Annual Report 2015-16
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1. Introduction

Welcome to the 5th annual report from the North of Scotland Paediatric Gastroenterology, Hepatology and Nutrition Network’s (NOSPGHANN). 2015-16, which is the twelfth year the network has been in operation but 5 years since the network was formally established following funding from the Scottish Government National Delivery Plan for Specialist Children’s Services 2008-2011. It has been another busy year in the provision of secondary and tertiary gastroenterology, hepatology and nutrition services across the North of Scotland. This report and previous years’ reports can be accessed at – http://www.nospg.nhsscotland.com/index.php/child-health-camhs/nospghann

The main aims of the network continue to be to provide safe, efficient, effective, equitable, person-centred, and timely care of the highest quality. Excellent partnerships exist between tertiary, secondary and primary care with local teams working collaboratively on a daily basis in the acute and community sectors across five North of Scotland Health Board boundaries. Multidisciplinary teams of clinicians work extremely hard in each of the 3 main centres at Royal Aberdeen Children’s Hospital, Tayside Children’s Hospital, Dundee and Raigmore Hospital, Inverness to support children and young people with disorders of the gastrointestinal tract, the liver and complex nutritional issues.

2. Network Governance

The network is accountable to the North of Scotland Planning Group. Dr Mike Bisset was appointed as the North of Scotland Regional Medical Director from April 2015 (2 year secondment, 5 PA post). During the year he stepped back from the NoSPGHANN Clinical Lead role (2 PAs) which was advertised but unfortunately there were no applicants. However from 1st November, Kathleen Ross, Lead Paediatric Dietitian, NHS Grampian, agreed to take on the network Clinical Lead role for a temporary period (2 sessions). Carolyn Duncan continues as Network Manager.

We are very proud of the excellent team working and good communication carried out by our network’s multi-disciplinary teams across the region. Staff continually review the models of care to make improvements to services provided across the wide geographical area that is the North of Scotland. Patients and families continue to benefit from delivery of safe, appropriate care as close to their homes as is possible and we continually strive to ensure equity of services across the region.

GP and in hospital referrals to gastro services across the region continue to rise year on year, due to increasing numbers of chronically ill gastro and hepatology patients. In Dundee and Inverness referrals are managed by patients being seen initially in general paediatric clinics which can reduce the burden on the specialist tertiary service. In RACH there is not the same support from a general paediatric service therefore the acute increase in referrals puts extra pressure on an already busy team. Numbers of patients being diagnosed with coeliac disease, increase demand for endoscopy and the use of biological therapies all continue to rise year on year with no increased resources becoming available within services. Due to the above reasons capacity is an issue and work will be carried out in the coming year to identify future network staffing needs.

We continue to ensure provision of a highly trained workforce and we support staff by encouraging training and learning either by formal or informal educational opportunities. A weekly multi-disciplinary meeting takes place in RACH and monthly team discussions in Dundee and Inverness.
3. Service Updates

3.1 Staffing

Staffing vacancies or absences have made this year extremely challenging when delivering secondary and tertiary gastroenterology, hepatology and nutrition services. Staff work consistently over and above to ensure patients are seen or treated timeously across the network.

Medical Staffing

Due to the 5 PA gap in service in NHS Grampian with Dr Bisset moving to his North of Scotland Planning Group Regional Medical Director role, a secondment vacancy was advertised but was unable to be recruited to. However the network was delighted when Dr Gamal Mahdi, who had previously worked full-time in RACH and with the network, agreed to provide Locum Consultant cover on a flexible basis. This means that a large number of additional out-patient clinics and theatre endoscopy sessions have been able to be carried out and indeed waiting times have been reduced due to his experienced, targeted input.

Unfortunately, in January we bid farewell to our Consultant colleague, Dr Sabari Loganathan, who moved back to Nottingham. Dr Loganathan had been in Aberdeen for almost 6 years and had made a valued contribution to the work of the network. Together with his work in RACH, Elgin and Shetland, he had also delivered a monthly endoscopy session and clinics in Perth and Dundee. We will really miss him but wish him and his family all the very best down south. Arrangements are in place to recruit to the full-time Consultant post (National Delivery Plan funding) during summer 2016 and the post has been advertised.

The current gap in Consultant cover in Aberdeen and Tayside (network tertiary activity) due to Dr Loganathan's resignation is being able to be covered by Dr Savvas Karkelis, who commenced as a full-time Locum Consultant in RACH at the start of January. Dr Karkelis will also carry out clinics in Perth.

