Scottish Paediatric Epilepsy Network

Annual Report

2022/23

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Introduction

Epilepsy is the most common serious neurological disorder in children. In the absence of a Scottish paediatric epilepsy register there are currently no accurate prevalence figures for Scotland. It is estimated that the prevalence of paediatric epilepsy in Scotland is around 4,200 children and young people (SPEN GP Audit, 2005), with approximately 800 to 1,000 new diagnoses being made each year. The diagnosis of epilepsy is very complex and the misdiagnosis rate continues to range from 25 to 50%. A fatal accident inquiry into the sudden unexpected death of a young person with epilepsy in Glasgow highlighted the need for improved communication between GP practices and hospital services and the importance of developing joint care plans for individuals with epilepsy.

Since its inception, SPEN has been driving the implementation of evidence based, safe and effective epilepsy care for children in Scotland, underpinned by SIGN Guideline 81 “Diagnosis and management of epilepsies in children and young people” (published in 2005). This guideline has been refreshed by SIGN and replaced with SIGN guideline 159 “Epilepsies in children and young people: investigative procedures and management”, supporting the implementation of this updated guidance now forming a core part of SPEN’s role.

Care for children with epilepsy is available across Scotland through general paediatric services with support from tertiary specialists in Glasgow, Edinburgh, Dundee and Aberdeen. Pathways for first seizures and ongoing epileptic seizures were developed by the network in 2007 and revised an updated regularly. Scottish data in the UK-wide Epilepsy 12 audit of paediatric epilepsy services showed in 2012 and 2014 that Scottish epilepsy services for children and young people performed very well, in many regards better than comparable services in other parts of the UK but SPEN continues to strive for improved care for children and young people with epilepsy in Scotland.

Current Position

The network achieved 89% of its objectives in 2021/22 (8/9). Due to clinical pressures, finalising the data collection for the transition scoping has taken longer than expected but it is expected that meetings with each of the services to gather the information will be completed by July 2023.

Highlights

“The New Normal”

A key piece of work the network has been undertaking is exploring how to use learning about new technologies used during COVID-19 to support the delivery of an effective and efficient paediatric epilepsy service. This has to balance financial and climate sustainability with clinical requirements and patient and family needs and preferences.

Throughout the pandemic, as with other conditions, much of paediatric epilepsy care was provided online through NearMe appointments. In addition, Professor Zuberi and team identified a solution to the remote sharing of seizure videos through vCreate which has now rolled out across Scotland to support paediatric epilepsy care. These tools will continue to play a key role in epilepsy care going forward.

A review of the evidence around the use of these tools highlighted that there could be some challenges for people accessing services this way, particularly the number of people that did not have easy access to internet. SPEN consulted with patients and their families and almost all of them wanted to have mostly face-to-face appointments (42%) or to have a mix of face-to-face and video appointments (53%). The proportion of people wanting mostly face to face was slightly higher in the teenage age group.

Through workshops held at the network members day, key areas were identified where there was a need for more face to face interaction. These included:

- New diagnoses
- Infants under 2
- Those with complex needs
- Teenagers

It was also recognised that there were various considerations including geography, relationship building, family preference and clinical need.

Guidance has now been developed based on all the information gathered and supporting the implementation of this guidance will be a key role for SPEN in 2023/24.

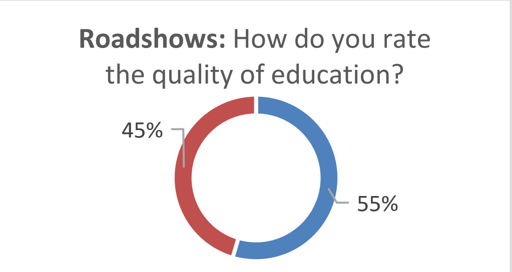
SIGN 159: Epilepsies in children and young people – Investigative Procedures and Management

Following on from the publication of SIGN 159, SPEN has been auditing compliance in health boards with the SIGN 159 recommendations. This has included recording what is being done locally to address any areas of non-compliance and what can be done nationally to support implementation. Results so far suggest that compliance with the recommendations has generally been positive with the main areas where there are challenges across health boards relating to mental health and transition, both of which are part of the SPEN work plan for 2023/24. A further action plan will be developed to address other needs that arise.

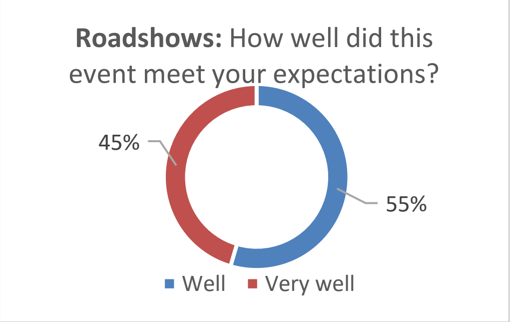
Education Programme

SPEN continued to support the development of knowledge and expertise in paediatric epilepsy in Scotland through the delivery of a programme of education. This included:

- Delivery of 3 paediatric epilepsy roadshows delivered to local clinicians in Dumfries and Galloway, Livingston and the North of Scotland. The roadshows reach a much wider audience of professionals who may care for children and young people with epilepsy in a variety of settings. The roadshow programme enabled sharing of the “new normal” work and findings with a wider audience in advance of the publication of the guidelines as well as covering an update on epilepsy syndromes and an opportunity for the local team to present cases.
- Delivery of 3 Scottish Paediatricians with an Interest in Epilepsy Group (SPIEG) meetings.



