epilepsy action

ISSN 2631-7400

Paediatric Epilepsy

Volume Eighteen | Number Two | June 2024

CURRENT AWARENESS SERVICE

Medicine shortages becoming a “new normal”

Medicine shortages are becoming “shockingly” commonplace according to a report from the Nuffield Trust, an independent health think tank. [Dayan et al, 2024].

It said the past two years had seen “constantly elevated medicines shortages” and a “frequent disruption to crucial products”, which worsened in 2023 and is now becoming a “new normal”.

Epilepsy medicines including Tegretol (carbamazepine) and Lamictal (lamotrigine) were among the medicines consistently affected by shortages. There was a brief problem with Epistatus (buccal midazolam) in 2023 and also in early 2024 but fortunately this was for a relatively brief period and particularly in the context of its important role in the treatment of prolonged tonic-clonic seizures in out-of-hospital settings. There is currently a similar but less serious issue with the availability of intravenous lorazepam (Ativan) which in part is due to one manufacturer ceasing to make this emergency anti-seizure medication.

The report, titled ‘The future for health after Brexit’, said this had placed a “significant burden on pharmacists and affected the medicines available to patients”.

The Nuffield Trust stated that the shortages reflect “significant problems in the global medicine market”, and that while Brexit was not to blame it had “contributed to difficulties by lowering the value of sterling and removing the UK from European Union supply chains”.

It added that the English NHS had been forced to increase medicine prices to deal with the supply problems and these cost the taxpayer £220 million more in just one year.

In February 2024, the Epilepsy Action helpline had received five times as many enquiries on medication stock compared to the same time in 2023. People had reported coming close to completely running out of their medication, having more seizures because of the stress around the shortages and being advised to switch to other brands’ formulation of their medicine.

Reacting to the Nuffield report, Epilepsy Action deputy chief executive Rebekah Smith said: “Epilepsy medication availability has been a fluctuating issue for years, but it has definitely reached a precarious point more recently.

“Most people with epilepsy rely on medication to control their seizures, and very often finding the right one, or the right combination, is a tough journey. Medication is the first step to getting some degree of stability, and the potential of this stability being taken away is devastating.

PUBLISHER
Epilepsy Action

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"We have heard of many people struggling to find the right medication over the past few months, and the stress surrounding running out or having to take a substitute has been overwhelming. It could mean more seizures, or having a seizure after being seizure-free for years, which could have a massive knock-on effect on other aspects of a person's life, such as their ability to drive, or their job. But at its worst this can be life threatening.

"People with epilepsy and other conditions affected shouldn't have to worry about whether their symptoms are going to worsen for factors totally out of their control. Our helpline team has listened to the worries and struggles of a record number of people since the start of this year. They deserve to know why this is happening, and when it's going to get solved."

Smith called on the government to review the medicine supply chain so that people with epilepsy could be confident about getting their medications.

She added: "The Department of Health and Social Care needs to ensure a robust review of all the processes and procedures to ensure an open and transparent supply chain, so that people with epilepsy do not have to worry about not being able to get their medication."

Jointly with the Association of Independent Multiple Pharmacies (AIMP), Epilepsy Action, Epilepsy Society, SUDEP Action and Parkinson's UK, warned the government in April 2024 that unless there is greater openness with drug manufacturers, medicine shortages will continue and inevitably cause harm to many patients. They called for an urgent meeting with the UK health secretary at the time, Victoria Atkins.

A survey from the charities found 70% of respondents had difficulties getting hold of medication in the past year. The same survey found 22% had experienced problems in the last month. Of the responders, 55% needed to visit multiple pharmacies before managing to obtain their medication. It is of equal concern that approximately two-thirds were only given a fraction of their prescription.

The AMPI added that community pharmacists were spending two hours every day trying to track down potentially life-saving medications for patients.

Chief executive of the AIMP, Dr Leyla Hannbeck, echoed Smith's calls for more transparency.

She said: "The medicines supply chain is broken at every level and unless the Department of Health reviews its processes and procedures, we will never achieve the stability that will guarantee patients their prescription when they need it.

"The UK has a smaller medicines budget than anywhere else in Europe or the US. The NHS is continually driving down the price of medications, which means that manufacturers prefer to sell outside of the UK where they can make a larger profit.

