



North of Scotland Paediatric Gastroenterology, Hepatology and Nutrition Network

Annual Report 2020-21



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1. Introduction

The past year for the network has been a year like no other we have ever experienced. The global pandemic changed our lives unbelievably but it highlighted the vital role the North of Scotland Paediatric Gastroenterology, Hepatology and Nutrition Network (NOSPGHANN) plays in cross-boundary collaboration and being able to deliver safe, effective and equitable care for our patients across the North.

Nationally from February 2020 the priority was to prepare for and deal with Covid 19 and the impact that had on services provided to network patients and their families. Services were heavily impacted and understandably many services were paused or delayed. In the very early days as far as the network was concerned, routine endoscopies were not undertaken as they are aerosol generating procedures – urgent cases were still able to be undertaken and the service resumed from July 2020 in RACH at a reduced level due to changes in theatres protocols and the requirement for enhanced deep cleaning of the theatres. During the pandemic, staff were often redeployed from their primary role and colleagues had to pick up duties of colleagues who were absent or self-isolating. Non-urgent waiting lists grew considerably over the period and network staff worked above and beyond to ensure patient care was never compromised in any way.

In order to ensure that patients could still receive essential infusions in hospital (for example, infusions of biologic medications for Inflammatory Bowel Disease), the infusions service in RACH was completely redesigned, with infusions taking place in a separate area of the hospital (a "Green Zone").

Network out-patient consultations were still able to be undertaken, however not in the routine face-to-face manner, but by video call or telephone. Clinicians had to very quickly get used to the Scottish Government's 'Near Me'/'Attend Anywhere' clinical appointments video call system which mainly took over from routine hospital out-patient appointments at the start of the pandemic so that patients were seen virtually. This system has been extensively used across the network and will continue in some form in future. There was still capacity to see patients face-to-face in designated Green zones or hubs if this was urgent or felt appropriate. The hubs were also available to patients to have bloods and heights and weights taken.

The network underwent significant staffing issues during the year in medical and nursing in RACH and in dietetics in Ninewells and Raigmore. There was also a gap in tertiary consultant support for Ninewells which was affected due to Dr Kishore's absence in Aberdeen, however this improved from October 2020. Dr Umer Ghafoor also supported the service when he took over the running of the Elgin gastro service in Dr Kishore's absence. As of March 2021, network endoscopy theatre lists in Aberdeen and Dundee are increasing as routine services start to return, however these are still some way off returning to pre-pandemic levels. Due to changes in the number of day case beds available, pressures on theatre staffing and changing requirements to theatre cleaning and turnover time between cases, both RACH and Ninewells paediatric endoscopy services are only operating at around 66% of pre-pandemic capacity.

As hospital services return to a 'new normal', no-one could have predicted that the pandemic would have continued for as long as it has done. Network staff have to be thanked for their amazing capacity to deliver safe, effective care and for continuing to facilitate the sharing of first-class skills and knowledge to ensure patients received the best care possible with the best clinical outcomes even during these adverse conditions.

2. Network Governance

Since 2001, the NoSPGHANN has been delivering gastroenterology, hepatology and nutrition in-patient and out-patient services, e.g. medical, nursing, dietetics, pharmacy and psychology services to paediatric patients with disorders of the gastrointestinal tract, the liver and complex nutritional issues across 5 North of Scotland Health Boards – NHS Grampian, NHS Tayside, NHS Highland, NHS Orkney and NHS Shetland.

Network clinicians are committed to ensuring the sustainability of services across the North of Scotland and specialist services are delivered to provide person-centred, efficient, effective, timely care. Multi-disciplinary teams of highly experienced clinicians are based in Royal Aberdeen Children's Hospital, Tayside Children's Hospital, Dundee and Raigmore Hospital, Inverness.

The main aims of the network continue to be to –

- provide patients and families with first-class safe, quality care as close to their homes as possible
- ensure provision of a reliable system of clinical care such that the patient and their family see the appropriate professional in a timely manner for the most effective and safe care
- ensure an equitable system of care taking into account the geography of the North of Scotland
- ensure the development of local professional expertise across the network
- ensure multi-disciplinary training and education opportunities as well as case discussions for staff working in the network
- ensure participation in audits and outcome measures for the network's work.

Network Leadership

The network is accountable to the NHS Scotland North Regional Team (formerly the North of Scotland Planning Group) and links into the Child Health Clinical Planning Group.

A massive thank you goes to Dr Dagmar Kastner-Cole (NHS Tayside) who was the network Clinical Lead for almost 4 years. Dagmar led the network with great knowledge, skill and experience until mid 2020. In the autumn Dr Iain Chalmers and Dr Su Bunn were appointed as Joint Network Clinical Leads for a 2-year term in the first instance. Carolyn Duncan continued as the Network Manager (North Regional Team).

The network continues to place a great deal of importance on the continued professional development of staff to develop their knowledge and skills and to ensure provision of a highly trained workforce. Formal and informal educational and learning opportunities are available either in person at local multi-disciplinary meetings or by video call to network staff.

