

NeSCANN

*North of Scotland Child and
Adolescent Neurology Network*

Annual Report 2016-17



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1. Executive Summary

Welcome to the sixth annual report of the North Scotland Child and Adolescent Neurology Network (NeSCANN), which is the fourteenth year the network has been in operation. The NeSCANN delivers neurology, neurodisability and epilepsy in- and out-patient services by all disciplines, e.g. medical, nursing, physiotherapy, dietetics, neuropsychology, in NHS Tayside, NHS Grampian, NHS Highland, NHS Orkney and NHS Shetland.

If you wish to view previous network annual reports, these can be accessed on the North of Scotland Planning Group website at

<http://www.nospg.nhsscotland.com/index.php/child-health-camhs/nescann>

2. Introduction

It has been a busy year for our dedicated network multi-disciplinary staff. The network is committed to ensuring the sustainability of the tertiary and local neurology services and provides a mixture of cross board and locally based specialist neurology and epilepsy services. The main aims of the network continue to be to provide patients and families with patient-centred, safe, effective, equitable and timely care across the North of Scotland.

Multi-disciplinary teams of clinicians based in Royal Aberdeen Children's Hospital, Tayside Children's Hospital, Dundee and Raigmore Hospital, Inverness, collaborate across Health Board boundaries on a daily basis to deliver care as close to patients' homes as possible. Although not a single service, every effort is made to deliver the best possible equitable care across the region. Teams of highly experienced staff do their best to ensure patients are cared for in their home Board whenever possible without the need to transfer.

Regional collaboration continues on network protocols and pathways, e.g. continuing seizures, video telemetry and Vagus Nerve Stimulation (VNS). There are good established links with other areas of Scotland through the national Scottish paediatric epilepsy managed clinical network (SPEN), the Scottish Muscle Network (SMN) and the national Neurosurgery Managed Service Network (MSN). North network colleagues hold formal positions within national networks which further strengthens these partnerships and results in bi-lateral learning with these national networks.

NESCANN staff have contributed significantly to the national Paediatric Epilepsy Surgery MSN over the last year. Activity Data for the North of Scotland from April 2016 – March 2017 is detailed below:

	Tayside	Grampian	Orkney	Highland	Shetland	Totals:
MDT New Referrals:	3	2	0	2	0	7
MDT Re-discussions:	6	4	0	0	0	10
Resective Surgeries:	2	1	0	1	0	4
Invasive Cases:	2	1	0	0	0	3*

*One of the invasive cases did not lead to a resective procedure being performed

It has been difficult for our colleagues outwith the North to acquire specialist imaging including detailed 3 Tesla MRIs and FDG-PET CTs of the brain under general anaesthetic for children being investigated for surgical treatment of their epilepsy. Both the RACH and Tayside Children's Hospital have been able to assist with 3 Tesla scanning whilst FDG-PET CT and reporting has been achieved with support from our colleagues at the University of Dundee and Kings College London.

Staff work hard to collaborate with the national networks to ensure consistency of treatment, standards/guidelines and protocols across Scotland. The regional 'Watcher's List' (to monitor and to discuss patients who might be suitable for neurosurgery for their epilepsy) set up in the North was flagged up in the national review of the Neurosurgery MSN as being a very good model of care.

3. Network Governance

The network reports to the North of Scotland Planning Group (NoSPG). Dr Martin Kirkpatrick (Clinical Lead) and Carolyn Duncan (Network Manager) continue to lead and support the network across the region in collaboration with local Health Board clinician colleagues and managers.

Excellent team working and good communication is embedded in the work of our network's multi-disciplinary teams. Staff review the models of care on an ongoing basis to make improvements to services provided across the wide geographical area that is the North of Scotland. Patient safety comes first in all that we do and network staff continue to drive standards up in the way care is delivered to children and young people with a neurological condition.

