Tomson, 2019B]. Additional strategies to reduce valproate exposure have been implemented, including mandatory risk acknowledgement and pregnancy prevention programmes. This further demonstrates the importance of planning pregnancy and having epilepsy reviews to optimise ASMs and seizure control before conception [EMA, 2018; MHRA, 2019].

Pre-pregnancy commencement of folic acid supplementation has been proposed to have a positive influence the neurodevelopmental outcomes of children born to mothers with epilepsy [Meador, 2011]. Due to the risk of unplanned pregnancy, women taking ASMs are recommended to take a high-dose folic acid supplement (5 mg/day) [RCOG, 2016].

Improving the provision of risk information ahead of pregnancy helps support informed decision-making. It is proposed that preconception interventions such as improved knowledge of a person's own condition and promoting shared decision-making help reduce the risk of adverse pregnancy outcomes. It helps to support the completion of ASM changes prior to pregnancy, thereby reducing the rates of abrupt withdrawal of ASMs or termination of an otherwise wanted pregnancy for fear of causing harm to the baby [Widnes, 2012; PHE, 2018A].

The opportunity for women with epilepsy to access preconception is variable and influenced by socioeconomic, cultural and geographical variations in epilepsy care provision. These variations have been shown to increase the risk of pregnancy complications. These include risks of sudden unexpected death in epilepsy (SUDEP) and poorer pregnancy outcomes for women with epilepsy living in areas of high deprivation [Knight, 2020].

Improving rates of a planned pregnancy for women with epilepsy will result in more women having preconception epilepsy reviews and appropriate changes in prescribing

Importance of the Delphi study

This study will answer the research question: What are the essential elements of preconception care for women with epilepsy that will improve maternal and foetal outcomes along the preconception care pathway?

This study aims to:

- Address the need to reduce variations in the delivery of preconception care for women with epilepsy in the UK
- Develop a patient-acceptable,

NHS-feasible 'preconception care pathway' to improve rates of planned pregnancy for women with epilepsy, improve preconception health and reduce missed opportunity for preconception care interventions

The need to increase planned pregnancy underlines the potential for the missed opportunity for women with epilepsy to improve or optimise epilepsy care before conception. This offers rationale for the planned Delphi study.

The objective of this study is to improve access to preconception care for women with epilepsy. Preconception care interventions have the potential to provide balanced risk information and support informed decision-making. This is critical in managing the potential over-estimation of drug risk and fears of harm to the unborn child [Widnes, 2012; Turner, 2008]. The benefit of this study is its focus on women with epilepsy of childbearing age, and preconception care providers.

Why women do not receive preconception care is unclear and, with mixed opinions and n the absence of evidence, we need the community and stakeholders to form a consensus

Why women do not receive preconception care is unclear and, with mixed opinions and in the absence of evidence, we need the community and stakeholders to form a consensus achieved through Delphi methods.

This study will target recruitment for those women not currently engaging with epilepsy services, and those from socially deprived regions most at risk of health inequalities. The importance of improving preconception care of women with epilepsy has increased exponentially following the valproate scandal. It has formed an impetus to ensure public funds are appropriately allocated and their impact appropriately evaluated. What exactly preconception care should comprise of, and when it should be offered, is not clear. The fact that current evidence relies on expert (professional) opinion [Winterbottom, 2008; 2021], provides the rationale for this Delphi study.

This study was awarded a National Institute for Health Research grant for Research for Patient Benefit in recognition of the unique challenges facing women with epilepsy. It will build on the increased focus on the benefits of preconception care [WHO, 2013], as a complex intervention to improve reproductive health [PHE, 2018A]. The need for this study was further confirmed in an online survey and patient and public involvement meeting supported by Epilepsy Action. This highlighted the need to include outcomes of relevance to women with epilepsy and their key supporters.

Staged mixed-methods Delphi with consensus meeting

The study is supported by an update and extension of the original Cochrane review of the effectiveness of preconception counselling for women with epilepsy [Winterbottom, 2008]. The update is to include a mixed methods synthesis of quantitative and qualitative evidence [Winterbottom, 2021].

Stage 1 Qualitative exploration of patient experience, to identify the essential components of

preconception care, stages of support and outcomes of importance to women with epilepsy, their partner, family and friends. A thematic analysis will combine these findings and results from the literature review to develop the Delphi survey for use in study stage 2. We are currently recruiting into study stage 1, and welcome women with epilepsy aged 16-50 years along with their partner, family and friends to join us for interviews and focus groups. Participation is remote by virtual meetings on Zoom.

