

Scottish Paediatric Epilepsy Network

ANNUAL REPORT 2018/19

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1. Executive Summary

2018/2019 has been a successful year for the Scottish Paediatric Epilepsy Network (SPEN), but not without its challenges. This report provides an overview of the achievements of SPEN, the challenges and the plans for 2019/2020.

The networks key achievements include:

- Delivery of a programme of multi-disciplinary education which includes road shows, a study day, a research day and Scottish Paediatrician with an Interest in Epilepsy Group meetings
- Development of joint clinic guidance to provide guidance and support around joint paediatric epilepsy clinics
- Increased reach of SPEN by engaging with a wider range of stakeholders including adult services, General Practitioners and Education
- Successful pilot of the Psychology Adding Value: Epilepsy Screening (PAVES) project to address unmet mental health support needs of children and young people with epilepsy
- Development of an updated paediatric epilepsy SIGN guideline in partnership with the Scottish Intercollegiate Guidelines Network (SIGN)

The main challenge for SPEN in 2018/2019 continues to be participation in the UK-wide Epilepsy 12 audit. The clinical consensus within the network is that Epilepsy 12 presents the best way forward for meaningful audit in support of quality improvement. However, to date Scottish Government have not supported Scottish participation in the audit. Taking into account the positive impact of Epilepsy 12 in England, discussions about Scottish participation are still ongoing. However, pending a definitive answer the network has been unable to progress data collection and audit as until there is a final outcome regarding Epilepsy 12 it is difficult to seriously investigate alternative options.

Plans for 2019/2020 include:

- Continue to engage with wider range of stakeholders, in particular GPs and the Scottish Ambulance Service
- Explore options for establishing a patient reference group
- Support the implementation of newly developed joint clinic guidance where joint clinics are the preferred model of care
- Continue to deliver multi-disciplinary education programme
- Support the implementation of the new SIGN guideline

2. 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).

Care for children with epilepsy is available across Scotland through general paediatric services with support from tertiary specialists in Glasgow, Edinburgh and Dundee. Pathways for first seizures and ongoing epileptic seizures were developed by the network in 2007 and revised in 2017/2018. 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.

In line with national commissioning policy, there was a review of SPEN during 2017/2018. On considering the findings NSSC agreed that SPEN should continue to be designated for another commissioning cycle. The review group recognised that SPEN had been very effective and had added value to NHS Scotland. The review group also made a number of recommendations for SPEN:

1. develop its communication and engagement to be more effective by:
 - a. Engaging with a broader range of stakeholders, most notably:
 - adult epilepsy services,
 - the education sector,
 - Integration Joint Boards,
 - primary care
 - b. Linking with other national networks to explore the feasibility of delivering joint events to address generic or cross-cutting themes that affect multiple networks
 - c. Utilising additional funding sources to enable increased engagement with patients and families
2. better demonstrate the measurable benefit its work has on patient outcomes by increasing its audit activity and its use of quality improvement methodology – this should look at exploring ways of securing access to Epilepsy 12 in the short term, and longer term, building up additional audit capacity within the network
3. establish the unmet need for mental health and wellbeing support among children and young people with epilepsy in Scotland

This annual report sets out the Scottish Paediatric Epilepsy Network’s progress from 1st April 2018 to 31st March 2019.

3. Report on Progress against Network Objectives in 2018/19

National networks have agreed core objectives that reflect the Scottish Government's expectations for managed clinical networks, as described in CEL (2012) 29¹. The network's core objectives are:

- a) Design and ongoing development of an effective Network structure that is organised, resourced and governed to meet requirements in relation to SGHSCD Guidance on MCNs (currently CEL (2012) 29) (see Annex C) and national commissioning performance management and reporting arrangements;
- b) Support the development and delivery of services that are evidence based and aligned with current strategic and local and regional NHS planning and service priorities.
- c) Effective Stakeholder Communication and Engagement through design and delivery of a written strategy that ensures stakeholders from Health, Social Care, Education, the Third Sector and Service Users are involved in the Network and explicitly in the design and delivery of service models and improvements.
- d) Improved capability and capacity in paediatric epilepsy care through design and delivery of a written education strategy that reflects and meets stakeholder needs.
- e) Effective systems and processes to facilitate and provide evidence of continuous improvement in the quality of care (CQI).
- f) Generate better value for money in how services are delivered.

This report gives an overview of progress against these objectives in the year 2018/19.

3.1. Effective Network Structure and Governance

The Network is overseen by a multidisciplinary, multiagency Advisory Board chaired by Carol Goodman, Regional Programme Manager, North of Scotland Planning Group. In addition the Network has a smaller executive Steering Group that supports the Lead Clinician and network Programme Manager with the day to day running of the Network. This group reports to the Advisory Board. Both the Advisory Board and the Steering Group have third sector partner representation. Dr Krishnaraya Kamath Tallur, Consultant Paediatric Neurologist, NHS Lothian, has been Lead Clinician since February 2017 and his tenure is scheduled to run until 31st January 2020.

The Service Agreement for SPEN runs from 1st April 2019 until 31st March 2022. The network has a strategic three year work plan which runs until 2021. Terms of reference for the Steering Group are due to be reviewed during 2019/2020.

3.2. Service Development and Delivery

1. SIGN guideline

A revised SIGN guideline for children and young people with epilepsy has been completed and is due to be formally launched later in 2019. Work took place in partnership with SIGN to revise the guideline over a series of multi-disciplinary meetings. This guideline will replace the now withdrawn SIGN 81 guideline. Supporting the implementation of the new guideline will be a key network objective during 2019/2020.