3. Service Delivery Updates

Network colleagues provide high quality secondary and tertiary gastroenterology, hepatology and nutrition services across the North of Scotland and collaborate across Health Board boundaries on a daily basis. Consultant Paediatric Gastroenterologists Dr Su Bunn, Dr Iain Chalmers and Dr Shyla Kishore are based in RACH. As well as providing specialist tertiary and secondary care services in Grampian (including for Orkney & Shetland patients), Dr Bunn provides tertiary input to Raigmore Hospital, Inverness and Dr Chalmers to Tayside Children's Hospital in Dundee (including Perth & Kinross and North Fife patients).

Dr Dagmar Kastner-Cole and Dr David Goudie, Consultant Paediatricians with a special interest, continue to lead their services locally for NHS Tayside and NHS Highland in Inverness.

Network patients requiring treatment using specialist biological therapies continue to rise in number as do the numbers of patients with complex gastrointestinal issues. In addition, there is a pressing issue regarding the need for a network specialist nutrition service in relation to patients requiring home parenteral nutrition – there are now 4 network patients requiring this specialist treatment. Local teams are under continued pressure due to the huge amount of care required by these patient groups and the high risk of potential complications of their treatments. Despite the increasing pressures from these patients there have been no additional staffing resources awarded since the National Delivery Plan 2008-2011 across each of the main centres to support patients and staff. It is vital that a dedicated, specialist regional nutrition service is set up to ensure the best service for parenteral nutrition patients and so that national standards for care and treatment are met. Discussions and work have begun to look at how network resources can be increased.

Hepatology

Dr Tassos Grammatikopoulos, Consultant Hepatologist from Kings College London, was unable to visit Dundee and Aberdeen during the year to deliver hepatology clinics however he was able to carry out joint video call clinics from London to each of the main centres for which we are very grateful.

3.1 Work Plan

Although we were able to hold quarterly network meetings by Teams during the year, it was challenging getting the time to work on our network's work plan due to the pressures of the pandemic, please see *Appendix 2*. The work plan is continually performance managed by a red/amber/green/blue status system.

3.2 Endoscopy services

Due to the increasing numbers of Inflammatory Bowel Disease patients and the increase in complex nutrition patients, there is naturally an increasing demand for endoscopy in the network. Despite the many changes in theatre pathways due to the Covid 19 pandemic which slows down the number of patients that are able to have endoscopies, over 330 patients were still able to have an endoscopy procedure in Aberdeen and 78 in Dundee during 2020. In order to ensure that patients requiring most urgent endoscopic assessment are prioritised effectively, the network has been allocating priority categories to all patients requiring endoscopy, in line with local and national guidelines. Despite this priority categorisation and the number of endoscopic procedures able to be performed, the waiting time for a routine diagnostic endoscopy in the network is now around 4 months. Discussions have commenced with regards the possibility of establishing an endoscopy service in Raigmore in future so that Highland paediatric network patients are treated closer to home in Inverness.

3.3 Staffing

In addition to the pressures of the pandemic, there was significant staff absence in Grampian in consultant and nursing time. The network was fortunate to have part-time assistance from Dr Mike Bisset (Locum Consultant Gastroenterologist and former Clinical Lead of NoSPGHANN), who worked hard using Near Me to ensure patients were seen virtually in a timely manner.

Dr Bisset retired completely in March 2021 and we wish him well in his well-earned retirement.

The network was also grateful for the support of Dr Kamal Hassan (Locum Consultant Gastroenterologist) who supported both the in-patient and out-patient service in Aberdeen from March 2021.

In nursing in RACH during the year, Chantelle Stewart, Specialist Nurse, has helpfully been seconded to assist Carol Cameron due to the long-term absence of Brenda Smart.

The region's dietetic services continued to experience service pressures due in part to vacancies and absences in Dundee and Inverness. This is an improving situation at the end of the period with a post having been filled in Raigmore and interviews being planned in Dundee.

3.4 Retiral

In October 2020, Kathleen Ross, Lead Dietitian in RACH, decided to retire after 42 years' service. It was with much sadness that we said farewell to her after so many years of dedication to the network and to her patients and families and her dietetics team. Kathleen used to deliver specialist nutrition clinics twice per year in Shetland which are attended by gastro, hepatology and coeliac patients however this was unable to be carried out in person during the pandemic.

3.5 Collaboration with Crohn's & Colitis UK

Network involvement with Elaine Steven from Crohn's & Colitis UK continues at our network steering group meetings and has been very helpful. Elaine is heavily involved in the work with the Scottish Government IBD Cross Party Group which continues to increase awareness of the issues faced by patients living with Inflammatory Bowel Disease, the high incidence of IBD in Scotland and the increasing incidence of childhood IBD. Dr Chalmers and Dr Kastner-Cole attend the Cross Party Group on behalf of the network.

