

# Scottish Paediatric Endocrine Group (SPEG) Clinical Network ANNUAL REPORT 2017/18

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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 2017-March 2018 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 delievery of education and training at National, Regional and Local levels.
- Successful development and launch of on-line learning module through the Learnpro platform.
- Continued increase in the usage of the Endocrine Clinical Audit System with more meaningful data now being displayed using Tableau software.
- 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. This includes
  the development of a website forum to aid communication.. 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.
- Capture of feedback from families regarding patient experiences at clinic and from families/educational organisations regarding two patient information leaflets.
- The Network contributed to a review following the national commissioning process from which it
  was concluded that the network added value to healthcare in Scotland and should continue to be
  designated as a national network.
- Development of a draft 3-5 year strategic work plan based on the recommendations from the recent network review.

#### Network Plans for 2018/19:

Endorsement and implementation of 3-5 year strategic plan to take the network forward based on the recommendations from the recently completed network review, including:

Development, endorsement and implementation of a formal Communication Strategy as part of one
of the main recommendations from the review. This will mainly focus on engagement from a wider
cohort of stakeholders from primary care, regional planning, board managers, education, voluntary
groups as well as families. The network will also continue to develop communication tools to
support communication strategy including-website, newsletter, membership directory and service
map.

- Development of a Patient Engagement Strategy
- Continue to develop guidelines to include: review/update of existing guidelines; methodology on prioritising new guidelines; raising awareness of SPEG guidelines and audit of awareness and use.
- Review/update of existing patient information leaflets, develop new leaflets to compliment current guidelines, and continue to audit usefulness.
- Work with the Scottish Ambulance Service to improve the alert system for all children with adrenal insufficiency.
- Continued implementation of revised education strategy- targeting clinicians who treat patients at
  each stage of their care pathway, particularly in primary care, as well as development and
  implementation of a Nurse Education Strategy for nurses who see children with endocrine
  conditions in Scotland.
- Implement new patient consent procedure for CAS in line with new General Data Protection Regulation.
- Review and refine minimum dataset on CAS and the network quality indicators to ensure that
  measuring them will provide useful measures of service delivery and can result in quality
  improvement. This will include the review of the SPEG Clinical Network Standards document of
  2014. Initial project will focus on audit of Ql's developed from adrenal insuffciency standards.
- Implementation of the Transition Strategy

#### 1. Introduction

Paediatric endocrinology is a specialty of children's medicine (paediatrics), caring for babies, children and adolescents with growth, puberty, sexual development problems and other disorders of the hormone producing glands of the body. These include thyroid and adrenal gland problems, early and late puberty, and growth hormone deficiency.

There is a significant overlap between conditions managed by general paediatricians and by paediatric endocrinologist, particularly around normal variations and common disorders of growth and pubertal development. Many of these conditions can be managed by a general paediatrician with an interest in paediatric endocrinology. At the other end of the spectrum, many endocrine conditions in children are classified as rare disorders. 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. 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 (RACH), Royal Hospital for Children (RHC), Glasgow and the Royal Hospital for Sick Children (RHSC), 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, Orkney and Shetland.

#### 2. Network Aims

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

 Design and ongoing development of an effective Network structure that is organised, resourced and governed to meet requirements in relation to SGHSCD Guidance on MCNs (currently CEL (2012) 29) and national commissioning performance management and reporting arrangements;

- 2. Support the development, design and delivery of services that are evidence based and aligned with current strategic and local and regional NHS planning and service priorities.
- 3. Effective Stakeholder Communication and Engagement through design and delivery of a written strategy that ensures stakeholders from Health, Social Care, Education, the Third Sector and Service Users are involved in the Network and explicitly in the design and delivery of service models and improvements.
- 4. Improved capability and capacity in paediatric endocrine care through design and delivery of a written education strategy that reflects and meets stakeholder needs.
- 5. Effective systems and processes to facilitate and provide evidence of continuous improvement in the quality of care (CQI).
- 6. Generate better value for money in how services are delivered.
- 7. To enable timely and effective care for paediatric endocrine patients across Scotland, delivered at the most appropriate point of contact according to, nationally-agreed procedures and guidelines which are evidence-based wherever possible.

#### 3. Report against Workplan

A detailed report on progress with the agreed network workplan for 2017/18 is available on page 24 of this report. The main work priorities for 2017/18 include:

#### 3.1. Data Collection and Analysis

The following Quality Indicators (QI) have been measured:

# 3.1.1. 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 and to obtain a complete picture of service delivery in Scotland.

There are currently 2,297 patients registered on the SPEG Clinical Audit System (CAS). This number includes patients who are now over the age of 18 years and therefore might no longer be active paediatric patients. The data analysis below excludes patients over the age of 18.

Figure 1 shows a breakdown per health board of residence for the 2,098 patients that have been recorded on CAS.

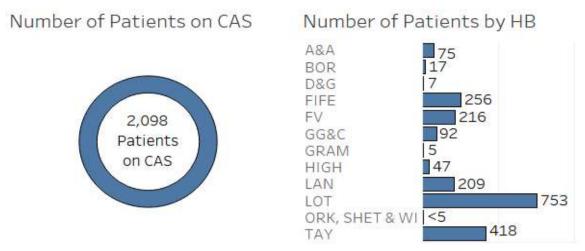


Figure 1: Total patient population on CAS (aged 0-18 years)

In the year 2017/18, 461 new patients were entered into CAS. Figure 2 shows the breakdown of new patients per health board.