"The system is overly complex and shrouded in secrecy – what we need is openness and transparency. Pharmacists are in the same position as patients – we are at the end of the supply chain but are the last people to find out about medication shortages. Consequently, we are unable to plan in advance and support the people who rely on us for their medications."

Responding to the calls, a Department of Health and Social Care spokesperson said: "We have taken swift action with NHS England and other stakeholders to improve the supply of epilepsy medications and access to some has already improved while we expect supplies of others to improve in the coming months.

"We have issued guidance to health professionals on how to support patients while supply is disrupted."

The Nuffield report also made a number of recommendations to the government. It called for:

- Better – and specifically – an earlier anticipation of medicine shortages
- More openness about shortages in line with other European countries
- A plan for the EU's stockpiling and medicine transfer schemes

Latest ASM shortages update

Epilepsy Action's drugwatch [Epilepsy Action, 2024] offers up-to-date information and updates on epilepsy medicine shortages as the organisation finds out about them. Some of the latest medicines affected are:

Accord lamotrigine
Accord have told Epilepsy Action that they are out of stock of 25mg, 50mg, 100mg and 200mg with an estimated return date of all strengths of August 2024.

Crescent carmabazepine
Carbamazepine 100mg and 200mg tablets made by Crescent are currently out of stock, with an estimated return date of mid-June 2024, Epilepsy Action has been told.

Accord phenobarbital
Epilepsy Action are aware that phenobarbital 15mg tablets by Accord are currently out of stock with no confirmed return date.

Nuffield Trust's Brexit programme lead, Mark Dayan said: "The rise in shortages of vital medicines from rare to commonplace has been a shocking development that few would have expected a decade ago.

"More and more patients across the UK are experiencing a pharmacist telling them that their medication is not available, it may not be available soon, and it may not be available anywhere nearby. This is also creating a great deal of extra work for both GPs and pharmacists.

"We know many of the problems are global and relate to fragile chains of imports from Asia, squeezed by Covid-19 shutdowns, inflation and global instability. Officials in the UK have put in place a much more sophisticated system to monitor and respond, and used extra payments to try to keep products flowing. But exiting the EU has left the UK with several additional problems – products no longer flow as smoothly across the borders with the EU, and, in the long term, our struggles to approve as many medicines might mean we have fewer alternatives available."

It is inevitable that this shortage of the most commonly prescribed anti-seizure medications will have a knock-on or 'domino' effect with worried and concerned patients or in the case of children, their parents contacting their GP but also (and particularly with children), their paediatrician or paediatric neurologist and epilepsy specialist nurse. This will consequently add to the workload of the doctors and nurses involved in their care.

Grace Wood
Publications officer
Epilepsy Action

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Dayan M, Hervey T, McCarey M, Fahy N, Flear M, Greer S and Jarman H. The future for health after Brexit. *Nuffield Trust*. 2024. [online] Available at: https://www.nuffieldtrust.org.uk/sites/default/files/2024-04/Health%20after%20Brexit_WEB_April_24.pdf [Accessed 06 Jun 2024]

Epilepsy Action. *Drugwatch*. [online] Available at: https://www.epilepsy.org.uk/category/drugwatch [Accessed 6 Jun. 2024].

Forthcoming courses and conferences

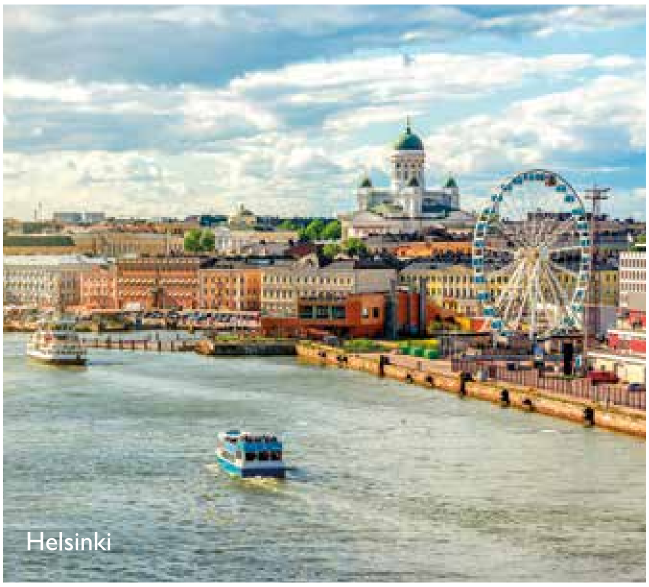
The following are details of forthcoming conferences and courses in epilepsy and general paediatric neurology.