Scottish Government IBD Cross Party Group

The Paediatric sub-group work on developing a work plan is ongoing in the Group. Data management continues to be highlighted as a challenging issue for paediatric services across Scotland and this will be discussed further in the coming year.

3.6 Network Data Collection

The inability to collect sufficient data continues to be a recurring theme within NoS child health networks. This means that the network is unable to measure performance as well as it would like. A regional Care Portal has been developed by regional IT colleagues and this has improved the ability to access data out with the clinician's home Health Board. This cross boundary access to North of Scotland Health Boards' clinical data allows clinicians to see up-to-date correspondence and test results regardless of the geographic location of the clinician and patient. However there is still a huge gap in being able to collect meaningful network data which would support the development of improved and increased network services moving forward - more data on a variety of conditions needs to be collected in future, e.g. IBD, coeliac disease, eosinophilic oesophagitis and a complex nutrition service. Unfortunately due to a lack of admin support and clinician time during the year, data input to the national IBD Registry was unable to be completed.

3.7 Blended Diet Update

The use of blended diet in enterally fed children has been growing over the past 10 years and this has mainly been parent/carer driven. There has been consistent anecdotal reporting of improved GI symptoms, tolerance and patient quality of life which is now being reflected in formal research. In Grampian it is estimated around 10% of our enterally fed patients are now using blended diet. The professional consensus on use of blended diet has been cautious due to the lack of evidence base, however there has been a shift in opinion from the most recent British Dietetic Association position statement released in 2019.

It is important that we as healthcare professionals continue to adapt to the continued advances in health, using a combination of the evidence base as well as best practice. Guidance on the use of blended diet is down to each individual health board and there is a continued lack of consensus leading to varying support for families. On this basis, Hilary Rennie, along with a group of paediatric dietitians from across Scotland came together to develop a national guideline. The title of the document is 'Initiation and Administration of Blended Diet via Gastrostomy Feeding Devices' which is in its final draft and will be published later this year. This has been an excellent example of team working across the network and beyond with other Scottish centres. It also ensures provision of equitable patient centred care and consistency for families who may travel between more than one health board.

In keeping with this theme, I am currently in the final stages of my dissertation entitled 'Are blended diets nutritionally adequate when compared with commercial enteral feed in gastrostomy fed children' and the initial findings are encouraging. This is towards achieving an MSc in Advanced Professional Practice in Paediatric Dietetics. An abstract has been submitted for the British Dietetic Association research symposium at the end of the year and I hope to be able to share the findings across the network once the final dissertation has been submitted.

**Rachel Arthur and Hilary Rennie
Paediatric Dietitians, NHS Grampian**

3.8 RACH Psychology Service

Some Personal Reflections from these Covid times

A moment to reflect on the challenges of the past year. The challenges have been many –

- working within ever changing COVID parameters
- finding ways of using technology helpfully either to deliver therapeutic care through Near Me or working with colleagues using Teams
- flooding; practically due to the volume of rain that one day in August 2020 and metaphorically in relation to the volume of emails
- wearing a mask, sometimes an apron and for a time goggles, whilst always being aware that the real PPE challenge has been faced by my colleagues
- hearing how hard it has been for patients for a range of reasons including surgery delays, financial worries or absence of social support
- often only being able to offer patients the space and time to talk, to be listened to and to be heard; sometimes there is no therapeutic approach that fits this kind of need
- sharing this experience with patients – COVID time is really the first time I have sometimes known exactly how a patient feels because I feel it too (but not been able to share this with them)
- fatigue; not a normal 'I can't wait for a holiday' feeling but a worn down sense of I NEED a rest

- not having the expected, routine everyday ways of easily connecting with colleagues

The learning has been varied too and of course I do try and find benefit (as we naturally often do after a challenging experience); for example, the ways that COVID has accelerated better ways of working. This time has also underlined the value of the NHS and my own continued admiration of colleagues. Yet, regardless of the human need to find the light amidst the struggle, it is for me, the COVID challenges that define this time.

**Dr Anna Clancy
Clinical Psychologist**

3.9 Home Bowel Preparation for Colonoscopy

Previously, all bowel preparation for paediatric colonoscopy in RACH was performed on an in-patient basis, with patients being admitted to the children's hospital on the day before their procedure. The majority of bowel preparation in Tayside has been completed with the patients taking the medications at home, but there have been concerns about the feasibility of this in RACH due to the larger geographical distances involved for Grampian and Highland patients. In March 2020, RACH introduced a home bowel preparation protocol for all patients undergoing colonoscopy. Clear, written instructions regarding diet, allowed foods, and when to take medications were developed and these are sent out to families in advance of their procedure. Prescription of the medications required for bowel clear out is requested from the patient's GP by letter or electronic clinical note.