2. Joint clinic guidance

Joint clinic guidance, which specifies minimum standards for joint clinics between local and tertiary specialist epilepsy clinicians, has been developed to supplement the SPEN Quality Standard. Joint clinics are in place across many network centres, however there was no agreed standard arrangement. This document was developed to provide guidance and to facilitate discussion around creating more formal arrangements for joint paediatric epilepsy clinics.

¹ Please see: https://www.sehd.scot.nhs.uk/mels/CEL2012_29.pdf

3. *SPEN Quality Standard audit*

SPEN developed a clinical quality standard in 2017/18. Discussion was planned with regional child health planning groups as to how to best implement this in practice. However, so far the regional child health planning groups were unable to engage in this discussion due to a number of cancelled meetings. This will now be circulated electronically for comment. The lack of progress with the Epilepsy 12 audit in Scotland (please see section 3.5 below) also impacted on the network's ability to confirm the audit mechanism for the quality standard audit. The objective has been carried forward into 2019/2020.

Two nursing projects, defining care planning and review of the epilepsy nurse career path have been carried forward into 2019/2020 due to capacity issues within nursing.

3.3. Stakeholder Communication and Engagement

1. *Engagement with education*

Throughout 2018/2019 efforts were made to engage with a wider range of stakeholders. One of these identified key stakeholders was the education sector, particularly aimed at linking with teacher training with a view to including epilepsy awareness training in the undergraduate curriculum. SPEN initially wrote to the General Teaching Council in July 2018 to ask whether this was achievable and to meet to discuss. Despite attempts to follow up on this initial letter there had been no useful response by 31 March 2019.

2. *Engagement with primary care*

In addition to the education sector, SPEN identified primary care as a priority for improved engagement. In order to build a better relationship with primary care colleagues SPEN wrote to all GP leads in Scotland with information about SPEN and an invitation to meet to discuss better engagement. Of the 150 GP leads across Scotland only one positive response was received from North East Glasgow. Dr Tallur and Mr Durkan presented to the North East Glasgow GP forum in October 2018. Although this was a good opportunity to raise awareness of SPEN within the North East of Glasgow this was clearly only a small part of the GP community across Scotland. Further plans are being taken forward through 2019/2020 to increase engagement with Primary Care.

3. *Engagement with adult services*

Adult epilepsy services were another area identified as a priority. An adult service representative has expressed interest, via Epilepsy Scotland, in joining the SPEN advisory board.

4. *Patient engagement*

As well as engagement with professionals SPEN hosts patient and family events to ensure that patient and their families' inform the strategic direction of SPEN. The most recent event took place in June 2018 at the Glasgow Science Centre.

Eleven families provided feedback via the evaluation forms provided on the day. Overall, feedback was positive for all aspects of the adult programme, as shown in figure 1 below.

Adult Programme - Ratings

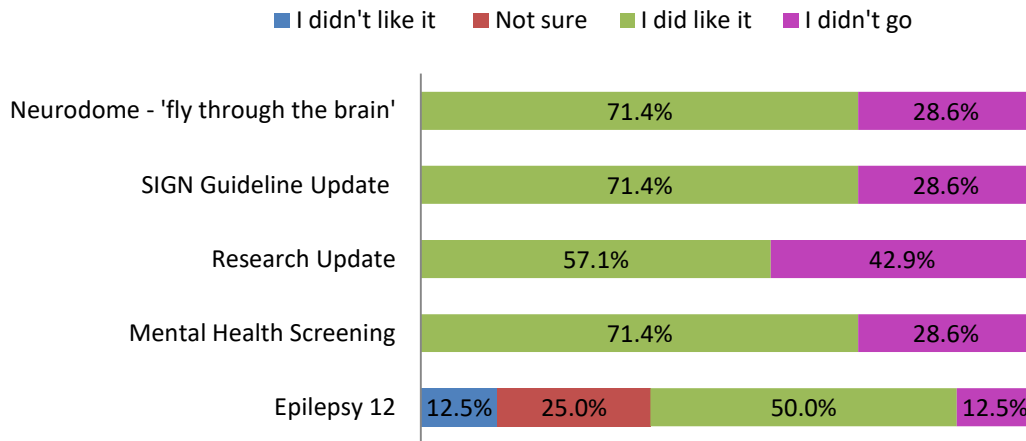


Figure 1: SPEN Family Day Adult Programme Participant Feedback

Feedback from patients/ siblings is shown in figure 2 below:

Children/ Young People Programme - Ratings

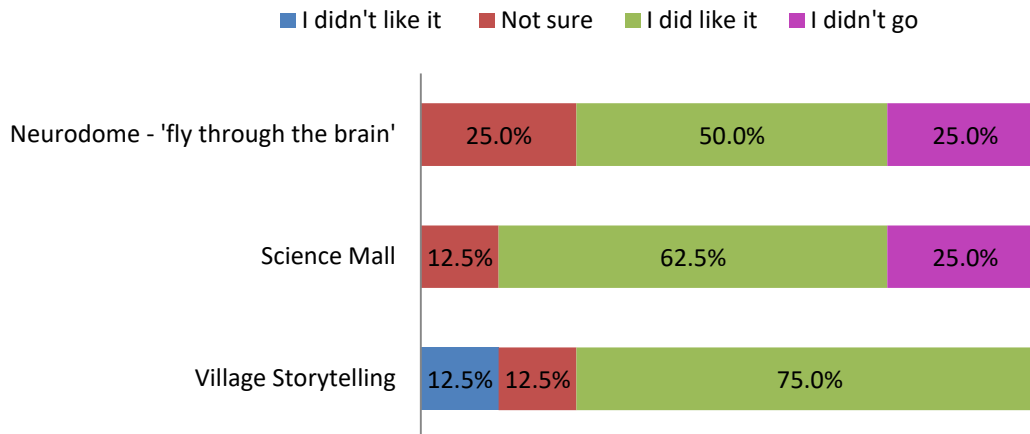


Figure 2: SPEN Family Day Children/ Young People Programme Feedback

As part of the patient/ young people's programme, both patients and their siblings were invited to participate in a 'Village Story Telling' session. The aim was to discuss with the children what their experiences and issues are and to ascertain what changes they would suggest for paediatric epilepsy service. By asking the children to describe this child/ young person and his/ her circumstances, feelings and experiences, key insight can be gained into their own experiences. Full feedback of this session is available from the post event evaluation report.

As well as engaging directly with patients and families SPEN also work closely with third sector organisations. SPEN regularly engage with Epilepsy Connections and Epilepsy Scotland both of whom are on the advisory board.

5. *Stakeholder engagement*

Quarterly email newsletters had previously been established as the primary mechanism for communicating with members. As newsletters were circulated by email it was difficult to measure their reach, which made evaluating and improving them challenging. In order to address this the SPEN newsletter has been moved onto the SPEN website. This allows for standard website analytics to be used to measure engagement with individual stories and the newsletters as a whole. An email will still be circulated advising the newsletter is available however rather than having the newsletter attached it will simply hyperlink to the newsletter page or individual story. As this change in process was only implemented after the February 2019 Steering Group meeting, it is too soon to report on the impact of this move. It is hoped that benefits will be shown by the 2019/2020 mid-year report.

An annual member's day is held each year to engage with the wider membership of the network on key issues. This also provides an opportunity to update members on progress over the previous year and plans for the year ahead. This year's meeting was held in conjunction with SIGN, the afternoon was dedicated to consulting on the new SIGN guideline.

6. *Sudden Unexplained Death in Epilepsy information leaflet (SUDEP)*

A SUDEP patient leaflet has been developed to increase awareness and understanding of SUDEP. Although the content of the leaflet has been agreed it was felt that the design of the leaflet could be improved to be less text heavy and more visual. The leaflet has been passed to the NSS communications team for their design input with a view to publishing the final leaflet in 2019/20.

3.4. Education

SPEN delivers a programme of professional education based on identified need as defined by the SPEN education strategy, which was ratified by SPEN in August 2018.

1. *SPEN Road shows*

Two road shows took place in 2017/2018 in Wishaw and Edinburgh. A third road show planned for NHS Borders was postponed until 2019/2020 due to local capacity issues. These road shows are aimed at general paediatricians, nursing staff and medical students. The content of the road show programme is updated periodically (usually over a two to three year cycle) to respond to learning priorities identified by attendees. The current cycle, which is due to conclude with the Borders road show, covers the differential diagnosis of non-epileptic seizures, an update on newer anti-epileptic drugs and the recently revised SPEN pathways.

35 delegates attended across the two sessions with evaluations received from 27 delegates. Key evaluation data is included below. Full evaluation reports for all education events are available from the [SPEN website](#).

