

Scottish Paediatric Endocrine Group (SPEG)

Annual Report 2024/25

This document has been prepared by NHS National Services Scotland (NSS) National Networks. Accountable to Scottish Government, NSS works at the heart of the health service providing national strategic services to the rest of NHSScotland and other public sector organisations to help them deliver their services more efficiently and effectively. Working across professional and organisational boundaries, National Networks support the delivery of safe, effective healthcare that's designed around patients, carers and families.

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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.

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.

The 2024/25 reporting year has been a particularly challenging one for all NMCNs. This is mainly due to external factors that have impacted on the networks' ability to carry out key objectives.

2. Current Position

In light of the ongoing Scottish Government review of national networks, planning has been adapted to focus on core priorities and ensure continuity of essential services. We await further guidance to inform future strategic development.

SPEG prioritised the Annual Scientific Meeting (ASM), transition service mapping and general SPEG service mapping. The network also continued to progress with the development of a Power BI dashboard that will benefit Clinical Audit System (CAS) users.

The network achieved 22/22 (100%) of its 'Business as Usual' objectives and 3/3 (100%) of its 'Service Development Plan' priority objectives in 2024/25. Additionally, the network's three strategy documents (Education, Quality and Communication) were updated prior to identifying key priorities, and the development of the Clinical Audit System (CAS) Power BI dashboard has continued.

A new Steering Group Chair was appointed in 2024/25, with Dr. Rohana Wright (Consultant Endocrinologist, NHS Lothian) taking on the role.

The network developed a strategic planning report as a result of the consultations that took place last year and were in the process of developing a 5-year workplan, which was due to commence in 2024/25. Further work on this has been paused until there is clarity on the future role of networks.

The Terms of Reference for the network replaced the service level agreement and covered the 2024/25 period.

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). Most of the subgroups were less active in the latter half of the year due to the pause in some of the service development objectives that were aligned to each. Membership has also dropped off due to some stakeholders retiring and others stepping back. This would need to be addressed as a priority, should the subgroups be fully remobilised as part of a longer-term arrangement.

Strategies

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

3.2 Service Development and Delivery

Strategic Planning

In 2023/24, a 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

Various methods of engagement were applied and key themes and objectives extrapolated, formulating a report into the long-term strategic direction for SPEG. Unfortunately, this work was paused, given the uncertainty around the future of the network, however, the content remains applicable (see Appendix 1).

Clinical Guidelines

All clinical guidelines have remained up to date throughout the year. Reviews are already underway in advance of clinical guidelines that are due in 2025/26. The 'Management of Congenital Hypothyroidism Guideline' has recently been updated and is the first to go onto the new standard template (see figure 1). The 'Guidance on the use of growth hormone devices for children & adults' has also been updated to reflect the changes to the growth hormone framework. This, along with the 'Adrenarche Guideline' will be published on the SPEG website in May 2025. A new 'Hypocalcaemia' guideline has also been developed and is going through the final stages of approval. The network successfully migrated versions of nine clinical guidelines to the Right Decision Service application, hosted by Health

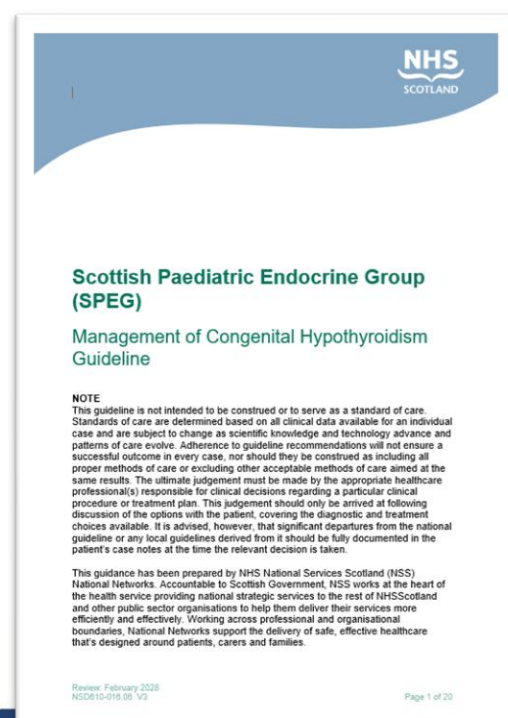


Image 1: Example of SPEG Clinical Guideline

Improvement Scotland (HIS), however, work has paused on this, whilst awaiting further updates on the future of the network.

Nurse Growth Hormone Guidance

The Nurses' Group finished developing the 'Endocrine Nurses' Guide to Growth Hormone' resource to assist Nurses with learning. The document provides a mix of information, useful signposting, templates and sections for Nurses to complete as they learn. The document is now available on the [SPEG website](#).