Following this change in practice, the network reviewed the effectiveness, safety and impact on length of hospital stay of the new home bowel preparation protocol, compared to the previous in-patient bowel preparation. Average distance from hospital for patients receiving home bowel preparation was 46.2 miles (range 1.2 – 121 miles). Effectiveness of the bowel preparation in allowing good views at colonoscopy was similar between home and in-patient bowel preparation. A slightly higher rate of patients receiving home bowel preparation required IV fluids during or after their procedure compared to the previous cohort of in-patient bowel preparation (26.5% vs 21.1%). 72% of the patients receiving home bowel preparation had only a day case admission to hospital, resulting in a reduction in in-patient bed days equal to a cost saving of around £18,000 between March and October 2020. Patient satisfaction has not been formally assessed, but anecdotally patients and parents who have experienced both in-patient and home bowel preparation have expressed a preference for being able to do this at home.

Overall, the change to home bowel preparation has proven to be similarly effective to in-patient bowel preparation, and has been well tolerated by patients, even those travelling long distances to hospital. We plan to further review the possible signal towards an increased need for IV fluids and review patient satisfaction with the home bowel preparation process.

The results of the audit of this change in practice were presented by Dr Jamie Motion at the British Society of Paediatric Gastroenterology Hepatology and Nutrition (BSPGHAN) Annual Meeting in April 2021 and were well received.

3.10 Paediatric GI Physiology Service

Since 2017, paediatric impedance pH studies in RACH have been calibrated and downloaded by the paediatric respiratory physiologist, with studies reported by the paediatric gastroenterology consultants. Early in 2020, a second impedance pH recorder was purchased to increase the capacity of this service, in line with increased demand for this investigation, and to allow these studies to also be performed in Ninewells hospital. Other GI physiology studies, including Bravo

pH studies (wireless pH probe inserted at the time of endoscopy), oesophageal manometry and video capsule endoscopy have been provided on a good will ad hoc basis by the adult GI physiology department at Aberdeen Royal Infirmary.

This year, a formal service agreement has been created with the GI Physiology department in Aberdeen Royal Infirmary to provide a Paediatric GI Physiology service to RACH. Funding has been transferred to allow this new service to deliver the above investigations in a robust and sustainable manner, with improvements in the standardisation of reporting, and quality assurance of these investigations.

3.11 Paediatric Endoscopy Equipment, Tayside

Over the past couple of years, the difference in the quality of endoscopy images obtained in Ninewells hospital compared to RACH has become increasingly clear. The image processing "stack" and monitor used in Tayside is now more than 15 years old and provided much lower quality endoscopy images than those obtained with the same endoscopes in Aberdeen, to the point that it was making diagnostic assessment more difficult.

The network is hugely grateful to Jenny Melville, Charge Nurse in Paediatric Theatres, Ninewells, for the work she has completed over the past 6 months to improve endoscopy image quality there. Liaising with the adult endoscopy unit in Ninewells and Medical Physics, Jenny has been able to secure an updated monitor which has dramatically improved the image quality of endoscopy images, to bring them to being comparable to those obtained in Aberdeen. She has also been successful in securing the equipment and IT updates required to allow the endoscopy unit to connect to a PC in the theatre, making it possible for electronic endoscopy reports with electronic image capture to be created for the first time in paediatric theatres in Tayside. Use of electronic reporting for paediatric endoscopy improves the standardisation of reporting, ease of review of images and reports in future (as these are instantly uploaded to the patient's electronic record), and ease of audit of endoscopy quality and safety measures and so is a significant improvement for the service. Combined, the improvements to image quality and move to electronic reporting have brought paediatric endoscopy services in Dundee in line with those already provided in Aberdeen. The future of this standard of investigation in Dundee also looks to be secure, with planned renewal of the paediatric endoscopy equipment scheduled for 2022.

4. Education & Training

The network continues to prioritise the provision of education for all staff and links in with the Scottish Paediatric Gastroenterology, Hepatology and Nutrition Network (SSPGHAN). Regular SSPGHAN virtual teaching sessions were suspended for several months during the pandemic, but have now restarted. These are now easier to access with a move to the Microsoft Teams platform, rather than hospital based teleconferencing facilities, resulting in improved attendance. NoSPGHANN continues to contribute to running these regular education sessions along with colleagues across Scotland. SSPGHAN was also able to host their annual meeting in a virtual format on 20th November 2020 which many staff were able to link into.

The network has continued to contribute to departmental education sessions in Aberdeen and Dundee with "Grand Round" presentations delivered on Coeliac Disease, Paediatric Acute Liver Failure, Complex feeding in Neurodisability, Functional Nausea, Non-IgE Mediated Food Allergy, Neonatal Liver Failure, Overview of Enteral Tube Feeding and Overview of Paediatric Liver Disease.

The past year has also seen the network welcome its first dedicated sub-specialty ("grid") trainee. Dr Jamie Motion began his paediatric gastroenterology training in Aberdeen in August

2020 and has been a tremendous asset to the network over the past year, making excellent progress in his gastroenterology and endoscopy training. In August 2021 Jamie moves to Glasgow to complete a further year of gastroenterology training, with more focus on complex nutrition training. We look forward to welcoming him back to the North of Scotland in 2023 once he has completed this and his hepatology training.

