

**Scottish Paediatric Endocrine Group
(SPEG)
National Managed Clinical Network (NMCN)
ANNUAL REPORT 2020/21**

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1. Introduction

The 2020/21 reporting year for the Scottish Paediatric Endocrine Group (SPEG) National Managed Clinical Network (NMCN) has been one of the most challenging to date. This has been the case for all national networks and services due to the COVID-19 pandemic. Throughout the year, the network has had to adapt to new ways of working, with all meetings and events having taken place via online platforms - primarily Microsoft Teams. In the first quarter of the year, a number of meetings were put on hold whilst the network explored how to adapt to the evolving situation.

Dr Amalia Mayo's tenure as Lead Clinician was due to end on 31st December 2020; however due to the exceptional circumstances brought about by the pandemic, this was extended to 31st December 2021, which was welcomed by Steering Group members.

Ultimately, the network still managed to achieve a number of outcomes and identified additional programs of work beyond the workplan to help build towards the new reporting year, which is outlined in section 2 of the report.

2. Highlights

2.1 Effective Structure

The first SPEG Steering Group meeting of the year was postponed, along with several subgroup meetings, due to clinicians being deployed to support their boards' response to the COVID-19 pandemic. The network was back up to running full meetings by quarter two. All of these took place on Microsoft Teams.

2.2 Service Development & Delivery

2.2.1. Clinical Guidelines

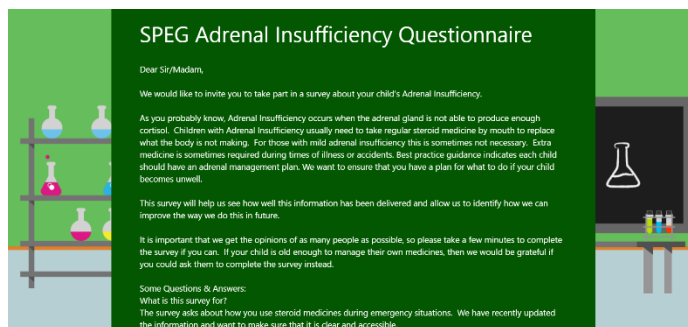
Over the course of 2020/21, the clinical guidelines have continued to be reviewed and refreshed on the SPEG website. There are now a total of 8 guidelines up-to-date and 4 that are in the process of being reviewed. The layout on the website was updated to make these more accessible and transparent. The new table format makes it easy to see at a glance when guidelines were last reviewed and when they will be due for another review, as well as other categorisation. The clinical guidelines page can be accessed [here](#). It continues to be the most accessed page on the website, with a 14% increase in page views compared to last year. This demonstrates the effectiveness of this system for providing access to guidelines to promote the best clinical practice that is both safe and effective.

2.2.2 NSS National Procurement to Develop a Framework for Prescribing Growth Hormones

During the reporting period the framework agreement for prescribing growth hormones was completed and came into effect from January 2021. Its terms and conditions will be applicable for a fixed two-year period. More details can be found in [section 2.6](#).

2.2.3 Adrenal Insufficiency (AI)

A quality improvement project on Adrenal Insufficiency (AI) was introduced in 2019. Quality indicators associated with specific AI clinical interventions were identified and clinicians record when these are complete in the Clinical Audit System (CAS). The aim is to improve care quality through consistent and timely completion of these interventions. In addition, a 'making a 999 call' concertina



card was distributed at the Steering Group meeting in January 2020 to share with patients, which outlines what to do (and say) in case of an emergency. Unfortunately, due to the impact of COVID-19, it has been difficult to ascertain how effective these have been so far. During the reporting year, the Nurses' Group began to develop an Adrenal Insufficiency questionnaire, which will gather feedback from patients and/or parents/ carers on knowledge and awareness as well as ongoing needs around the condition. This has been created using Microsoft Forms, which will provide live analytics and allow easier access for those completing it. The questionnaire will also be available in print form, for those unable to access the electronic version.

2.3 Stakeholder Communication & Engagement

2.3.1 Newsletter

The 2020 spring SPEG newsletter was circulated for as a PDF document. The summer/ autumn newsletter was created using Microsoft Sway - an easy-to-use, interactive digital platform that that is designed to look more professional and provide more flow to the newsletters. Sway can also incorporate videos and other multimedia. With the new Sway format, it is possible to produce analytics on views and the amount of time individuals spend reading the document.

2.3.2 Stakeholder Engagement

The SPEG clinical directory and distribution lists were reviewed and brought up-to-date at the end of 2020. This was a particular challenge due to the migration of email addresses to Office 365. The format of these documents has been updated to make them more user-friendly as there is a requirement to maintain them on an ongoing basis. It is anticipated that the clinical directory will be reviewed at Clinical and Academic Meetings (CAM) as well as at the Annual Scientific Meeting (ASM).

2.3.3 Direct Communication

The online forum that was set up on the SPEG website in 2019 to facilitate collaboration amongst clinicians has been removed and individual channels for each subgroup have been established on Microsoft Teams. Most recently, a channel was set up exclusively for SPEG Clinical Audit System (CAS) users. It is anticipated that these channels will be more accessible and used on a more frequent basis, particularly for sharing best practice and discussing any challenges.

2.3.4 Website

The SPEG website continues to be developed, with new content uploaded in a timely fashion. Regular news is added to the newsreel on the homepage. The patient information leaflets have been updated on the website to allow for electronic data entry in the appropriate fields.

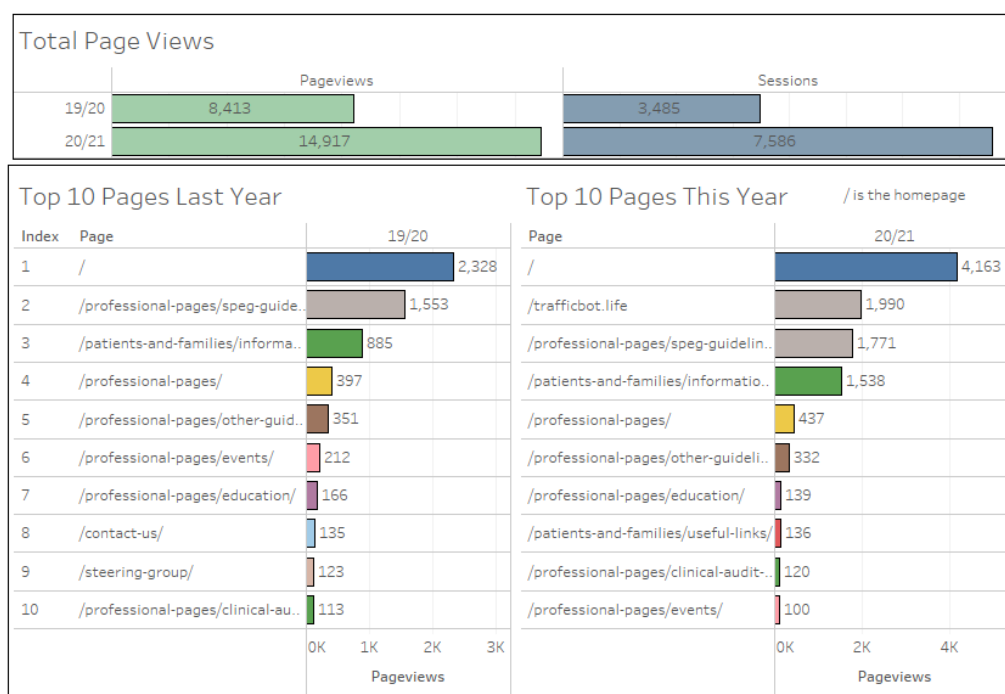


Figure 1 – SPEG website analytics 2020/21 compared with 2019/20

The above web analytics demonstrate an increase of 77% in page views compared to last year and an increase of 117% sessions compared to last year. The clinical guidelines and patient leaflets continue to be the most accessed pages.

2.4 Education

2.4.1 Clinical and Academic Meeting (CAM)

The first SPEG Clinical and Academic Meeting (CAM), scheduled to take place in May 2020, was cancelled due to the impact of the pandemic on clinician availability. This was rescheduled to September 2020, and took place via Microsoft Teams. Topics covered included genetics, obesity and anorexia in relation to paediatric endocrinology. The CAM was attended by 48 delegates and worked extremely well on Microsoft Teams.

