Scottish Paediatric Epilepsy Network

Annual Report
2024/25

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(1 April 2024 – 15 November 2024)
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This document has been prepared by NHS National Services Scotland (NSS) on behalf of the Scottish Paediatric Epilepsy network (SPEN). Accountable to Scottish Government, NSS works at the heart of the health service providing national strategic services to the rest of NHS Scotland and other public sector organisations to help them deliver their services more efficiently and effectively. SPEN is a collaboration of stakeholders involved in the care of paediatric epilepsy who are supported by an NSS Programme Team to drive improvement across the care pathway.

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 highly complex, with the misdiagnosis rate ranging from 20% to 30% according to NICE. 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 was 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 first developed by the network in 2007 and revised regularly, with the most recent review underway since March 2025 and should be completed in early 2025/26. 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

In light of the ongoing Scottish Government review of national networks, planning has been adapted to focus on core priorities and ensure continuity of essential services. We await further guidance to inform future strategic development.

The objectives identified by SPEN and the progress against them are set out in table 1.

Priorities	Progress to date
Identify areas for improvement for newly diagnosed epilepsy patients through audit undertaken in all centres and develop action plan	Data received has been collected by all centres in Scotland and analysis and action planning underway.
Identify areas for improvement and develop action plan for transition from paediatric to adult services	Scoping of existing arrangements completed. SLWG established to review output of scoping and patient engagement and identify actions.

Support the implementation of the new normal and SIGN 159 recommendations	Local progress and plans for all recommendations mapped for all 11 health boards delivering paediatric epilepsy network services and national support required identified

Table 1: Priorities and progress against SPEN objectives

The network achieved all its business as usual (BAU) objectives in 2024/25.

In the 2023/24 annual report, it was noted that a mental health strategy for children with epilepsies was in development and expected to be finalised in 2024/25. During 2024/25, SPEN have been working on implementing the strategy with the NSS Health and Care Innovation team and they have now taken the lead on this piece of work. SPEN remain committed to supporting this transition and are confident in the initiative's continued progress.

Highlights

Transition (moving from paediatric to adult services)

The Transition project is currently in Phase 2: Patient experience. Progress has been delayed due to the necessary governance and permission processes required to secure patient input. While this phase is now underway, it is expected to take several months to complete, as patients will transition at varying stages and times.

Figure 1: Transition progress

Education

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 the Scottish Epilepsy Group (SEG) annual research event. The face-to-face event was held on 28 February 2025 in NHS Education for Scotland, Edinburgh. It brought together professionals and students from across Scotland to present recent, current, and

future research studies in epilepsy. SEG welcomed keynote speaker Professor Hannah Cock from St George's, University of London.

