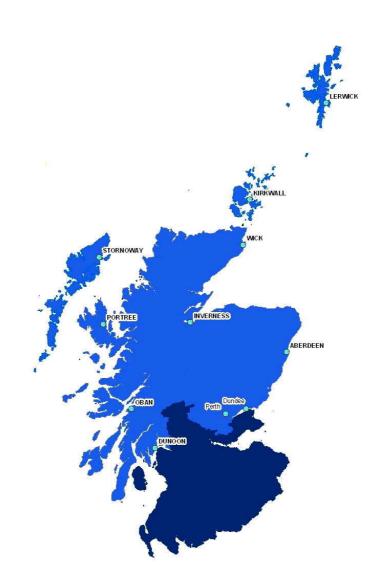


### NORTH OF SCOTLAND PLANNING GROUP



### **NOSPGHANN Annual Report 2012-13**

North of Scotland Paediatric Gastroenterology, Hepatology and Nutrition Network



1.	Introduction	2
2.	Background	3
	2.1 Benefits of Networking	4
	2.2 Network Links	4
3.	Updates	6
	3.1 NoSPGHANN Steering Group	6
	3.2 Staffing	6
	3.3 Work Plan	6
	3.4 Training & Education	7
	3.4.1 Family Fun Day	8
	3.5 Clinics	8
	3.6 Theatres/Endoscopy	9
	3.7 Research & Audit	10
	3.8 Specialist Nursing	10
	3.9 Allied Health Professionals	12
	3.10 Psychology	12
4.	Plans for Next Year	14
	4.1 Network study day 2013	14
	4.2 SSPGHAN 2013	14
5.	Key Challenges	15
	5.1 Clinical data – Clinical Audit System	15
	5.2 Access to Clinical Portals	15
6.	Looking Abood	16
0.	Looking Ahead	10
	Appendices	
	Appendix 1 – Staff List	17
	Appendix 2 – 2011-2013 Work Plan	18

#### 1. Introduction

The North of Scotland Paediatric Gastroenterology, Hepatology and Nutrition Network (NOSPGHANN) is a managed service network. 2013 sees the 10<sup>th</sup> anniversary since the establishment of the network on an informal basis. The network was able to start up in the early days due to the co-operation of Grampian and Tayside health boards and professionals agreeing to work together to provide a tertiary paediatric gastroenterology service, initially between Aberdeen and Dundee. This was developed further in 2004 by the start of joint out-patient clinics between tertiary and secondary care specialists in Inverness.

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 and
- maintain and develop professional expertise locally and across the network.

#### 2. Background

The Scottish Executive issued NHS HDL (2002) 69 "Promoting the Development of Managed Clinical Networks in NHS Scotland" confirming their commitment to the development of networks. There is a slight difference with NoSPGHANN in that services are provided to patients in each Health Board area and the network would therefore be regarded as a Managed Service Network as opposed to a Managed Clinical Network. Nevertheless the definition of an MCN in the HDL would still be true for NOSPGHANN –

'Linked groups of health professionals and organisations from primary, secondary and tertiary care, working in a co-ordinated manner, unconstrained by existing professional and health Board boundaries, to ensure equitable provision of high quality clinically effective services'.

Multi-disciplinary members of NOSPGHANN work closely with local teams providing secondary and tertiary services supporting children and young people with disorders or problems of

- the gastrointestinal tract
- the liver and
- complex nutritional issues.

In-patient facilities are provided in –

Royal Aberdeen Children's Hospital Tayside Children's Hospital, Ninewells, Dundee Raigmore Hospital, Inverness

The network's first report was published in 2012. This year's report provides updates on the work of the network that has been built upon over the past year. A number of projects have been started during the period and a large amount of collaborative work across the network continues to go from strength to strength.

National Delivery Plan (NDP) investments 2008-2011 have ensured equitable access to the best multi-disciplinary services as locally as possible for chronically ill patients. The network continues to empower local staff and multi-disciplinary teams whether they are medical, nursing, AHP or Psychologists to deliver the best quality care as locally as possible.

