

**Scottish Paediatric Epilepsy National  
Managed Clinical Network  
ANNUAL REPORT 2019/20**

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## 1. Executive Summary

2019/2020 has been a successful year for SPEN. This report provides an overview of the achievements of SPEN, the challenges and the plans for 2020/2021.

The key network achievements include:

- Delivery of a programme of multi-disciplinary education which includes a study /members day, a research day and Scottish Paediatrician with an Interest in Epilepsy Group meetings as well as the re-establishment of an education sub-group to oversee the education programme
- Further increased engagement through collaboration on projects with Scottish Ambulance Service and the education sector
- Refreshed approach to engagement allowing the network to better understand the reach of network mailings
- Development of a leaflet on Sudden Unexplained Death in Epilepsy leaflet to increase awareness and understanding of SUDEP amongst patients and their families

Plans for 2020/2021 include:

- Continued engagement with stakeholders to ensure that the network continues to be effective. This includes:
  - Piloting of a teacher training session in Aberdeen
  - Taking forward actions alongside Scottish Ambulance Service.
  - Formalising GP input with NES
- Development and piloting of a patient experience questionnaire to understand what matters to patients and their families.
- 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. Building on the work to understand the current models.
- Continue to deliver a multi-disciplinary education programme

### *COVID-19*

Since February 2020, understandably NHS Scotland priority has been to prepare for and deal with COVID-19 impact and this has seen clinical and other resource diverted from network activity. The network has undertaken an exercise to not only capture the impact of this unprecedented situation on the current reporting period but also to assess the likely impact on delivery of the 20/21 work plan.

SPEN hosts a number of education events each year. Due to the COVID-19 situation these events have all had to be either cancelled or re-arranged. The possibility of some education taking place virtually is currently being scoped.

A number of other objectives can still be taken forward or at least the initial development can take place. It is however unclear what impact wider measures such as working from home, school closures or staff redeployment may have on the ability of stakeholders to engage with the network. Once the situation returns to normal there may also be a period of catch up for staff due to clinics being cancelled.

## 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 1<sup>st</sup> April 2019 to 31<sup>st</sup> March 2020.

### 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) 29<sup>1</sup>. 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 2019/20.

#### 3.1. Effective Network Structure and Governance

The Network is overseen by a multidisciplinary, Steering Group that supports the Lead Clinician and network Programme Manager with the day to day running of the Network. The Steering Group also has third sector partner representation. Dr Krishnaraya Kamath Tallur, Consultant Paediatric Neurologist, NHS Lothian, has been Lead Clinician since February 2017 and his tenure was scheduled to run until 31<sup>st</sup> January 2020. Dr Tallur kindly agreed to remain as lead clinician until a replacement could be appointed. The current COVID situation is likely to delay the appointment of a new lead clinician until late 2020.

The Service Agreement for SPEN runs from 1<sup>st</sup> April 2019 until 31<sup>st</sup> 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.

##### 1. *Links to primary care*

Following the review recommendations from 2017/2018 work has continued to engage with a broader range of stakeholders. Contact was made with Royal College of General Practitioners to establish if they could support some GP engagement. Following an initial positive conversation RCGP advised that engagement would be too specific for them to take forward. It was agreed that a more generic NMCN/NNMS approach may be more worthwhile although this remains embryonic.

Although the network was unsuccessful in engaging with primary care via RCGP, Paediatric Neurologists have been supporting NES with primary care education. It has been agreed that it would be worthwhile to formalise this arrangement to enable a more structured approach rather than accommodating ad hoc requests as happens at the moment.

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<sup>1</sup> Please see: [https://www.sehd.scot.nhs.uk/mels/CEL2012\\_29.pdf](https://www.sehd.scot.nhs.uk/mels/CEL2012_29.pdf)

## *2. Direct patient / family input*

Following a review of the options on how best to establish direct patient / family input to the network, it was agreed by the Steering Group that it would be worthwhile to refresh the network's "Getting Involved" leaflet. A request has been submitted to NSS Communications team for support with developing this. Once complete this leaflet would be handed out to patients at local epilepsy clinics. Any responses will be collated and used to create a patient reference group.

