Scottish Paediatric Endocrine Group (SPEG)

Annual Report
2023/24

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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.

The 2023/24 reporting period has been a productive one, with long-term strategic planning as the main priority. The network core team engaged with Steering Group members, subgroup members and individual boards in order to pull together the network's priority areas of focus for the next few years.

The network has continued to deliver on its objectives while facing a number of challenges, including - increased scrutiny over expenditure, limited capacity and engagement of stakeholders and other external factors.

A National Services Directorate (NSD) proposal was taken to the SPEG Steering Group to look at joining with the Scottish Differences of Sex Development (SDSD) clinical network on a more formal basis. The idea being that combining resources and stakeholders would safeguard the future of both networks by making them more resilient, with greater influence. Both networks worked together to deliver a joint education meeting in January 2024 and other examples of shared resources have also been emerging. Despite some initial reservations, the networks have agreed to work together over the course of 2024/25 to determine how this could work long-term.

The development of meaningful data outputs remains a challenge for the network. A proposal was submitted to develop a Power Apps instance to replace the outdated Clinical Audit System, however, this has been held up by wider challenges around ongoing maintenances of such developments.

Mark Strachan (Consultant in Diabetes and Endocrinology, NHS Lothian) took the decision to step down as Chair of the Steering Group at the end of 2023/24 after five years in the role. The network would like to acknowledge and thank Mark for his outstanding commitment and contribution throughout this period. A new Chair will be sought as soon as possible.

2. Current Position

The network achieved 18/18 (100%) of its 'Business as Usual' objectives and 14/14 (100%) of its 'Service Development Plan' objectives in 2023/24. Two objectives planned to carry over into next year's plan remain 'green' in status.

The network is expected to have a new 5-year workplan in place by the middle of 2024/25. This will be based on the report that was developed as a result of the strategic engagement work that took place throughout 2023/24.

A new Terms of Reference has been drafted for the network to replace the service level agreement. This covers 2024/25.

The existing Education, Quality and Communication strategy documents were updated to cover the period up to the end of 2023/24. New strategy documents will be developed in 2024/25 to incorporate the long-term strategic direction of the network.

3. Highlights

3.1 Effective Network Structure and Governance

Steering Group and Subgroups

The network currently has five subgroups (Education, Clinical Guidelines, Quality Indicators, Nurses' and Transition). After several years, Dr Louise Bath (Consultant Paediatric Endocrinologist, NHS Lothian) has stepped down as Chair of the Education subgroup. The network would like to acknowledge and thank Dr Bath for her outstanding leadership and contribution, particularly with the organisation of the highly valued Annual Scientific Meetings and Clinical and Academic Meetings. Dr Tarini Chetty (Consultant Paediatrician, NHS Lothian) and Dr Ching Chen (Consultant Paediatric Endocrinologist, NHS Greater Glasgow and Clyde) will be jointly chairing the group going forward. A new Chair will also be leading the Nurses' subgroup going into the next reporting period. The network would like to thank Jill Gibb (Paediatric Endocrine Nurse, NHS Tayside) for her leadership over the past year.

With a number of staff within the community retiring and moving on, there is a need for SPEG to recruit new members to the Steering Group and various subgroups.

Strategies

The network has its three strategy documents in place (Education, Quality and Communication). New strategy documents will be developed in 2024/25 to align with the strategic planning objectives.

3.2 Service Development and Delivery

Strategic Planning

A strategic planning exercise took place between May and September 2023, which aimed to identify network priorities over the coming 5 years.

This strategic planning exercise was conducted with the following objectives in mind:

1. to develop a SPEG workplan for the next 5 years
2. to engage SPEG network members in developing the workplan
3. to ensure that SPEG continues to meet members' needs

In the first instance, an online questionnaire was developed within Microsoft Forms using a Strengths, Weaknesses, Opportunities, Threats (SWOT) analysis approach. This questionnaire was distributed to SPEG members (n=40) in advance of a scheduled strategic planning session. There were 15 responses (38%).

The strategic planning session was a two-hour Microsoft Teams discussion, coinciding with a planned Steering Group meeting to maximise attendance. The exercise was facilitated by the SPEG core team with additional contribution from the Senior Programme Manager for National Managed Clinical Networks.

A series of scheduled interviews were then organised across several territorial health boards to allow more in-depth discussions. Interviews were conducted by the network core team on Microsoft Teams.

