Scottish Paediatric Epilepsy Network

Annual Report

2023/24

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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 and 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 96% of its objectives in 2023/24 (all BAU and 6 out 7 service development activities). Due to clinical pressures, developing a mental health strategy for children with epilepsies was delayed. The strategy was drafted and will be approved early in 2024/25.

Highlights

Transition (moving from paediatric to adult services)

A key piece of work undertaken by the network was an audit of current transition and transfer processes for young people with epilepsy across Scotland. Transition was highlighted by SPEN members as an area for improvement. The audit is part of an overall project reviewing how young people move from paediatric services into adult services and identifying challenges and gaps to understand areas for improvement. The project would be delivered using a phased approach as demonstrated in the diagram below.

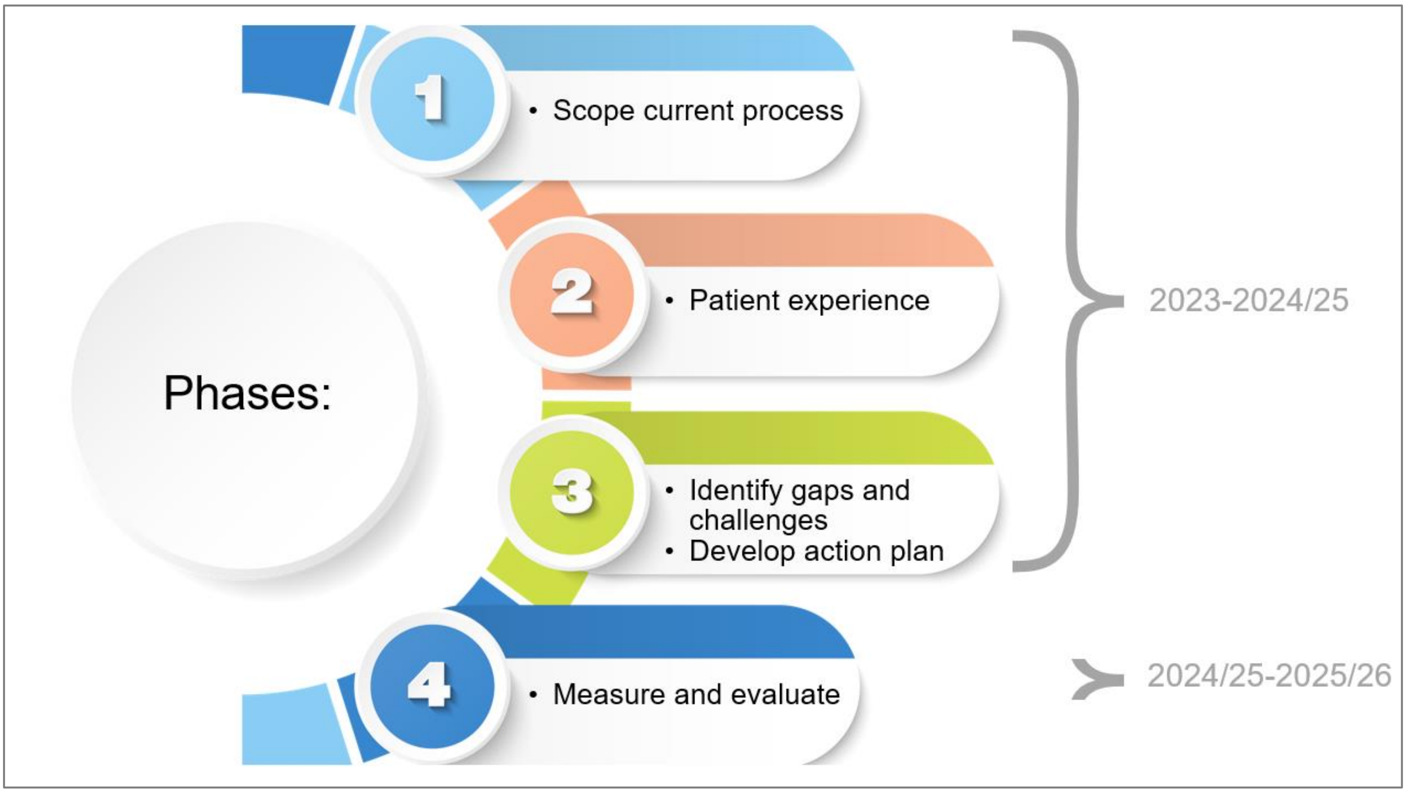

Figure 1: Transition project timeline

The assistant programme manager and senior programme manager met with the relevant boards through MS Teams between June and October 2023. A standard question set was used to ensure consistency across responses. This completed phase 1 of the project - scope current process. The collated information was presented at the SPEN members day in November 2023 and contributed to the facilitated sessions on transition. Progress through the project will continue into 2024/25.

“The New Normal”

In 2022/23 we reported on the work to explore how to use learning about new technologies during the COVID-19 pandemic to support the delivery of an effective and efficient paediatric epilepsy service. Recommendations were developed and approved by the steering group in August 2023. The recommendations document was added to the SPEN website and circulated in February 2024 to paediatric epilepsy services across NHS Scotland along with a self-assessment form for each board to complete. The purpose of the self-assessment was to benchmark current practice against the recommendations. Nine of the 11 NHS Boards have completed the self-assessment. Of the boards that responded, there was 81% compliance across the 16 recommendations. There were varying reasons where boards were not compliant, including lack of resource and capacity. However, most boards have plans in place to review their practices to meet the recommendations. Some boards requested support from SPEN which will be reviewed in 2024/25.

