North of Scotland Paediatric Gastroenterology, Hepatology and Nutrition Network (NOSPGHANN)

Annual Report 2013-14
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1. Introduction

The North of Scotland Paediatric Gastroenterology, Hepatology and Nutrition Network (NoSPGHANN) achieved the 10th anniversary since the establishment of the network in 2003. This is NoSPGHANN’s third annual report following another very busy year providing secondary and tertiary services across the North of Scotland. We continued to progress the objectives of the collaborative 2013-15 network work plan.

The main aims and purpose of the network are to –

- provide clinical care of the highest quality
- provide safe and appropriate care as close to the patient’s home as possible
- ensure the appropriate skill mix of professionals
- encourage staff training and education
- maintain, develop and empower professional expertise locally and across the network
- work collaboratively with colleagues across Health Board boundaries
- support service delivery and governance
- promote good communication and the sharing of best practice across the North.

Multi-disciplinary network members of NoSPGHANN work closely with local teams in Royal Aberdeen Children’s Hospital, Tayside Children’s Hospital, Ninewells, Dundee and Raigmore Hospital, Inverness providing secondary and tertiary services supporting children and young people with disorders or problems of the gastrointestinal tract, the liver and complex nutritional issues.

2. Background and Network Governance

One of the main advantages and successes of the network is the collaborative multi-disciplinary approach taken by all of its members to ensure the best possible care for their patients in the region. A team approach is very evident and excellent partnerships exist between specialist visiting staff and local teams through shared working in clinics, together with enhanced educational opportunities, to ensure staff are professionally well supported and appropriately skilled.

National Delivery Plan (NDP) investments from 2008-2011 have ensured recurring funding for valuable posts and equitable access to the best multi-disciplinary services as locally as possible for often chronically ill patients. Telehealth technology plays a major part in the day-to-day running of the network and is being increasingly used by means of video-conferencing for patient follow-up appointments in remote locations.

A third Consultant, Dr Shyla Kishore, was appointed in April 2013 in RACH, which enabled the Elgin gastro clinics to become monthly from September 2013. In addition, Inflammatory Bowel Disease transition medical and nursing clinics have been a great improvement to patient care by preparing young people well for the move from paediatrics to the adult service.

An increased number of endoscopy procedures were carried out in Aberdeen and Dundee during the year by 4 Consultant staff.

Aberdeen – 156
Dundee – 73
Additional theatre sessions were also possible due to increased medical staffing capacity meaning that patients were able to be seen and treated within the appropriate waiting times. Strong links and collaboration with surgical colleagues continue across the region and endoscopy or surgical procedures can be carried out timeously in Inverness and Shetland if urgently required.

2.2 Network Links

Scottish Society for Paediatric Gastroenterology, Hepatology and Nutrition (SSPGHAN)

The SSPGHAN annual meeting takes place every year in November, attended by multi-disciplinary staff from across Scotland. In 2013, NoSPGHANN members organised the SSPGHAN 2 day education event. The organising team of Kathleen Ross (President of the Society), Dr Mike Bisset, Dr Sabarinathan Loganathan, Carolyn Duncan and the Society’s Administrator, Karen Fraser, planned a very successful conference from 20th - 21st November at the Stirling Management Centre, University of Stirling. It was the first time the event had been held at the venue which proved to be an ideal central location and the facilities were first-class.

SSPGHAN is an important meeting in Scotland and provides opportunities to network with colleagues from all of the Scottish centres providing specialist tertiary and secondary care services. The programme and topics presented were very varied and interesting with guest speakers also presenting from England and Germany, covering subjects such as:

- Treating Hepatitis B and C
- Non-IgE Mediated Allergies and Eosinophilic Disorders
- Immunodeficiency and GI Disease
- Paediatric Feeding Tube Weaning
- Surgical Support in Feeding the Child with Neurodisability
- Pouch and Bariatric surgery
- Autoimmune Liver disease in Children
- Polyposis Conditions in Children

All who attended the event agreed that the programme was very interesting and informative, allowing participants to keep up-to-date with current and emerging gastroenterology and hepatology practice and insight into the latest surgical techniques.

European Society for Paediatric Gastroenterology, Hepatology and Nutrition

Some members of NoSPGHANN attended the ESPGHAN conference in London in May. Carol Cameron, PGHN Specialist Nurse in RACH was pleased to present a poster on behalf of network colleagues entitled ‘Paediatric Gastroenterology Patients Reviewed by Video Consultation’.