Monthly clinics in Elgin will be increased in 2013 with the recruitment of a third Consultant Gastroenterologist in Aberdeen. Further discussion will take place with secondary care Paediatricians in Grampian with regards the potential for delivery of a tertiary out-patient service on Orkney. 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.

Endoscopy facilities are provided in Aberdeen and Dundee. There are also strong links with surgical colleagues across the region that attend weekly/monthly regular team meetings and who often carry out timely endoscopy or surgical procedures in Inverness and Shetland for the benefit of network patients.

#### 2.1 Benefits of Networking

There can be many positive benefits from working in a network and in particular some very good examples of working in NoSPGHANN are as follows:

- Provision of locally delivered clinics, including Perth, Elgin and Shetland, have meant that patients have access to the best possible services delivered as close to their homes as possible.
- Better communication and greater interaction with colleagues across 3 main centres has built better relationships and standardisation of care across the network. Collaboration and partnership working across the network have ensured the patient journey is made as easy as possible.
- Increased staffing and MDTs link together to share good practice and provide a co-ordinated approach across the North.
- Sharing of expertise has meant that staff have access to high quality peer support. Staff have felt empowered due to sharing of information and increased opportunities for training and education, e.g. network Education Day, Journal Club, case discussions.
- Better access to specialist nursing and dietetics has meant improved support for patients and families and their ability to cope with their child's disease and has also improved clinical outcomes.
- Transition clinics are now possible there are good links with adult colleagues and nurse-led clinics are provided in addition to Consultant-led clinics.
- Video-conference/telehealth technology has enabled review consultations by VC reducing the need for patients and families to travel to a main centre.
- Work has taken place collaboratively with regards standardisation of care pathways/guidelines/information to families across the network.
- Added value of working with similar regional networks in neurology, respiratory and paediatric surgery which map to the same catchment area. Able to review patients for or have patients seen by 'sister' networks.
- A regional model of care for any service is more likely to be funded by regional or national bodies than a proposal from professionals working separately in different centres.

#### 2.2 Network Links

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

Many members of NoSPGHANN are also members of SSPGHAN. Kathleen Ross, Head of Paediatric Dietetics in Aberdeen, is the current President of the Society. Every year in November a 2 day multi-disciplinary conference takes place in Scotland, which includes international speakers, on a range of medical, nursing and dietetic topics and research. The 2012 conference in Edinburgh was a very successful event and is always an excellent way to network face-to-face with colleagues from other regional networks in the West (**WoSPGHAN**) and East (**SEAT**).

#### King's College Hospital, London

There are very good links with King's College London with Dr Alistair Baker having provided specialist hepatology clinics for several years for North liver patients. Dr Tassos Grammatikopoulos has now taken over this service and provides clinics twice a year in both RACH and Tayside Children's Hospital.

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

Dr Mike Bisset (Clinical Lead) and Mrs Carolyn Duncan (Network Manager) are members of the North of Scotland Child Health Clinical Planning Group (CHCPG) and Child Health Operational Delivery Group. Dr Bisset is Chair of both groups. The CHCPG meets quarterly and drives forward the strategic aims of child health networks in the North in line with national projects and initiatives. The Child Health Operational Delivery Group is an operational group comprising NoSPG Programme Manager, Clinical Leads, Network Managers and Service Managers from the 3 mainland Health Boards.

#### 3. Updates

#### 3.1 NOSPGHANN Steering Group Meetings

Four network meetings by video-conference took place during the year in January, May, July and September and were all well attended. There were no major changes to the membership of the group during the year. Dr Mike Bisset chairs the meetings as Clinical Lead, supported by Carolyn Duncan, Network Manager. As in previous years, there were a variety of issues, plans and developments discussed e.g. staffing, work plan, training and education, clinics, theatre sessions, care pathways, National Delivery Plan reporting, website, Clinical Audit System and research and audit.