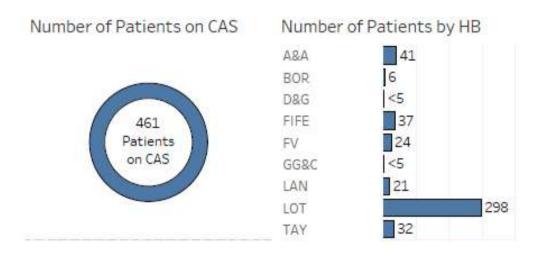


Figure 2: New Patients on CAS in 2017/18

The number of entries per health board reflects the variation in uptake of the CAS in different areas. Current challenges to data collection include staff availability to input data, the absence of an agreed national dataset and a lack of current national audit programmes in the specialty.

Figure 3 gives a breakdown of new patients by diagnosis. The majority of new patients had a diagnosis recorded but the data does highlight issues with incompleteness of CAS data as 116 records lacked information about the patient's diagnosis. The range of diagnoses is representative of the conditions seen in a typical general paediatric endocrine clinic.

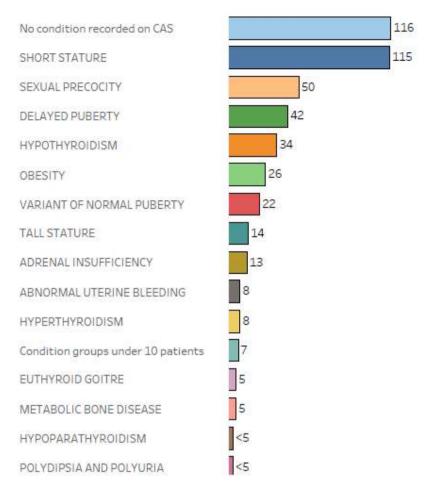


Figure 3: Condition breakdown for patients recorded in 2017/18

# 3.1.2. SPEG Quality Standard SS1: Review whether all children and young people with endocrine disorders had access to the local DGH endocrine team

Figure 4 below illustrates where patients registered in the last year were seen according to their registered treatment centre on CAS.



Figure 4: New patients by Treatment Centre

The health board where the patient lives is along horizontal axis, and the treatment centres are noted along the vertical axis. The table shows that the majority of patients are treated locally. Some of the variations might reflect patients treated in their nearest hospital in a neighbouring health board or local arrangements with visiting specialists from a tertiary centre. Due to the small numbers of new patients in some areas over the one year reporting period, there are some visible anomalies in the data, e.g. the very small number of new GGC patients who attended RHSC in Edinburgh.

# 3.1.3. SPEG Quality Standard RR4: turnaround time for reporting of 17-OHP results from central lab to local centre

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. Plasma samples collected throughout Scotland are sent to the regional laboratory at Glasgow Royal Infirmary for analysis.

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 laboratory and available to the clinical team.

Figure 5 shows the percentage of 17-OHP results reported within the 7 day target from the date the sample was collected, whilst figure 6 shows the percentage of results reported within 7 days of arriving to the regional laboratory. Both charts show significant improvement over time. However, the agreed target of 95% is still not being met. There appear to be several reasons for this, including delays between the sample being collected and recieved by the regional laboratory due to significant variation in transport times

from local to regional laboratory. There is however an agreement between laboratories that any urgent samples can be notified to the regional laboratory in order to fast track the analysis and reporting.

Percentage of 17-OHP Results reported within 7 Days from Date Sample Collected to Date Authorised in Scotland



Figure 5: Reporting of 17-OHP results

Percentage of 17-OHP Results reported within 7 Days from Date Sample Received to Date Result Authorised in Scotland



Figure 6: 17-OHP reporting

3.1.4. 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.

#### Adrenal insufficiency Scottish Ambulance Service (SAS) alerts

The network continues to focus on ensuring that an emergency care plan (ECP) for children with adrenal insufficiency was available to all patients, parents/carers and health professionals. This work follows an audit carried out previously on patients with adrenal suppression which showed the majority of treatment centres had issued this ECP to families (*N.B.: no audit data was available from NHS Greater Glasgow and Clyde*).

The overall objective of this project is to administer hydrocortisone earlier to these children in an emergency situation and thus improve clinical outcomes. The aim is for the Scottish Ambulance Service to have a

record of all children with adrenal insufficiency who have an alert instructing the ambulance crew to administer IM hydrocortisone to the child in an emergency situation.

During 2016-2017 an audit highlighted significant discrepancies in patient recording on the CAS compared to the SAS database. There is a risk that this may result in children and young people with this condition receiving inadequate care in an adrenal crisis emergency situation. The quality of information on the SAS database was also found to be extremely variable.

In 2017/18, a plan was put in place to address this. The first step was to develop a new hazard alert sheet to capture relevant data in a way that is compatible with the SAS database. This has recently been completed. During 2018/19 these forms will be issued to all endocrine sites which will capture the relevant data for these patients to reconcile the CAS and SAS registers. There are also plans to make changes to CAS to capture information on emergency management.