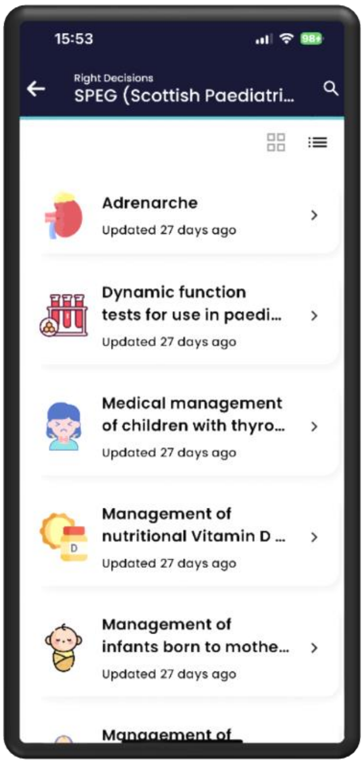
Qualitative data was extracted from a combination of free text questionnaire responses and discussion notes. The analysis looked for common themes with aligned aims and strategic objectives. Where possible, these strategic objectives were aligned to the Realistic Medicine framework. These objectives were further broken down into a series of proposed projects which will form the basis of the network's 5-year workplan.

There were three identifiable themes as to where participants felt that the network should focus: stakeholder engagement, education and promoting research, and service development.

A summary of the themes, aims, objectives and proposed actions is included as Appendix 1.

Clinical Guidelines

After the business plan objective applicable to clinical guidelines closed with a 'red' status at the end of 2022/23, there has been a real push to get these up to date via the Clinical Guidelines subgroup. As well as bringing all the clinical guidelines up to date on the website, there have also been new guidelines developed for 'Precocious and Delayed Puberty' and 'Short Stature'. The guidelines are currently hosted on the SPEG website and will shortly be available on the Right Decision Service platform.



Right Decision Service

The Clinical Guidelines subgroup and network core team have been working with the Right Decision Service team in NHS Health Improvement Scotland to develop a new SPEG toolkit[1] to host the clinical guidelines.

The Right Decision Service takes a 'Once for Scotland' approach and should be the go-to place for all NHS Scotland guidelines.

It provides the network with a range of tools and guidance, including general governance and risk assessments. The guidelines are presented in user-friendly accordion-style format that allows the user to navigate the sections by expanding and collapsing them. The platform champions accessibility and has a web version as well as a downloadable mobile app. SPEG currently has nine guidelines on the platform that are live. The core team has also received training to be able to make edits as required.

Image 1: Screenshot of Right Decision Service Application for SPEG Toolkit

Nurse Growth Hormone Guidance

The Nurses' Group have continued to work on a Growth Hormone guide to assist Nurses with learning. The document provides a mix of information, useful signposting, and sections for Nurses to complete as they learn. Nurses from the Scottish Differences of Sex Development (SDSD) Steering Group have also been involved in the work. It is anticipated that this will be used as a template for further guides to be developed. This one will be published on the SPEG website and Right Decision Service platform in June 2024.

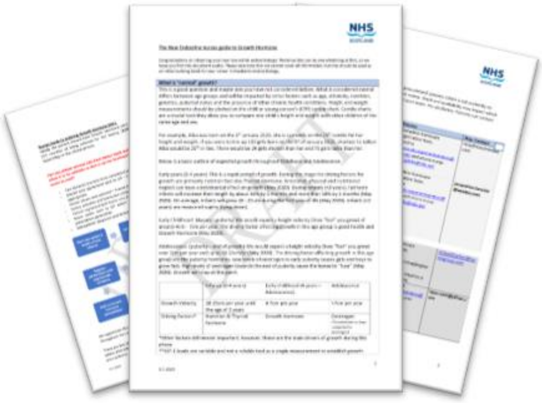


Image 2: Draft Nurse Growth Hormone Guidance

Transition from Paediatric to Adult Services

A cross-network short life working group within the National Managed Clinical Networks (NMCN) team was set up to look at transition themes. Stakeholders across various networks expressed an interest in Transition training. Therefore, a 1-hour Microsoft Teams session was arranged, which was delivered by Dr Rohana Wright, (Consultant Physician in Endocrinology and Diabetes, NHS Lothian/ Chair of the SPEG Transition subgroup) and was open to all clinical network stakeholders. 28 delegates attended. The session covered the following topics:

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[1] SPEG (Scottish Paediatric Endocrine Group) | Right Decisions

- what do we know about adolescent care and transition? And are we trained well enough?
- guidance
- adolescent development – why is it important?
- issues of importance for young people
- communication
- where should we be heading next

An extensive Microsoft Form has been created to capture an in-depth look at transition services across the various health boards in Scotland. This will be rolled out in 2024/25 to identify areas for improvement and share best practice.