#### 3.2 Staffing

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

An appointment to the permanent third Consultant Paediatric Gastroenterologist post for Aberdeen has been made with Dr Shyla Kishore commencing in April 2013. This will ensure further development in secondary and tertiary service provision for the whole of the network as well as increased endoscopy capacity. Plans are already in place to increase specialist gastroenterology clinics in Elgin to monthly from summer 2013.

Positive 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. It is proposed that the paediatric service will be provided by protected NDP funding from the adult technician in future.

There were a number of absences during the year in Psychology, Specialist Nursing and secretarial in Aberdeen, which at times has been very challenging. It is hoped that appointment to the vacant Psychology post (0.5 wte) will be completed in Spring 2013. Timely access to increased Psychology input for patients at Ninewells in line with the NDP resource continues to be discussed.

#### 3.3 Work Plan

Work on the seven objectives in the current work plan progressed well during the year. The work plan has been performance managed with a red/amber/green traffic light system with all of the items now being listed as green, meaning they have been achieved (*Appendix 2*). Some of these items are being rolled forward and extended further as well as additional items being added to update the 2013-15 work plan in the coming year.

Collaboration has taken place with regards network pathways and standards. IBD clinical guidance for GPs and general Paediatricians has been agreed and discussion continues on local, national and European guidelines and standards, such as, national coeliac protocols, persistent jaundice, oesophageal reflux, milk-free diets and ulcerative colitis.

Specialist Nursing colleagues have produced information for families who need to attend as an out- or in-patient at a North of Scotland tertiary hospital away from their area, e.g. family information is now available for families coming to Royal Aberdeen

Children's Hospital, Tayside Children's Hospital, Ninewells and Raigmore Hospital, Inverness.

Video-conference review consultations continue to be carried out between the main centres and more remote locations close to patients' homes, reducing the need for families to travel long distances. This innovative way of working has been chosen as a poster presentation to be presented at the European Society of Paediatric Gastroenterologists and Hepatologists in London on behalf of network colleagues by Carol Cameron in May 2013.

#### 3.4 Training & Education

A very successful Network Education Day was held at the Suttie Centre, Aberdeen on 13<sup>th</sup> June 2012 attended by multi-disciplinary colleagues. Several interesting presentations were well received on topics such as weaning off gastrostomy and psychological therapy, transitional care, biliary atresia, care pathways and audit.

There was also initial discussion during the day on a network draft education & training framework document. Further work has taken place so that this document is a working document; the framework includes such items as:

- principles for delivery of network continuing education and development, network
- learning and educational opportunities
- future network developments and
- website development.

A further Education & Training sub-group meeting took place in November to update the framework and to discuss the development of the network web pages. The network page is currently located on the North of Scotland Planning Group web site however discussion will be required in the coming year in order to improve accessibility of network information by proposing a network specific website is established.

In future, it would be the network's intention to include pages on topics such as:

About Us News & Events Frequently Asked Questions Families & Young People Clinical area Projects Web links to national patient information/packs,

where information for patients and families will be posted so that it can be easily available to aid patients in the management of their disease. It is also intended to post network documents and clinical guidelines for staff.

Monthly **Journal Club sessions** for all network staff are planned by VC again in 2013 on the last Monday in the month from 12-1 pm. A very interesting 'PEG insertion audit' was presented in January with others on practical aspects of a milk-free diet ESPGHAN guidelines, action plans regarding paediatric Ulcerative Colitis guidelines and management of diabetic coeliac patients planned for future meetings.

**Educational Opportunities** – a list of learning opportunities has been included within the Training & Education Framework, so that new staff to the network are aware of what is available on a multi-disciplinary local, regional, national and international basis.

#### 3.4.1 Family Fun Day

A successful Crohn's & Colitis UK sponsored family day took place on 10<sup>th</sup> June 2012 in Dundee with assistance from network nursing and medical staff for network families from Tayside and Grampian (60 attendees). This was a very welcome addition for North families as there had not been a regional family day for this patient group previously.

The day gave families the opportunity to meet with other families and to use the facilities of the Discovery Point to have a look around Captain Scott's ship. The afternoon session was arranged so that the children could take part in activities such as art sessions, the opportunity to dress up in Captain Scott's expedition gear and to learn more about his travels. The teenage/young person age group were given a 'breakout space' to chill out but they were also invited to attend the educational sessions in the afternoon.