### **3.2. Service Development and Delivery**

#### *1. SIGN guideline*

A revised SIGN guideline for children and young people with epilepsy was due to be launched in 2019. The launch has so far been delayed by SIGN. SPEN still plans to support the implementation of this new guideline however this cannot begin until the guideline is finalised. Although the guideline is not officially launched the network has been doing some work in preparation. A "SIGN guideline update" was included at the recent study day and is one of the topics included in the new road show cycle.

#### *2. Joint clinic guidance*

Joint clinic guidance, which specifies minimum standards for joint clinics between local and tertiary specialist epilepsy clinicians, was developed in 2018/2019. In order to properly implement this in all areas it was agreed that the first step needed to be to understand current arrangements. All centres where joint clinics are the method of delivering joint care were surveyed. The results of this survey are being used to identify which areas need improvement.

#### *3. SPEN Quality Standard audit*

SPEN developed a clinical quality standard in 2017/18. Initial plans had been to discuss with regional child health planning groups on how best to implement it. Due to a number of cancelled planning meetings this was not possible. The lack of progress with the Epilepsy 12 in Scotland had impacted on the network's ability to confirm the mechanism for the quality standard audit. It was agreed that this audit would be postponed until the situation had been resolved. A plan to scope data requirements has been developed alongside the IMS, see item 3.5.2.

Two nursing projects, defining care planning and review of the epilepsy nurse career path had been carried forward into 2019/2020 due to capacity issues within nursing in the previous year. In order to take forward these objectives a nurses meeting had been planned. This meeting has had to be postponed due to COVID-19 and will be rescheduled for later in the year.

### **3.3. Stakeholder Communication and Engagement**

#### *1. Engagement with education*

SPEN initially wrote to the General Teaching Council in July 2018 to ask whether it was achievable for SPEN to link in with teacher training with a view to including epilepsy awareness training in the undergraduate curriculum. Following discussions with the General Teaching Council SPEN subsequently wrote to all nine universities in Scotland who offer Initial teacher training (ITE). Responses have been received from two. It was agreed at the recently re-established education group that a pilot session would take place in Aberdeen.

#### *2. Engagement with primary care*

See above section 3.1.1

#### *3. Stakeholder engagement*

Quarterly email newsletters had previously been established as the primary mechanism for communicating with members. However, it was difficult to measure their reach, which made evaluating and improving them challenging. In order to address this SPEN newsletters are now published on 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 is still circulated advising the newsletter is available however rather than including it as an attachment it will simply hyperlink to the newsletter page or important individual stories. Although this approach is still in its infancy the overall SPEN news page had 132 views across 2019/2020 with a number of the stories having 20+ views. Work continues on this to ensure that SPEN continues to engage with its stakeholders as well as possible.

The 2019/2020 annual member's day was combined with the annual study day. This approach was more efficient in that it resulted in less time away from day jobs for stakeholders and organising one rather than two separate events saved on network resources. The morning session focussed on transition with a presentation from Dr Arvind Nagra, Consultant Paediatric Nephrologist, Southampton. The afternoon session provided a SPEN update on progress over the previous year and plans for the year ahead. This was a useful opportunity to engage the wider membership on key network issues.

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

A SUDEP patient leaflet has been developed to increase awareness and understanding of SUDEP amongst patients and their families. The leaflet has been finalised and a small pilot is taking place in Edinburgh. Once feedback is received from those patients the leaflet will be rolled out across the country.

### **3.4. Education**

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

#### *1. Education sub-group*

Until recently SPEN had been operating without an education sub-group due to a previous decision to reduce the number of meetings. This resulted in difficulties engaging with members to arrange education programmes and events. The education sub-group was re-established in 2019/2020 and has had one initial meeting. The meeting allowed for the planning of a new cycle of road shows and the planning for the combined study day/members day. Re-establishing this sub-group will make it easier to manage the network's extensive education opportunities.

#### *2. SPEN Road shows*

Despite numerous attempts it was not possible to arrange suitable dates for the two remaining road shows in the 2019/20 cycle. It was therefore agreed by the Steering Group to move to a new cycle. The re-established education group has developed two new topics; SIGN guideline update and revision of epilepsy syndromes. It is planned to deliver 3 road shows in 2020/2021.