Network clinics continue to be delivered in Dundee, Perth, Aberdeen, Elgin, Inverness, Orkney and Shetland. Use of video-conferencing with several NoS centres continues to be utilised when safe and appropriate to do so to deliver review clinics and on an ad hoc basis for clinical purposes. This can also negate the need for families to travel to the mainland.

Epilepsy transition clinics are in place in Tayside and Grampian however discussions will continue to take place with NHS Highland adult neurology colleagues to set these up in the near future. Epilepsy nurse-led clinics have now commenced in Tayside (following a new diagnosis patients are referred to this clinic).

4. Service Updates

4.1 Staffing

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

As in previous years, various staffing and data and IT access issues have proved challenging.

Dr Ann O'Hara, a very experienced Associate Specialist in RACH, retired during the summer and a local consultant vacancy continues to be a major gap in delivery of secondary care services within Grampian. The redesigned vacant post has been advertised twice with further redesign discussions now commenced locally to look at how options can be appropriately resourced in future. One of the benefits of working within a network during times of workforce pressures meant that Consultant Neurologist colleagues from Tayside were available to assist by providing additional support to colleagues in Grampian.

In Grampian there has been a long-standing Consultant Neurophysiologist vacancy in Aberdeen Royal Infirmary which puts extra pressure on paediatric medical staff however paediatric Consultants have been able to carry out reporting on paediatric EEGs in a timely manner.

The network was delighted when Dr Philip Brink, Consultant Paediatric Neurologist, was appointed to the substantive consultant paediatric neurologist post in Tayside following a lengthy application process for his Certificate of Eligibility for Specialist Registration (CESR).

We welcomed Julie Burslem, as Regional Paediatric Neuromuscular Physiotherapist to the network during the summer (13 hrs). The post job description was reviewed and this post now includes additional signposting responsibilities due to no additional funding being available regionally or nationally. The post now includes acting as the patients' and families' point of contact for advice and support to services in their local areas and continues to be the regional physio co-ordinating link across North of Scotland health board boundaries for staff training. Julie will continue to link into the national Scottish Muscle Network regarding physiotherapy.

4.2 Work Plan

Objectives in the network's collaborative work plan were progressed during the year, please see *Appendix 2*. The work plan is continually performance managed by a traffic light status system.

Good progress was made on the following pieces of work:

- Development of a network ambulatory EEG leaflet and VNS checklist.
- Review of parents'/carers' experiences of epilepsy services provided in Scotland and involvement in development of key performance indicators (Epilepsy 12).
- Review of network clinics, tertiary and secondary.
- Work on regional IT access issues e.g. remote cross border access to EEGs.
- Network staff participation in the PIE study and several national research studies.

In addition to the above, a lot of work was also undertaken by network staff who worked collaboratively on national projects, research and care pathways with SPEN, the SMN and the Neurosurgery MSN.

4.3 Highland-Moray Epilepsy Service

Bi-monthly paediatric epilepsy clinics were held in Dr Gray's Hospital in Elgin by with Specialist Epilepsy Nurse support from Kirsteen Mackintosh and Kelly McBeath. There are 30 patients with seizures on our database of whom 27 are on treatment. One child has been referred for epilepsy surgery assessment due to symptomatic focal seizures. Two patients would be regarded as epilepsy plus (epilepsy with other neurological issues). Currently there are 6 patients with a diagnosis of Childhood Absence seizure, 4 with Benign Rolandic Epilepsy and 2 with Juvenile Absence seizures. We had to admit 2 children over the year to Raigmore, the first for 24 hour EEG monitoring and the second because of refractory absence seizures. Two patients transitioned to adult services, the first to ARI neurology and the second to Raigmore neurology.

2 patients were referred for paediatric neurology review.

Dr Alan Webb

4.4 Intrathecal Baclofen Service

The service in each of the main centres continued to develop during the year. Clinics run in Dundee and Inverness with Dr Martin Kirkpatrick, Nicola Whatley (covering for Jo Clough whilst on maternity leave) and Dr Lesley Henderson. In addition Dr Elma Stephen delivered 2 Aberdeen clinics during the year with Dr Kirkpatrick and a successful ITB study day was also held.

