

Scottish Paediatric Endocrine Group (SPEG)

Annual Report 2022/23

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1. Introduction

The Scottish Paediatric Endocrine Group (SPEG) National Managed Clinical Network (NMCN) was formalised in April 2009. The clinical remit includes endocrine and growth disorders in children and young people throughout Scotland.

During the 2022/23 reporting period, the network has seen several personnel changes within the core team, including the recruitment of Nicholas Conway (Consultant Paediatrician, NHS Tayside) as Lead Clinician. The network had been without a Lead for the entire 2022 calendar year until Dr Conway's appointment in January 2023. Despite the challenges the network has faced, much of the work has progressed as planned.



Image 1: Nicholas Conway

Challenges remain around the capacity and availability of clinical stakeholders. The network will look to review its membership and engagement in 2023/24 and will reach out to the wider clinical community to try and recruit new members. Data entry to the Clinical Audit System (CAS) has been a particular issue. A proposed move to a new PowerApps platform would make this process less time-consuming and would provide useful outcomes. Clinicians also struggled to find the capacity to review clinical guidelines. However, all outstanding guidelines are now expected to be updated within quarter 1 of 2023/24 after they were distributed amongst members more evenly.

2. Current Position

The network achieved 12/14 (86%) of its 'Business as Usual' objectives and 11/12 (92%) of its 'Service Development Plan' objectives in 2022/23.

Under 'Business as Usual', the network had an outstanding objective to update its strategy documents. This had been delayed due to process updates and a wider exercise to standardise templates. All three strategy documents will be reviewed and updated in 2023/24.

The other outstanding objective related to clinical guidelines that were overdue for review. Despite the core team's best efforts, the assigned reviewers struggled to find the capacity to address this until the end of the year. All have since been updated and are awaiting final approval before being updated on the website.

The outstanding 'Service Development Plan' objective related to the effective use of the adrenal insufficiency and Turner syndrome quality indicators on the CAS. There remain significant gaps in this data. The core team took an action to try and collect missing data through alternative means, including Microsoft Forms and a spreadsheet. This prompted three boards to provide an update, with the rest remaining outstanding.

With the full core network team in place and a strategic planning session organised for May 2023, the network is now in a strong position to shape its longer-term objectives.

3. Highlights

3.1 Effective Network Structure and Governance

Steering Group and Subgroups

The network delivered all of its planned Steering Group and subgroup meetings in 2022/23.

The network currently has five subgroups (Education, Clinical Guidelines, Quality Indicators, Nurses' and Transition), with new Chairs appointed to the Quality Indicators and Clinical Guidelines groups over the past year

Attendance has been relatively low throughout the year among some of the subgroups. A review of engagement is currently underway and members who have not been attending will be contacted individually. This issue will be highlighted at the upcoming strategic planning session. The network is keen to expand its reach and that will likely mean the recruitment of new members to the Steering Group and subgroups.

Strategies

The network has its three strategy documents in place (Education, Quality and Communications). However, as they are overdue for review, they will be picked up in the 2023/24 Business Plan. This objective remained incomplete in 2022/23 due to a wider project to standardise these documents.

3.2 Service Development and Delivery

Clinical Guidelines

There are twelve clinical guidelines on the SPEG website. Four of these are currently overdue for renewal. Of these, three have already been reviewed and are awaiting final sign-off to go on the website. The fourth on *Secondary Care Management of Suspected Adrenal Crisis in Children and Young People* is on hold due to some parallel work being done by the British Society for Paediatric Endocrinology and Diabetes (BSPED) on their guidance. There have been some challenges around getting the appropriate individuals to find capacity to review these throughout the year. Something that remains an ongoing issue and meant this objective remained outstanding at the end of 2022/23.

In order to assess how useful the clinical guidelines are, (outwith the usual web hit activity) a clinical guidelines survey was carried out amongst SPEG stakeholders. Despite this being run over several months (including many reminders), it only generated seven responses; six from Consultants and one from a Clinical Nurse Specialist. Figure 1 below outlines the results. The majority of responses were positive, with all twelve guidelines considered by more than half to be either "very

useful” or “somewhat useful”. The guideline that was deemed to be the least useful was in fact a Visual Impairment Network for Children and Young People (VINCYP) guideline on *Optic Nerve Hypoplasia*.