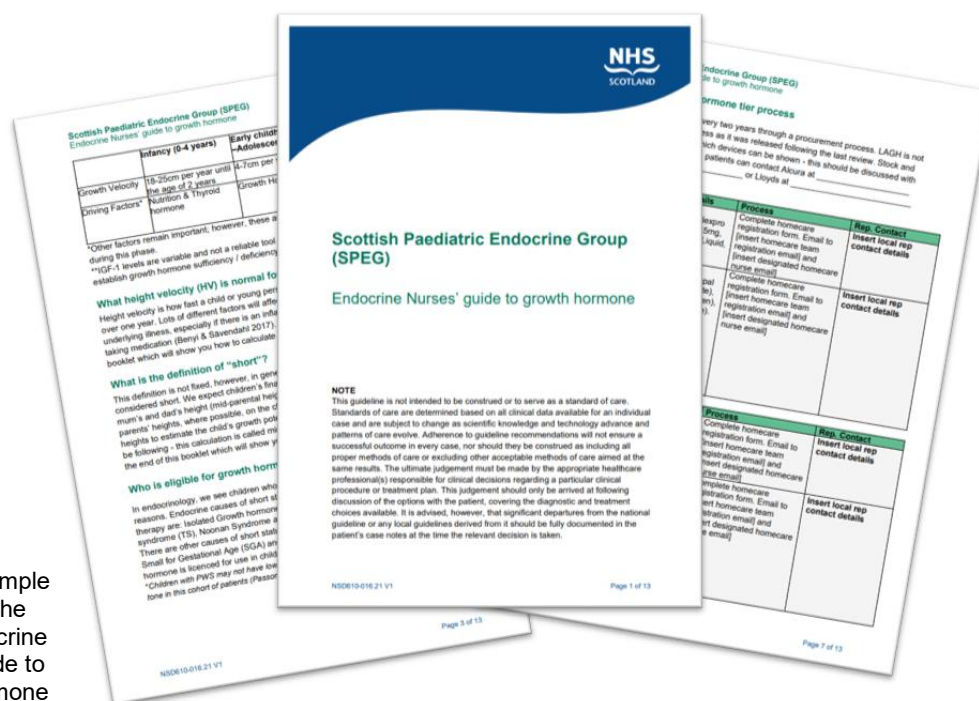


Image 2: Sample pages from the SPEG Endocrine Nurses' Guide to Growth Hormone

Transition from Paediatric to Adult Services

A questionnaire was created on Microsoft Forms to capture an in-depth picture of transition services across the eleven health boards involved with SPEG in Scotland. A single named Consultant Paediatrician completed this on behalf of their health board, with responses received from 10/11 (91%). An overview of the results was captured in a separate report.

The network provides a range of resources and support for paediatric patients transitioning to adult services. The aim of this piece of work was to identify any gaps in service provision with a view to informing network strategic planning for the next few years.

There were 26 questions (around transition) in total, which included a mix of multiple choice and free text questions. The questionnaire sought information on current transition arrangements, use of guidelines and frameworks to assist with transition, support and communication with children and young people (and their families), and suggestions for future SPEG involvement in this area.

Some of the results are shown in tables below.

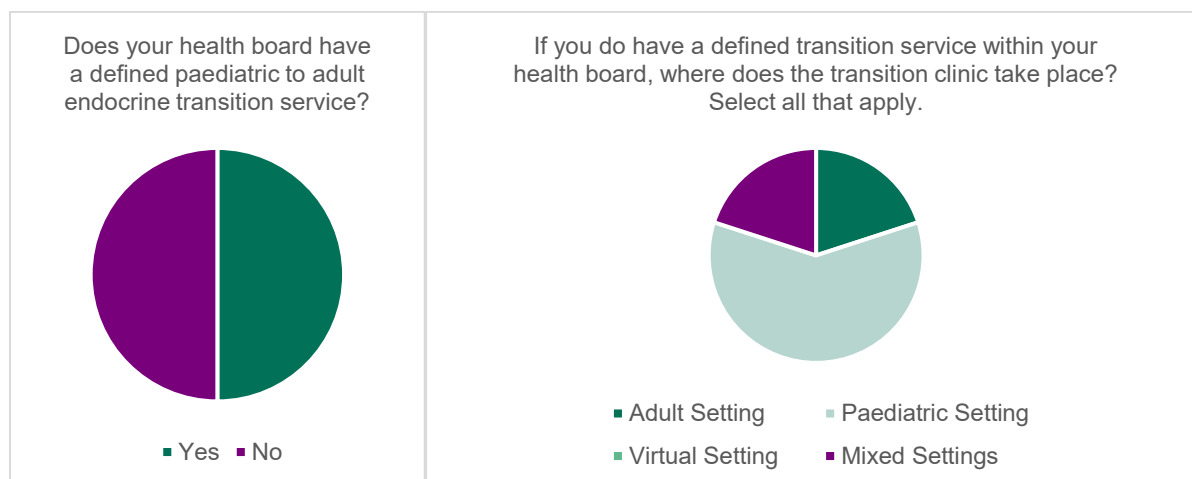
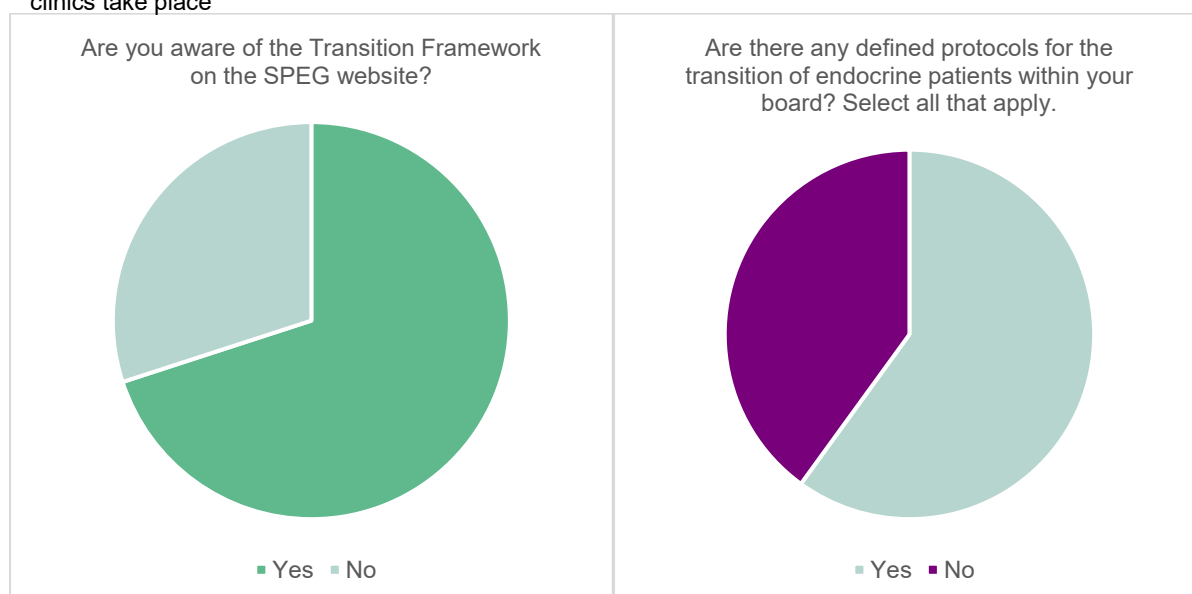