2.4.2 The SPEG Annual Scientific Meeting (ASM)

The SPEG Annual Scientific Meeting (ASM) took place in January 2021 via Microsoft Teams and was attended by 93 delegates, compared to 48 in person at the 2020 event. This year's Memorial lecture in honour of Professor Mike Wallace was on 'Obesity Research and Practical Application – Past, Present and Future' and was presented by Professor Sadaf Farooqi (University of Cambridge). The full programme can be found in [Appendix 4](#).

106 individuals registered to attend the Annual Scientific Meeting 2021 and (at least) 94 attended; an attendance rate of 89%. Comparatively, there were 48 attendees at the 2020 event, which was held at the Golden Jubilee Conference Hotel in Clydebank. This highlights a major advantage of holding meetings online; removing travel as a barrier to attending. 11 of the 14 regional health boards were represented at this year's event, compared to 9 last year, with attendees from NHS Ayrshire & Arran and NHS Borders joining.

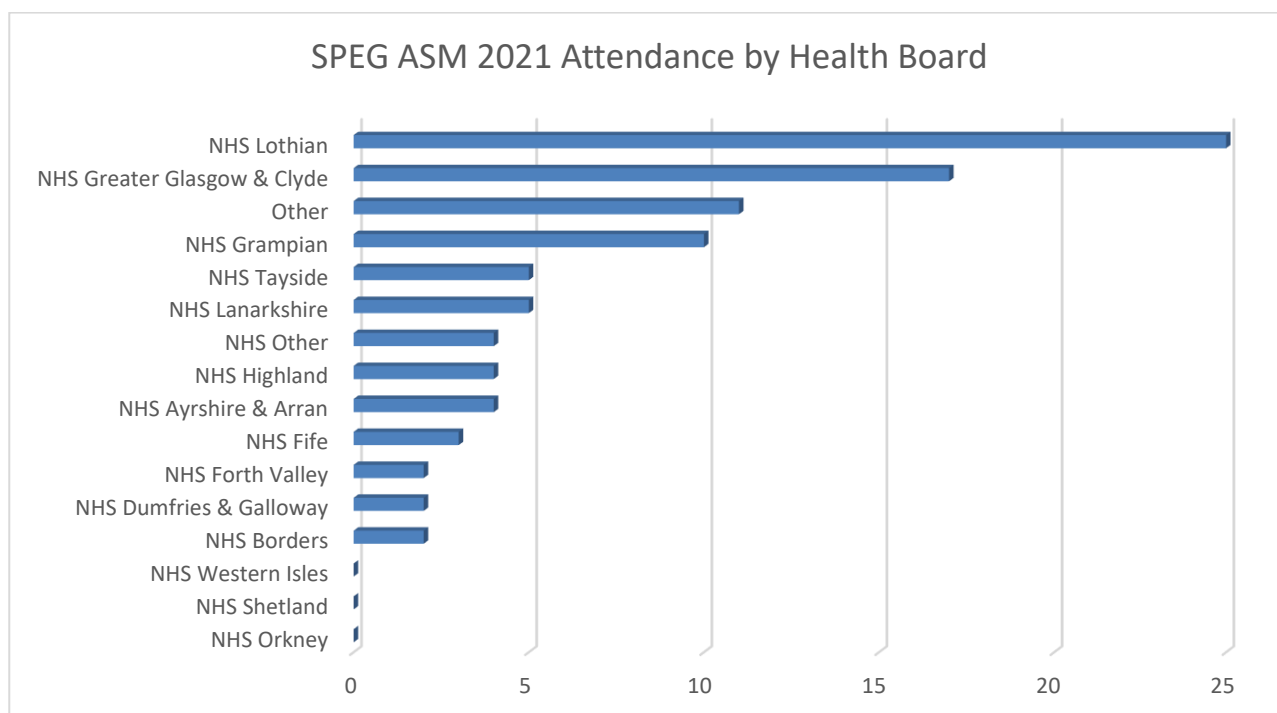


Figure 2 – SPEG Annual Scientific Meeting 2021 Attendance Rate by Health Board

Feedback for the event was gathered via Microsoft Forms. 36 individuals completed this. Some of the highlights have been included in [Appendix 5](#).

2.4.3 TURAS E-Module on ‘Growth and Puberty in Children’

The SPEG website provides access to an online learning module on “Growth and Puberty in Children”. This was originally hosted on LearnPro, and migrated to TURAS in 2019/20 to ensure all boards had access to the module. In 2020/21, 176 individuals completed and passed the module, with a further 40 currently in progress. This compares to 117 in 2019/20 (100 on LearnPro and 17 on TURAS). Of those that completed the module this year, 109 were medical students, 43 were Nurses and the others were a mix of Health Visitors, Support Workers, those working in Education and other specialists. Learners are asked to rate the course out of 5 upon completion. The average score for this over the past year was 4.5.

2.5 Audit & Continuous Improvement

The Clinical Audit System (CAS) continues to be the main focus of the Quality Indicators and Information Technology (QI/IT) Subgroup. Below are some of the highlights from 2020/21.

2.5.1 Clinical Audit System Highlights

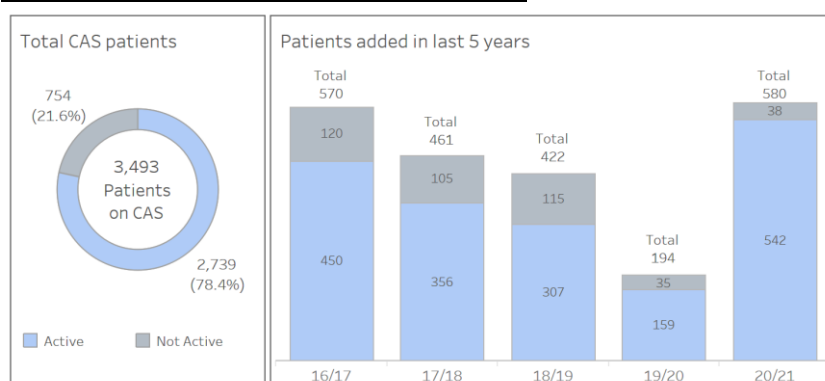


Figure 3 – SPEG patients added to CAS in 2020/21 and previous 4 years.

The above graphic demonstrates the significant increase in the number of patients that have been added to the CAS over the past year. This is after numbers of new patients being added had been decreasing year-on-year to a low of 194 in 2019/20.

Currently, the majority of patients being added are coming from four Health Boards. These are NHS Grampian (29%), NHS Lothian (54%), NHS Tayside (11%) and NHS Highland (6%). Last year the majority of patients only came from three Health Boards, with NHS Highland now making it four.

There are currently 2739 active patients on the CAS. Of these, 16.3% are now over the age of 18. Although there are exceptional cases, generally SPEG patients should be transitioning to adult services by the age of 18. The Transitions Group are due to meet for the first time on over 18 months, in order to address this.

Of the 2739 active patients on the CAS, 16% have no condition recorded. When looking at those that have been added in the last year, 12.9% have no condition recorded. The table below shows the primary conditions recorded for the CAS patients.