Dr Kirkpatrick has been involved in setting up a national ITB group which met several times during the year. The aim of the group is to agree upon a set of standards at a clinical governance level for both children and adults across the whole of Scotland.

4.5 Paediatric Neuromuscular Physiotherapist Update

Julie Burslem commenced in the 13 hrs post in August 2016 after a gap of several months following the resignation of Faye Chappell. Julie also works in Inverness in a Highland Council role providing physiotherapy to paediatric patients. Julie's regional role now includes a care advisory signposting element for patients and families and referrals are directed to her to assist in identifying services that will support for families. She has been in contact with a number of families requesting help in sourcing funding for adaptations, equipment and holidays as well as information about patient conditions.

Julie has been working hard to update the numbers of diagnosed patients with a neuromuscular condition in the North of Scotland. There are currently 110 patients known to professionals who require physiotherapy input.

She has developed generic PowerPoint presentations for DMD, BMD, CMD and LGMD that can be used by fellow professionals to provide presentations and she has also presented at a few schools in Highland and Grampian. Training has also been given to the Community Physio team in Tayside for DMD assessments. Julie is in contact with Muscular Dystrophy UK and SMA UK and has attended training sessions with the North Star project.

Paperwork and protocols have been disseminated to all areas for standardised assessments and there is also a respiratory pathway and assessment in place for patients who have respiratory issues. Protocols have also been distributed for the use of spirometry and breathstacking.

Julie is the NoS neuromuscular physiotherapy link with the Scottish Muscle Network and attends network meetings and disseminates relevant information to local physiotherapy teams.

Julie Burslem, Regional Neuromuscular Physiotherapist

4.6 Neuropsychology Research – PIE Study Update

As highlighted in last year's Annual Report, the neurology team at RACH successfully contributed to the recruitment and delivery of a national Randomised Control Trial research study that evaluated the efficacy of a six weekly (2-hour sessions) psychosocial group intervention for adolescents with epilepsy.

Termed the PIE (Psychosocial Intervention in Epilepsy) study, the project was aimed at improving adolescents' epilepsy knowledge, self-management skills, mood and quality of life. The study is now complete. In total, 83 participants (33:50 m/f; age range 12-17 years) were recruited from the seven tertiary UK paediatric neuroscience centres that took part. Data analysis highlighted participants as demonstrating increased knowledge about epilepsy and improved confidence in discussing their epilepsy with others. Although no statistically significant changes in mood or quality of life measures were found, it would be relevant to note that there was a low baseline incidence of self-reported mental health difficulties. Participants described the opportunity to meet others with epilepsy, learning how to cope with difficult feelings, and learning about their epilepsy as particularly valuable. High ratings on acceptability of the intervention, together with overwhelmingly positive caregiver and facilitator feedback, suggests that PIE, with modification, could form a useful part of the care pathway for young people with epilepsy. An empirical paper providing more detail on the findings from the project has recently been accepted for publication in the scientific journal *Epilepsy and Behaviour*.

Dr Bruce Downey, Neuropsychologist

4.7 Ketogenic Diet Service

Helen Grossi (North Scotland Ketogenic Diet Coordinator) and Tracy Cameron (Based in Tayside)

The numbers of patients being referred for the ketogenic treatment in the North continues to rise as more research is being carried out and more families are aware of the potential benefits of the diet to their children who suffer from intractable epilepsy.

Joint clinics are held in Ninewells Hospital, Dundee, RACH, Aberdeen, Raigmore Hospital, Inverness and Balfour Hospital, Kirkwall with Dr Martin Kirkpatrick, Dr Alice Jollands, Dr Linda MacLellan and Dr Philip Brink alongside the local Epilepsy Specialist Nurses and Paediatric Dietitians.