SPEN Roadshows 2018/19: Delegates

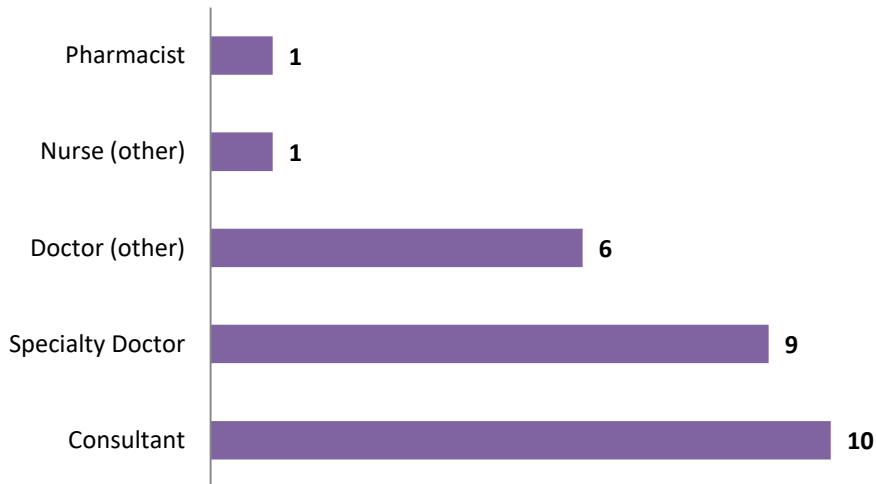


Figure 3: SPEN road show delegates by staff groupings

SPEN Roadshows 2018/19: Effectiveness of Education

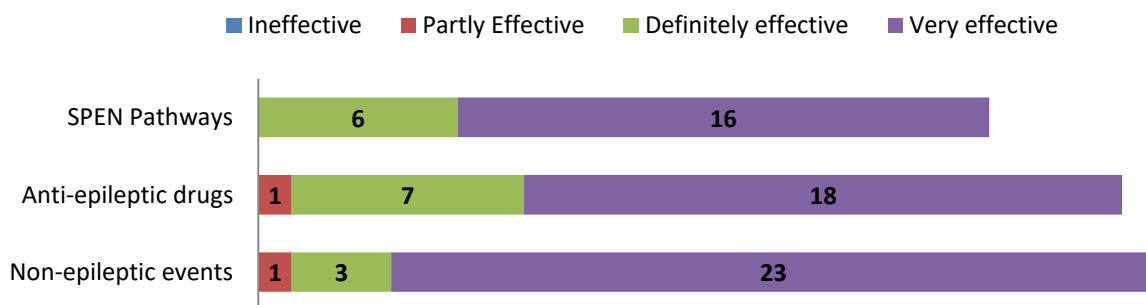


Figure 4: SPEN road show effectiveness of education

Figure 4 above highlights the effectiveness of the education delivered at road shows. The feedback shows that delegates value the effectiveness of road shows in delivering education. All but one attendee rated the effectiveness of the education as definitely effective or very effective across all three presentations.

Impact of road shows on practice

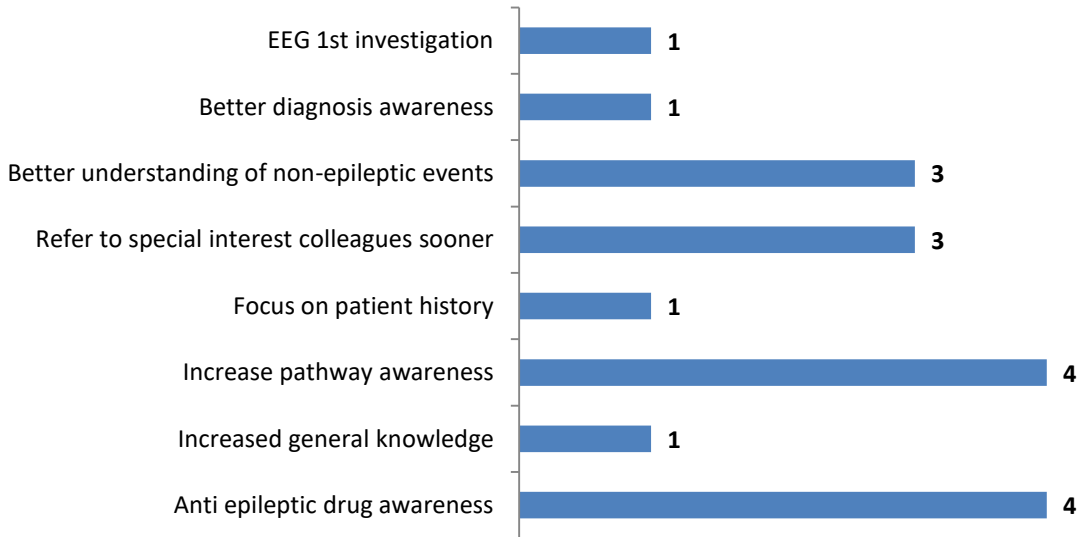


Figure 5: SPEN road show impact on practice

Figure 5 highlights the impact on delegates' clinical practice as a result of attending the event.

2. Study days

Each year SPEN hosts a study day aimed at clinicians who care for children and young people with epilepsy. The 2018 event was held on 5th October at the Discovery Centre in Dundee. The event was attended by 50 delegates, which was an improvement on previous years. The Study Day provided updates on a range of clinical topics to clinicians from across Scotland and evaluation showed that respondents considered the day relevant to their practice and well structured, both in terms of format and content.

