

Scottish Paediatric Endocrine Group (SPEG)

Annual Report 2025/26

This document has been prepared by the National Services Directorate (NSD) of Public Services Delivery Scotland (PSD Scotland) on behalf of the Scottish Paediatric Endocrine Group (SPEG). Accountable to Scottish Government, PSD Scotland works at the heart of the health service providing national strategic services to the rest of NHS Scotland and other public sector organisations to help them deliver their services more efficiently and effectively. SPEG is a collaboration of stakeholders involved in the care of paediatric endocrinology who are supported by a PSD Scotland Programme Team to drive improvement across the care pathway.

The network is supported by a dedicated programme team within Public Services Delivery Scotland (PSDS), consisting of:

Programme Manager: Jamie Nimmo

Assistant Programme Manager: Laura Craig

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.

Paediatric endocrine services are provided through the 11 mainland territorial health boards with Grampian providing services for patients in Orkney and Shetland and Glasgow providing services for patients in the Western Isles. All 11 health boards participate in SPEG.

2. Current Position

Activity during 2025/26 reflected national prioritisation set during a period of review. Alongside evolving national planning arrangements, Managed Clinical Networks were asked to focus activity on a number of core priorities.

Looking ahead, and consistent with the direction set by the Health and Social Care Service Renewal Framework and Scotland's Population Health Framework (June 2025), and recognising that Chief Executive Letter (CEL) 29 (2012) *Managed Clinical Networks: Supporting and Delivering the Healthcare Quality Strategy* remains the extant mandate for Managed Clinical Networks, SPEG will build on its established approach by undertaking a Strategic Needs Assessment to inform the 2026/27 workplan and ensure priorities remain aligned to population need, current pathways, available data and stakeholder perspectives.

The priorities for SPEG in 2025/26 were:

- 1) Deliver an Annual Scientific Meeting for professional colleagues
- 2) Deliver at least one Clinical and Academic Meeting for professional colleagues
- 3) Develop and rollout a Power BI user dashboard to allow clinical colleagues to access their own data on the Clinical Audit System (CAS)
- 4) Review all patient information leaflets and transfer them to a new standardised, template
- 5) Update and publish new versions of the Transition Framework and Transition Checklist on the website

3. Highlights

3.1 Effective Network Structure and Governance

During 2025/26, subgroup activity was driven by emerging priorities, with meetings convened on an as-needed basis to support delivery of key workstreams.

Dr Nicholas Conway (General Paediatrician, NHS Tayside) continued as Lead Clinician for SPEG, while Dr Rohana Wright (Consultant Endocrinologist, NHS Lothian) continued as Chair of the SPEG Steering Group.

3.2 Service Development and Delivery

Clinical Guidance

Two clinical guidance documents were reviewed and approved in 2025/26: 'Management of Congenital Hypothyroidism' (CHT) and 'Adrenarche'. The new 'Hypocalcaemia' guidance was also approved. The CHT and Hypocalcaemia documents are currently awaiting pharmacy review and sign-off prior to publication on the website.

The network has nine clinical guidance documents on the Right Decision Service application, hosted by Healthcare Improvement Scotland (HIS). Some of these are now due for review. The number of views and users since the beginning of 2024 can be seen in figure 1 below.

One of the main priorities for the Clinical Guidance Group in 2026/27 will be to review any guidance within the appropriate timeframes and to continue to update the Right Decisions toolkit at the same time.