5. Patient Stories & Updates

5.1 Ninewells update

'The care I have received has been incredible. All the nurses have been fantastic and they have always made sure I'm not bored and they don't talk to me as if I don't know what I'm doing or what's wrong with me.

They have always made sure I'm not upset or if it's sore they will try and make sure it hurt as least as possible. They make sure that I know what's going on and they have proper conversations with me and they remember stuff I have told them.

The nurses have really helped me come to terms with my IBD and made sure I know exactly what is wrong with me and have answered all my questions about my medication.

When I was first admitted they made sure that I wasn't scared and made me feel like I wasn't just another sick kid and made sure that nothing was confusing me. They have helped me through the hardest time in my life and they did a fantastic job.'

'All the way throughout having Crohn's disease, from my diagnosis a few years ago to now, the Gastro team nurses and doctors have been great. The doctors are always very informative and make sure I understand everything going on and that I can ask any question I want to.

The nurses are very friendly and easily make you feel very comfortable in the hospital environment. They, like the doctors, are also very informative with any questions I have.

In total the Gastro team are a very positive and comforting team who always are very informed and make sure you know your options and what would work out good for you individually. They help make the hospital a very nice, positive and calm place.'

Ninewells gastro Team Care

Up until September 2020, we had a perfectly healthy teenager. Within the space of 3 days, we went from a child who spent forever in the bathroom, to a very ill child who was in hospital.

We were put straight into the care of the GI team at Ninewells as soon as she was admitted. From there on in, it became apparent that every member of the team we dealt with, was going above and beyond to help get to the bottom of what was going on.

Our dealings with the team are going to be long-term until my daughter gets moved to the adult GI team and it couldn't be a bigger silver lining! Every nurse, doctor and consultant has been patient, kind and understanding. Every aspect of the disease has been explained, all our questions answered and all in a way that's easy for us, and a teenager, to fully understand. The ladies we deal with the most, Karen and Sarah, have answered messages and they're our port in what has been a whirlwind of a storm for us, and we couldn't be more grateful for all their support. They have the utmost patience, kindness and cheery personalities that go so far in getting our daughter to respond to her diagnosis.

What has been one of the most terrifying few months of our parent lives has been made so much easier with the professionalism, care and compassion of Dr Chalmers, Dr Kastner, Karen and Sarah. We are so very grateful that we have them on our team.'

'Our daughter was diagnosed with Crohn's in 2017 at the age of 12. It was a worrying and stressful time for us as she was very unwell and things moved quickly from her first appointment at Ninewells.

In the initial stages following her diagnosis we were dealing with every member of her gastro team. This was quite daunting as we were still trying to come to terms with her diagnosis and what it all meant. However, every member of the team was patient, knowledgeable and inclusive. It felt as though they weren't just treating our daughter but they were treating us too. We were given contact numbers for the team members which helped us to realise we weren't in this alone. We have also been given a lot of written information over the years, which has been invaluable. If we have any questions we know we can ask and if they don't have the answer they will find someone who does. It has taken time and different treatments to find what works best for our daughter. Every test, procedure and treatment has been explained to us in detail, what to expect and the reason for it. It has always been explained in a way for us and our daughter to understand. It has always felt as though we have a say in her treatment plan although we rely heavily on their advice and experience.

The staff are always friendly and approachable and show that they care how our daughter is. They see her as a person and not just an illness or a person with an illness. If any of the team sees us at the hospital they always say hello or if they have time they will stop to have a chat.

As the time approaches for our daughter to move to the adult services, her current team are giving her all the information she needs of what to expect during and after the transition. It isn't being rushed and again we are left feeling included in the decision of when the right time will be. Recently the gastro nurse took the time to sit with us to go back over all the different treatments our daughter has been through, why the treatment was given and why it was changed. It has helped her regain a better understanding of her illness.

We have nothing but gratitude and appreciation for the care our daughter has received from the Ninewells paediatric gastro team.

**Karen McIntyre and Sarah Nicoll
Specialist Nurses**

5.2 Raigmore Update

We have had another busy year and a further increase this year in the number of patients requiring biologics that require intensive input in Raigmore. Numbers have gone up from 12 to 19 this year. Another patient group that need a lot of support are the patients on home parenteral nutrition. We now have 3 patients and we have provided training for all of the families.

The gastroenterology clinics in Inverness are always very busy. Dr Goudie and I have restarted our local clinic once a month to supplement this vital part of the service. We have also moved the discussion on patients to out with clinic time, where local consultants can bring patients to discuss.

Our patients and families appreciate the easy access to us, good advice and prompt treatment when required. I have a couple of patients who are finding coming to terms with their diagnosis and accepting advice on treatment express their appreciation of the team's effort in supporting them through it all. I have several young people whose IBD is under control but

who suffer from general fatigue and low mood and I support them with pacing themselves to increase their activity over time (this may be in addition to support they also receive from our psychology colleagues).

