

**Scottish Paediatric Endocrine Group (SPEG)  
Clinical Network  
ANNUAL REPORT 2016/17**

**Lead Clinician: Dr John Schulga**

**Programme Manager: Hugh Kennedy**

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## **Executive summary**

The Scottish Paediatric Endocrine Group (SPEG) has been a National Managed Clinical Network since April 2009 (SPEG NMCN). The network is concerned with endocrine and growth disorders in children and young people up to the age of 16 years. These children and young people may require specialist intervention which can be provided locally as well as in specialist centres.

The vision of SPEG is one of collaboration and multi-disciplinary team working, to ensure significant and continued improvements in the outcomes of children and young people with endocrine conditions.

Between April 2016-March 2017 the network has continued to mature and has made significant developments.

## **Key achievements in this report:**

- Continued emphasis on teaching and training, with ongoing delivery of the MCN's agreed Education Strategy. This includes continued delivery of education and training at National, Regional and Local levels.
- Significant increase in the usage of the Endocrine Clinical Audit System with more meaningful data now being displayed using Tableau software.
- Ongoing addition to an increasing range of information leaflets for parents/carers, teenagers and staff employed in education. These cover a range of endocrine conditions and this year includes information leaflets about endocrine stimulation tests.
- Continued development, reviewing and updating of evidence based guidelines for health professionals who manage endocrine conditions.
- Relaunch and update of the SPEG website, the Network's main communication hub. The website gives clinicians access to all the necessary information that the network provides, as well as providing links to helpful information provided by other relevant agencies.
- Regular engagement with patients and families through family days.
- Completed audit of the number of patients with adrenal insufficiency registered with the Scottish Ambulance Service (SAS), which highlighted a number of issues to address.
- The network is currently undergoing a Network Review, which aims to provide an objective assessment of the extent to which SPEG NMCN delivers against its agreed objectives, and its commitment to continuous development and quality improvement.
- The Network review process included gathering views of its stakeholders through an online survey and a Strategic Planning Day.

## **Network Plans for 2017/18:-**

- Agree objectives following the conclusions of the Network review in June 2017

- Complete the LearnPro package for basic growth and puberty assessment, which will hopefully be made available to all health professionals in Scotland, from Primary care to Tertiary care.
- Continue to develop relevant clinical guidelines, and to review completed guidelines due for review.
- Aim to improve patient and carer participation and engagement in the network, including capturing service user feedback in a meaningful and measurable way and continued hosting of family events.
- Continued entry of patients onto CAS so that it will become an accurate national endocrine conditions register.
- Work with the Scottish Ambulance Service to improve the alert system for all children with adrenal insufficiency.
- Finalise the Nurse Education Strategy for nurses who see children with endocrine conditions in Scotland.
- Review the SPEG Education Strategy which is due for review in 2017.
- Maintain and update the SPEG service directory, and ensure this is used as a tool for manpower resource benchmarking for regional planning groups and health boards.
- Audit the use and usefulness of SPEG documents, namely guidelines and patient information leaflets
- Review and refine the network quality indicators to ensure that measuring them will provide useful measures of service delivery and can result in quality improvement.

## **Introduction**

Paediatric Endocrinology deals with disorders of the endocrine glands. More common endocrine disorders include disorders of growth and puberty, and less common glandular abnormalities such as thyroid and adrenal glands. Endocrine disorders are wide ranging, can affect children of all ages and can be primary or secondary to other conditions.

Many endocrine conditions in children are classified as rare disorders.

Many endocrine conditions can be managed by a general paediatrician with an interest in paediatric endocrinology.

The management of rare or more complex conditions requires more specialist care at tertiary centres with direct access to specialist laboratory, radiology and other services.

The current model of service delivery for specialised endocrine care involves Multi-Disciplinary Teams (MDT) consisting of doctors (general paediatricians and paediatric endocrinologists), nurses (general and endocrine), dieticians, clinical psychologists, pharmacists and biochemical laboratory, screening laboratory and diagnostic imaging services. These services are mainly delivered from three regional centres with the majority of specialist care provided by specialist MDTs in Glasgow and Edinburgh. With appropriate support from these specialist teams, many children are managed in local centres in District General Hospitals with outreach by the tertiary centres through a system of shared care and/or joint clinics.

The network supports local and tertiary paediatric endocrine services in improving standards of clinical care of children through the establishment of continuous education and training, guideline development, and quality improvement systems.

Paediatric endocrine services are currently delivered in most health board areas in Scotland with the exception of the island boards. Care is managed by local multi-disciplinary teams in each District General Hospital supported from the three regional tertiary centres (Royal Aberdeen Children's Hospital, Royal Hospital for Children, Glasgow and the Royal Hospital for Sick Children, Edinburgh) through joint outreach clinics and shared care systems where appropriate.

This model ensures the network provides services that are person centred, and delivered locally where possible.

The Paediatric Endocrine team from RHC Glasgow provides shared care support to Ayrshire & Arran, Clyde, Lanarkshire and Forth Valley health board areas.

The Paediatric Endocrine team from RHSC Edinburgh provides shared care support to Dumfries & Galloway, Highland, Fife, Tayside and Borders health board areas.

The Paediatric Endocrine team from Aberdeen provides shared care support to Elgin.

## **Aims and Purposes of the network**

The overall key aims and objectives of the network are as follows:

- Establish and maintain effective systems and processes to support continuous quality improvement (CQI) including data collection and reporting, audit and research.
- Develop standardised care (guidelines and investigations) and referral pathways for specific conditions, promoting equity of care across the region and supporting District General Hospitals, enabling care to take place locally, including joint outreach clinics.

- Identify training needs and facilitate the design, development and delivery of education and training both for those directly involved in the care of children with endocrine conditions, as well as ensuring training and education for general paediatricians, AHP's and primary care colleagues, who may be involved in the management of these children.
- Promote local multidisciplinary meetings with access to teleconferencing to overcome difficulties in attending. This enables staff from around Scotland to participate in network business and education while avoiding unnecessary travel costs and pressure on clinical commitments.
- Develop and deliver a stakeholder communication and engagement strategy to support effective internal and external communication. This includes the availability of guidelines and information leaflets for all network members, and health professionals and families, encouraging family and patient support group engagement. This is achieved by the use of the website as the main hub of communication for use for all members and stakeholders, as well as for anyone who might wish to use the information.
- Facilitate and continue to develop links with other specialties.

**The designation objectives for the network are:**

- To enable timely and effective care for paediatric endocrine patients across Scotland according to, nationally-agreed procedures and guidelines which are evidence-based wherever possible.
- To enable excellent provision of care for paediatric endocrine patients in as cost effective manner as possible.
- To promote equity of access and service delivery at the most appropriate point of contact.
- To facilitate effective service interfaces and support good practice in multidisciplinary and interagency working both within the NMCN and associated service delivery.
- To establish and maintain effective systems and processes to facilitate and provide evidence of continuous improvement in the quality of care (CQI).
- To facilitate the various strands of user involvement in service delivery and future planning of services.
- To engage with NHS managers and planners to support service development, improvement and redesign.
- To meet the core principles specified within extant SGHSCD guidance on managed clinical networks, currently CEL (2012) 29.

## Report against Workplan

A detailed report on progress with the agreed network workplan for 2016/17 is available on page 21 of this report. The main work priorities for 2016/17 include:

### 1. Data Collection/Analysis

The following Quality Indicators (QI'S) have been measured:-

#### **SPEG Quality Standard CG2**

- **Audit of the use of CAS as a register of patients seen in the endocrine service.**

The purpose of this data collection is to have a complete record of patient numbers and conditions across each Board in Scotland, to obtain a more complete picture of service delivery in Scotland.

Patients are continuing to be entered on CAS, which is becoming a more meaningful register of endocrine patients.

There are currently 1601 patients registered on the SPEG CAS Instance. The reported figures do not include patients over the age of 18 years, which have been removed since last year's reported figures as they are not part of paediatric endocrine services. Using this criteria for last years figures as well to show a like-for-like comparison, March 2017 figures reported show an increase of 595 (48%) compared with March 2016. This continues the trend shown in the previous year where the year on year increase was 793 patients registered, a 63% increase.

The NNMS team is reviewing how they might be able to support the data capture in Greater Glasgow and Clyde and Grampian.