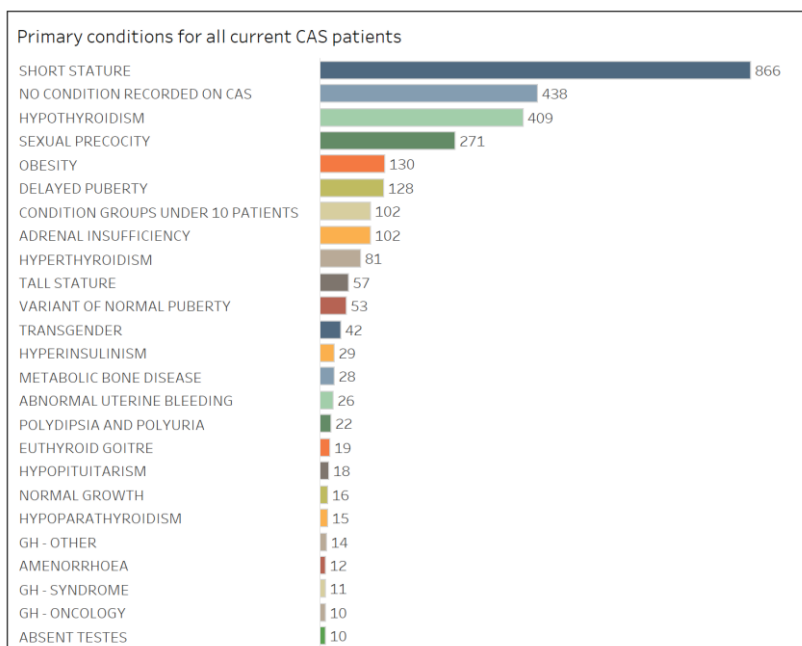


Figure 4 – Primary Conditions for all current SPEG CAS patients

The network currently records quality indicators for adrenal insufficiency (AI) patients. These indicators are important interventions that ensure the best possible care is being provided for these patients. Of the 108 adrenal insufficiency patients currently active, 20 were added in the last year. Figure 5 shows that there has been a slight drop in the number of children with each of the indicators populated.

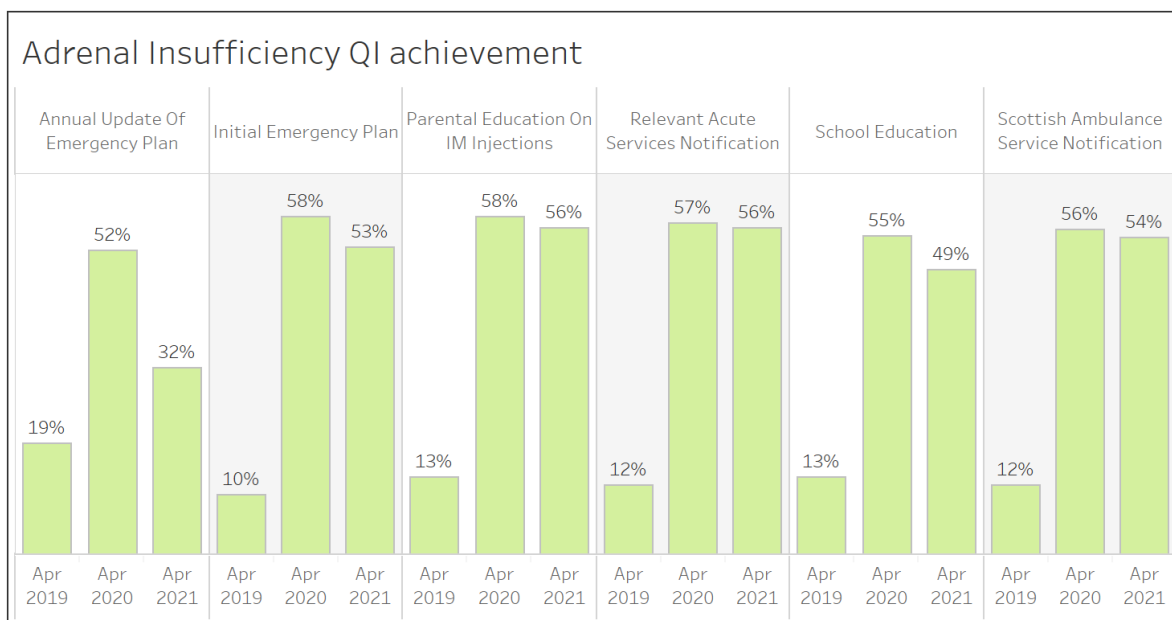


Figure 5 – Completion rate of Adrenal Insufficiency (AI) patient quality indicators over the last 3 years

A proposal was taken to the Steering Group by the QI/IT Subgroup in 2020 to utilise some of the network's budget to develop the CAS to include new quality indicators for Turner Syndrome. This was agreed and development of these indicators was progressed in March 2021.

2.5.2 Congenital Hypothyroidism

Another major development that the network progressed during the reporting period was to develop the CAS to host congenital hypothyroidism data. For the past 40 years this data has been held and managed in NHS Greater Glasgow and Clyde on an open access database. It was identified that no data had been added since 2018 when the data analyst retired. The anticipated benefits to NHS Scotland of developing CAS to incorporate this data are:

- 1) Historic data can be migrated and will be more easily accessible to CAS users
- 2) The missing data from 2018 can be collated and added
- 3) The data fields can be modernised
- 4) The data will be protected through the CAS governance measures
- 5) Any CAS user will be able to upload the data directly rather than on paper forms

A project team has been working on developing the data fields to ensure they are fit for purpose going forward, whilst still being able to incorporate the historic data to be migrated. The proposed fields will be taken by the NHS NSS Information Management Services (IMS) team to developers, to get an estimated cost for development. It is anticipated that this project will be progressed in 2021/22.

Newborn Blood Spot Screening Programme – diagnostic referral

A capillary blood spot measurement of thyroid-stimulating hormone (TSH) is taken as part of the Newborn Screening programme. This sample is used to detect suspected congenital hypothyroidism (CHT). If a sample has a TSH result of between 8mU/L and 19.9mU/L, a repeat sample is required.

All babies referred to specialist endocrinology clinicians as screen positive should be seen in a timely manner. According to the UK Newborn Blood Spot Screening standards, if CHT is suspected on the first sample, the first clinical appointment should take place by the age of 14 days. If CHT is suspected on a repeat sample, the first clinical appointment should take place by the age of 21 days.

In 2020/21, 16 out of 17 babies (94%) were seen within 14 days from the first sample, with one baby seen on day 15. The average age at the first clinical appointment, based on the first sample, was 11 days.

7 out of 8 babies (88%) were seen within 21 days from the second sample, with one baby seen on day 23. The average age at the first clinical appointment, based on the second sample, was 18 days. Two of these results, including the one seen on day 23, were recorded as false positives. It should be noted that there were an additional 2 premature babies that had a repeat sample taken after 28 days. Both were seen within one day of the sample being received.

The network views this data as an indication that the Newborn Blood Spot Screening Programme for CHT is effective. The effectiveness of the Programme is monitored and considered by its Programme Board, with which the SPEG network would liaise to support performance improvements.

2.6 Value

2.6.1 Growth Hormone Framework Agreement

It is anticipated that the new growth hormone framework agreement will offer significant savings of £669,000, whilst still adhering to NICE standards and offering patient choice. This projection is based on direct price savings from suppliers. A guidance document has also been created for staff reference. The guidance has been produced to ensure:

- NICE guidance is adhered to, allowing for patient choice
- There is inclusion of several growth hormone options
- Product rationale
- A collaborative approach is maintained between prescribers and patients, reserving the option to prescribe from tier 2.

Work is currently underway to get a version of the framework and guidance document on the SPEG website, ensuring commercially sensitive information is removed. Prescribing and costing data will be provided by National Procurement on at least a quarterly basis.



2.6.2 Patient Information Leaflets

Patient Information Leaflets on the SPEG website have been updated over the course of the year, so that staff and patients/ families can complete each of them electronically. This reduces the need for printing, completing by hand, and in some cases, scanning or posting. The leaflets are still in PDF format, with only the appropriate fields updated to allow them to be edited. The leaflets can be found [here](#).

2.6.3 SPEG Collaboration

At the SPEG Annual Performance Review (APR), the networks commissioners highlighted that the network should ensure it engages proactively with other networks and specialist and screening services within National Services Division (NSD). This is to ensure appropriate alignment and collaboration across projects and programs of work for the benefit of all stakeholders involved.

SPEG and Scottish Differences of Sex Development (SDSD)

SPEG has already been engaging with the Scottish Differences of Sex Development (SDSD) network to look at ways of collaborating on communications, events and clinical guidelines.

SPEG and New Born Screening

Following the APR, the network proactively re-established links with colleagues in New Born Screening and Genetics. It is anticipated that a refreshed approach to this partnership work will allow the network to identify areas for improvement as well as pathways of care, which will also facilitate an improvement in capturing and developing important data on patient care.