Stage 2 Online Delphi survey. This will bring together all key stakeholders as experts of preconception care, including women with epilepsy, their partner, family and friends; health professionals; commissioners and the voluntary sector. The online Delphi survey will be run over two consecutive 'rounds' (approximately two months apart) anticipated to commence autumn 2021. **We welcome expressions of interest, and further details are available on the study website at: *tinyurl.com/epilepsypreconceptionstudy* or email the study team at preconceptionstudy@thewaltoncentre.nhs.uk**

Stage 3 A consensus meeting will bring together key stakeholder perspectives to develop the final interventional pathway and content of the patient-reported outcome measure for future testing. A representative subgroup of participant

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MHRA. Public Assessment Report of

stakeholder groups completing both online surveys will be invited to attend the consensus meeting.

How you can support this study to get involved

The preconception care pathway research team is keen to recruit experts with experience of the challenges facing women with epilepsy. This includes women who are not known to epilepsy services and at disadvantage and at risk of poor pregnancy outcome. We welcome any help in spreading the word about the study and welcome sharing the study details. We are also inviting those involved in any aspect of support to women with epilepsy to take part in the study. This includes pharmacists, GPs, neurologists, epileptologists, midwives, epilepsy specialist nurses, obstetricians, family planning, sexual health, and contraception care providers, as well as commissioners of services for women with epilepsy.

Get involved

The preconception care pathway study is still recruiting women with epilepsy, partners, family and friends to take part in focus group, interviews and the online Delphi survey. We are also inviting expressions of interest from health professionals to take part in the online Delphi survey.

Email: ***preconceptionstudy@thewaltoncentre.nhs.uk***

Website: ***tinyurl.com/epilepsypreconceptionstudy***

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Highlights

Top picks from *Seizure*

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

Since the serendipitous discovery of its anticonvulsant properties in 1962 [Meunier *et al*, 1963], sodium valproate has gone on to become the world's most widely prescribed antiseizure medicine [Perucca 2002]. Unfortunately, subsequent experience has shown that sodium valproate does not only have therapeutic, but also adverse effects – specifically teratogenic effects in babies exposed to the drug in pregnancy.

In view of mounting evidence since the 1980s [Brown *et al*, 1980; Diliberti *et al*, 1984; Adab *et al*, 2004; Meador *et al*, 2004; Bromley *et al*, 2010; Cummings *et al*, 2011; Bromley *et al*, 2013], in February 2018, the European Medicines Agency (EMA) changed its guidance in relation to valproate. It recommended that this drug should only be used in women of childbearing age if their epilepsy has not responded to other anti-seizure medications (ASMs), if they cannot tolerate alternative drugs, and if they are enrolled in a pregnancy prevention programme ('PREVENT') [European Medicines Agency, 2018]. Concerns about the use of valproate have also increased among young women not actively planning pregnancy. This is due to evidence documenting the potential of this drug to cause polycystic ovary syndrome, a disorder associated with reduced fertility and a number of other long-term complications [Isojärvi *et al*, 2005].

However, in parallel with these discoveries, this drug has also been confirmed to be the most effective AED when an idiopathic generalised epilepsy (IGE) syndrome is suspected [Marson *et al*, 2007; Marson *et al*, 2019]. The dilemma raised for young women with IGE and their clinicians is obvious. The clear evidence of potential of harm on the one hand and the equally clear evidence of therapeutic advantages over alternative medicines on the other has given rise to complex ethical debates. These have featured previously in *Seizure* [Davies *et al*, 2020].

My Editor's Choice from issue 85 of *Seizure* is a 'state of the art and guidance' document written by Barbara Mostacci *et al* [2021] on behalf of the Italian branch of the ILAE. It is intended to help those affected by the valproate dilemma by summarising what is known about the effectiveness of alternatives to valproate in a range of different IGE treatment scenarios. Mostacci *et al* have used what evidence there is from a number of rather heterogeneous studies to provide detailed treatment algorithms. These go well beyond initial alternative antiseizure medicine choices for particular types of IGE. The evidence Mostacci *et al* have gathered for this document does not remove the dilemma, but it should allow readers to make the best possible choice in a difficult situation.

CBD interactions

In recent years, there has been a steady supply of new anti-seizure medicines (ASMs). In the UK, lacosamide became available in 2008, perampanel in 2012, brivaracetam in 2016, cannabidiol (CBD) in 2018, and there is a good chance that fenfluramine will be licenced soon. In this sort of list, the introduction of cannabidiol seems routine and not extraordinary. However, CBD is different from other ASMs in more ways than one.