**The number table shows for the 1601 patients that have been recorded on CAS- a breakdown of where they are being treated across Scotland on the top table , with their health board of residence shown in the second table.**

**Gender and age breakdown are also shown in separate charts below.**

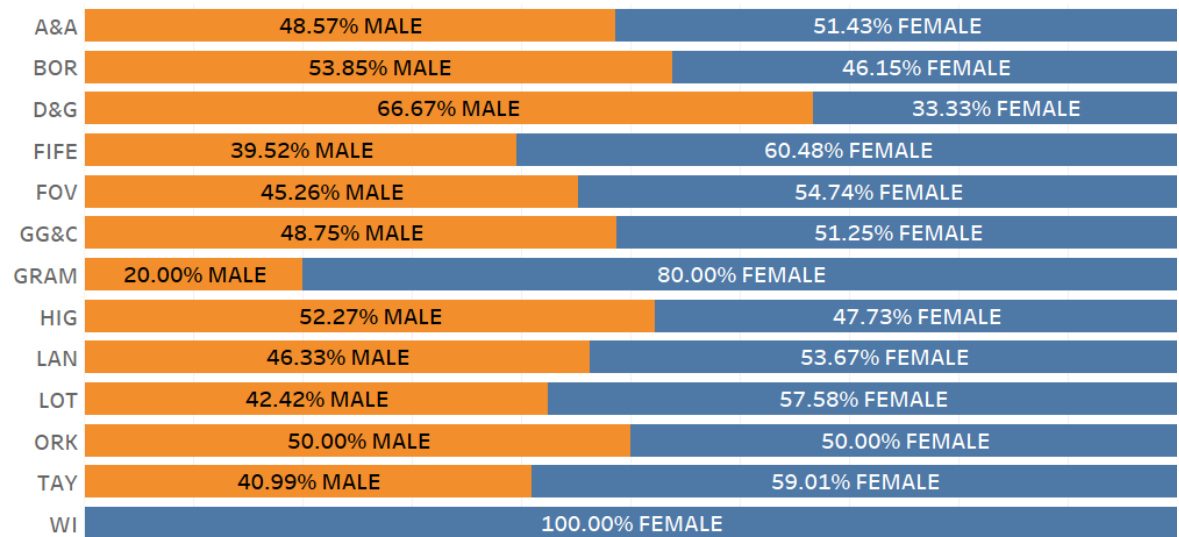
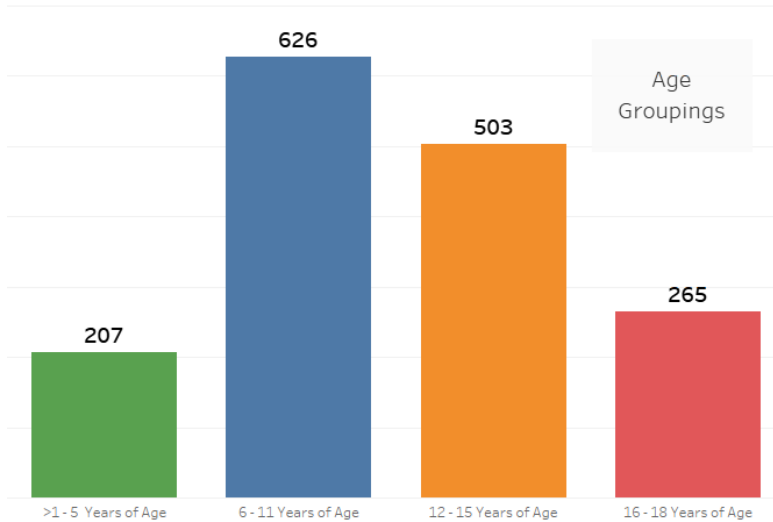
# Scottish Paediatric Endocrine Group (SPEG) National Managed Clinical Network: Annual report 2016/17

Patients treated in Endocrine Clinics across Scotland per Treatment Centre  
(Children and young people up to and including 18 Years)

CROSSHOUSE	FORTH VALLEY ROYAL HOSPITAL	NINEWELLS	RAIGMORE	RHSC EDINBURGH	RHSC GLASGOW	VICTORIA HOSPITAL	WISHAW GENERAL HOSPITAL	TC's with <5 Pts	Grand Total
16 1.00%	192 11.99%	428 26.73%	41 2.56%	486 30.36%	131 8.18%	139 8.68%	159 9.93%	9 0.56%	<b>1,601</b> <b>100.00%</b>

Patients treated in Endocrine Clinics across Scotland per Health Board  
(Children and young people up to and including 18 Years)

A&A	BOR	D&G	FIFE	FOV	GG&C	HIG	LAN	LOT	TAY	HB with <5 Pts	Grand Total
35 2.19%	13 0.81%	6 0.37%	210 13.12%	190 11.87%	80 5.00%	44 2.75%	177 11.06%	455 28.42%	383 23.92%	8 0.50%	<b>1,601</b> <b>100.00%</b>





It is estimated that the total number of patients currently on CAS represents approximately 50% of the total number of patients with recognised endocrine disorders in Scotland.

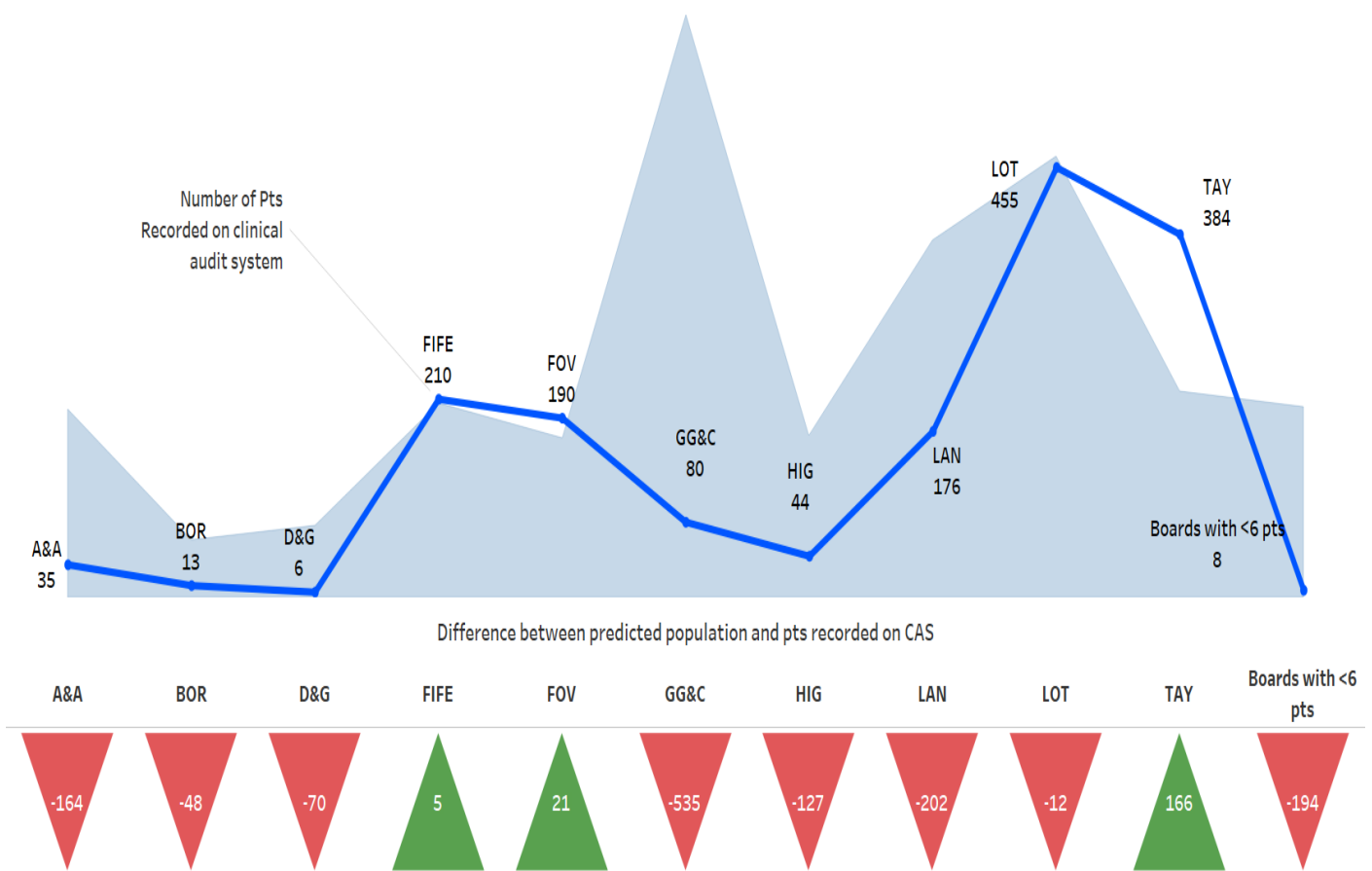
The following chart below shows the number of children and young people up to the age 18 recorded on CAS for each health board vs. average prevalence for Scotland.

The estimated prevalence figure of 3.0 per 1,000 population has been used. This was derived from combining the prevalence of the more common endocrine conditions in children. The network understands that this may not be accurate, but currently there is no agreed estimate for the total prevalence of endocrine conditions in children.