AHP Staffing

We welcomed Michelle Nimmons, Dietitian and Dr Tracy McGlynn, Psychologist, back from maternity leave in early summer 2015. Michelle is now working 3 days per week and Dr McGlynn has also reduced her hours.

Both dietetic services in Aberdeen and Dundee have experienced many staffing pressures due to absences and vacancies over the past year. Dietetic services were delivered as best as possible throughout the year however due to the lack of staffing services were often seriously overstretched.

The ongoing issue of the gap in a local clinical physiology service of over 5 years in RACH continues (NDP funding). However the excellent Inverness service has been happy to assist in providing additional testing, e.g. pH impedance testing, that is not available in RACH.

It has been an exceptionally busy year for network clinicians with endoscopy procedures – 311 procedures were carried out in RACH and 84 in Ninewells. Close collaboration with paediatric surgeon colleagues continues and they will carry out endoscopy or surgical procedures for network patients in Inverness and Shetland if needed urgently.
3.2 Work Plan

The network work plan was reviewed and work continues on the agreed objectives (see Appendix 2) with progress being noted as below. Routinely the Terms of Reference for the Steering Group is updated and a network Risk Register is updated at every steering group meeting.

**Service Satisfaction Questionnaire** – This is intended for gaining parental opinion from across the network and was written and agreed during the year. The recommendations from the national IBD audit were borne in mind when writing the questionnaire. Valuable advice and direction on the wording was provided by Cathryn Travis and Brenda Lurie in the NHS Grampian Clinical Effectiveness Team, who have agreed to analyse the survey results. The questionnaire pilot had been delayed due to pressure of work however this was carried out in December 2015 and was confirmed as fit for purpose.

The questionnaire is ready to be undertaken but due to the changes in consultant staffing over the year and more so from January 2016, it has been decided that it will be better to delay the full survey until there is a full complement of permanent staff in post.

**‘Attending a Review Clinic Appointment by Video Conference’** - A guide for parents and families attending a review appointment by video conference was written and published during the year. It can either be printed off or parents can be directed to the network page on the North of Scotland Planning Group website [http://www.nospg.nhsscotland.com/child-health-camhs/nospghan/](http://www.nospg.nhsscotland.com/child-health-camhs/nospghan/). The leaflet has also been agreed for use by the paediatric North of Scotland Paediatric Respiratory (NoSPRN) and Neurology networks (NeSCANN) (Carolyn Duncan is also the Network Manager for these networks).

**Data collection** - A network activity template was developed and data started to be collected from April 2015. Unfortunately due to staff absences and work pressures, this information is currently not as complete as we would like and the template will be reviewed.

Collection of meaningful data has been a recurring theme within all child health networks for a number of years, with no one IT system or database available in the North of Scotland that will allow collection of data in each centre of network patients. In addition there have been cross boundary access issues to Health Boards’ clinical systems allowing clinicians to see up-to-date data or test results. These issues have been raised through NoSPG with the North of Scotland e-Health Leads group and it is hoped that in collaboration with this group that solutions can be found to some of these access issues. Scoping of a regional version of Sci Store for clinicians to gain access to NoS Health Boards’ clinical systems where appropriate is being investigated.

**Protocols and pathways** – Work continues on listing national and local standards and protocols in use within the network. The Clinical Guidance Intranet (CGI) for professionals in NHS Grampian is currently in development. Discussions have commenced to begin working on further network guidance on gastro, hepatology and nutrition services. Network discussions are in progress to review existing care pathways, guidelines and protocols that will be made available to health professionals on Intranet sites.

3.3 **RACH Specialist Nurse Telephone Clinics & Telephone Helpline**

Carol Cameron and Brenda Smart, Specialist Nurses in RACH, have implemented weekly telephone clinics with set times to follow up their patients who are on medications requiring review, discussions regarding implementing new medications or review of patients’ health. This has been well received as many of our parents work full time and being able to book a day and
time to expect a call has been useful for families. It will also enable us to capture this workload which was not previously measured.

**RACH Clinical Nurse Specialist (CNS) Telephone Helpline**

This helpline has received **1585** calls from parents over the past 12 months. Parents of children with a range of conditions including inflammatory bowel disease, liver disease, enteral tubes and stomas are helped. Messages are checked twice daily with the aim to return all calls within two working days.

Examples of how the Clinical Nurse Specialist (CNS) can make a difference include -

- Concerns from parents regarding potential relapse of their child’s condition - the CNS will take a history and plans for any investigations to be carried out, changes current medication doses or arranges an urgent review in clinic.
- Parent or teenager may be worried regarding side effects being experienced from medications and information and support is given with a plan for further contacts.
- Parent worried about a child's gastrostomy or stoma site and advice and reassurance is given, with prescription if required, to prevent hospital attendance.