Ms Sarah Smith (Principal Healthcare Scientist, New Born Screening Laboratory, NHS Greater Glasgow & Clyde) has been an active member of the project team looking at incorporating the congenital hypothyroidism database into the Clinical Audit System (CAS). It is anticipated that both New Born Screening Lab and SPEG members will have access and enter data, which will ensure completeness and accuracy of the patient dataset.

SPEG and National Gender Identity Clinical Network (NGICNS) - Puberty Blockers

SPEG members are also currently actively involved in working on a new shared clinical guideline on puberty blockers alongside the National Gender Identity Clinical Network for Scotland (NGICNS). This is an important piece of work that has political implications due to a recent court case in England challenging the age of consent concerning puberty blockers. The guideline aims to outline a clear position (both clinical and legal) that is based on clinical expertise and experience, whilst also highlighting the risks associated with puberty blockers.

Steroid Management

Dr Mayo has created a pack of materials that have been produced by the SPEG network over recent years and plans are under way to share these materials with other networks and services with an interest in steroid management. The aim is to promote uniform best practice across the different specialties.

Clinical Obesity Panel

Members of the SPEG network have also been involved in discussions with genetics colleagues regarding the establishment of a genetic obesity panel that can be carried out in Scotland. The Clinical and Academic Meetings have provided a valuable and productive forum for the discussions. Introduction of this genetic panel to Scotland has been dovetailed with the update of the clinical guideline on obesity, which will reflect the ongoing changes and will include a link to a new proforma that should be completed by anyone referring patients.

3. Risks and Issues

The main issue that SPEG and all other networks and services have faced in 2020/21 has been the impact of the COVID-19 pandemic. Although there was great uncertainty at the time of the outbreak of the pandemic at the start of the reporting year, the network has managed to overcome a great number of barriers in order to effectively deliver on the workplan. Some meetings were initially cancelled or postponed in April and May, however this ultimately did not affect the network's progress throughout the year.

Some specific objectives within the workplan were directly affected by the impact of the pandemic. These have been outlined in more detail in Appendix 1.

Looking at the year ahead, there are risks that remain around the impact of the pandemic as well as the resources that may be required during the remobilisation period. The network will continue to adapt, innovate and evolve as they have done over the past year.

4. Finance

£207.76 was spent on the hire of West Park venue that had to be cancelled earlier in the year due to COVID-19. This was 20% of the full cost to hire the venue.

£2,373 was spent on the development of Turner Syndrome quality indicators being added to the SPEG Clinical Audit System. Work began on this in March 2021.

Of the network's £5,000 budget, £2,580.76 was utilised, leaving an underspend of £2,419.24.

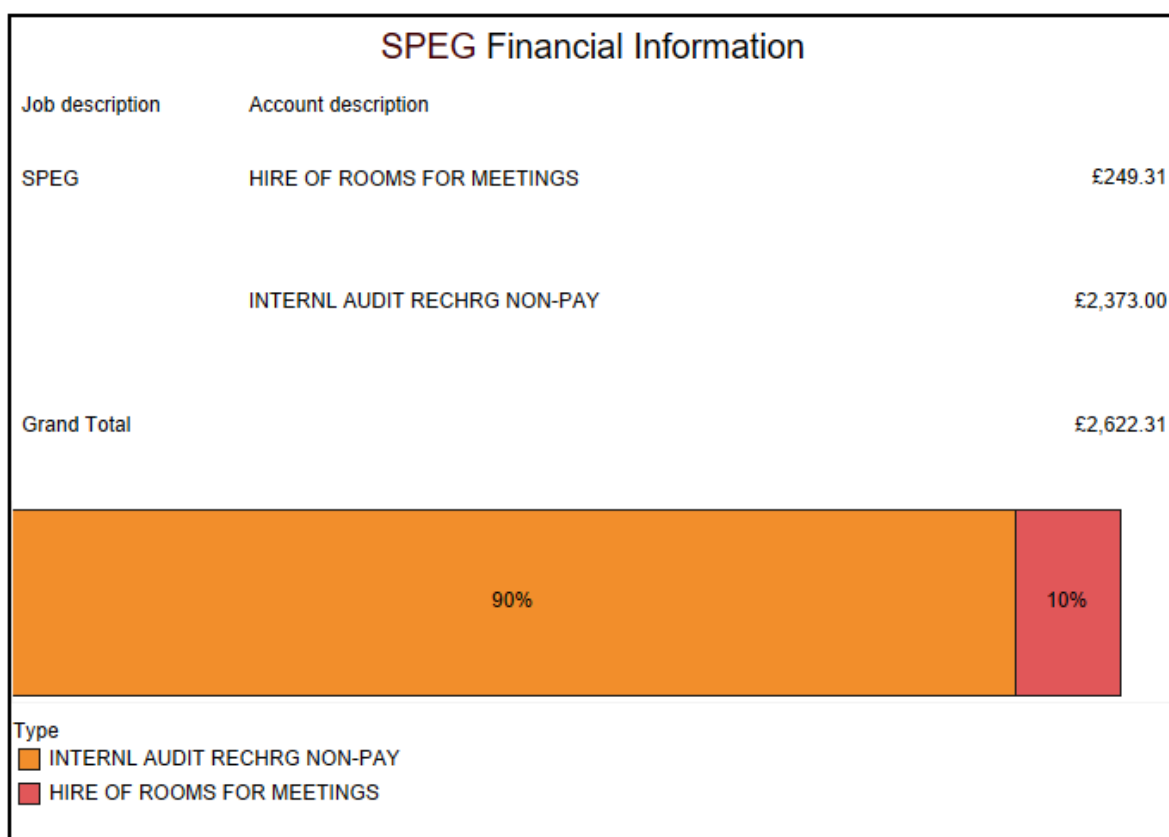


Figure 6 SPEG Annual Spend for 2020/21

5. Looking forward

All network strategies and terms of reference documents will be updated in 2021.

Based on the data analytics over the past year, the SPEG QI/IT Subgroup will be focussing on the following areas in the year ahead:

- 1) Addressing patients with no condition added
- 2) Addressing patients that are aged 18 and over (via the Transitions Subgroup)
- 3) Focussing on the most common conditions
- 4) Ensuring all quality indicators are completed for AI patients
- 5) Encouraging more boards to use the CAS

The Transitions Group is due to meet by June 2021 after over a year's hiatus due to clinician redeployment. The membership is currently under review and new terms of reference will be drawn-up in advance of the first post-hiatus meeting.

The Adrenal Insufficiency Patient Questionnaire will be live from May 2021 and will remain open for a six-month period in order to gather as many responses as possible. These will be collated by the network core team and updates shared periodically. Questions have also been included to gauge interest on a family engagement event, which addresses the issue of being unable to organise a face-to-face event in 2020 as planned. Feedback will help address any gaps in provision and guidance going forward.

As part of a website review in 2021, the network will be exploring options to get more up-to-date stock images to freshen up the look and feel of the website as well as other communications materials.

The network has begun to explore how it can facilitate a family engagement event online, as the regional pilot event scheduled to take place in Aberdeen in 2020 had to be put on hold due to the pandemic. Work is underway to determine whom the audience should be and what availability there is amongst SPEG clinicians to present at such an event. As outlined earlier in the report, some questions have been added to the patient Adrenal Insufficiency Patient Questionnaire around a family engagement event to determine whether there is any appetite for holding such an event online and what families and patients would be covered should this go ahead.

In 2021/22, a questionnaire will be produced to capture feedback on how these guidelines are being used and what difference they are making to clinical practice.