**Numbers of patients (up to 18 years of age) in Scotland seen in Endocrine clinics registered on CAS on a health board basis compared to the estimated prevalence of that age group with endocrine conditions per Health board - shown below.**

**Additional reports then follow showing a breakdown of conditions in more detail.**

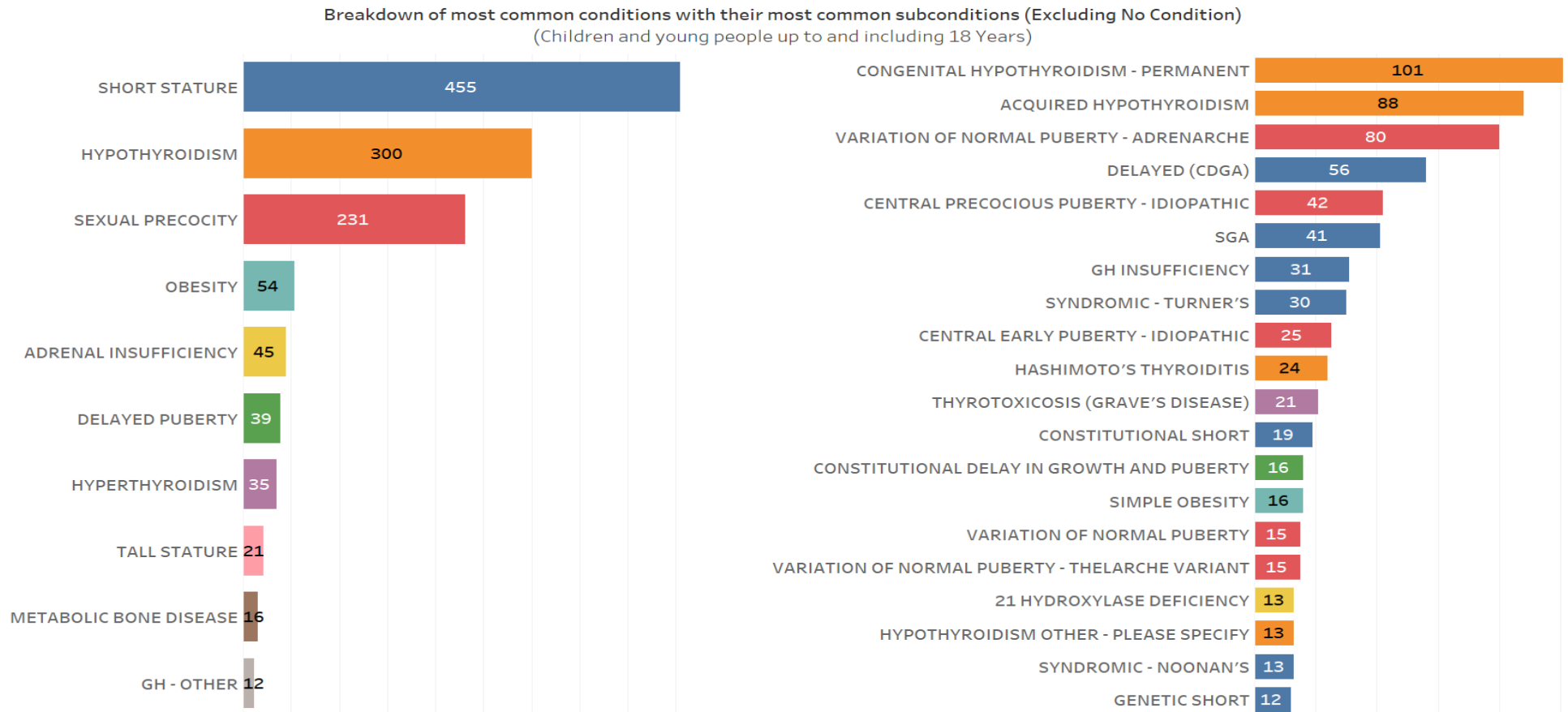
Patients recorded per resident Health Board against estimated expected patients with endocrine conditions  
(Children and young people up to and including 18 Years)



**Additional report presenting a breakdown of conditions in more detail is shown below:-**

Currently the number of patients with no condition registered against their demographics is 26.5% of have no recorded condition, work is underway to include the conditions that were not recorded on CAS and through highlight reports we will ensure all patients have a recorded condition.

The number of patients registered with a condition have been analysed to show the most common main conditions and the most common sub-conditions of the main conditions.



## **SPEG Quality Standard SS1-**

- **Review whether all children and young people with endocrine disorders had access to the local DGH endocrine team**

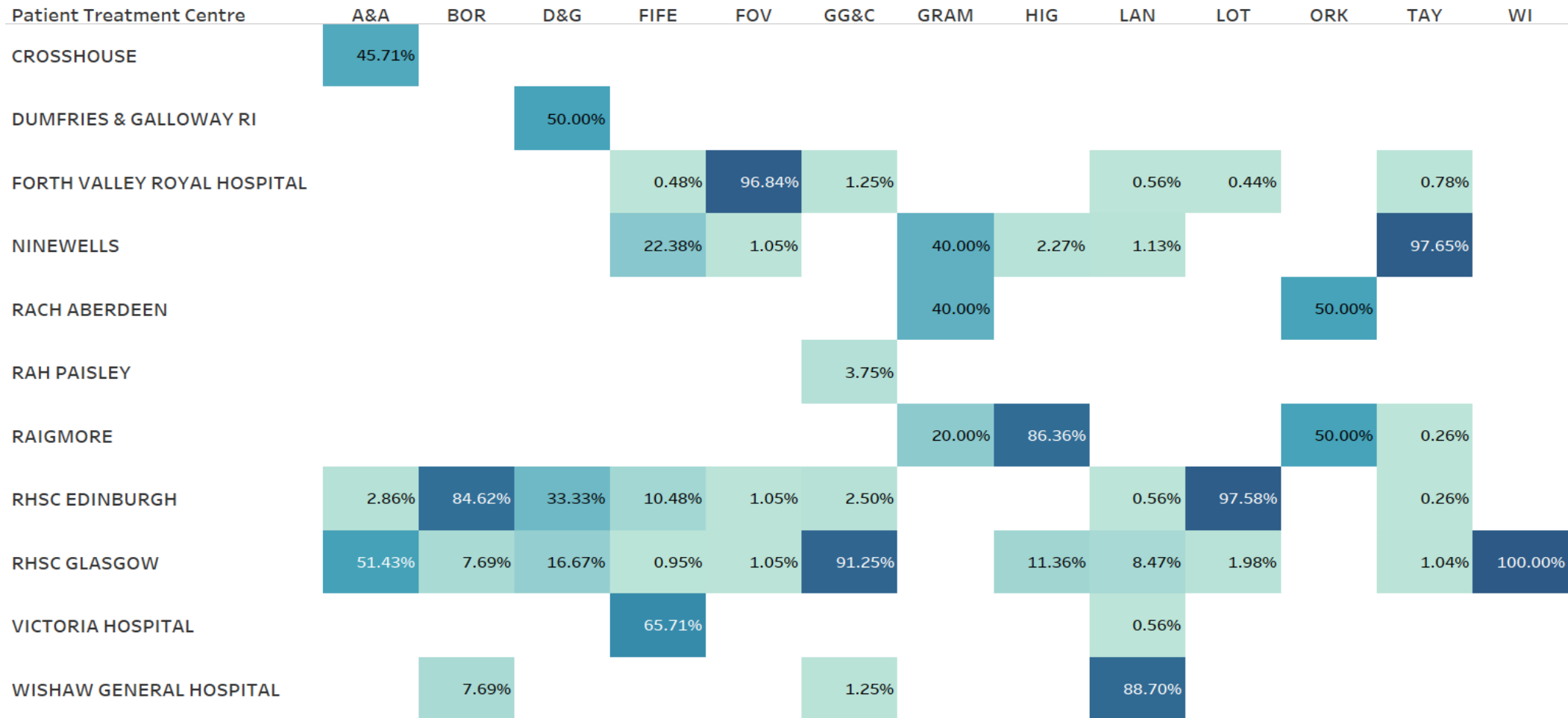
All boards across Scotland, with the exception of the island boards, have local endocrine clinics and tertiary outreach clinics which together with SPEG care pathways and guidelines are designed to ensure that optimal care is provided for all patients across Scotland either locally or at the most appropriate point of contact, whether a patient should be seen locally or continue to be seen in a tertiary centre, or a combination of centres. This is decided according to clinical needs of the patient. E.g. children who are survivors of cancer, and attend late endocrine effects clinics are generally seen in tertiary centres where other aspects of their cancer care are also provided.

The following chart illustrates where patients are seen according to their registered treatment centre on CAS.

The health board where the patient lives is along the top of the table, and the treatment centres are noted along the first column. The table shows that the majority of patients are treated locally, (e.g. over 96% of patients living in Tayside are treated in Ninewells). However, the table shows that there is significant variation in whether or not patients are treated locally or in other treatment centres, e.g. Ayrshire and Arran (A&A) and Borders. The reasons for this are being explored.

