

Scottish Paediatric Epilepsy Network (SPEN)

Annual Report 2021/22

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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”

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.

Current position

SPEN delivered on almost all objectives agreed in the 2021/2022 work plan. Several objectives however are taking longer to progress than expected due to the ongoing COVID-19 pandemic. This has mainly affected objectives where there has been third party involvement such a charity and support groups or other NHS organisations who have had more pressing priorities and/or fewer staff due to furloughs. Where it is considered that it is unrealistic that these objectives can be delivered in the near future they will be removed from the workplan until a later date. A full work plan update is available on page 8.

The cancellation of face to face events continues to have a big impact for SPEN. SPEN hosts several education and stakeholder events each year. These events not only ensure that stakeholders have up to date knowledge, but they allow for networking between teams and allow SPEN to engage effectively to ensure that the work plan continues to reflect member’s priorities. In 2021/2022 all meetings and events continued to be held virtually. While the virtual education delivered so far has been an overwhelming success it has not yet been possible to properly replicate the engagement of face to face meetings. Various tools such as breakout rooms have been utilised however so far it has not been possible to properly replicate those networking aspects. It is intended to reintroduce some face to face meetings and events as restrictions allow.

The wider impact of the pandemic has not completely disappeared. Stakeholders continued to cover other aspects of clinical work i.e. acute services and objectives were paused multiple times to lessen the burden on boards.

Lead Clinician Update

Following two challenging years we are looking forward to a return of some normality. COVID continued to be particularly challenging for patients, families and network stakeholders. The lack of face-to-face appointments required us to develop new ways of working including remote access and our new normal working group will inform how we will be shaping the delivery of epilepsy services across Scotland in the future. Engagement with the Scottish Ambulance Service, GPs and education sector has been impacted by the pandemic and we will continue this work in coming years.

The publication of the SIGN guideline has been a major milestone and we are looking forward to its implementation and SPEN will continue to assist local teams to achieve this. The PAVES project highlighted the importance of Mental Health screening in epilepsy which will continue to be rolled out across Scotland.

Our education program has gone from strength to strength with delivery of a new set of epilepsy road shows and very well attended research meetings showcasing Scottish led epilepsy research.

The SPEN members day identified a number of challenges we are facing in the future including transition and mental health in epilepsy which will form an important part of our five year plan going forward.

Progress against network objectives in 2021/2022

1. Effective Network Structure and Governance

Development of a new 3 – 5 year workplan – An extensive engagement exercise took place to develop a new strategic workplan for SPEN. This was a new challenge for the network as all meetings are now virtual and so the usual engagement events were impossible. Following initial conversations at a steering group meeting a number of virtual breakout sessions were arranged as part of the November 2021 Network members day. This involved four breakout sessions, Data, Education, Patient Involvement and Service Development. Using a mixture of workshops and whiteboards participants were encouraged to discuss and prioritise the objectives of the network for the next 3 to 5 years. This feedback was then used to develop a new strategic workplan.

2. Service Development and Delivery

SIGN guideline – The new SIGN guideline: 159 - Epilepsies in children and young people: Investigative procedures and management was finally published following a long delay. In order to support the implementation of the guideline across Scotland, an implementation pack designed in NHS Lothian has been shared with centres in the rest of the country. This allows each centre to measure their service against the SIGN recommendations and whether their service is compliant. The pack also contains a risk matrix to allow for the impact of the recommendations to be measured across 9 areas including patient experience, staffing and service disruption. It is hoped that this single approach will ensure consistent application of the guideline across Scotland and so reduce variation. An audit of the guideline recommendations is planned for 2022/2023 to monitor the implementation.

Develop “new normal” plans – Work has begun on “new normal” discussions to develop guidance based on what clinician’s feel is suitable to be delivered going forward post COVID.

A Short Life Working Group was set up to look at how epilepsy services in Scotland (and the network) can learn and adapt from the impact of COVID. Some of the challenges to services were also seen as an opportunity for development. The group plans has looked at how these changes could be taken forward. The objective of the group is to develop guidance for use across Scotland on how service should be delivered post COVID. This should include:

- Evaluating the impact of virtual clinics for both clinicians and patients / families
- Supporting the wider roll out of new technologies such as vCreate neuro across Scotland

The views of both patients/ families and clinicians will be important in understanding what can be delivered and when. The impact of virtual clinics for clinicians has been received via survey and is being used to develop the guidance. Feedback from patients has been difficult, likely due to additional pressures caused by the pandemic, a pilot in Grampian received little response. Discussions are ongoing with patient groups on how best to seek views.