Figure 1 and 2: Results of Transition Questionnaire on presence of defined transition service and where clinics take place



Figures 3 and 4: Results of Transition Questionnaire on SPEG Transition Framework awareness and whether or not defined protocols are in place

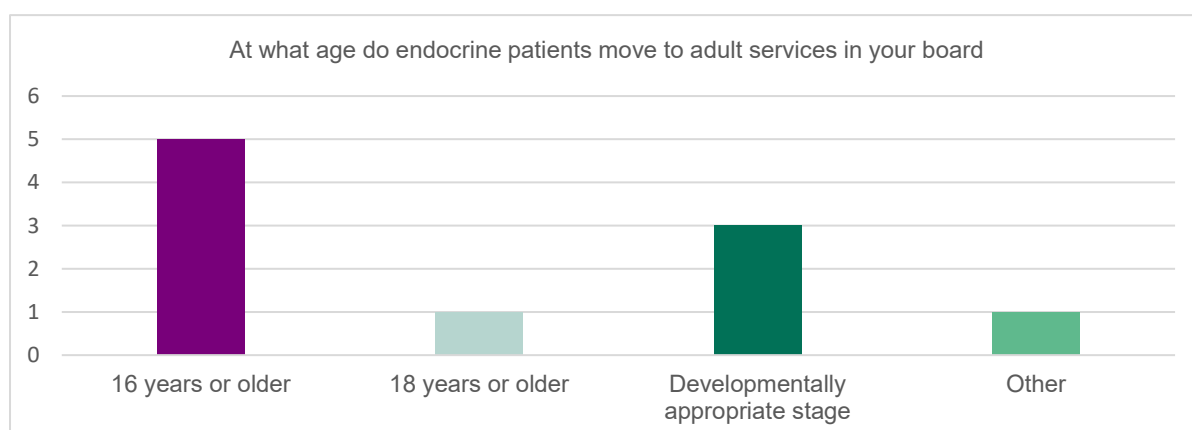


Figure 5: Results of Transition Questionnaire on age of transition

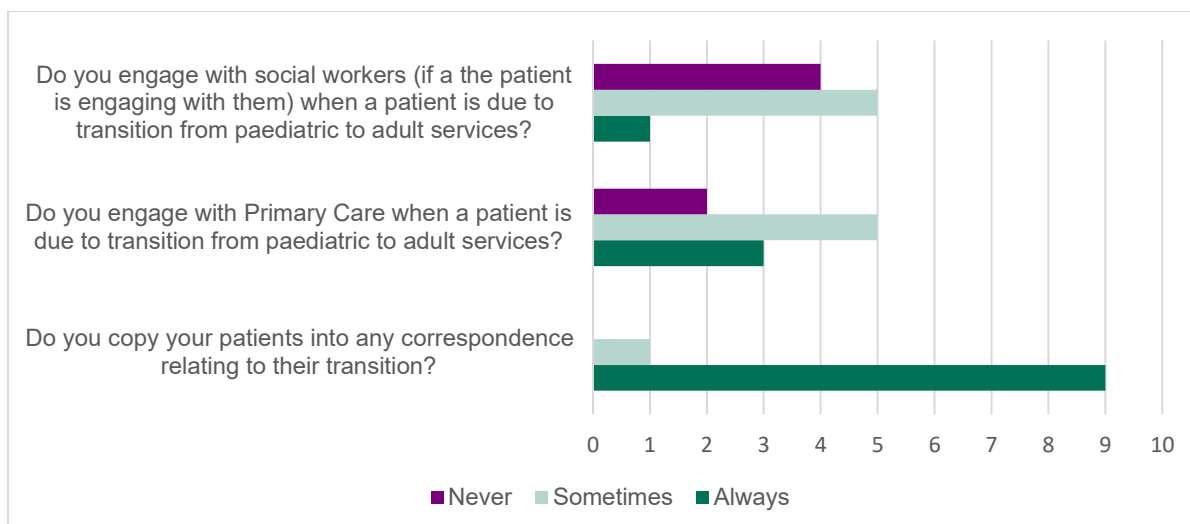


Figure 6: Results of Transition Questionnaire on engagement with social worker, primary care and whether or not patients are included in correspondence.