#### 3.1.5. Congenital Hypothyroid Newborn Screening

The Scottish Congenital Hypothyroidism (CH) database dates back to 1979 when screening for primary CH by capillary blood spot measurement of thyroid-stimulating hormone (TSH) commenced. There are currently over 1000 patients in the database. The CH guideline was the first one to be developed by the original SPEG group and guides clinicians on the investigation and management of babies identified through the Newborn Screening programme. The guideline is currently being revised to include clearer medication advice, advice on imaging and updated contact numbers. Evidence-based quality indicators for the CH Neonatal Screening programme are described in the document *Indicators for Pregnancy and Newborn Screening* (Health Improvement Scotland 2013).

The Newborn Bloodspot Screening Laboratory produces an annual report in relation to CH screening that reports on performance against these quality indicators. From a network perspective indicator 19 is of particular interest as it relates to the endocrine clinical service response to new suspected cases.

Indicator 19: Newborn bloodspot screening – timeliness of initiation of specialist care

Indicator 19 measures the timeliness of initiation of specialist care (first clinical encounter) for all screen positive babies: Proportion of babies referred for specialist care whose care is initiated within the specified timeframe for congenital hypothyroidism (on first sample) – 14 days of age. The median age for starting treatment in 2017 was 10.5 days (7-19).

Referrals [n]	Prems <37 weeks	Median Birth Weight	Median OFC	Median Age (1 <sup>st</sup> bloodspot)	Median Age (Screening)
[36]	4 [23]	3.23 (2.13-4.5) [23]	33.5 (30.6-36) [11]	5 (4-6) [36]	7 (4-13) [35]
Median	Median Age	Median	Number	Median	Median
Age	Treatment	TSH	Of 2 <sup>nd</sup>	TSH	Age
(Notified)	Started	(1 <sup>st</sup> bloodspot)	bloodspot	(2 <sup>nd</sup> bloodspot)	(2 <sup>nd</sup> bloodspot)
11	10.5	33.2	[12]	21.7	11.8
(7-25)	(7-19)	(4.29-261)		(1.03-186.59)	(5-20)
[26]	[14]	[30]		[12]	[12]

[n] = number with data

(r) = range

Figure 7: Data for 2017 showing demographics, testing, referral and treatment times for patients with an abnormal TSH identified in the neonatal screening

Bloodspot TSH range [29]		
	Minimum TSH	8.35
	Maximum TSH	>261
Venus TSH range [8]		
	Minimum TSH	9.18
	Maximum TSH	>500
Venus Free T4 [8]		
	Minimum Free T4	5.6
	Maximum Free T4	36.6
Number of days test to referral		
•	Minimum Days	0
	Maximum Days	5
Number of days from test to seen		
	Minimum Days	1
	Maximum Days	6

Figure 8: Abnormal bloodspot TSH Results (includes 1<sup>st</sup> & 2<sup>nd</sup> tests)

The data indicates that babies with CH identified by neonatal screening are tested, notified and commenced on treatment in a timely manner.

#### 3.1.6. Data Protection

The process of consenting patients for CAS has changed in line with new General Data Protection Regulation. Explicit "opt in" consent for all patients recorded on CAS, both existing and new patients, must be obtained and documented. Each existing patient will be sent a new form for completion, with patients also being targeted at clinics to encourage completion of the consent form with the aim to of yielding a higher return rate. This new legislation means that by May 2019, all new patients registered on CAS must have actively consented to their information being held on this system.

#### 3.2. Patient Centred Care/Family Engagement

The Network organised a family day during 2017/18, targeting children and their families affected by Adrenal Insufficiency. Unfortunately the event had to be cancelled due to minimum participant numbers not being reached. There are plans to reconsider the event in the forthcoming year. The event will focus on the following:

- Opportunities to talk to other families affected by this condition and share ideas, problems and solutions
- Opportunities to feed back to clinicians and the SPEG network office about patients' and families' priorities and needs
- Sessions for teenagers, providing them with education, opportunities to feed back on what is important to them and to share their experiences with their peers
- Sessions for young children, including entertainment and education

The network has previously developed a Patient Experience Questionnaire and Getting Involved Leaflet to engage with patients and families. Both of these have had limited success. In 2017/18 the network has undertaken a range of engagement initiatives:

- SPEG distributed cards at clinics with the link to a revised Patient Experience questionnaire. It has also sent the link to voluntary groups to reach families.
  - ➤ 18 families responded (15 complete responses)
  - ➤ The patient experience questionnaire was divided into three sections, covering the clinic experience; understanding the endocrine condition and the overall patient experience.
  - ➤ The majority of responders thought services met their needs in all of these areas with particular emphasis in their feedback on the support from all the clinical staff, particularly the nurses. The only concern raised by one responder was that the staff should treat older patients by their actual age and not the age they look.
- Plans to develop a family support group have been unsuccessful. The network plans to look at other ways of engaging with families to ensure their views, needs, values and preferences drive services.
- Through links on the website family section SPEG continues to signpost to a number of charities
  and voluntary groups who offer support for families and patients with endocrine conditions. The
  network continues to contact charities to seek a reciprocal arrangement with those organisations to

raise awareness of the SPEG MCN and improve engagement with the voluntary sector. It now has an additional two charities who have agreed to place the link on their own websites, making four in total.