2024

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

September
7-11
15th European Epilepsy Congress
Rome, Italy
ilae.org/congresses/15th-european-epilepsy-congress

September
19-22
14th International Summer School for Neuropathology and Epilepsy Surgery
Erlangen, Germany
bit.ly/3UCYOWp



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

2025

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

August-September
30-3
36th International Epilepsy Congress
Lisbon, Portugal
ilae.org/congresses/36th-international-epilepsy-congress

Your child and epilepsy

Grow your confidence managing epilepsy in your family

Your child and epilepsy is a new online course for parents and carers of children with epilepsy. It's been developed with parents, epilepsy nurses and psychologists.

This course is a helping hand to support families on their epilepsy journey. It's full of advice and stories from parents. It aims to give parents and carers the confidence, skills and knowledge to support their child to manage their epilepsy.

There are eight parts that cover:

- Understanding epilepsy
- Supporting your child with their epilepsy
- Keeping your child safe
- The impact of epilepsy on family life
- Your child's wellbeing
- Learning and behaviour
- Growing up and independence
- Sources of help and support

Free course

The course is free and flexible. It can be accessed at any time on a computer, tablet or smartphone with internet access.

Leaflets about the course to give to families can be requested by emailing **nurseorders@epilepsy.org.uk**

To view the course go to: **epilepsy.org.uk/yourchild**
Get in touch **learning@epilepsy.org.uk**

Epilepsy Action
Information you can trust

Find out more
epilepsy.org.uk/trust

Epilepsy networks: an overview

Dr Dan Hindley, consultant paediatrician, Bolton NHS Foundation Trust
Professor Richard Appleton, Clinical professor in Paediatric Neurology (University of Liverpool) and Suffolk

It is probably relevant and useful to look at the definition of 'network' to gain some idea as to why networks are important. This applies to both the structural and biochemical function of the brain in the pathophysiology of seizure-onset and termination and epileptogenesis, as well as the clinical management of the epilepsies. This article will address only the latter scenario.

Noun: a group or system of interconnected people or 'things'

Verb: connect as, or operate with a network; interact with others to exchange information and develop professional (or social) contacts.

Although not integral to the above definitions, a crucial consequence of a network, whether using the noun or verb, is to improve communication and therefore improve knowledge and understanding – which further improves communication. This can only be good. Clearly, an essential criterion of any new network is that it must improve communication.

Managed Clinical Networks were formally introduced as part of the Scottish NHS National Services Division in 1999. These clinical networks are defined as: "Linked groups of health professionals and organisations from primary, secondary and tertiary care, working in a co-ordinated manner, un-constrained by existing professional and administrative boundaries, to ensure equitable provision of high quality clinically effective services" (Kirkpatrick et al, 2014). The word 'managed' is vague and could be interpreted at one extreme as being entirely 'informal' and ad hoc and at the other end, with a clearly-recognised structured administration. Within this spectrum, as far as we are aware, the first informal network in England and Wales was established in 2000 in Merseyside and Cheshire. It was given the acronym, 'Epilepsy in Children' ('EPIC'). Alder Hey Children's Hospital (AHCH) was the tertiary epilepsy centre or hub and the secondary care district hospitals (SCDH) within its catchment area being the spokes. At the time of its inception, eleven SCDHs lay within the catchment area and all with outreach neurology and epilepsy clinics provided by paediatric neurologists from AHCH. The North West network, with the Royal Manchester Childrens' Hospital (RMCH) as the tertiary epilepsy centre operated in a very similar format.