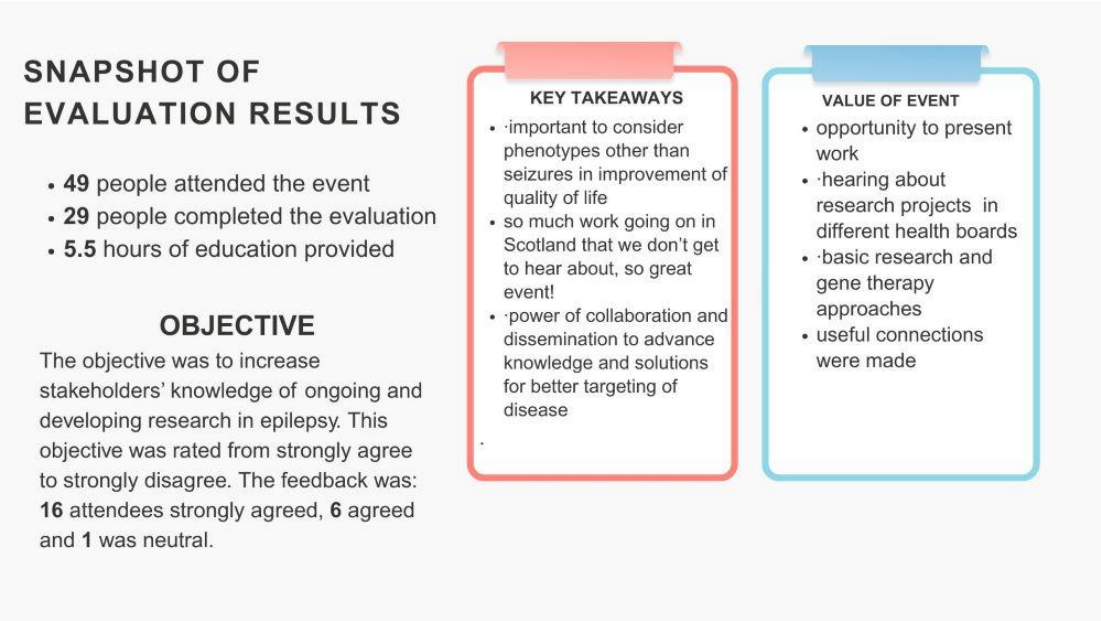


Figure 2: Summary of SEG research day evaluation responses

- Delivery of three Scottish Paediatricians with an Interest in Epilepsy Group (SPIEG) meetings. These meetings allow paediatricians who take the lead in paediatric epilepsy in their health boards to come together for peer support and education. This is through sharing of cases and presentations from professionals. A paediatric neurologist attends the meetings to provide expert opinion.

  To streamline the feedback process and reduce survey fatigue, only one consolidated evaluation survey was produced. Responses were received from 8 of the 18 members (44%). A couple of the respondents did not attend any of the meetings primarily due to clinical pressures and commitments, therefore most of the main feedback is from 6 members.
  Five of the 6 respondents delivered a case presentation and reported that having the opportunity to speak to colleagues in this forum supported clinical practice. All respondents confirmed the meetings are used towards their appraisal and revalidation.

  Across all three meetings, there was 18 attendees from 7 health boards (NHS Ayrshire & Arran, Fife, Greater Glasgow & Clyde, Highland, Lanarkshire, Lothian and Tayside).

Suggestions for improving or modifying future meetings to make them more applicable or practical in your role?	General comments
I enjoy the format we have - opportunity for teaching from paediatric neurologists and peer review. Teams meeting more practical but do prefer to meet face to face. I personally preferred venue in Stirling rather than Perth (parking in latter not so good). Attendance generally the same faces.	I remain keen to take part in meetings in future
Perhaps rotating locations - some more central belt ones at times.	VERY valuable resource. In person meeting is extremely valuable to allow proper case discussions.
To continue having these important SPIEG meetings as part of SPEN	SPIEG meetings are extremely useful and educational. It's good to catch up with similar colleagues and have the Peer review session. Always thoroughly enjoy these days. Good topics discussed from a variety of guest speakers. Also good having a Tertiary Neurologist to oversee the Peer Review cases. It's good to hear updates from the SPEN Committee regarding on going SPEN business.
I really feel this meeting is super perfect for me to be honest	This meeting and the SPEN MCN are what allow quality paediatric epilepsy care to be delivered at the DGH level. Without them the equitable management of these children within their localities would not be possible.
Asking for common issues for all to then plan future sessions around I think is helpful	Thank you this is the first meeting I have been to for many years as a general paediatrician with an interest - peer support often from tertiary teams but I enjoyed the support of a team of people working in a similar environment to myself

Table 2: snapshot of other questions asked in the survey

- Delivery of the Annual Network Members' Day: A key event for SPEN to showcase the results of projects and work undertaken since April 2024, as well as to highlight ongoing initiatives and upcoming projects to stakeholders.