Traditionally paediatric patients with gastrointestinal conditions have been reviewed in out-patient clinics in hospitals. In the past this often meant families having to travel vast distances from remote locations to be seen in one of the main centres. The National Delivery Plan provided funding for the development of the use of video-conferencing facilities for clinical consultations which has decreased the need to travel and the resulting disruption to family life. Two audit questionnaires were developed –
one for the parent or carer and one for the young person – to gain families’ opinions on the video consultation experience.

The poster on the audit of the use of the technology for review appointments was very well received and Carol received good feedback at the conference (see Appendix 2).

King’s College Hospital, London

Dr Tassos Grammatikopoulos, Consultant Hepatologist, continued to provide expert advice and support attending liver clinics twice a year in both RACH and Tayside Children’s Hospital during the year. Approximately 35 patients are seen in Aberdeen or Dundee without the need to travel all the way to London.

North of Scotland Planning Group (NoSPG) – Child Health Groups

Dr Mike Bisset (Clinical Lead) and Mrs Carolyn Duncan (Network Manager) continue as members of the North of Scotland Child Health Clinical Planning Group (CHCPG). The CHCPG meets quarterly and drives forward the strategic aims of child health networks in the North in line with national projects and initiatives.

During the year, Dr Bisset and Carolyn were involved in producing a helpful NoSPG document for a North of Scotland Framework for Tertiary Paediatric Clinics Guideline, which clarifies the roles and responsibilities within specialist networks in relation to key themes such clinical practice, job plans, education and governance.
3. Services Updates

3.1 Staffing

The network was delighted to welcome Dr Shyla Kishore, Consultant Paediatrician with a Special Interest, who was appointed in RACH in April. Her appointment will ensure further development in secondary and tertiary service provision for the whole of the network as well as increased endoscopy capacity. Specialist gastro input in Dr Gray’s Elgin was been able to be increased to provide monthly clinics in Elgin on the 3rd Monday of the month.

Collaborative discussions are ongoing between RACH Child Health and ARI management teams with regards the provision of a physiological technician service in RACH so that services such as pH impedance, pH studies, breath tests, manometry and capsule endoscopy can be provided locally.

A staff list of those involved in the network during the year is attached at Appendix 1.

There were a number of absences during the year in Psychology (RACH maternity leave), Specialist Nursing and secretarial in Aberdeen, which at times has been very challenging. In addition, Julie Knight, Specialist Nurse in RACH, left her part-time post in June. However the RACH team was pleased to welcome two further very experienced members of staff during the year. Stephanie Ramsay, Medical Secretary, joined the team in April and Brenda Smart, Specialist Nurse, in January 2014. Timely access to increased psychology input for patients in Tayside in line with the NDP resource continued to be unresolved during the year. However collaborative discussions are progressing with local medical and service management who are actively working with the psychology service to ensure the resource awarded is used appropriately for the benefit of gastro and hepatology patients.

3.2 NOSPGHANN Steering Group Meetings

Quarterly network meetings by video-conference took place during the year in January, May, July and September. Dr Mike Bisset chairs the meetings as Clinical Lead, supported by Carolyn Duncan, Network Manager. A great deal of work took place on the progressive work plan and as in previous years, there were a variety of issues, plans and developments discussed e.g. staffing, training and education, clinics, theatre sessions, care pathways, National Delivery Plan reporting, patient information, Clinical Audit System and research and audit.

3.3 Work Plan

Work on the objectives of the progressive 2013-2015 work plan was undertaken during the year with excellent multi-disciplinary team collaboration in evidence. The attached work plan has been performance managed with a red/amber/green traffic light system (Appendix 3).

Video-conference review consultations are increasingly being carried out between the main centres and close to patients’ homes, reducing the need for families to travel long distances. A guideline in the use of VC is currently being prepared in order to provide a better VC experience for families at remote locations.
Care Pathways

Operationally all services in the 3 main centres are dealing with increased patient numbers (particularly in IBD and coeliac), which at times can impede time available to work on network pathways and to increase time carried out on additional audits. However work continues developing regional care pathways, whilst being cognisant of national pathways, standards and guidelines. IBD clinical guidance for GPs and general Paediatricians has been published and discussion continues on local, national and European guidelines and standards, e.g. national IBD standards, coeliac protocols, oesophageal reflux, milk-free diets and ulcerative colitis.