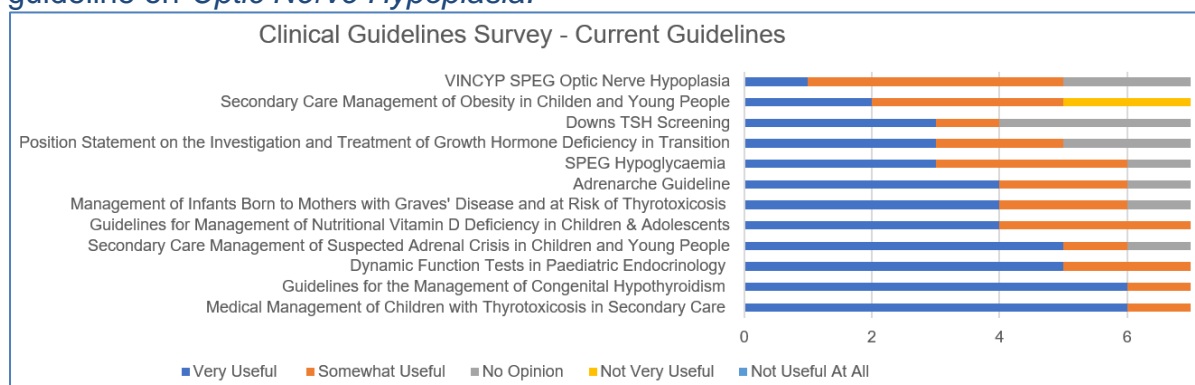


Figure 1: Clinical Guidelines User Survey Results

The survey also asked stakeholders how useful they thought some proposed new clinical guidelines would be. All four received the same responses, with 86% suggesting they would be “very useful” and 14% “somewhat useful”. This will be given consideration for the 2023/24 Business Plan, however, given the aforementioned challenges it is unlikely that all four will be able to progress this year. The proposed four were:

- Obesity
- Short Stature
- Hypercalcaemia and Hypocalcaemia
- Early and Late Puberty

There was also a suggestion from one of the survey respondents to develop some guidance around hormone therapy for transgender patients. However, this has already been developed recently by SPEG stakeholders in partnership with the National Gender Identity Clinical Network for Scotland (NGICNS), and is awaiting publication.

Nurse Growth Hormone Guidance



Image 2: Draft Nurse Growth Hormone Guidance

The Nurses Group and core team have developed a draft Growth Hormone guidance document to assist Nurses with learning. The document provides a mix of information, useful signposting and sections for Nurses to complete as they learn. The plan going into 2023/24 will be to expand this resource to include other key areas of paediatric endocrinology as well as incorporating content around differences of sex development in collaboration with the Scottish Differences of Sex Development (SDSD) clinical network.

Transition

This year, the Transition subgroup has done some work around amalgamating two historic growth hormone patient information leaflets into a single resource, which is due to be signed off. Further patient information leaflets are also being considered for development.

Rohana Wright (Consultant Physician and Chair of the Transition subgroup) has developed a generic training session around transition, which she has delivered to a number of audiences over the past year. In 2023/24 other clinical networks will be given the opportunity to get involved with this training as part of the efforts to improve strategic alignment. Rohana has also developed more specific training for SPEG that she will look to roll out in 2023/24.

Strategic Planning

It has become clear over the past year, particularly with the leadership gap, that SPEG is in need of a strategic refresh. There remain risks around membership, engagement and capacity. A strategic planning session has therefore been organised for May 2023 to pick up on these risks as well as developing a longer-term vision for the network.

3.3 Stakeholder Communication and Engagement

Website and Social Media

Due to a web-related adverse event in one of the other clinical networks in 2022, much website activity was put on hold across all national clinical networks. This applied to social media too. There is an ongoing review of website governance, with a new sign-off process expected as a result. The SPEG website remains up-to-date with its current content.

The development of an interactive map with high-level board contact and service information was outlined as an objective for 2022/23. However, through best practice sharing with other networks, it was determined that this would take up too much bandwidth and a more static version would produce the same result.

Therefore, a flat mapped image of the territorial boards will sit on the website, alongside buttons for each board that will reveal further details. Information has been gathered and the content is ready to be uploaded for the majority of boards.

Newsletters

The network continued to produce and circulate its quarterly newsletter via Microsoft Sway. This has allowed SPEG to share important information around leadership and recruitment, education, clinical guidelines, data, surveys, upcoming dates, learning opportunities, patient resources and other wider clinical network activity. The most recent spring edition attracted 67 views, with 64% completing it and an average of 3 minutes spent reading. This was up from the previous (winter) edition, which attracted 51 views, with 63% completing it.

**Image 3:
Newsletter
Example**



SPEG has its own clinical directory that includes hospital contact information as well as contact details for all SPEG clinical stakeholders within each board. This information was updated in the run up to (and at) the 2023 Annual Scientific Meeting and will continue to be reviewed every 4 months. In 2022/23, new columns were added to the directory to establish who should be invited to the various SPEG education events, thus allowing separate distribution lists to be created.