Further to this, a scoping exercise took place, resulting in a quality improvement project outline to audit patient attendance before and after being referred from paediatrics to adult clinics. A specific condition with a small population was chosen to make the data collection more manageable – Congenital Adrenal Hyperplasia (CAH). It is anticipated that the data will pick up on any patients “lost” during transition, which will prompt follow up action. It is also expected that there will be unwarranted variation in attendance rates (after transition) between boards, which will highlight areas for improvement as well as identifying best practice. The data collection will be carried out in 2024/25 and reporting will be picked up from 2025/26.

Survey

A national survey was conducted in March 2024 to capture feedback on the network. The survey was issued to paediatric endocrinology stakeholders known to the network including Consultant Endocrinologists, Nurses, General Paediatricians, Psychologists, Pharmacists, Scientists and third sector representatives. The survey was shared with over 110 stakeholders and there were 19 responses, 32% of whom described themselves as not currently actively involved with the network.

The overall feedback was generally positive, especially around education and guidelines. All 19 respondents recognised the value the network brings to clinical guidance. 89% reported increased knowledge through the network’s education programme and 84% had increased confidence. Communication and networking were also highlighted as strengths.

One of the main areas for improvement that was highlighted was the need for an improved data system for collecting and reporting on national data and the IT support that goes along with this. Several respondents also raised concerns about cuts to funding and limiting face-to-face meeting opportunities, with 95% of respondents placing value on the annual face-to-face education event.

A summary of the survey responses around strengths, areas for improvement, priorities, and challenges, is included as Appendix 2.

3.3 Stakeholder Communication and Engagement

Website

The SPEG website[2] has recently moved to a shared web offering along with all the other national clinical networks. This allowed another opportunity to ensure content was up to date. The shared web offering means all networks share the same search function and the formatting is standardised to make it more user friendly.

Newsletters

The network continued to produce and circulate its quarterly newsletter via Microsoft Sway. This has allowed SPEG to share important information around events, clinical guidelines, data, surveys, upcoming dates, learning opportunities, patient resources, and other developments. Figure 1 below shows the continuous improvement in readership throughout the year, with the most recent version attracting 248 views. Time spent reading the newsletter itself fell throughout the year along with completion rates. Therefore, the team will look to cut down on content and ensure the newsletters are not too long and capture essential and attention-grabbing updates only.

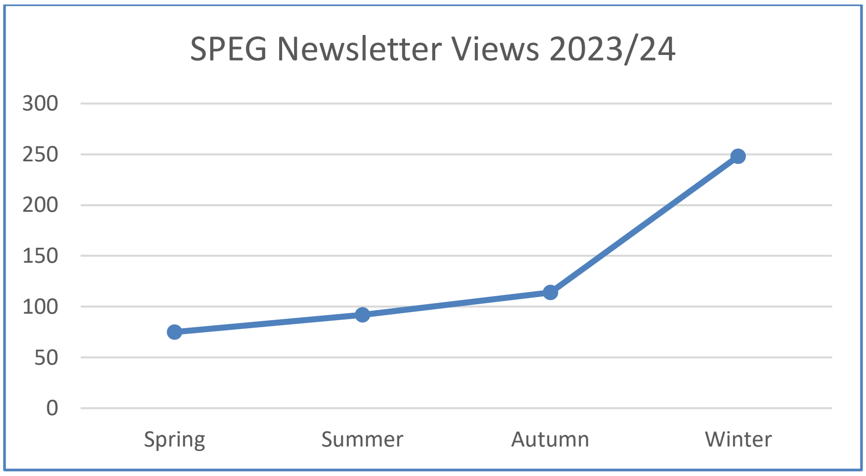

Figure 1: Newsletter views throughout 2023/24

Image 3: Example of SPEG Newsletter

Brand Identity

On the old iteration of the SPEG website and in other communication documents, it was noted that there were inconsistencies in branding. There were also issues with the existing colour palette in that it was limited to three colours and there was a poor contrast of white text on these. Therefore, some work was done to generate a new colour palette that would offer more choice and allow better contrast for accessibility. The new SPEG colour palette will be used on various communications documents going forward, including patient leaflets, internal reports, and presentations. The intention was also to update the website, however now that this has moved to a shared platform, the colours are standard. The below image shows the old and new colour palettes.