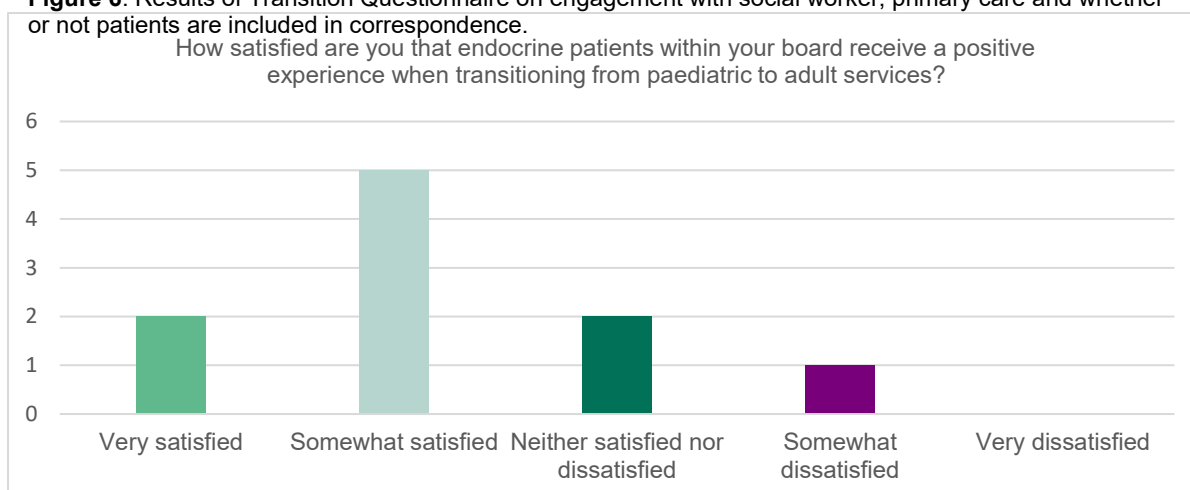


Figure 7: Results of Transition Questionnaire on patients receiving a positive experience

Respondents were asked for suggestions as to how their service could be improved upon. Suggestions included: more dedicated clinical time in job plans, reducing adult waiting lists, and providing a more equitable service to all.

The questionnaire provided an overview of current service provision across Scotland. The high response rate has ensured that the data represents the national picture, however the low overall numbers mean that it is difficult to draw statistical inference from the data. The current provision varies according to geography, patient numbers, age of patient and care setting.

Despite this heterogeneity, there were some common themes across all settings. For example, it was notable that no health boards had a written agreement in place for how transition services should be provided. All health boards provide written communication with patients and families. SPEG resources were used to some extent (e.g. patient leaflets), but it could be argued that other resources are underutilised (e.g. SPEG transition framework and website).

Transition Attendance Audit

Another SPEG objective that was outlined initially for 2024/25 was to carry out an attendance audit of patients with a specific condition (e.g. Adrenal).

Hyperplasia) at their first two appointments after transitioning from paediatric to adult services. The idea was that the data acquired alongside the transition service mapping exercise would provide a clearer picture of best practice as well as the issues caused by gaps in provision.

This would allow SPEG/ clinicians to:

1. re-establish follow up for patients that had been lost, ensuring they received appropriate care
2. learn from good practice examples - if an area had a very low rate of loss of patients during transition, what model did 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 piece of work was paused as it would not have been possible to complete the work by the end of March 2025, which was a stipulation for selecting key priorities to proceed with.

Service Mapping in Scotland

For some time, SPEG has sought to create a service map of paediatric endocrinology services available throughout Scotland. As the network had produced a transition questionnaire on Microsoft Teams, it was agreed that the wider service mapping questions could also be included to avoid sending multiple forms to individuals in each health board. The following four questions were asked:

- 1) Personnel employed by local health board
- 2) Imaging services available within local health board
- 3) Specialist endocrine services available in local health board
- 4) Which (if any) condition-specific clinics are provided

A service map would be made available on the SPEG website, which would allow anyone with an interest to identify what support and services are available where. The service directory could also be used to identify any inequity of access in Scotland, leading to potential quality improvement work for the network going forward.

A snapshot of one of the pages of the service map is shown below.

Personnel (employed by local health board)											
	NHS Ayrshire and Arran	NHS Borders	NHS Dumfries & Galloway	NHS Fife	NHS Forth Valley	NHS Grampian	NHS Greater Glasgow & Clyde	NHS Highland	NHS Lothian	NHS Tayside	
Paediatrician with an interest in paediatric endocrinology	✓	✓	✓	✓	✓	✓		✓	✓	✓	✓
Paediatric endocrinologist						✓	✓			✓	
Paediatric endocrinology advice outside normal working hours (on call service)						✓	✓				
Paediatric endocrine nurse specialist		✓		✓	✓		✓	✓	✓	✓	✓
Local access to a gynaecologist with an interest in paediatric and adolescent gynaecology	✓					✓	✓	✓	✓	✓	
Clinical geneticist	✓			✓		✓	✓		✓	✓	✓
Paediatric surgeon	✓	✓		✓		✓	✓	✓		✓	✓
Paediatric radiologist or radiologist with an interest in paediatrics	✓	✓	✓	✓		✓	✓		✓	✓	✓
Child psychologist and/or CAMHS	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Play specialists	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓

¹ Outreach clinics and day case lists provided, but no on site paediatric surgical service

Image 3: An example page from the new SPEG service map.

3.3 Stakeholder Communication and Engagement

Website

The SPEG website remains a useful resource for staff and patients alike, with access to a range of resources including patient information leaflets, reports, newsletters and clinical guidelines. A review was conducted in January 2025 to ensure the website remained up to date.

Newsletters

The network continued to produce and circulate its quarterly newsletter via Microsoft Sway for the first three quarters of the year. This has allowed SPEG to share important information around events, clinical guidelines, data, surveys, upcoming dates, learning opportunities, patient resources, and other developments. Engagement with the newsletters tailed off throughout the first three quarters, reflecting the general increase in dissatisfaction of network stakeholders due to the ongoing uncertainty around the future. A decision was made to hold off on developing a newsletter for quarter 4, whilst awaiting an update on the Scottish Government's review of networks.