SPEG delivered its 24th Annual Scientific Meeting in January 2023 at the Stirling Highland Hotel. There were 49 attendees and feedback was overwhelmingly positive. The programme included a lecture on the management of thyrotoxicosis by Dr Malcolm Donaldson. The full programme can be found in appendix 1.

The genetics talk provided “Clear messages on how to suspect rare conditions”, with one delegate reporting that it was, “thought provoking and clinically relevant”, adding that it would make them, “consider further investigations and plans for some of [their] patients”



Image 4: SPEG Annual Scientific Meeting – Mike Wallace Memorial Lecture by Dr Malcolm Donaldson

Plans are already underway to make the 2024 Annual Scientific Meeting a joint event alongside the Scottish Differences of Sex Development (SDSD) clinical network on the topic of Congenital Adrenal Hyperplasia (CAH).

Clinical and Academic Meetings

A decision was taken by the Education subgroup, after taking it to a vote, to continue to host the Clinical and Academic Meetings on Microsoft Teams. This will help to cut down on costs and carbon footprint. It was also agreed that as of 2023, the meetings would be organised by each of the main SPEG boards on a rotational basis, with NHS Greater Glasgow and Clyde earmarked to organise the May 2023 event.

The network only managed to deliver one meeting instead of two in 2022/23. This was mainly down to the gap in leadership and change in personnel within the core team. The September meeting was attended by 36 people and covered a wide range of topics including: differences of sex development, iatrogenic adrenal insufficiency, genetic cancer predisposition syndromes and CAH.

Some of the feedback around knowledge gained is outlined in the quotes below:

“Talks on adrenal suppression/ CAHH would be helpful in my own practice.”

“Better knowledge about CAH monitoring.”

“Found the case study and discussion around adrenal suppression from steroids really helpful and will use this learning to inform future practice.”

“Great to an update from DSD and transition group for useful resources.”

“The clinical cases were very interesting with some good practice points shared.”

3.5 Audit and Continuous Improvement

Clinical Audit System (CAS)

The clinical audit system (CAS) continues to prompt the same concerns from clinicians around inputting data. The system is viewed as cumbersome and time-consuming. As the dataset is far from complete, the outputs are also lacking. A national highlight report (snapshot) is provided in appendix 2. This outlines some of the current issues, including:

- More than half of the patients added do not have a date of diagnosis
- 13% of patients have no condition recorded (although this is down from 16% last year)
- 799 patients remain “active” despite being over 18 (although this is down from 997 last year)

A decision was taken in previous reporting years to try and hone in on specific conditions. Adrenal insufficiency and Turner syndrome were considered to be the most valuable in terms of benchmarking and so a series of quality indicators were introduced. Again, only a handful of boards have been contributing data. The core team took an action to try and collate the missing boards’ data via alternative means, including Microsoft Forms and a spreadsheet. NHS Highland were the only additional board to provide this data, outwith the usual contributors to the CAS. This data has subsequently been added to CAS.

PowerApps

In order to address some of the issues outlined above, the network has been developing a business case to move its data to a new PowerApps platform. This would allow SPEG to have more influence over what data points are included and in a more intuitive order. It would also allow access to outputs via interactive dashboards, thus providing more incentive to input data. The SPEG team have been working with the SDSD clinical network to develop a joint business case, given the cross-over of patients and shared interest. It is anticipated that the business case will be submitted in early 2023/24.

A development request has also been submitted to pull over 40 years’ worth of congenital hypothyroidism (CHT) data across from an historic database in NHS Greater Glasgow and Clyde. The PowerApps business case will supersede this request and include the transfer as part of the new development.

3.6 Value

Clinical Network Synergies

The SPEG clinical network has been engaging with other networks a lot more over the past year. Collaborative work has been done with the National Gender Identity Clinical Network for Scotland (NGICNS) network on guidance around puberty blockers, hormone therapy and fertility preservation. More work has also been done with the SDSD network around shared data interests and education events.

Patient and Family Event

The network delivered an online patient and family event on the topic of adrenal insufficiency in June 2022. The event was well received and another event is already being planned for 2023, in person. Some quotes from the feedback are included below.

“Exceeded expectations - it was brilliant to see conversations between parents happen easily and naturally over Microsoft Teams. It was very supportive.”

“The scenarios were useful as it is very difficult at times to advise parents when to increase medication.”

“Option for face-to-face events in future; I appreciate though it is less time consuming for families to attend a Teams event but I think families who want to meet other families would do this.”

Patient Information Leaflets

There are currently 19 patient information leaflets on the SPEG website, with a new transition leaflet for adrenal insufficiency due to go on soon too. In 2023/24 the core team will take on a project to ensure all leaflets are available in both electronic and print format on the website.