Helen has been providing teaching sessions throughout the North to Health, Education and Social Care staff to increase awareness and knowledge of the Ketogenic Diet and to help improve the care of the children on this dietary treatment. She also presented at and chaired sessions at the Ketoconference, held in London in April and is a member of the National Ketogenic Advisory Group. She also leads the Scottish Ketogenic Diet Group where work is being carried out to streamline documentation and treatment used throughout the whole of Scotland. This also provides a forum for networking and collaborative working. Both Helen and Tracy are members of the newly formed Ketogenic Dietitians Research Network. There have also been opportunities for research on new Keto products which is ongoing.

The Ketogenic Diet Service held Two Ketogenic Diet Cookery Days, in Dundee and in Aberdeen. These days give families of children on the diet across Scotland a chance to meet up, discuss their experiences and make continuing connections with parents who have children on this treatment. Neil Palliser-Bosomworth (a Keto chef who works with both Matthew's Friend's, a charity which supports families on the Ketogenic Diet and

with Vitaflo) carried out these demonstrations and gave the families a chance to try new and different foods and new recipes. These fun days give families the opportunity to ask questions of the chef and the Keto Dietitians in an informal situation. These demonstrations had very positive feedback from the families who attended.

Tracy Cameron RD has been working on an Audit entitled 'Audit of the Ketogenic Diet service across Tayside' which has shown that the Ketogenic Diet continues to be a successful treatment option for children with intractable epilepsy. With the correct resources we could benefit from using the Ketogenic Diet with families at an early stage of their epileptic journey to reduce anti-epileptic drugs usage.

4.8 Patient Stories

Story kindly provided by a Ninewells patient's family -

On Tuesday 20th December 2016, at just 9 weeks old, our son Max was diagnosed with Spinal Muscular Atrophy (SMA) Type 1. This is a genetically inherited condition that affects the motor-neurons and muscles in the body. It is a degenerative, life-limiting condition, with babies diagnosed under 6 months rarely seeing their second birthday. After a series of tests at Ninewells Hospital Dundee, we returned to see the neurologist, Dr Kirkpatrick, on 4th Jan 2017 to confirm the condition. Max's bloods had tested positive for SMA. After speaking at length with Dr Kirkpatrick, we were given a small glimmer of hope when told about the drug Nusinersen which has been produced as a treatment for SMA and has recently been successful in clinical trials in the U.K.

We had to go home and wait to find out whether or not Max would be a suitable candidate for the treatment. After what felt like weeks, but was in fact only one week, we received the phone call from Dr Kirkpatrick that would change everything. It was 7.30pm on a Thursday evening and he had called to tell us that Max was eligible to participate in the Expanded Access Programme, following the success of the third phase of the clinical trials. It was the news we had been desperate to hear and having done some of our own research, we knew that we were about to embark on a journey without knowing where it would take us. All we knew was that we had to trust Dr Kirkpatrick and his team of professionals and place our child's future in their hands. There was nothing else we could do for him and we had nothing left to lose.

The treatment programme involves injecting the drug Nusinersen into the spine via a lumbar puncture. Max started his treatment at Ninewells hospital on Tuesday 17th January 2017 and has so far had his first four loading doses with his fifth dose due in June. We have gone from being a fairly humble family of four, adjusting to life with our newest addition, to suddenly having a team of therapists, specialists and a variety of professionals in our lives on a weekly basis. Hospital visits are fairly common place.

We have had to learn how to carefully handle Max, tube feed him via his recently fitted NG-tube, use a pep mask for chest physio and suction machine to keep secretions to a minimum. We try to do daily physio with him to help him move and ensure that he has a nice long bath every night as this is where Max is free to move his arms and legs more easily. Most importantly we have had to try and remember to still be his mummy and daddy and to spend just as much time with Max's big sister as we would have done normally. Trying to fit all of this into our daily routine can definitely prove tricky, especially when we have appointments and therapy visits. However, we feel extremely lucky to have behind us, a fantastic team at Ninewells as well as all the community based professionals who see Max on a regular basis. They have helped to make us feel much more full of hope about Max's future. A good friend

once told me that you wouldn't eat an elephant all at once, you would tackle it bit by bit, and that's what we are doing with SMA, tackling it bit by bit.

