

NORTH OF SCOTLAND PLANNING GROUP



North of Scotland Paediatric Gastroenterology, Hepatology and Nutrition Network

Annual Report 2017-18





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1. Introduction

Welcome to the 7th annual report from the North of Scotland Paediatric Gastroenterology, Hepatology and Nutrition Network (NOSPGHANN). The network was established in 2002 and supports children with disorders of the gastrointestinal tract, disorders of the liver and complex nutritional issues across 5 Health Boards. The network's core aims are to provide the highest quality of clinical care as close to patients' homes as is safe and appropriate to do so.

This year has been a year of great challenges and changes. We started the year with acute medical staffing pressures however we are happy to report that due to the hard work of network and local management teams that we had a fantastic outcome - 2 new Consultant Paediatric Gastroenterologists joined the network team in Royal Aberdeen Children's Hospital in the second half of the year. Dr Iain Chalmers joined in September following completion of his specialty training and Dr Su Bunn returned to the North of Scotland having worked in Newcastle for several years. Dr Mike Bisset, the founder of the network, retired from clinical practice in November however he left the service happy in the knowledge that the network is now in a very good position moving forward. We wish him well in his well earned retirement.

Network staff continue to work in partnership across Health Board boundaries for the benefit of children and young people across the North of Scotland providing safe, efficient, effective, person-centred care. There continues to be a year on year increase in the numbers of complex patients who require specialist care with large numbers now being treated using biological therapies. Depending on the type of biologic therapy used, this often means the patient having to attend the hospital every 8 weeks to have their infusions. The multi-disciplinary teams are under unrelenting pressure due to the additional care this patient group requires, with no additional resource being allocated to support existing staff.

Specialist visiting gastroenterology clinics continue to be delivered in Aberdeen, Dundee, Perth, Inverness and Elgin with specialist nutrition clinics also taking place in Shetland.

Our priority for last year was to be able to sustain a full gastroenterology service across the North and this was achieved through very hard work. Recruitment to the vacant Consultant post was the main aim and due to additional funding becoming available in Grampian, not one but 2 Consultant Gastroenterologists (a total of 18 PAs) were successfully recruited. We also agreed to work on the issue of data collection and small steps have been made to address this in collaboration with RACH management. Meantime regional discussions regarding IT cross boundary access and data are ongoing in view of the Scottish Government announcement that all Health Boards are required to work more collaboratively and to produce Regional Delivery Plans by March 2018.

The development of a local clinical physiology service in RACH to carry out pH impedance for network patients was also successfully commenced, with new equipment having been purchased and relevant training carried out.

2. Network Governance

The network steering group is accountable to the North of Scotland Planning Group and reports into the NoS Child Health Clinical Planning Group. We have a mission statement, agreed remit and terms of reference.

We were pleased that Dr Dagmar Kastner-Cole, Consultant Paediatrician in Tayside Children's Hospital, was appointed as our network Clinical Lead in Spring 2017. Carolyn Duncan continues to support NoSPGHANN as Network Manager.

The network was delighted when Elaine Steven, from Crohn's & Colitis UK, agreed to become a member of our network steering group. Elaine's input and advice to our network from a patient perspective has already been invaluable and we look forward to working together in the coming year.

From April to October Dr Bisset provided a tertiary service in Dundee, Inverness and also supported the Aberdeen service. Dr Shyla Kishore provided a specialist service in Grampian together with Dr Gamal Mahdi, Locum Consultant, working on an ad hoc basis until October 2017. Dr Dagmar Kastner-Cole and Dr David Goudie continue to lead their services locally in Dundee/Perth and Inverness.

Several times a year there are virtual biologics clinic held by video-conference between clinicians in Aberdeen, Dundee and Inverness to review patients being treated by biologics across the network. Patients are also discussed who are being considered for starting a biologic therapy.

The network continues to identify the importance of continued development for professionals to develop their knowledge and skills to ensure provision of a highly trained workforce. Formal and informal educational and learning opportunities are available either in person or by video-conference (monthly) to network and other interested local staff for their professional development. In addition there is the annual 2 day Scottish Paediatric Gastroenterology, Hepatology and Nutrition conference in November in Stirling which North network staff take part in and which is well attended by many of our staff.

We are also committed to the teaching and training of our multi-disciplinary staff. Network staff are presently supporting 2 paediatric trainees in the North of Scotland who are currently doing SPIN modules in gastroenterology (special interest in gastroenterology modules).