Sustainability

The SPEG network has moved all of its clinical and academic meetings online, along with its Steering Group and subgroup meetings, with the exception of those that take place at the time of the Annual Scientific Meeting. This will significantly cut down on costs as well as reducing the network's carbon footprint.

All resources are accessible on the website and most forms are now completed online, reducing the need to print copies.

SPEG underwent a procurement process in 2019/20 to create a growth hormone framework, which has been extended into 2023. This framework is expected to generate significant savings, with the first update around this due imminently from National Procurement.

Looking forward – 2023/24

SPEG will be running a strategic planning session in May 2023. This will help shape a longer-term plan. However, in 2023/24 the objectives include:

- Submitting a PowerApps business case
- Annual Scientific Meeting with SDS on CAH and 2 Clinical and Academic Meetings
- Patient and Family event in NHS Lothian on Adrenal Insufficiency
- Expanding on nurse guidance resource
- Network branding
- Working with NGICNS on updating guidance and taking forward recommendations
- Review of patient information leaflets
- CAH transition appointment attendance audit and follow up
- Roll out of transition learning

- Updating all strategy documents
- Improving use of quality indicators on CAS
- Development of at least one new clinical guideline based on feedback

Finance

The network spent £2429 on the Annual Scientific Meeting at the Stirling Highland Hotel, including Speaker expenses, leaving and underspend of £2571.

Risks and issues

Due to attendance falling off in some of the subgroups over the past year, there is a risk that parts of the business plan will be more difficult to fulfil and that decisions cannot be taken. The same risk applies to the fact that some long-standing members of SPEG will be retiring in the near future. The strategic planning session in May will look to address wider membership and engagement and how to target new recruits to the network. New Chairs have already been appointed for some of the subgroups.

There is a risk that survey responses remain low when the network seeks feedback on clinical guidelines and the network as a whole. SPEG will seek to expand on its communication channels and widen its distribution list to include more general staff as well as those working in primary care.

There is a risk that SPEG will continue to only have the Clinical Audit System available to capture national data over the next year and that data entry continues to fall off. More work will be carried out by the Quality Indicators subgroup to look at options to support national datasets until a more viable option (i.e. PowerApps) becomes available.

Appendix 1 – Annual Scientific Meeting Programme

Scottish Paediatric Endocrine Group (SPEG) 24th ANNUAL SCIENTIFIC MEETING The MacLaren Suite, Stirling Highland Hotel, Spittal Street, Stirling, FK8 1DU 26th - 27th January 2023		
Thursday 26th January		
SESSION 1	<u>Memorial lecture in honour of Professor Mike Wallace</u>	<u>Chair: Louise Bath</u>
19.00 - 20.00	Management of thyrotoxicosis	Malcolm Donaldson
20.00	Dinner	
Friday 27th January		
SESSION 2 (part 1)	<u>How do we manage....</u>	<u>Chair: Tarini Chetty</u>
09.00 – 09.45	Obesity – in England: CEW centre update	Nikki Davis
09.45 – 10.05	Obesity – genetic testing and the results?	Joanne McLean and colleagues
10.05 – 10.15	Discussion on obesity services in Scotland	
10.15 – 10.45	<u>Tea/Coffee</u>	
SESSION 3	<u>Congenital Hypothyroidism</u>	<u>Chair: Guftar Shaikh</u>
10.45 – 10.55	Delayed diagnosis: case discussion	Raj Shyam
10.55 – 11.20	Processes of screening: lab to clinician	Sarah Smith
11.20 – 11.35	Biochemistry: what should we check and why?	Karen Smith
11.35 – 11.45	Discussion about CH management and next steps	
SESSION 2 (part 2)	<u>How do we manage....</u>	<u>Chair: Tarini Chetty</u>
11.45 – 12.30	Sick day dosing in adrenal insufficiency?	Talat Mushtaq
12.30 – 13.30	<u>Lunch</u>	
SESSION 4	<u>Free Communications Sessions</u>	<u>Chair: Amalia Mayo</u>
13.30 – 13.50	An update on DHEAs service provided by GRI Biochemistry.	Kirsten Grant
13.50 – 14.10	Case of 17 alpha OH deficiency CAH presenting with delayed puberty.	Amy Frank
14.10 – 14.30	Assessment of the accuracy of automated bone age by AI.	Mehreen Malik
SESSION 5	<u>Genetics</u>	<u>Chair: Clare Webster</u>
14.30 – 15.00	Endocrine genetics: what can we learn from the adult experience?	Joanne McLean and Paul Newey
15.00 – 15.30	Insulin resistance syndromes: diagnosis and therapies	Prof Robert Semple
15.30	Close of meeting	

Appendix 2 – CAS Highlight Report