For a start, it has a much longer history than the other compounds introduced as ASMs over recent years. Almost 5,000 years ago, the Chinese Emperor Fu Hsi described cannabis as having sacred yin (weak, passive forces) and yang (strong, active forces) features, suggesting that it might help to restore a healthy balance of these forces. Cannabis was used in ancient times and in the 19th century, its potential benefits in epilepsy were confirmed [Rosenberg *et al*, 2015]. Cannabis has been regarded as a drug of abuse, making it fall out of favour as a medicine, but increasing understanding of the endocannabinoid system from the 1990s has helped differentiate between different cannabinoid compounds.

A second important way in which CBD differs from other recently introduced ASMs is the great interest of patients with epilepsy and their families, as well as society at large, in this particular medicine. Not many clinicians will have been asked by patients or their families when they might finally be able to try lacosamide, perampanel or brivaracetam. In contrast, there has been considerable pressure on clinicians as well as politicians, licencing authorities, healthcare purchasers and insurers to make CBD available to patients with epilepsy. This suggests that patients and

families have much higher expectations of this drug than of any other ASM. A third way in which CBD differs from other recently developed ASMs is that CBD has a much greater potential for drug interactions than most newer anti-seizure compounds.

I have chosen the narrative review by Christopher George Sean Gilmartin *et al* [2021] as my editor's choice from the issue 86 of *Seizure*. This review demonstrates the potential for pharmacokinetic interactions between CBD and brivaracetam, clobazam, eslicarbazepine, lacosamide, gabapentin, oxcarbazepine, phenobarbital, potassium bromide, pregabalin, rufinamide, sirolimus/everolimus, stiripentol, tiagabine, topiramate and zonisamide. Pharmacodynamic interactions were identified for clobazam, valproate and levetiracetam. Last but not least, an animal study showed that brain concentrations of other ASMs may be changed by CBD while serum concentrations remain the same. Of course, not all pharmacological interactions between medicines are clinically relevant. However, experience with the combination of CBD with other ASMs is still limited, so it is important to be vigilant. This is especially true, as the high expectations patients and their families have of CBD may lead them to tolerate side-effects they would not accept if they were related to other drugs.

Dravet syndrome in adults

Dravet Syndrome (DS) was first described by Charlotte Dravet in 1978. It was initially known as "Severe Myoclonic Epilepsy of Infancy", but was renamed after its describer in 1989, not least because it had become clear that the condition is not restricted to infancy.

DS starts during the first year of life, often with frequent febrile seizures around six months of age. It is recognised in between 1 in 15,000 and 1 in 41,000 children. Once it has manifested, the condition progresses and goes on to cause cognitive impairment, behavioural problems such as hyperactivity and impulsivity and motor deficits such as ataxia. Like the seizures, the EEG changes of DS get worse with increasing age [Anwar *et al*, 2019]. DS is associated with a markedly increased mortality – many patients die in childhood. At least 50% of deaths are directly attributable to seizures which respond poorly to most antiepileptic drugs and can even be aggravated by some (especially sodium channel blockers) [Shmuely *et al*, 2016].

DS is an autosomal dominant genetic disorder. Seventy to 80% of DS patients have been shown to carry disease-causing abnormalities in one of the two copies of their SCN1A gene. While it is never good to carry a copy of the SCN1A gene that is abnormal enough to cause DS, there are grounds for optimism that the near future will be a better time to be diagnosed with DS than the recent past. The ASM which may become available for DS in the near future (soticlestat) is not the only reasons to be hopeful. Researchers are also pursuing a number of different approaches targeting the underlying cause of the disease. Different viruses are being used to infect neurons and carry correct copies of the defective gene into the brain. Another approach involves the use mechanisms to enhance the transcription of the good copy of the SCN1A gene which all patients with DS have (*bit.ly/3g0YACs*).

One of the practical problems which many patients with DS – especially adults – will face, even in rich countries where access to these exciting treatments may be possible, is a lack of a genetic diagnosis. The genetic tests which are now used to confirm the diagnosis may not have been available before these patients transitioned to adult care. There is still a lack of awareness of specific, genetically diagnosable epileptic encephalopathies among adult neurologists (or a lack of the belief that genetic diagnoses make a difference to their patients' management). Even those adult neurologists trying to make specific diagnoses, may not have access to childhood records and may have an incomplete understanding of the course of their patients' disorder.

My editor's choice from issue 87 of *Seizure*, a systematic review of the literature about DS in adults by Arunan Selvarajah *et al* [2021] should help to make adult neurologists more familiar with this disorder. It's one which they can do a lot for already (if they recognise it) and which they may have even more exciting treatments for in the not-too-distant future.