Dietetic colleagues in Aberdeen, Dundee and Inverness have also worked together on harmonising their local care pathways to produce network pathways during the year, e.g. coeliac guidelines, specific feed pathways.

3.4 Education & Training

There are a number of educational opportunities available across the network further supporting staff and increasing their knowledge and skills, e.g. –

- Monthly Journal Club presentations
- MDT team meetings in Aberdeen
- Education lunchtime sessions in Elgin
- Lunchtime case discussions in Inverness and Dundee (it is hoped that some lunchtime education sessions for Raigmore clinicians will be able to be offered from Spring/Summer 2014).
- Discussion is also taking place in the network about the possibility of providing an educational session on Shetland during one of the year’s visits.

Regular monthly Journal Club sessions took place during the year by VC on the last Monday of the month with topics presented on new developments in:

Faecal Calprotectin
Nutritional Screening in Crohn’s disease
Eosinophilic oesophagitis
Peri-anal disease

A network study day is planned for June 2014 in Inverness with VC capabilities.

3.5 Joint Study Day – Gastroenterology and Neurology – 31st October 2013

A very successful Education Day was held in MACHs 2, University of Dundee, Ninewells in October attended by multi-disciplinary colleagues from across 5 centres (over 40 attendees). This was the first time both networks had come together for a joint study day and uniquely the first study day which included the use of video-conferencing technology allowing staff at 5 remote VC sites in Orkney, Shetland, Aberdeen, Elgin and Inverness to take part. It was extremely valuable being able to come together to listen to presentations and to discuss topics that relate to patients who are known to both gastroenterology and neurology networks. Some of the topics presented included, for example:

- Oromotor dysfunction and feeding assessment in the neurologically impaired child
- Fundoplication in children with neurological disease
- Jejunal feeding
- How does it feel? Acknowledging the emotional impact of tube feeding
- The Child with Cerebral Palsy – energy expenditure and growth
- Ideal enteral feeds – from calories to ketones.

Feedback from the event was excellent and the technology worked tremendously well across such a wide geographical area. It is hoped that a further joint study day can be planned for 2015.
3.6 Clinics

Two network service planning meetings in addition to steering group meetings took place during the year to map and review current clinic provision in the network across the 3 main centres, Elgin, Perth and Shetland and to look at what new initiatives could be developed moving forward.

A large number of specialist tertiary, secondary care, Nurse-led and Dietitian-led clinics are delivered in each of the 3 main centres in Aberdeen, Dundee and Inverness covering general gastroenterology, Inflammatory Bowel Disease, hepatology, coeliac disease and transitions.

There are network clinics in:

- Aberdeen (weekly GI clinics and other specialist clinics as detailed below)
- Dundee (weekly)
- Inverness (monthly, with 5 clinics being 2 day clinics – Dr Bisset and Dr Goudie see patients jointly as well as with local Paediatricians when appropriate)
- Elgin (monthly IBD from September 2013)
- Shetland (2 visits per year)
- Perth (monthly).

The majority of the above clinics are supported by Specialist Nurses and often by Senior Dietitians. Routine coeliac clinics are Dietitian-led in Aberdeen and Dundee. The potential for specialist clinic input to Orkney was discussed with RACH General Paediatrician Consultants who carry out clinics on the island during the year, however there is currently no requirement for specialist gastro input.

Multi-disciplinary team meetings continue to be invaluable to local teams to discuss clinics and in-patient admissions, as well as educational sessions during the year. Meetings take place every Monday in Aberdeen, at the end of the Tuesday clinic in Dundee and following the specialist clinics in Inverness.

Hepatology clinics

The North of Scotland paediatric hepatology service continues to be well supported by Dr Tassos Grammatikopolous from King’s College Hospital, London through their outreach clinics. There are 2 clinics per year in Aberdeen and 2 clinics per year in Dundee. The patients from the Highlands travel to Aberdeen. Outwith the 2 joint paediatric hepatology clinics, 4 network multi-disciplinary hepatology clinics are delivered by Dr Sabarinathan Loganathan, a Specialist Nurse and Dietitian. The complex patients from Inverness travel to Aberdeen however some of the stable patients were discussed via video-conference in collaboration with Reay Urquhart, Specialist Nurse and Dr David Goudie, based in Inverness who provide the clinical information and results.