Full details of the proposed workplan for 2021/22 are outlined in Appendix 2. Some of the highlights are:

- Review of SPEG subgroup membership and terms of reference
- Review of strategies
- Deliver an Annual Scientific Meeting and 2 Clinical and Academic Meetings
- Review and add new Clinical Guidelines
- Produce and circulate 3 newsletters
- Website review
- Look at options to develop new stock images for communications and website
- Create an interactive map with details on each health board's SPEG services
- Run a family engagement event
- Work with Medical Illustration in NHS GG&C to produce educational videos
- Develop Turner Syndrome Quality Indicators
- Develop CAS with Congenital Hypothyroidism database and migrate data from old open access database in NHS GG&C
- Share steroid resource pack with other relevant networks and services
- Collate responses to Adrenal Insufficiency patient questionnaire and create an action plan based on results
- Continue to work with colleagues in NGCINS and SDSD on shared resources and opportunities
- Re-engage with the Scottish Ambulance Service to continue develop hazard alert process for Adrenal Insufficiency patients

Appendix 1 – Workplan Progress in 2020/21

Scottish Paediatric Endocrine Group (SPEG) Network WORKPLAN – 2020-21

When defining network objectives please consider the Institute of Medicine's six dimensions of quality, which are central to NHS Scotland's approach to systems-based healthcare quality improvement:

1. **Person-centred:** providing care that is responsive to individual personal preferences, needs and values and assuring that patient values guide all clinical decisions;
2. **Safe:** avoiding injuries to patients from healthcare that is intended to help them;
3. **Effective:** providing services based on scientific knowledge;
4. **Efficient:** avoiding waste, including waste of equipment, supplies, ideas, and energy;
5. **Equitable:** providing care that does not vary in quality because of personal characteristics such as gender, ethnicity, geographic location or socio-economic status; and
6. **Timely:** reducing waits and sometimes-harmful delays for both those who receive care and those who give care.

Key

RAGB status	Description
RED (R)	The network is unlikely to achieve the objective by the agreed end date.
AMBER (A)	There is a risk that the network will not achieve the objective by the agreed end date but progress has been made.
GREEN (G)	The network is on track to achieve the objective by the agreed end date.
BLUE (B)	The network has been successful in achieving the network objective to plan.

Objective Number	Smart Objective	Planned start/ end dates	Detailed Plan Available / Owner	Description of progress towards meeting objective as at 31.03.2021 (Annual Report)	Anticipated Outcome	RAGB status
1. Effective Network Structure and Governance [linked to Quality Dimensions 3,4,5,6]						
2020-01	The network will organise 3 Steering Group meetings and 3 (of each) sub-group meetings by 2021 to ensure effective delivery of the 2020-21 workplan.	01/04/2020 - 31/03/2021	Steering Group and Sub-Group membership	The first Steering Group meeting was cancelled due to the outbreak of COVID-19, however the group has met twice since and three are planned for 2021/22. Each of the subgroups have met at least 3 times, with the exception of the Transitions Group, which has been on hold this year.	Effective delivery of the SPEG network workplan to ensure continuation of progress	B
2. Service Development and Delivery [linked to Quality Dimensions 1,2,3,4,5,6]						
2020-02	By March 2021 review existing and develop new clinical guidelines relevant to the Scottish Paediatric Endocrine population.	01/04/2020 - 31/03/2021	Clinical Guidelines Group	The SPEG Clinical Guidelines group have continued to review and update the guidelines and there are currently 4 that are under review. These have been delayed due to clinician availability.	Delivery of evidence-based practice and equity of access to high quality care across Scotland to reduce harm and unwarranted variation	G
2020-03	By March 2021 review existing and develop new patient and family information leaflets, relevant to paediatric endocrine care, including transition.	01/04/2020 - 31/03/2021	Nurses' Group and Transitions Group	All leaflets are currently up-to-date and any with text fields have been updated this year to allow the PDFs to be completed electronically.	Patients and families are supported to manage their condition and to share in informed decision-making	B

Objective Number	Smart Objective	Planned start/ end dates	Detailed Plan Available / Owner	Description of progress towards meeting objective as at 31.03.2021 (Annual Report)	Anticipated Outcome	RAGB status
3. Stakeholder Communication and Engagement [linked to Quality Dimensions 1,3,4,5,6]						
2020-04	By March 2021, produce and circulate three newsletters covering the latest developments in relation to SPEG	01/04/2020 – 31/03/2021	Steering group	Only two newsletters have been circulated this year. The third was put on hold as part of the NSD capacity planning exercise.	Stakeholders across Scotland will be kept up-to-date with network developments and news.	B
2020-05	By March 2021, deliver a family engagement pilot event in Aberdeen to engage families, offering advice, guidance and networking opportunities.	01/04/2020 – 31/03/2021	Programme Manager/ Lead Clinician/ Third Sector	A family engagement event could not go ahead due to COVID-19 restrictions. A patient survey has been circulated in March 2021 to see what interest there is in this being held online in 2021.	Through shared decision-making SPEG will deliver what matters most to patients	A
4. Education [linked to Quality Dimensions 1,2,3,4,5,6]						
2020-06	By March 2021, deliver one annual scientific meeting and two Clinical and Academic Meetings (CAMs).	01/04/2020 – 31/03/2021	Education Group	The Annual Scientific Meeting took place in January 2021 and a Clinical and Academic Meeting was held in September. The CAM that was set for May was cancelled due to the COVID-19 pandemic.	Healthcare professionals across Scotland share and increase their skills and knowledge of paediatric endocrinology	B
5. Audit and Continuous Quality Improvement [linked to Quality Dimensions 1,2,3,4,5,6]						
2020-07	By December 2020 increase the Clinical Audit System (CAS) dataset and provide clinical access to dashboard.	01/04/2020 – 31/12/2020	QI/IT Group	There has been an improvement in numbers recorded with AI quality indicators this year, however	Clinicians are able to access their data and audit patient	B

Objective Number	Smart Objective	Planned start/ end dates	Detailed Plan Available / Owner	Description of progress towards meeting objective as at 31.03.2021 (Annual Report)	Anticipated Outcome	RAGB status
				more work is required to develop a useful dataset overall. The QI/IT Group are currently looking at developing a bundle on CAS for Turner Syndrome as well as incorporating the congenital hypothyroidism data that is currently stored on an open access database in NHS GGC. Part of the annual SPEG budget has been used to fund the Turner Syndrome development. The CHT development will be carried over into next year.	outcomes to drive improvement	
2020-08	By March 2021, audit collaboration between the Scottish Ambulance Service and SPEG regarding implementation of the Adrenal Insufficiency Hazard Alert.	01/04/2020 – 31/03/2021	QI/IT Group/ Lead Clinician	Collaboration with SAS and testing of Red Flag Warning is currently on hold due to the ongoing COVID-19 crisis and a lack of communication from SAS. However, a questionnaire is being developed by the Nurses' Group to gather feedback from families on the use of the newly developed 'making a 999 call card', as well as general awareness around the hazard alert system. The network is currently looking at other potential partnership work across other networks, including newborn screening and genetics. It is hoped that SAS can be involved in the family engagement	Patients will benefit from organisations working together to provide optimum care and manage risks	A

Objective Number	Smart Objective	Planned start/ end dates	Detailed Plan Available / Owner	Description of progress towards meeting objective as at 31.03.2021 (Annual Report)	Anticipated Outcome	RAGB status
				event and attempts have been made to re-engage.		
6. Value [linked to Quality Dimensions 1,2,3,4,5,6]						
2020-09	By December 2020, SPEG will support NSS National Procurement to deliver a national prescribing approach for Growth Hormone Treatment.	01/04/2020 – 31/12/2020	SPEG Clinical Advisory Panel	Members of SPEG formed part of the Clinical Advisory Panel (CAP) with NSS National Procurement. A new Framework Agreement was in place from 1st January 2021. Alongside the tender process the CAP have developed a guidance document that encompasses a list of recommended suppliers for the use in the majority of patients, whilst still providing patient choice (as per NICE guidance) based on a two-tiered recommendation. This new approach to growth hormone procurement is expected to deliver significant savings.	Patients and families are involved in shared decision-making while maximising value for money and realising cost savings	B

Appendix 2 – Proposed Work Plan for 2021/22

Scottish Paediatric Endocrine Group (SPEG) Network WORKPLAN – 2021-22

When defining network objectives please consider the Institute of Medicine's six dimensions of quality, which are central to NHS Scotland's approach to systems-based healthcare quality improvement:

7. **Person-centred:** providing care that is responsive to individual personal preferences, needs and values and assuring that patient values guide all clinical decisions;
8. **Safe:** avoiding injuries to patients from healthcare that is intended to help them;
9. **Effective:** providing services based on scientific knowledge;
10. **Efficient:** avoiding waste, including waste of equipment, supplies, ideas, and energy;
11. **Equitable:** providing care that does not vary in quality because of personal characteristics such as gender, ethnicity, geographic location or socio-economic status; and
12. **Timely:** reducing waits and sometimes harmful delays for both those who receive care and those who give care.