• The network continues to audit two patient information leaflets 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". The network previously used electronic methodology to capture this feedback with little success. Following this, a new approach has been used which has improved patient/family response rates. The nurses sub-group will analyse the results to be reported on the SPEG website

#### 3.3. Stakeholder Engagement/Communication

Due to limited availability of members for sub group meetings progress of the network's work plan has been adversely affected. To address this the network has recently developed a discussion forum for professionals on the SPEG website and the network Quality Improvement and IT sub group has started to pilot the forum. Membership of the forum was limited to SPEG steering group and sub group members with access controlled by individual usernames and passwords. The plan is to monitor how successful this project is after a trial period of 6 months. If successful, the network would look at rolling this approach out more widely.

#### 3.4. Professional Education

#### 3.4.1 SPEG Education Meetings

Education remains a priority for the network. The network's Education Strategy was reviewed during 2017/18 and updated. Education delivered during 2017-2018 included:

**Local education** is provided by tertiary paediatric endocrinologists to clinicians involved in delivering paediatric endocrine services through regional clinical meetings in the West of Scotland and through lunchtime meetings at outreach clinics in the East.

An **Annual Scientific Meeting** was organised and successfully held in January 2018. The target audience includes 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, Scottish research and interesting cases.

The 2018 event was attended by 55 people and 33 feedback forms were completed (60% response rate). The feedback received was split into the professional groups as per figure 9 below.

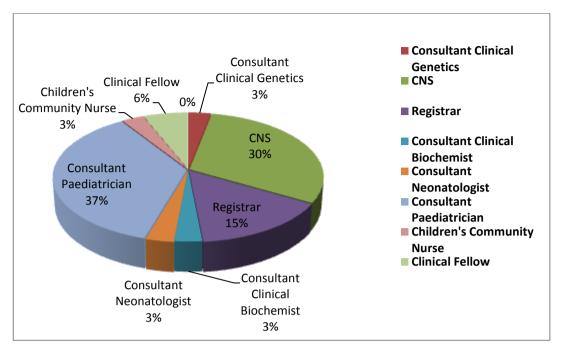


Figure 9: SPEG Annual Scientific Meeting Delegates

As shown in figures 10 and 11 below, delegates rated the meeting highly in terms of its relevance to their clinical practice and the overall quality of the education offered.

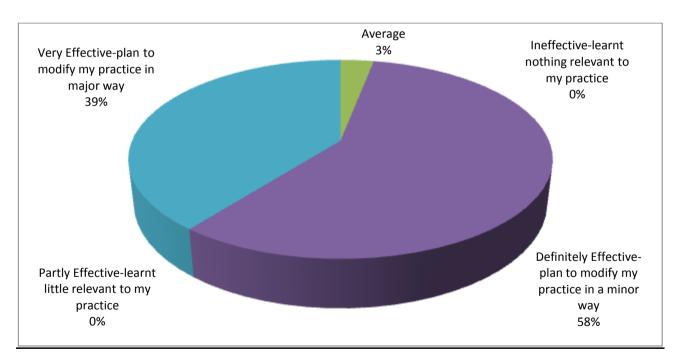


Figure 10: Relevance to Clinical Practice

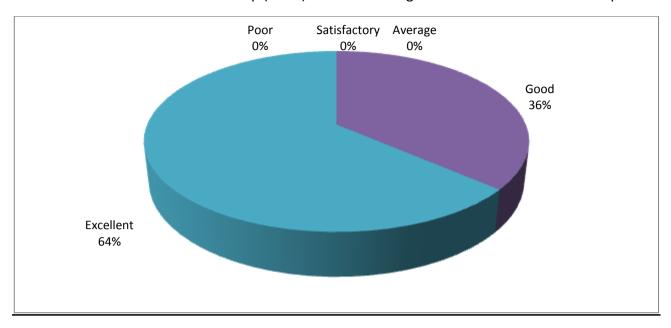


Figure 11: Overall Quality of Education offered

94% of respondents deemed the learning aims/objectives to be met with only 3% feeling that they were only partially met. All responders felt the event met their expectations.

There were **two clinical and academic meetings** (CAM) throughout the year, which were also well attended. Videoconferencing facilities are generally 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.

#### 3.4.2. Education for Nurses

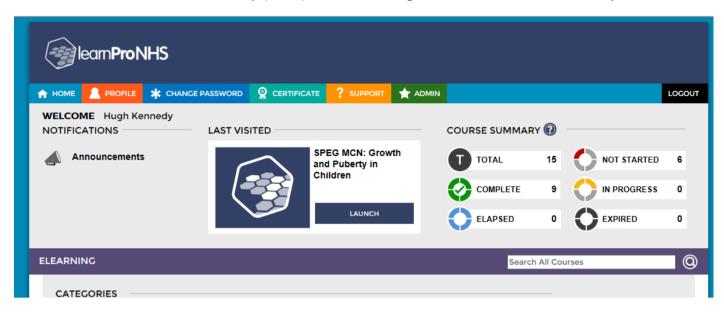
The education strategy for nurses is currently being refreshed. This is now near completion and will be implemented in 2018/19.

Through the SPEG website the network aims to ensure that all nurses that are involved in the care of children and young people with endocrine conditions are made aware of the following educational opportunities. Some of these will be specifically provided by the network, whilst others are events that are already in place and provided by other organisations.

SPEG will continue to evaluate the education it makes available and tailor the education to the needs of the health professions in Scotland, ensuring that nurse education is being provided as part of the overall education strategy for SPEG.