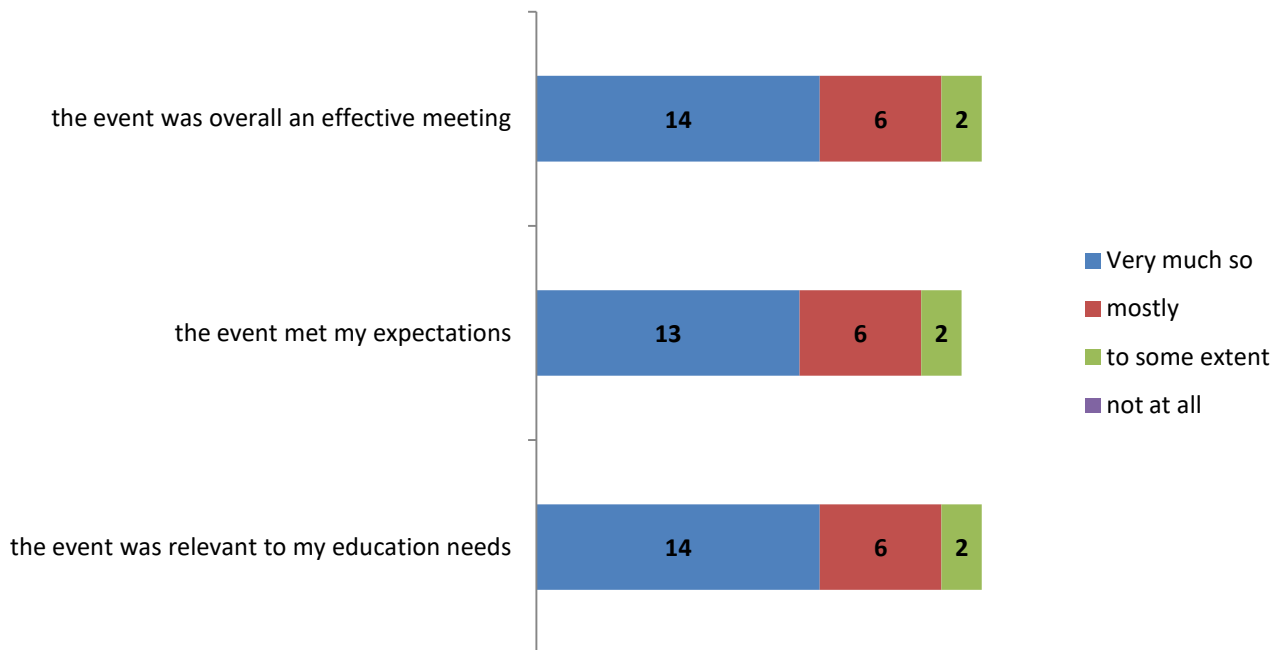


Figure 6: SPEN road show impact on practice

Impact on practice of study day

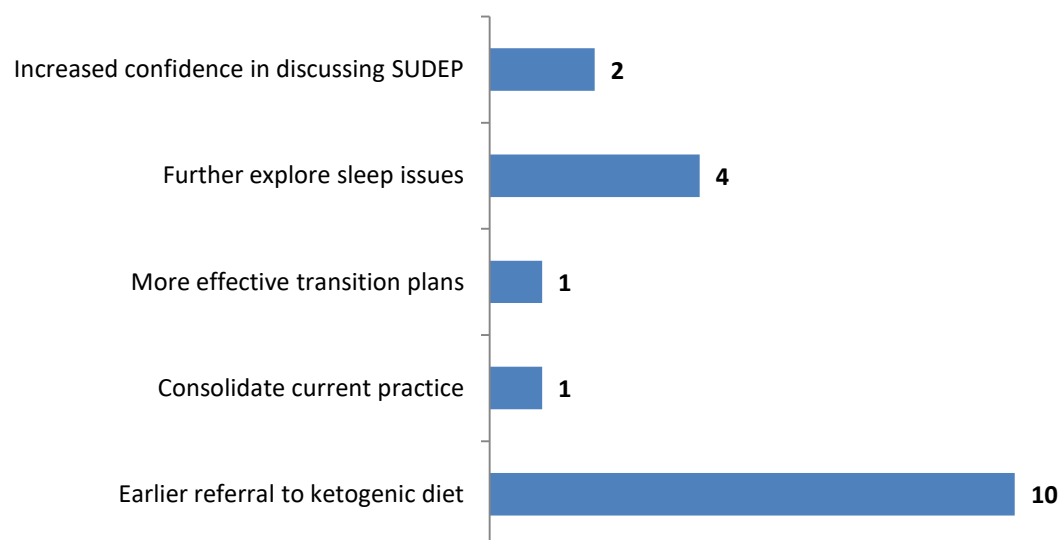


Figure 7: SPEN study day impact on practice

Figure 7 shows the positive impact on clinical practice for the delegates who attended the event and completed an evaluation.

3. Scottish Paediatrician with an Interest in Epilepsy Group (SPIEG)

In addition SPEN supports three SPIEG meetings annually. This group provides education, peer review and tertiary input for district general hospital (DGH) paediatricians with an interest in epilepsy. Although attendance at these meetings is generally good there is agreement that it could be better. Work in 2017/18 to improve uptake has been successful in broadening the active engagement of paediatricians, enabling colleagues to attend who had previously been unable to do so. However, discussions are ongoing in order to increase engagement further.

3.5. Audit and Continuous Quality Improvement

1. Psychology Adding Value: Epilepsy Screening (PAVES)

The PAVES project was developed under the auspices of SPEN as a pilot project in NHS Lothian to identify unmet mental health support needs in children and young people with epilepsy and design effective pathways for early intervention. Following the successful pilot in Edinburgh an application was made to the Scottish Government's Realistic Medicine Fund to further develop the PAVES approach to allow for a wider roll out. This would involve the use of electronic tools to automate certain aspects of the screening approach. This application was successful. With support from National Procurement a formal tender exercise is taking place to develop an electronic PAVES screening tool.

2. Epilepsy 12

The clinical consensus within the network is that Epilepsy 12 presents the best way forward for meaningful audit in support of quality improvement. However, to date the Scottish Government have not supported Scottish participation in the audit. Taking into account the positive impact of Epilepsy 12 in England, discussions about Scottish participation are still ongoing. The failure to secure Scottish participation in round 3 of the Epilepsy 12 audit has continued to impact on SPEN's capacity for data collection, audit and Quality Improvement. While the discussion about Scottish participation in Epilepsy 12 continues it is difficult to move onto investigating alternative systems for data collection and audit without some risk for the case for Epilepsy 12 being weakened.

3.6. Value

Much of the focus of SPEN during the reporting period 2018/2019 has been to address the recommendations of the SPEN review. This has involved engaging with wider stakeholders such as GPs and the education sector. This will continue into 2019/2020 with continued GP engagement and engaging with Scottish Ambulance Service.

SPEN continues efforts to reduce variation in care. A revised SIGN guideline has been completed and is due to be launched during 2019/2020. Implementation of this guideline will be supported by SPEN. Joint Clinic guidance and a quality standard audit continue to provide a framework for improving epilepsy services for children and young people across Scotland.

SPEN also has a well established programme of education which continues to build expertise and increase capacity across services in Scotland. Attendance at these events continues to grow and feedback shows that they continue to be relevant and effective.