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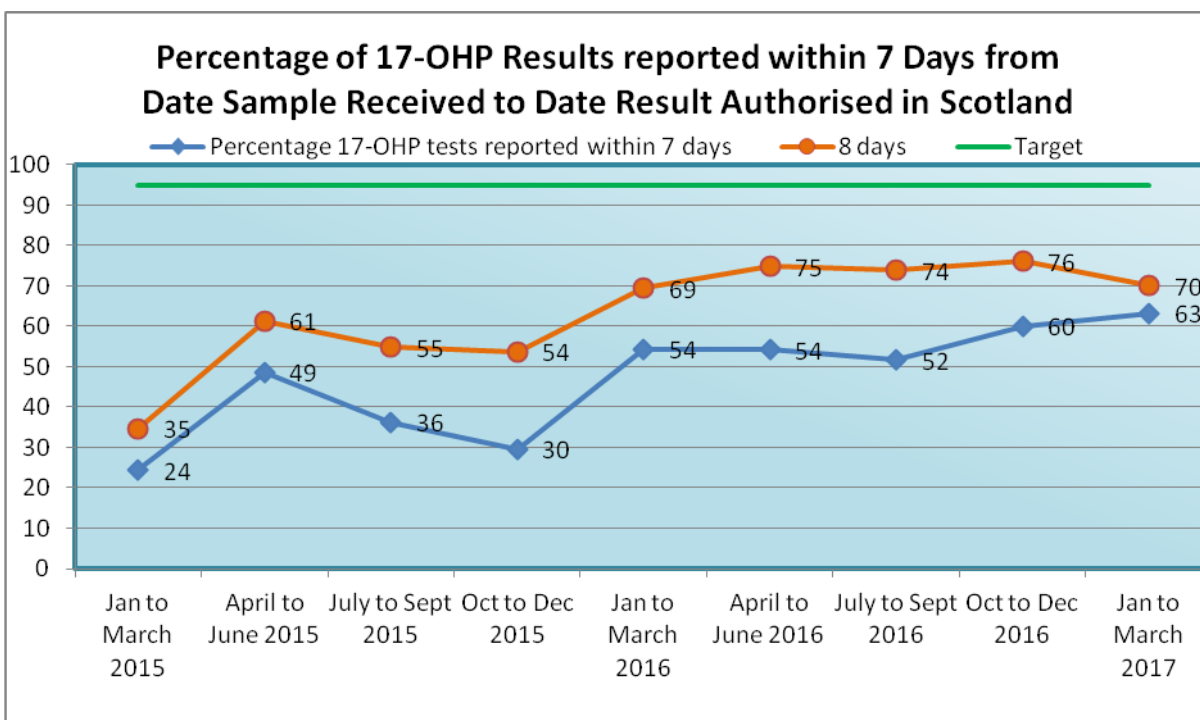
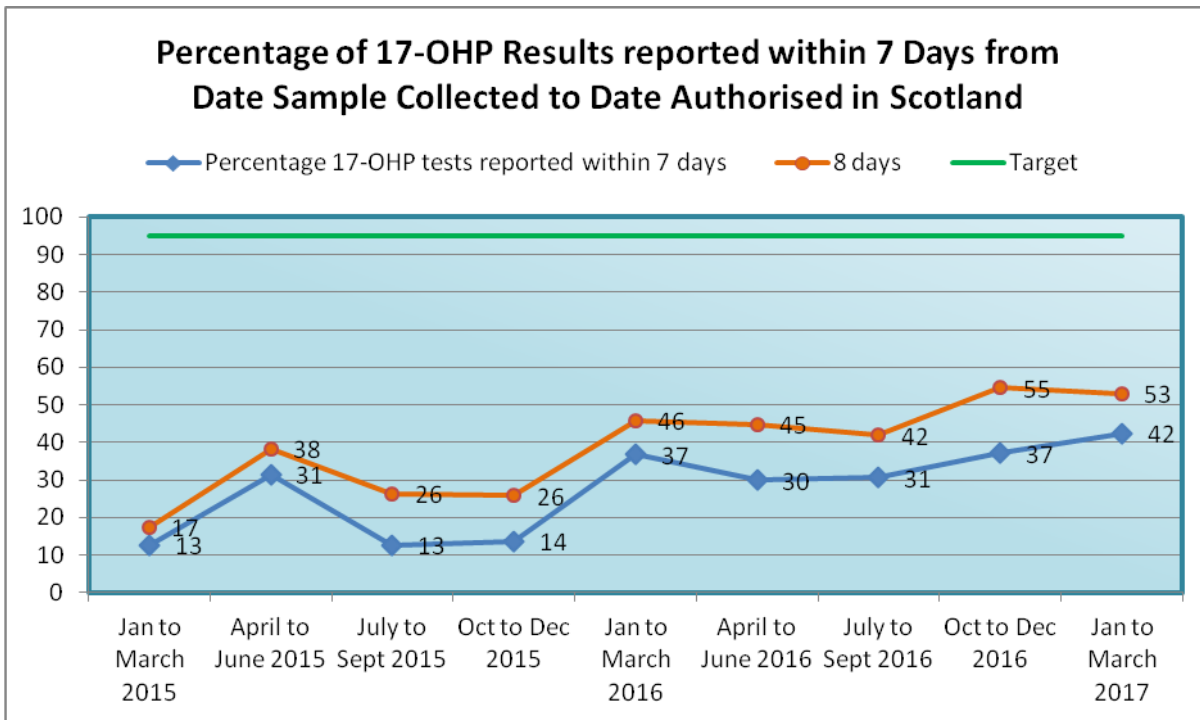
Breakdown of where patients are treated across their resident Health Board  
(Children and young people up to and including 18 Years)



**SPEG Quality Standard RR4**

- **turnaround time for reporting of 17-OHP results from central lab to local centre**

**SPEG MCN Run Charts of Turnaround times of samples collected for 17-OHP January 2015 to March 2017**



17-Hydroxyprogesterone (17-OHP) is a hormone that is measured to help diagnose and monitor treatment of Congenital Adrenal Hyperplasia (CAH) secondary to 21-Hydroxylase deficiency. This is a rare genetic disorder of the adrenal glands that can cause adrenal insufficiency and sexual ambiguity in children.

The standard is for at least 95% of results to be available within 7 days from the time the sample is collected in the local centre to being authorised at the regional lab and available to the clinical team. The charts have also shown the data for the results to be available within 8 days.

The bottom chart is the run chart for the percentage of samples that are received by the regional lab to the date they are reported.

The charts show significant improvement over time. However, the agreed target is still not being met. There appear to be several reasons for this, including the observation that there can be significant delays between sample collected and sample reported. It appears that there is significant variation in transport times from local to regional lab.

SPEG are currently considering whether it is possible to evaluate the times for urgent samples sent. They plan to feedback to the labs if they manage to obtain this information and see if it is possible to find reasons for any delays and explore if there are ways to reduce transport times.

### SPEG Quality Standard SS6.

- **Where appropriate, children with life-threatening endocrine disorders will have an emergency management plan that is shared by the family and /or carers and all health professionals.**

The network has continued to focus on ensuring that an emergency care plan (ECP) for children with adrenal insufficiency was available to all patients/parents/carers/health professionals. This work focused on improving immediate care for patients with adrenal suppression. The network continues to audit the number of paediatric patients with adrenal insufficiency in each Board and whether the families and relevant health professionals had been issued with an ECP. The plan includes ensuring that the Scottish Ambulance Service (SAS) have a record on their database of all children with adrenal insufficiency which has an alert instructing the ambulance crew to administer IM hydrocortisone to the child when they are called out in an emergency situation. Part of this project involved giving training on administering IM hydrocortisone injections to the ambulance crew. The SAS would receive this information from the endocrine clinical teams in the form of a Hazard Alert Sheet which would include all the relevant patient details. The overall objective of this project would be to administer hydrocortisone earlier to these children in an emergency situation and thus improve clinical outcomes.

Results to date are as follows:-

<b>Health Boards</b>	<b>Number of patients with Adrenal Insufficiency recorded on CAS</b>	<b>Number of these patients issued with an ECP</b>	<b>Number of these patients with Hazard Alert Sheet sent and received by SAS</b>
Fife	7	7	7
Tayside	14	14	14

Lothian	51	51	51
Grampian	47	47	47
Forth Valley	4	4	3
Highland	7	7	5
Lanarkshire	13	13	12
Ayrshire	5	5	5
Dumfries & Galloway	7	7	7
Borders	1	1	1

*NHS GGC were unable to send the network this information as they did not have the data available.*

During 2016-2017 a follow-up audit with the SAS was undertaken to ensure that the data that was sent to them was in fact recorded accurately on their database so that the desired outcome would be achieved. This involved comparing a sample of adrenal insufficiency patients from the CAS register with the SAS register of adrenal insufficiency patients.

The audit has highlighted a number of discrepancies where patients on CAS were not recorded on the SAS database. The quality of information on the SAS database was also extremely variable. The audit has highlighted that further work needs to be between SAS and SPEG to ensure that patients are accurately recorded with SAS.

### **Congenital Hypothyroid Newborn Screening**

The Newborn Bloodspot Screening Laboratory produces an annual report in relation to Congenital Hypothyroid (CHT) screening. There are various standards in relation to the management of infants who are screened positive, according to the CHT management guidelines produced by SPEG.

During the period 2016/2017 21 infants screened positive. All the infants were seen within the time agreed in the Newborn Screening Standard (NBS) and SPEG guidelines. Of the 21 who screened positive, 14 (67%) were commenced on thyroxine, 1 had transient hypothyroidism and did not need continued treatment, and in the remaining 7 (33%) there was no data available.

SPEG and the newborn screening lab are looking at ways in which the availability of outcome data can be improved

## **2. Patient Centred Care/ Family Engagement**

- A second family day focussing on 'Living with Growth Hormone Therapy' was held on Saturday, May 21<sup>st</sup> 2016. There were 33 families (over 100 people) who attended the event. This followed a successful first event held on 8th June 2014 at the same venue. Feedback from the event was positive:-
- The event provided combined education for parents/carers on various issues including dealing with GH problems, managing children on GH therapy, the different products available, and how to deal with injection issues.

- Small group discussions were held with parents, together with consultant paediatricians, clinical psychologists and paediatric endocrine nurses.
- The children were involved in various themed fun activities that combined education and confidence building from interaction and sharing feelings with other children.
- ‘Village Story Telling’ sessions identified likes and dislikes from children relating to hospitals and injections. This feedback has been passed to the relevant clinical staff in the network. This feedback highlights a need for information about growth and growth hormone.