#### 3.4.3. LearnPro Module on Growth and Puberty Assessment

A Learnpro e-learning module has been developed by a multidisciplinary working group (Dr John Schulga, Dr Guftar Shaikh and Barbara Wardhaugh). The content of the module is based on the materials that were developed for a growth and maturation workshop produced in 2014.



#### The module covers:

- Understanding normal growth and puberty
- Understanding what influences growth
- Understanding variations in normal growth and puberty
- Measuring children properly and accurately plotting measurements on growth charts
- Understanding and interpreting growth charts
- Identifying abnormal growth and causes of abnormal growth

All clinicians and other health care professionals involved in the monitoring of growth in babies, children and young people are expected to benefit from the completion of this module. The module includes an assessment of knowledge on completion and a CPD certificate.

The module was launched in November 2017 and details about its availability distributed across all SPEG members and to a wider target audience. An information leaflet and poster was produced to advertise the module at the Royal College of Paediatric and Child Health annual meeting in Glasgow in March 2018. Further leaflets have been made available to network member to distribute locally. The aim is to target all health professionals in Scotland who are involved in growth monitoring and provide care for children with growth and pubertal disorders, providing basic training in growth and puberty assessment. The uptake of the module will be monitored through user data analysis available from the developer.

There have been practical difficulties in providing all of the target audience across Scotland with access to the module, due to internal governance requirements for online training in some boards and issues with access to the Learnpro platform in some areas. Many primary care staff also have had problems in accessing the module, which has been raised with relevant local learning and development teams and with Learn Pro.

The figures below show the uptake from launch in November 2017 to 31<sup>st</sup> March 2018.

	Enrolments	Completions	% Complete
NHS Ayrshire and Arran	37	9	24
NHS Borders	2	1	50
NHS Dumfries and Galloway	6	0	0
NHS Education for Scotland	4	1	25
NHS Fife	20	7	35
NHS Forth Valley	20	12	60
NHS Grampian	0	0	0
NHS Greater Glasgow and Clyde	0	0	0
NHS Highland	17	6	35
NHS Lanarkshire	18	6	33
NHS Lothian	49	15	31
NHS National Services Scotland	3	1	33
NHS Orkney	2	1	50
NHS Tayside	18	5	28
Total numbers	196	64	32.65

Figure 12: LearnPro Growth module Uptake to 31.03.18

There has been significant interest in the module in the last four months since the launch with 196 enrolling on it through the LearnPro platform. Of those enrolling, 64 people (32.65%) have completed the module, with a steady uptake each month



Figure 13: Learnpro module completion

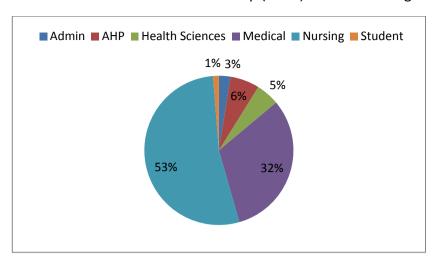


Figure 14: Professional group of those completing the module

Figure 14 indicates that most of the health professionals who completed the module were nurses working across primary and secondary care, with medical professionals the second biggest group.

#### In 2018/19 the network will:

- Continue to try and resolve the problems with access for all primary care staff, particularly GPs
- Continue to monitor usage. This will include analysis of usage by staff type within health board.
   across both primary and secondary care
- Evaluate the module

#### 3.5. Guidelines - Effective care

The SPEG protocols sub group have developed new guidelines, reviewed and updated two guidelines and a number are in the development stage.

#### New Guideline

Neonatal Thyrotoxicosis

#### Guidelines reviewed and updated

- Congenital Hypothyroidism
- Adrenal Crisis for Sick Children

#### **Draft Guidelines awaiting completion**

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

#### **Guidelines requiring review**

In line with new NSD guidance on guideline development and governance for NMCNs (which states that guidelines need to be reviewed at least every 3 years to ensure that they are still fit for purpose and up to date), all SPEG guidelines requiring review were assessed and deemed safe by network. Robust review of these guidelines is part of the 2018/19 workplan.

The network continues to look for ways to successfully audit the use of guidelines across Scotland. The network is planning to develop a formal communication and engagement strategy during 2018/2019 which will include engaging with health professionals across Scotland and auditing their views and use of these guidelines.

The SPEG MCN website analytics show that the guidelines page is the most visited one in the website and where people spend most time looking at content. The next most visited page contains the patient information leaflets.

Page	Views	Unique Views	Avg time on page
Index	425	326	00:00:36
SPEG guidelines	278	225	00:05:01
Information leaflets	241	169	00:03:01
Education	177	139	00:02:48
Professional pages	122	102	00:00:22
Community (forum)	92	37	00:01:00
QI/IT sub-group (forum page)	80	30	00:00:53
Other guidelines	67	46	00:01:18
Patients and families	58	46	00:00:14
Family Events	58	38	00:02:09

Figure 15: Website analytics to April 2018 with details of the 10 most visited pages

#### 3.6. Network Review

SPEG has undergone its first Network Review, which started in September 2016 and was completed in July 2017. This review provided 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 to NHS services and patient care and is committed to continuous development and quality improvement.

Following analysis of the evidence presented, the Expert Review Group (ERG) concluded that the Network added value to healthcare in NHS Scotland through:

- Implementation of an Education Strategy that met stakeholders needs
- Development of a wide range of protocols and guidelines
- Development of a large number of patient and family information leaflets
- Good stakeholder engagement through the family events provided

The ERG recommended that the network should retain its designation status going forward.