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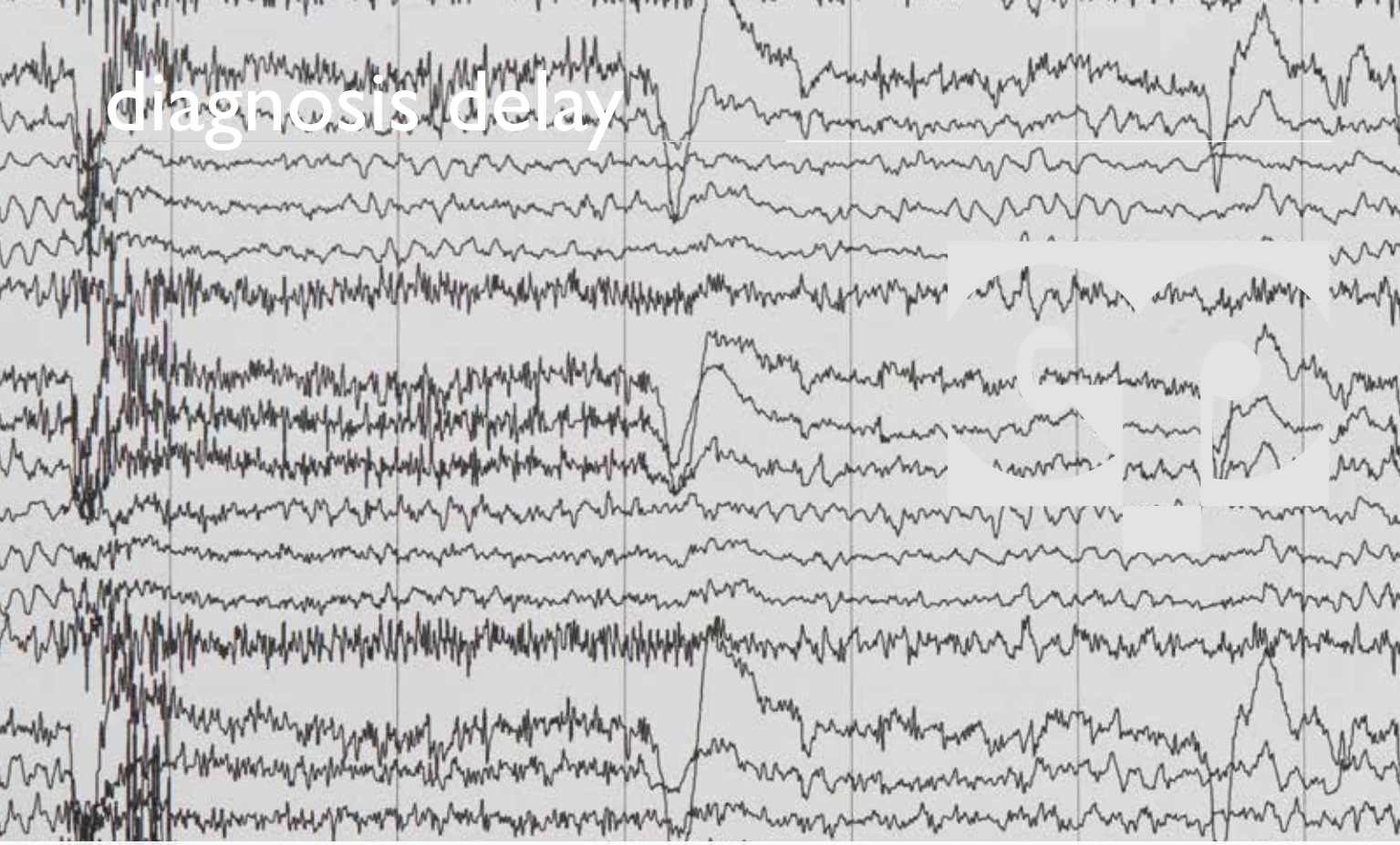


Subtle seizures

Improving recognition can make a difference

Dr Pellinen describes reasons for missed diagnoses of subtle nonmotor seizures and discusses some ways to close this treatment gap

In clinical practice, it is common for neurologists and epilepsy specialists to receive referrals for new onset seizures or 'single' seizures. Unfortunately, after obtaining a thorough history from patients, it is also common to find that they have actually been experiencing subtle seizures for months or years leading up to the more overt seizure that prompted the referral. Subtle nonmotor seizures frequently go unrecognised, undiagnosed, or misdiagnosed for long periods of time. Many patients only come to medical attention and find their way to a specialist after experiencing a more disruptive seizure. This may be a bilateral tonic-clonic seizure, or a seizure that causes an accident or injury. Delayed diagnosis has been a well-recognised issue in the field of epilepsy for many years, and yet contributing factors and potential interventions are ongoing areas of investigation.