BSPGHAN Standards

The British Society of Paediatric Gastroenterology, Hepatology and Nutrition in collaboration with the Royal College of Paediatric and Child Health published the 'Quality Standards for Paediatric Gastroenterology, Hepatology & Nutrition' in 2017. Network staff were involved in the development of these standards. A network benchmarking exercise was undertaken with positive results.

The Standards that would be challenging to meet across Scotland are –

<u>Standard Two</u> – Access to telephone advice with adequate capacity to transfer to the tertiary centre 24 hours a day 7 days a week.

<u>Standard Eight</u> – Children receiving home parenteral nutrition (HPN) are cared for by an intestinal failure or designated HPN unit with a multi-disciplinary team. (There is no designated paediatric HPN unit in Scotland at present).

• The de-designation of the national HPN MCN in January 2011, which ensured the coordination of standards of care for patients requiring parenteral nutrition, has been perceived by PGHN staff as a bad decision for patients.

It is clear that there are now well established regional PGHN networks in Scotland working hard to provide safe, equitable, sustainable care for patients. Over the past couple of years it has been acknowledged that in order to provide equitable, high quality care across Scotland, discussion on certain aspects of PGHN care (e.g. intestinal failure) and the potential to deliver these in a more co-ordinated manner nationally will continue to be discussed.

3. Network Updates

3.1 Staffing

Despite the Consultant Gastroenterologist vacancy earlier in the year, continuity of care was not diminished due to the efficient care provided by specialist medical and nursing staff, dietitians, psychology, pharmacy and speech and language therapy staff.

- The 6 hrs nutrition nurse vacancy in RACH unfortunately continued during the year. This added to the pressure on existing specialist nurses. Ideally there should be a third specialist nurse as data shows gastro patient numbers and the complexity of their care has increased considerably over the past 5 years. However there is no additional resource available. Discussions have commenced with regards to redesign use of these hours.
- During the year there were several pressures in the region's dietetic services due to vacancies and absences. Tayside Children's Hospital in particular has experienced a huge gap and severe pressures at times and has been running at 60% capacity. Although vacancies have been advertised recruitment has been unsuccessful and discussion with adult managers continues as to how these posts might be filled in future.
- Dr David Goudie and Mhorag Robertson (Specialist Nurse) have started to deliver 2 joint liver clinics a year with Dr Tassos Grammatikopoulos from Kings College London by videoconference. This saves patients and families travelling long distances to Aberdeen or Dundee to be seen in the twice yearly clinics in these locations. Patients come to see Dr Goudie and Mhorag in Inverness and are examined by Dr Goudie. This also relieves the pressure on Aberdeen and Dundee clinics which are always very busy.

Inverness transition clinics were also improved during the year. Dr Goudie and Mhorag attend adult MDT meetings and present the young person who will be transitioning. The patient is then seen in the paediatric GI clinic where they meet the new consultant and the adult IBD nursing team. Mhorag is also able to meet with the young person on several occasions before the final transition to discuss and support them through the process. Mhorag uses the Ready, Steady, Go transitions information pack (developed in Southampton) with the patient and also facilitates visits to the adult infusion suite and meetings with the adult nursing team.

- A full endoscopy service for network patients was carried out during the year. There is increasing need for endoscopy in the network with more requirements for complex patients. The theatre sessions are very busy in Aberdeen and Dundee and are always fully utilised. In addition endoscopists are very flexible in carrying out extra sessions when available and also for making urgent diagnoses. Over 300 patients were seen in Aberdeen and 82 in Dundee during the year for a variety of procedures, e.g. upper GI endoscopy, colonoscopy, polypectomy, feeding tube issues, biopsies.
- The network is grateful to paediatric surgeon colleagues, Mr Driver, Mr Patel, Mr Salloum and Miss Clarke based in Aberdeen, who work in collaboration with network staff to provide timely surgical procedures and upper GI endoscopies as close to patients' homes as possible. The National Delivery Plan 2008-2011 provided funding to resource paediatric surgery provision in the Highlands and Islands and over the years since this has meant that upper GI endoscopy is carried out in Raigmore and Shetland timeously for network patients. This often negates the need for patients to travel to Aberdeen causing less disruption to families. Paediatric surgeons attend the RACH weekly MDT to discuss complex network patients which is invaluable. They also treat Tayside patients in Aberdeen when they have been involved in their care jointly with the network GI consultants.

3.2 Reporting against Work Plan

Work continues on the agreed objectives however greater progress was hampered by operational pressures in each of the mainland Health Boards (see Appendix 2).