It also identified the need for the Network to improve how it communicates and engages with stakeholders and to further develop its audit programme. The key recommendations to take the network forward were as follows:

- The network should develop and improve its communication systems and processes with all stakeholder groups, setting this out in a formal communications strategy which should include improvement and maintenance of the website.
- Continue with the implementation of the Education Strategy with greater focus on Primary Care staff
   specifically General Practitioners
- Improve engagement with patients and their families to ensure that what is important to them drives Quality Improvement in the Network and that the work of the Network, in areas such as the development of information leaflets, meets their needs.
- 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.
- Ensure the Network takes cognisance of the Scottish Government's strategic plans for healthcare delivery over the next 10-15 years-both the National Clinical Strategy and the Health and Social Care Strategy.

Subject to endorsement of these recommendations by the National Specialist Services Committee (NSSC), the network will implement these findings in the form of a 3-5 year strategic workplan.

#### 4. Plans for the year ahead

The Network has identified a number of priority areas for 2018/19 including:

- Development, endorsement and implementation of a formal Communication Strategy as part of one
  of the main recommendations from the review. This will mainly focus on engagement from a wider
  cohort of stakeholders from primary care, regional planning, board managers, education, voluntary
  groups as well as families. The network will also continue to develop communication tools to
  support communication strategy including-website, newsletter, membership directory and service
  map.
- Development of a Patient Engagement Strategy
- Continue to develop guidelines to include: review/update of existing guidelines; methodology on prioritising new guidelines; raising awareness of SPEG guidelines and audit of awareness and use.
- Review/update of existing patient information leaflets, develop new leaflets to compliment current guidelines, and continue to audit usefulness.
- Work with the Scottish Ambulance Service to improve the alert system for all children with adrenal insufficiency.
- Continued implementation of revised education strategy- targeting clinicians who treat patients at
  each stage of their care pathway, particularly in primary care, as well as development and
  implementation of a Nurse Education Strategy for nurses who see children with endocrine
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- Implement new patient consent procedure for CAS in line with new General Data Protection Regulation.

- Review and refine minimum dataset on CAS and the network quality indicators to ensure that
  measuring them will provide useful measures of service delivery and can result in quality
  improvement. This will include the review of the SPEG Clinical Network Standards document of
  2014. Initial project will focus on audit of QI's developed from adrenal insuffciency standards.
- Implementation of the Transition Strategy

#### 5. 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.

The network appointed a new lead clinician, Dr Amalia Mayo, Consultant Paediatrician in Aberdeen, who took up post from January 1<sup>st</sup> 2018. Dr Mayo replaced Dr John Schulga who had been lead clinician since 2013 and gave up his position in July 2017. 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 publicly available for clinicians and patients to view.

# SCOTTISH PEDIATRIC ENDOCRINE GROUP MANAGED CLINICAL NETWORK 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 Dimensi ons of Quality	Planned start/ end dates	Detailed Plan Available / Owner	Description of progress towards meeting objective as at 31/03/2018	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 /Protocols Sub Group	Guidelines finalised and placed on SPEG website:- Congenital Hypothyroidism Neonatal Thyrotoxicosis Adrenal Crisis for Sick Children Still in draft and being discussed:- Hypoglycaemia Vitamin D	Promoting equity of care as close to home as possible across Scotland	G
2017-01 (b)	Audit usefulness of SPEG protocols and guidelines	2,3,4,5,6	01/05/2017 – 31/03/2018	Yes /Protocols Sub Group	SPEG MCN website analytics show that the guidelines page is the most visited one and where people	Ensuring endocrine patients are treated according to the latest evidence based practice.	Α

Objective Number	SMART Objective	Linked Dimensi ons of Quality	Planned start/ end dates	Detailed Plan Available / Owner	Description of progress towards meeting objective as at 31/03/2018	Anticipated Outcome	RAGB status
					spend most time		
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 /QI Sub Group /Network Office	4 Ql's currently being measured -	Evidence provided of Continuous Quality Improvement.	G
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/Netw ork Office	Meeting took place in May 2017 to identify dataset needed by SAS from endocrine services through Hazard Alert Sheets. This has been finalised and form SAS approval- will progress with plan 2018/19	Ensure system is robust and safe for patients	Α

Objective Number	SMART Objective	Linked Dimensi ons of Quality	Planned start/ end dates	Detailed Plan Available / Owner	Description of progress towards meeting objective as at 31/03/2018	Anticipated Outcome	RAGB status
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/Netw ork Office	Initial meeting planned for May 2 <sup>nd</sup> with sub group lead to take this forward	Ensure they measure what is important and can drive improvement.	Α
SPEG- 2017-03 (a)	Review the SPEG Education Strategy:-	2,3,5	01/04/2017 – 31/03/2018	Yes /Education Sub-group	Strategy reviewed and agreed-placed on website	Ensure education is continually delivered to right people in efficient and effective way.	В
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	Successful annual scientific meeting held, January 2018. Annual education day postponed to 2018/2019	Staff delivering endocrine services has increased skills and knowledge.	В
SPEG- 2017-03 (c)	2 Clinical and Academic Meetings	2,3,5	01/04/2017 – 31/03/2018	Yes /Education Sub-group	2 held in May and Sept 2017	Staff delivering endocrine services has increased skills and knowledge.	В