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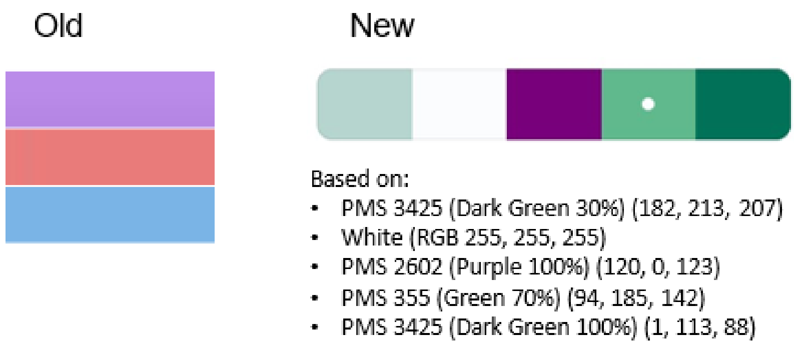
[2] Scottish Paediatric Endocrine Group – National Managed Clinical Network (nhs.scot)



Based on:

- PMS 3425 (Dark Green 30%) (182, 213, 207)
- White (RGB 255, 255, 255)
- PMS 2602 (Purple 100%) (120, 0, 123)
- PMS 355 (Green 70%) (94, 185, 142)
- PMS 3425 (Dark Green 100%) (1, 113, 88)

Image 4: SPEG Brand Identity Colour Palette

3.4 Education

Annual Scientific Meeting

The network delivered its 25th Annual Scientific Meeting in January 2024 at the Stirling Highland Hotel in collaboration with the SDSD clinical network, with a focus on Congenital Adrenal Hyperplasia (CAH).

There were 48 delegates in attendance from across Scotland. Evaluation feedback was received from 37 delegates.

Image 5: SPEG/ SDSD Annual Scientific Meeting

The below table outlines the overall impression of the event, with most delegates scoring the programme, organisation and venue as “excellent”.

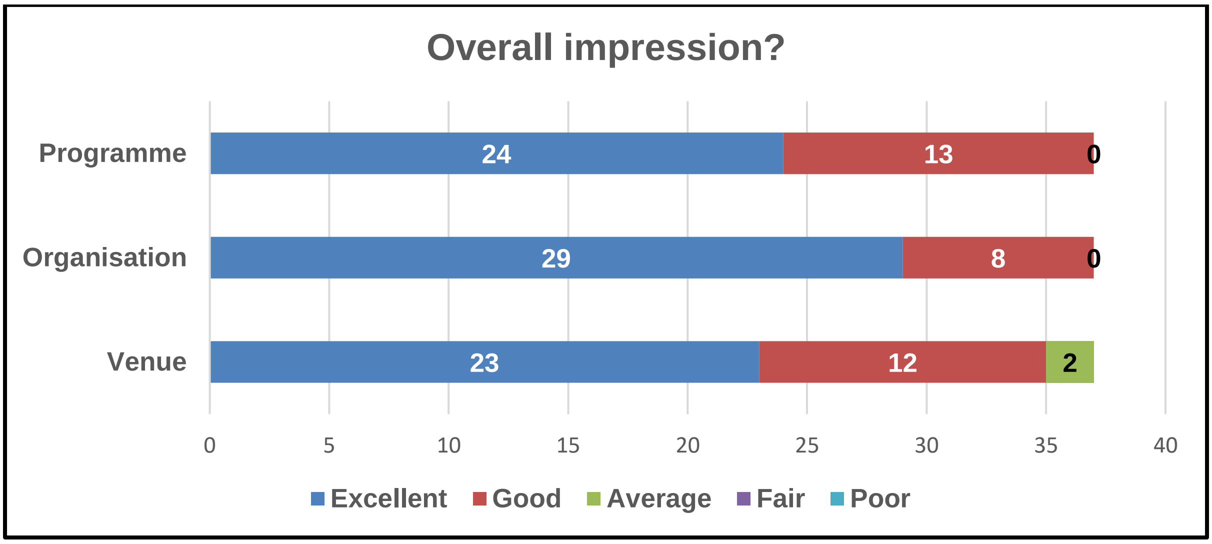


Figure 2: SPEG ASM Feedback – Overall Impression

Figure 3: SPEG ASM Qualitative Feedback Word Cloud

The word cloud on the left has been generated based on the qualitative feedback received.

Suggested topics for future events included:

- DSD, late effects
- Hyperthyroid management
- Diabetes insipidus
- Obesity management
- General endocrinology
- Calcium metabolism
- Pseudo parathyroid
- Lab talks
- Pituitary pathology
- Genetics of hypopit
- Precocious puberty
- Hypopituitarism
- Obesity treatments
- Transgender treatments
- Transition to adult services
- Endocrine late effects
- MRKH/ AIS
- Genetics of short stature
- Hyperinsulinism
- Growth hormone treatment outcomes

Clinical and Academic Meetings

Continuing from last year, the Clinical and Academic Meetings have continued to take place on Microsoft Teams to cut down on costs and carbon footprint.