It was the network's standard operating procedure that its primary organisers would be the paediatricians with a specific interest in epilepsy based in the secondary care hospitals. In practice, one of these paediatricians would be the secretary of EPIC and arrange the meetings and venue and decide on an agenda with input from other secondary care hospitals as well as AHCH. The role of secretary would then rotate to another secondary care paediatrician after three years. Numerous other children's regional epilepsy networks were subsequently, and quite rapidly, established throughout the UK. The composition of these networks was similar and comprised of paediatricians and paediatric neurologists (consultant and trainees), epilepsy specialist nurses, specialised electrophysiologists (EEG physiologists), psychologists, paediatric neurosurgeons and the voluntary sector. Families were not included but were invited to attend in specific circumstances; for example, to discuss trials of new anti-seizure medications (ASMs), notably Epidyolex for the treatment of refractory seizures in Dravet and Lennox-Gastaut syndromes.

The networks in England and Wales would meet between two and three times a year and either in an afternoon (2-6pm) or evening (6-10pm). The venue would either be in a hospital or, as with EPIC, in a hotel. Pharmaceutical companies would be invited to sponsor the meetings (including with refreshments) and could advertise their product(s) but would have no input into the agenda or programme.

The 'Scottish Paediatric Epilepsy Network' was formed in 2004 and included clinicians, nurses, voluntary sector representatives, and families. Its broad aims were (and are) to promote the delivery of high quality care to children and ensure equity of services across Scotland. This Network is described in more detail later in this article. Although the Children's and Long Term Conditions National Service Frameworks make reference to managed clinical networks, no formal NHS structure existed for such networks in England until 2017, when the Organisation of Paediatric Epilepsy Networks (OPEN) was established.

The principal objectives of all the UK's epilepsy networks were (and are) to provide educational support and encourage service collaboration. This was delivered by the following:

- Facilitating meetings of all those interested in epilepsy in children to share ideas and discuss key issues
- Providing updates on:

  - Any changes to the classification of epilepsy and epilepsy syndromes recommended by the International League Against Epilepsy (ILAE)
  - ASMs; this would include new ASMs and the emergence of new and potentially serious adverse side effects with older ASMs
  - Guidelines on the diagnosis, investigation and management of epilepsy
- Offering an educational topic, often by an invited speaker (e.g. advances in surgical techniques for epilepsy or the role of genetic investigations in the diagnosis of the epilepsies)
- Discussing difficult and challenging cases from around the region

However, with time these networks were able to provide additional benefits:

- A forum in which to discuss studies of new ASMs in managing epilepsy, including their protocols. This subsequently facilitated rates of patient recruitment to a number of studies across specific regions. This was exemplified by the two SANAD studies (Marson et al, 2007 and Marson et al, 2021) and the use of Epidyolex in the management of Dravet syndrome (Devinsky et al, 2018)
- A forum in which to discuss regional research projects by the network. This would be likely to be more challenging than participating in a well-funded and administered national research study (e.g. SANAD) because of the clinical and teaching commitments of full-time NHS medical staff. However, 'EPIC' was able to design and undertake two research projects that were subsequently published (Appleton and the Mersey Region Paediatric Epilepsy Interest Group, 2002 and Klimach and EPIC Clinical Network, 2009)
- A forum in which to discuss which children should be referred for possible epilepsy surgery. This became important from 2012 onwards after the launch of the commissioned Children's Epilepsy Surgery Service or 'CESS' (in England and Wales) (Epilepsy Action, CESS) and also the Scottish Paediatric Epilepsy Surgery Programme (SPESP). The reasons for the development of CESS and SPESP were to increase the number of children being evaluated for, and undergoing, a surgical treatment to treat their medically-refractory epilepsy, and therefore optimise their quality of life.
- To support and facilitate the appointment of paediatric epilepsy specialist nurses in the secondary care hospitals within the network. For instance, when 'EPIC' was established in 2000, only two of the 11 secondary care hospitals in the group had an epilepsy specialist nurse, one part and the other full-time. By the end of 2013 and before the impact of 'Epilepsy12', this had increased to nine, six being full-time.