The network produces a Risk Register which is updated at regular intervals and discussed at steering group meetings. Higher level risks are reported to the North of Scotland Planning Group when appropriate. Recruitment to the vacancies, the lack of data support and data collection, cross boundary IT systems access issues and service pressures were all raised and discussed during the year.

• <u>Network Education Framework</u>

The network continues to support and develop professional expertise through several local, regional and national educational opportunities. Monthly video-conferences for multidisciplinary staff take place on a variety of topics. A joint network study day is being organised with the NoS regional complex respiratory network (NoSPRN) in Aberdeen on 25th May 2018.

• <u>Service Satisfaction Questionnaire</u>

Due to staffing pressures it was not possible to carry out the network service satisfaction questionnaire during the period. Elaine Steven (Crohn's & Colitis UK) helped greatly in reviewing the questionnaire to improve the wording and it is hoped that the responses from patients and families will be more informative. The NHS Grampian Clinical Effectiveness Team will support the network again to carry out this survey in May 2018.

Data & Access to IT systems

The ability to collect meaningful data continues to be a recurring theme within NoS child health networks. The lack of a regional data collection system persists. However there are now plans for Health Boards to work together regionally to share information therefore it is hoped that provision of regional solutions may be possible in the near future.

Issues with cross boundary access to North of Scotland Health Boards' clinical systems allowing clinicians to see up-to-date data or test results continue. This hampers clinical decision making if clinicians do not have access to patients' data outwith their home board and could potentially pose a risk to patient safety with not having access to up-to-date patient information. NHS Tayside has now also started to use Trakcare which will hopefully help with access between Grampian, Highland and the Islands in future.

• UK IBD Registry & audit

Following successful discussions with NHS Grampian Child Health management, admin support became available for support one day per week so that the network could input to the national IBD Registry (including biologics therapies data collection) and audit. Vongai Chipadza carried out a huge amount of work in order to get Caldicott Guardian approval from the 3 mainland Health Boards so that she could input data to the Registry on their behalf. The transfer of network information from the paediatric database held by the RCPCH previously to the new IBD Register (adult and paediatric data merged) managed by the Royal College of Physicians was commenced successfully. However due to maternity leave this was unable to be continued from autumn 2017. Recent communication with Edinburgh and Glasgow gastro services has indicated that this database may not be fit for purpose for Scottish units therefore further discussion will take place as to our need to take part in future.

• Gastro Physiology Service in RACH

A pH impedance service started in March 2018. Trish Flanagan now works one day per week to provide this service for network patients. New equipment was purchased, with supplier training sessions for relevant staff taking place in February. Reporting of results by Trish will be supported by colleagues in Glasgow initially. The adult service in ARI has now also purchased the same impedance equipment which will ensure continuity on site in future.

Dialogue with the adult service in Aberdeen to carry out small numbers of manometry and capsule endoscopy for paediatrics is ongoing.

• Crohn's & Colitis UK involvement in NoSPGHANN

Elaine joined us during the year. She will act as a conduit between this well known patient organisation and the steering group to develop the communication needs of families. She will also provide advice and guidance to the network on what patients and families might need to improve health services delivery. She will also ensure disease specific communications from Scottish Government or national organisations are shared with the network.

3.3 Patient Stories

Lovely Compliment for the Tayside Gastro Nurses

L. was diagnosed with Crohn's Disease in January 2016, in the same week I was having surgery for breast cancer following chemotherapy. This was a difficult time for us as a family, juggling everyone's treatment and emotions. We were supported fully by the gastro nurses, Karen and Sarah who were always contactable if I had any questions or just needed support.

The diagnosis of Crohn's Disease was a shock to L. and he immediately had to go on a 3 month liquid only diet which was very difficult and did impact on family life but again we got through this stage with the support of Karen and Sarah.

For the last 2 years we have been attending hospital regularly and when I noticed that L. was not too well a phone call to the gastro nurses meant a quick response and attention of treatment. L. is very well at the minute, having regular treatment at PRI and Ninewells where we have dealt with such lovely and supportive staff. It is a fantastic service and for me as a single mother of a child with a chronic illness I appreciate the support we have all be given.

Karen McIntyre & Sarah Nicoll

Grampian Specialist Nurse Compliments & Service Update

We have had a number of young people with IBD transition over the past year to adult services and have received thanks from both the young people and their parents for Specialist Nurse support from Carol & Brenda.

