Scottish Paediatric Epilepsy Network

Annual Report
2025/26

The network is supported by a dedicated programme team within Public Services Delivery Scotland (PSD Scotland) consisting of:

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This document has been prepared by the National Services Directorate (NSD) of Public Services Delivery Scotland (PSD Scotland) on behalf of the Scottish Paediatric Epilepsy Network (SPEN). Accountable to Scottish Government, PSD Scotland 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 a PSD Scotland Programme Team to drive improvement across the care pathway.

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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 for children and young people under the age of 15 (Public Health Scotland GP Audit, 2025), 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. This finding formed a key part of the rationale for establishing the network.

Since its inception in 2004, 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 completed in September 2025. Scottish data from the UK-wide Epilepsy12 audits of paediatric epilepsy services in 2012 and 2014 demonstrated strong performance across Scottish services, with outcomes comparing favourably to other parts of the UK. SPEN continues to build on this foundation to drive further improvements in care for children and young people with epilepsy in Scotland.

Current Position

Activity during 2025/26 reflected national prioritisation set during a period of review. Alongside evolving national planning arrangements, Managed Clinical Networks were asked to focus activity on several core priorities.

Looking ahead, and consistent with the direction set by the Health and Social Care Service Renewal Framework and Scotland's Population Health Framework (June 2025) and recognising that CEL 29 (2012) *Managed Clinical Networks: Supporting and Delivering the Healthcare Quality Strategy* remains the extant mandate for Managed Clinical Networks. SPEN will build on its established approach by undertaking a Strategic Needs Assessment to inform the 2026/27 workplan and ensure priorities remain aligned to population need, current pathways, available data and stakeholder perspectives.

The priorities for SPEN in 2025/26 were:

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 and presented at Annual Members Day. Further information gathering to be undertaken to update service profiles and outputs will inform the Network's strategic needs assessment in 26/27
Identify areas for improvement and develop action plan for transition from paediatric to adult services	Short Life Working Group (SLWG) established to review output of scoping and patient engagement and identify actions.
Support the implementation of the new normal and SIGN 159 recommendations	Complete

Table 1: Priorities and progress against SPEN objectives

The network achieved all its business as usual (BAU) objectives in 2025/26.

Highlights

Transition (moving from paediatric to adult services)

Transition from paediatric to adult epilepsy services was identified as a priority for improvement at the network's Members' Day in November 2021 and subsequently included in the 2022-23 workplan. A review of transition arrangements across Scotland was initiated to identify good practice, challenges, gaps and recommendations for improvement and that phase is completed. The project remains in Phase 2, focused on patient experience and currently being piloted in NHS Grampian. Progress has been slower than anticipated due to low response rates to the patient questionnaire and the extended timescales required to capture transition experiences. As a result, advancement of this work has been limited and the project remains ongoing.

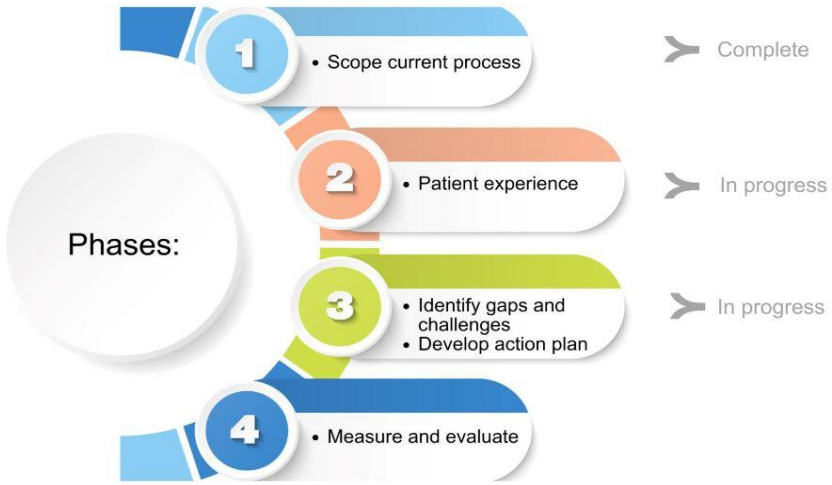

Figure 1: Transition progress

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 in-person event was held on 27 February 2026 in Perth Royal Infirmary. It brought together professionals and students from across Scotland to present recent, current, and future research studies in epilepsy. SEG were delighted to welcome two keynote speakers, Professor Tony Marson and Dr Gashirai Mbizvo from the University of Liverpool. In addition to the evaluation results outlined below, discussions from the presentations generated improvement ideas that the Steering Group will consider.