These additional benefits reflect the many years that EPIC had been functioning and the consequent effective collaboration amongst its members. The COVID pandemic was a very challenging period for the country and for most of 2020, many, if not all, networks in the UK ceased to operate. From 2021 onwards, regional networks began to meet with the rapid introduction and use of virtual meeting rooms, specifically 'Zoom' and 'Teams'. A number of networks then saw an increase in the rate of attendance compared to that before COVID. This was readily explained by the fact that it was easier for many secondary care epilepsy teams to participate virtually rather than in person given the distance they would have to travel to the meeting venue and therefore time they would have to spend away from their hospital base. For 'EPIC', this often entailed a distance of over 30 miles and often in rush hour. In 2023, meetings tended to be held as hybrid events (with attendees participating in person as well as virtually). It will be interesting to see how this develops in the near and distant future.

The North West Paediatric Epilepsy Interest Group was formally set up in 2004 and has run on similar lines to EPIC. There have been four meetings a year with most districts in the region taking turns to organise and host meetings. The focus of this group has been on providing continuing professional development to a range of professionals with a paediatric epilepsy interest. Presentations have included 'hot topics', local and national audits, journal articles, case presentations, sharing local guidance and pathways. Speakers have often been from the secondary care setting hosting the meeting, but also our regional paediatric neurology colleagues, radiologists, neurosurgeons, national experts and third sector representatives. As with EPIC, the informal networking opportunities were significantly affected by COVID and we are still often holding virtual meetings which also have their advantages for busy professionals.

This group has been run on goodwill and without external resources. From time to time, there have been attempts to broaden the remit of the group so that it performs some of the other possible functions of a network, such as:

- Quality improvement (e.g. regional audit, research, pathways, guidelines, service reviews)
- Quality control (e.g. peer review, benchmarking, 'Epilepsy12' audit results between centres with feedback to the 'Epilepsy12' steering committee)
- Strategy, lobbying and advocacy (e.g. raising the profile of epilepsy regionally, and highlighting the need for funding and commissioning)
- Patient feedback and participation (e.g. patient stories and voices and also their participation at meetings)

Unfortunately, with limited resources this has not been possible. It is worth a wistful (and possibly even an envious) look at and comparison with other North West networks with their sparkling websites (National Children & Young People's Diabetes Network; North West

Neonatal Operational Delivery Network), as well as remunerated structures which include business, education and data managers. For the diabetes network, each hospital Trust pays an annual contribution to fund the network which is based on the number of patients, and this is mandated as part of 'Best Practice' funding. The Neonatal Network is a commissioned and mandated network through NHSE with a formal service specification and therefore comes with funding and deliverables that are measurable regionally and nationally.

There are currently 17 regional paediatric epilepsy networks across England, Wales, Scotland and Northern Ireland according to the RCPCH-hosted Organisation of Paediatric Epilepsy Networks ('OPEN UK'). OPEN UK aims to unite children's regional and national epilepsy networks to improve integrated care for children and young people with epilepsies. It has representation from all the regional epilepsy networks. It also aims to:

- Encourage collaboration and sharing of regional and national ideas, pilots, and resources
- Be a national resource and professional UK body to which other organisations may come for information, support, data and strategic or clinical input
- Facilitate links to local, regional and national funding bodies

To achieve this, the OPEN UK Working Group meets three times per year and holds an annual conference focusing on quality improvements in the paediatric epilepsies (RCPCH OPEN UK) (https://www.rcpch.ac.uk/resources/open-uk-organisation-paediatric-epilepsy-networks-uk).

We recently designed a simple questionnaire that was sent to all network or interest group leads through OPEN to try to better understand how paediatric epilepsy networks currently function. Replies were returned from five of the 17 networks. This response rate is likely to primarily reflect the lack of time available to busy clinicians to complete the survey.

England and Wales

The following results summarise data received from the five networks in England and Wales.

The numbers of meetings held annually were once for one network and three to four-times monthly for the remaining four. Meetings were held at a single venue for two and rotated around a region in two; one group didn't answer this question. Meetings were face-to-face for two and a mix (virtual, hybrid and face-to-face) for three. The duration of the meetings was all day for three and a half-day for two.

The organisation and administration of the meetings, including setting the programme, was either done by the network epilepsy lead (two) or by a committee (three). Four networks had no dedicated administrative support. Pharma sponsorship for the meetings was accepted by all five networks but none included promotional talks. No other funding was available to four networks, although one had some extra funding through 'membership fees'. Four network leads stated that they had no provision for the role in their job plan, but one did.

