



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

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SPEG

Midyear Report

Highlights

- **Family Involvement-**

- The Getting Involved leaflet has been distributed to all sites. The Network plans to distribute these to families at clinic to encourage involvement in network and possibly recruit to a family support group which has been recently formed.
- Two patient information leaflets have begun 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.
- A Growth Hormone Family Day was held May 2016. An evaluation was completed. Over 30 families attended (over 100 people). Overall the event was a success. In particular, feedback identified a need for information about growth and growth hormone which the network will take on board. There was also some useful feedback from the 'Village Story Telling' sessions which identified likes and dislikes from children relating to hospitals and injections. This feedback has been passed to the relevant clinical staff in the network.

- **Education Strategy-**

- A learning needs analysis questionnaire for nurses was sent out in Sept 2015 to neonatal, general paediatric, school and community nurses as well as SPEG link nurses with an interest. There were over 100 responses and the results of this will inform the development of nurse education strategy. This is now in draft stage.
- Preliminary discussions with Learn Pro have been held about developing on-line training modules using material from growth and maturation training workshops and turning it into a learn pro training package. This is now complete and requires just a few tweaks before demonstration.
- An Annual Education Day was held in May 2016. An evaluation was completed. 38 delegates attended with a wide representation across Scotland representing both secondary and primary care. Despite some minor negative feedback which the network will take on board the event 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 and to have some small group discussions will be considered for the next education day.

- **Data Collection and Audit-**

- Work continues to try and complete the capture of patient and condition data on the clinical audit system. Significant progress has now been made in most areas with over 1400 patients registered. There continue to be challenges in some health board areas.

- **Protocols and Guidelines-**

- A Septo-dysplasia guideline has been completed in collaboration with VINCYP and this is available on the SPEG website.
- A guideline development process document and guideline tracker document has been developed agreed by steering group and placed on website.

Risks or issues

- There is a continued risk that measurement of one of the QI's (ensuring all children and young people with adrenal insufficiency have an emergency care plan shared with appropriate health professionals and the Scottish Ambulance Service (SAS)) will fall behind plan as one board (GGC) has failed to respond to requests despite numerous emails and offers of support in collecting this information.
- Capture of data using CAS has had some success (i.e. patient register) however quality of some of the data could be better (e.g. over 300 patients registered with no condition). Plans are in place to improve quality during 2016/2017 so that analysis of data can be more meaningful. Inability to capture the NHS Grampian and GGC data is also an issue as these two large boards represent an estimated 50% of Scottish patients.
- Parent/patient engagement with the network has proved challenging-hopefully relaunch of 'getting involved' leaflets could help.

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.

2016/2017 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 30/09/2016	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 /Protocols Sub Group	<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:-</p> <p>Hypoglycaemia</p> <p>Congenital Hypothyroidism</p>	Promoting equity of care across Scotland and ensuring endocrine patients are treated according to the latest evidence based practice.	A

Objective Number	SMART Objective	Linked Dimensions of Quality	Planned start/ end dates	Detailed Plan Available / Owner	Description of progress towards meeting objective as at 30/09/2016	Anticipated Outcome	RAGB status
					Vitamin D 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 /QI Sub Group /Nurses Sub Group/Network Office	4 QI's continue to be measured. Others agreed:- Measurement of guidelines used by clinicians No of clinicians education events	Evidence provided of Continuous Quality Improvement.	A

Objective Number	SMART Objective	Linked Dimensions of Quality	Planned start/ end dates	Detailed Plan Available / Owner	Description of progress towards meeting objective as at 30/09/2016	Anticipated Outcome	RAGB status
					attended by clinicians with an interest in endocrinology		
SPEG-2016-03	Continued Implementation of the SPEG Education Strategy:- An annual national education day and annual scientific meeting.	2,3,5	01/04/2016 – 31/03/2017	Yes /Education Sub-group	Successful annual education event held May 2016 –feedback from meeting available Progress made in organising Annual Scientific Event Jan 2017	Staff delivering endocrine services has increased skills and knowledge.	A

Objective Number	SMART Objective	Linked Dimensions of Quality	Planned start/ end dates	Detailed Plan Available / Owner	Description of progress towards meeting objective as at 30/09/2016	Anticipated Outcome	RAGB status
	<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 programme for nurses.</p>				<p>CAM held Sept 29th 2016</p> <p>Work progressed on learn-pro package</p> <p>Nurses LNA completed and analysed –draft education strategy developed</p>		

Objective Number	SMART Objective	Linked Dimensions of Quality	Planned start/ end dates	Detailed Plan Available / Owner	Description of progress towards meeting objective as at 30/09/2016	Anticipated Outcome	RAGB status
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>	1,2	01/04/2016 – 31/03/2017	Yes /Family Support sub-group/Nurses Sub-Group	<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>	A

Objective Number	SMART Objective	Linked Dimensions of Quality	Planned start/ end dates	Detailed Plan Available / Owner	Description of progress towards meeting objective as at 30/09/2016	Anticipated Outcome	RAGB status
	<p>Explore the use of the patient opinion website.</p> <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 is continually updated</p> <p>Patient information leaflets being audited</p>		

<p>SPEG- 2016-05</p>	<p>Benchmarking- update and maintain Service Directory annually.</p>		<p>01/04/2016 – 31/03/2017</p>	<p>Yes /John Schulga/Hugh Kennedy</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>	
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