Dr Mike Bisset and Dr Richard Hansen gave very interesting presentations during the afternoon. There was also a presentation generously provided by parents of a young person giving their family's experience and sharing their journey. Paediatric Specialist Gastroenterology nurses Carol Cameron and Sarah Nicoll took part in a question and answer session together with Dr Bisset and Dr Hansen.

Feedback on the day was gathered by families completing a questionnaire when they expressed they liked the format of the day and its content. It is hoped to plan a similar day in future with the inclusion of paediatric dietetic and psychology input.

#### 3.5 Clinics

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.

Specialist clinics in Inverness take place every month and during the year 4 clinics were increased to 2 day clinics due to increased numbers of patients (43 new and 100 return patients were seen in 2012). Weekly specialist clinics take place in Aberdeen and Dundee.

There are network clinics in:

- Elgin (bi-monthly IBD currently for follow-ups due to the large numbers of patients). It is intended that this clinic will become a monthly clinic during summer 2013 and will also therefore include new IBD and general gastro patients.
- Shetland (twice per year)
- Perth (monthly).

The majority of the above clinics are supported by Specialist Nurses and also often by Dietitians. Routine coeliac clinics are mostly Dietitian-led.

A new joint gastroenterology clinic with genetics colleagues in Tayside commenced in February 2013. This successful joint clinic, seeing 5 patients was a very positive new addition for families and professionals. It is hoped to hold 2 clinics per year.

There is still an aspiration to provide tertiary clinics on Orkney. Discussions will take place again with NHS Grampian Consultant colleagues in the coming year to monitor types of patients that are currently seen in general paediatric Orkney clinics who may benefit from tertiary gastroenterology or hepatology input in future. Coeliac clinics in Aberdeen and Dundee are likely to increase in number over the next year due to increased demand. Prior to any increase in patient appointments, the opportunity will be taken to review the current model of care.

Multi-disciplinary Team meetings have been found to be invaluable to local teams during the year. They take place every Monday in Aberdeen, at the end of the Tuesday clinic in Dundee and at the end of the specialist clinics in Inverness.

#### Hepatology clinics

Traditionally the North of Scotland paediatric hepatology service has been supported by colleagues 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. The patient numbers have increased and it was difficult to fit in all the patients into a one day clinic. The patients who require more frequent follow-up are followed up in our general gastroenterology clinics.

For these complex patients, in order to provide high quality multi-disciplinary holistic care, we redesigned this service in Aberdeen. Outwith the 2 joint paediatric Hepatology clinics we have set up 4 multi-disciplinary Hepatology clinics which are delivered by Dr S Loganathan, a Specialist Nurse, and a Dietician. With this new design we are able to provide enough time and the quality required for the management of these out-patients. The complex patients from Inverness travel to Aberdeen however some of the stable patients were consulted via video- conferencing facilities along with Reay Urquhart, Specialist Nurse and Dr David Goudie, based in Inverness to provide all the clinical information and results.

The above model is very much appreciated both by parents and by colleagues from King's College Hospital in London as it provides an environment for multi-disciplinary assessment and also continuity of care by the same team. We are working on introducing the same model of care in the Tayside Children's Hospital outwith the current multi-disciplinary joint paediatric Hepatology clinic.

#### 3.6 Theatres/Endoscopy

Dr Bisset and Dr Loganathan carry out theatre sessions in RACH and at Ninewells with over 300 procedures carried out during the year. Procedures include upper and lower endoscopy, capsule endoscopy, liver biopsies, gastrostomies, PEG/button insertions or changes and jejunostomy.

There is good communication with surgical colleagues across the region. NDP funding has enabled surgical colleagues, Mr C Driver, Mr Y Patel and Mr A Salloum to carry out timeous endoscopies or biopsies for network patients in Inverness and Shetland during their routine visits.