The usual attendance at meetings was between 20 and 100, comprising a cross-section of professionals from secondary and tertiary care. Four networks had a database of interested professionals who were sent programmes and other relevant documents of interest (e.g. updated classifications, guidelines, 'drug-alerts'). The numbers on these databases ranged from 67 to 150. Two networks had some involvement of Integrated Care Boards (ICBs) at meetings, but three did not. 'Epilepsy12' data were reviewed as part of network meetings in three of the five networks. Three networks involved other groups outside of the epilepsy network group and specifically in quality improvement work in epilepsy. This included the NHS England transformation programme.

The responses indicated that networks mostly successfully achieved continuing professional development (CPD) and professional support. The CPD programme for each of the networks was usually approved by the Royal College of Paediatrics and Child Health (RCPCH). Quality improvement, quality control and strategy, lobbying and advocacy were more variably achieved. None of the five networks included patient participation in their meetings.

When asked '**what works well**', the following answers were given:

- 'Peer review, standardisation of care plans or guidelines or both'
- 'The network aligns well to NHS England's Bundle of Care. The hybrid meeting allows optimised attendance'.
- 'Close bonds between epilepsy professionals through the region, quality improvement, well received academic programme.'
- 'ICB involvement' 'Pathway updates' 'Keeping going without resources'

When asked '**what could be done better**' the following answers were given:

- 'Improved patient participation, using 'Epilepsy 12' data'
- 'There needs to be a different forum for consulting on the transformation programme which is the purpose of our new monthly meetings. There should also be a website platform for sharing guidelines, mapping with contacts, recordings of meetings and making resources available'
- 'Variable participation, some Trusts engage a lot but some not at all. It would be great if participation in a regional network was made mandatory for local

paediatric epilepsy services with set criteria and expectations.'
- 'Opportunity to share learning from the Quality Improvement Programmes (QUIP)'
- 'More engagement from the wider team including trainees'
- 'Database of teams included in the network'
- 'A lot of help with some funding / personnel / resources'

Scotland

The Scottish Paediatric Epilepsy Network (SPEN) was established in 2004. It received pump prime funding from the Scottish Government as part of their commitment to the development of managed clinical networks in Scotland. This was outlined in their executive letters, links to which can be found in the references list at the end of this article.

A small group of clinicians, working with Epilepsy Scotland, approached the Scottish Government to fund a nationally-managed clinical network for children with epilepsy. This was supported by evidence gathered through an engagement event undertaken with colleagues from across the country, together with a mailed questionnaire. Funding was provided for a two-year period. This was used to employ a network manager, provide administrative support and fund some meetings and events.

Following this initial two-year pump-prime, SPEN was taken on as a nationally-commission-managed clinical network in Scotland. As with all nationally commissioned networks and services, SPEN was commissioned and funded through the National Services Directorate (NSD) of NHS National Services Scotland (NSS). Funding for all national services is top sliced from health boards with the agreement of the National Specialist Services Committee

Table 1. Key communication routes between the network and the clinical community

Meeting or event	Purpose	Stakeholder engagement	Feedback	Frequency and attendance
Steering Group (16 members)	Accountability for the delivery of the work plan and oversight of all the activity of the network	Regional geographic representation Multidisciplinary representation Third sector representation Working group leads	To the constituent groups they represent	Quarterly
Scottish paediatricians: 'Interest in Epilepsy Group'	Peer review and support via case discussion Education via invited speakers Overview of the current priorities and progress of the network	Paediatricians from each health board who have a specialist interest in paediatric epilepsy Paediatric neurology representation	Paediatric colleagues in their local health board. Wider MDT where relevant	3 times per year Approximately 10 people per meeting
'Paediatric Epilepsy Nurse Specialists Group'	Peer support and development of national approaches to the role of the paediatric epilepsy nurse specialist	Paediatric epilepsy nurses from all health boards in Scotland	Local MDT where relevant. Nursing colleagues in their health board where relevant	Twice per year Approximately 15 people per meeting
'Network Members Day'	All members: to hear about current progress and influence future priorities	All network members	Local colleagues	Once per year Approximately 60 people
Roadshows	General epilepsy education in local areas for all clinical staff that care for children with epilepsy. Raise awareness of network and local link clinicians	All clinical staff	N/A	Every other year in each area Varies depending on Health Board size: usually 15-50
Research meeting	Share updates on ongoing research and possible opportunities for participating in new trials	Four tertiary centres	Regional colleagues	Monthly Approximately 8-10 people