The above model is very much appreciated both by parents and by colleagues from King’s College Hospital as they provide an environment for multi-disciplinary assessment and also continuity of care by the same team.
Patient Story

Ben* is a 2 ½ year old boy who was diagnosed as having Alagilles syndrome shortly after birth. The main complication for Ben was liver failure and he has undergone 2 liver transplants due to the first transplant failing in the past year. His care is provided by clinicians working as part of NoSPGHANN, in collaboration with our consultant colleague from Kings College Hospital, London.

Ben’s mum was introduced to the Gastroenterology team when he was less than 2 months old and she recalls that she felt the Consultants and Specialist Nurses were caring and compassionate whilst Ben was undergoing investigations prior to diagnosis. She commented that the honest and open communication displayed by the team allowed her the time to come to terms with the diagnosis of Alagilles syndrome.

Throughout his treatment Ben has had regular specialist reviews in Dundee and Aberdeen and has also travelled to London’s Kings College Hospital if required. Ben’s mum is very appreciative of the fact that without the care provided by network clinicians, she and Ben would have had to spend a great deal more time away from home in London.

Ben’s mum explained that she “did not know how they would have managed without the support of the Specialist Nurses” during stressful times and she believes that the patience and understanding shown helped her to cope at such a difficult time in her son's life.

On reflection Ben’s mum feels she has always been able to ask any questions and has found staff to be approachable and helpful and always has full confidence in the care they provide to her son. Having direct contact with the Specialist Nurses has been “invaluable” in giving Ben and his family the support and advice they have needed locally and at the right time.

Ben is now progressing well and continues to be reviewed locally in the specialist hepatology clinic.

* Not his real name

3.7 New Developments

- **Gastroenterology/genetics clinics** - This new service facilitates the planning of a co-ordinated approach for the management of existing and new patients with a family history of genetic conditions affecting the gastrointestinal tract and other systems. Two clinics were conducted in Tayside by Dr Loganathan with local gastroenterology and genetics teams during the year. He is also in discussion with the Aberdeen team to develop a similar service.

- **Virtual biologics clinic** – A new monthly clinic has commenced in RACH initially (3rd Wednesday morning of the month) to discuss patients who present with more extensive disease and for whom biologics therapies are required to optimise their management. It was important to have a multi-disciplinary forum including all members of the team managing IBD patients i.e. gastroenterologists, nurses and AHPs to have dedicated time to review patients’ management and treatment plans and for planning future treatments. The addition of Dundee and Inverness Consultant and nursing colleagues joining this clinic by VC to discuss their patients commenced in February. In round 4 of
the UK IBD audit, network patient data for the biological audit was included to measure the efficacy, safety and their appropriate use.

- **Feeding Clinic** – this multi-disciplinary clinic, including input from medical staff, Speech and Language therapists, Psychologists and Dietitians commenced in February (first Wednesday bi-monthly). This clinic is a forum to discuss patients who have the most complex feeding needs.

### 3.8 Theatres/Endoscopy

Dr Bisset and Dr Loganathan carry out theatre sessions in RACH and at Ninewells and Dr Kishore also now in RACH. Over 250 procedures were carried out during the year by network specialist staff, including upper and lower endoscopy, capsule endoscopy, liver biopsies, gastrostomies, PEG/button insertions or changes and jejunostomy. Discussions are ongoing with Ninewells colleagues with regards future planning so that increased capacity for an additional theatre session might be possible.

Routine communication and collaboration takes place with paediatric surgical colleagues across the region enabling endoscopies or biopsies to be carried out in Inverness and Shetland during their routine visits, so that network patients are treated as early and as close to their homes as possible.

Network staff contributed and presented at an RACH theatres study day in June on IBD and gastrostomy tubes.

### 4. Research & Audit

#### UK IBD Audit

Network staff in Royal Aberdeen Children’s Hospital, Tayside Children’s Hospital and Raigmore Hospital have been collecting data for the national IBD audit for paediatrics during the year. The network is enrolled in the 4th round 2012-2014 and has submitted data on all 4 elements.

Data has been submitted on the following 4 elements –

1. In-patient care of ulcerative colitis admissions
2. In-patient experience questionnaires of those patients following acute hospital admissions
3. Biologics audit
4. Organisational audit – a re-audit of (Round 3 2010) structure and service provision.