Key

RAGB status	Description
RED (R)	The network is unlikely to achieve the objective by the agreed end date.
AMBER (A)	There is a risk that the network will not achieve the objective by the agreed end date but progress has been made.
GREEN (G)	The network is on track to achieve the objective by the agreed end date.
BLUE (B)	The network has been successful in achieving the network objective to plan.

(THEME) BAU Action Plan		
Core Principle	Program of Work	Owner

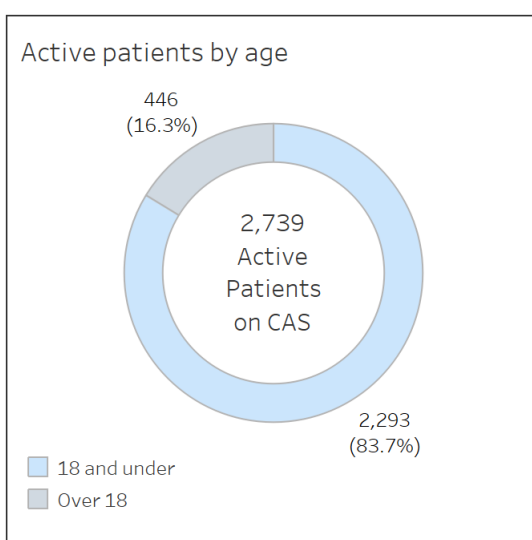
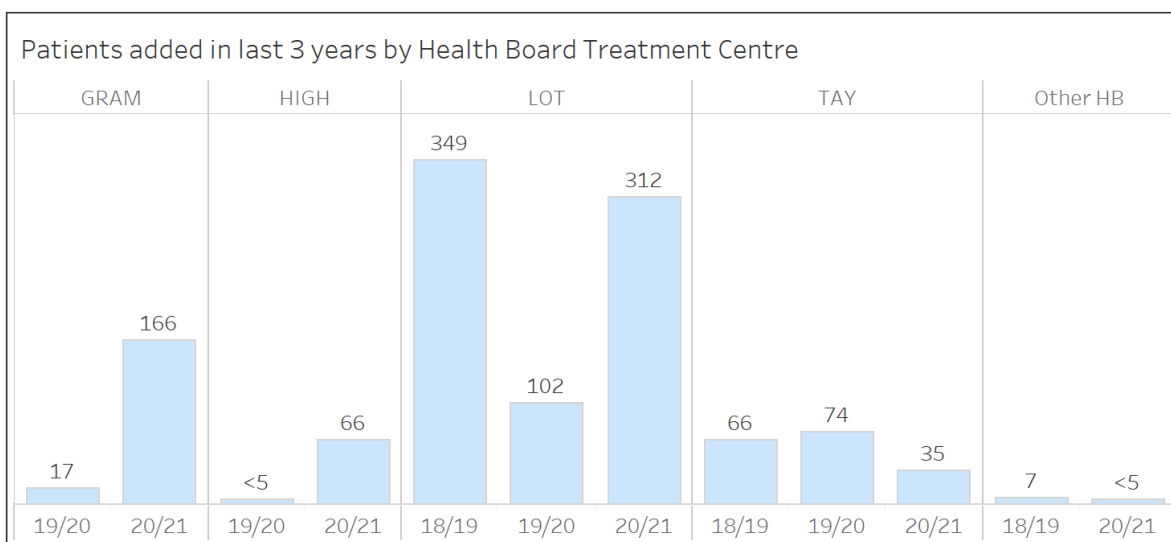
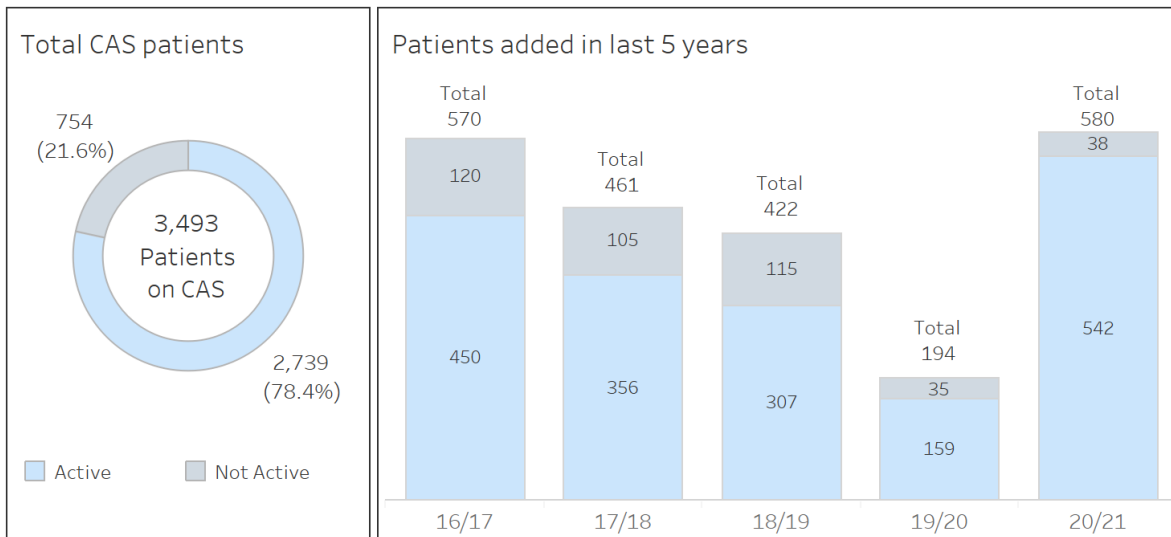
Effective Network Structure and Governance	The network will organise 3 Steering Group meetings and 3 (of each) sub-group meetings by the end of March 2022 to ensure effective delivery of the 2021-22 workplan.	Steering Group
Effective Network Structure and Governance	Review subgroup membership to ensure there is representation from different professional branches as well as different health boards. Present at the Steering Group meeting to address any imbalances.	Steering Group and Subgroups
Effective Network Structure and Governance	Update the SPEG clinical directory at each Clinical and Academic Meeting (CAM) as well as at the Annual Scientific Meeting (ASM).	Network Team
Service Development and Delivery	Review all strategies	Network Team
Service Development and Delivery	Ensure all SPEG clinical guidelines are up-to-date and on the correct templates on the SPEG website.	SPEG Clinical Guidelines Subgroup
Stakeholder Communication and Engagement	Produce 3 newsletters by March 2022.	Network Team
Stakeholder Communication and Engagement	Carry out a fresh review of the SPEG website to ensure all links, documents, pages etc. are up-to-date.	Network Team
Education	By September 2021, deliver two Clinical and Academic Meetings (CAMs).	SPEG Education Group
Education	Deliver and Annual Scientific Meeting (ASM) in January 2022.	SPEG Education Group
Value	Review CAS fields and develop additional fields to make the data more clinically relevant.	SPEG QI/IT Subgroup