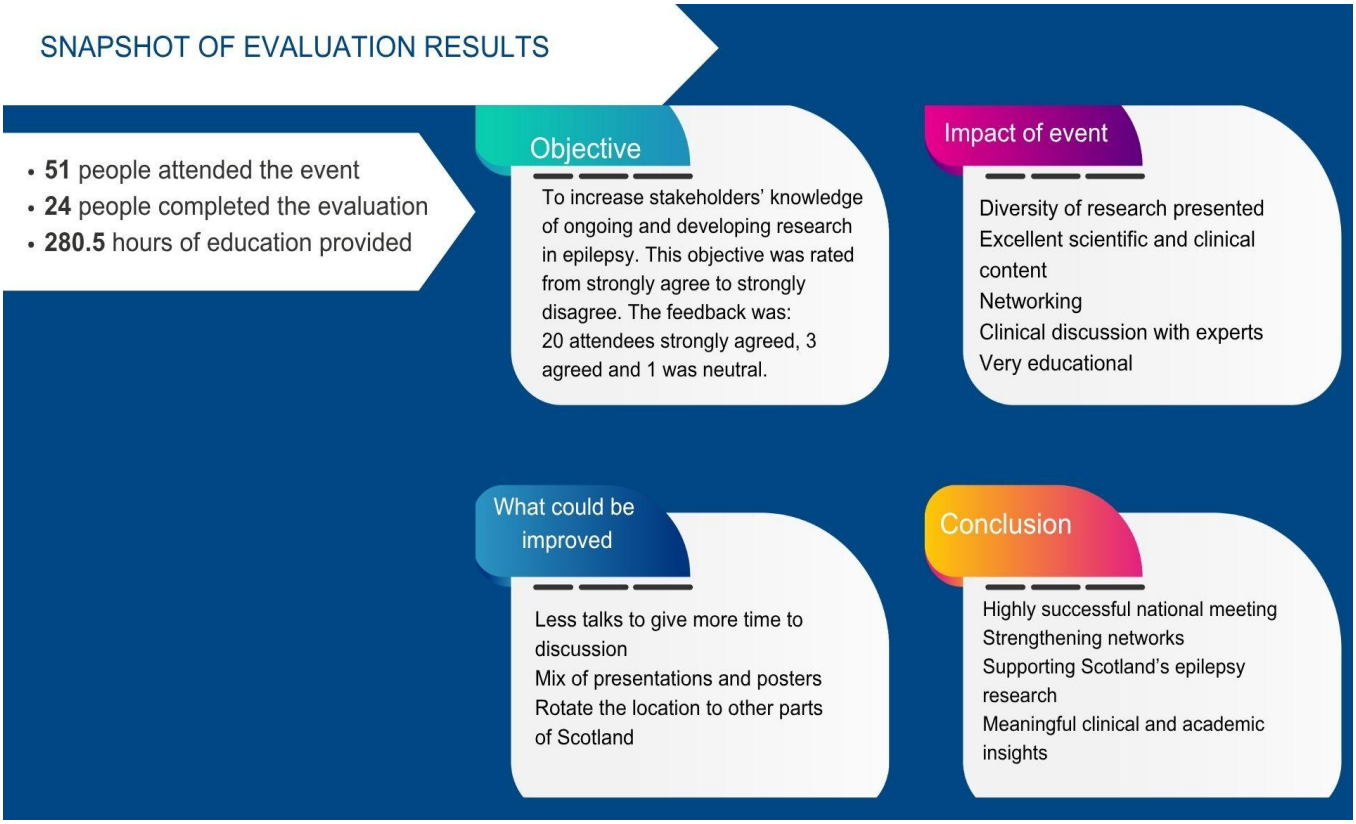

Figure 2: Summary of SEG research day evaluation responses

Three Scottish Paediatricians with an Interest in Epilepsy Group (SPIEG) meetings were delivered, providing an important forum for paediatricians leading epilepsy services across Scottish health boards. These meetings support national consistency and service improvement by enabling peer support, shared learning, and continuing professional development. Learning is supported through the discussion of clinical cases and presentations delivered by a range of professionals, with each meeting benefiting from the attendance of a paediatric neurologist who offers specialist insight, guidance, and expert advice.

Across all three meetings, there were 12 attendees from 6 health boards (NHS Ayrshire & Arran, Fife, Highland, Lanarkshire, Lothian and Tayside).

All respondents confirmed the meetings are used towards their appraisal and revalidation.

While clinical capacity constraints are recognised as a major factor affecting attendance, it is important that we continue to consider and identify ways to improve engagement.

- This year's Annual Network Members' Day was held on 30 October 2025 in Glasgow Royal Infirmary. This is a key event for SPEN where stakeholders can showcase the results of projects and work undertaken since April 2025, as well as to highlight ongoing initiatives and upcoming projects.
  A session was focused on spotlighting epilepsy charities alongside emergency services including Scottish Ambulance Service and NHS24 exploring the topic "unplanned care". Feedback highlighted this as especially useful, supporting a better understanding of how families experience emergency services and how professionals can support them more effectively. SPEN has identified areas for improvement in unscheduled care, and these would be considered within the strategic needs assessment. The session also included a lived-experience perspective which reinforced the vital role of community and charitable support for families.