Two meetings took place over the past year – one in May 2023 and one in September 2023. The meetings took place on Microsoft Teams as previously agreed, to cut down on the network's carbon footprint and spend. 25 delegates attended the first meeting, which was organised by colleagues in NHS Greater Glasgow and Clyde. 35 delegates attended the second meeting, which was organised by colleagues from NHS Lothian and surrounding boards.

Some of the feedback across both meetings around how the learning will be applied in practice are highlighted below.

- look to see how we can utilise registries to improve clinical practice/ services
- increased awareness of complex monitoring in Long Acting Growth Hormone
- consider using Long Acting Growth Hormone in a case with poor compliance

- good cases, always useful to think of some of these when interpreting results
- look at registering cases with i-DSD
- considering earlier karyotype
- discussion with experts across Scotland and further afield
- awareness of surgical options for tall stature
- availability of guidelines investigating gynaecomastia
- good resources identified for future reference, including information leaflets
- learning from other people's experience
- the cases were so varied with different presentations. It will certainly make me request further clinical details if I see unusual/unexpected results
- aware of different strategies in managing primary amenorrhea
- I think that if I encounter similar clinical cases I will reflect on these presentations and the way in which they were managed

3.5 Audit and Continuous Improvement

Clinical Audit System (CAS)

Capturing data in the clinical audit system (CAS) has once again proved difficult, with clinicians continuing to voice concerns around how cumbersome it is, with a lack of meaningful outputs. A total of 276 new patients were added to the SPEG CAS in 2023/24 by 4 health boards.

Quality Indicators were added to the system for Adrenal Insufficiency (AI) and Turner Syndrome (TS) over the last few years. Five out of the six quality indicators for AI were over 50% completed (51% to 63%). The sixth indicator requires an annual update of the patient’s emergency plan and was only 2% compliant. The core dataset fields for TS were added in 2021, therefore there is a backlog of patients that were added before then that need to have this added retrospectively.

Power Apps

A business case was submitted by the network to develop a Power Apps instance to improve the user experience and access to outputs. It is anticipated that this would encourage more data input throughout Scotland, leading to more meaningful outputs. However, this has stalled due to a wider issue around resource requirements in maintaining Power Apps.

CAH Attendance Audit at Transition

Young people with congenital adrenal hyperplasia (CAH) need to transition from paediatric to adult services at developmentally appropriate stage. It is known from previous studies that young people are often lost to follow up during this vulnerable stage of life. CAH is a lifelong condition requiring regular monitoring and healthcare advice and can be life threatening or have long term morbidity impact if not managed appropriately.

The SPEG Transition subgroup has outlined a quality improvement project to carry out an attendance audit of CAH patients before and after being referred to adult clinics. This will allow clinicians to:

1. re-establish follow up for patients that have been lost, ensuring they receive appropriate care

2. learn from good practice examples - if an area has a very low rate of loss of patients during transition, what model do they utilise?
3. tackle any inequities in care delivery
4. use the findings for this relatively rare endocrine condition to extrapolate to other long term health conditions

This project will be a long-term one across several years.

3.6 Value

Growth Hormone Framework

SPEG has worked closely with the national procurement team over the past few years to develop a framework for prescribing growth hormones. The framework took effect from 1st January 2021 and has been extended twice now, taking it up to the end of 2024.

This was projected to save around £670k per annum. The procurement team provided SPEG with an update on the actual savings. Using the full calendar year of 2022 as a sample, the network generated savings of over £827k.

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) on guidance around puberty blockers, hormone therapy and fertility preservation and regular meetings have been taking place between the paediatric endocrinology teams in NHS Lothian and NHS Greater Glasgow and Clyde and the Sandyford Sexual Health Clinic.

As outlined earlier in the report, SPEG has also been working more closely with SDSD, and the two networks successfully delivered a joint annual education event. A more formal arrangement to bring the two networks together has been proposed and throughout 2024/25, a short life working group will be convened to look at this transformational change.

Patient and Family Event

SPEG hosted a family event for children and young people with Adrenal Insufficiency and their families on Saturday 24 June 2023 in the Royal Hospital for Children and Young People, Edinburgh. This was organised and facilitated by the SPEG Nurses' subgroup and core team. The event was attended by 17 families (48 people) and feedback was received from 14 families. The day incorporated a mix of patient and professional talks, practical demonstrations, children's entertainment, and peer discussions. The whole event only cost the network £275.