This helpline is also utilised by an increasing number of health professionals including GPs, Health Visitors and School Nurses with queries regarding medication, blood monitoring and the care of children and young people.

**Carol Cameron & Brenda Smart**

### 3.4 Education and Training

There were a number of educational opportunities for network staff during the year where key teaching and learning took place.

There were a number of regional, national and European events available, e.g. weekly MDT in RACH, weekly MDT case discussions in Ninewells and monthly lunchtime case discussions in Inverness.

There is also a number of annual meetings e.g.

- SSPGHAN (Scottish Society for Paediatric Gastroenterology, Hepatology & Nutrition)
- BSPGHAN (British Society for Paediatric Gastroenterology, Hepatology & Nutrition) and
- the European equivalent, ESPGHAN.

The network was delighted when Carol Cameron, Specialist Nurse in RACH, was invited to present at the European gastroenterology conference (ESPGHAN) in Amsterdam in May 2015 on the clinic review work undertaken by clinicians conducted by means of video-conferencing technology.

The Scottish Paediatric Gastroenterology, Hepatology & Nutrition 2-day conference took place at the Stirling Court Hotel in November. This is always an excellent opportunity to network with colleagues from across the country and to be updated on what’s new in clinical medical and surgical care and research, but also to learn from case studies. Presentations included topics on Inflammatory Bowel Disease, blood test monitoring, enteral feeding, biologicals, helicobacter pylori practice and liver disease. The network team will organise the 2016 conference.

The Scottish BAPEN (British Association for Parenteral and Enteral Nutrition) meeting saw Kathleen Ross and Dr Shyla Kishore present on trace elements & enteral feeding.
Network staff were also fortunate to hear a presentation from Dr Mairi McLean on ‘Intraluminal Interleukin’, a potential future therapeutic treatment for patients with IBD. Dr McLean has carried out a number of years’ research in the USA before arriving in Aberdeen.

3.5 ESPGHAN & BSPGHAN Presentations

As well as ESPGHAN, Carol Cameron was invited to present at the BSPGHAN 2015 conference.

‘ESPGHAN has an annual meeting and I was asked to present on the Allied Health Professional Course during the conference. NoSPGHAN network staff carry out many video consultations with our families to save them having to travel long distances to attend out-patient clinics and my 30 minute presentation was entitled ”Patient Consultation by Video Consultation”. I attended my first European meeting with network members and am pleased to say that the presentation was well received with several UK and European colleagues keen to explore the excellent results of our video consultation audit. Thanks go to our local group of Crohn’s & Colitis UK who helped to sponsor my attendance at the meeting.

Following ESPGHAN I was then asked to present at the BSPGHAN associate and trainee members meeting in London. After an interesting journey travelling across London (I have no sense of direction), I attended a really good meeting and again the presentation was well received with many colleagues asking how we had set up our video consultation service as they hoped to implement this locally in the future.

One of the other presentations at the BSPGHAN meeting was from an IBD Nurse Consultant who spoke about managing her service. Following this we have now made some changes in our local support to families. We now have an answer machine service where we listen to messages at set times which enables us to prioritise parent calls. This has been well received and parents are happy to leave messages knowing we will return calls in a timely manner.’

Carol Cameron
3.6 Patient Stories

RACH teenage patient parent compliment

Our daughter was diagnosed with Inflammatory Bowel Disease and this has proved very stressful for her and us as her family supporting her. In the last number of months, we have been extremely grateful of the care provided by the Specialist Gastroenterology nurses to us all. Having a point of contact from professionals who are empathetic, knowledgeable and able to assist is invaluable and we are extremely grateful that our daughter and us as her carers are able to access this.

Carol Cameron & Brenda Smart

Gastroenterology and Surgical Collaboration at Ninewells

There was a very good example of excellent collaboration between the paediatric gastro and surgical services with regards to a 6 year old patient with a recurrent painful rectal prolapse. The patient was taken to the Ninewells paediatric theatre for examination and for a biopsy. The surgeon found the patient to have a rectal tumour. The specialist surgery was carried out successfully in Edinburgh where a whole mass was removed (this was technically a very difficult procedure due to the site of the tumour). The pathology showed it to be an extremely rare semi-benign tumour and the patient continues to have regular review endoscopies locally for monitoring purposes. The case was presented to the Scottish PGHAN group via telelink at a national educational session. The very good outcome has been that the patient is currently very well.