4. Plans for the Year Ahead

Plans for 2019/2020 include:

- Continue to engage with addition stakeholders to ensure that the network continues to be effective. This includes education, primary care and ambulance services.
- Explore options for establishing a patient / family reference group
- Support the implementation of new SIGN guideline
- Support the implementation of joint clinic guidance in areas where joint clinics are the preferred model of care
- Continue to deliver a multi-disciplinary education programme
- Progress a strategic approach to audit and quality improvement for the network

b) Risks

As mentioned above, the main challenge for SPEN continues to be audit, chiefly the question of Scottish participation in Epilepsy 12. Without a definitive answer to this question, it is difficult to move the discussion within the network on to investigate alternatives mechanisms of data collection and audit.

Engagement with a wider range of stakeholders has been a key objective for SPEN throughout 2018/2019 and into 2019/2020 however this relies on those wider stakeholders – such as GPs or the education sector – willingly engaging with SPEN. It is recognised that there are competing demands on the time and attention of these wider stakeholders. This must be factored in to the efforts of the network and places the onus on SPEN to clearly express the value of engagement SPEN will provide to these stakeholders.

5. Detailed Description of Progress in 2018/19

Objective Number	Smart Objective	Linked Dimension s of Quality	Planned start / end dates	Detailed Plan Available / Owner	Description of progress towards meeting objective as at 31/03/2019	Anticipated Outcome	RAGB status
SPEN-2016-02	Develop a tool to identify those children with epilepsy who have the highest need for psychological support	1, 2, 3, 4, 5, 6	Sept 2016 – Mar 2019	Kirsten Verity	Tool now developed. To be taken forward and rolled out under 2018-11	Improved access to psychological support for those with the highest need	B
SPEN-2016-03	Promote continued patient engagement following transition: Investigate epilepsy morbidity in 18-25 age group	1, 2, 3, 4, 5, 6	Sept 2016 - Oct 2018	Ailsa McLellan; Celia Brand	Cases identified for detailed follow-up/audit; results of the audit were presented at Members day in November 2018.	Better understanding of scale and causes of patient disengagement through transition process	B
SPEN-2016-06	Develop the evidence base for safe and effective epilepsy care: Review findings from the GACE study and the study of causes of death in epilepsy to inform clinical practice (link with ongoing SIGN guideline development)	2, 3, 4, 5, 6	Aug 2018 Aug 2018	Sameer Zuberi Ailsa McLellan	GACE findings presented at research day in May 2018. Findings being incorporated into updated SIGN guideline Cases of death in epilepsy continue to be reviewed	Increased understanding of disease processes; learning shared among network members	B

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Objective Number	Smart Objective	Linked Dimension s of Quality	Planned start / end dates	Detailed Plan Available / Owner	Description of progress towards meeting objective as at 31/03/2019	Anticipated Outcome	RAGB status
SPEN-2017-04	Communication and engagement: Host a family day in Glasgow to identify	1	Jun 2018	Carsten Mandt	Event held on 9 June 2018 at the Glasgow Science Centre. 11 families attended, positive evaluation and feedback about patient/sibling service experience collected	Understanding of patient/family priorities for service development and strategic actions to be taken forward by SPEN	B
SPEN-2018-01	Communication and engagement: Hold an annual network members day	4,5,6	Nov 2018	Carsten Mandt; Steering Group	Members day scheduled for 8 November 2018 in Stirling	Effective dialogue with wider network membership to inform future work priorities	B
SPEN-2018-02	Communication and engagement: Increase engagement with adult services	4,5,6	Feb 2018 – Mar 2019	Anissa Tonberg; Steering Group	Epilepsy Scotland contacted adult services who expressed interest in a joint meeting. Expression of interest for an adult service representative on SPEN Advisory Board – final details to be confirmed.	More effective network through involving additional key stakeholders	B
SPEN-2018-03	Communication and engagement: Increase engagement with primary care	4,5,6	Apr 2018 – Mar 2019	K Kamath Tallur; Steering Group	Letter sent in June 2018 to GP leads in each territorial Board. Only one positive response, NE Glasgow – invite for SPEN to attend GP forum meeting on 24 October 2018	More effective network through involving additional key stakeholders	B

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Objective Number	Smart Objective	Linked Dimension s of Quality	Planned start / end dates	Detailed Plan Available / Owner	Description of progress towards meeting objective as at 31/03/2019	Anticipated Outcome	RAGB status
SPEN-2018-04	Communication and engagement: Engagement with the education sector, focusing on teacher training	1,2,3,4,5,6	Apr 2018 – Mar 2019	Jo Campbell; Steering Group	Letter sent to General Teaching Council in July 2018 to explore possibility of including epilepsy awareness in teacher training. No response to date.	More effective network through involving additional key stakeholders	G
SPEN-2018-05	Provide multi-disciplinary paediatric epilepsy education for healthcare professionals: Develop a network education strategy (ensuring that it addresses question of CPD requirements for a “paediatrician with an interest in epilepsy”	2, 3	May 2018 - Oct 2018	Carsten Mandt; Kirsty Young, Steering Group	Education strategy drafted and consulted on. Signed off at August Steering Group meeting.	Assurance that education delivery is comprehensive and cohesive to address core learning requirements for all key professionals in the network	B
SPEN-2018-06	Provide multi-disciplinary paediatric epilepsy education for healthcare professionals: 1. Annual study day 2. Minimum of 4 local education road shows in DGHs 3. Ongoing support for the Scottish Paediatricians with an Interest in Epilepsy	2, 3, 5	Apr 2018 - Mar 2019	Carsten Mandt	Roadshows held in Wishaw and Edinburgh. Borders roadshow rescheduled until 2019/20. Study day scheduled for 5 October 2018 in Dundee. Three SPEIG meetings held	Improved knowledge in childhood epilepsy for relevant healthcare professionals that either reinforce existing best practice or results in changes in practice	G