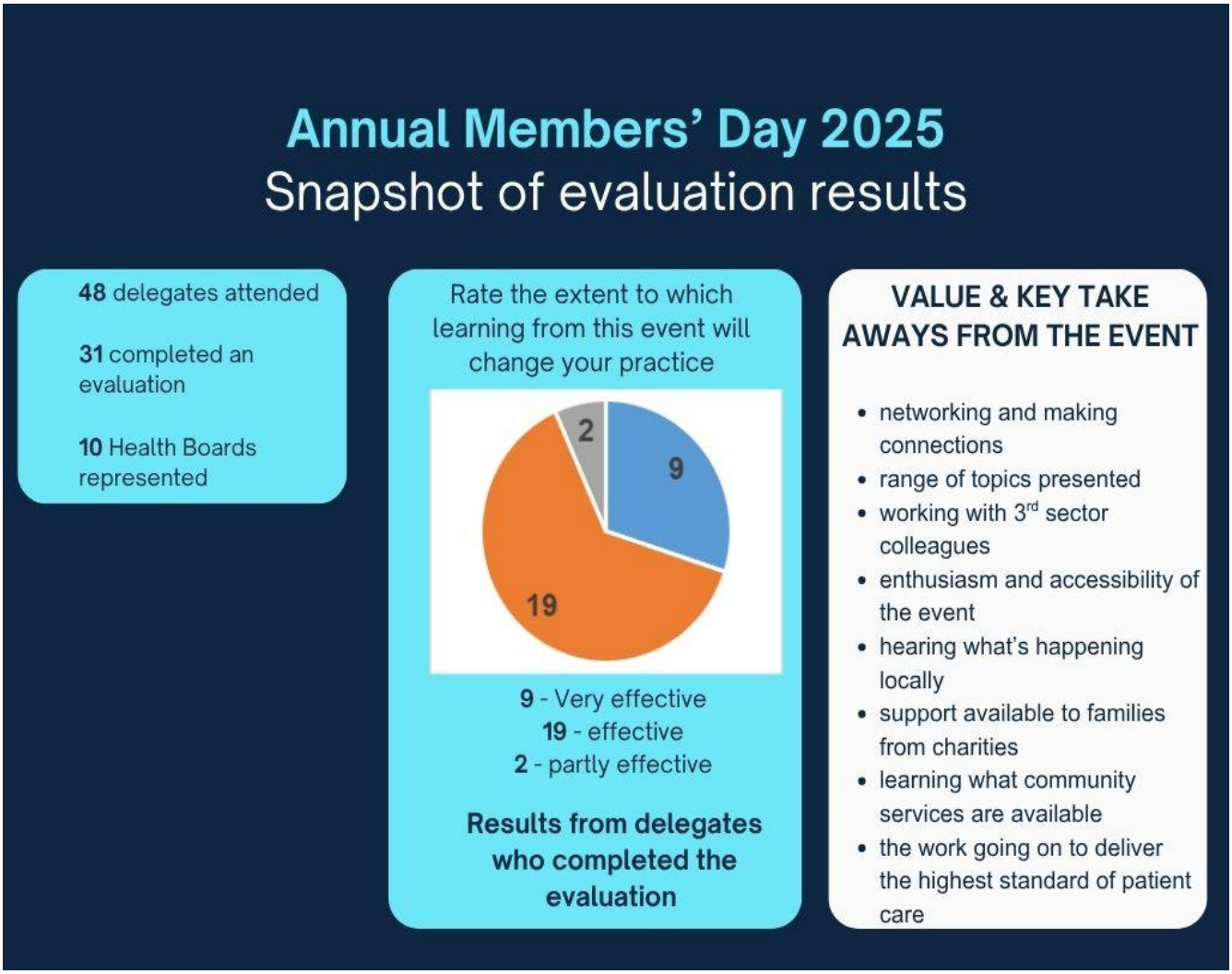

Figure 3: Summary of Annual Members' Day evaluation responses

- Three Roadshows were delivered to local clinicians across Lanarkshire, Fife and Tayside. Across all three roadshows, a total of 61 delegates attended, of whom 34 (56%) completed the evaluation.
  These events reached a broader audience of professionals, including nurse practitioners, accident & emergency consultant, pharmacists, paediatric registrars and consultant paediatricians who are 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.
  The table represents responses to "**rate the extent to which learning from the roadshow would change your practice**"

	Lanarkshire	Fife	Tayside
Very effective	75%	57%	14%
Effective	20%	29%	86%
Partly effective	5%	14%	0%

Table 2: responses to Roadshow question

  All respondents would highly recommend the roadshows to colleagues.
  The cycle of current topics is nearing completion, and SPEN will now consider new topics for implementation in the next two-year cycle.