A 16 year old girl said "Putting the gratitude I owe you into words would be near impossible, you have gone above and beyond your role as I feel that my "journey" has been made much easier due to the level of care I received from you both and the IBD team."

Parent of L, 17 year old girl said "I can't thank you both enough for all the support and knowledge you have given me, answering my many phone calls and supporting L in clinics and hospital stays over the last four years, we couldn't have done it without you both."

Parent of C, 17 year old girl gave her thanks to the whole team for supporting their whole family through very difficult times and for being on the end of the phone when they needed advice.

Specialist Nurse Service Update

Monthly enteral training sessions are held in RACH and attendees include professionals from health, education and social work. An additional support needs school feedback "thank you so much for your input, staff were delighted with their update and your session has greatly increased the confidence of the pupil support assistants who are completing the feeding regime for our pupils."

When patients are newly diagnosed with IBD or if certain medications are used the Gastroenterology Specialist Nurses call families to provide advice and support and to review their child's symptoms and if required also prescribe or increase medications. However, with working parents it has been difficult at times to be able to contact families. Two new telephone clinics have been established which means that families are now given a date and time the

nurse will call and this has made it much easier to get in touch with parents. It also enables the nurse to have formal documentation which is shared with primary care.

Student Nurses in both 2nd and 3rd year spend either a 4 or 6 week placement with the Gastroenterology Specialist Nurses in RACH and we also have students on spokes for 1/2 days during the year. The placement enables students to gain an understanding in the specialist nurse role of, advising, teaching and empowering parents to care for their child at home with a chronic health condition. Students work alongside the Specialist Nurse and all students have indicated how they thoroughly enjoy both the varied opportunities available and working closely with all members of the multi-disciplinary team.

Congratulations from the network go to Carol who graduated from Napier University with an MSc in Advanced Practice (Child Health) following two years of intensive studies.

Carol Cameron & Brenda Smart

Aberdeen Psychology service

I like to meet, wherever possible, with children, young people and their families at the beginning of their contact with the gastro team. This is for two reasons. Firstly, it allows me to be known as a normal part of the team rather than someone they need to know only when faced with health-related psychological difficulties. Secondly, it enables me to begin to build a relationship with them, which I think helps them make contact with me in times of need. Also, the focused goal of my work with patients can often unfold and change over time. We initially meet for one reason, then close the case and then months or years pass and we meet again about the original issue or something different. This patient's story below exemplifies both the importance of meeting at the time of diagnosis and the changing form therapeutic contact can take.

I met this young person first in 2014 to think together about the worries and concerns she held about her newly diagnosed Crohn's disease. Moreover, she found that these worries and concerns were getting in the way of her getting back to doing the things she enjoyed. We spent time together understanding her anxieties. She also had some health-related questions about her diagnosis, which the gastro team happily answered. The combination of addressing her health concerns and making sense of her anxieties together with her own resilience and family support led to her re-engaging with school and valuing everyday activities.

I then met with her again in 2017 due to her anxieties around taking one form of her medication. We spent time understanding her worry and we practiced therapeutic techniques. Again, she is a remarkably resilient young person and she managed to continue to take the medication.

Dr Anna Clancy, Clinical Psychologist

4. Research & Audit

During the year network staff continued to contribute to national and international research projects e.g. the GEM study (genetic, environmental and microbial interactions in IBD) and the CAPE study (long-term observational study of patients with Crohn's disease on adalimumab).

Network involvement in the PREdiCCT study was also investigated. This is the first study of its kind and is specifically directed toward understanding how environmental factors and the gut microorganisms influence IBD flare and recovery. Involvement in a new study is also being explored regarding the new biologic Vedolizumab.

Audit – various audits were carried out across the network during the year, including work on copper deficiency in jejeunal feeding, Azathioprine metabolites, Infliximab and blood levels and coeliac disease.

5. Plans for the Year Ahead

We have had an extremely busy year due to several staff vacancies which resolved during the period and the network is now in an excellent position moving forward.