The extent of diagnostic delay in epilepsy has been highlighted in recent studies covering several different regions and patient populations. A major recent contributor to our current knowledge is data from the Human Epilepsy Project (HEP). This is a large multinational study on people with newly treated focal epilepsy (***humanepilepsyproject.org***). When participants enrolled in this study, data was collected on their pre-diagnostic histories, making it a valuable window

into patients' experiences leading up to diagnosis and treatment. In this cohort, the median time-to-diagnosis was 219 days [Pellinen *et al*, 2020]. This is comparable with other recent studies, which have shown that delayed diagnosis in new-onset focal epilepsy is common, and can be months to years from symptom onset [Firkin *et al*, 2015; Parviainen, Kälviäinen and Jutila, 2020]. In addition to showing the extent of delay, these studies have also highlighted some important contributing factors.

The most significant and consistently recognised factor contributing to diagnostic delay is seizure semiology. Specifically, seizures with motor involvement, such as bilateral tonic-clonic seizures, are easy for patients, families, and healthcare providers to recognise, and therefore are associated with earlier diagnosis. Other, more subtle seizure semiologies often go unrecognised for long periods of time. They get noticed after gradually becoming worse and culminating in bilateral tonic-clonic seizures or leading to injuries, prompting urgent medical evaluation. The subtle seizures that frequently go unrecognised are those classified by the International League Against Epilepsy (ILAE) as being focal onset and being characterised by nonmotor symptoms (autonomic, behaviour arrest, cognitive, emotional, or sensory) [Fisher *et al*, 2017]. Importantly, the majority of people with new-onset focal epilepsy initially only experience nonmotor seizures – 55% in the case of the HEP study. Therefore, this a significant potential contributor to diagnostic delay among people with new-onset focal epilepsy [Ngugi *et al*, 2010; Pellinen *et al*, 2020a].

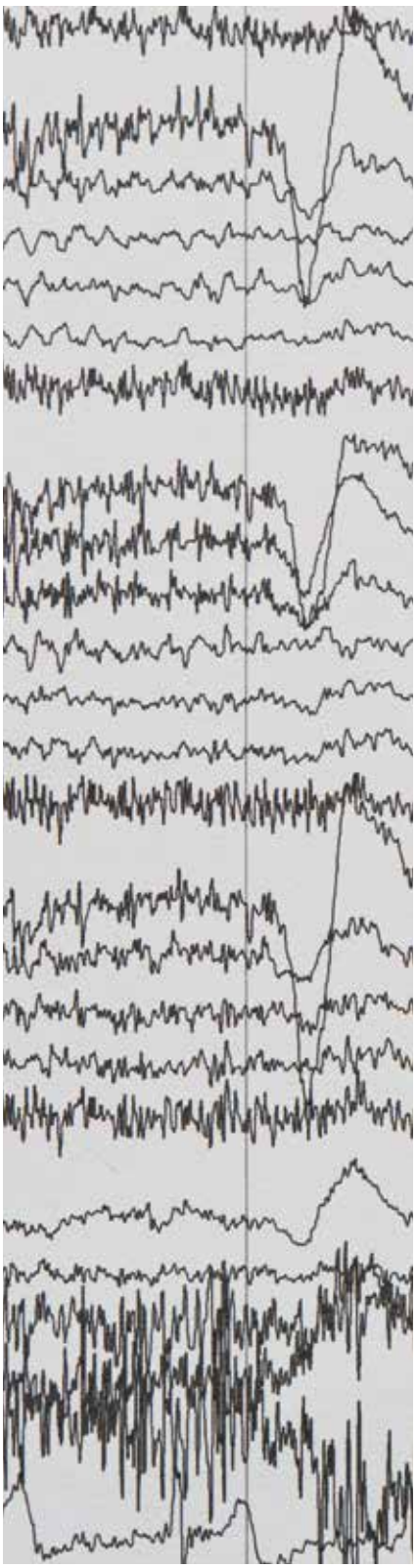
Data from the HEP study also showed that patients who have focal epilepsy beginning with only nonmotor seizures go 10-times longer without a diagnosis than those with motor seizures [Pellinen *et al*, 2020]. A separate analysis specially looked at how frequently a history of preceding nonmotor seizures was elicited by emergency physicians when patients presented for evaluation of a first-lifetime motor seizure. This showed that preceding nonmotor seizures were frequently overlooked – there was no difference in rates of treatment between people who had a single lifetime motor seizure with preceding nonmotor seizures and those without