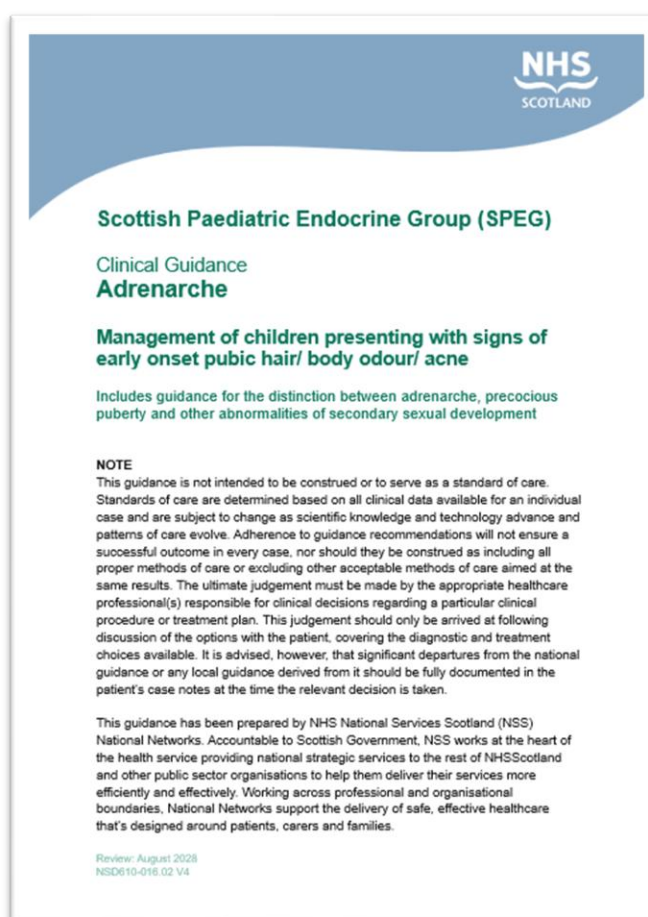


Image 1: Example of SPEG Clinical Guidance Document

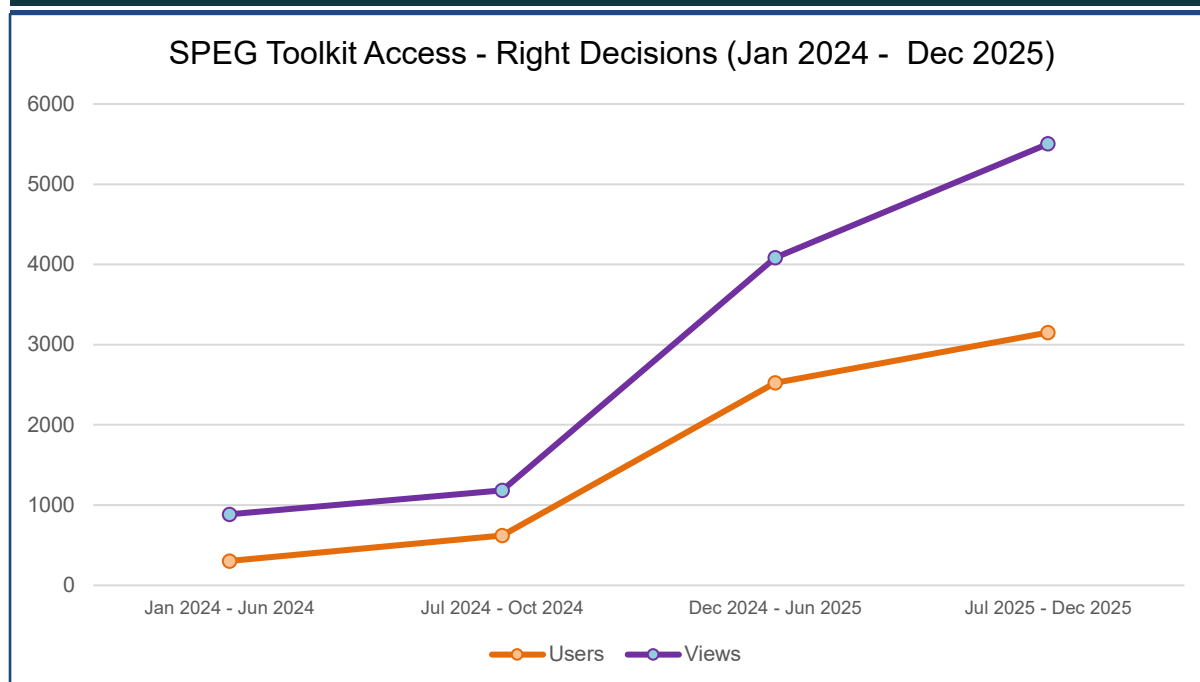


Figure 1: Analytics for SPEG Toolkit on Right Decision platform from January 2024 to December 2025

There has been a sharp increase in both the number of users and views on the SPEG toolkit within the Right Decisions platform. In the two-year period from January 2024 to December 2025, there have been a total of 6601 unique users and 11656 total views. App use is also becoming more prominent, with 1314 users accessing the SPEG Toolkit on the app between July 2025 and December 2025. A total of 6013 interactions were recorded within the SPEG toolkit during the same six-month period. SPEG aims to eventually migrate all its guidance onto the Right Decisions platform.

Patient Information Leaflets

SPEG recognises the importance of providing accessible, high-quality information to support children and young people with endocrine conditions, their families and healthcare professionals. During 2025/26, ten patient information leaflets were reviewed, updated and transferred to a new standardised template. Resources are available for patients, parents and carers, as well as school nurses and teachers.