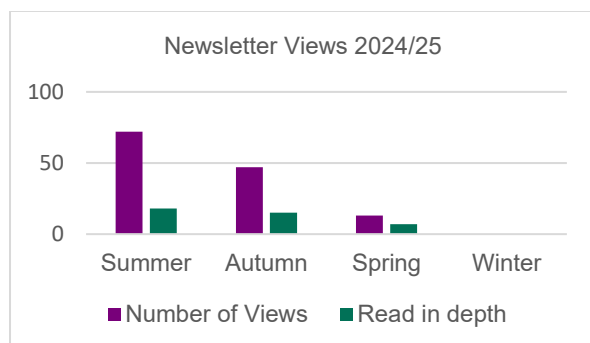


Figure 8: Newsletter views over 2024/25



Image 4: Example of newsletter on mobile

3.4 Education

Annual Scientific Meeting

SPEG delivered its 26th Annual Scientific Meeting at the Steele Lecture Theatre in Perth Royal Infirmary on 31 January 2025.

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

- 1) Hypoglycaemia
- 2) Developmentally appropriate healthcare in endocrinology
- 3) Abstracts/ case presentations
- 4) Research

The meeting was face to face with 39 delegates in attendance, based on 41 registrations. The event attracted a range of delegates from throughout Scotland and across a range of designations, as shown below.

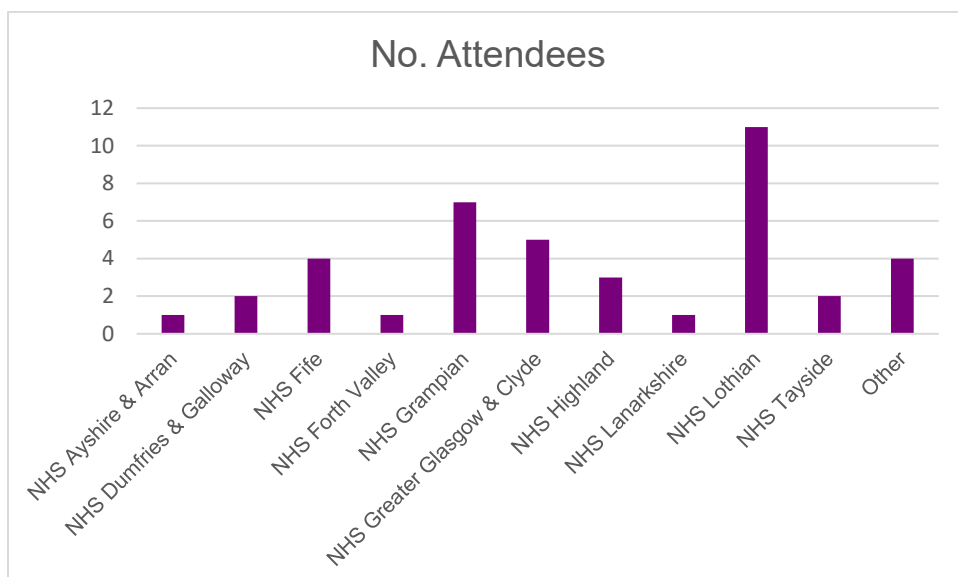


Figure 9: ASM attendees by health board

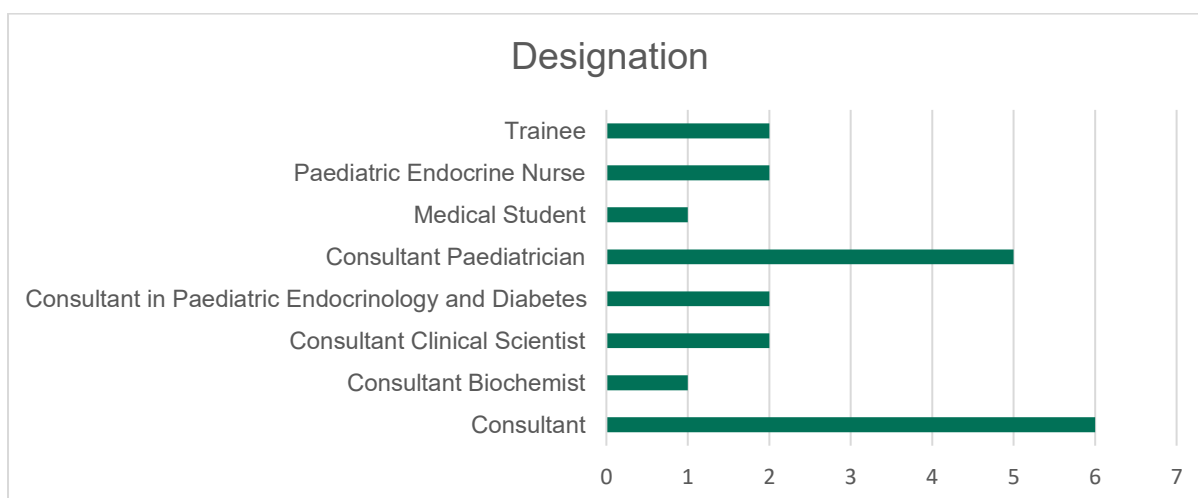


Figure 10: ASM attendees by designation

Below is an outline of the extent to which the delegates felt the objectives were met as well as the overall impression of the event.