It had been hoped that it would be possible to develop and deliver a patient experience questionnaire in 2021/2022 however the resource required has meant it was not possible

during a pandemic. An initial scoping exercise to review existing questionnaire has been completed and it is hoped that this can be delivered in 2022/2023.

3. Stakeholder Communication and Engagement

Engagement with stakeholders – many of the ongoing objectives such as developing a strategic workplan and “new normal” discussions have involved extensive engagement with stakeholders, both professional and patients / patient groups. As well as this the network has developed a SWAY newsletter to ensure communication with the wider network membership. Initial feedback has been positive and it is hoped this can be further developed in 2022/2023.

A few other communication and engagement objectives have been on hold due to the COVID-19 pandemic. These include developing teenage specific SUDEP information and taking forward a project with Scottish Ambulance Service. While much of the initial work had already begun for these objectives it was felt that they should be postponed due to the COVID-19 pressures facing these partner organisations. Discussions are ongoing as to whether it will be possible to deliver these objectives in 2022/2023. If this is not possible then it will be removed from the workplan until it can realistically be achieved.

Network members day –This year’s member’s day was again a virtual event and was well received. In total 30 delegates attended this year’s event. Topics on the day included “The ‘New Normal’ for epilepsy services – COVID19 “, “SIGN Guideline” and “DLA Support for patients and families”. A session also took place to develop a new 3 – 5 year workplan as described above.

Feedback was received by 16 delegates and a snapshot of the responses is included below: -

Delegates were asked where or not the event met its objective which was to engage the network membership on key issues and to facilitate discussion around a 3-5 year strategic workplan for SPEN. 94% of attendees agreed with 56% strongly agreeing that the event met this objective.

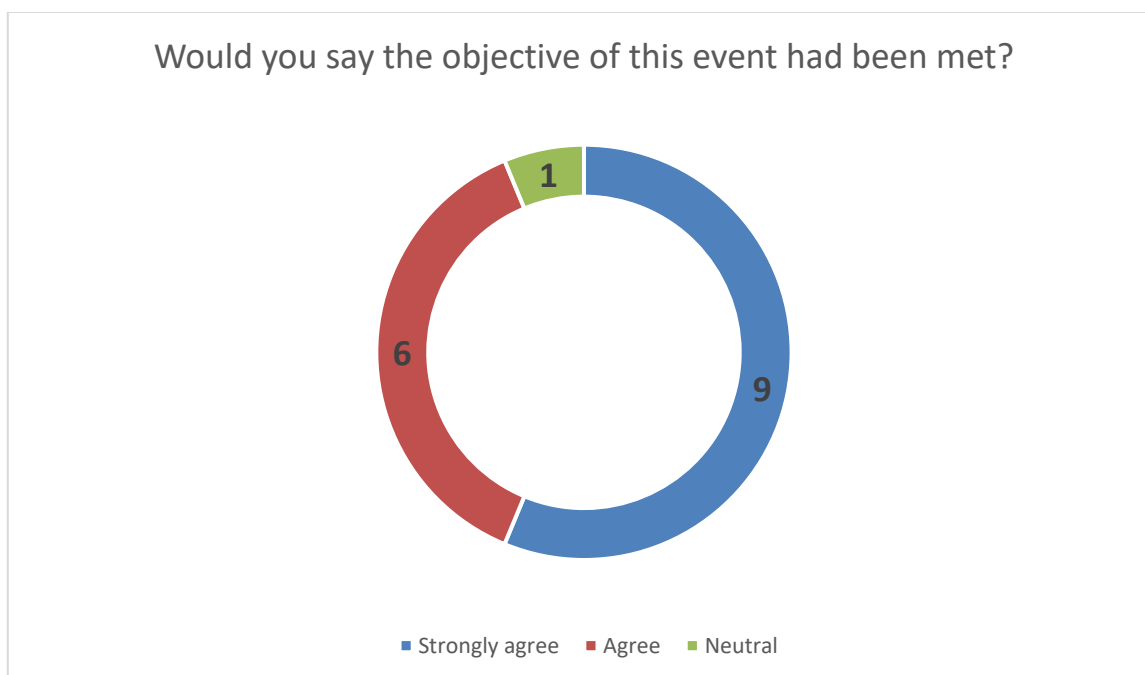


Figure 1 – event evaluation responses

Sessions on the day included a mix of education and stakeholder engagement. The feedback for individual presentations and the overall event was overwhelmingly positive. Two delegates in particular commented –

“SPEN plays a vital role in highlighting and setting standards, and driving forward improved care for paediatric patients with epilepsy. It is great to have access to a really friendly and approachable professional body, and for smaller services to feel supported particularly when there is a need to highlight resource requirements.”