Objective Number	SMART Objective	Linked Dimensi ons of Quality	Planned start/ end dates	Detailed Plan Available / Owner	Description of progress towards meeting objective as at 31/03/2018	Anticipated Outcome	RAGB status
SPEG- 2017-03 (d)	2 Regional Educational Sessions	2,3,5	01/04/2017 – 31/03/2018	Yes /Education Sub-group	West of Scotland has held 2 Regional Sessions to date.	Staff delivering endocrine services has increased skills and knowledge.	
					East and North deliver education to local sites using different methodology		G
SPEG- 2017-03 (e)	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 /Education Sub-group	Learn Pro package live from Nov 2017.  Usage monitored – results in main body of report	Increased skills and knowledge of endocrine conditions to primary and secondary care	В
SPEG- 2017-03 (e)	Finalise Nurses Education Strategy and place on SPEG website	2,3,5	01/04/2017 – 31/03/2018	Yes /Education Sub- group/Nurse s Sub Group	Education Strategy has still some issues to be resolved before completion	Increased skills and knowledge of endocrine conditions for nurses across tertiary, secondary and primary care	A

Objective Number	SMART Objective	Linked Dimensi ons of Quality	Planned start/ end dates	Detailed Plan Available / Owner	Description of progress towards meeting objective as at 31/03/2018	Anticipated Outcome	RAGB status
2017-04 (a)	Develop and implement formal communications and engagement strategy	1, 2, 3, 4, 5, 6	01/04/2017 – 31/03/2018	Yes /Network Manager /Steering Group	Plan to finalise at Steering Group meeting, May 2018	Improved stakeholder engagement: better understanding of needs of stakeholders	Α
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 /Network Manager /	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	В
2017-04 (c)	Establish a family support group,	1,2	01/04/2017 – 31/03/2018	Yes /Network Manager /Family Support Group	Initial approaches made unsuccessful- need to focus on different aims, e.g. focus group-will discuss as part of Communication	Improve patient and carer participation in the network,	Α

Objective Number	SMART Objective	Linked Dimensi ons of Quality	Planned start/ end dates	Detailed Plan Available / Owner	Description of progress towards meeting objective as at 31/03/2018	Anticipated Outcome	RAGB status
					Strategy		
2017-04 (d)	Hold adrenal insufficiency family event	1,2	01/04/2017 – 31/03/2018	Yes /Network Manager /Family Event sub- group	Planned for June 2018	Increased engagement with patients and carers and better understanding of their priorities to address in future	Α
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 – improved response 24 AI for Schools 6 Adrenarche Analysis sent to	Ensure information provided to stakeholders is relevant and captures what is important to them	В

Objective Number	SMART Objective	Linked Dimensi ons of Quality	Planned start/ end dates	Detailed Plan Available / Owner	Description of progress towards meeting objective as at 31/03/2018	Anticipated Outcome	RAGB status
					Nurse Group		
2017-04 (g)	Relaunch of SPEG newsletter	1,2,5,6	01/04/2017 – 31/03/2018	Yes /Network Manager /QI IT sub- group	Almost complete – planning to launch May 2018	Improve stakeholder engagement	G
SPEG- 2017-05	Benchmarking- update and maintain Service Directory annually.  Plan and implement new round of site visits to update service directory.		01/04/2017 – 31/03/2018	Yes /John Schulga/Net work Manager	Plan too ambitious for 2017/18. –will look at in Strategic Plan	Providing equitable care that does not vary in quality because of personal characteristics such as gender, ethnicity, geographic location or economic status	R
SPEG- 2017-06	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.	1, 2, 3, 4, 5, 6	July 2017	Yes /Network Manager /Steering group	Draft Strategic Plan developed- sent to Steering Group for discussion at May 2018 meeting	Ascertain network performance and refresh network strategic aims and objectives	G

# SCOTTISH PEDIATRIC ENDOCRINE GROUP MANAGED CLINICAL NETWORK DRAFT WORKPLAN 2018-2019

#### Workplan – Scottish Paediatric Endocrine Group

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# 2018/2019 Workplan - Scottish Paediatric Endocrine Group

Objective Number	SMART Objective	Linked Dimensi ons of Quality	Planned start/ end dates	Detailed Plan Available / Owner	Description of progress towards meeting objective as at 01/04/2018	Anticipated Outcome	RAGB status
SPEG- 2017-01 (a)	Update available SPEG guidelines in line with review timetable and NSD guidance	2,3,4,5,6	01/05/2018 – 31/03/2019	Yes /Protocols Sub Group	Risk analysis carried out pending full review	Promoting equity of care as close to home as possible across Scotland	
2017-01 (b)	Review and, when appropriate, endorse existing BSPED, ESPE and regional guidelines that are felt to serve the needs of the Scottish paediatric population	2,3,4,5,6	01/05/2018 – 31/03/2019	Yes /Protocols Sub Group		As above	
2017-01 (c)	Development of new guidelines; Vitamin D Hypoglycaemia Include prioritisation methodology when developing new guidelines -look at priorities of network members and involve other disciplines affected (e.g. radiology)	2,3,4,5,6	01/05/2018 – 31/03/2019	Yes /Protocols Sub Group	Already in draft and being discussed	As above	