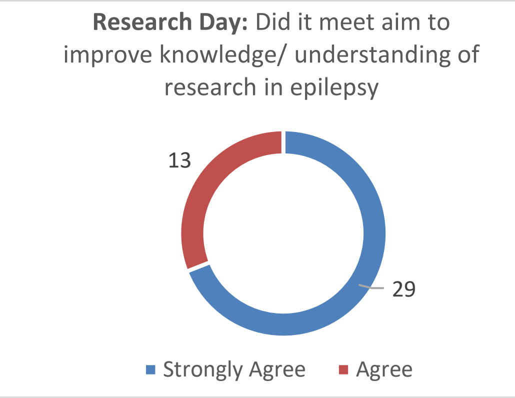
Roadshows: How do you rate the quality of education?



Roadshows: How well did this event meet your expectations?

These meetings allow paediatricians who take the lead in paediatric epilepsy in their health boards to come together for peer support and education through sharing of cases and talks from professionals. One of the paediatric neurologists attends the meetings to provide expert opinion where required. From the latter two meetings, there were 7 cases discussed and representatives from 6 health boards attended. It also highlighted areas for development that have been taken to the steering group and provided paediatrician engagement into key pieces of SPEN work.

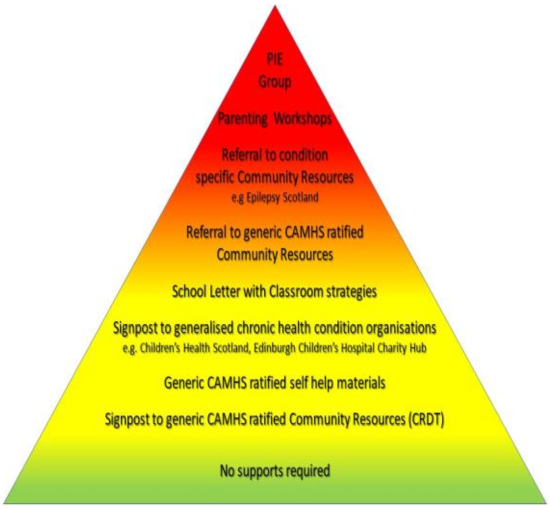
- Delivery of an annual research day. The research day enables sharing of updates about advances in epilepsy research from basic science and clinical that may influence how care is provided in the future. There is also a section to allow trainees to present and display posters about epilepsy research they have undertaken to encourage interest in epilepsy care from the next generation of clinicians. A certificate is offered to the student presentation judged to be the best. In February 23 the event was attended by 57 people.



- The Paediatric Epilepsy Nurse Specialists (PENS) meet twice per year for peer support and development. They have developed and launched a TURAS module for healthcare, social care, and education staff and aims to improve their understanding of epilepsy and the principles that relate to the safe management of seizures, and the administration of Buccal Midazolam. Over 1300 people have accessed it, the majority from the education sector Feedback has been positive with 89% rating it 4 or 5 stars out of 5.

Mental Health and Wellbeing in Children with Epilepsy

There have been a number of developments in Scotland supporting mental health and wellbeing in children and young people with epilepsy, in particular the development of the Psychology Adding Value Epilepsy Screening (PAVES) with NHS Lothian. PAVES enables screening to take place through the epilepsy team to signpost to the most appropriate level of resource as outlined in the PAVES pyramid.



Evidence has been gathered through use in NHS Lothian that suggests use of PAVES reduces the number of CAMHS referrals and saves the NHS money.

Workshops have been held by SPEN in 2022/23 to scope the resources available across Scotland in relation to mental health and wellbeing and to identify the challenges. In 2023/24, a short life working group will review this, and the opportunities to make effective use of PAVES, to develop a strategy for supporting the mental health and wellbeing of children and young people with epilepsy in Scotland.

Service Mapping

An extensive mapping of services was undertaken based on the service requirements outlined in Epilepsy12 and additional questions relating to SPEN work. This will allow some benchmarking against service delivery in other areas of the UK. Data has now been received from 10/11 health boards which will be analysed to identify any gaps or variation.

Looking forward – 2023/24

Priorities for SPEN in 2023/ 24 include:

- Building on the scoping work around mental health and wellbeing, a short life working group will be drawn together to develop a mental health strategy for children and young people with epilepsy in Scotland
- Supporting the implementation of the new normal guidance
- Developing a national action plan to complement the action taken at health board level to implement the recommendations of SIGN 159
- Delivery of the education strategy including:
    - Signposting to existing paediatric epilepsy education and training resources
    - Providing locally delivered general paediatric epilepsy training
    - Peer support and education through national case discussion forum and epilepsy nurse specialist meetings
    - Sharing information on advances in epilepsy through national research event
- Refresh of the communications and engagement strategy to maximise the use of technology to support effective communication

- Identify further areas for improvement arising from the service mapping data and some focused audit work
- Reviewing the transition pathway for young people with epilepsy and identifying areas for improvement
- Development of a collaborative approach to paediatric epilepsy research in Scotland

Finance

The network spent £3,812 of its £5,000 budget. This was made up of £351 on printing (Patient Experience Questionnaires and SUDEP leaflet) and £3,461 on face to face events (Network Member’s Day, Research Day and SPIEG).

Risks & Issues

None identified.