How biological treatments can make a huge difference

A teenage patient presented with weight loss and diarrhoea. It had been the hope of the family and the patient that they would have coeliac disease rather than IBD but the endoscopy revealed severe panenteric Crohn’s disease (a long-term condition that causes inflammation of the lining of the digestive system). Inflammation can affect any part of the digestive system, but most commonly occurs in the last section of the small intestine (ileum) or the large intestine (colon).

The patient was started on Modulen (a powdered feed that is made into a drink to supply all the nutrients needed) and the family were very worried about starting on immuno-suppressive medication. The multi-disciplinary team provided a lot of time and support to advise and counsel the family in this regard. The patient started on Azathioprine but relapsed when Modulen was stopped despite the patient’s condition improving. The decision was taken to move to biological therapy treatment for a second time and this was met with huge anxiety by the patient and the family. However the family was keen, due to the child’s very active lifestyle and school exams, to start Adalimumab. The patient had had a school ski trip planned and was given 80mg twice 2 weeks apart and this produced an excellent response.

The good news was that the patient had a very successful trip and is now clinically in ongoing remission on a weekly treatment of 40 mg Adalimumab. The family and patient were very appreciative about the support, time and explanations they were given by the multi-disciplinary team and have decided to participate in 2 research studies to help others in future.

Dr Dagmar Kastner
Patient Story written by the father of a young person with complex needs

A’s gastro journey over the last few years has been challenging at times. Living on the Islands also has its own challenges to get the necessary input of paediatric services.

A. was in Aberdeen for a liquid swallow test (which proved unsafe), as she had been choking when drinking. When we were at the clinic we also met with Kathleen Ross who thought A. looked dehydrated, this led to A. having a gastrostomy in 2006. This was a positive step forward to ensuring A. got her correct fluid intake and medication. Since then A. has been looked after by the Gastro team in Aberdeen. We have had regular video conferences with Dr Bisset and Kathleen Ross and have been supported locally by Caitriana McCallum (Dietitian).

A. had a run of infections when Caitriana liaised with Aberdeen to ensure correct treatments and we used email to send photos of the site to the gastro nurses in Aberdeen to help us manage A. at home.

Unfortunately during the last few years more problems have developed where she only eats once a day and uses a feeding pump the rest of the time to get her calorie intake up. She then developed problems with excessive wind/air swallowing which led to making the decision to change A’s gastrostomy to a jejunostomy, so we can now feed and drain her tummy. This was done a few months ago in Aberdeen.

Without our local input from Caitriana, who has organised video conferences, phone calls and emails, A. would have been required to travel to clinics in Aberdeen.

Letter from a Grampian parent

‘Being a mother of two children with IBD I cannot stress enough the importance of having our devoted gastroenterology nurses (Carol Cameron and Brenda Smart). The confidence that they have teaching/showing us how to inject our son, giving enemas/suppositories to our daughter and explaining all medication is first class.

The gastro nurses play a vital part in our and the children’s life’s, we couldn’t imagine coping with this horrid disease without them.

Life with Crohn’s and Colitis is awful it’s certainly a roller coaster which is controlled through medication, with daily problems and questions. We are in regular contact through email and phone calls, with the gastro nurses who understand our children’s complications that arise, some of which have included hospitalisations and serious medication changes.

When I mentioned to the children that not everyone has gastro nurses they were outraged and shocked, my daughter said it’s not something they want it’s something they need!!’

Mrs Louise Greig
3.7 Evolution of the GI service

The NoSPGHAN clinical network has evolved and new treatments have been developed since its conception in 2003. In the last three years since the appointment of the third gastroenterology Consultant the spectrum of workload has expanded in several areas.

Previously there were no patients on home parenteral nutrition. However in the last three years there has been a considerable increase in the numbers of jejunally fed patients, long term TPN (Total Parenteral Nutrition) and Home parenteral patients in the network. Complex nutrition patients of all types have increased particularly in the neurodisability population. This has required considerable expertise in addition to increasing the workload in the hospital and in the community.

**Coeliac disease** - The dietetic-led coeliac clinics in all 3 main centres has been a huge success and has released medical time.

**IBD** - There has been a considerable increase not only in the incidence of IBD (inflammatory bowel disease) but also in the severity of the disease at diagnosis. There has been a huge increase in the number of patients on biologics for complex IBD.

**Hepatology** - The hepatology service is expanding with increasing numbers of liver transplant patients. Joint liver clinics are held in Aberdeen and Dundee with Dr Tassos Grammatikopoulos, paediatric Hepatologist at King’s College London, which have been very productive. Availability of video-conference facilities at King’s College has made VC consultations more convenient for the patient as they do not have to travel to London.