Data from the HEP study also showed that patients who have focal epilepsy beginning with only nonmotor seizures go 10-times longer without a diagnosis than those with motor seizures

[Pellinen *et al*, 2020b]. This corroborates findings from other studies showing that up to half of patients presenting to emergency departments for evaluation of convulsive seizures have a history of preceding nonmotor seizures that have gone unrecognised [Appleton, 2002; Ting and Kwong, 2010; Shorvon and Goodridge, 2013; Holper *et al*, 2020]. These studies highlight the importance of history taking in epilepsy recognition, particularly in settings where patients present with a first-time motor seizure. There is strong evidence establishing diagnostic delay as a considerable problem, and nonmotor seizure semiology as a major contributor. However, understanding the consequences this has on the lives of patients and the communities in which they live is an even more salient issue.

From both an individual and public health perspective, the consequences of diagnostic delay in epilepsy are substantial. In the HEP study, it was a common pattern for participants to experience nonmotor seizures for months or years, and then transition to motor seizures, including bilateral tonic-clonic seizures. The majority of injuries occurred due to patients experiencing bilateral tonic-clonic seizures, though the majority of pre-diagnostic motor vehicle accidents occurred in people experiencing recurrent undiagnosed nonmotor seizures [Pellinen *et al*, 2020]. This was likely due to the fact that the latter group went longer without a diagnosis, during which time they did not refrain from driving and did not receive treatment. This implies that many negative outcomes could potentially be avoided if a diagnosis was made earlier.

There are also other direct and indirect costs associated with diagnostic delay. The delay can amplify healthcare costs by leading to recurrent emergency care and hospitalisations. Redundant or unnecessary diagnostic testing, additional non-emergent medical evaluations, and unnecessary or incorrect medications are among the other potential direct costs. There are some data reported on such costs in patients with new-onset epilepsy. An early study on the topic suggested the annual healthcare cost per patient with new-onset epilepsy is approximately five times as much in the first year of diagnosis as it is when taking care of people with an established diagnosis [Berto *et al*, 2000]. More recent reports have also shown that the overall economic burden of epilepsy is substantial. They found that up-front costs, including initial diagnostic testing and care, are significantly higher than costs associated with ongoing care once a



diagnosis is made [Jędrzejczak *et al*, 2021; Widjaja *et al*, 2021]. The role diagnostic delay plays in increasing these costs is largely unknown. However, it is reasonable to assume that the up-front costs are magnified when the time-to-diagnosis is delayed, due to the potentially avoidable direct costs such as repeat A&E or emergency department (ED) visits.

In addition to direct costs, there are indirect costs associated with diagnostic delay. Even with newly diagnosed epilepsy, the indirect costs remain largely underreported, with most studies focusing on overall cost analyses associated with the disease rather than costs at different stages of the disease. It is possible that delayed diagnosis has an impact on work productivity, work capacity, and quality of life above and beyond what is found among patients with established diagnoses. Comorbid mood disorders, such as depression, may also be exacerbated by lack of recognition and delayed diagnosis. The relationship between the timing of diagnosis and onset of comorbid mood symptoms in this regard is an interesting area of investigation. It will also be important for future studies to further evaluate the impact of socioeconomic status and demographic variables on recognition and treatment of both epilepsy and comorbidities. Improving early recognition of both epilepsy and comorbidities such as depression and anxiety is likely to have positive impacts on quality of life for individuals, as well more broad impacts on the direct and indirect costs associated with delayed diagnosis. The best avenues for making improvements are still being identified.

One area for potential intervention may be in A&E and EDs. In the HEP study, 279 of patients (62%) reported going to EDs for initial evaluation of undiagnosed epilepsy. Of those, 117 (42%) presented for evaluation of a first lifetime motor seizure after having preceding nonmotor seizures. However, only 46 of those (39%) were started on an antiseizure medication even though they could have been diagnosed with epilepsy at that time [Pellinen *et al*, 2020b]. This highlights a clear gap in recognition and treatment of epilepsy in EDs. This could be improved by increasing recognition of nonmotor seizures in this setting – particularly a history of preceding nonmotor seizures in patients who present for evaluation of first lifetime motor seizures. However, there is a need for clear evidence from interventional studies to support recommendations for large-scale changes in ED decision making.