Objective Number	SMART Objective	Linked Dimensi ons of Quality	Planned start/ end dates	Detailed Plan Available / Owner	Description of progress towards meeting objective as at 01/04/2018	Anticipated Outcome	RAGB status
2017-01 (d)	Develop simple audit measures for each guideline as they are developed	2,3,4,5,6	01/05/2018 – 31/03/2019	Yes /Protocols Sub Group	Website analytics data collected at regular intervals	Ensuring endocrine patients are treated according to the latest evidence based practice.	
SPEG- 2017-02 (a)	Review and refine the Scottish Paediatric Endocrine Group Managed Clinical Network Standards 2014 document to ensure that the QI serve the objectives of the network	3,4,5,6	01/04/2018 – 31/03/2019	Yes /QI Sub Group/Netw ork Office	Discussions with the information management team are ongoing	Evidence provided of Continuous Quality Improvement.	
2017-02 (b)	Review of CAS. Establish minimum dataset to be collected Initiate 1 audit project with the use of CAS (adrenal crisis instructions and alerts)	3,4,5,6	01/04/2018 – 31/03/2019	Yes /QI Sub Group/Netw ork Office	Discussions with the information management team are ongoing	Evidence provided of Continuous Quality Improvement.	
2017-02 (c)	Implement new consent procedure for patients registered on CAS.	3,4,5,6	01/04/2018 – 31/03/2019	Yes /QI Sub Group/Netw ork Office	Consent leaflet nearly ready for distribution	Evidence provided of Continuous Quality Improvement.	
2017-02 (d)	Implement new procedure for registering patients with adrenal insufficiency with the SAS-aim to have all adrenal insufficiency	3,4,5,6	01/04/2018 – 31/03/2019	Yes /QI Sub Group/Netw	Discussions with SAS clinical governance team are	Evidence provided of Continuous Quality Improvement.	

Objective Number	SMART Objective	Linked Dimensi ons of Quality	Planned start/ end dates	Detailed Plan Available / Owner	Description of progress towards meeting objective as at 01/04/2018	Anticipated Outcome	RAGB status
	patients across Scotland with both Emergency Care Plan and registered on SAS			ork Office	ongoing		
SPEG- 2017-03 (a)	<ul> <li>Annual Scientific Event</li> <li>Clinical and Academic Meeting biannual</li> <li>Annual Education Day</li> <li>Regional Sessions</li> <li>On-Line Materials</li> </ul>	2,3,5	01/04/2018 – 31/03/2019	Yes /Education Sub-group	Dates for Annual scientific meeting & CAM confirmed Analysis of usage and impact of learnpro across secondary and primary care ongoing	Staff delivering endocrine services has increased skills and knowledge.	
2017-03 (b)	Conduct learning needs analysis to target primary care	2,3,5	01/04/2018 – 31/03/2019	Yes /Education Sub- group/Nurse s Sub Group		To inform education strategy	

Objective Number	SMART Objective	Linked Dimensi ons of Quality	Planned start/ end dates	Detailed Plan Available / Owner	Description of progress towards meeting objective as at 01/04/2018	Anticipated Outcome	RAGB status
SPEG- 2017-04 (a)	Development of a formal Communication Strategy which includes engagement with a wider cohort of stakeholders from primary care, regional planning, board managers, education, voluntary groups and families as well as development of the website as the main tool for communication.	1, 2, 3, 4, 5, 6	01/04/2018 – 31/03/2019	Yes /Network Manager /Steering Group	Plan to finalise at Steering Group meeting, May 2018	Improved stakeholder engagement: better understanding of needs of stakeholders	
2017-04 (b)	Start service mapping process to provide stakeholders with a clear overview of endocrine service provision in Scotland	1,2,5,6	01/04/2018 – 31/03/2019	Yes /Network Manager /QI IT sub- group		Ensure information provided to stakeholders is relevant and captures what is important to them	
2017-05	Develop a Patient Engagement Strategy –this will include forming a short life working group that will facilitate the development of the strategy	1,2,5,6	01/04/2018 – 31/03/2019	Yes /Network Manager		Increased engagement with patients and carers and better understanding of their priorities to address in future	
2017-06	Implement the Transition Strategy	1,2,5,6	01/04/2018 – 31/03/2019	Yes /Network Manager /Transition subgroup		Improve transition process across Scotland	

### **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 Amalia Mayo (Lead Clinician)	Consultant Paediatrician	Grampian
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 John Schulga	Consultant Paediatrician	Forth Valley
Dr Nick Conway	Consultant Paediatrician	Tayside
Dr Stuart Henderson	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
Jacquie 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	

#### **Appendix 2: Finance Report**

The annual budget for SPEG expenditure (not including staffing costs) is £5,000. Spending against this budget for 2017/18 was £2,821, resulting in an underspend of £2,179. The majority of the cost was a result of a large number of patient information leaflets being printed.

SPEG Financial Information

Network	Туре	2017-18					
SPEG	OTHER PROVISIONS	£64.20					
	PRINTING (OUTSIDE PRINTERS)	£2,820.83					
Grand Total		£2,885.03					
£2,821 98%							

Туре

PRINTING (OUTSIDE PRINTERS)

OTHER PROVISIONS

The annual education day is self-financing through a combination of delegate fees and industry sponsorship and therefore does not appear in the above budget statement.