**GI Physiology** - There has always been a recognised gap in availability of GI physiology in RACH which has now widened after the retirement of the GI physiologist in Raigmore who kindly assisted with paediatric studies. Work is in progress to develop availability of some of these tests in RACH in the near future.

Empowering local clinicians and offering specialist advice when needed has been the main theme of our gastro network as we continue to deliver high quality care.

Dr Shyla Kishore
3.8 A Week in the Life a Regional Clinician working in the North of Scotland

I work half-time as 1 of 3 consultant Paediatric Gastroenterologists for the North of Scotland Paediatric Gastroenterology, Hepatology and Nutrition Network (NOSPGHANN). This service was set up as a collaboration between the Health Boards in the north of Scotland in 2003 and runs as a virtual single service across 5 Health Boards (not Western Isles). Multi-disciplinary clinical teams (nurses, dietitians, doctors, psychologists and pharmacists) provide the main service from Aberdeen, Dundee and Inverness.

Monday morning: start with 3 email clinical enquiries from colleagues in Dundee and Inverness. The Inverness patient is causing concern so a joint video-conference (VC) consultation is set up with the local paediatrician for later that morning. There is an ill child with rectal bleeding in Ardnamurchan who needs scoped. How do we get him to Aberdeen or would it be easier to refer on to our sister network in Glasgow? A phone call to mother by our specialist nurse and a lift from a friend is sorted for Wednesday. Public transport would otherwise be 4 buses, a ferry and a train!! Monday morning is the weekly multidisciplinary team (MDT) meeting in Aberdeen which I VC into. The main topic for discussion with the surgeons is 2 babies from Inverness with short gut syndrome who are presently in Aberdeen on Total Parenteral Nutrition (TPN).

Tuesday is spent most weeks in Dundee with an out-patient clinic in the morning and endoscopy list in the afternoon. After the clinic is our weekly MDT with myself, the local paediatrician, 2 specialist nurses and our dietitian. A 15 year old girl with Crohn’s disease is recovering from surgery and we jointly make a discharge plan. The afternoon is spent in theatre with a colonoscopy and 3 upper endoscopies completed. Fortunately no major pathology was seen and there is the opportunity to speak to all the parents and children at the end of the afternoon.

Friday is the monthly clinic in Inverness. In order to start promptly I travel up the night before. 7:30 – 8:30 am is spent reviewing old correspondence and the patients coming to clinic with the specialist nurse, dietitian and local paediatrician starts at 9 am. There are 3 new patients, 8 returns and 1 child transitioned to adult GI services jointly with a local adult GI colleague. The lunchtime MDT is ‘open house’ with 15 patients discussed and one of the community paediatricians in attendance. The next clinic is organised with the medical secretary and finished by 4:15 pm, in good time to get the 5:15 train back to Inverurie.

I really enjoy working the way I do. Patients are seen near to their homes and success is measured when a patient does not need to come to Aberdeen because we have set the service up locally or we can do our clinic appointment by VC. We support each other to add value. Our present clinical lead is a senior dietitian.

What could be better? The IT is inefficient at times and do I really need to have 3 security and 3 health checks, 1 for each Health Board I work in. I’ve heard that that is all going to get sorted!!!

Dr Mike Bisset
4. Patient & Family Events

4.1 Crohn’s & Colitis UK Family Day, Inverness

A successful family day took place in Inverness at the beginning of September at the local leisure centre where lunch was also provided. Talks were given by Dr David Goudie, Mhorag Robertson and Professor Angus Watson (adult surgeon) and patients and families had the chance to ask questions and discuss various issues. Approximately 40 people from the North attended and patients and families found it very helpful to be able to meet other people with similar conditions and to be able to discuss similar challenges. Entertainment was provided by circus entertainers who were very funny and interesting.

Mhorag Robertson

4.2 CICRA Family Day for Inflammatory Bowel Disease patients, Aberdeen

A family day was held at the Hilton Treetops Hotel, Aberdeen on 3rd October. This was jointly organised by the Aberdeen team and CICRA and was well attended by families, with several network clinicians presenting on various topics, such as IBD diagnosis, research, diet & nutrition and clinical psychology. Young adult ambassadors also attended and took part in the discussion groups which was very helpful to the families. Feedback from the day was very positive –

- ‘We as a family found the day to be very helpful and informative, thank you so much.
- Excellent informative day.
- Had a great day and found it very informative and very nice to meet other parents and kids who understand what you’re going through. Fantastic work you all do. Thank you.
- Learning we are not alone and listening to other people’s stories was really good.
- The day helped me a great deal – thank you.
- Discussion groups all well thought out and different subjects – excellent!
- I met another girl with Crohn’s which was really good.
- My son was so pleased to meet others with the same condition.’
5. Research & Audit