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

All health boards in Scotland providing paediatric epilepsy care reported their compliance against the recommendations outlined in SIGN 159 and their local action plans to achieve this. Areas for national support were identified as transition and mental health, both of which are part of the SPEN workplan for 2024/25.

The table below provides a summary of NHS Scotland compliance overall.

SIGN 159 Recommendation Type	Overall compliance	Areas for improvement
Key	89%	• Transition
Conditional or strong	87%	• Transition • Cognitive, developmental, and psychiatric comorbidities
Best practice	86%	• Transition • Cognitive, developmental, and psychiatric comorbidities

Mental health and wellbeing in children with epilepsy

A Short Life Working Group (SLWG) was established in 2023/24 to develop a mental health strategy building on developments in this area and the evidence outlined in the SIGN 159 guideline. In line with SIGN 159, and the ambitions of the Scottish Government Mental Health and Wellbeing Strategy, the SPEN strategy focuses on:

- Making available a tool to identify mental health and wellbeing needs. Following successful implementation in NHS Lothian, SPEN will work with the NSS Innovation Team to make the Psychology Adding Value: Epilepsy Screening tool available to all paediatric epilepsy teams to identify and mental health and wellbeing needs.
- Mapping early interventions where mental health and wellbeing challenges are identified. This will include a review of what could be provided at a national or regional level.
- Work with the National Autism Implementation Team to explore improvements in accessing support for young people with epilepsy and neurodiversity.

Education

SPEN carried out a mapping exercise to understand what education resources were available to professionals caring for children with epilepsy. It enabled the network to identify any gaps and challenges to professionals accessing education and training resources. As part of this, the paediatric nurse specialist group have agreed with the Roald Dahl charity to widen the support and access to their courses for epilepsy nurses in Scotland. This will be through extending the Roald Dahl adoption scheme to relevant epilepsy nurses.

A deliverable from this exercise was a comprehensive list of educational opportunities. The list will be added to the SPEN website and circulated to SPEN members. The list and outcomes of the resource mapping contributed to the SPEN education strategy review and refresh.

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 day. The event, held on 23 February 2024 in Perth Royal Infirmary, brought together professionals and student from across Scotland to present recent, current, and future research studies in epilepsy. SEG welcomed keynote speaker Dr Elaine Hughes from Evelina Children's Hospital and Kings College London.

- built so much knowledge
- new knowledge on care
- understanding Dravet for patient like PTSD
- more confidence
- insight
- very informative
- broad overview

- collaboration
- networking
- hear from other areas
- share experience
- input from clinical work

"Such an excellent and interesting day"
"Great day and very interesting to hear from so many professionals"

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 where required.

Audit

SPEN have initiated an audit of children and young people with newly diagnosed epilepsy to identify any improvements that can be made for this process. The audit will focus on children and young people who had an EEG between 1st January 2023 and the 31st March 2023 and went on to be diagnosed with epilepsy.

Each centre will collate some key measures about each of these young people and they will be submitted anonymously to SPEN for review of the national picture and identification of any improvements.

Annual stakeholder survey

A stakeholder survey was shared in March 2024 to gather feedback from people who currently work within, are involved in, or are impacted by the network. The survey was issued to approximately 150 SPEN stakeholders. The response was 19.

- 95% responses ‘strongly agreed’ or ‘agreed’ that the network provided a structure to make service improvements in paediatric epilepsy care
- 84% responses ‘strongly agreed’ or ‘agreed’ that the networks service development activity adds value to paediatric epilepsy care
- 79% responses from staff ‘strongly agreed’ or ‘agreed’ that the networks education programme adds value to paediatric epilepsy care
- 68% responses ‘strongly agreed’ or ‘agreed’ that the networks audit and continuous quality improvement activity adds value to paediatric epilepsy care.

The survey was also an opportunity for stakeholders to share feedback on network strengths, network challenges, areas for improvement and the priorities for the next few years. The responses are summarised below:

Strengths	**Areas for Improvement**
• Networking • Sharing knowledge and developments • Strong leadership and engagement • Good connections and networking • Special interest subgroups • In person education days • Communication and collaborative working • Very approachable and always willing to help • Rapid spread of good ideas • Raising standards of care through network • Good education programme	• Better ability to engage colleagues in remote areas • Increased opportunity for third sector contributions • A return to Epilepsy 12 (Scottish Government) • More involvement with patients and families • Better participation
Suggested Future Priorities (3-5 years)	**Network Challenges/Threats**
• Support existing activities which provide excellent value for money in terms of improving lives for young people with epilepsy • Education for staff • Keeping people safe - patients and staff difficulties • Support, maintain and develop our workforce • Robust data collection to enable change • Transition • Support mental health and wellbeing • New medications and research • Support delivery of evidence-based practice • Working together on clinical pathways	• Finances detracting from effective delivery of shared learning events • Need to maintain good communication between tertiary centres and district general hospitals • Disengagement due to increased pressures at work, time etc. • Professional engagement • There is a need for F2F meetings for clinicians to exchange experiences and ideas • Scarce engagement

The feedback will be considered by the SPEN steering group and action plan will be developed to support areas for improvement.

Looking forward – 2024/25

Priorities for SPEN in 2024/25 include:

- Implement the SPEN mental health strategy
- Complete phases 2 and 3 of the transition project
- Audit of newly diagnosed epilepsy
- Convene a communication and engagement working group to deliver communication and engagement as outlined in the strategy
- Delivery of the education strategy
- Finalise the SPEN approach to information on SUDEP.

Finance

The network spent £2,341.97 of its £5,000 budget on education events and meetings.

Risks & Issues

None identified.