Our experience of the Ketogenic Diet by the Family of F

F was at the stage where he was constantly having seizure after seizure day and night our family life was quite difficult. However, it took only 3-4 weeks from the start (of the Ketogenic Diet) to change our lives completely. F has been seizure free since then and that was 7months ago.

At first, it's a daunting task I didn't think I would be able to manage, but my Dietitian did say I would be an expert in no time – I didn't think so. However, she was correct.

It's difficult at first, especially if you're not a cook, like me. But, after a few weeks it's like riding a bike – you wonder what you were stressing about. The EKM Calculator is a godsend though it takes only 5 minutes to get the values for a meal if F decides to change his mind about what he wants to eat.

F has seen the benefits of his 'magic' diet as well. At first, because of how he felt, with all the seizure activity, he wasn't happy. After a couple of weeks of seeing the benefits of being able to play and concentrate the way he used to, he never wants to stray/cheat on his diet. He is a much happier boy – the way he used to be. There is still the odd occasion where he gets an upset tummy, but F just shrugs it off and says it doesn't last long anyway.

New Development – Tayside Epilepsy Specialist Nurse-Led Clinic

A very useful weekly nurse-led clinic commenced at Ninewells from October 2016. Patients from 3-16 years of age are seen by the Epilepsy Specialist Nurses so that patients have the opportunity to discuss their epilepsy and how this affects their daily lives. The clinics have 4 slots for patients to be seen. These are open for Karen Berry and Pauline McEachen to use for seeing patients, family members or respite carers who need emergency buccal Midazolam training and/or first-aid seizure management training.

The traditional child-friendly information booklets on epilepsy continue to be used by the Specialist Nurses to explain the condition to their patients. In addition Mandalas colouring sheets have been used as an experiment to see if these would help to relax the patients so that they open up to nursing staff more about 'living with epilepsy'. These sheets have been found to be a useful tool benefitting the patients by –

- 1) reducing patient anxiety as there is less eye-to-eye contact made with the professional
- 2) enabling patients to chat more about their issues when colouring in which helps to make them feel less overwhelmed

One mature 9 year old girl asked to see a nurse on her own as she wanted to discuss her worries and as a result she agreed to put all her worries in a bag. On her parents joining the consultation, the child agreed to share her worries with her parents and they then all agreed to take her bag of worries home to burn them on the fire - so far the patient has not required further input from the Specialist Nurse.

This clinic has proven to be a welcome addition at Ninewells for patients, to enable them to better understand their condition. Review of the clinic will take place in autumn 2017.

5. Training & Education

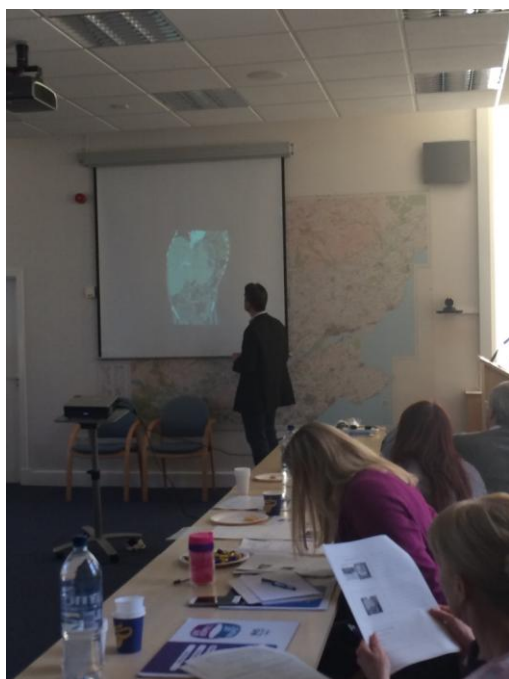
NeSCANN is committed to ensuring a highly skilled and trained workforce. Professional support continues to be regularly available by way of formal and informal teaching or learning opportunities and case discussions. There is a comprehensive diary of monthly education and learning opportunities by VC for network multi-disciplinary staff. Junior medical staff are also supported and encouraged to attend these sessions. However there are limited opportunities for staff from the North of Scotland to attend events/meetings that take place in the Central Belt as travel time can be challenging due to the time away from base to travel south and the lack of meetings organised to take place in the North.