The Network has been able to obtain information leaflets about growth hormone originally produced by one of the pharmaceutical companies, and has been able to adapt them for use by the network.

The three leaflets are now available under the SPEG banner and are accessible from the SPEG website and will be printed for distribution to all clinics in Scotland.

A summary of the evaluation from this event is below:-

Event	Attendees (families)	Evaluations returned	Good Networking with families	Were expectations met (Excellent - good)	Would attend a similar event (Yes)
2016 –	33	16	100%	100%	100%

The network recognises that two family events were held in the East of Scotland resulting in attendance being mainly from that region and will plan future events in other areas in order to increase engagement with families from other areas.

The network has tried in the past to capture the views of families as well as engage with them through use of a Patient Experience Questionnaire and distributing an updated Getting Involved Leaflet at clinics. Both of these have had limited success.

- The network will distribute cards at clinics with the link to a new Patient Experience questionnaire that is more meaningful and measurable. It has also sent the link to voluntary groups to reach families.
- Work continues to develop a family support working group who will feed into the steering group through the formal governance structure. The patient representative on the steering group has agreed to lead this working group.
- Through links on the website family section SPEG signposts to a number of charities /voluntary groups who offer support for families and patients with endocrine conditions. The network is seeking a reciprocal arrangement with those organisations to raise awareness of the SPEG MCN and improve engagement with the voluntary sector. It already has two



charities who have agreed to place the link on their own websites and they have been sent the link.

- Two patient information leaflets continue to be audited to identify how useful they are. They are “Adrenal Insufficiency-a guide for school nurses and teachers” and “Adrenarche-a guide for parents and carers”. Feedback from 6 patient information leaflets has been gathered. The leaflet: “Adrenarche –a guide for parents and carers” was evaluated by sending questionnaires to school nurses. There has been little response from the questionnaire relating to school nurses. Following this, a new approach has been used to attempt to improve engagement with this health care group. The questionnaire has been made into a lime survey questionnaire and sample schools have been contacted and given the link to complete the questionnaire.

### **3. Professional Education**

Education remains a priority for the network. The Education sub-group chaired by Dr John Schulga developed an Education Strategy in 2014-2015 based on the results of a Learning Needs Analysis (LNA) carried out during 2012.

#### **Education delivered during 2016-2017 included:-**

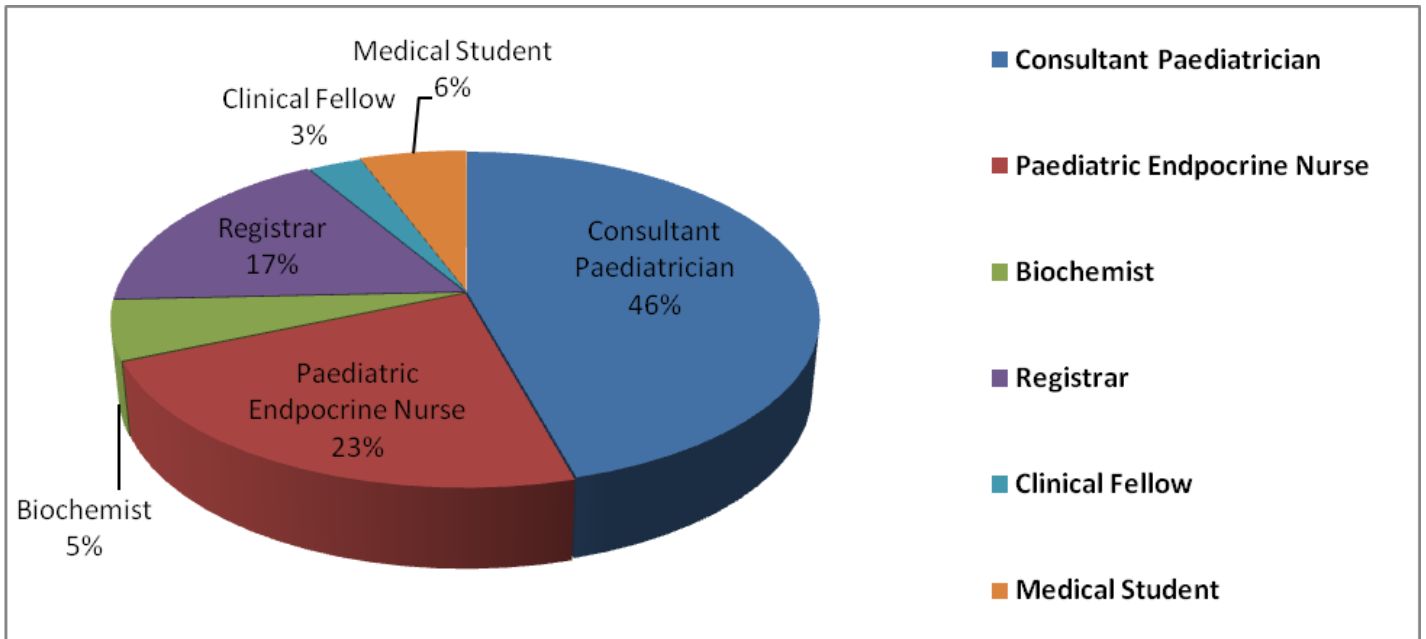
A National Endocrine Study Day organised and held on May 26<sup>th</sup> 2016. This followed previous successful study days held in 2011 and 2013. This event was aimed at general paediatricians and primary care and is part of a 5 year rolling programme to cover common endocrine conditions identified in the LNA. An evaluation was completed. 38 delegates attended with a wide representation across Scotland from both secondary and primary care. Feedback from the event demonstrated that it was an overall success. It focused on two areas of paediatric endocrinology: pituitary disorders and adrenal disorders. 92% of delegates found the presentations and discussions on the former relevant to their training needs with 94% stating that they also increased their knowledge on this topic. With regards to adrenal disorders, 95% of delegates found the teaching relevant to their training needs with 94% stating that it increased their knowledge. In addition, delegates reported a good choice of topics and good interactive presentations as particular highlights. The suggestions made for future topics will be considered for the next education day.

Two Regional Clinical Meetings have also taken place in the West of Scotland, which aimed to provide education locally to clinicians involved in delivering paediatric endocrine services. These events are organised and hosted locally and supported by the tertiary paediatric endocrinologists. It is expected that all centres within a region will attend these sessions. The sessions focus on clinical care of patients with endocrine conditions, and involve case discussion, as well as discussions around guideline implementation. Clinicians in Lothian have reported that they currently provide this education at lunchtime when they do their joint outreach clinics. They currently provide these to Highland, Tayside, Fife, Borders and Dumfries and Galloway.

An Annual Scientific Meeting, directed towards clinicians working in endocrinology was organised and successfully held. This regularly attracts 60-70 delegates that include the wider network membership; representatives from Biochemistry, Radiology, Genetics, Orthopaedics as well as General Paediatricians, Endocrinologists and Nurses involved in the care of endocrine patients. The aims of this event are to provide education about current paediatric endocrinology practice, recent advances and research. It also gives clinicians and paediatricians in training an opportunity to present audit projects and interesting cases.

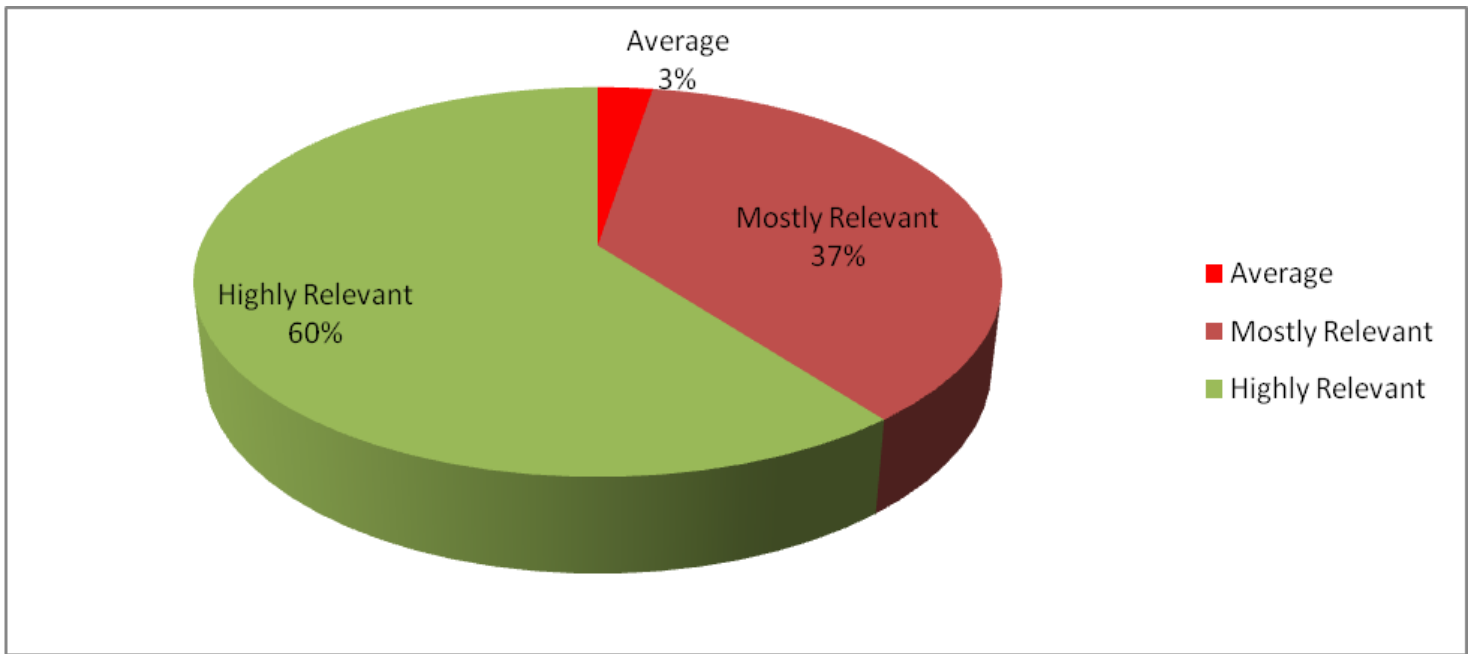
Summary of Feedback from Annual Scientific Meeting 2017

The event was attended by 59 people, 38 feedback forms were completed (68%). The feedback received was split into the professional groups below.