It is possible that delayed diagnosis has an impact on work productivity, work capacity, and quality of life beyond what is found among patients with established diagnoses

Emergency physicians often have reservations about initiating antiseizure medications in EDs. Although there are several reasons for a general hesitancy, a common reason cited is that early initiation of an antiseizure medication does not change the long-term prognosis of people with epilepsy [Leone *et al*, 2016]. However, there are issues with relying on this prognostic data for short-term diagnostic and treatment decisions. The main is that such studies do not account for outcomes in people who experienced missed

diagnosis and do not assess the impact of delayed diagnosis. There are short-term consequences of delayed diagnosis. These include injuries and car accidents, potentially preventable pre-diagnostic mortality related to seizures, and excess healthcare expenditures related to repeat ED visits for undiagnosed and untreated seizures. So, there are some clear reasons why making a prompt diagnosis and starting an antiseizure medication early in the course of epilepsy may benefit patients, the communities in which they live, and the healthcare system. But there is a need for interventional studies showing specific benefits in these clinical situations in order to prompt changes in standards of care. Improving recognition in A&E and EDs is just one of many avenues that has the potential to make an impact on improving morbidity and mortality in the undiagnosed population. It may also help reduce the many direct and indirect costs associated with delay. Similar improvements in recognition may also make an impact in primary care settings.

Both the clinical and research communities in epilepsy should strive to find new ways to help close the diagnostic and treatment gap experienced by people with new onset epilepsy. Educational initiatives could go a long way in improving recognition of nonmotor seizures among both the public and non-specialist healthcare professionals. There are many avenues for improvement beyond educational initiatives as well, such as utilising quality improvement methods in clinical settings, and testing interventions in larger prospective trials.

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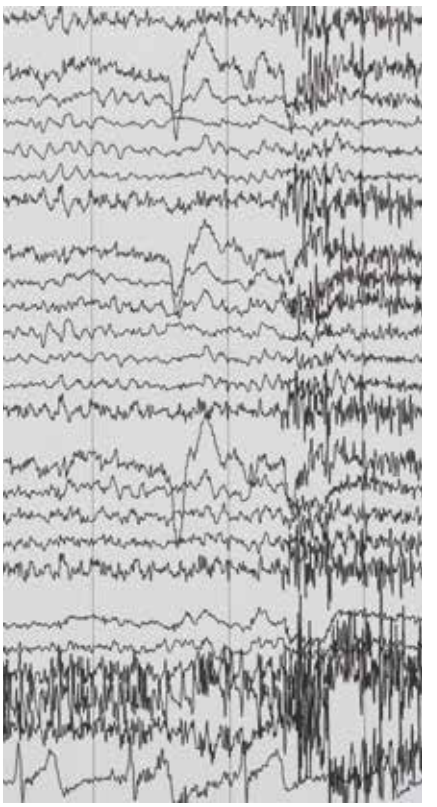

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Climate change and the epilepsy community

Climate change is in the air. The COP26, UN Climate Change Conference, has been scheduled for November 2021 in Glasgow, and the UK has imposed a ban on peat compost sales to gardeners from 2024. In advance of both of these, I thought it might be worth reflecting on the direct and indirect effects the pandemic has had on climate change and therefore also on the epilepsy community at large.

I recently tuned in – or rather 'zoomed' in – to the climate change special interest group via the Association of British Neurologists annual meeting. I felt suitably challenged to consider my own personal interaction with climate change. I wanted to share some of my learning, considering how climate change will influence epilepsy practice in the days, weeks and years ahead. Other, more esteemed epilepsy clinicians have also written eloquently on the subject and I felt, together with my simple musings, some of their messages were worth sharing [Sidoya *et al*, 2019].

From the outset and from a general scientific perspective, it is probably worth considering the effect an increasing planet temperature would have on the incidence of epilepsy. Epilepsy is already one of the most common neurological diseases worldwide, with an even higher incidence in the developing world due to neonatal infections. It, therefore, seems plausible that climate change could precipitate emerging new or an increased rate of infections, which, in turn, could have a detrimental effect on humans and other species. Apart from a knock-on increase in brain infections and subsequent epilepsy, any damaging effects on other species could, of course, have a downstream effect on research platforms for drug delivery and development.

Climate change has the potential to worsen the rich-poor divide, causing radical changes in weather systems, resulting in unpredictable flooding, droughts and famine, and increasing poverty and economic hardship. We know epilepsy incidence follows social deprivation, so it seems possible that this, coupled with an increased infection rate, could trigger an increase in many diseases and conditions including epilepsy.

Climate change discussions often take place on a global scale, and I, for one, often feel a bit lost as to how I can make an impact. However, as we continue to live through the COVID-19 pandemic, some of the

subtle enforced changes in my day-to-day working and personal life might be a good a place to start.