One of the successes of the network is the number of tertiary outreach clinics that provide more than a simple visiting clinic as highlighted below. Monthly multi-disciplinary meetings take place in the 3 main centres providing teaching and education sessions, i.e.

- "Brainwave" (Ninewells) – available across the region by VC
- "Neurology Open Day" (Royal Aberdeen Children's Hospital)
- Raigmore Hospital, Inverness – lunchtime sessions alongside the visiting Consultant Neurologist clinics. In addition, 2 MDT days now take place at Raigmore twice per year covering topics such as continuing professional development, EEG, neurophysiology and neurosurgery reviews.

These provide regular teaching and educational forums for learning, e.g. discussions on complex cases, developments, audit, brain imaging and neurophysiological investigations.

Study Day - An excellent network study day took place in Dundee on 27th September 2016. We welcomed Dr David Campbell, Consultant Paediatric Gastroenterologist, from Sheffield who presented a novel, informative talk on feeding dystonia in patients with neurodevelopmental problems. There were also very interesting presentations from Dr Alice Jollands on genomics and cerebral palsy mimics and status dystonicus from Dr Laura Combe.



In addition our network clinicians continue to lead the distance learning Paediatric Epilepsy Training (PET) both nationally and internationally through the British Paediatric Neurology Association.

A number of national meetings have also been attended by network clinicians, e.g.

- BPNA annual conference, Cambridge
- Scottish Paediatric Neurology Group
- SPEN Members' and Research days
- SPEN special interest group meetings
- RCPCH annual conference, Liverpool

6. Research & Audit

6.1 GACE (Genetic & Autoimmune Childhood Epilepsy) Study

Recruitment to this national Scottish study continues to go well. It aims to study all children under 3 years of age who present with new onset epilepsy, looking at both the aetiology of their epilepsy and their outcome. Around one third of these children has seizures uncontrolled by medication and often associated with learning disability and behaviour problems. Some early findings were presented at the SPEN Members' Day meeting in November.

6.2 SANAD2

North of Scotland clinicians continue to be involved in this study regarding network patients. There had been problems recruiting to the study and a general acknowledgement that the Medicines and Healthcare Products Regulatory Agency (MHRA) recommendations had hindered progress. Therefore the study has been extended until June 2017. It is comparing the effectiveness and cost-effectiveness of anti-epileptic drugs and examines the quality of life in patients with newly diagnosed epilepsy.

6.3 Epilepsy 12

Network staff have been involved in writing performance indicators in epilepsy care being led by the Epilepsy 12 audit group. The parent and carers' experience questionnaire undertaken in the last round of the audit returned 2,500 UK wide. The group's work on the findings has moved forward with regional network assistance from Dr Kirkpatrick and Dr Aileen McCafferty and these were presented at the Scottish Epilepsy Research Group annual meeting in Dundee on 10th March 2017.

6.4 NeSCANN Research Group

Discussions have commenced within the network about the potential to set up a regional group looking at collating information on and discuss current or potential research projects in the North of Scotland.