Image 6: SPEG Adrenal Insufficiency Patient and Family Day Pictures

Satisfaction ratings are provided in the table below.

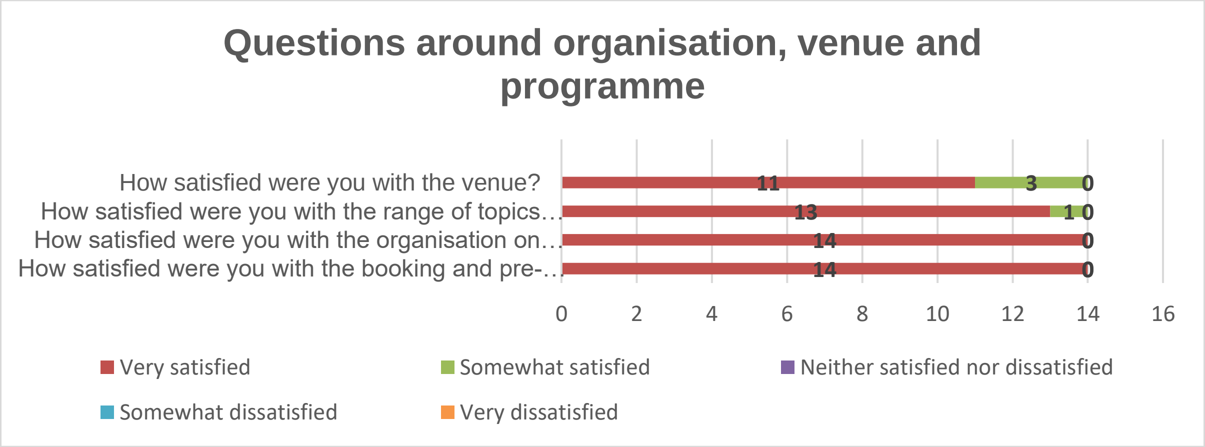


Figure 4: SPEG Patient and Family Day Feedback

Some of the qualitative feedback is highlighted below.

- the event was excellently managed
- I was nervous before attending but the staff and other participants put me at ease straight away
- the doctors and staff were great and very helpful with all questions
- I really liked the medical info and the Q&A session
- the injection demo and patient journeys were valuable

- Teapot Trust and entertainer excellent for kids
- children love loved it
- speakers were inspirational
- lovely to meet other families with children with the same condition
- good to hear about support services
- gaining new info on medicine and sharing tips and info with other parents
- the patient journey was most beneficial to me as it demonstrates that with careful planning these conditions are not a barrier to living a life to the full
- excellent day. Very informative, friendly, fun for all adults and kids
- the event exceeded my expectations
- I have left feeling inspired and informed
- there is a community of support for these conditions, and we need to reach out more

Attendees were asked for feedback on the service they receive as well as the event itself. Suggested areas for improvement are noted below and have been incorporated into the strategic planning exercise and will help to shape the network's priorities for the next five years.

- Sharing of standards across hospitals and services
- More education
- Moving away from an IM injection to an epi pen style injection
- I'm not good at reaching out for support so perhaps reminding families of the support networks available to them.

During the parent and carer "heart to heart" session, attendees shared their personal experiences and also some useful hints and tips. This highlighted a potential need for more signposting to non-clinical resources on the SPEG website and reinforced the idea of setting up a parent/ carer/ patient group again. Something that the network had in place a number of years ago.

Sustainability

The SPEG network has moved all 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 cut down on costs as well as reducing the network's carbon footprint.

The Annual Scientific Meeting was delivered as a collaboration with SDSD this year, which has saved money and cut down on the number of face-to-face meetings even more.

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

The growth hormone framework has saved the NHS hundreds of thousands of pounds per annum since its implementation in 2020.

Looking forward – 2024/25

A summary of the draft Service Development objectives for 2024/25 is included below.