### 5. Nursing & Allied Health Professionals

#### Nursing - Grampian

In early 2013 Carol Cameron, RACH Specialist Nurse, registered as an Independent Prescriber following a 6 month MSc course. This has had huge benefits for families. Children can be reviewed by telephone consultation which prevents hospital attendance and she can prescribe medications to effectively manage their condition. This has enhanced the patient journey and provides a more holistic approach to patient care.
Eleven young people have been transitioned from RACH to adult services over the year and there has been positive feedback for the nurse led transition clinics held with adult service colleagues. A thank you letter was received from a parent of a young person who has transitioned “I don’t know how we would have managed without the team; you have enabled us to get through the last few years”. (Similar transition clinics take place in Tayside and Highland).

The specialist nurse telephone helpline continues to be very busy with a marked increase in calls. This service is valued by parents looking for advice regarding their child’s condition, drug management or queries relating to various issues including immunisations, enteral tubes or stoma care. One of the families has had 182 contacts during the last two years empowering them to care for their child at home.

The team uses video conferencing facilities to review patients to prevent families having to travel considerable distances to attend out-patient clinics in one of the main centres. An audit of families’ experiences demonstrated that video consultations provide an effective method of consulting with families. A poster presented at the European Society of Paediatric Gastroenterology, Hepatology and Nutrition conference in May 2013 also won the best poster for Person Centred care at a Quality and Safety event in NHS Grampian.

Allied Health Professionals

Dietitians – Coeliac Disease

During the year the 3 Paediatric Dietitians from Aberdeen, Inverness and Dundee who look after children with coeliac disease met to review what input they had with these families at diagnosis and at review. Work is ongoing to review the paperwork used at each appointment including producing a checklist for seeing a new patient, a plan regarding frequency for reviewing patients after diagnosis and documentation that can be used at each visit.

In 2013 all paediatric patients in NHS Tayside were moved over to the NHS Tayside Gluten Free Food Scheme. This is a new scheme whereby patients get their gluten free prescribed products direct from a community pharmacist, rather than by visiting the GP, requesting a prescription for the product which they then take to the community pharmacist. Patients need to register with a community pharmacist of their choice and they are given an NHS Tayside Gluten Free Food Formulary which enables families to order on a monthly basis up to the recommended number of units. The new scheme has been received positively by the majority of patients.

The Scottish Government was interested in the NHS Tayside scheme and a pilot Scottish Gluten Free Food Service has started and will run until the 31st March 2015. For patients in Tayside it will only mean small changes to the way they currently get their gluten free foods but will be a bigger change for patients in NHS Grampian and Highland. It will be interesting to get patient feedback on the new scheme to assess how patients and families feel about this way of getting gluten free foods.
Gluten free tasting session – May 2013

The Dietitians at Royal Aberdeen Children’s Hospital organised a tasting session aimed at all patients with coeliac disease and their families on 11th May 2013.

75 families were invited and, despite worrying no one would turn up, 33 families of over 100 people attend the day.

The day was supported by national companies like Glutafin and Juvela who gave cookery demonstrations and tips. There was also a local butcher, a great display from Asda, Tilquillie oats, Pulsetta and J G Ross. A real highlight was the delivery of Dominos Pizza at lunchtime. We were supported by the local branch of Coeliac UK and The Archie Foundation. This, along with donations from local restaurants, made for a really successful day which was very well received by everyone.

Fun with Food Group update

This group continued during 2013/14. It was initially set up in collaboration with Occupational Therapy and Dietetics colleagues to encourage patients with nutritional issues to increase the amount and range of oral food and drink.

Pre-group work involves parents/carers completing questionnaires about sensory responses, attitudes towards eating, and a food diary. Parents are also invited to meet prior to group to discuss their expectations, the aims and format of the group and ask any questions. A follow-up questionnaire about attitudes is then completed which can be used as a tool to measure change. In addition parents meet with the team post-group to feedback their experience, plans for follow up and any further questions.

Two groups were run in 2012 and 2013, with similar planned for 2014. Very good feedback has been received from families. The group has helped to address and treat any functional and/or sensory issues around feeding. Once these are addressed the Clinical Psychologist is then in a position to address behavioural issues and concerns.