#### *3. Study days*

Each year SPEN hosts a study day aimed at clinicians who care for children and young people with epilepsy. As above in 3.3.3, the 2019 event was combined with the members' day to make better use of the time. 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. A snapshot of the data is included below:

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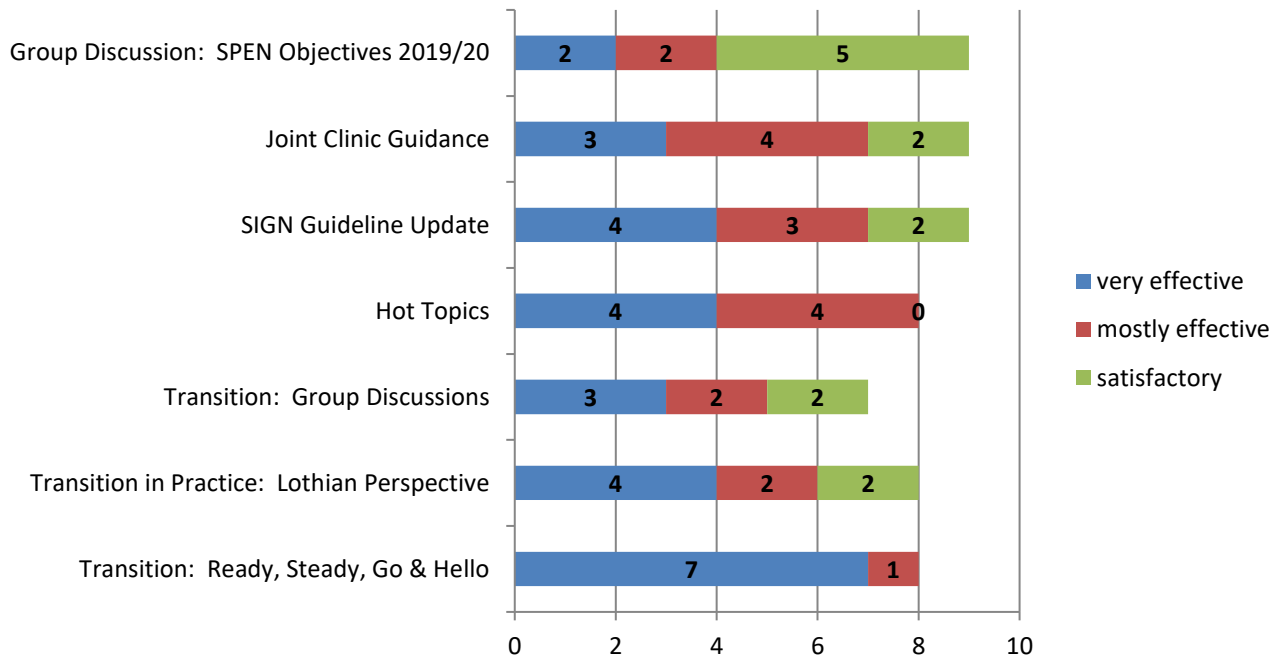


Figure 1: Effectiveness of study day presentations in meeting education need

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

In addition, SPEN continues to support 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 still be better. Previous attempts to encourage participation have shown modest rewards. Discussions are ongoing in order to increase participation further.

## 3.5. Audit and Continuous Quality Improvement

### 1. Psychology Adding Value: Epilepsy Screening (PAVES)

SPEN continues to support the further development and wider roll out of PAVES to other areas. Project progress was delayed as the NSS IT Medical Director advised late in the process that the tool should be classed as a medical device. This resulted in further work for the network as medical devices require extensive governance. NSS currently does not have the governance in place to support medical devices so this needs to be sourced from a health board that does. NHS Lothian and NHS Greater Glasgow and Clyde have been identified as potential options. The project was also set back by a key member of the team moving onto a new role, this has resulted in a vacancy which will now likely be difficult to fill quickly in the current climate.

### 2. Data collection

A data plan has been developed alongside the NNMS Information Management Service (IMS). This began with an exercise scoping the data requirements of the network. Following conversations with NSS Digital and Security (formerly NSS IT) a minimum dataset has been developed. This dataset is currently being tested by the network data leads. Once agreed it will be piloted locally before a full rollout across Scotland.