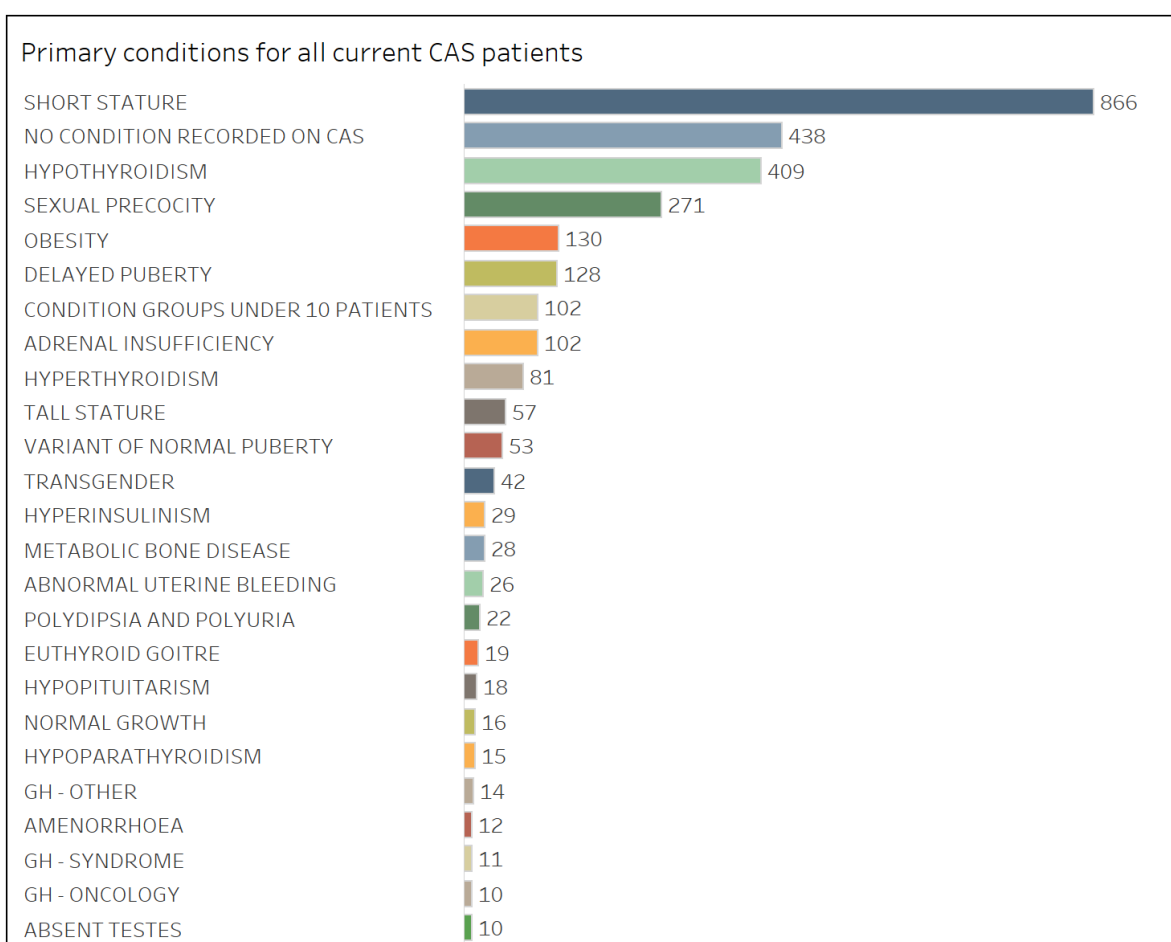
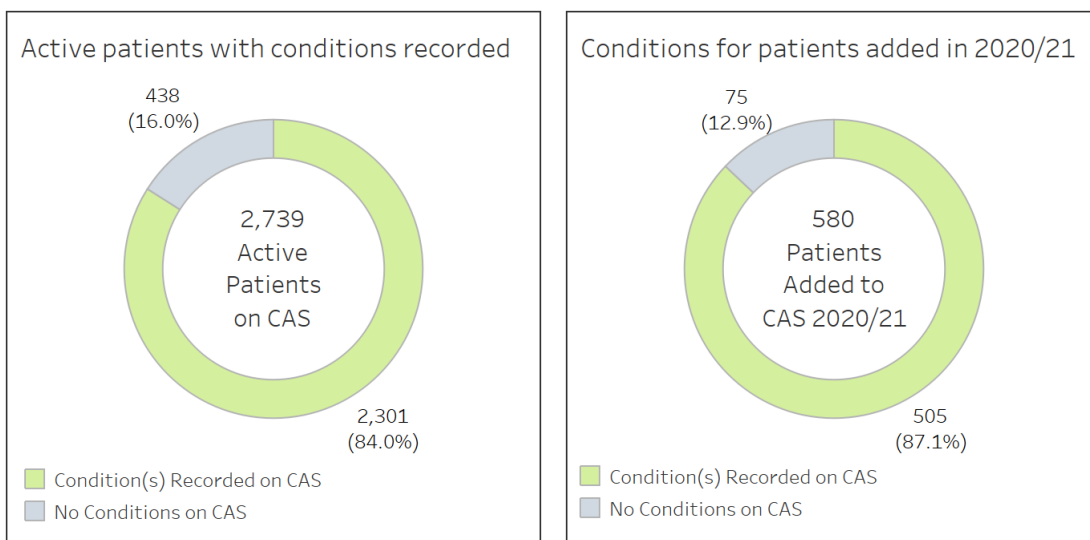
(THEME) Special Programmes Action Plan

Core Principles	Description of Work	Owner
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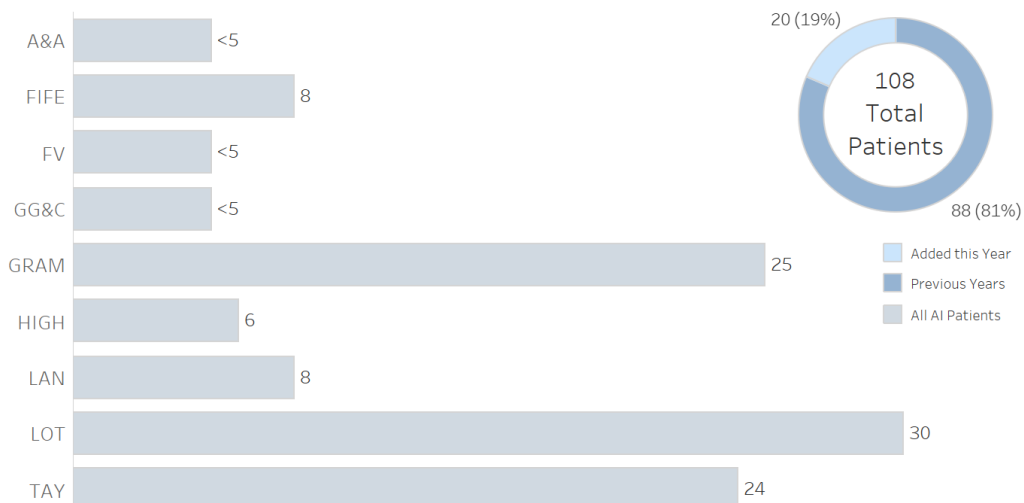
Service Development and Delivery	Develop new clinical guidelines (TBC). Develop a survey to send to SPEG members, to see how useful the clinical guidelines are perceived to be and gain feedback on what other guidelines people would like to see. Do as part of CAM in May.	SPEG Clinical Guidelines Subgroup
Stakeholder Communication and Engagement	Explore options to get new 'stock' pictures for use in SPEG materials/ website etc. Also include staff pictures for 'meet the team' on website (LC/PM/PSO/DA/Chairs).	Steering Group
Stakeholder Communication and Engagement	Explore options create an interactive map with basic information for each health board (clinicians, generic email, services provided, e.g. transition clinic/ Turner clinic)	Network Team
Stakeholder Communication and Engagement	Review willingness for a family engagement event once feedback has been gathered from AI patient survey. Explore options based on feedback.	Lead Clinician/ Network Team
Education	In collaboration with Medical Illustration in NHS Greater Glasgow and Clyde, develop a series of short scripted videos on how to administer common SPEG medications.	SPEG Nurses' Group
Audit and Continuous Quality Improvement	Continue to develop Turner Syndrome Quality Indicators on the SPEG Clinical Audit System (CAS). The SPEG QI/IT subgroup should monitor this to ensure the system is being used effectively. A new SPEG CAS User Microsoft Teams channel has been set up for users to communicate for efficiently.	SPEG QI/IT Subgroup
Audit and Continuous Quality Improvement	Circulate the recently developed Adrenal Insufficiency Patient Survey via the SPEG Nurses' Group to patients and families over a 6 month period to gather as much feedback as possible on knowledge, access to information, additional requirements etc.	SPEG Nurses' Subgroup
Audit and Continuous Quality Improvement	Develop a new subset of data fields on the SPEG CAS for capturing historic and new data on congenital hypothyroidism (CHT). This data is currently being held in an open access database in NHS GG&C and has not been updated for the last 2 years.	SPEG QI/IT Subgroup
Value	Share 'steroid information' packs with other relevant networks based on documentation developed by the SPEG network over recent years.	Lead Clinician
Value	Continue to work with the New Born Screening Lab on the development of the SPEG CHT CAS data fields. The New Born Screening Lab will be able to access this and will add initial data for future patients, which will provide SPEG clinicians with instant access to data/ alerts, rather than forms being sent back and forth.	SPEG QI/IT Subgroup
Value	Continue to work with NGCINS NMCN to develop guidelines on hormone treatment for transgender young people.	Steering Group
Value	Work with colleagues in genetics to develop a new obesity clinical guideline and invite colleagues to share updates at one of the CAMs or ASM. Clinical panel – Guftar has volunteered to represent the network.	Steering Group/ Education Group/ Clinical Guidelines Group