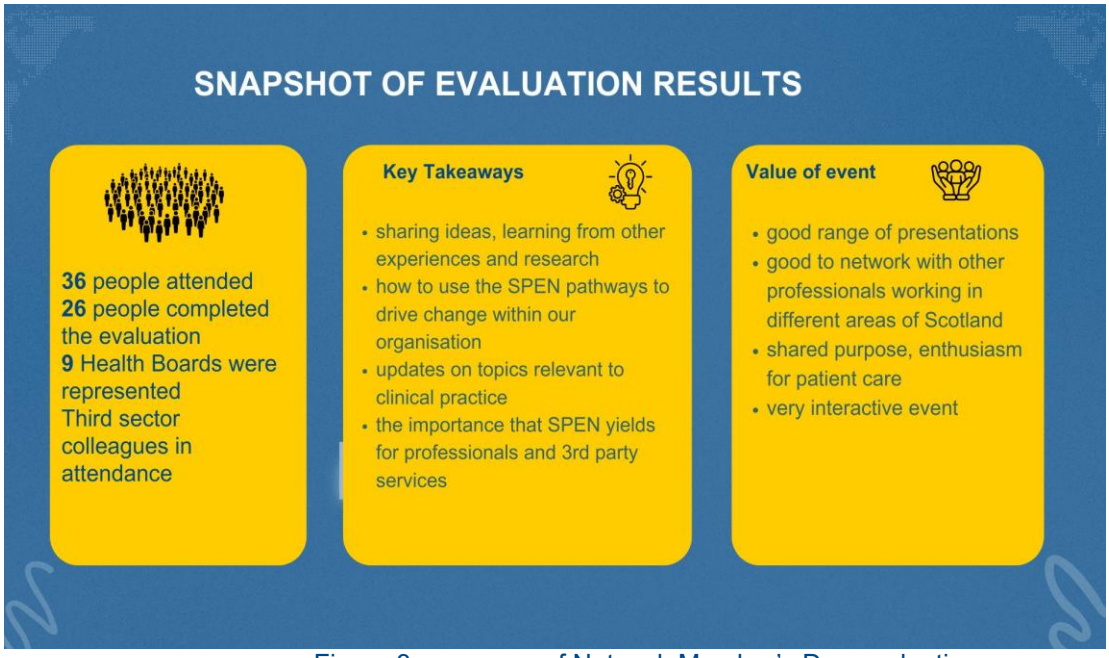
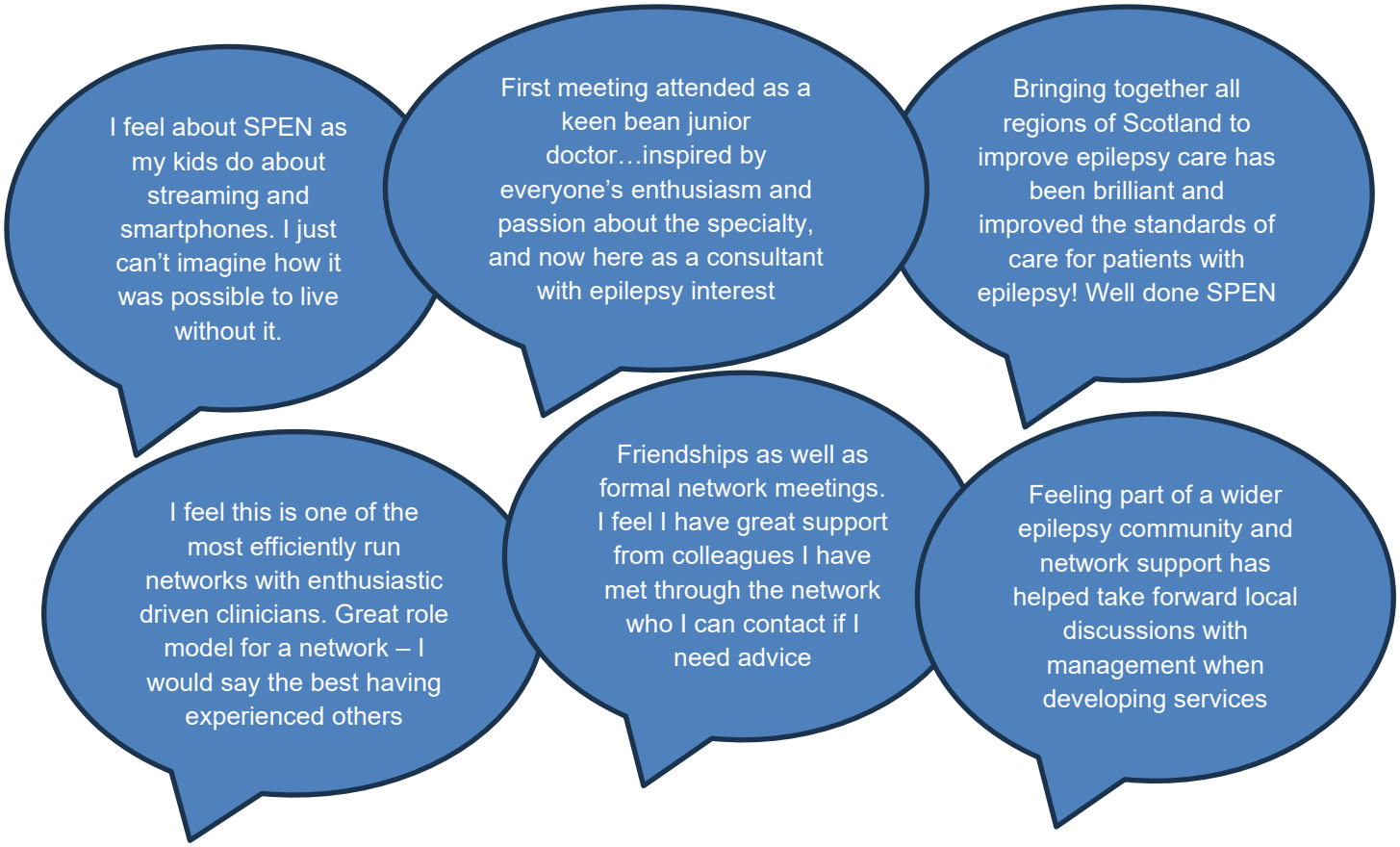