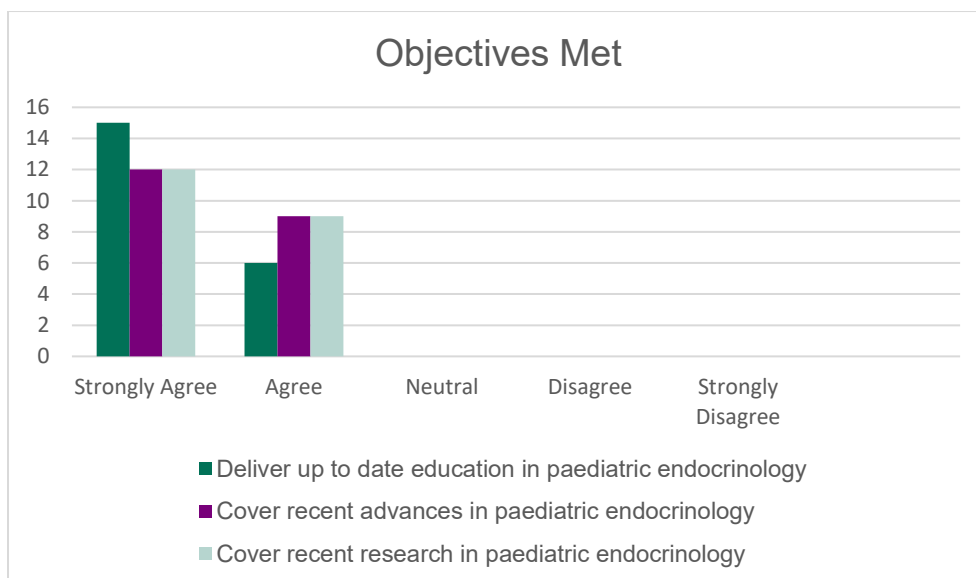


Figure 11: ASM feedback on whether or not objectives were met

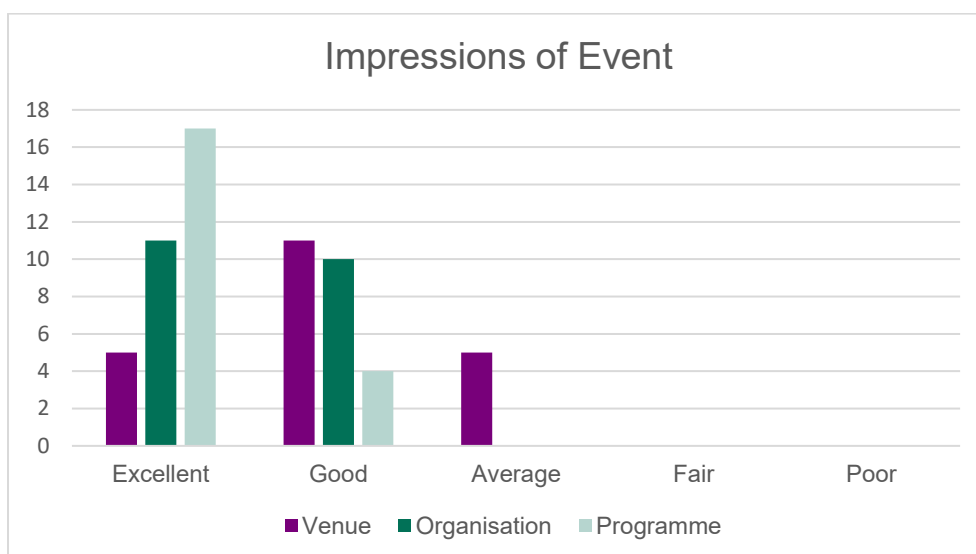


Figure 12: ASM feedback on overall event impressions

Below are some qualitative response highlights from the feedback

By attending this event, how will your practice change?

- I will now look out for Kabuki in patients with CHI
- Be aware of new guidelines, studies, and know people across Scotland/ networking
- This has highlighted some areas as a biochemist I was unfamiliar with and has prompted me to do some further reading around some of the cases covered
- Links with Manchester re hyperinsulinism
- Will look at local transition arrangements and see if can improve to align with best practice
- Better understanding of investigation of hypoglycaemia and when to consider a metabolic cause
- Furthered depth of understanding around HI particularly around biochemical tests and pitfalls - understand which tests need to be captured when
- Aim for involvement in globe registry and potential use of this for QI

Any other general comments?

- The SPEG MCN is an important network for sharing knowledge, developing clinical practice and improving efficiencies in paediatric endocrinology. It is important that it continues to be supported.
- The meeting was really good - I honestly came away feeling I had learnt a lot. The SPEG team did a fantastic job given the circumstances that the networks currently find themselves.
- Enjoyed the whole day, looking forward to the next one, everyone involved was friendly and approachable.
- All things considered, I think PRI was a good venue - central, friendly, catering facilities and well attended.
- Keen to continue the meeting, very useful especially for junior trainees and new consultants.
- As someone who is fairly new to the Scottish region it was great to be able to meet some of my colleagues face to face.



Image 5: Dr Conway presenting at the 2025 ASM at Perth Royal Infirmary



Image 6: Dr Wright presenting at the 2025 ASM at Perth Royal Infirmary

Clinical and Academic Meetings

The SPEG Clinical and Academic Meetings have continued to take place on Microsoft Teams.

Two meetings took place over the past year – one in May 2024 and one in September 2024. The meetings took place on Microsoft Teams as previously agreed, to cut down on the network's carbon footprint and spend.

34 delegates attended the May CAM from across eight different health boards. This meeting was organised by NHS Grampian colleagues. Colleagues from NHS Lothian organised the September meeting, which was attended by 35 delegates from across nine different health boards.

Delegates were asked how their clinical practice would change as a result of attending the CAMs. Some of the responses are included below.

- I learnt so much from today's presentations and I realise I have a great deal more to learn about paediatric endocrinology.
- All the topics were relevant to my clinical practice. We have no experience of water deprivation test in children in our health board.
- The information on prolactin will definitely influence how I interpret results.
- Measuring early morning cortisol is sufficient for children with central DI. Short synacthen test is not required.
- Consider genetic testing more in thyroid disease.
- I have a better awareness of the wide differential diagnoses to consider and need for keeping an open mind in thyroid problems in children, especially if difficult to treat.
- Greater consideration of alternative causes for thyroid disturbance.
- There can be more than one pathology occurring at the same time so if the signs & symptoms are not explained by the biochemistry/imaging, continue to look.