Mhorag Robertson
Specialist Nurse

5.3 RACH Nursing Update

The COVID pandemic has made the past 18 months the most challenging time for our service. It changed the way we support our families as phone lines were initially closed as it was anticipated that nursing staff would be deployed to the clinical areas. New email contacts were successfully embedded into our service and continue to be well utilised by parents even now phone lines have been reinstated. The CNS have had to work intermittently in the clinical areas during the past year and continue to work clinical shifts due to ward staffing pressures and we are also required to have the senior nurse bleep for RACH.

Brenda, Gastroenterology CNS, received a difficult diagnosis and following extended leave made the hard decision to retire through ill health. She was an important and respected member of the team over the past 7 years and is missed by both the team and her families. Chantelle Stewart, Pain CNS was initially seconded to cover and has now been appointed to the Gastroenterology CNS post and we welcome her to our team.

The use of Near Me technology has changed the way we review our patients in the IBD clinics. Some families had initial concerns that we would not see them face to face in clinic but they now report that the benefits of being able to be reviewed without having to travel with the subsequent interference to home, work and school life has been very positive. I have recently had video appointments with families on holiday on the North Coast 500, Ayr and Edinburgh Zoo and it enables the child to have their chronic condition assessed without disrupting family life.

Transition clinics usually run twice a year with an initial Gastro CNS transition clinic followed two months later with the adult transition clinic. These have been paused this year with the pandemic and it is anticipated that they will restart early 2022 with young people continuing to receive care with our paediatric team until then.

Carol completed the Introduction to Good Clinical Practice and Informed Consent in paediatric research eLearning modules and is now able to take consent from parents and children and young people when involved in paediatric IBD research.

We have had many 2nd and 3rd year student nurses spending 6-12 weeks with our team. Students opted to be NHS Grampian employees during 2020 and our student Rhona Wilkinson made a great contribution to the team and was NHSG employee of the week while working with our service before leaving to work in PICU.

Comment from parent

With both children having IBD we have been so grateful to the specialist Gastro nurses. Not only for answering our questions and worries, but to be there for both our children, reassuring them and explaining their treatment plans and of course their medications - ranging from daily medications, steroids to infusions and self-injections not to mention theatre appointments.

The children and us as parents know that the consultants are very thorough but they are also very busy, and having the Gastroenterology nurses gives us and the doctors I believe so much - they are our lifeline in so many ways.

Comment from parent

I was first introduced to Carol when my daughter was diagnosed with IBD 4½ years ago. Carol from the very beginning took us under her wing, explaining every process that would eventually prove to thankfully give our daughter a fabulous response to the treatments undertaken.

There were many hurdles to overcome and Carol being the positive person that she is provided the encouragement and support; visiting us daily whilst in hospital for 2½ weeks; thereafter contacting us throughout the difficult journey we had to endure. My daughter fully understands the treatments she requires, the medications she takes, the side effects she may experience, this all down to Carol and the Gastro Teams' dedication and time spent explaining every procedure.

The transition from the children's to adults hospital was daunting but the feedback, encouragement and introductions we have been given has made it more bearable than first anticipated. I can't thank Carol and the Gastro Team enough for the support they have given us as a family.

Comment from parent

The Gastroenterology Nurses are extremely important part in care of our son. Nothing is ever a problem for them and are always very supportive and happy to help and give advice. Very recently one of them Carol Cameron helped to saved family holiday as I miscounted medication and we were short for 2 days , so Carol managed to get supply with super short notice.

They always try to combine appointments to one day i.e. bloods appointment with appointments in x-ray department which is very helpful and handy for us as we don't live in Aberdeen so it's saving us a lot of time and money.

Comment from Nursing Students/Associate Practitioner

Thank you so much for the fantastic placement, you made me feel like one of the team from my very first day and I loved spending time with you both.

Thank you very much for the past few months, you taught me so much about everything gastro but also taught me about being the best nurse I can be.

Thanks for all your help and guidance over the last six months, I really appreciated it.

Comment from young adult

I just wanted to say that the gastro team have been amazing in supporting me and my family with my IBD diagnosis. I have been so inspired with the nurses that I have applied and have been successful in starting nursing at university this year.

**Carol Cameron
Specialist Nurse**

6. Research & Audit

CAPE study – (long term observational study of patients with Crohn’s disease on adalimumab)

The Covid 19 pandemic has caused some difficulties following up the recruits to the CAPE study. The Patient Reported Outcomes were unable to be obtained as patients were not being seen face to face in clinic, however we have continued to complete physician reported disease activity scores for each patient when they are reviewed in clinic.

We initially had 8 patients enrolled in this study and there are now 6 patients still under paediatric follow up. The remaining two patients have now transitioned to adult services, and long term follow up data continue to be collected by the research nurses.

iPENS study - (The intensive Post Exclusive Enteral Nutrition Study (iPENS): A randomised trial to evaluate CD-TREAT diet as a food reintroduction regime in children and young adults with Crohn’s Disease).