Figure 3: summary of Network Member's Day evaluation responses

This year's event was even more special as SPEN marked a significant milestone of 20 years since its establishment. To mark the celebration, time was allocated within the programme to hear some anecdotes and memories from colleagues, past and present. A poll was conducted to gather real-time feedback from delegates on "**how has the network added value to you**", "**what are your memories of SPEN"?**



Two Roadshows were delivered to local clinicians across Grampian and Ayrshire & Arran. These events reached a broader audience of professionals involved in the care of children and young people with epilepsy. The roadshows provided an opportunity to share updates on “Paediatric Status Epilepticus” and “Emergency intervention for seizures in the community”. The events also allowed local teams to present and discuss clinical cases. Responses to the evaluation from both events, confirmed that 86% of respondents would use the learning to contribute to their Continuous Professional Development (CPD) requirement for revalidation. It was not applicable to the remaining 14%. All respondents would highly recommend the Roadshows to colleagues.

Audit

SPEN has now completed the audit of children and young people with newly diagnosed epilepsy to identify if there are any improvements that can be made for this process. The audit focussed on children and young people who had an EEG between 1 January 2023 and 31 March 2023 and went on to be diagnosed with epilepsy.

All centres participated and submitted their key data to SPEN for a national review. The results will be analysed and an action plan developed.

Thank you to everyone who contributed to this piece of work.

TURAS module – Paediatric Epilepsy awareness and emergency medication training

The module has been available since 2022 with the aim to improve the understanding of Epilepsy and the principles that relate to the safe management of seizures and the administration of Buccal Midazolam

In line with governance policy, the module was recently assessed to ensure it remained clinically and patient safe and has been given a further 3-year extension without any amendments.

In this reporting year, 2,330 people accessed the module, with the following outcomes.

STATUS	LEARNERS	LEARNERS %
Completed	1946	83.5%
Failed	34	1.16%
In progress	350	11.95%

Table 3: numbers accessing Turas module

Website

An annual review of the website was conducted in December 2024. The review focused on streamlining the site for easier navigation, reducing the number of pages to view, and carefully managing potential risks and variations.

A statistical report was carried out on the website. Over the period, 1 April 2024 to 31 March 2025, there were 7,045 visitors to the site, which was down over the same period in 2023/24 which had 10,056 visitors. The decrease may be attributed to the recent review and streamlining of the website, which could have affected traffic patterns.

Looking forward – 2025/26

Due to the Scottish Government's ongoing review of national clinical networks, SPEN has been advised to plan only business-as-usual activity for the first quarter of 2025/26, i.e. through to the end of June. In terms of meetings, a Scottish Paediatricians with an Interest in Epilepsy Group (SPIEG) meeting is scheduled for mid-June. A Steering Group meeting, along with several subgroup meetings, have also been planned during this quarter.

Priorities for SPEN include:

- complete action plan for transition project
- complete the review of 3 clinical pathways
- complete the audit of newly diagnosed epilepsy patients
- Convene a communication and engagement working group to deliver communication and engagement as outlined in the strategy
- Delivery of the education strategy
- Review and update the joint clinic guidance and the SPEN Standards of Care

Finance

The network spend was £223 to support two education events.

Risks & Issues

The network recognises the importance of maintaining national coordination in areas such as education, clinical guidance, and quality improvement. Continued support will be essential to sustain these benefits for patients and professionals.

Stakeholders have highlighted the importance of maintaining national coordination to sustain improvements in care. Continued support will be essential to build on existing progress and deliver future benefits.