E-Learning Module

SPEG developed an e-learning module on **the assessment of growth and puberty** as this is an important part of the overall assessment of any child's health.

The intended learning outcomes from the module are:

- To better understand normal growth and puberty
- To understand what influences growth
- To understand the variations in normal growth and puberty
- To understand growth charts and their uses and be able to measure children correctly
- To understand common causes of abnormal growth

From 1 April 2024 to 31 March 2025, 143 people completed the module, with a further 41 "in progress". Those who completed the feedback scored the module an average of 4/5. The below chart shows a breakdown of the professional roles completing the module.

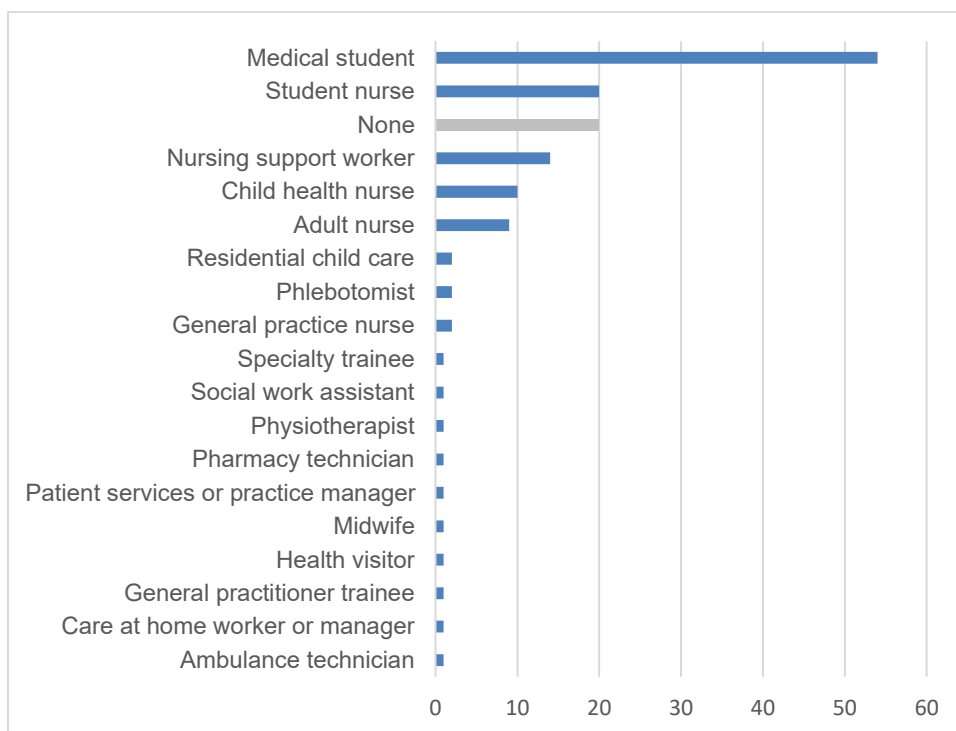


Figure 13: Breakdown of professional roles completing e-learning module

Some of the feedback noted that the video links were not working, which is in the process of being fixed. A couple of other quotes are included below.

- “Really enjoyed this module, interesting and informative for my new role of paediatric clinical nurse specialist in growth and endocrinology.”
- “This module is extremely informative, and provides key information to help guide you through how growth and puberty works on infants and children.”

3.5 Audit and Continuous Improvement

Clinical Audit System (CAS)

Despite the challenges outlined in previous years with the CAS, there has been some improvement in the number of patients entered, with 616 added in 2024/25, which is the most patients entered in a single year to date, up from 276 in 2023/24 (an increase of 123%). There was also an improvement in the percentage of patients with a condition populated, up to 88% from 87%, whilst the percentage of patients with the date of diagnosis added remained at 52%. The number of patients with no condition added also went down from 600 patients to 431.

The quality indicators remained at similar levels for adrenal insufficiency, with input levels dropping slightly across four measures (no more than 4%) and improving slightly for parental education on IM injections (up 0.44%) and a significant improvement in the annual update to emergency plans (up 18.53%).

The input levels for the Turner Syndrome quality indicators dropped off for four out of five measures, with only growth hormone treatment increasing (up 2.44%).

Once the quality indicators are being used more effectively, this will help to monitor performance through benchmarking and in turn will improve patient outcomes.

The full CAS report is included in Appendix 2. This highlights some of the key areas the network needs to focus on. For example, there are a significant number of patients over the age of 18, which could be used to prompt actions around transition to adult services. The health condition prevalence is also useful in ensuring there are efficient resources in place and can help to target interventions or areas of focus for the network (for example in developing guidelines or arranging education events).

Power BI Dashboard

One of the main concerns around utilising the CAS has been around the lack of a user interface for outputs. The SPEG core team and Quality Indicators group have been working closely with the Information Management Service (IMS) to develop a new Power BI dashboard that will allow all CAS users to access their board's data outputs in a user-friendly application that can be accessed easily through Microsoft Teams. The dashboard also allows you to compare your data with other boards in Scotland. The dashboard has been developed and it was anticipated that it would be rolled out in 2025/26.

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 several times.

A new procurement process for the growth hormone framework agreement concluded in 2024, with the latest version of the framework taking effect from January 2025.

It was highlighted previously that this process was projected to save around £670k per annum but evidence suggests that it is actually over £800,000 per year. 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 will continue to offer the NHS these significant savings.

Sustainability

The SPEG network has continued to run its Clinical and Academic Meetings online, along with its Steering Group and subgroup meetings. This has cut down on costs as well as reducing the network's carbon footprint.

The Annual Scientific Meeting was reduced to a single day event on 31 January 2025 at a free NHS venue – Perth Royal Infirmary.