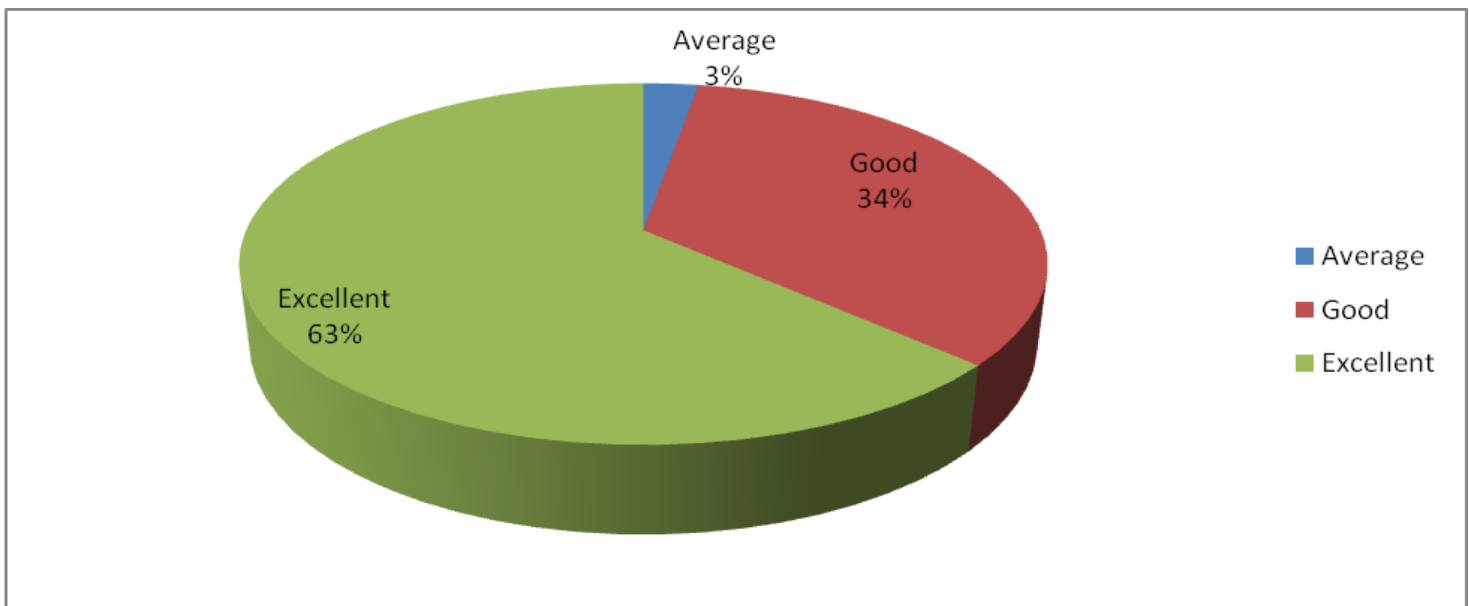


The relevance of this CPD activity to the delegate’s current practice and the overall quality of education were thought to be of a high standard with each of these being rated in the top two fields as evidenced in the charts below.

Relevance to Clinical Practice



Overall Quality of Education offered



95% of attendees deemed the learning aims/objectives to be met with only 3% feeling that they were only partially met. All responders (100%) felt the event met their expectations. A number of comments reflected on how relevant the event was this year.

There was a good mix of different disciplines with the majority (85%) feeling that there was no bias or conflict of interest evident in the course.

There were two clinical and academic meetings (CAM) throughout the year, which were also well attended. Videoconferencing facilities were available for these meetings. The CAM is a more informal meeting aimed at health professionals with an interest in paediatric endocrinology. Discussions related to guideline development, research projects and updates in endocrine care are presented and discussed.

### **Education for Nurses**

A Nurses LNA was undertaken in 2015. It included responses from community, neonatal, school, general paediatric nurses in District Generals, as well as nurses with an interest in Paediatric Endocrinology. There were over 100 responses, 62% of whom had no endocrine training. In the remainder of those who had undergone training, the training had taken place more than five years previously. The findings were used to inform an education strategy for nurses that is currently being developed. This will be completed in 2017.

### **LearnPro Module on Growth and Puberty Assessment**

A learnpro module has been developed by three members of SPEG (John Schulga, Guftar Shaikh, and Barbara Wardhaugh). This is based on the materials that were developed for a growth and maturation workshop produced in 2014.

The LearnPro module is almost complete, having taken a year to produce.

The aim is that this will be available to all health professionals in Scotland who provide care for children. It aims to provide basic training in growth and puberty assessment.

It is anticipated that this will be available in 2017

## **4. Guidelines-Effective care**

The SPEG protocols sub group have developed new guidelines; have a number that are in the development stage, and number of guidelines being reviewed.

### **Completed Guideline**

- Septo-optic dysplasia-in collaboration with VINCYP

### **Draft Guidelines awaiting completion**

- Neonatal Thyrotoxicosis
- Vitamin D
- Hypoglycaemia-acute management at presentation-in collaboration with Inherited Metabolic Diseases

### **Guidelines currently under review**

- Management of Congenital Hypothyroidism

- Management of Adrenal Crisis
- Dynamic Function Testing Handbook

The network has developed a formalised Guideline Process. This provides guidance for producing, reviewing finalising and approving guidelines for paediatric endocrinology. The network has also developed a 'Guideline Process Tracker' document which ensures that guidelines are produced within agreed timelines. The aim of the tracker is for the network management team to support the process of producing guidelines in a more timely way.

The network continues to look for ways to successfully audit the use of guidelines across Scotland. This so far has proved to be challenging. The network is planning to develop a formal communication and engagement strategy during 2017/2018 which will include engaging with health professionals across Scotland and auditing their views and use of these guidelines.

## **Network Review**

SPEG has undergone its first Network Review during 2016-2017. It is a requirement of Scottish Government Health & Social Care Directorate (SGHSCD) national commissioning processes for all NMCNs to be reviewed every three to five years to ensure they meet the criteria for national commissioning. This review provides an objective assessment of the extent to which SPEG continues to deliver against the agreed network objectives, meets the needs of its stakeholders, adds value including initiating improvements in patient care, and is committed to continuous development and quality improvement.

The review was conducted using standard NSD service review methodology which involved the establishment of an Expert Review Group (ERG) to review and appraise the evidence collected by SPEG against each of the networks designation objectives and the core principals of NMCN's. The ERG then produced recommendations on the future status of the network and its priorities.

The views of stakeholders were gathered through a survey and a Strategic Planning Day was held in January 2017 to provide stakeholders with the opportunity to appraise the evidence gathered for the Review, and to influence the future strategic direction of the network.

A final report was then produced, reviewed and signed-off by the ERG. The report has been submitted to the Senior Management Team (SMT) at NSD for final review and will be considered by the National Specialist Services Committee (NSSC) when it meets on June 12<sup>th</sup> 2017 for approval.

## **Plans for the year ahead**

The Network has identified a number of priority areas for 2017/18

- Agree objectives following the conclusion of the Network review in June 2017
- Complete the LearnPro package for basic growth and puberty assessment, which is hoped, will be made available to all health professionals in Scotland, from Primary care to Tertiary care in 2017.
- Continue to develop relevant clinical guidelines, and to review completed guidelines due for review.

- Aim to improve patient and carer participation in the network, and to capture service user feedback in a meaningful and measurable way.
- Work to increase the number of patients held within CAS and the quality of the patient records.
- Improve the system of registering patients with adrenal insufficiency with the SAS, to ensure it is robust and safe.
- Finalise a Nurses Education Strategy for Nurses who see children with endocrine conditions in Scotland
- Review the SPEG Education Strategy.
- Continued family engagement, finding more efficient ways of engagement.
- Continued organisation of family days, targeting specific patient groups such as children with adrenal insufficiency.
- Maintain and update the SPEG service directory, and ensure this is used as a tool for benchmarking for regional planning groups and health boards.
- Audit the use and usefulness of SPEG documents; protocols and guidelines and patient information leaflets
- Review and refine the network quality indicators to ensure they measure what is important and can drive improvement.