Both RACH and Ninewells Hospital have been approved as recruiting centres for the iPENS study. This is a nationwide, multi-centre randomised controlled trial looking closely at what happens to bowel inflammation in the weeks immediately following the use of exclusive enteral nutrition for treatment of Crohn’s disease, the role that dietary factors may play in any changes which take place, and whether inflammation can be altered by the use of a specific diet mimicking exclusive enteral nutrition (the CD-TREAT diet).

5 patients have been enrolled to the study so far (4 in RACH, 1 in Ninewells), with recruitment planned to continue until the end of 2022.

PINPOINT study – (The **P**rospective **I**ncidence of **P**aediatric-**O**nset **I**nflammatory bowel disease in the United Kingdom)

This year, the network has also been approved as a recruiting centre for the PINPOINT study. This nationwide, multi-centre, observational study aims to accurately record the incidence of new diagnoses of paediatric inflammatory bowel disease across the whole of the UK, as well as establishing a large prospective cohort of paediatric IBD patients to allow future research on long term outcomes and risks of IBD.

Recruitment to the study has only recently opened, with 10 patients included to date.

IBD Benchmarking Tool

Early in the year, the network participated in the IBD Benchmarking process, a national service audit run by IBD UK designed to assess how well IBD services are performing against the IBD Standards. The process involved collection of information about how the current IBD service operates as well as data collected from patient feedback. Unfortunately, during this round of the Benchmarking process we did not receive enough patient feedback for these reports to be included in the reports. However, the available results of the Benchmarking exercise highlighted that the network largely performs well at meeting the IBD standards, with results either similar to, or better than, the national average. Particular areas identified for improvement include regular departmental audit of the IBD service and inclusion of patients and families in service development. Our main goal for the next round of the Benchmarking exercise will be to increase awareness of the patient feedback arm of this to our patients to be able to review this aspect of the Benchmarking as well. More detailed review of the Benchmarking reports in network meetings has had to be postponed due to the additional

pressures on the network over the past year. However, this is planned to take place in the coming year to identify priority areas for improvement ahead of the next round of the Benchmarking exercise.

BSPGHAN/RCPCH Quality Standards Audit

The joint BSPGHAN and RCPCH Quality Standards for Paediatric Gastroenterology, Hepatology and Nutrition were published in 2017. Their aim is to improve health outcomes and quality of life for all infants, children and young people with gastroenterology, liver or intestinal disorders by reducing variation in care and ensuring equitable services across the UK. Last year a National Audit, run by RCPCH, was launched to map how UK services are currently meeting these standards and to highlight important areas for development. NoSPGHANN completed all data submission for the Audit. Unfortunately, the Audit had to be put on hold at the end of 2020 due to the increasing impact of COVID-19 at that time. It is now restarting, with plans to complete data collection and publish reports of results.

In addition to the above, the network has been actively involved in contribution to a number of other national research projects, including contribution of data to national, multi-centre studies of the impact of COVID-19 on paediatric gastroenterology, endoscopy and IBD services; national survey of practices related to chronic and recurrent pancreatitis in children; paediatric eosinophilic oesophagitis; and a national review of bowel preparation prior to paediatric colonoscopy.

**Dr Iain Chalmers, Dr Shyla Kishore and Maggie Connon on behalf of the
NoSPGHANN Team**

7. Key Challenges

The need for numbers of clinics is reviewed regularly across the network with local service managers. There has always been a lack of data available on network patients to enable network staff to plan services with a greater degree of accuracy. Added to this there is a lack of resources across all disciplines to be able to deal with and to support the increasing numbers of patients that require biologic therapies and those that require home parenteral nutrition.

Both groups of patients require a great deal of support therefore a large piece of work to develop a business case will be required in order to gain increased resources to set up a regional nutrition service. A dedicated team will be needed to be able to develop network pathways and protocols for these patients with complex nutritional issues that will ensure safe, effective, quality care and that will ensure national and international standards are being met.

8. Plans for the Year Ahead

The network continues to support the delivery of an equitable, high quality service across the North of Scotland and will ensure continued monitoring and re-alignment of provision of services according to patient need. We will continue to provide safe, effective, timely care and to drive up standards and to make improvements by working collaboratively and sharing best practice within the network and nationally.

Development of network data collection remains a priority in the coming year. This will inform existing service provision but will also be important with regard to the setting up of a specialist network nutrition team.

Grateful thanks go to all of our network team for their continued dedication, commitment and hard work. We remain proud of our achievements in being able to deliver first class gastroenterology, hepatology and nutritional care to patients and families as close to their homes as possible across the North of Scotland.