Collection of the data by theatres staff has changed during the year in Aberdeen and Dundee to using the Opera IT system. This is a new system used by surgical, nursing and admin teams which has made the extraction of data more complex than previously when manual figures were collected in theatre operation books. In the longer-term it is anticipated that access to accurate information and more in-depth knowledge of the Opera system will improve.

#### 3.7 Research & Audit

#### UK IBD Audit

Dr Loganathan registered NOSPGHANN as a single unit in 2012 which included Royal Aberdeen Children's Hospital, Tayside Children's Hospital and Raigmore Hospital for the 3<sup>rd</sup> round of the UK inflammatory bowel disease audit, i.e. the 2<sup>nd</sup> round for paediatric sites. The North of Scotland is the only unit registered as a Network within this audit.

There are two audit elements,

- 1. the organisation of services for paediatric inflammatory bowel disease and
- 2. the clinical audit of paediatric inflammatory bowel disease in-patient care.

With the investment in posts due to the National Delivery Plan, the network has managed to meet the standards to provide high quality, safe and integrated care for IBD patients based on multi-disciplinary team working and collaboration. Specifically in relation to the audit standards, Aberdeen, Dundee and Inverness have met the minimum requirement of 0.5 WTE of a Gastroenterology Specialist Nurse, immediate access to paediatric surgical services and Dieticians. There has been progress since that time with regards to essential support services such as psychology and multi-disciplinary meetings, communication between primary care and secondary care like immunosuppressive therapy monitoring which will be reflected in the next round of the audit.

For the clinical audit, we managed to input data on 11 ulcerative colitis patients and 10 patients with Crohn's disease. Our network results are on par compared to the national data and also better in some areas. However there is always scope for improvement. We discussed these results in our Network Education day and

Dr Loganathan proposed three key recommendations in the improvement of care; collection of stool samples, pubertal assessment and annual review.

#### 3.8 Specialist Nursing

## RACH Gastroenterology Nursing Service Parent/Carer Experience Audit – July 2012 (*Carol Cameron*)

The above audit led by an RACH Gastroenterology Specialist Nurse, Carol Cameron, was completed during the year. NDP provided funding for the above post in 2010 and the audit was undertaken after being in post for 12 months to evaluate the difference the post was making to the service provided to families. A questionnaire was distributed to parents/carers of children/young people (between the ages of 2 and 16 years) with inflammatory bowel disease (IBD).

The return rate of 94% (44 questionnaires) indicated that parents 'agreed' or 'strongly agreed' that they felt supported in managing their child's IBD and that the gastroenterology nursing service met their requirements.

88% indicated that they were likely to call with any concerns or queries as there is a nurse in post and 96% 'strongly agreed' or 'agreed' that the nurse gave appropriate advice.

25% of families indicated that they had contacted the Specialist Nurse via email which families felt is a fast, reliable way of contacting the nurse when it suits them.

51% of parents indicated that they would like to meet other parents of children with IBD. There was a recent family IBD day in Dundee and several families from NHS Grampian attended. It is hoped to organise an event for network families in the Grampian area in summer 2013.

The evidence from the audit has demonstrated that the post has provided improved support and information for families. In addition, the service was enhanced in 2011 with the appointment of an additional part-time Specialist Nurse which has made an even greater improvement to the support received.

#### 2 day Paediatric Gastroenterology Course, Great Ormond Street Hospital, London (*Sarah Nicoll*)

In November 2012, Sarah had the opportunity to attend a specialist two day course entitled 'Practical Paediatric Gastroenterology' delivered by the Academy for Paediatric Gastroenterology at the UCL Institute of Child Health and Great Ormond Street Children's Hospital.

The course was designed to be practical and easily applied to the clinical practice of a Specialist Nurse. Over the course of the two days the content was delivered in a mixture of lectures, workshops and interactive case sessions, e.g.

**Functional GI Disorders** – Cyclical Vomiting Syndrome & Gastro-oesophageal Reflux.

**Nutrition & Nutritional Therapies** – Dietary management of the Food Allergic Child, Intestinal Failure and Home Parenteral Nutrition & Congenital Diarrhoea.