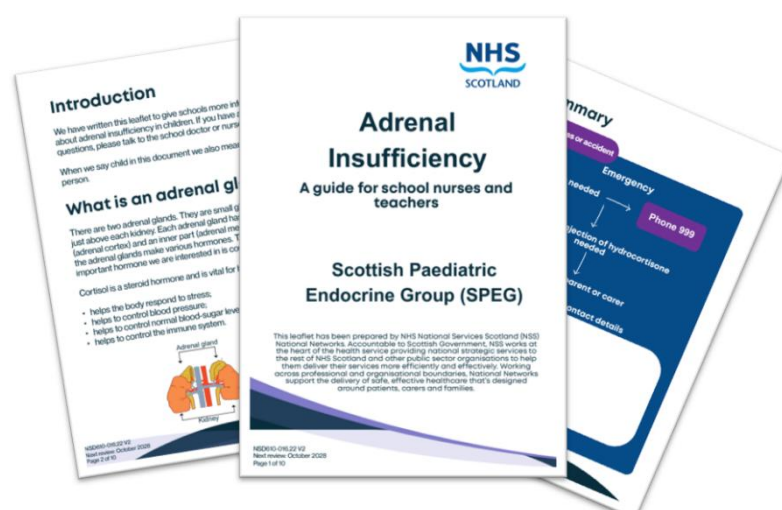


Image 2: Example of SPEG Patient Information Leaflet

The leaflets are as follows:

- Adrenal Insufficiency - a guide for parents
- Adrenal Insufficiency - a guide for school nurses and teachers
- Adrenarche - a guide for parents and carers
- GnRH test - a guide for parents and carers
- How to give Emergency injection of liquid Hydrocortisone
- How to give thyroxine to babies and children - a guide for parents
- How to prepare an emergency injection of powder Hydrocortisone
- Insulin Tolerance Test - a guide for parents
- Precocious puberty in boys - a guide for parents
- Precocious puberty in girls - a guide for parents

Transition from Paediatric to Adult Services

The transition from childhood to adulthood is an important stage in a young person's life. Adolescents with endocrine conditions can lose contact with healthcare services during the transition period, which can have adverse effects on health.

In 2024/25, the network captured a more in-depth picture of transition services for paediatric endocrinology through the dissemination of a questionnaire to each health board. The next phase of this work will involve an attendance audit for patients with a specific condition following transition to adult services. This will help identify any inequalities, highlight best practice and inform future quality improvement activity, and is planned as a priority for 2026/27.

In the meantime, the Transition subgroup focussed on updating two key resources.

A comprehensive 'Transition Framework' has been developed and published on the SPEG website. This guidance is based on work carried out by the paediatric subgroup of the Scottish Diabetes Group, which in turn based its transition policy on work undertaken by the North-West Paediatric Network. The framework covers definitions, aims, guidance, principles and processes, as well as an information matrix.

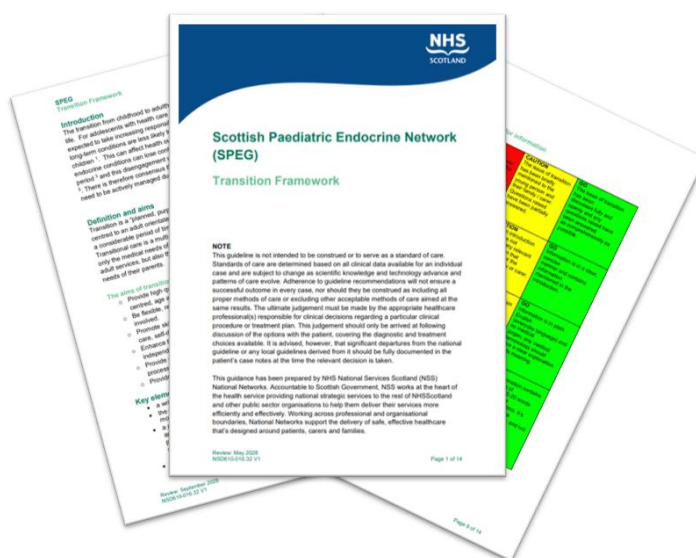


Image 3: SPEG Transition Framework

A 'Transition Checklist' was also designed for the medical and nursing team to support the young person and their family/ carer as they begin their journey into adult services. This is to ensure they are provided with all the essential information, as set out in the Transition Framework, as well as access to any additional support and resources.

3.3 Stakeholder Communication and Engagement

Website

The SPEG website (<https://www.nn.nhs.scot/speg/>) remains a useful resource for staff and patients alike, with access to a range of resources including patient information leaflets, reports, newsletters and clinical guidance. A review was conducted in December 2025 to ensure the website remains up to date.

Newsletters

SPEG produced two newsletters in 2025/26. One in May and the other in December. The newsletters are designed to ensure stakeholders are kept informed about changes and developments within, and beyond, the network. They also provide useful information around access to resources and learning and development opportunities. News items included: advertising education events, rollout of the Clinical Audit System (CAS) Power BI dashboard, Growth Hormone Framework updates, new SPEG resources and third sector updates.

The average number of SPEG newsletter views increased from 41 in 2024/25 to 75 in 2025/26.