Our network has always been very actively involved in research activities. In Aberdeen the appointment of Margaret Connon as Research Nurse to cover gastroenterology research projects has enabled their smooth running. Current ongoing projects are as follows:

**GEM Project:** A multi-disciplinary human study on the Genetic, Environmental and Microbial Interactions that Cause IBD is a multi-centre prospective study each Subject (healthy individual) is linked to an enrolled, eligible Proband (patient with Crohn’s disease). Dr John Thomson the adult gastroenterology consultant in ARI was the principal investigator (PI) and Dr Loganathan was the co-investigator. After Dr Loganathan’s departure Dr Shyla Kishore has taken over as co-investigator. So far we have recruited 10 probands and more than 10 subjects in Aberdeen. I am also pleased to report that Aberdeen won the prize for the May/June competition. Dr Dagmar Kastner is the principal investigator in Tayside Children’s Hospital.

**CAPE study:** A Long-Term Non-Interventional Registry to Assess Safety and Effectiveness of Humira® (Adalimumab) in Paediatric Patients with Moderately to Severely Active Crohn’s Disease (CD). There was a delay in recruiting patients into this study due the changes in the PI. Dr Shyla Kishore has now taken over as the PI and after the pre-initiation site visit we shall start recruiting patients. Dr Dagmar Kastner is the PI in Tayside Children’s Hospital.

**Hepatitis C study:** Observational study on Hepatitis C to investigate the host and viral factors associated with outcomes of infection with hepatitis C virus (HCV Research UK). The outcome of the study is to calculate the degree to which IL28B SNP (single nucleotide polymorphism) contributes to defined clinical endpoints (clearance/non-clearance of infection; response/non-response to therapy; fast versus slow fibrosis progression; development of hepatocellular carcinoma) in comparison to other viral and host factors (including: viral genotype; viral load; BMI, age; gender; risk factors for infection; duration of infection; alcohol intake; ethnicity) known to influence these outcomes. Dr Andrew Fraser the Adult Hepatologist in ARI is the PI.

We have presented some audit projects in the Aberdeen audit meeting and there are ongoing projects we are involved in. The audit on gastro-esophageal reflux had highlighted the importance of setting up an in-house pH impedance study and a business case is underway so that this can be carried out in RACH. The audit on monitoring thiopurine metabolites has enabled us to reflect on the effectiveness of the monitoring. A paediatric eosinophilic oesophagitis audit looking at numbers and management was also undertaken.

In Tayside we have completed 2 audits and both were presented at a local Tayside improvements event:

- Hepatitis A and B immunisation rates for liver patients showed low immunisation rates for Tayside patients. This has since been addressed with letters to GPs for existing patients and a local protocol has been written for new patients.
- **Paediatric Eosinophilic oesophagitis** – this was also undertaken in Tayside. Interestingly there were higher numbers than had been found in Grampian.

Other ongoing audits in Tayside include –

- Biological drug levels and azathioprine drug levels.
- Patients on Infliximab started on new generic biosimilars/existing patients moved over.
6. Key Challenges

- Despite increasing and continuing pressures for staff including a greater number of patients than in the past, the continued increase in patients on biological therapies (a national increase in patients with IBD and coeliac disease) and workforce challenges, staff have coped admirably during the year and continue to provide timely, safe, effective care across the network. The issue of capacity is becoming a major issue and staff in each main centre will be unable to sustain an increased workload. Therefore a large piece of work will be carried out during the coming year to look at past activity and to try to anticipate what this will mean for the network in the years ahead.

- Due to budgetary constraints, the issue of backfill and the inability of Boards to fill maternity leave posts particularly in the AHP and Dietetics services means there can be less timely access to care for chronically ill patients. Temporary cover at clinics or within services is often provided on an ad hoc basis and often at the goodwill of staff.

- The ability to collect data on network patients remains an issue with no regional database available. Despite valiant 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 NoS Health Board systems (e.g. Sci Store/Trakcare for patient results and clinical letters) have been highlighted to the North of Scotland e-Health Leads Group and it is hoped that the group will be able to help resolve some of these issues in the coming year.

- There are continued gaps in clinical physiology services in RACH and Ninewells. However in RACH it is hoped that an existing respiratory technician will be trained to calibrate pH equipment and to set up capsule endoscopy equipment so that this can be available locally.