“The event was a great opportunity to network with colleagues. Particularly the workshops. I enjoyed the input from Epilepsy Scotland and feel I now have a better understanding of the role they play in supporting our families. As a result I shall be utilising their services more”

4. Education

Local education road shows in DGHS aimed at general paediatrics:

The current cycle of roadshows continues with two more taking place in NHS Ayrshire and Arran and NHS Borders. Presentations included an update on Epilepsy Syndromes, Epilepsy and COVID: Challenges & Opportunities and Peer Review.

Annual Scottish Research Day: The purpose of this event was to provide stakeholders with an update on current research taking place in Epilepsy. This event was attended by 51 delegates across paediatrics, adults and 3rd sector.

26 responses were received to the post event evaluation. Of the 26 responses 100% agreed that this event met its objective to give an update on current research in epilepsy.

Overall feedback was overwhelmingly positive as always with one attendee in particular commenting:

“This was my first opportunity to present some research & I hugely enjoyed the experience - thank you to everyone for such a welcoming reception for all the presenting medical students! The event was very well run & interesting & I look forward to hopefully attending similar such events in future!”

5. Audit and Continuous Quality Improvement

Pilot of data set: A minimum core data set has been developed in conjunction with Information Management Service (IMS) as an alternative to Epilepsy 12. A short pilot took place in Glasgow and Edinburgh to assess the data being collected.

A snapshot of the data collected is below, the data from this short pilot will be used as a baseline with further development of the data set planned for 2022/2023:



Figure 2 – snapshot of pilot data

Support for Psychology Added Value: Epilepsy Screening (PAVES): Following a long delay, the mental health screening tool has been launched and is in use in Lothian. The web address (www.paves.scot.nhs.uk) is sent to patients / families ahead of clinic appointment so that responses are received in advance of clinic, those missed are then

picked up in the clinic waiting area. 35 families have so far completed the screening questionnaire.

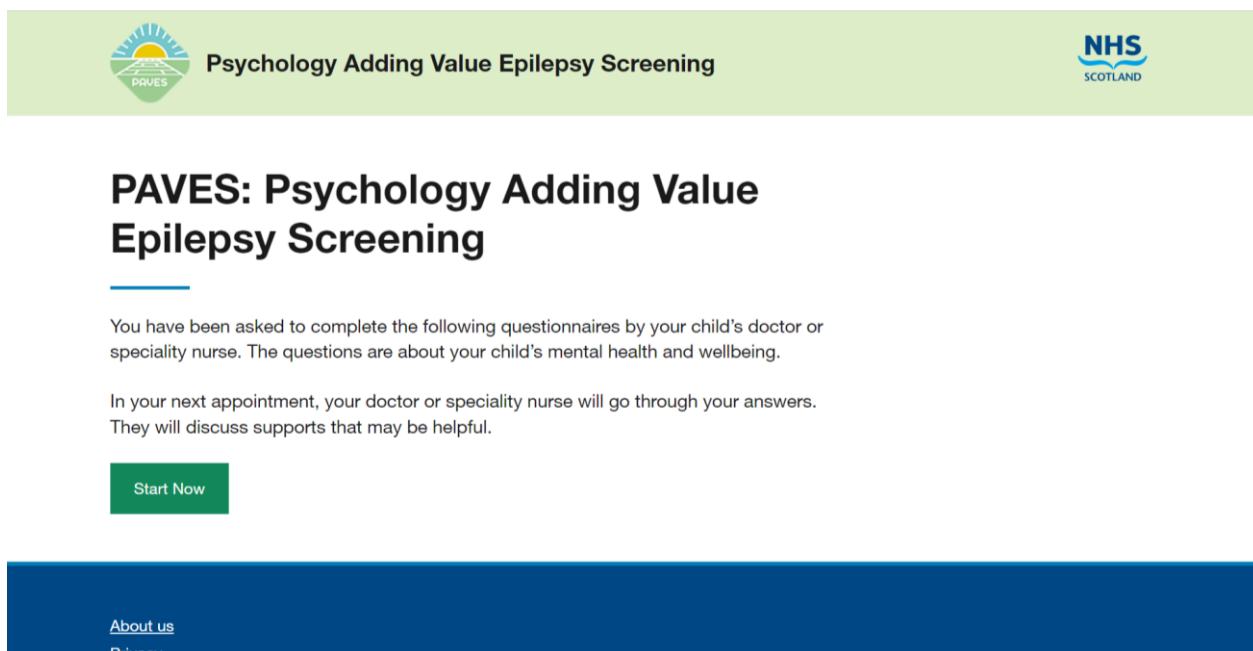


Figure 3 – PAVES front screen

Now that the tool is live, next steps including measuring the impact and evidencing the benefit it has had in clinic.