Appendix 3 – Clinical Audit System Data Highlights 2020/21

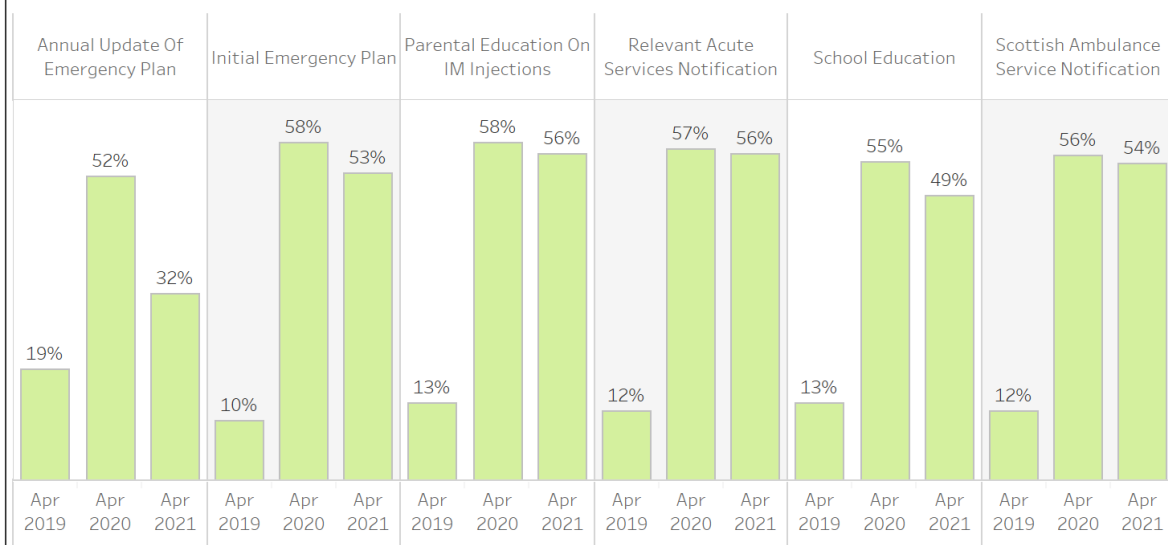




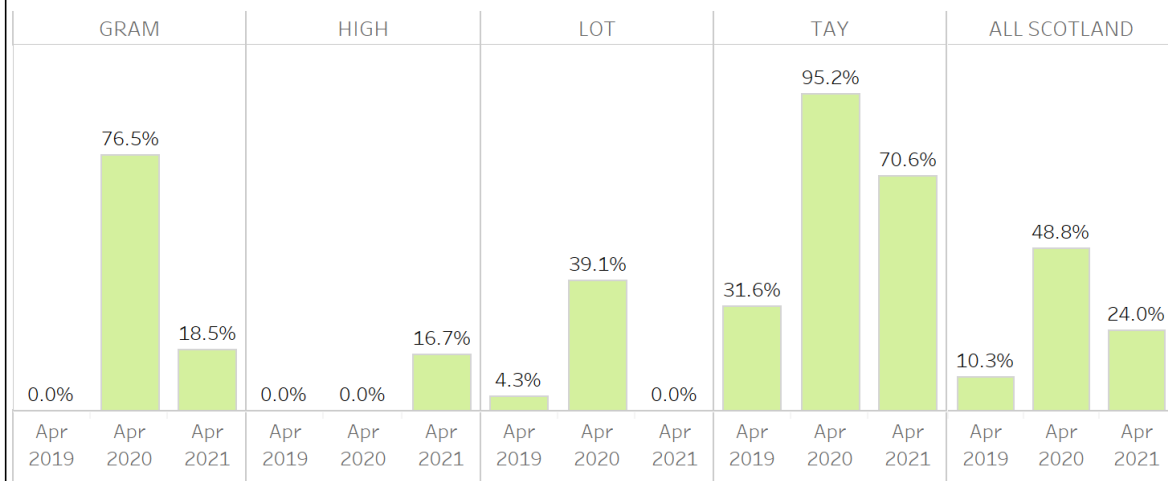
Adrenal Insufficiency patients by Treatment Centre HB and year created



Adrenal Insufficiency QI achievement



% of AI patients achieving all 6 indicators



Appendix 4 – SPEG Annual Scientific Meeting 2021 Programme

Scottish Paediatric Endocrine Group (SPEG) 23rd ANNUAL SCIENTIFIC MEETING 29th January 2021 on Teams

Friday 29th January Chair: Louise Bath

SESSION 1 **Obesity**

08.45 – 09.00 Welcome from Louise Bath

09.00 – 10.00 Memorial lecture in honour of Professor Mike Wallace: Obesity Research and Practical Application – Past, Present and Future - **Sadaf Farooqi**

10.00 – 10.30 PWS: Optimising Clinical Care - **Guftar Shaikh**

10.30 – 11.00 Genetics of Obesity Panel: Clinical Application - **Joanne McLean**

11.00 – 11.15 **Tea/ Coffee**

SESSION 2 **Bone**

11.15 – 11.45 Achondroplasia - Best Practice and New Therapies - **Helen McDevitt**

11.45 – 12.15 Osteogenesis Imperfecta - Optimising Bone Health - **Paul Arundel**

12.15 – 12.45 Scoliosis - Identification and Management - **Thanos Tsirikos**

12.45 – 13.45 **Lunch**

SESSION 3 **Free Communications Sessions**

13.45 – 14.00 Hypothyroid Screening in Children with Downs Syndrome – A Service Evaluation - **Rachel Harley**

14.00 – 14.15 PCOS or Hyperandrogenism in Adolescence - **Tina Lund Leunbach**

14.15 – 14.30 Macromastia in a Teenage Girl – An Unusual Case in Endocrinology Clinic – **Sabine Grosser**

SESSION 4 **Adolescent Gynaecology**

14.30 – 15.00 Heavy Menstrual Bleeding in Girls: Assessments and Interventions – **Shoina Coutts**

15.00 – 15.30 PCOS and MOSH. What Therapeutic Interventions - **Colin Duncan**

15.30 Close of meeting

Appendix 5 – SPEG Annual Scientific Meeting 2021 Feedback Highlights

Each speaker was given a rating out of 5, with 5 being “excellent”. The average scores that the presentations received ranged from 4.1 to 4.8, with an overall average 4.5. The feedback form also provided an opportunity to comment on each presentation, including how they may influence the individual’s clinical practice going forward. The delegates were asked to score the use of Microsoft Teams as a platform out of 5, and this received an average score of 4.6.

Some highlights from the comments are included below.

- *“I actually really liked it being on Teams. I would have had to have travelled the night before and found accommodation or have left the house just after 5am to have been in Glasgow or Edinburgh had it been there.”*
- *“Well organised & educational, but missed the social networking opportunity.”*
- *“A really good programme, well delivered with good technical back up. I think a lot of the content today was what I’d previously asked for, so thanks!”*
- *“Teams meeting was much better than anticipated and in some ways allows more access to these meetings.”*
- *“A scheduled networking session would be helpful (and enjoyable!) in addition to the excellent presentations.”*
- *“Look forward to seeing people F2F in the future!”*