**Gastroenterology Emergencies & Chronic Pain** – Diagnosis and Management, GI Radiology, Managing Chronic Pain in the GI Patient.

**Inflammatory Bowel Disease and Adolescent GI Medicine** - Adolescents and Transition, IBD management, Impact of Bacteria on Mucosal Immunity and IBD (delivered by Prof Denise Kelly from Aberdeen).

Day Two workshops and interactive sessions:

#### Hepatology & Surgery

**Interactive Clinical cases Sessions –** pulling together the sessions from day one

**Practical Sessions** – Specialised Feeds, Clinical Nurse Specialist 'Practical Tips', Insight into GI Pathology, Investigations in GI Disease (capsule Endoscopy & pH Impedance & Manometry).

The afternoon session included the opportunity to use the endoscopy simulator, which was very interesting.

The course was worthwhile and very informative. It was both educational and stimulating with an excellent range of speakers and topics, with the interactive sessions being extremely valuable.

#### **3.9 Allied Health Professionals**

#### Fun with Food Group (*June Fair, SALT*)

This group was set up and run jointly 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. Clinical Psychology colleagues are also now involved as many of the issues around feeding often result in behaviours which need to be addressed by them. This has been an excellent example of multi-disciplinary teamworking.

Pre-group work now involves parents/carers completing questionnaires about sensory responses, attitudes towards eating, and a food diary. A follow-up questionnaire about attitudes is then completed which can be used as a tool to measure change.

Two groups were run in 2012, with similar groups planned for 2013. 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 commenced in September 2012, following the success of the multidisciplinary approach used for Fun with Food. Due to the multi-faceted reasons for EDS difficulties, it was felt that a joint assessment clinic would allow functional and sensory aspects to be assessed jointly by Speech & Language Therapy and Occupational Therapy. Dietitians are available if there are any nutritional concerns and Clinical Psychology are alerted and involved where there is a behavioural aspect.

Referrals to this clinic are made from all of the disciplines involved. It is providing 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.

#### 3.10 Psychology – Raigmore (*Dr Tracy McGlynn*)

Dr Tracy McGlynn and Dr Rachel Smith both work 0.5 of the Highland Paediatric Psychology full-time post. Rachel has been on a 6 month career break during the year. During Rachel's absence Tracy's job plan, which also covers 0.5 Child and Adolescent Mental Health Services (CAMHS), was revised to allow for continued cover to be provided to paediatric medical specialties. This has meant that children, young people and families continue to have a short waiting time to be seen, approximately 4-6 weeks for routine cases and children of more urgent need are prioritised that same week where possible.

NES designed training for health care staff entitled 'Psychosocial Interventions for Improving Adherence, Self Management and Adjustment to Physical Health Conditions' has been delivered as two full day workshops in Inverness and will form part of a rolling staff development programme. Tracy has also recently undertaken the first part of NES Acceptance and Commitment Therapy (ACT) training. This is a cognitive behavioural psychotherapy that uses mindfulness and behavioural activation to increase clients' psychological flexibility i.e. increase their ability to engage in positive health promoting behaviours when experiencing difficult thoughts, emotions or physical sensations.

Close links have been developed and open communication fostered between paediatric health psychology and the medical teams. The gastro team and patients have benefited from direct input at clinics by Dr McGlynn during the year. This has been a great benefit to patients generally in being able to have early psychology intervention, but they are also able to be seen almost immediately if there is urgent need. The team is also very appreciative of Dr McGlynn's attendance at monthly speciality meetings (prior to clinics) and weekly team meetings to discuss the ongoing management of chronically ill patients.

#### 4. Plans for Next Year

#### 4.1 Network Study Day 2013

With 2013 being the 10<sup>th</sup> year of the North of Scotland gastroenterology and neurology networks, discussions have taken place with clinicians in the North of Scotland Child & Adolescent Neurology Network (NeSCANN) about holding a joint study day in October 2013. Both networks have patients who are known to both gastroenterology and neurology and it is hoped that this will be an interesting day to look at topics that are relevant to both specialties e.g. reflux in the neurologically impaired child, oromotor dysfunction and feeding, mitochondrial disease and gut dysmotility.