(NSSC) which has representatives at director level from all health boards, and the Board of Chief Executives. However, as with the pump-priming funds, this only covers some hours for a network manager, administrative resource and a small budget for meetings, events and developments. Finally, the funding also allowed some time for a clinical lead, and approximately one programmed activity (PA) a week.

The network structure has evolved over its lifespan, but it is currently overseen by a multidisciplinary steering group. This includes clinicians representing the three regions of Scotland and the various working groups, as well as third sector representation. The different working groups take forward the work of the network and report to the steering group, which is accountable for the delivery of the overall plan. When the network first started, ongoing work groups were established, but this has now moved to a mix of ongoing groups and short-life groups to deliver specific projects, including improvements. Each of these groups has a nominated lead or chair.

With the introduction of Teams, many of these meetings are now held virtually, making them easily accessible to everyone in Scotland. It is clear that there are some objectives that can be better met with face-to-face meetings, including ideas about workshops and potential nation-wide projects, as well as developing new – and strengthening existing – relationships. Meetings and their venues are organised by the network programme team, based on member availability.

The clinical leadership role is the only specifically funded clinical time. It is expected that health boards support their staff to participate because all of the Board Chief Executives have supported the development of the networks. In reality, this has proved challenging, particularly for nursing and allied healthcare professional (AHP) colleagues. This may deteriorate in light of the financial challenges faced by NHS Scotland.

Network stakeholders include young people with epilepsy in Scotland, anyone who is involved in their care, and their representatives. To function effectively, the network relies on those representing their discipline or geographical location on various groups to provide effective inter-communication between the network and the all stakeholders. More active clinical stakeholders are usually those clinicians for whom paediatric epilepsy care forms a significant part of their role, although, clearly, the network needs to communicate with the wider clinical community. Some of the key communication routes are outlined in *Table 1*.

In addition, the core team manage a generic mailbox and website and communicate regularly with members by email and newsletter.

Third sector colleagues are active members of the network and facilitate engagement with young people and their families through their forums, as well as supporting the network to engage directly.

Improvements

SPEN influences improvement through working collaboratively with Health Boards. This relies on the network being able to demonstrate the importance of changes to practice through clinical experience, collating views from young people and their families, and evidence. This has included:

- Development of pathways of care for children and young people with epilepsy throughout their journey. These pathways provide all boards with a model for service provision and are reviewed regularly to ensure that they continue to reflect good practice.
- Development and implementation of an education strategy, building on what is already available in paediatric epilepsy education, and identifying gaps and developing resources to meet these gaps. The network hosts an annual research event that informs all participants in Scotland of ongoing or new research. This is usually attended by approximately 60 people, including colleagues in adult epilepsy and basic science.
- Development of a model, and application for funding, for a nationally commissioned paediatric epilepsy surgery service in Scotland, to allow young people requiring surgery to be supported as close to home as possible.
- Making a case for, and supporting the development of, a new SIGN guideline for paediatric epilepsy (SIGN 159).
- Development of guidance to support clinicians and Health Boards to consider medical practice in the 'new normal', post-COVID 19 technology landscape. This guidance collated input from clinical staff, third sector, parents and young people from across Scotland.
- Development of implemented guidance for 'joint' clinics between tertiary and secondary care.
- Development of quality standards for paediatric epilepsy care in Scotland.
- In conjunction with NHS Lothian, support of the development of an early intervention screening tool to help the paediatric epilepsy team to identify mental health needs and signpost or refer to appropriate psychological support.
- Development of a plan for the administration of emergency medication.

SPEN also provides a forum for consensus approaches to more challenging issues (e.g. approach to midazolam prescribing) and a framework for clinicians to work together effectively. This has included the successful roll-out of vCreate across Scotland and the ability to attract funding for national research studies and projects.