Gastroenterology, Hepatology & Nutrition network staff involved in delivery of NoSPGHANN – 2020-21

Appendix 1

Network Management	POST	Comment
Dr Su Bunn	Joint Clinical Lead	Cons Paediatric Gastroenterologist
Dr Iain Chalmers	Joint Clinical Lead	Cons Paediatric Gastroenterologist
Carolyn Duncan	Child Health Network Manager NHS Scotland North Regional Team	Also Network Manager for NoS neurology and respiratory networks

ABERDEEN	<i>POST</i>	<i>Comment</i>
Dr Su Bunn	Consultant Paediatric Gastroenterologist	
Dr Iain Chalmers	Consultant Paediatric Gastroenterologist	
Dr Shyla Kishore	Consultant Paediatric Gastroenterologist	
Dr Mike Bisset	Consultant Paediatric Gastroenterologist	Retire
Dr Umer Ghafoor	Consultant Paediatrician with a special interest in Gastroenterology	
Ann Morrice	Medical Secretary	
Stephanie Ramsey	Medical Secretary	Left September 2020
Michelle Kirkham	Medical Secretary	Started October 2020
Carol Cameron	PGHN Specialist Nurse	
Chantelle Stewart	PGHN Specialist Nurse	
Brenda Smart	PGHN Specialist Nurse	
Kathleen Ross	Lead Dietitian	Retired October 2020
Hilary Rennie	Dietitian	
Rachel Arthur	Dietitian	
Dr Anna Clancy	Clinical Psychologist	
Lorna Grant	Speech & Language Therapy	
Angie McCallum	Dietetic Assistant	
Martina Freeman	Pharmacist	Left March 2021
Trish Flanagan	Physiological Technician	
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		
Dr Dagmar Kastner-Cole	Consultant Paediatrician with a special interest in Gastroenterology	
Gillian Cormie	Medical Secretary	
Joanna Mulreany	Medical Secretary	
Karen McIntyre	PGHN Specialist Nurse	Also Rheumatology Specialist Nurse.
Sarah Nicoll	PGHN Specialist Nurse	
Clare McLeish	Lead Dietitian	
Marysia Maxwell	Dietitian	
Siobhain Swaine	Clinical Associate Psychologist	
Dr Paul Fettes	Consultant Anaesthetist	2 sessions to support endoscopy
INVERNESS		
Dr David Goudie	Consultant Paediatrician with a Special Interest in Gastroenterology	
Agnes MacIntyre	Medical Secretary	
Mhorag Robertson	PGHN Specialist Nurse	Part-time
Michelle Brown	Dietitian	
April Sutherland	Dietitian	
Dr Tracy McGlynn	Psychologist	
SHETLAND		
Dr Susan Bowie	GP with a Special Interest	Retired

**Paediatric Gastroenterology, Hepatology
& Nutrition Network (NOSPGHANN)
Work Plan 2020-21**

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.

RAGB 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 February 2020
1.	Continue to map, develop and agree care pathways Person-Centred, Efficient, Safe	Update as required regional care pathways to ensure consistency across the network, establishing links to other regional networks	<ul style="list-style-type: none"> Ongoing review of existing care pathways and link with national/regional groups to inform existing or new protocols and standards. Ensure care pathways and protocols on local intranets are comparable to ensure equitable standards of care across network 	2020-21	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. Amber
2.	Continue collaboration on support for appropriate paediatric gastro data collection across the North Person-centred, safe, equitable, timely	Improved clinical data collection to have ability to collect patient demographic and disease information to facilitate audit and quality improvement	<ul style="list-style-type: none"> Continue discussions locally, regionally and nationally with regards sufficient support in order to collect network data, e.g. IBD Registry 	2020-21	I Chalmers S Bunn D Kastner C Duncan	Lack of appropriate admin resources/to collect adequate data for improved service planning. Noted at Scottish Government. Amber

	Objectives	Outcome	Tasks	Timescales	Lead Professionals	Progress at February 2020
3.	Audit clinical care and research Safe, efficient, effective,	Identify projects suitable to carry out audit of children's care and review parents' and carers' experiences of service provided	<ul style="list-style-type: none"> Continue to participate in and collate data to input to national IBD Registry (including biologics therapies data collection) and have capacity to audit data Participate in the CAPE study (long-term observational study of patients with Crohn's disease on adalimumab) 	2020-21	S Kishore D Kastner C Cameron S Nicoll I Chalmers	Input to IBD Registry commenced Scotland-wide. Staff and patients involved in CAPE study. Amber
4.	Carry out Royal College of Physicians JAG Paediatric Global Rating Scale assessments for endoscopy provision across network Safe, efficient, effective,	Organise and complete appropriate assessments so that JAG endoscopy standards are met. This to ensure network endoscopy centres are recognised as training centres.	<ul style="list-style-type: none"> Ensure correct linkage between the Endoscopy Management System (EMS) reporting/audit tool and the JAG assessments Ensure assessments are carried out so that there is the capacity to train a GRID trainee in the network in future 	2020-21	I Chalmers S Bunn S Kishore D Kastner	Consultant training undertaken. Trainee training and support commenced. Green
5.	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	<ul style="list-style-type: none"> Liaise with Service Manager with regards endoscopy, IT and other equipment Liaise with Ninewells theatres and management team regarding future theatre sessions provision 	2020-21	I Chalmers S Bunn D Kastner	Clinical Lead continues to discuss capacity and requirements for extra sessions meantime. Amber