7. Looking Ahead

We have had an extremely busy year with many challenges due to several staff vacancies. A principal task for 2016 will be to recruit to the vacant Consultant Paediatric Gastroenterologist post in Aberdeen together with the work on network capacity.

We will continue to provide safe, effective, timely care and to drive up standards and service improvements by working on network care pathways and protocols and by providing access to regular learning and educational opportunities.

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 of care to patients and families as close to their homes as possible across the North of Scotland.

Although it was with sadness that we said goodbye to Dr Sabari Loganathan in January, we enjoyed a great get-together once again with network staff coming up from Dundee to enjoy an excellent lunch at a local Aberdeen restaurant.
## Appendix 1

### Gastroenterology, Hepatology & Nutrition network staff involved in delivery of NoSPGHANN – 2015-16

<table>
<thead>
<tr>
<th>Network Management</th>
<th>POST</th>
<th>Comment</th>
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<tbody>
<tr>
<td>Kathleen Ross</td>
<td>Network Clinical Lead</td>
<td>Interim Lead from 1/11/2015</td>
</tr>
<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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<tr>
<th>ABERDEEN</th>
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<tr>
<td>Dr Mike Bisset</td>
<td>Consultant Paediatric Gastroenterologist</td>
<td>Also NoSPG Regional Medical Director</td>
</tr>
<tr>
<td>Dr Sabarimuth Loganathan</td>
<td>Consultant Paediatric Gastroenterologist</td>
<td>Left January 2016. Vacant post to be recruited to Summer 2016</td>
</tr>
<tr>
<td>Dr Shyla Kishore</td>
<td>Consultant Paediatrician with a Special Interest</td>
<td></td>
</tr>
<tr>
<td>Ann Morrice</td>
<td>Medical Secretary</td>
<td>Part-time</td>
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<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 Metabolic Specialist Nurse</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>
<td></td>
</tr>
<tr>
<td>Hilary Rennie</td>
<td>Dietitian</td>
<td></td>
</tr>
<tr>
<td>Hazel Weir</td>
<td>Dietitian</td>
<td></td>
</tr>
<tr>
<td>Dr Anna Clancy</td>
<td>Clinical Psychologist</td>
<td>0.4 wte</td>
</tr>
<tr>
<td>June Fair</td>
<td>Speech &amp; Language Therapy</td>
<td></td>
</tr>
<tr>
<td>Angie McCallum</td>
<td>Dietetic Assistant</td>
<td></td>
</tr>
<tr>
<td>Marta Freeman</td>
<td>Pharmacist</td>
<td></td>
</tr>
<tr>
<td>Physiological Technician</td>
<td>vacant</td>
<td>Services ‘purchased’ from ARI/Raigmore</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>DUNDEE</th>
<th>POST</th>
<th>Comment</th>
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</thead>
<tbody>
<tr>
<td>Dr Dagmar Kastner</td>
<td>Consultant Paediatrician with a Special Interest</td>
<td></td>
</tr>
<tr>
<td>Dr Buddhi Gunaratne</td>
<td>Consultant Paediatrician with a Special Interest</td>
<td>1 session – Perth</td>
</tr>
<tr>
<td>Gillian Cormie</td>
<td>Medical Secretary</td>
<td></td>
</tr>
<tr>
<td>Joanna Mulreany</td>
<td>Medical Secretary</td>
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</tr>
<tr>
<td>Karen McIntyre</td>
<td>PGHN Specialist Nurse</td>
<td></td>
</tr>
<tr>
<td>Sarah Nicoll</td>
<td>PGHN Specialist Nurse</td>
<td></td>
</tr>
<tr>
<td>Clare McLeish</td>
<td>Senior Dietitian</td>
<td></td>
</tr>
<tr>
<td>Siobhain McIntosh</td>
<td>Clinical Associate Psychologist</td>
<td>0.2 wte</td>
</tr>
<tr>
<td>Dr Paul Fettes</td>
<td>Consultant Anaesthetist</td>
<td>2 sessions to support endoscopy theatre sessions</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>INVERNESS</th>
<th>POST</th>
<th>Comment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dr David Goudie</td>
<td>Consultant Paediatrician with a Special Interest</td>
<td></td>
</tr>
<tr>
<td>Agnes MacIntyre</td>
<td>Medical Secretary</td>
<td></td>
</tr>
<tr>
<td>Christine Sutherland</td>
<td>Medical Secretary</td>
<td></td>
</tr>
<tr>
<td>Morag Robertson</td>
<td>PGHN Specialist Nurse</td>
<td></td>
</tr>
<tr>
<td>Michelle Nimmons</td>
<td>Dietitian</td>
<td>Part-time</td>
</tr>
<tr>
<td>Dr Tracy McGlynn</td>
<td>Psychologist</td>
<td>Part-time</td>
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</table>