The network also provides a vehicle for engaging with young people and their families to understand their priorities and to try to ensure their needs are reflected in

Dr Dan Hindley, Bolton NHS Foundation Trust
Prof Richard Appleton, University of Liverpool

the work plan or in any piece of work. Third sector partners are actively involved with the network and support this work through their own networks, but other methods of engagement used have included patient or parent group memberships, questionnaires and patient and family events.

SPEN is part of 'OPEN UK' and is represented at meetings by the Lead Clinician.

Challenges

The Scottish Government are currently reviewing the managed clinical network model and the impact of this on the way the network operates is currently unknown.

The full impact of the financial challenges in NHS Scotland is currently unknown.

Changing consultant contracts and transforming nursing, midwifery and health professions' roles is likely to make it more challenging for all healthcare professionals to engage with and contribute to the network.

Conclusion

It makes absolute sense that managed clinical networks help to maintain and improve standards of care (Lawson 2015). There are a number of well-organised and successful networks in other specialities, particularly in diabetes and cancer. Clearly, it is entirely understandable why these diseases, particularly cancer, need and have excellent networks. Over the past 20 years, there has been an increase in regional networks for paediatric epilepsy and this has been strengthened by the development of an overarching national network (OPEN) that links all networks, both old new. The SPEN provides an excellent model for how this can be achieved successfully.

This is a good foundation, but it has been based on interested and enthusiastic clinicians that have provided organisation, commitment and time without much administrative support, if not none at all in most regions (apart from Scotland). This is becoming less sustainable as clinicians' time is increasingly scrutinised and programmed. Although some clinicians (including one of us, RA) always tried to enact the logo printed on some of Nike's merchandise, 'Just do it!', this attitude is becoming much less popular and less likely to succeed for many reasons. It is clear that more resources are required to not only improve the potential effectiveness of these networks but to ensure they continue and survive.

As with most new or innovative developments in medicine, those clinicians that manage epilepsy in children and young people will be challenged to show, and in many situations prove, that networks improve patient outcomes and represent 'value for money' – and can therefore be supported with funds and not just kind words. This may be very difficult for many reasons, one of which is the marked heterogeneity of the epilepsies. I (RA) had just such a 'prove it' conversation with the chief executive at Alder Hey Children's Hospital in early 1991when trying (and eventually succeeding in 1992/3), to establish and then fund the first full-time post of an epilepsy specialist nurse in the UK. However, this was only possible after a visionary and very generous two-year, pump-prime donation from the charity 'The Roald Dahl Foundation' (now the 'Roald Dahl's Marvellous Children's Charity').

However, if we as clinicians fail to even address this challenge, we will never achieve improvements in services for children and young people with epilepsy and their families.

The authors thank the respondents to our survey and particularly Ms Karyn Robertson, SPEN Manager and Dr Ailsa McLellan, Consultant Paediatric Neurologist and President of the British Paediatric Neurology Association and Dr Richard Brown, Consultant Paediatrician and Chairman of OPEN

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Scotland-specific links:

- HDL (2002) 69 Promoting the development of Managed Clinical Networks in NHS Scotland
- CEL (2012) 29 Managed Clinical Networks: Supporting and Delivering the Healthcare Quality Strategy

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Recently published papers

This section highlights recently published papers. There are many (often more than 300) epilepsy papers published every three months, so what follows has been edited. All animal papers have been excluded.

We hope you find the papers of interest in your pursuit to keep abreast of the very latest knowledge.

BENNETT SD, Cross JH, Chowdhury K, Ford T, Heyman I, Coughtrey AE, Dalrymple E, Byford S, Chorpita B, Fonagy P, et al.
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Paediatric Epilepsy Current Awareness Service is published by: Epilepsy Action,
New Anstey House, Gate Way Drive, Yeadon, Leeds LS19 7XY, UK
Date of preparation: February 2024

Epilepsy Action is a working name of British Epilepsy Association. British Epilepsy Association is a Registered Charity in England and Wales (No. 234343) and a Company Limited by Guarantee (No. 797997).

ISSN 2631-7400
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tel: 0113 210 8800 | fax: 0113 391 0300 | Epilepsy Action Helpline
freephone: 0808 800 5050 email: editor@epilepsy.org.uk epilepsy.org.uk
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