- The issue of capacity continues to be a major issue and staff in each main centre will be unable to sustain this increasing workload in the longer term. As in previous years the network service plan will be reviewed and resources adjusted where possible according to patient need.
- Despite attempts to manually collect network data during the year, these efforts were thwarted due to the many operational pressures which took precedence across the region. A number of IT issues with regards remote clinician access to North of Scotland Health Board systems (e.g. Sci Store/Trakcare for patient results and clinical letters) have been highlighted to the North e-Health Leads and it is hoped that the push towards greater collaboration across the North will make efforts to resolve some of these issues in the coming year.
- Looking to the future and succession planning in the medical workforce, plans have commenced in discussion with colleagues in Glasgow and the CSAC with regards the creation of a North GRID post from August 2019 (rotation between Aberdeen, Glasgow and Kings College London).
- Royal College of Physicians JAG Paediatric Global Rating Scale for endoscopy there is now a requirement to meet these endoscopy standards nationally. Dr Chalmers will lead this work to ensure network endoscopy centres in Aberdeen and Dundee meet the standards. This is also required so that the network is recognised as a training centre ensuring there is the ability to train a GRID trainee in future.

We will continue to provide safe, effective, timely care and to drive up standards and service improvements by working collaboratively and sharing best practice across NoS health board boundaries. We will continue to encourage and provide access to regular network learning and educational opportunities locally, nationally or internationally to ensure a skilled workforce.

Grateful thanks go to all of our network staff for their continued dedication, commitment and hard work. We remain proud of our achievements in being able to deliver the best quality gastroenterology, hepatology and nutritional care to patients and families as close to their homes as possible across the wide geographical area that is the North of Scotland.

Gastroenterology, Hepatology & Nutrition network staff involved in delivery of NoSPGHANN – 2016-17

Network Management	POST	Comment			
Dr Dagmar Kastner-Cole	Network Clinical Lead	Network Clinical Lead and Consultant Paediatrician with a special interest			
Carolyn Duncan	NoSPG Child Health Network Manager	Also Network Manager for NoS neurology and respiratory networks			
ABERDEEN	POST	Comment			
Dr Mike Bisset	Consultant Paediatric Gastroenterologist	Retired November 2017			
Dr Shyla Kishore	Consultant Paediatric Gastroenterologist				
Dr Gamal Mahdi	Locum Paediatric Gastroenterologist	Part-time until October 2017			
Ann Morrice	Medical Secretary	Part-time			
Stephanie Ramsey	Medical Secretary				
Carol Cameron	PGHN Specialist Nurse	Also Metabolic Specialist Nurse			
Brenda Smart	PGHN Specialist Nurse				
Kathleen Ross	Lead Dietitian				
Hilary Rennie	Dietitian				
Hazel Weir	Dietitian	On maternity leave			
Dr Anna Clancy	Clinical Psychologist	0.4 wte			
June Fair	Speech & Language Therapy				
Angie McCallum	Dietetic Assistant				
Martina Freeman	Pharmacist				
Trish Flanagan	Physiological Technician	1 day per week - pH impedance input			
Vongai Chipadza	Data Admin support	1 day per week prior to maternity leave			
Mr Chris Driver	Consultant Paediatric Surgeon	And Shetland			
Miss Melanie Noble	Consultant Paediatric Surgeon				
Mr Yatin Patel	Consultant Paediatric Surgeon	And Inverness			
Mr Adnan Salloum	Consultant Paediatric Surgeon	And Inverness			
DUNDEE					
Gillian Cormie	Medical Secretary				
Joanna Mulreany	Medical Secretary				
Karen McIntyre	PGHN Specialist Nurse	Also Rheumatology Specialist Nurse.			
Sarah Nicoll	PGHN Specialist Nurse	27 1			
Clare McLeish	Senior Dietitian				
Suzie Stephen	Dietitian	Maternity leave from July 2017			
Tracy Cameron	Dietitian	Until autumn 2017			
Siobhain Swaine	Clinical Associate Psychologist	0.2 wte			
Dr Paul Fettes	Consultant Anaesthetist	2 sessions to support endoscopy			
INVERNESS					
Dr David Goudie	Consultant Paediatrician with a Special Interest				
Agnes MacIntyre	Medical Secretary				
Mhorag Robertson	PGHN Specialist Nurse				
Michelle Brown	Dietitian	On maternity leave			
Dr Tracy McGlynn	Psychologist	Maternity leave until end 2017			
Stephanie Bannon	Psychologist	Provided cover until Nov 2017			
SHETLAND					
Dr Susan Bowie	GP with a Special Interest	Based at Hillswick Health Centre			

Paediatric Gastroenterology, Hepatology & Nutrition Network (NOSPGHANN) Work Plan 2017-18

This work plan contains objectives that the network will work on during the year. The content will be reviewed at regular network steering group meetings.

A risk register is produced by the network and will apply alongside this work plan.