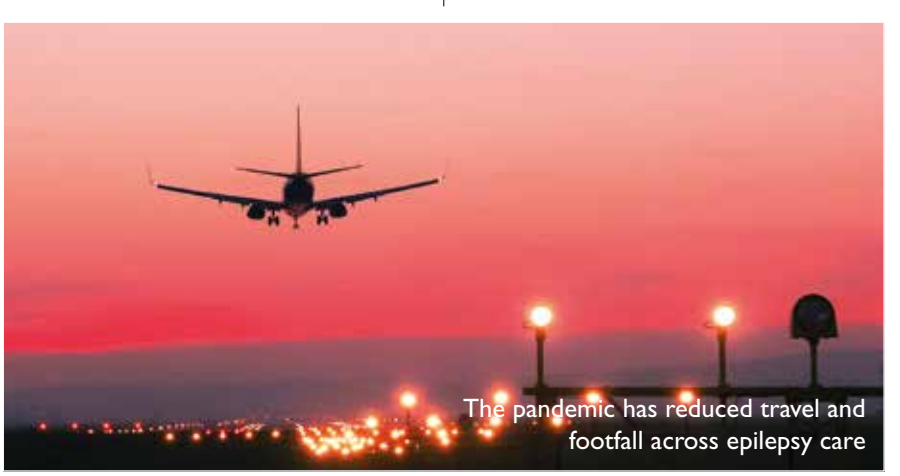
If we consider travel, we know that overall population travel – and carbon footprint – was significantly reduced during the pandemic, due to the government's stay-at-home message. For patients with epilepsy, this is probably less than the general population anyway, due to driving restrictions. And it's probably reduced further due to the stay-at-home message and the national pause in routine hospital appointments. This facilitated the evolution in new ways of working, delivering healthcare for patients with epilepsy in telephone clinics, video clinics and sometimes a hybrid version of both. Although a by-product of the pandemic, these methods do reduce the need for personal and public transport. If they are adopted by large numbers of patients and clinicians, this could start to make a more permanent dent in overall carbon footprint across epilepsy care.

If we consider artificial intelligence, epilepsy communities are generally avid users of new technology, with a high uptake in wearable smart electronic devices electronic apps to record seizures. So, are paper seizure diaries a thing of the past? In turn, epilepsy clinicians are increasingly using electronic databases to record patient activity, with ever more hospital trusts and GP practices going paperless.

Climate change probably also mandates that we need to use fewer resources and promote more holistic, patient-centred care. I'm afraid there's no real getting away from the continued need for anti-seizure medication, but we must also consider wider health issues for our patients. These are things such as smoking cessation, weight loss, mental health and other comorbidities.

As we tiptoe through different stages of this pandemic, hoping for some return to normal living, I wonder if we, as a group of clinicians, can consider other ways in which our lives and practices interact with, and impact climate change? We don't need to wait for or attend COP26 to do this.

Will we still consider it acceptable to fly around the world to international conferences when video-conferencing has proved itself to be so successful? Or what about our day-to-day commute? Or the way we eat, or what we eat, or how we take our coffee and in what type of cup? I'm hoping the pandemic, despite the terrible death rates and loss of loved ones for so many, has at least brought some lasting sustainable messages and actions for our climate and this planet.



The pandemic has reduced travel and footfall across epilepsy care

Further reading

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coming up

Dates for the diary

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

2021

28 August – 1 September
34th International Epilepsy Congress
Virtual congress
epilepsycongress.org/iec/

9-12 September
11th International Summer School for Neuropathology and Epilepsy Surgery (INES 2021)
Erlangen, Germany
ilae.org/files/dmfile/INES-2021-Flyer.pdf

13-15 September
Annual Meeting on Imaging in Epilepsy, Epilepsy Surgery, Epilepsy Research and Cognitive Neurosciences (AMIE)
Bochum, Germany
bit.ly/3owHYX3

23-24 September
ILAE British Branch Virtual Annual Scientific Meeting
Virtual congress
www.ilaebritishconference.org.uk/

19-22 October
7th Global symposium on medical ketogenic dietary therapies
Brighton, UK
globalketo.com

28-30 October
3rd International Congress on Mobile Devices and Seizure Detection in Epilepsy
Copenhagen, Denmark
na.eventscloud.com/ehome/index.php?eventid=574764&

2022

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

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

Next issue:

Hayley Gorton

Dr Hayley Gorton *et al* describe discuss alcohol use, self-harm and suicide in people with epilepsy

Taylor Abel

Dr Abel discusses VNS efficiency in children under six years old with drug-resistant 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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