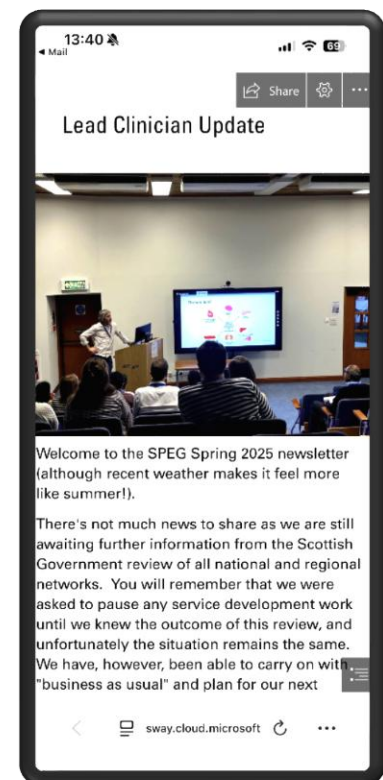


Image 4: SPEG newsletter example

3.4 Education

Annual Scientific Meeting

SPEG delivered its 27th Annual Scientific Meeting at the Steele Lecture Theatre in Perth Royal Infirmary on 30 January 2026.

The programme was split across four distinct sessions, as follows:

- 1) Recent Advances in Endocrinology
- 2) Presentation of Abstracts
- 3) Endocrine sequelae in childhood cancer
- 4) Research

The meeting was face to face, with 32 delegates in attendance. The event attracted a range of delegates from throughout Scotland as shown in figure 2 below. Designations included Consultant Paediatricians, Consultant Paediatric Endocrinologists, Endocrine Nurse Specialists, Medical Students, Consultant Clinical Scientist, Clinical Lecturer and Clinical Fellow.

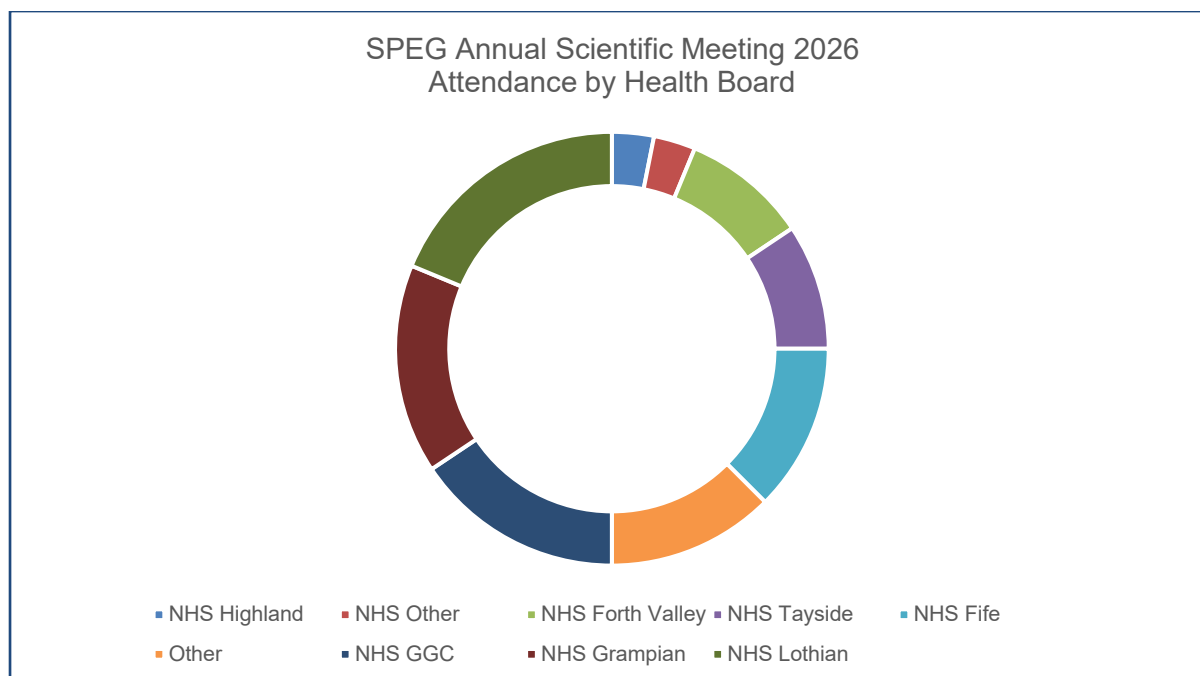


Figure 2: ASM attendees by health board

Feedback was received from eight individuals. The majority of respondents either “strongly agreed” or “agreed” that each of the event’s key objectives were met. The highest number of ratings for each of the talks was either “excellent” or “good”.

Some of the highlights from the qualitative feedback are included below.

Do you have specific comments about any of the individual talks?