Description of Work
Work with the Scottish Differences of Sex Development NMCN to bring the networks together on a more formal basis. The 2024/25 reporting year should be utilised as a period of transformational change by working in conjunction with the Lead Clinician of SDSD. The networks should identify common areas of interest/ focus as well as areas that do not align. Consideration to be given as to how formal arrangements will work from 2025/26. (LOGIC MODEL)
Develop a five year workplan based on the strategic planning work that began in 2023/24 and the subsequent report that was developed with recommendations.
Deliver a patient and family engagement event on a specific condition or set of conditions. Topic/ theme to be determined, based on wider strategic planning. Scoping required.
Continue to engage with the Right Decision Service (NHS Health Improvement Scotland) to publish all SPEG clinical guidelines. Develop and embed feedback forms and consider scope around expansion opportunities within the toolkit.
Continue to engage with the National Gender Identity Clinical Network for Scotland on the latest developments and advice around prescribing puberty blockers and cross-sex hormones and ensure guidance remains up to date.
Continue with the audit of CAH patient attendance at adult clinics to identify areas for improvement across transition from paediatric to adult services. Scoping took place in 2023/24 and reporting will fall into 2025/26. (LOGIC MODEL)
Circulate Microsoft Form to scope current landscape of paediatric to adult transition services throughout Scotland, based on inequity highlighted via strategic planning discussions. Rollout online tailored transition training sessions for SPEG stakeholders based on outputs.
Develop a comprehensive service map for paediatric endocrinology services in Scotland and publish on the SPEG website. This should highlight areas with specialist subject matter expertise and services available.
Develop first draft of clinical guideline for paediatric calcium disorders.
Scope and develop congenital hypothyroid quality improvement project with clear quality indicators. Engage with newborn screening lab, SCI Store and PBPP to access the required data.

Finance

The network spent £3180.02 of its £5000 budget in 2023/24. A breakdown is provided below. It should be noted that the ASM and speaker expenses are for SPEG and SDSD combined and have not been split.

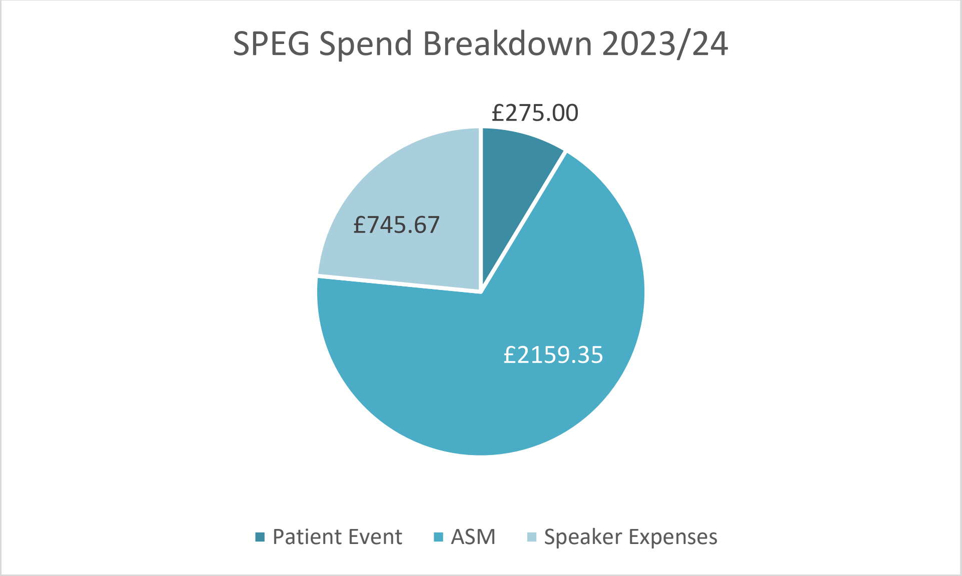


Figure 5: SPEG annual spend 2023/24 breakdown

Risks and issues

There is a risk of loss of engagements of some staff groups though bringing together the SPEG and SDSD Networks where they are only associated with one network. Engagement with stakeholders throughout the process will be critical to mitigating this risk.

Risks remain around the lack of useful national data outputs. Without a complete national picture, it is difficult to identify where there are areas for improvement and where there may be unwarranted variation in practice and outcomes. Driving quality improvement is one of the main reasons for having a national network. Without meaningful data, there is a risk that the network is not doing this to its full potential. The Power Apps development will help mitigate this if and when it proceeds.

The Steering Group is currently without a Chair. Nicky Conway (Lead Clinician) has agreed to chair the first meeting of 2024/25, as the search for a new Chair progresses.

A number of key stakeholders within the network are retiring in the next year. There is a risk that the network will lose valuable members and there may be gaps in support in terms of leadership and geographical spread. An exercise will be carried out as part of the long-term strategic planning to recruit new members.

There is a risk that the network is unable to evidence its impact due to limited response to surveys when it 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.