Multidisciplinary EDS (Eating/Drinking/Swallowing) assessment clinic

This monthly clinic continued to run during the year. The clinic time has been extended during 2013 to be able to offer more appointments as required. Due to the multi-faceted reasons for EDS difficulties, a joint assessment clinic allows functional and sensory aspects to be assessed jointly by Speech & Language Therapy and Occupational Therapy. Dietitians are available if there are any nutritional concerns. Following the clinics a meeting with clinical psychology often takes place to discuss any potential referrals regarding any behavioural aspects patients may be experiencing. A large majority of the children who attend the joint clinic go on to attend the above Fun with Food groups. The clinic provides a one stop assessment clinic and allows improved communications rather than referrals being made between departments, after a child is seen for a uni-disciplinary initial assessment.

6. Key Challenges

6.1 Staffing

Staffing has at times been challenging during the year. There has been a lack of resources in nursing in Aberdeen and Inverness due to delays in recruitment or staff absences. In addition there have been some problematic issues with regards access to
psychology in Tayside as well as a maternity leave in Grampian. In these efficiency saving times for Health Boards, it has not been possible to recruit temporary staff to cover, which creates gaps in manpower and puts additional pressure on existing staff when trying to deliver a quality service. It is also already known that there will be 3 maternity leaves and one resignation amongst network staff in the coming year which, together with increasing numbers of IBD patients, will no doubt present challenges for service delivery.

6.2 Clinical Data – Clinical Audit System

Cross-boundary working brings many challenges and access to comprehensive clinic and procedures data continues to be a problem for all child health networks across the North of Scotland.

There have been several discussions during the year with the system developer with regards the technical aspects for a North of Scotland instance, which have been further complicated due to the interconnectivity and governance arrangements with the national Scottish Paediatric Epilepsy Network version of the system (which will be used by neurology network staff). In addition, funding of the CAS has been delayed due to NoSPG discussions on the Intelligent Region. Ongoing discussions will continue over the coming months however progress is much slower than had been anticipated at the outset. It remains the intention of the network to adopt a version of the NSD funded system to ensure easy access to information on network patients in the North of Scotland to ensure safe, efficient, equitable, person-centred care.

7. Looking Ahead

Collaborative multi-disciplinary working, carried out by a flexible workforce is demonstrated extremely well by members of the network. NoSPGHANN will work to maintain and add to the services that are provided across the network in 2014/15. With the addition of the 3rd Consultant post and the positive addition of new biologics, genetics and feeding clinics, the network is well set to build upon services provided in the coming year. Numbers of IBD and coeliac patients are increasing year on year putting additional pressure on resources within the network and it is well recognised that data collection on network patients needs to be embedded into everyday practice, therefore this will be a major priority for 2014/15.

This work is all carried out by caring, highly motivated, conscientious, well trained staff that are very proud of the quality of care they provide to their patients on a daily basis. Together we look forward to developing the aims and work of the network in the coming year.
8. **Network Social Event – June 2013**

In addition to all the hard work, we did have time to play during the year. We all came together to have some fun, with a bit of exercise! Dr Bisset hosted an excellent barbecue and football match in rural Aberdeenshire, which was thoroughly enjoyed by all and the Scottish weather even held up.

Thank you to all staff involved in the network for their continued hard work and contributions to this report.
### Appendix 1 – Gastroenterology, Hepatology & Nutrition network staff involved in delivery of NoSPGHANN – 2013/14