- “The talk on radiotherapy in oncology was excellent and for the first time I think I understand the different types of therapy and what effects they have on surrounding tissues/cells.”
- “Covered long-acting growth hormone which is new in field, good revision on late effects.”
- “All were excellent.”

By attending this event, how will your practice change?

- “This built a really good foundation for my interest in paediatric endocrinology and I will always think about the future implications of any treatment I give.”
- “My first experience presenting research which will lead to many more.”
- “It has provided me with a better understanding of endo-oncology.”
- “It helps to keep me up to date and increasing my knowledge and confidence. It's a great way to meet and socialise with other endocrine teams as we are so remote in the Highlands.



Image 5: Annual Scientific Meeting at Perth Royal Infirmary

Clinical and Academic Meeting

The September Clinical and Academic Meeting (CAM) was attended by 40 delegates. Feedback was received from 18 individuals (45%) across seven separate health boards.

Figure 3 demonstrates consistently high scores received across all sessions, with the majority receiving “very good” or “excellent” ratings. Case-based discussions were particularly well received, with over half of respondents rating each case session as “Excellent”. Results indicate a high level of attendee satisfaction and educational value.

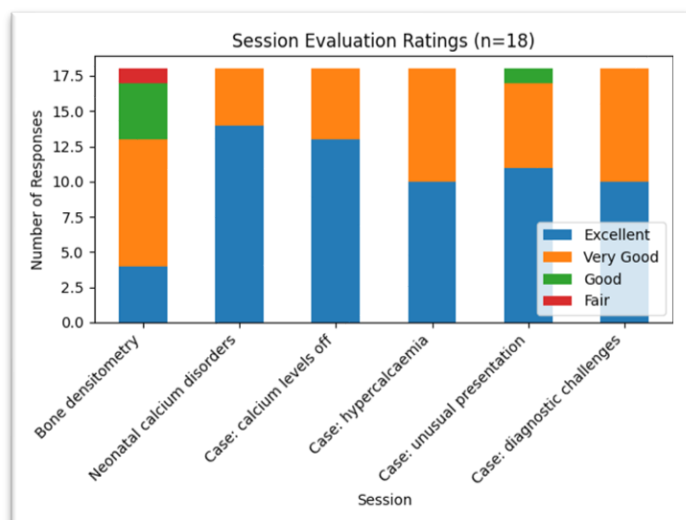


Figure 3: Feedback for Clinical and Academic Meeting individual sessions - September 2025

Attendees were asked to rate the extent to which learning from the meeting would influence their practice. The data demonstrates a clear and positive impact for all. Ten respondents (56%) rated it as “*very effective (major change or significantly clearer understanding)*” and eight (44%) rated it as “*effective (minor changes or reinforcement of current practice)*”.

This was another highly successful meeting, with excellent feedback received and objectives met. Results strongly support the continuation of these meetings.

E-Learning Module

Several years ago, SPEG developed an e-learning module on the assessment of growth and puberty, which is an essential part of the overall assessment of any child's health.

The intended learning outcomes from the module are to understand:

- Normal growth and puberty
- What influences growth
- The variations in normal growth and puberty
- Growth charts and their uses and be able to measure children correctly
- Common causes of abnormal growth

An average of 17 learners completed the module per month in 2025/26 compared to 12 in 2024/25. Those who completed the feedback scored the module an average of 4.7 out of 5.

The below list highlights the range of learners that accessed the course over the past year.

- | | |
|----------------------------|--|
| • Adult Nurse | • Attainment Mentor |
| • Child Health Nurse | • Counselling Psychologist |
| • Foundation Year 1 Doctor | • Health Visitor |
| • Mental Health Nurse | • Nursing Support Worker |
| • Practice Education | • Student Pharmacist |
| • Pharmacist | • Family Nurse |
| • Business and Projects | • Medical Student |
| • Student Nurse | • Specialist Community Public Health Nurse |

SPEG worked with colleagues from Learning and Development within Public Services Delivery Scotland (PSD Scotland) and NHS boards to implement required updates to embedded videos and refresh the module. A further review was also undertaken using an interactive "Review 360" version of the content to ensure it remained current and fit for purpose.

3.5 Audit and Continuous Improvement

Clinical Audit System (CAS)

The Clinical Audit System (CAS) has been established as the platform for SPEG data collection for a number of years. The aim of this data collection is to have a record of patient numbers of children and young people with endocrine conditions across each health board, and to capture service delivery in Scotland. The data can then be utilised for service planning, monitoring, quality improvement and research.

The CAS report for 2025/26 is included in Appendix 1.

The network's main focus in the past year has been to improve the accuracy of the core dataset by completing missing information and removing inactive patients. After a data cleanse, there has been significant progress in this regard, with some of the highlights included Table 1 below.