## 3.6. Value

SPEN has added value to healthcare in Scotland through a number of initiatives:

- An extensive programme of education which continues to build expertise and increase capacity across services in Scotland



- Engaging with a wide range of stakeholders ensuring the network is as effective possible. This included involving additional key stakeholders such as Scottish Ambulance Service and Education sector.
- Developed patient information to increase awareness and understanding of SUDEP amongst patients and their families

#### **4. Plans for the Year Ahead**

Plans for 2020/2021 include:

- Engagement with wider stakeholders to ensure that the network continues to be effective. This includes:
  - Piloting of a teacher training session in Aberdeen
  - Taking forward actions alongside Scottish Ambulance Service.
  - Formalising GP input with NES
- Development and piloting of a patient experience questionnaire to understand what matters to patients and their families.
- 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. Building on the work to understand the current models.
- Continue to deliver a multi-disciplinary education programme

##### *b) Risks*

Arrangements put in place due to the recent COVID-19 outbreak may restrict SPEN education opportunities. As SPEN host multiple events this has the potential to be disruptive. As many events as possible have been postponed until later in 2020 or into 2021. Work is also ongoing to deliver some events via alternative models such as virtually or pre-recording. There is however a risk that some of the events cannot be rescheduled or delivered alternatively resulting in a reduced education programme.

## 5. Detailed Description of Progress in 2018/19

Objective Number	Smart Objective	Planned start/end dates	Detailed Plan Available / Owner	Description of progress towards meeting objective as at 31 <sup>st</sup> January 2019	Anticipated Outcome	RAGB status
<b>1. Effective Network Structure and Governance</b> <small>[linked to Quality Dimensions 3,4,5,6]</small>						
2019-01	Continue to engage with primary care. Discuss next steps following initial engagement	April 2019/ March 2020	K Kamath Tallur; Steering Group	Contact made with RCGP. Following initial conversations RCGP advised that engagement was too specific for them to take forward. To be replaced with formalising engagement with NES and a potential NNMS wide approach.	More effective network through involving additional key stakeholders	<b>R</b>
2019-02	Explore options for establishing direct patient/family input	April 2019/ March 2020	Michael Durkan	Agreed to take forward a refreshed getting involved leaflet. Request sent to NSS comms.	Direct input of patient and family priorities into SPEN objectives	<b>G</b>
<b>2. Service Development and Delivery</b> <small>[linked to Quality Dimensions 1,2,3,4,5,6]</small>						
2018-09	Define “care planning” (links with SPEN-2018-08)	April 2019/ March 2020	Jo Campbell; Celia Brand	To be taken forward at nurses meeting. Nursing meeting postponed due to COVID-19 measures. Carried forward to 2020/2021.	Consistent practice in Scotland delivering patient-centred care planning	<b>A</b>

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Objective Number	Smart Objective	Planned start/end dates	Detailed Plan Available / Owner	Description of progress towards meeting objective as at 31 <sup>st</sup> January 2019	Anticipated Outcome	RAGB status
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	To be taken forward at nurses meeting. Nursing meeting postponed due to COVID-19 measures. Carried forward to 2020/2021.		<b>A</b>
2019-03	Support implementation of new SIGN guideline	April 2019/ March 2020	Jay Shetty / Michael Durkan	Awaiting the formal launch of new SIGN guideline	Delivery of improved and consistent services	<b>G</b>
2019-04	Implement 'Joint Clinic' Guidance in areas where joint clinics are the model of care	April 2019/ March 2020	Mary Callaghan / Michael Durkan	Local centres have been surveyed to understand what current practice looks like. These results are being analysed to identify areas for improvement.	Consistent application of joint clinics across Scotland to allow tertiary input close to home	<b>G</b>
<b>3. Stakeholder Communication and Engagement</b> <small>[linked to Quality Dimensions 1,3,4,5,6]</small>						
2018-10	Develop SUDEP patient information leaflet	April 2019/ March 2020	Martin Kirkpatrick / Michael Durkan	Leaflet has been finalised and being piloted with patients in Edinburgh before a full roll out.	Standardised, high quality information to inform families about SUDEP	<b>G</b>
2019-05	Hold an annual network members day	Nov 2019	Michael Durkan; Kirsty Young	Event was held in November 2019 in Stirling.	Effective dialogue with wider network membership to inform future work priorities	<b>B</b>