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<tr>
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<th>POST</th>
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<tr>
<td>Dr Mike Bisset</td>
<td>NoSPG Child Health Clinical Lead and Network Clinical Lead</td>
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<tr>
<td>Carolyn Duncan</td>
<td>NoSPG Child Health Network Manager</td>
<td>Also Network Manager for NoS neurology and respiratory networks</td>
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<th>ABERDEEN</th>
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<td>Dr Mike Bisset</td>
<td>Consultant Gastroenterologist</td>
<td>Also working in Tayside &amp; Highland</td>
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<tr>
<td>Dr Sabarinathan Loganathan</td>
<td>Consultant Paediatric Gastroenterologist</td>
<td>Also working in Tayside &amp; Shetland</td>
</tr>
<tr>
<td>Dr Shyla Kishore</td>
<td>Consultant Paediatrician with a Special Interest</td>
<td>Took up post in April 2014 Also working in Elgin</td>
</tr>
<tr>
<td>Ann Morrice</td>
<td>Medical Secretary</td>
<td>Part-time</td>
</tr>
<tr>
<td>Stephanie Ramsay</td>
<td>Medical Secretary</td>
<td>Part-time</td>
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<tr>
<td>Carol Cameron</td>
<td>PGHN Specialist Nurse</td>
<td>Also working in Shetland specialty clinic and Metabolic Specialist Nurse</td>
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<td>Julie Knight</td>
<td>PGHN Specialist Nurse</td>
<td>Retired from post in June 2013</td>
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<td>Brenda Smart</td>
<td>PGHN Specialist Nurse</td>
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<tr>
<td>Kathleen Ross</td>
<td>Head of Paediatric Dietetics</td>
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<td>Hilary Rennie</td>
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<td>Hazel Edward</td>
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<td>Dr Anna Clancy</td>
<td>Psychologist</td>
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<td>Senior Occupational Therapist</td>
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<td>Angie McCallum</td>
<td>Dietetic Assistant</td>
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<tr>
<td>Martina Freeman</td>
<td>Pharmacist</td>
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<tr>
<td>Dr Richard Hansen</td>
<td>University of Aberdeen/NHS</td>
<td>Clinical Researcher</td>
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<td>Physiological Technician</td>
<td>Post provision under discussion</td>
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<td>Dr Dagmar Kastner</td>
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<td>Dr Buddhi Gunaratne</td>
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<td>1 session</td>
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<td>Gillian Cormie</td>
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<td>shared NDP funding</td>
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<td>Joanna Mulreany</td>
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<tr>
<td>Karen McIntyre</td>
<td>PGHN Specialist Nurse</td>
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<td>Sarah Nicoll</td>
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<td>Clare McLeish</td>
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<td>Unnamed</td>
<td>Psychologist</td>
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<td>Dr Paul Fettes</td>
<td>Consultant Anaesthetist</td>
<td>2 sessions to support endoscopy theatre sessions</td>
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<tr>
<td>Dr David Goudie</td>
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<tr>
<td>Agnes MacIntyre</td>
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<td>Lis Jackson</td>
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<td>Reay Urquhart</td>
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<td>Michelle Nimmons</td>
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<td>Dr Tracy McGlynn</td>
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<tr>
<td>Dr Susan Bowie</td>
<td>GP with a Special Interest</td>
<td>Based at Hillswick Health Centre</td>
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Paediatric Gastroenterology Patients Reviewed by Video Consultation

C Cameron¹, WM Bisset¹, S Loganathan¹, D Goudie², B Lurie³, C Travis³

¹ Paediatric Gastroenterology, Royal Aberdeen Children's Hospital
² Raigmore Hospital, Inverness
³ Clinical Effectiveness, NHS Grampian

INTRODUCTION

The North of Scotland Paediatric Gastroenterology, Hepatology and Nutrition Network (NoSPGHN ANN) works across five health boards aiming to provide high quality clinical care as close to the patients home as is safe and appropriate to do so.

Children and young people with gastrointestinal conditions are traditionally reviewed in outpatient clinics in a hospital setting. The North of Scotland covers a wide geographical area with remote and rural locations including rural Highlands and Islands, which means families have to travel considerable distances to attend a clinic.

Better Health, Better Care: National Delivery Plan for Children and Young Peoples Specialist Services in Scotland, provided funding for the development of the use of video conferencing facilities for clinical consultations. All rural hospitals and GP surgeries in the North of Scotland have these facilities, enabling families to be reviewed by video consultation without having to travel long distances.

An audit of families experiences was designed to improve the quality and effectiveness of this service².

AIM: Identify if video consultation is an effective method of consulting with parents and young people.

METHODS

- The network has reviewed 19 patients (11 patients had inflammatory bowel disease) aged between 2 and 16 years - by 29 video consultations over a 15 month period.
- Two audit questionnaires - for the parent and young person - were developed by the specialist nurse and clinical effectiveness department.
- 20 questions - including 10 graded questions - were designed to gain opinions on the video consultation experience.
- Phone call consent was obtained prior to questionnaires being posted to families.
- 19 questionnaires were sent to parents and 13 questionnaires were sent to young people over the age of 10 years.
- Data entry and analysis was undertaken by the clinical effectiveness team.

RESULTS

19 questionnaires were sent to parents and 14 were returned (73.7%).
13 questionnaires were sent to young people over the age of 10 years and 11 were returned (84.6%).
- 85.7% of parents and 81.8% of young people rated their overall experience of the video consultation as very good / good.
- 92.8% of parents strongly agreed / agreed that attending a video consultation was more convenient for their families.
- 64.2% of both parents and young people would like to receive information on what to expect prior to attending a video consultation.
- A limitation of video consultation is that the child is not able to be examined by the Consultant and 42.9% of parents stated this was a concern.
- 85.7% of parents and 72.8% of young people strongly agreed / agreed that they were more relaxed attending a video consultation closer to home.