	2024/25	2025/26
Number of active patients	3491	2547
Number of patients over 18 years old	1262	826
Missing condition	431	185
Date of diagnosis added	52%	61%
Condition added	88%	93%

SPEG also has quality indicators included within the CAS for two specific conditions: adrenal insufficiency and Turner syndrome. There has been a drop off in the completion of these over the past year, with the focus being on the core dataset. However, it is anticipated that there will be improvements across all data measures, including the quality indicators, with the introduction of the Power BI dashboard.

Power BI Dashboard

In 2025/26, SPEG introduced a Power BI dashboard to enhance access to and visualisation of Clinical Audit System (CAS) data. The SPEG Quality Improvement Group worked closely with the Information Management Service (IMS) to develop a user-friendly application, accessible through Microsoft Teams, that enables users to view and explore health board data outputs more effectively. The dashboard has been extremely well received and continues to evolve, with new functionality introduced to support data quality improvement, including the development of "gap reports" to identify missing information.

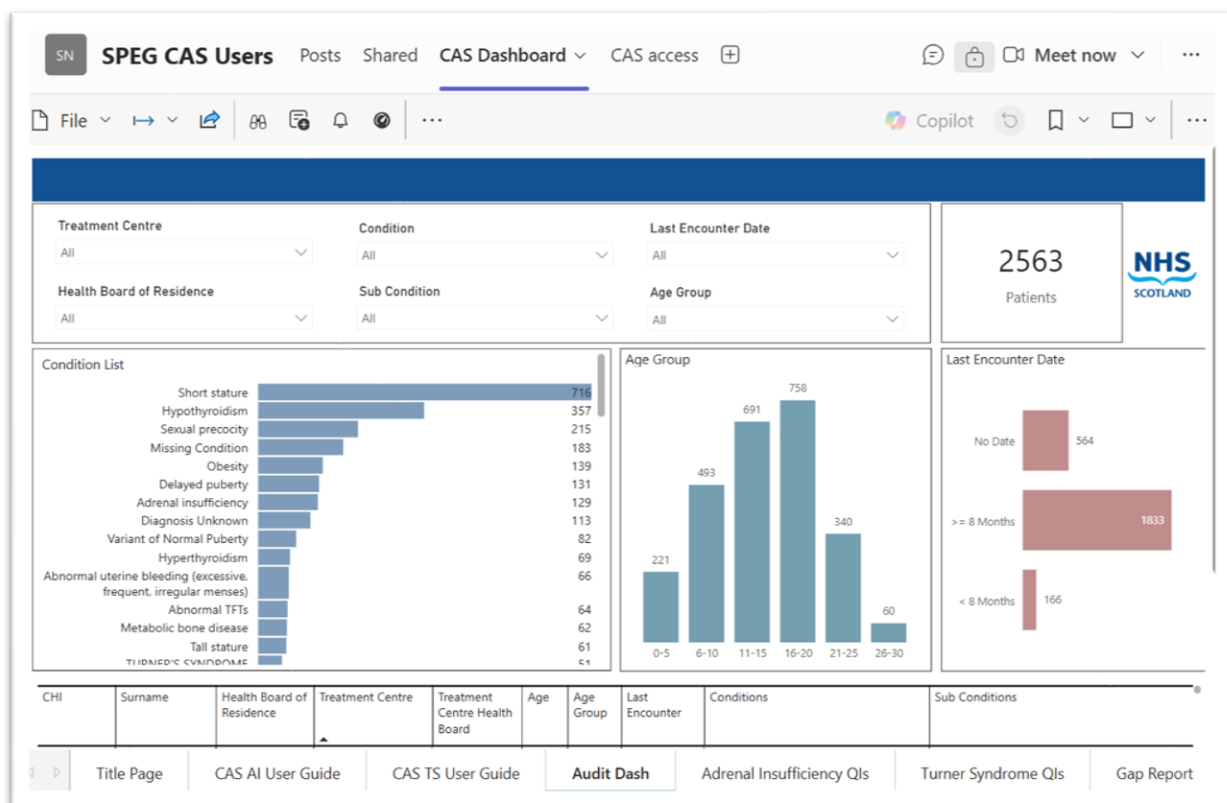


Image 6: Screenshot of SPEG Power BI user dashboard for Clinical Audit System data

Scottish Newborn Screening Laboratory

SPEG members regularly contribute data to the Scottish Newborn Screening Laboratory (SNSL), for the purposes of quality improvement and audit. SNSL adhere to screening standards and key performance indicators (KPIs). SNSL currently screen for 11 different conditions via the newborn bloodspot screening test. Of these, congenital hypothyroidism is relevant to SPEG members, as babies who screen positive are referred to secondary care for assessment and management. In the year 2025/26, 31 babies had a positive screening test, and 19 babies had an equivocal screening test requiring a repeat sample prior to referral to secondary care.