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Objective Number	Smart Objective	Planned start/end dates	Detailed Plan Available / Owner	Description of progress towards meeting objective as at 31 <sup>st</sup> January 2019	Anticipated Outcome	RAGB status
2019-06	Continue engagement with education sector, focusing on teacher training	April 2019/ March 2020	Jo Campbell; Kirsty Young	Response received from GTC. Recognised importance however suggested contacting ITE programme's direct.  Letters sent to all ITE providers. Response received from two, Aberdeen and Strathclyde. A session is to be piloted in Aberdeen.	More effective network through involving additional key stakeholders	<b>G</b>
2019-07	Review information currently on SPEN website to ensure it is relevant and up to date	April 2019/ March 2020	Kirsty Young	Ongoing. Begun with moving SPEN newsletter online.	Improved engagement with both patients and professionals	<b>G</b>
2019-08	Engage with Scottish Ambulance Service to improve communication	April 2019/ March 2020	Kirsty Young	Meeting took place and actions agreed. Further meeting to take place.	More effective network through involving additional key stakeholders	<b>G</b>
<b>4. Education</b> [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	Combined study day and members' day held in November 2019.	Improved knowledge in childhood epilepsy for relevant healthcare professionals that either reinforce existing best practice or results in changes in practice	<b>B</b>

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Objective Number	Smart Objective	Planned start/end dates	Detailed Plan Available / Owner	Description of progress towards meeting objective as at 31 <sup>st</sup> January 2019	Anticipated Outcome	RAGB status
2019-10	Minimum of 4 local education road shows in DGHs aimed at general paediatrics	April 2019/ March 2020	Michael Durkan; Kirsty Young	No road shows took place this year. Moved to a new cycle of road shows. Although none have taken place this year presentations have being designed by a re-established education group to allow for road shows to restart next year.	Improved knowledge in childhood epilepsy for relevant healthcare professionals that either reinforce existing best practice or results in changes in practice	A
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	Ongoing, dates now set for 2020/202. Paediatric Neurologist and invited speakers have been agreed.	Improved knowledge in childhood epilepsy for relevant healthcare professionals that either reinforce existing best practice or results in changes in practice	G
<b>5. Audit and Continuous Quality Improvement</b> <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	As it has not been possible to secure approval for the Epilepsy 12 audit a plan B is being investigated alongside the IMS. This objective will be closed and replaced with 2019-14	Identified service improvement projects based on emerging outcome data	R
2019-14	Scope the data requirements to allow for SPEN to develop a mechanism for data capture and analysis alongside		Michael Durkan/ Claire	Data requirements have been scoped. Following conversations with DaS a	Identified service improvement projects based on emerging	G

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Objective Number	Smart Objective	Planned start/end dates	Detailed Plan Available / Owner	Description of progress towards meeting objective as at 31 <sup>st</sup> January 2019	Anticipated Outcome	RAGB status
	IMS		Lawrie	Clinical Audit System has been developed and is being tested.	outcome data	
2019-12	Baseline audit for new pathways and quality standard		Ailsa McLellan / Michael Durkan	Following the agreement to prioritise 2019-14 this has been carried forward to 2020/2021		R
2019-13	Continue support for PAVES rollout to further areas to address unmet need for mental health support.		Kirsten Verity	Network continues to support the role out and further development of PAVES	Improved and more consistent service delivery in Scotland	G
<b>6. Value</b> [linked to Quality Dimensions 1,2,3,4,5,6]						

## 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 30 <sup>th</sup> April 2020	Anticipated Outcome	RAGB status
<b>1. Effective Network Structure and Governance</b> <small>[linked to Quality Dimensions 3,4,5,6]</small>						
2020-01	Explore options to formalise existing GP engagement delivered by Paediatric Neurologists		K Kamath Tallur; Steering Group		More effective network through involving additional key stakeholders	
2020-02	Establish direct patient/family input. Beginning with refreshed getting involved leaflet being developed and handed out at clinics.		TBC			
<b>2. Service Development and Delivery</b> <small>[linked to Quality Dimensions 1,2,3,4,5,6]</small>						
2018-09	Define "care planning" (links with SPEN-2018-08)		Jo Campbell; Celia Brand	To be taken forward by nurses group once re-established	Consistent practice in Scotland delivering patient-centred care planning	
2018-13	Review epilepsy specialist nurse career path and develop a strategy for epilepsy specialist nursing in Scotland		Jo Campbell; Celia Brand	To be taken forward by nurses group once re-established		
2019-03	Support implementation of new SIGN guideline		Jay Shetty / Michael Durkan	Awaiting the formal launch of new SIGN guideline	Delivery of improved and consistent services	