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 – 2025/26

The network will continue with its 'business as usual' activity throughout quarter one in 2025/26, with further updates expected from the Scottish Government via NSD in the near future.

Finance

The network spent £120 on teas and coffees at the Annual Scientific Meeting.

Risks and Issues

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.

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

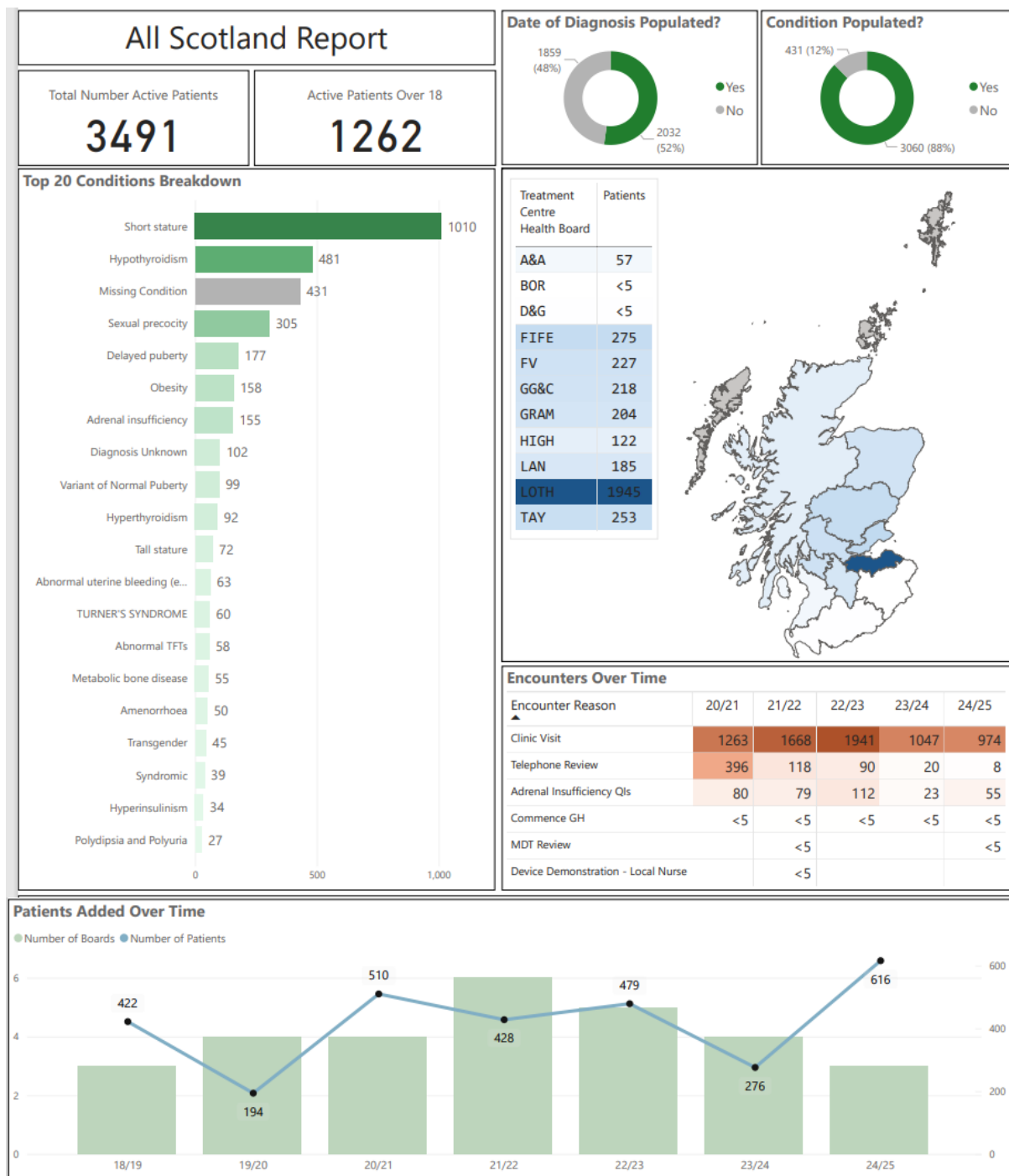
Theme 1	Stakeholder Communication
Aim	1. To improve engagement and communication between the network and its members, the public and wider clinical community.
Objectives	1.1 Provide useful information to all health care professionals 1.2 Ensure the network is meeting requirements of wider clinical community 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
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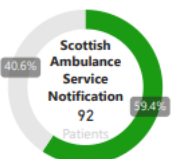
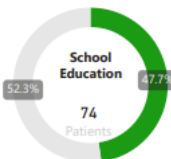
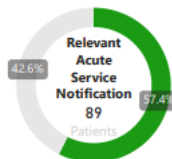
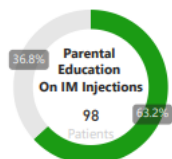
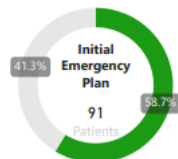
Theme 3	Service Development
Aim	3. To support delivery of paediatric endocrine services throughout Scotland
Objectives	3.1 Promote equity of access to services 3.2 Reduce harm and waste 3.3 Become improvers and innovators
Proposed Actions	• Map current service provision across Scotland • Ensure SPEG 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 – SPEG CAS Highlight Report 2024/25



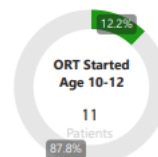
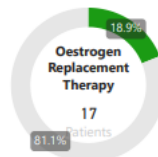
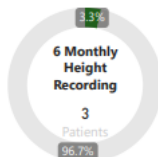
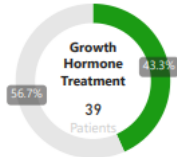
Adrenal Insufficiency

155 Total Patients



Turner Syndrome

90 Total Patients



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