Appendix 1 – Summary of Themes, Aims, Objectives and Proposed Actions

Theme 1	**Stakeholder Communication**
Aim	1. To improve engagement and communication between the network and its members, the public and wider clinical community.
Objectives	1.1 Provide useful information to all health care professionals 1.2 Ensure the network is meeting requirements of wider clinical community 1.3 Support parents/ carers and children and young people with endocrine disorders by providing relevant information and education
Proposed Actions	• Map educational provision to Royal College of Paediatrics and Child Health (RCPCH) Progress+ curriculum • Create “Educational opportunities” channel within SPEG MS Teams and/or website • Develop CPD modules for common conditions (e.g. thyroid disorders) within the Right Decision Service • Continue current programme of Annual Scientific and Clinical & Academic meetings • Create “SPEG clinical research” channel within SPEG MS Teams and/or website • Develop transition guidance for specific conditions • Develop guidelines/pathways for paediatric calcium disorders • Develop guidelines/pathways for genetic conditions relevant to paediatric endocrinology

Theme 2	**Education**
Aim	2. To improve clinical care in accordance with the principles of realistic medicine
Objectives	2.1 Provide relevant Continuing Professional Development (CPD) 2.2 Promote clinical research 2.3 Reduce unwarranted variation in practice
Proposed Actions	• Map educational provision to Royal College of Paediatrics and Child Health (RCPCH) Progress+ curriculum • Create “Educational opportunities” channel within SPEG MS Teams and/or website • Develop CPD modules for common conditions (e.g. thyroid disorders) within the Right Decision Service

	• Continue current programme of Annual Scientific and Clinical & Academic meetings • Create “SPEG clinical research” channel within SPEG MS Teams and/or website • Develop transition guidance for specific conditions • Develop guidelines/pathways for paediatric calcium disorders • Develop guidelines/pathways for genetic conditions relevant to paediatric endocrinology

Theme 3	**Service Development**
Aim	3. To support delivery of paediatric endocrine services throughout Scotland
Objectives	3.1 Promote equity of access to services 3.2 Reduce harm and waste 3.3 Become improvers and innovators
Proposed Actions	• Map current service provision across Scotland • Ensure SPEG participation available to all relevant HCPs • Work with national procurement to identify “once for Scotland” options • Work with Public Health Scotland to develop clinical pathways for obesity management • Improve Clinical Audit System user experience • Develop measurable quality standards for specific conditions

Appendix 2 – National Network Survey Summary of Responses

Strengths	**Areas for Improvement**
• Very productive and always striving to ensure we are sharing and producing the best care for patients. • Always open to ideas and ways to improve the service. • Collegiate atmosphere of peer support. • Great education and networking. • Getting to know peers in other areas. • Small team working well together. • Subdivided into smaller groups with clear purpose and deadlines. • Regular meetings for networking and learning. • Regular meetings online and the annual network meeting allow for collaboration and discussion between the tertiary centres and district general hospitals. • Working together gives a better continuity of care. • Collaborative approach, shared enthusiasm driven by personal connections. • Great networking with both paediatricians and adult physicians. • Excellent website and guideline resource. • Supporting staff with learning opportunities and empowering change. • Uses national data to highlight areas of good practice and identify areas for development. • Excellent educational events. • Guidance and sample requirements around the investigation of rare disorders is invaluable. • Collaboration, knowledge and experience. • Lining with other centres, support and clinical guidance.	• Develop a usable data collection platform, providing board level data, which is available to clinicians real time to drive quality improvement. • Meaningful IT support.
Suggested Future Priorities (3-5 years)	**Network Challenges/Threats**
• Continue doing what we are doing and producing guidelines and protocols that are relevant to our patient group. • See strategic review. • Meaningful IT support. • Continue to support this group. • Continue to keep guidance and resources up to date. • Continue to host face to face meetings and learning events. • Develop a usable data collection platform, providing board level data,	• Could become redundant as other UK wide groups provide guidance and education. • Resource limitations - being asked to more with less money. • Network members may disengage if no opportunity to meet in person in a social environment. • Lack of investment in infrastructure resources. • Underfunding

which is available to clinicians real time to drive quality improvement. • Support patients and families who are living with endocrine conditions. • Patient involvement. • Maintain high quality updated guidance. • Sharing across the network any audit of practice highlighting good practice and areas for improvement.	• Removal of annual in person meeting takes away clinician links. • Informal discussions and engagement are not possible in a Teams/remote environment. • Without linking and developing relationships new clinicians will not feel a part of the network. • Most of the work is not reflected in individual job plans and relies on clinician good will and desire to improve the lives of their patients. • Resource funding and time of staff becoming more restrictive. • Changing of network structure across Scotland