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Objective Number	Smart Objective	Planned start/ end dates	Detailed Plan Available / Owner	Description of progress towards meeting objective as at 30 <sup>th</sup> April 2020	Anticipated Outcome	RAGB status
2020-03	Continue to implement 'Joint Clinic' guidance in areas where joint clinics are the model of care building on survey of local centre arrangements		Mary Callaghan / Michael Durkan		Consistent application of joint clinics across Scotland to allow tertiary input close to home	
<b>3. Stakeholder Communication and Engagement</b> <small>[linked to Quality Dimensions 1,3,4,5,6]</small>						
2020-04	Develop teenage specific SUDEP information		TBC		Standardised, high quality information to inform families about SUDEP	
2020-05	Hold an annual network members day		Michael Durkan; Kirsty Young		Effective dialogue with wider network membership to inform future work priorities	
2020-06	Continue engagement with education sector by piloting a session in Aberdeen.		Jo Campbell; Kirsty Young		More effective network through involving additional key stakeholders	
2020-07	Ongoing review of information currently on SPEN website to ensure it is relevant and up to date. Building on electronic newsletter.		Kirsty Young		Improved engagement with both patients and professionals	
2020-08	Take forward actions agreed following engagement with Scottish Ambulance Service to improve communication.		Kirsty Young		More effective network through involving additional key stakeholders	



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Objective Number	Smart Objective	Planned start/ end dates	Detailed Plan Available / Owner	Description of progress towards meeting objective as at 30 <sup>th</sup> April 2020	Anticipated Outcome	RAGB status
2020-09	Develop and pilot a patient experience questionnaire designed to understand what matters to patients and their families.		Kirsty Young		Improved engagement with patients and ensure SPEN objectives reflect patient priorities	
<b>4. Education</b> [linked to Quality Dimensions 1,2,3,4,5,6]						
2020-10	Provide multi-disciplinary paediatric epilepsy study day for healthcare professionals		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	
2020-11	Minimum of 3 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	
2020-12	Ongoing support for the Scottish Paediatricians with an Interest in Epilepsy Group (SPIEG) and the re-establishment of Epilepsy Specialist Nurses Group. This should include providing a SPEN update and arranging guest speakers/visiting paediatric	April 2019/ March 2020	Kirsty Young		Improved knowledge in childhood epilepsy for relevant healthcare professionals that either reinforce existing best practice or results in changes in practice	