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.

During this reporting year, 4,165 people accessed the module, representing almost a two-fold increase compared with 2024/25 (2,330 users). This substantial increase reflects the growing relevance, visibility and impact of the module. Feedback from the online survey details that approximately 95% of learners are from education and community social care settings, with the remaining proportion from nursing. The overwhelmingly positive comments consistently describe the module as informative, well structured, and particularly enhanced by engaging video content.

The table below provides a breakdown of this total across the three categories highlighted, alongside a comparison with 2024/25.

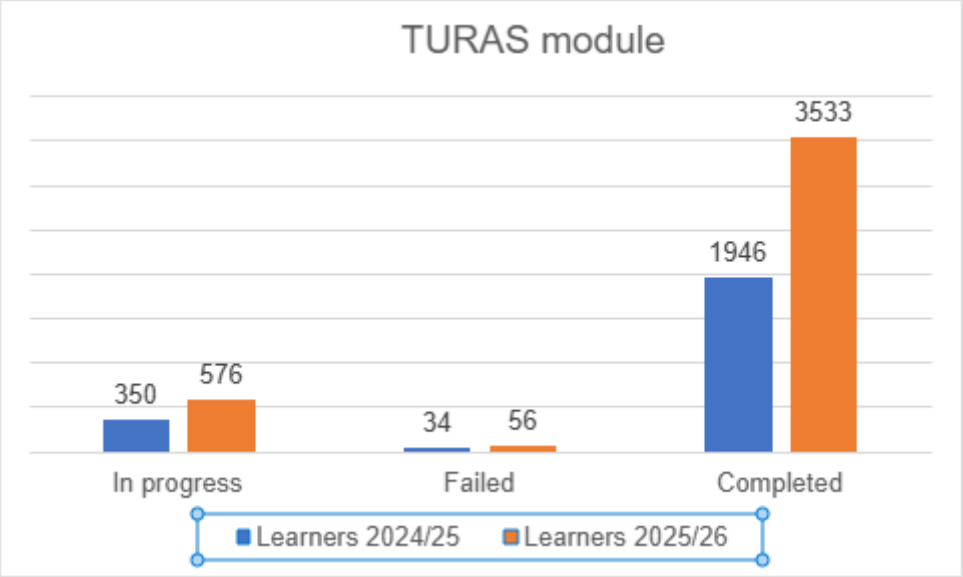

Table 3: numbers accessing Turas module

Audit

The audit of children and young people with newly diagnosed epilepsy was completed in 2025 and the results presented at the Annual Members Day. This identified a need to update the service profile for each health board and work is underway to refresh this. This will inform the Network's strategic needs assessment to be carried out in 26/27.

Review of pathways and guidance

Pathways

In early 2025, a short-life working group was established to undertake an in-depth review of three clinical pathways. This work involved significant input from members, with the group meeting on a few occasions and maintaining ongoing discussion and progress via email between meetings.

Pathway 1 – First seizure
Pathway 2 – Diagnosis and initial management of epilepsy
Pathway 3 – Continuing epileptic seizures

By September, the review had been completed and, in line with governance process, was signed off by the Steering Group. Reviews are conducted on a three-year cycle with the next review scheduled for September 2028.
The pathways are available on the SPEN website:
https://www.nn.nhs.scot/spen/professionals/spen-pathways-and-standards/

Website

An annual review of the website was conducted in January 2026. The review continues to focus on streamlining the site for easier navigation and carefully managing potential risks and variations.

A statistical report was carried out on the website. Engagement rose substantially during the reporting year, with 15,711 visitors accessing the site. This reflects a significant increase compared with the previous year (4,261 visitors).

Looking forward – 2026/27

SPEN will undertake a strategic needs assessment to inform the workplan for the next three to five years and to agree clear, evidence-based and measurable outcomes. This is an extensive piece of work, spanning scoping, gap identification and the formalisation of a workplan, and is therefore expected to continue throughout this reporting year.

SPEN will work collaboratively with other clinical networks on a project to develop a consistent, Scotland-wide process for notifying the Scottish Ambulance Service, via the Emergency Care Summary, of children and young people with epilepsy who have anticipatory care plans.

Other priorities for SPEN include:

- complete action plan for transition project
- review the joint clinic guidance and the Buccal Midazolam guidance
- finalise a consistent approach to providing information about Sudden Unexpected Death in Epilepsy (SUDEP)

Further areas for development have been identified and will be considered through the strategic planning process to ensure they are prioritised appropriately.

Finance

The network is funded through Public Services Delivery Scotland and operated within its approved budget during 2025/26.