Of the 31 babies with an initially positive screening test, 27 (87%) were reviewed within secondary care within 14 days of age. Pre-laboratory delays accounted for the 4 babies referred later than 14 days of age (i.e. late sampling) and all babies referred to secondary care were reviewed within 24 hours of initial referral.

Of the 19 babies with a positive bloodspot sample on repeat testing, 14 (73%) were reviewed in secondary care within the first 21 days of age. Again, all babies referred to secondary care were seen promptly (16/19 (84%) within 24 hours, the remainder within 72 hours of referral), with pre-laboratory delays accounting for babies reviewed >21 days old.

3.6 Value

Growth Hormone Framework

SPEG has worked closely with the national procurement team over the past few years to develop and continuously review a framework for prescribing growth hormones. The latest version of the framework took effect from 1 January 2025 and will run until December 2028.

In 2025/26 the Clinical Advisory Panel (made up of SPEG stakeholders) updated the guidance document to encompass a list of recommended products for the use in majority of patients, whilst still providing patient choice. The final recommendations are currently in draft form, with a plan to publish in the coming year. The network will continue with a two-tier recommendation, based on the scores from the procurement process. There are as follows:

- Tier 1 - Preferred products for use in the majority of patients, which include three suppliers who scored the highest from the procurement process
- Tier 2 - Products for use in patients with specific needs (remainder of the suppliers who bid on the tender and met the minimum criteria)

Using the full calendar year of 2022 as an example, the procurement team calculated that the network generated savings of over £827k. It is expected that the framework *has and will continue* to offer the NHS significant savings.

Sustainability

The SPEG network has continued to deliver Clinical and Academic Meetings, Steering Group meetings and subgroup meetings virtually where appropriate, helping to maximise participation while reducing travel requirements and associated costs. The Annual Scientific Meeting has continued as a single-day event, with the 2026 meeting held at Perth Royal Infirmary.

All SPEG resources are accessible via the network website, with electronic forms and guidance available through the Right Decisions platform, improving accessibility for users.

The Growth Hormone Framework remains a particularly strong example of network value, with procurement analysis demonstrating savings of over £827k for NHS Scotland while supporting a nationally consistent approach to prescribing growth hormone therapies.

Looking forward – 2026/27

The network will undertake a strategic needs assessment (SNA) to prioritise future planning. The SNA will assess SPEG's impact and how it benefits service users, and will include looking at the patient pathway, a review of available data, a look at workforce requirements and engagement with all stakeholders.

The SNA will build on a previous strategic planning exercise undertaken through network engagement to identify long-term priorities and ensure SPEG continues to meet stakeholder needs. This work identified a number of key themes and

objectives, which informed the network's long-term strategic direction and will help shape future priorities and areas of focus.

The network will continue to deliver its 'business as usual' activity. Several other priorities have already been outlined for the upcoming year, including:

- Carrying out a Strategic Needs Assessment
- Working with other clinical networks and the Scottish Ambulance Service to develop a pathway for updating the emergency care summary plan
- Developing new nurse-led patient information resources
- Continuing to migrate guidance to the Right Decisions platform
- Picking up the previously paused transition attendance audit for CAH patients
- Continuing to rollout the CAS Power BI user dashboard
- Working with the 'GLP-1/GIP RA for the treatment of obesity in NHS Scotland' national working group to develop guidance around obesity from a paediatric endocrinology perspective
- Exploring options to improve engagement with primary care
- Highlighting research activity and opportunities
- Engaging with procurement with regard to potential supply chain issues and developing templates for effective communication with stakeholders