Looking ahead

Following the development on a new 3 – 5 year workplan the network plans to begin a number of new projects. This will include auditing the current transition process across Scotland with a view to developing an action plan and further support mental health screening provision across Scotland. Other ongoing projects such as supporting the implementation of SIGN 169 and developing new normal guidance will continue.

Finance

No costs have been incurred in this financial period. This is mainly due to the move to remote working which has resulted in meetings and events being held virtually.

WORKPLAN – 2020-21

Core Principles	Description of Work	Current status	RAG Status
Effective Network Structure and Governance	Develop 3-5 year work plan	Complete. Initial session delivered at SG meeting in September, wider network session took place at annual event in November.	B
Service Development and Delivery	Support the implementation of new SIGN Guideline	Implementation packs circulated to teams across Scotland. Guideline implementation to be audited in 6 months.	G
Service Development and Delivery	Implement joint clinic guidance	Now linked in with "new normal" discussions below.	B
Service Development and Delivery	Develop 'new normal' plans	Patient and professional surveys have been developed and circulated. Action plan to be developed.	B
Stakeholder Communication and Engagement	Develop teenage specific SUDEP materials	Conversations had begun with OPEN UK. On hold due to COVID. Removed until can realistically be achieved.	R
Stakeholder Communication and Engagement	Establish a system to improve communications with Scottish Ambulance Service (SAS)	Action plan previously agreed with SAS however was paused due to COVID	R
Service Development and Delivery	Deliver Patient experience questionnaire	Carried forward and to be completed as part of new normal work	R
Education	Continue engagement with education sector by piloting a session in Aberdeen.	Planning took place and session agreed however session on hold until later in the year at Aberdeen University's request. Due to impact of pandemic.	R
Audit and Continuous Quality Improvement	Develop data plan	Refreshed data plan developed.	G
Audit and Continuous Quality Improvement	Deliver Service descriptor audit	To be completed as part of "new normal"	G

Audit and Continuous Quality Improvement	Continue support for PAVES rollout to further areas to address unmet need for mental health support.	Screening tool developed, www.paves.scot.nhs.uk – now being used in Lothian ahead of wider roll out	G
Audit and Continuous Quality Improvement	Take forward next steps and any actions following the audit of SPEN pathways	Pathway's audit circulated to SPS and SPIEG members. Action plan to be developed.	G

WORKPLAN – 2022-23

NSS Strategic Objectives	Quality Domains	Realistic Medicine Aims	Description of Work	Owner
Improving the way we do things	Health Improvement	2 - Personalised Approach to Care	Finalise development of new normal guidance, building on work from 2021/2022	New Normal SLWG
Improving the way we do things	Health Improvement	4 - Reduce Unwarranted Variation	Develop and deliver a revised data plan	JS/Data group
Increasing our service impact	Access to Treatment	6 - Become Improvers and Innovators	Continue to support PAVES project including measuring the impact of pilot	TBC
Improving the way we do things	Access to Treatment	4 - Reduce Unwarranted Variation	Audit mental health provision across Scotland with view to identifying further improvements	TBC
Improving the way we do things	Treatment, effectiveness	4 - Reduce Unwarranted Variation	Audit current transition process for epilepsy patients across Scotland and identify an action plan	SG
Customer at the heart	Health Improvement	2 - Personalised Approach to Care	Review Patient / Family engagement to understand if remote meetings are a possibility in light of lack of face to face	SG
Improving the way we do things	Treatment, effectiveness	4 - Reduce Unwarranted Variation	Audit the implementation of SIGN guideline across Scotland	SG
Increasing our service impact	Health Improvement	4 - Reduce Unwarranted Variation	Deliver actions from SPEN pathways audit	PM
Customer at the heart	Efficiency	6 - Become Improvers and Innovators	Review of SPEN education to ensure it continues to meet stakeholder needs - both SPEN delivered and signposting to external ie PET	Education group