7. Key Challenges

- The need for numbers of clinics is reviewed regularly across the network with local service managers. However 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.
- For 7 years now there has been no fit-for-purpose regional data collection system for the network (as well as for other North child health networks) and no ability or capacity to record numbers of patients or to document patients' diagnoses on a network basis. In addition there is no resource available to fully participate in national audits despite several attempts to fund data management support, e.g. the Clinical Audit System (SPEN), collection of data to feed into Epilepsy 12 and the epilepsy performance indicators which are under discussion nationally. The lack of a regional database severely hampers further improvements on cross-boundary co-ordination and planning of services.
- Clinician access to IT systems across boundaries such as Sci Store to sign/view clinical letters or to review test or EEG results is limited which can often hamper or delay clinical decision making, e.g. when patients are being discussed in the national MDT as potential neurosurgery candidates. Network and child health colleagues collated a table of IT issues which was shared with the North of Scotland Regional Planning Group and the North of Scotland eHealth Leads Group. It is hoped that discussions at the newly formed NoS e-Health Technical Group may assist with resolutions to some of these issues.

8. Looking Ahead

Our staff have been working extremely hard collaboratively across the NoS Health Board boundaries during the year to deliver quality care to their patients. Staffing vacancies and pressures and the lack of resources to collect and measure data to plan services more efficiently are ever present. However the main aims of the network continue to be to ensure delivery of safe, equitable, person-centred care to epilepsy and neurology patients across the north.

A Patient Satisfaction Survey regarding the service provided by our Epilepsy Specialist Nurses will be undertaken again in late autumn 2017 to gain families' opinions of the service across the network. The Clinical Effectiveness team in NHS Grampian has agreed to co-ordinate the submissions and analyse the data again for the network.

We will continue to progress the objectives in our work plan however we remain cognisant of the fact that there are no additional resources available to be able to develop services or to have the capacity to collect network data.

North Scotland Child & Adolescent Neurology network staff involved in delivery of NeSCANN

Network Management	POST	Comment
Dr Martin Kirkpatrick	Consultant Paediatric Neurologist	Clinical Lead
Carolyn Duncan	Child Health Network Manager	Also Network Manager for Gastroenterology and Respiratory NoS networks

NAME	POST	
ABERDEEN		
Dr Elma Stephen	Consultant Paediatrician	
Dr Vipin Tyagi	Consultant Paediatrician	Neurology/RACH & Dr Gray's, Elgin
Dr Ann O'Hara	Associate Specialist/Locum	Retired July 2016
Diane Honeyman	Medical Secretary	
Jo Campbell	Specialist Epilepsy Nurse	1 wte
Ena Cromar	Specialist Epilepsy Nurse	30 hrs
Dr Bruce Downey	Neuropsychologist	
Helen Grossi	Ketogenic Diet Co-ordinator	0.5 wte
Hilary Rennie	Dietitian	
Winnie Taylor	Lead Speech & Language Therapist	
Jane Tewnion	Physiotherapist Neuromuscular adviser	9 hours
Julie Dobson	Dietitian – Dr Gray's Elgin	
Physiological Technician		0.3 wte funding (purchasing services)
DUNDEE		
Dr Martin Kirkpatrick	Consultant Paediatric Neurologist	Also works in Grampian & Highland
Dr Alice Jollands	Consultant Paediatric Neurologist	Also works in Grampian, Highland & Orkney
Dr Philip Brink	Consultant Paediatric Neurologist	Also works in Grampian, Highland & Shetland
Dr Linda Clerihew	Consultant Paediatrician	
Sheila Kerr	Medical Secretary	
Karen Berry	Specialist Epilepsy Nurse	
Pauline McEachen	Specialist Epilepsy Nurse	
Aileen McCafferty	Neuropsychologist	
Jo Clough	Physiotherapist – Intrathecal Baclofen	On maternity leave from summer 2016
Nicola Whatley	Physiotherapist	Covering for Jo Clough
Tracy Cameron	Dietitian	0.4 wte for ketogenic diet
Heather Mitchell	Dietitian	
Zoë Whyte	Occupational Therapist	
INVERNESS		
Dr Alan Webb	Consultant Paediatrician with a Special Interest in Epilepsy	5 PAs for epilepsy service Moray/Highland
Christine Sutherland	Medical Secretary	
Dr Linda MacLellan	Consultant Paediatrician	
Dr Lesley Henderson	Consultant Paediatrician	
Kelly McBeath	Specialist Epilepsy Nurse	part-time/maternity leave
Kirsteen Mackintosh	Specialist Epilepsy Nurse	part-time
Julie Burslem	Regional Neuromuscular Physio	13 hrs (based in Highland)
Nikki Strachan	Dietitian	
Judy Shalcross	Dietitian - Wick	
Dr Tracy McGlynn	Psychologist	
SHETLAND		
Dr Susan Bowie	GP with a Special Interest	Based at Hillswick Health Centre
ORKNEY		
Catrianna McCallum	Dietitian	
Penny Martin	Physiotherapist	