## **Network governance**

The network is overseen by a multidisciplinary steering group. The purpose of the SPEG Steering Group is to support and steer the development of the network and ensure that progress continues against the agreed workplan throughout the year.

The Steering Group meets three times each year and is chaired by Dr Chris Kelly, Consultant Endocrinologist from NHS Forth Valley. Steering Group members also have a key role to play in ensuring effective two way communication between the Network and the local teams of clinicians. Through the management structure and terms of reference for the network Steering Group and sub-groups, SPEG meets the core principles of managed clinical networks as set out in CEL (2012) 29. Workplans and reports are published on the network website, and any documents produced by the network are publically available for clinicians and patients to view.

## Detailed Description of Progress over Reporting Period

### SCOTTISH PEDIATRIC ENDOCRINE GROUP

#### MANAGED CLINICAL NETWORK WORKPLAN 2016-2017

### Workplan – Scottish Paediatric Endocrine Group

Please develop and update the table below to include the network’s designation objectives and related agreed annual objectives. When planning for the year ahead, please consider the standard statements in the guidance section to inform the development of annual network objectives.

#### RAG status key

RAG status	Description
<b>RED (R)</b>	The network is unlikely to achieve the objective/standard within the agreed timescale
<b>AMBER (A)</b>	There is a risk that the network will not achieve the objective/standard within the agreed timescale, however progress has been made
<b>GREEN (G)</b>	The network is on track to achieve the objective/standard within the agreed timescale
<b>BLUE (B)</b>	The network has been successful in achieving the network objective/standard to plan

The Institute of Medicine’s six dimensions of quality are central to NHS Scotland’s approach to systems-based healthcare quality improvement; therefore objectives should be linked to these dimensions:

- 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.

## 2016/2017 Workplan – Scottish Paediatric Endocrine Group

Objective Number	SMART Objective	Linked Dimension s of Quality	Planned start/ end dates	Detailed Plan Available / Owner	Description of progress towards meeting objective as at 31/03/2017	Anticipated Outcome	RAGB status
SPEG-2016-01	<p>Deliver equitable care as close to home as possible:-</p> <p>Develop and place on the SPEG website standardised guidelines</p> <p>All centres to have tertiary outreach clinics provided locally</p>	2,3,4,5,6	01/05/2016 – 31/03/2017	Yes / <b>Protocols Sub Group</b>	<p>All centres now have tertiary outreach clinics provided locally</p> <p>Guidelines completed , endorsed by steering group and placed on website;-</p> <p>Septo-optic dysplasia (in collaboration with VINCYP MCN)</p> <p>Some guidelines are currently in draft, though almost complete:-</p> <p>Hypoglycaemia</p> <p>Neonatal Thyrotoxicosis</p> <p>Vitamin D</p> <p>Guidelines reviewed and updated:-</p> <p>Congenital Hypothyroidism</p> <p>Dynamic Function</p>	Promoting equity of care across Scotland and ensuring endocrine patients are treated according to the latest evidence based practice.	<b>G</b>



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Objective Number	SMART Objective	Linked Dimension s of Quality	Planned start/ end dates	Detailed Plan Available / Owner	Description of progress towards meeting objective as at 31/03/2017	Anticipated Outcome	RAGB status
					handbook  Other developments:- Guideline process and guideline tracker documents now developed and completed and placed on SPEG website.		
SPEG-2016-02	Measure QI's to support continuous quality improvement (CQI)	3,4,5,6	01/04/2016 – 31/03/2017	Yes <b>/QI Sub Group /Nurses Sub Group/Network Office</b>	4 QI's continue to be measured.  A report on Congenital Hypothyroidism newborn screening results has been produced by the SPEG network based on information received by the Scottish Bloodspot Screening Laboratory.  Others agreed:- Measurement of guidelines used by clinicians  No of clinicians	Evidence provided of Continuous Quality Improvement.	<b>A</b>

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Objective Number	SMART Objective	Linked Dimension s of Quality	Planned start/ end dates	Detailed Plan Available / Owner	Description of progress towards meeting objective as at 31/03/2017	Anticipated Outcome	RAGB status
					education events attended by clinicians with an interest in endocrinology		
SPEG-2016-03	<p>Continued Implementation of the SPEG Education Strategy:-</p> <p>An annual national education day and annual scientific meeting.</p> <p>2 Clinical and Academic Meetings</p> <p>Development of learnpro modules on growth and maturation training for primary and secondary care clinicians.</p> <p>Regional Education Sessions to be held twice a year in each region, hosted by local teams in rotation</p> <p>Development of education</p>	2,3,5	01/04/2016 – 31/03/2017	Yes <b>/Education Sub-group</b>	<p>Successful Events held:-</p> <p>Annual education event held May 2016 – feedback from meeting available</p> <p>Annual Scientific Event Jan 2017-feedback from meeting in body of report</p> <p>CAM's held April and Sept 2016</p> <p>Work progressed on learn-pro package</p> <p>2 Regional Education Sessions held</p> <p>Nurses LNA completed and analysed –draft education strategy developed</p>	Staff delivering endocrine services has increased skills and knowledge.	<b>G</b>

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Objective Number	SMART Objective	Linked Dimensions of Quality	Planned start/end dates	Detailed Plan Available / Owner	Description of progress towards meeting objective as at 31/03/2017	Anticipated Outcome	RAGB status
	programme for nurses.						
SPEG-2016-04	<p>Further develop communications strategy:-</p> <p>Involve families/ support groups/ other stakeholders in the network through:-</p> <p>Re-issue of getting involved leaflet</p> <p>Development of family support group</p> <p>Hosting a family day.</p> <p>Explore the use of the patient opinion website.</p>	1,2	01/04/2016 – 31/03/2017	Yes <b>/Family Support sub-group/Nurses Sub-Group</b>	<p>Leaflet reissued</p> <p>Successful Family Event held in May 2016-evaluation available</p>	<p>Improved stakeholder engagement, reflecting their needs in service decision making.</p> <p>Providing information to patients/parents/carers on their conditions.</p>	<b>A</b>

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Objective Number	SMART Objective	Linked Dimension s of Quality	Planned start/ end dates	Detailed Plan Available / Owner	Description of progress towards meeting objective as at 31/03/2017	Anticipated Outcome	RAGB status
	<p>Ongoing development of website and relaunch of newsletter.</p> <p>Continue to develop patient information leaflets and audit impact of 2 existing leaflets</p>				<p>Website relaunched in Wordpress-feedback from network members favourable-will continue to be developed</p> <p>Patient information leaflets continue to be audited</p>		
SPEG-2016-05	Benchmarking- update and maintain Service Directory annually.		01/04/2016 – 31/03/2017	Yes / <b>John Schulga/Hugh Kennedy</b>	This has not been progressed and is planned for 2017-2018	Providing equitable care that does not vary in quality because of personal characteristics such as gender, ethnicity, geographic location or economic status	<b>R</b>

## SCOTTISH PEDIATRIC ENDOCRINE GROUP

### MANAGED CLINICAL NETWORK DRAFT WORKPLAN 2017-2018

#### Workplan – Scottish Paediatric Endocrine Group

Please develop and update the table below to include the network’s designation objectives and related agreed annual objectives. When planning for the year ahead, please consider the standard statements in the guidance section to inform the development of annual network objectives.

##### RAG status key

RAG status	Description
RED (R)	The network is unlikely to achieve the objective/standard within the agreed timescale
AMBER (A)	There is a risk that the network will not achieve the objective/standard within the agreed timescale, however progress has been made
GREEN (G)	The network is on track to achieve the objective/standard within the agreed timescale
BLUE (B)	The network has been successful in achieving the network objective/standard to plan

The Institute of Medicine’s six dimensions of quality are central to NHS Scotland’s approach to systems-based healthcare quality improvement; therefore objectives should be linked to these dimensions:

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.

## 2017/2018 Workplan – Scottish Paediatric Endocrine Group

Objective Number	SMART Objective	Linked Dimensions of Quality	Planned start/ end dates	Detailed Plan Available / Owner	Description of progress towards meeting objective as at 31/03/2017	Anticipated Outcome	RAGB status
SPEG-2017-01 (a)	Develop and place on the SPEG website the following :-  New guidelines:-  Neonatal Thyrotoxicosis; Hypoglycaemia; Vitamin D  Review of existing guidelines:-  Congenital Hypothyroidism; Adrenal Crisis for Sick Children	2,3,4,5,6	01/05/2017 – 31/03/2018	Yes / <b>Protocols Sub Group</b>	Guidelines currently in draft:-  Congenital Hypothyroidism  Neonatal Thyrotoxicosis  Hypoglycaemia  Vitamin D	Promoting equity of care as close to home as possible across Scotland	<b>G</b>
2017-01 (b)	Audit usefulness of SPEG protocols and guidelines	2,3,4,5,6	01/05/2017 – 31/03/2018	Yes / <b>Protocols Sub Group</b>	Initial audit carried out – plan to progress	Ensuring endocrine patients are treated according to the latest evidence based practice.	<b>A</b>
SPEG-2017-02 (a)	Continue to measure 4 existing QI's in addition to reporting on Congenital Hypothyroidism newborn screening results based on information received by the Scottish Bloodspot Screening Laboratory.	3,4,5,6	01/04/2017 – 31/03/2018	Yes / <b>QI Sub Group /Network Office</b>	4 QI's currently being measured	Evidence provided of Continuous Quality Improvement.	<b>G</b>