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Objective Number	Smart Objective	Linked Dimension s of Quality	Planned start / end dates	Detailed Plan Available / Owner	Description of progress towards meeting objective as at 31/03/2019	Anticipated Outcome	RAGB status
	Group (SPIEG) and the Epilepsy Specialist Nurses Group						
SPEN-2018-07	Standardised best practice: Develop 'Joint Clinic' Guidance	1, 2, 3, 4, 5, 6	Apr 2018 - Mar 2019	Mary Callaghan; Carsten Mandt	Complete and added to SPEN website	Consistent application of joint clinics across Scotland to allow tertiary input close to home	B
SPEN-2018-08	Standardised best practice: Implementation of SPEN quality standard incl. baseline audit	1, 2, 3, 4, 5, 6	Apr 2018 - Mar 2019	Ailsa McLellan; Carsten Mandt	Due to discuss standard with regional child health planning groups – successive West of Scotland meetings cancelled. To be circulated electronically for comment	Improved and more consistent service delivery in Scotland	A
SPEN-2018-09	Standardised best practice: Define “care planning” (links with SPEN-2018-08)	1, 2, 3, 4, 5, 6	Apr 2018 - Mar 2019	Jo Campbell; Celia Brand	Carried forward to 2019/2020 due to capacity issues	Consistent practice in Scotland delivering patient-centered care planning	A
SPEN-2018-10	Patient Information: Develop SUDEP patient information leaflet	1, 2, 3, 4, 5, 6	Apr 2018 - Oct 2018	Martin Kirkpatrick	Final version circulated for comment. Agreed that it was too text heavy and would be better if it could be more visual. Submitted to NSS comms for revision.	Standardised, high quality information to inform families about SUDEP	A

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Objective Number	Smart Objective	Linked Dimension s of Quality	Planned start / end dates	Detailed Plan Available / Owner	Description of progress towards meeting objective as at 31/03/2019	Anticipated Outcome	RAGB status
SPEN-2018-11	Data / CQI improvement: Determine unmet mental health support needs (links with SPEN-2016-02)	1, 2, 3, 4, 5, 6	Apr 2018 - Mar 2019	Kirsten Verity	Discussions ongoing about wider roll out of Edinburgh pilot. Edinburgh data shows significant unmet need.	Identified areas for improvement re mental health support	B
SPEN-2018-12	Data / CQI improvement: Monitor interim data from Epilepsy 12 audit (subject to funding approval for participation in Epilepsy 12)	2, 3, 4, 5, 6	Oct 2018 - Mar 2019	Carsten Mandt; Kirsty Young; Mike Gunn Steering Group	Scottish Government rejection of funding bid. Urgent need to explore alternative options	Identified service improvement projects based on emerging outcome data	R
SPEN-2018-13	Service Development: Review epilepsy specialist nurse career path and develop a strategy for epilepsy specialist nursing in Scotland		Sep 2018 – Mar 2019	Jo Campbell; Celia Brand	To be started.		A

6. Proposed Work Plan for 2019/20

Objective Number	Smart Objective	Planned start/ end dates	Detailed Plan Available / Owner	Description of progress towards meeting objective as at 1 st March 2019	Anticipated Outcome	RAGB status
1. Effective Network Structure and Governance [linked to Quality Dimensions 3,4,5,6]						
2019-01	Continue to engage with primary care. Discuss next steps following initial engagement	April 2019/ March 2020	K Kamath Tallur; Steering Group		More effective network through involving additional key stakeholders	
2019-02	Explore options for establishing direct patient/family input	April 2019/ March 2020	Michael Durkan		Direct input of patient and family priorities into SPEN objectives	
2. Service Development and Delivery [linked to Quality Dimensions 1,2,3,4,5,6]						
2018-09	Define "care planning" (links with SPEN-2018-08)	April 2019/ March 2020	Jo Campbell; Celia Brand		Consistent practice in Scotland delivering patient-centered care planning	
2018-13	Review epilepsy specialist nurse career path and develop a strategy for epilepsy specialist nursing in Scotland	April 2019/ March 2020	Jo Campbell; Celia Brand			
2019-03	Support implementation of new SIGN guideline	April 2019/ March 2020	Jay Shetty / Michael Durkan		Delivery of improved and consistent services	
2019-04	Implement 'Joint Clinic' Guidance in areas where joint clinics are the model of care	April 2019/ March 2020			Consistent application of joint clinics across Scotland to allow	

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Objective Number	Smart Objective	Planned start/ end dates	Detailed Plan Available / Owner	Description of progress towards meeting objective as at 1 st March 2019	Anticipated Outcome	RAGB status
					tertiary input close to home	
3. Stakeholder Communication and Engagement [linked to Quality Dimensions 1,3,4,5,6]						
2019-05	Hold an annual network members day	Nov 2019	Michael Durkan; Kirsty Young		Effective dialogue with wider network membership to inform future work priorities	
2019-06	Continue engagement with education sector, focusing on teacher training	April 2019/ March 2020	Jo Campbell; Kirsty Young		More effective network through involving additional key stakeholders	
2019-07	Review information currently on SPEN website to ensure it is relevant and up to date	April 2019/ March 2020	Kirsty Young		Improved engagement with both patients and professionals	
2019-08	Engage with Scottish Ambulance Service to improve communication	April 2019/ March 2020	Kirsty Young		More effective network through involving additional key stakeholders	
4. Education [linked to Quality Dimensions 1,2,3,4,5,6]						
2019-09	Provide multi-disciplinary paediatric epilepsy study day for healthcare professionals	April 2019/ March 2020	Michael Durkan; Kirsty Young		Improved knowledge in childhood epilepsy for relevant healthcare professionals that	