North Scotland Child & Adolescent Neurology Network (NeSCANN) Work Plan 2016-2017

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

Objectives	Outcome	Tasks	Timescales	Lead Professionals	Progress at February 2017
Develop information on network, pathways & protocols for secondary and primary care staff as well as patients and families Patient-centred, Efficient, Equitable	Enhance clinician knowledge of service and of disease information	<ul style="list-style-type: none"> Develop already published information and pathways that could be regarded as network standards to be posted on each Health Board's Intranet site Identify local needs in addition to network needs Increase patient information available on network web page on NoSPG website Develop network ambulatory EEG leaflet and VNS checklist 	2016-17	A Jollands E Stephen C Duncan J Campbell	Work in progress – further work to be undertaken when time available. Ambulatory EEG leaflet completed (with local amendments). Dr Jollands and Jo Campbell to produce VNS checklist. Amber
Develop Performance indicators in epilepsy care in collaboration with Epilepsy 12 national audit group	Measure and have ability to benchmark network performance in children's national epilepsy care	<ul style="list-style-type: none"> Following regional participation in the Epilepsy 12 national audit be involved in discussions on formulation of national KPIs for epilepsy care 	2016-2018	M Kirkpatrick A Webb	News on KPIs work awaited from Epilepsy 12 national audit group. (Funding agreed by HQIP in England to take part in 3rd Round. Funding to be sought via Scottish Government and Health Improvement Scotland for Scotland to take part again). Amber

Objectives	Outcome	Tasks	Timescales	Lead Professionals	Progress at February 2017
Act on information provided in Epilepsy 12 parent and carers' experience questionnaire Efficient, Safe	Review of parents'/carers' experiences of epilepsy services provided in Scotland (2,500 questionnaires returned UK wide)	<ul style="list-style-type: none"> Review team established Present review findings to Scottish Epilepsy Research Group 	2016-17	M Kirkpatrick A McCafferty	Findings to be presented at Scottish Research group on 10 th March (Dundee University) Amber
Develop network requirements in collaboration with Health Boards' Physiology services Safe, Equitable, Efficient	Set up remote access for tertiary clinicians to patient EEGs across the network	<ul style="list-style-type: none"> Discuss and implement with Highland and Grampian Lead Technicians/Consultant Neurophysiologists remote access to patient EEGs (already set up across NHS Tayside) 	2016-17	A Webb C Duncan M Kirkpatrick	Remote access in Grampian being progressed by K Easton/IT colleagues. Issues with most appropriate IT security system are making this challenging. Dr Webb to investigate remote access to EEGs in Highland with Dr Patrick Fox (Consultant Neurophysiologist). Amber
Work with adult clinicians in the NoS to increase number of Transition clinics Patient-centred, Efficient, Equitable	Improved communication links with adult services for better transition to adult services for network paediatric patients	<ul style="list-style-type: none"> Set up individual Health Board meetings with adult medical staff and specialist nurses Review current transition clinic provision and jointly develop new clinics where required 	2016-17	M Kirkpatrick J Campbell K Mackintosh A Webb	No transition clinics available in Inverness or Elgin currently. Discussion also required with Grampian adult service re future provision at Dr Gray's/Moray (patients seen in RACH attend transition clinic with local adult Consultant and ESN). Amber