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Objective Number	SMART Objective	Linked Dimensions of Quality	Planned start/ end dates	Detailed Plan Available / Owner	Description of progress towards meeting objective as at 31/03/2017	Anticipated Outcome	RAGB status
SPEG-2017-02 (b)	Improve the system of registering patients with adrenal insufficiency with the SAS-aim to have all adrenal insufficiency patients across Scotland with both Emergency Care Plan and registered on SAS	3,4,5,6	01/04/2017 – 31/03/2018	Yes /QI Sub Group /Nurses Sub Group/Network Office	Initial work to identify gaps in SAS database has already taken place. Further meeting planned for May 2017 to progress	Ensure system is robust and safe for patients	A
SPEG-2017-02 (c)	Review and refine the network quality indicators	3,4,5,6	01/04/2017 – 31/03/2018	Yes /QI Sub Group Group/Network Office		Ensure they measure what is important and can drive improvement.	A
SPEG-2017-03 (a)	Review the SPEG Education Strategy:-	2,3,5	01/04/2017 – 31/03/2018	Yes /Education Sub-group		Ensure education is continually delivered to right people in efficient and effective way.	G
SPEG-2017-03 (b)	An annual national education day and annual scientific meeting.	2,3,5	01/04/2017 – 31/03/2018	Yes /Education Sub-group	Annual education event planned January 2018	Staff delivering endocrine services has increased skills and knowledge.	G

Scottish Paediatric Endocrine Group (SPEG) National Managed Clinical Network: Annual report 2016/17

Objective Number	SMART Objective	Linked Dimensions of Quality	Planned start/ end dates	Detailed Plan Available / Owner	Description of progress towards meeting objective as at 31/03/2017	Anticipated Outcome	RAGB status
SPEG-2017-03 (c)	2 Clinical and Academic Meetings	2,3,5	01/04/2017 – 31/03/2018	Yes <b>/Education Sub-group</b>	West of Scotland has held 2 Regional Sessions to date.	Staff delivering endocrine services has increased skills and knowledge.	<b>G</b>
SPEG-2017-03 (d)	Complete the LearnPro package for basic growth and puberty assessment  Plan is for education to be made available to all health professionals in Scotland, from Primary care to Tertiary care.	2,3,5	01/04/2017 – 31/03/2018	Yes <b>/Education Sub-group</b>	Learn Pro package almost complete	Increased skills and knowledge of endocrine conditions to primary and secondary care	<b>A</b>
SPEG-2017-03 (e)	Finalise Nurses Education Strategy and place on SPEG website	2,3,5	01/04/2017 – 31/03/2018	Yes <b>/Education Sub-group/Nurses Sub Group</b>	Draft Education Strategy completed	Increased skills and knowledge of endocrine conditions for nurses across tertiary, secondary and primary care	<b>A</b>
2017-04 (a)	Develop and implement formal communications and engagement strategy	1, 2, 3, 4, 5, 6	01/04/2017 – 31/03/2018	Yes <b>/Network Manager /Steering</b>		Improved stakeholder engagement: better understanding of needs of stakeholders	<b>A</b>



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Objective Number	SMART Objective	Linked Dimensions of Quality	Planned start/ end dates	Detailed Plan Available / Owner	Description of progress towards meeting objective as at 31/03/2017	Anticipated Outcome	RAGB status
				<b>Group</b>			
2017-04 (b)	Roll out patient/carer experience questionnaires across all paediatric clinics to capture service user feedback in a meaningful and measurable way	1, 2, 5, 6	01/04/2017 – 31/03/2018	Yes <b>/Network Manager /</b>	Feedback questionnaires on services /getting involved already distributed electronically to clinics for circulation to families.	Clear understanding of patient/family priorities for service improvement/ development	<b>G</b>
2017-04 (c)	Establish a family support group,	1,2	01/04/2017 – 31/03/2018	Yes <b>/Network Manager /Family Support Group</b>	Initial approaches made	Improve patient and carer participation in the network,	<b>A</b>
2017-04 (d)	Hold adrenal insufficiency family event	1,2	01/04/2017 – 31/03/2018	Yes <b>/Network Manager /Family Event sub-</b>		Increased engagement with patients and carers and better understanding of their priorities to address in future	<b>A</b>

Scottish Paediatric Endocrine Group (SPEG) National Managed Clinical Network: Annual report 2016/17

Objective Number	SMART Objective	Linked Dimensions of Quality	Planned start/ end dates	Detailed Plan Available / Owner	Description of progress towards meeting objective as at 31/03/2017	Anticipated Outcome	RAGB status
				group			
2017-04 (e)	Continued development of SPEG website largely based on stakeholder feedback	1,3,4,5	01/04/2017 – 31/03/2018	Yes  /Network Manager /QI IT sub-group	New wordpress platform launched with feedback mechanism in place	Raise awareness of network , improved stakeholder engagement and patient support and self management	G
2017-04 (f)	Audit of 2 SPEG information leaflets:-  Adrenal Insufficiency-information for school nurses and teachers  Adrenarche-information for parents/carers	1,2,5,6	01/04/2017 – 31/03/2018	Yes  /Network Manager /QI IT sub-group	Relaunch of audit after unsuccessful previous attempts, using different methodology	Ensure information provided to stakeholders is relevant and captures what is important to them	A
2017-04 (g)	Relaunch of SPEG newsletter	1,2,5,6	01/04/2017 – 31/03/2018	Yes  /Network Manager /QI IT sub-group		Improve stakeholder engagement	A

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SPEG-2017-05	<p>Benchmarking- update and maintain Service Directory annually.</p> <p>Plan and implement new round of site visits to update service directory.</p>		01/04/2017 – 31/03/2018	<p>Yes</p> <p><b>/John Schulga/Network Manager</b></p>		<p>Providing equitable care that does not vary in quality because of personal characteristics such as gender, ethnicity, geographic location or economic status</p>	<b>A</b>
SPEG-2017-06	<p>Support the NSD review of the network / develop strategic plans for the development of the network in the future based on recommendations from the review.</p>	1, 2, 3, 4, 5, 6	July 2017	<p>Yes</p> <p><b>/Network Manager /Steering group</b></p>		<p>Ascertain network performance and refresh network strategic aims and objectives</p>	<b>A</b>

## Appendix 1: Network membership

### Scottish Paediatric Endocrine Group (SPEG)-Steering Group

Name	Designation	Health Board Area
Dr Christopher Kelly (Chair)	Consultant Adult Endocrinologist	Forth Valley
Dr John Schulga (Lead Clinician)	Consultant Paediatrician	Forth Valley
Dr Guftar Shaikh	Consultant Paediatric Endocrinologist	Greater Glasgow & Clyde
Dr Paula Midgley	Consultant Neonatologist	Lothian
Dr Louise Bath	Consultant Paediatric Endocrinologist	Lothian
Dr Rohanna Wright	Consultant Paediatric Endocrinologist	Lothian
Dr Jane McNeilly	Consultant Biochemist	Greater Glasgow & Clyde
Dr Amalia Mayo	Consultant Paediatrician	Grampian
Dr Nick Conway	Consultant Paediatrician	Tayside
Dr Victoria Franklin	Consultant Paediatrician	Highland
Dr Anthony Tasker	Consultant Paediatrician	Fife
Dr Ian Hunter	Consultant Paediatrician	Lanarkshire
Dr Scott Williamson	Consultant Paediatrician	Ayrshire
Dr Loveline Ayuk	Consultant Paediatrician	Dumfries and Galloway
Dr Graeme Eunson	Consultant Paediatrician	Borders
Barbara Wardhaugh	Paediatric Endocrine Nurse Specialist	Lothian
Michael Browne	Paediatric Endocrine Nurse Specialist	Greater Glasgow & Clyde
Jacque Reid	Paediatric Endocrine Nurse Specialist	Grampian

Jill Gibb	Paediatric Endocrine Nurse Specialist	Tayside
Daniel Purton	Paediatric Endocrine Nurse	Lanarkshire
Angela Toruntay	Paediatric Endocrine Nurse	Fife
Anne Rock	Paediatric Endocrine Nurse	Ayrshire
Emily Gate	Paediatric Endocrine Nurse Specialist	Highland
Julie Lucas	Paediatric Endocrine Nurse Specialist	Forth Valley
Jill Lindsay	Paediatric Endocrine Nurse	Dumfries and Galloway
Ruth Magowan	Paediatric Endocrine Nurse	Borders
Arlene Smyth	Family support group representative	
Alison Kilgour	Patient and carer representative	
Hugh Kennedy	Network Manager	National Services Division
Kirsty Young	Programme Support Officer	National Services Division

## **Appendix 2: Finance**

### **Financial Report**

The annual budget for SPEG expenditure (not including staffing costs) is £5,000. Spending against this budget for 2016/17 was £7,120, resulting in an overspend of £2,120. The overspend in the budget for this year was due to the expenditure of over £5,000 from the networks Family Event held at Edinburgh Zoo in May 2016. The intention was to pay the full costs of this event from the network endowment account but unfortunately only 50% of the costs were allocated to this account. This anomaly was reported to NSS Finance Dept who advised that the network leave the full spend against NSS.