<table>
<thead>
<tr>
<th>SHETLAND</th>
<th>POST</th>
<th>Comment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dr Susan Bowie</td>
<td>GP with a Special Interest</td>
<td>Based at Hillswick Health Centre</td>
</tr>
</tbody>
</table>
## Appendix 2

**Paediatric Gastroenterology, Hepatology & Nutrition Network (NOSPghANN) Work Plan 2015-16**

<table>
<thead>
<tr>
<th>RAG status key</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>RED (R)</td>
<td>The network is unlikely to achieve the objective/standard within the agreed timescale</td>
</tr>
<tr>
<td>AMBER (A)</td>
<td>There is a risk that the network will not achieve the objective/standard within the agreed timescale, however progress has been made</td>
</tr>
<tr>
<td>GREEN (G)</td>
<td>The network is on track to achieve the objective/standard within the agreed timescale</td>
</tr>
<tr>
<td>BLUE (B)</td>
<td>The network has been successful in achieving the network objective/standard to plan</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Objectives</th>
<th>Outcome</th>
<th>Tasks</th>
<th>Timescales</th>
<th>Lead Professionals</th>
<th>Progress at February 2016</th>
</tr>
</thead>
</table>
| 1. Update network structure documents | Review network Terms of Reference, network Mission Statement and Risk Register | • Update steering group Terms of Reference (ToR).  
• Update and share Risk Register at each steering group meeting | 2015-16 | C Duncan  
K Ross | Network documentation reviewed and updated during the year.  
Blue |
| 2. 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 so that network documents are developed  
• Link with national/regional groups to inform existing or new protocols, standards and referral pathways  
• Discuss use of national/regional care pathways in NoSPGHANN  
• Develop biologics care pathways | 2015-16 | S Kishore  
C Cameron  
W M Bisset  
D Goudie  
D Kastner  
C Duncan | Biologics care pathways nearing completion.  
Ongoing - document local/national protocols in use and highlight network pathways to be developed.  
Green |
<table>
<thead>
<tr>
<th>Objectives</th>
<th>Outcome</th>
<th>Tasks</th>
<th>Timescales</th>
<th>Lead Professionals</th>
<th>Progress at February 2016</th>
</tr>
</thead>
<tbody>
<tr>
<td>3. Develop network web pages for professionals and families</td>
<td>Increase awareness of the network for all stakeholders and enhance families' knowledge of service and of disease information</td>
<td>• 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 to include protocols/guidelines in future. • Write guidelines for patients and families when using video-conference facilities.</td>
<td>2015-16</td>
<td>S Kishore C Duncan K McIntyre S Nicoll K Ross</td>
<td>Service satisfaction questionnaire piloted successfully in December. Delay audit until 2016/17 due to staff vacancies. VC guideline complete. Work commenced on NHS Grampian Clinical Guidance Intranet gastro pages.</td>
</tr>
<tr>
<td>4. Enhance network education framework</td>
<td>Ensure appropriate skill mix of professionals and maintain and develop professional expertise locally and across the network</td>
<td>• 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 4 per year) and attendance at SSPGHAN Telemed sessions by VC • Organise annual network study day</td>
<td>2015-16</td>
<td>S Kishore W M Bisset C Duncan K Ross D Kastner</td>
<td>A 2016 programme of learning &amp; education sessions in place. NoSPGHANN will organise 2016 SSPGHAN national meeting in Stirling. NoS study day date set for 14th September 2016.</td>
</tr>
<tr>
<td>5. Continue discussions on implementation of an appropriate paediatric clinical audit system</td>
<td>Improve clinical data collection to have ability to collect patient demographic and disease information to facilitate audit and to enhance patient care</td>
<td>• Continue discussions with NoSPG with need for a data collection system for NoS networks</td>
<td>2015-16</td>
<td>W M Bisset C Duncan</td>
<td>NoSPG eHealth Leads group to scope a regional version of Sci Store. Clinician IT access issues table submitted to NoSPG.</td>
</tr>
<tr>
<td>6. Audit clinical care and research</td>
<td>Identify projects suitable to carry out audit of children’s care and review parents’ and carers’ experiences of service provided</td>
<td>• Participation in and collation of UK IBD and audit data • Carry out Eosinophilic oesophagitis audit</td>
<td>2015-16</td>
<td>S Kishore C Cameron S Nicoll</td>
<td>UK IBD audit biologics funding terminated in England.</td>
</tr>
</tbody>
</table>