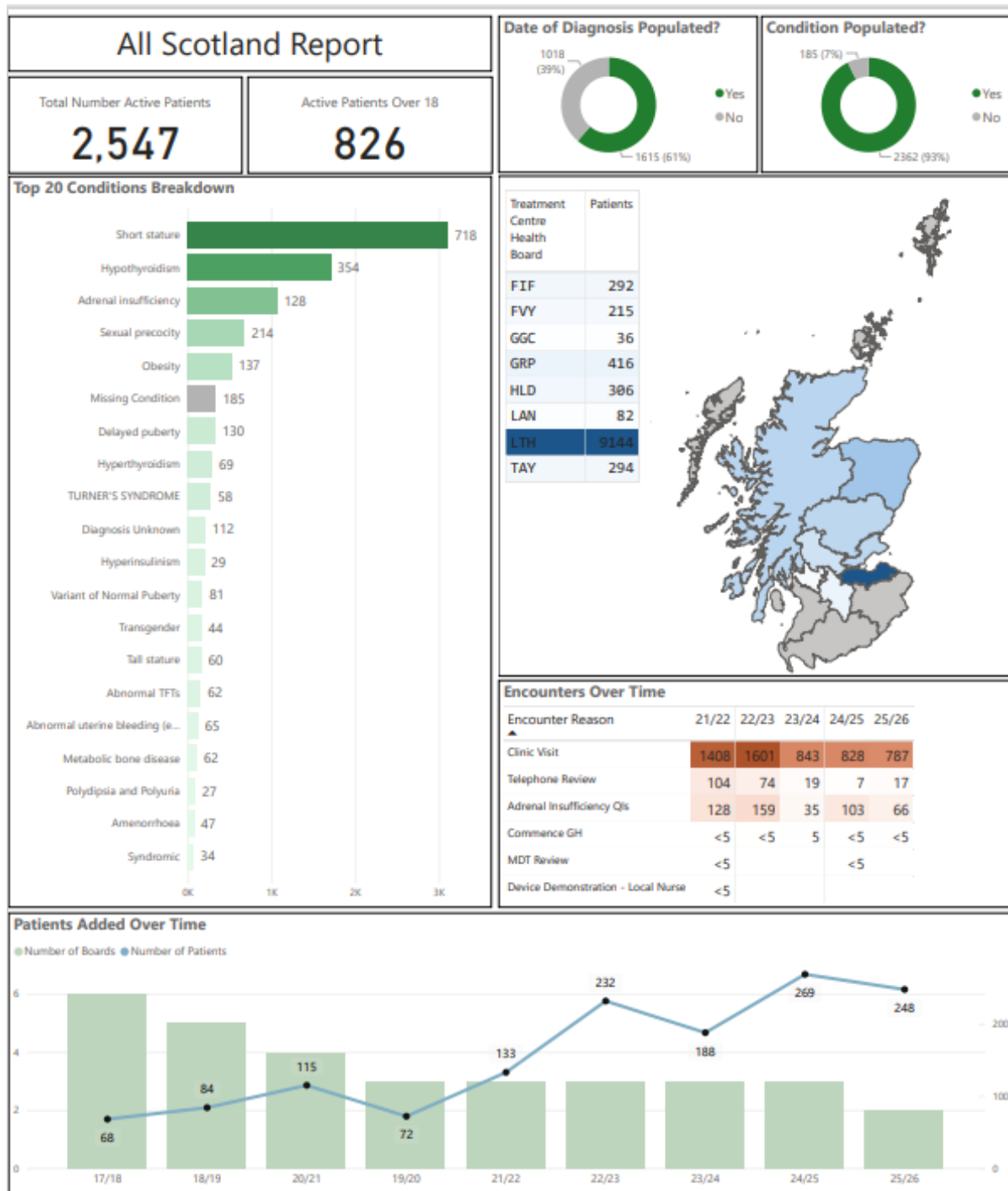
The network recognises the importance of maintaining national coordination in areas such as education, clinical guidance, and quality improvement. Continued support will be essential to sustain these benefits for patients and professionals.

Stakeholders have highlighted the importance of maintaining national coordination to sustain improvements in care. Continued support will be essential to build on existing progress and deliver future benefits.

Finance

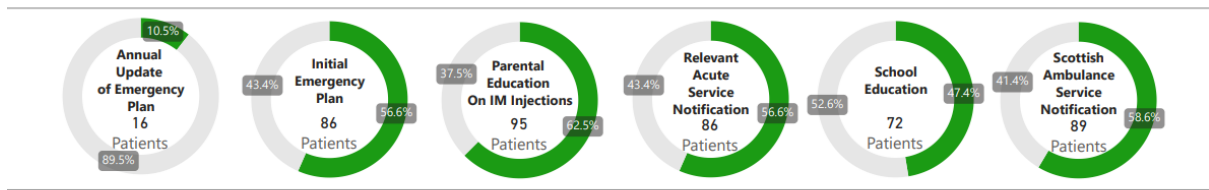
The Network is funded through Public Services Delivery Scotland and operated within its approved budget during 2025/26.

Appendix 1 – SPEG CAS Highlight Report 2025/26



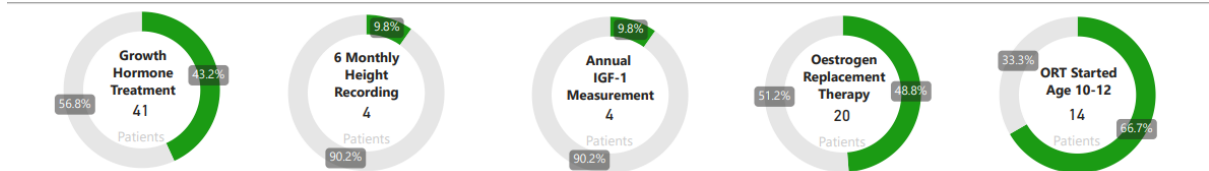
Adrenal Insufficiency

152 Total Patients



Turner Syndrome

95 Total Patients



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Contact email address: nss.speg@nhs.scot