CONCLUSION

Video consultations provide an effective method of consulting with parents and young people.
- Video consultations are more convenient than attending a clinic for families living in remote and rural areas.
- Parents should be given a choice of being reviewed in clinic or by video consultation.
- The North of Scotland network will develop guidelines for families using video consultations to enhance their experience. This will include the option of the child being examined by a local health professional.
- There are considerable time and cost savings for families.

Comments of parents / young people

I prefer video consultations as I don’t have to miss school
Clinic appointments are a long way to travel which is stressful if your child is unwell
The video consultation is a great idea, people should use it more often
I don’t like travelling or flying so prefer video consultations

REFERENCES

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<th>Objectives</th>
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<th>Timescales</th>
<th>Lead Professionals</th>
<th>Progress at January</th>
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| Continue to map, develop and agree care pathways                         | Develop regional care pathways to ensure consistency across the network, establishing links to other regional networks | • Agree on existing care pathways and identify any gaps  
• Link with national/regional groups to inform existing or new protocols, standards and referral pathways  
• Discuss use of national/regional care pathways in NoSPGHANN with WoSPGHANN/SEAT colleagues | 2013/15    | W M Bisset          | IBD pathway for GPs and General Paediatricians adopted as a network pathway. Work on national coeliac protocol, persistent jaundice, oesophageal reflux pathways, etc. continues |
| Implement planned outreach out-patient clinics across the North           | Ensure patients have access to a local, safe, sustainable, high quality service | • Develop monthly clinics at Dr Gray’s, Elgin (agreement gained from RACH management)  
• Twice yearly Shetland clinics ongoing, with potential to develop Orkney clinic if required (according to patient need) | 2013/14    | W M Bisset C Cameron S Kishore K Ross | Monthly Elgin GI clinics commenced September 2013 |
| Develop network web pages for professionals and families                 | Increase awareness of the network for all stakeholders and enhance families' knowledge of service and of disease information | • Develop a parent questionnaire in conjunction with nursing staff to seek views of current service and development possibilities.  
• Continue to develop patient information and involvement leaflets  
• Further develop network web pages to include protocols/guidelines in future | 2013/15    | C Duncan K McIntyre S Nicoll K Ross | Plan further sub-group meeting |
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| Enhance network education framework                                        | Ensure appropriate skill mix of professionals and maintain and develop professional expertise locally and across the network | • Describe educational opportunities – local/regional/national and distribute to network and Health Board education administrators  
• Deliver multi-disciplinary network learning sessions by VC (up to 12 per year)  
• Ensure annual multi-disciplinary study day | 2013/15    | W M Bisset C Duncan K Ross | Journal Club dates agreed and circulated. NoSPGHANN/NeSCANN networks joint study day took place October 2013 Plan network study day for June 2014 |
| (RAG status: Green) Effective, equitable                                 |                                                                        |                                                                                           |            |                    |                                                                                       |
| Continue discussions on implementation of a paediatric clinical audit IT System | Improve clinical data collection to have ability to collect patient demographic and disease information to facilitate audit and to enhance patient care | • Continue discussions with NoSPG and Clinical Audit System developer so that the gastro service is part of the North of Scotland version  
• Collaborate with WoS and SEAT colleagues to establish common disease/procedure codes for gastro networks across Scotland | 2013/15    | W M Bisset C Duncan | Discussions ongoing at NoSPG but stalled meantime due to NoSPG intelligent region discussions |
| (RAG status: Amber) Person-centred, efficient, effective                  |                                                                        |                                                                                           |            |                    |                                                                                       |
| Audit clinical care and research                                          | Identify projects suitable to carry out audit of children’s care and review parents’ and carers’ experiences of service provided | • Participation in and collation of UK IBD and audit data  
• Carry out Eosinophilic oesophagitis audit | 2013/15    | S Loganathan C Cameron S Nicoll S Kishore | Collaborative work carried out by staff in 3 main centres to collate/submit IBD audit data |
| (RAG status: Amber) Efficient, effective                                  |                                                                        |                                                                                           |            |                    |                                                                                       |

**Red/Amber/Green (RAG) status**

- red - not on target/little or no progress
- amber - satisfactory, significant progress to date but further work required
- green – the network has been successful in achieving the objective