### 4.2 Scottish Society of Gastroenterology, Hepatology and Nutrition (SSPGHAN) conference – November 2013

NoSPGHANN will take a lead role in organising the 2 day educational conference on 21<sup>st</sup> and 22<sup>nd</sup> November, 2013. The venue of Stirling Management Centre has been selected with the programme being developed over the course of the next few months. There will be several sponsors of the event from commercial companies as well as voluntary organisations. Registration for the event will take place during the summer.

#### 5. Key Challenges

#### 5.1 Clinical Data - Clinical Audit System

Access to comprehensive clinic and procedures data continues to be a problem for all child health networks across the North of Scotland due in part to the slow progress with the NSD Clinical Audit System. NoSPGHANN manages patients across health board boundaries and work is ongoing to integrate SCi Stores across North health boards which will allow clinicians timely access to patient information prior to adoption of the Clinical Audit System.

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). 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 and NoSPG to adopt a version of the NSD funded system to ensure easy access to information on network patients in the North of Scotland.

#### 5.2 Access to Clinical Portals

Clinicians working across Health Board boundaries continue to have issues with accessing other Boards' IT systems to view or sign clinical letters and results when working outwith their home Board. It has been possible to gain access whilst delivering clinics in specific Health Boards however access to individual systems from a remote location remains problematic and not ideal from the aspect of clinical governance. The issue of access to network patient information is improving with projects ongoing between NHS Grampian, Highland, Orkney and Shetland to allow authorised access to Grampian ECCI letters (clinical letters) but it is hoped that this can now be addressed by applying for remote access through e-Health departments.

#### 6. Looking Ahead

The network is in a very good position to continue to develop and to improve the way services are delivered and to sustain a first-class secondary and tertiary service to gastroenterology and hepatology patients across the North of Scotland in the year ahead. The dedicated work of the network has been built on through willingness and close collaboration across the North over the past 10 years. It is all carried out by 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 enthusiastically to developing the aims and work of the network further in 2013/14.

# Appendix 1 - Gastroenterology, Hepatology & Nutrition network staff involved in delivery of NoSPGHANN – 2012/13

Network Management	POST	Comment	
Dr Mike Bisset	NoSPG Child Health Clinical Lead and Network Clinical Lead		
Carolyn Duncan	NoSPG Child Health Network Manager	Also Network Manager for NoS neurology and respiratory networks	
ABERDEEN	POST	Comment	
Dr Mike Bisset	Consultant Gastroenterologist	Also working in Tayside & Highland	
Dr Sabari Loganathan	Consultant Paediatric Gastroenterologist	Also working in Tayside & Shetland	
Dr Gulshan Malik	Locum Consultant Paediatrician with a	Locum position ended in December	
Di Guishan Flank	Special Interest	2012	
Ann Morrice	Medical Secretary	Part-time	
Stephanie Taylor	Medical Secretary	Part-time - Commenced January 2013	
Carol Cameron	PGHN Specialist Nurse	Also working in Shetland specialty clinic and Metabolic Specialist Nurse	
Julie Knight	PGHN Specialist Nurse		
Kathleen Ross	Head of Paediatric Dietetics	Also working in Shetland NDP provided 0.3 dietetic network support	
Hilary Rennie	Dietitian		
Eleanor Davidson	Dietitian	On maternity leave	
Dr Murewa Akintola	Psychologist	On maternity leave	
Winnie Taylor/June Fair	Speech & Language Therapy		
Jo Thomas	Senior Occupational Therapist		
Angie McCallum	Dietetic Assistant		
Martina Freeman	Pharmacist		
Dr Richard Hansen	University of Aberdeen/NHS	Clinical Researcher – presently in Glasgow	
Physiological Technician	Post provision under discussion with adult service		
DUNDEE			
Dr Dagmar Kastner	Consultant Paediatrician with a Special Interest		
Dr Buddhi Gunaratne	Consultant Paediatrician with a Special Interest	1 session	
Gillian Cormie	Medical Secretary	shared NDP funding	
Joanna Malone	Medical Secretary	N	
Karen McIntyre	PGHN Specialist Nurse		
Sarah Nicoll	PGHN Specialist Nurse		
Clare McLeish	Dietitian		
Unnamed	Psychologist	Provided by NHST Psychology team	
Dr Paul Fettes	Consultant Anaesthetist	2 sessions to support endoscopy theatre sessions	
INVERNESS			
Dr David Goudie	Consultant Paediatrician with a Special Interest		
Agnes MacIntyre	Medical Secretary		
Reay Urguhart	PGHN Specialist Nurse		
Michelle Nimmons	Dietitian		
Dr Tracy McGlynn	Psychologist	NDP funding shared with neurology network	
Dr Rachel Smith	Psychologist	"	
SHETLAND			
Dr Susan Bowie	GP with a Special Interest	Based at Hillswick Health Centre	