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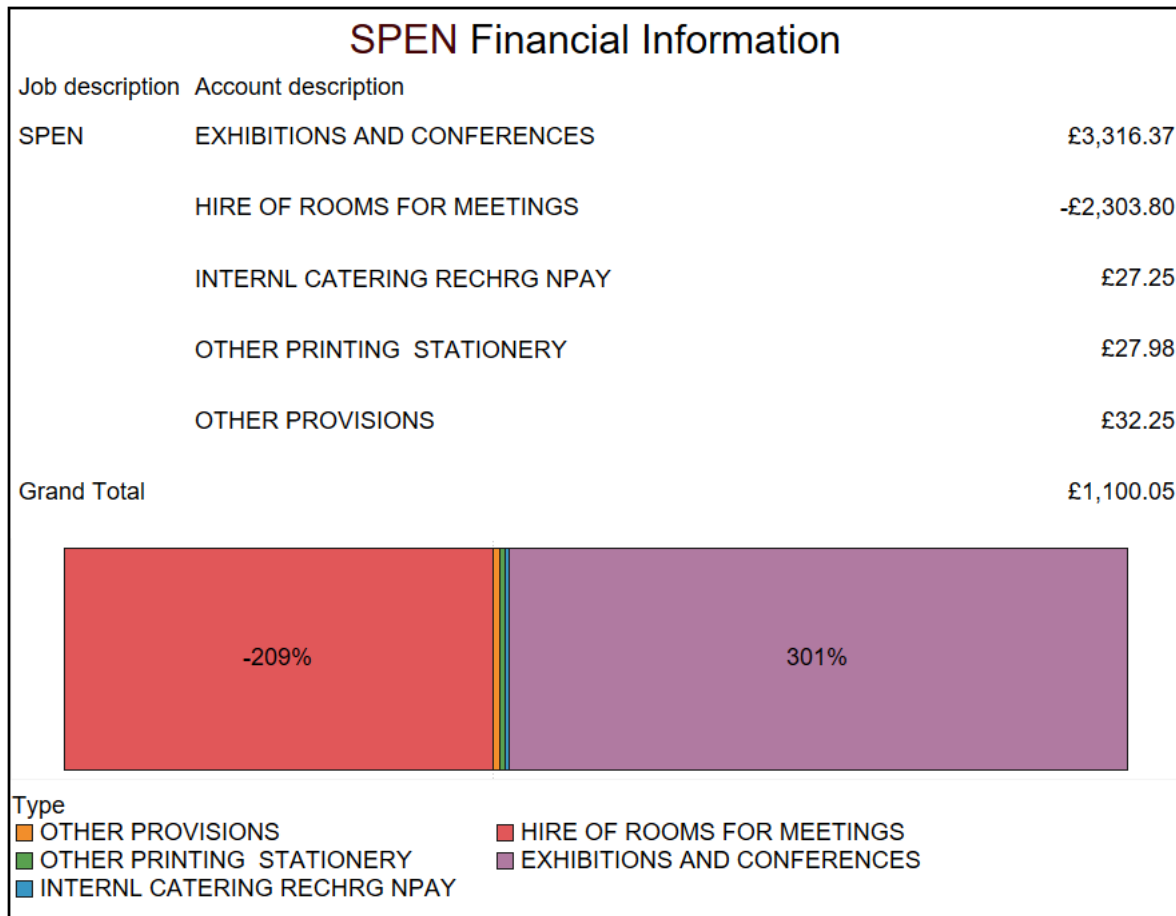
Objective Number	Smart Objective	Planned start/ end dates	Detailed Plan Available / Owner	Description of progress towards meeting objective as at 30 <sup>th</sup> April 2020	Anticipated Outcome	RAGB status
	neurologists at 3 SPEIG meetings. Also support for 1 nurse meeting.					
2020-13	Support for the Scottish Epilepsy Group's Annual Scottish Research Day.		Kirsty Young; Michael Durkan		Improved knowledge in childhood epilepsy for relevant healthcare professionals that either reinforce existing best practice or results in changes in practice	
<b>5. Audit and Continuous Quality Improvement</b> [linked to Quality Dimensions 1,2,3,4,5,6]						
2020-14	Pilot of data set developed in conjunction with IMS. Roll out following successful pilot.		Michael Durkan/ Claire Lawrie		Identified service improvement projects based on emerging outcome data	
2019-12	Baseline audit for new pathways and quality standard		Ailsa McLellan / Michael Durkan		Identified service improvement projects	
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	
<b>6. Value</b> [linked to Quality Dimensions 1,2,3,4,5,6]						

**Appendix 1: Steering Group Membership**

<b>Name</b>	<b>Designation</b>	<b>Organisation</b>
Celia Brand	Epilepsy Nurse Consultant	NHS Lothian
Andreas Brunklaus	Consultant Paediatric Neurologist	NHS Greater Glasgow & Clyde
Mary Callaghan	Consultant Paediatrician	NHS Lanarkshire
Jo Campbell	Paediatric Epilepsy Specialist Nurse	NHS Grampian
Jamie Cruden	Consultant Paediatrician	NHS Fife
Rona Johnson	Policy and Campaigns Officer	Epilepsy Scotland
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
Jay Shetty	Consultant Paediatric Neurologist	NHS Lothian
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 2019/2020 is below:



The finance figures above include the reimbursement of an accrual from 2018/2019. This resulted in an overspend for 2018/2019. The network had been working with the NSS finance team to correct it.