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Objective Number	Smart Objective	Planned start/ end dates	Detailed Plan Available / Owner	Description of progress towards meeting objective as at 1 st March 2019	Anticipated Outcome	RAGB status
					either reinforce existing best practice or results in changes in practice	
2019-10	Minimum of 4 local education road shows in DGHs aimed at general paediatrics	April 2019/ March 2020	Michael Durkan; Kirsty Young		Improved knowledge in childhood epilepsy for relevant healthcare professionals that either reinforce existing best practice or results in changes in practice	
2019-11	Ongoing support for the Scottish Paediatricians with an Interest in Epilepsy Group (SPIEG) and the Epilepsy Specialist Nurses Group	April 2019/ March 2020	Michael Durkan; Kirsty Young		Improved knowledge in childhood epilepsy for relevant healthcare professionals that either reinforce existing best practice or results in changes in practice	
5. Audit and Continuous Quality Improvement <small>[[linked to Quality Dimensions 1,2,3,4,5,6]</small>						
2018-12	Monitor interim data from Epilepsy 12 audit (subject to funding approval for participation in Epilepsy 12)		Carsten Mandt; Kirsty Young; Mike Gunn Steering Group		Identified service improvement projects based on emerging outcome data	
2019-12	Baseline audit for new pathways and quality standard		Ailsa McLellan /			

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Objective Number	Smart Objective	Planned start/ end dates	Detailed Plan Available / Owner	Description of progress towards meeting objective as at 1 st March 2019	Anticipated Outcome	RAGB status
			Michael Durkan			
2019-13	Continue support for PAVES rollout to further areas to address unmet need for mental health support.		Kirsten Verity		Improved and more consistent service delivery in Scotland	
6. Value	[linked to Quality Dimensions 1,2,3,4,5,6]					

Appendix 1: Steering Group Membership

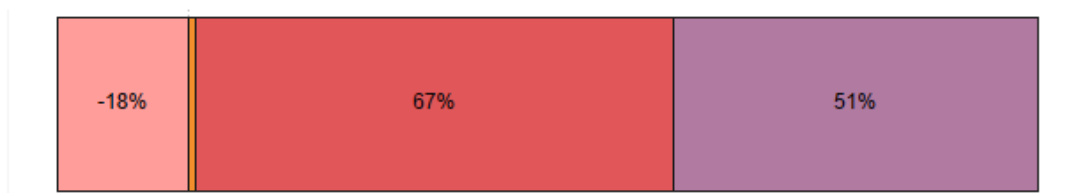
Name	Designation	Organisation
Celia Brand	Epilepsy Nurse Consultant	NHS Lothian
Andreas Brunklaus	Consultant Paediatric Neurologist	NHS Greater Glasgow & Clyde
Karen Burke	Pharmacist	NHS Lothian
Mary Callaghan	Consultant Paediatrician	NHS Lanarkshire
Jo Campbell	Paediatric Epilepsy Specialist Nurse	NHS Grampian
Jamie Cruden	Consultant Paediatrician	NHS Fife
Liam Dorris	Consultant Neuropsychologist	NHS Greater Glasgow & Clyde
Christine Findlay	Consultant Paediatrician	NHS Ayrshire & Arran
Sarah Finlayson	Consultant Neurophysiologist	NHS Tayside
Krishnaraya Kamath Tallur	Consultant Paediatric Neurologist	NHS Lothian
Martin Kirkpatrick	Consultant Paediatric Neurologist	NHS Tayside
Shirley Maxwell	Director	Epilepsy Connections
Ailsa McLellan	Consultant Paediatric Neurologist	NHS Lothian
Helen Shannon	Consultant Radiologist	NHS Highland
Jay Shetty	Consultant Paediatric Neurologist	NHS Lothian
Joe Symonds	Research Fellow	NHS Greater Glasgow & Clyde
Anissa Tonberg	Policy Officer	Epilepsy Scotland
Margaret Wilson	Epilepsy Nurse Consultant	NHS Greater Glasgow & Clyde
Sameer Zuberi	Consultant Paediatric Neurologist	NHS Greater Glasgow & Clyde

Appendix 2: Finance

The annual budget for SPEN is £5,000. A breakdown of the spend for 2018/2019 is below:

SPEN Financial Information

Job description	Account description	18/19
SPEN	EXHIBITIONS AND CONFERENCES	£5,369.03
	HIRE OF ROOMS FOR MEETINGS	£2,613.33
	OTH OPERATING INCOME NHS SCOT	-£1,450.00
	OTHER PROVISIONS	£64.50
Grand Total		£6,596.86



Type

- OTH OPERATING INCOME..
- EXHIBITIONS AND CONFE..
- OTHER PROVISIONS
- HIRE OF ROOMS FOR ME..

The finance figures above include a number of accruals and reimbursements that are still being processed. The network are working with NSS finance team to correct these. The expected total for SPEN spend is £5290.06