NoSPG/Child Health/NoSPGHANN/2012-13 Annual Report



#### Appendix 2 Paediatric Gastroenterology, Hepatology & Nutrition Network (NOSPGHANN) Work Plan 2011-13



Objectives	Outcome	Tasks	Timescales	Lead Professionals	Progress at Dec 2012
Establish a Paediatric Gastroenterology Steering Group	Identify membership across all North of Scotland Health Boards and ensure regional priorities for the network	<ul> <li>Develop role and remit</li> <li>Agree schedule of meetings</li> <li>Agree on work plan</li> <li>Develop a performance monitoring framework to monitor implementation of the work plan</li> </ul>	Oct 2011	W M Bisset C Duncan	Steering group established and work plan agreed and ongoing review.
Map, develop and agree care pathways	Develop region care pathways to ensure consistency across the network, establishing links to national/other regional networks	pathways and identify any gaps	2011/12	S Loganathan D Goudie D Kastner W M Bisset	Work complete on 3 <sup>rd</sup> draft of IBD care pathway for GPs and general Paediatricians Working on national coeliac protocols, persistent jaundice, oesophageal reflux, etc.
Implement planned outreach out-patient clinics across the North	Ensure patients have access to a local, safe, sustainable, high quality service	<ul> <li>First outreach clinics in Shetland, April &amp; October 2011</li> <li>Develop bi-monthly clinics at Dr Gray's, Elgin (first clinic August 2011)</li> </ul>	2011	W M Bisset C Cameron	Clinics working well. Looking to increase to monthly in Elgin when staffing allows.
Review and develop VC consultations with patients/families in remote locations	Improve equity of access by continual review of model of care and to reduce need for staff/patient travel and reduced costs		2011/12	C Cameron C Duncan	Survey final report completed July 2012.
Develop a network Communication Plan for professionals and families	Increase awareness of the network for all stakeholders and enhance families' knowledge of service and of disease information	<ul> <li>Develop a Communication Plan</li> <li>Develop patient information and involvement leaflets</li> <li>Investigate Web possibilities to develop network website</li> </ul>	2011-13	K Ross K McIntyre C Duncan	Communication Plan in place. Network web page now set up on NoSPG website, with further development planned for 2013.

Objectives	Outcome	Tasks	Timescales	Lead Professionals	Progress at Dec 2012
Develop network education framework	Ensure appropriate skill mix of professionals and maintain and develop professional expertise locally and across the network	learning needs		W M Bisset K Ross D Goudie C Duncan	VC teaching sessions commenced in RACH and will be rolled out across network. NOSPGHANN education framework document distributed at Network Education Day 13.6.12.
Implement 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	<ul> <li>For discussion and agreement at NoSPG to develop system according to needs of the network</li> <li>Discussions with preferred provider in order to tailor the system to meet service and network needs</li> </ul>	2011-13	W M Bisset C Duncan	Development of NSD Clinical Audit System for child health networks agreed in principle at NoS Clinical Leads project meeting on 22.8.12. Project Initiation Document taken to Child Health Clinical Planning Group 12.9.12.

#### Red/Amber/Green 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