RAG status key	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	

	Objectives	Outcome	Tasks	Timescales	Lead Professionals	Progress at March 2018
1.	Continue to map, develop and agree care pathways Person-Centred, Efficient, Safe	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 so that network documents are developed & reviewed Link with national/regional groups to inform existing or new protocols, standards and referral pathways 	2017-18	S Kishore C Cameron D Goudie D Kastner C Duncan	Local/national protocols in use and any new network pathways will be developed as needed.
	Linclent, Sale		 Discuss use of national/regional care pathways in NoSPGHANN 			Amber
2.	Develop network web pages for professionals and families Person-centred, safe, timely	Increase awareness of the network for all stakeholders and enhance families' knowledge of service and of disease information	 Develop a network service satisfaction questionnaire (in conjunction with Clinical Effectiveness in NHS Grampian) to seek views of current service and development possibilities. Further develop network web pages on NoSPG website to include 	2017-18	S Kishore C Duncan S Nicoll K Ross	Network service satisfaction questionnaire to be carried out in April/May. Analysis expected July/August 2018.
	-		protocols/guidelines in future.			Amber

	Objectives	Outcome	Tasks	Timescales	Lead Professionals	Progress at March 2018
3.	Continue discussions on implementation of an appropriate paediatric clinical audit system Person-centred, safe, equitable, timely	Improve clinical data collection to have ability to collect patient demographic and disease information to facilitate audit and to enhance patient care	 Continue discussions regionally with need for a data collection system for NoS networks 	2017-18	D Kastner C Duncan	Still no child health database within NoS. Regional Delivery Plan - regional IT staff now looking at provision of regional solutions.
4.	Audit clinical care and research Effective, efficient, safe	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 data to input to national the IBD Registry (including biologics therapies data collection) and have capacity to audit data Participate in the national GEM study (covering genetic, environmental and microbial interactions in IBD) Participate in the CAPE study (long-term observational study of patients with Crohn's disease on adalimumab) 	2017-18	S Kishore D Kastner C Cameron S Nicoll I Chalmers	Input to IBD Registry now in question Scotland-wide. Network staff and patients involved in GEM & CAPE studies. New PREDICT study potential.
5.	Develop a comprehensive network gastro physiology service in RACH Effective, efficient, person-centred, timely	Set up a pH impedance in RACH and fund assistance on manometry and capsule endoscopy service from ARI	 Meet with ARI physiology staff and managers to identify funding to carry out manometry and capsule endoscopy reporting 	2017-18	D Kastner C Duncan S Kishore I Chalmers	RACH pH impedance now in operation. Dialogue with adult ARI service re provision of manometry/capsule endoscopy ongoing.

	Objectives	Outcome	Tooko	Timescales	Lead Professionals	Progress at March 2018
6.	Develop deeper links with patient representative organisation/s specific to gastro conditions Person-centred, effective	Enlist a new network steering group member to be involved in future work of the network by providing advice and support on families' engagement.	 Tasks New member to act as a conduit between patient organisation/s and the group to develop the communication needs of families. Provide advice and guidance to the network on what patients and families need to improve health services delivery. Ensure relevant disease specific communications from Scottish Government or national organisations are shared with the network. 	2017-18	D Kastner C Duncan	Elaine Steven, Crohn's & Colitis UK, now network steering group member.
7.	Carry out Royal College of Physicians JAG Paediatric Global Rating Scale assessments for endoscopy provision across network Safe, effective, efficient	Organise and complete appropriate assessments so that JAG endoscopy standards are met to ensure network endoscopy centres are recognised as training centres	 Ensure correct linkage between the Endoscopy Management System (EMS) reporting/audit tool and the JAG assessments Ensure appropriate tools and equipment needed for Ninewells theatres are identified. Ensure assessments are carried out so that there is the capacity to train a GRID trainee in the network in future 	2017-2018	I Chalmers S Bunn S Kishore D Kastner	EMS software to be installed on paediatric theatre computer. Build of second Ninewells paediatric theatre on hold. Amber
8.	Involvement in provision of gastro equipment and theatre sessions capacity for endoscopy in Ninewells planned 2 nd theatre Efficient, equitable	Co-ordinate with Tayside Women and Children's Health Service management in the planning for the new 2 nd theatre to ensure appropriately equipped for gastro endoscopy service	 Liaise with Susan Bean, Service Manager with regards endoscopy, IT and other equipment Liaise with regards future theatre sessions provision 	2017-2018	I Chalmers S Bunn D Kastner	Work on hold meantime. Amber