

NeSCANN

*North of Scotland Child and
Adolescent Neurology Network*

Annual Report 2014-15



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1. Introduction

This is the North Scotland Child and Adolescent Neurology Network (NeSCANN) fourth annual report. This year's report is a compact version from previous years' reports. If you wish to view previous annual reports, these can be accessed on the Internet at <http://www.nospg.nhsscotland.com/index.php/child-health-camhs/nescann>.

Over the past year services have been delivered and enhanced by the dedication of the network's multi-disciplinary teams across the North of Scotland in providing the best possible care for their patients despite testing economic times. The network is committed to ensuring the sustainability of the network in providing families with patient-centred, safe, effective, efficient, timely, equitable access to services. Teams of clinicians collaborate across health board boundaries on a daily basis to deliver the best quality care as close to patients' homes as possible.

2. Background and Network Governance

Dr Martin Kirkpatrick (Clinical Lead) and Carolyn Duncan (Network Manager) continue to support, lead and drive the work of the network across the region in collaboration with local Health Board clinician colleagues and managers.

Network multi-disciplinary staff continue to build on previous years' successes and in everything we do we aim to make a difference to patients' and families' lives by making improvements to the way we deliver care. We aim to drive up standards and ensure we provide consistency of care across the North of Scotland whilst working in partnership with patients and families to enable better management of their conditions.

We aim to ensure provision of a highly trained workforce and continue to encourage staff training and education. Professional support is provided daily through formal and informal training opportunities and case discussions. Some of the learning opportunities available will be described later in this report.

2.1 Network Links

Scottish Paediatric Epilepsy Network (SPEN) - Dr Ann O'Hara, Clinical Lead

Dr Ann O'Hara, from Royal Aberdeen Children's Hospital, continued as the Lead Clinician until December 2014 when her term of office ended. Ann had led SPEN with great enthusiasm and was able to progress a number of key issues on behalf of the national network.

Members of NeSCANN attended the SPEN Members' Day in Stirling in November as well as other interest groups such as educational sessions, roadshows and family days. Jo Campbell presented the data from the audit on the use of monitoring devices for children and young people with epilepsy across the network which was very well received.

Scottish Muscle Network

There continues to be links with the Scottish Muscle Network, with network clinicians being closely involved in developments and service improvement updates. Scottish Government funding for 2 years for Neuromuscular Care Advisors to scope the current service to adult and paediatric neuromuscular patients came to an end in December 2014. North of Scotland Boards decided not to fund the continuation of the post in the region and following discussion at the NoSPG Executive Group it was agreed that a piece of work will be carried out with key clinicians to identify areas where work on pathways would be required and to drive an improvement plan regionally.

Scottish Paediatric Epilepsy Surgery MDT

Dr Kirkpatrick continues to attend this Scottish Multi-Disciplinary Team meeting on behalf of network patients who are being discussed for potential surgery to improve their epilepsy. Twice per year Professor Helen Cross attends from Great Ormond Street Hospital to review some patients referred to the MDT. Approximately 15 patients per year in Scotland can receive surgery predominantly at Edinburgh Sick Kids.

3. Updates

3.1 NeSCANN Steering Group

Four network steering group meetings were held during the year. Many network and national reports and issues were discussed and compared to practice in the north, e.g.

- the Child Health UK Death Reviews – including a focused report on Co-ordinating Epilepsy Care and a number of recommendations
- British Society of Clinical Neurophysiology guidelines for video-telemetry
- Epilepsy 12, Round 2 of this national audit
- Development of Botulinum Toxin (Scottish Government SBAR)

A number of pathways and standards were also worked on or discussed and where relevant implemented during the year, i.e.

- Detailed discussion and work was undertaken on the network Continuing Seizures pathway (where patients fail 2 or more drugs or who are under 2 years of age) – please see Appendix 4. An audit of relevant patients that have been recorded as failing 2 or more drugs is also being carried out.
- Muscle biopsy pathway
- Guidelines on metabolic screening for children with development delay
- Epilepsy Specialist Nurse standards.

There was a large amount of work carried out with regards network structure documents. The network updated the Terms of Reference of the group and produced a NeSCANN Mission Statement. In addition “An Individual’s Responsibilities in the Network” document was agreed by the group. All of the documents were ratified during the year.

The network maintains a risk register using the NHS Scotland risk management template. This is reviewed at every steering group meeting and when relevant we engage with Boards’ child health management staff to try to resolve any issues. Similar pieces of work are carried out for other NoS networks and the risks all feed into an overarching NoSPG risk register where appropriate. The highlighted risks are integral to the work of the network but also act as a way of highlighting Board risks which could have resulting effects on the network’s work streams.

Work was also undertaken to agree a Patient Information leaflet for families, explaining how the network functions with regards in- and out-patient services. This will be piloted in Royal Aberdeen Children’s Hospital during late Spring 2015. Following evaluation of the leaflet, it is hoped that this can be a network standard in future.

3.2 Staffing

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

Staffing pressures due to a lack of capacity continue to be noted across the network with increasing numbers of patients and families requesting training and/or telephone support from the Epilepsy Specialist Nurses. There is a need for additional Epilepsy Specialist Nurse resources in each of the 3 main centres however there are no new initiatives currently that might enable this resource to be increased in the short-term. There has been acknowledgement in NHS Grampian that additional resource is required and some temporary funding has been made available. In addition, the numbers of patients either on a ketogenic diet or referred by Consultants for starting on the diet due to refractory epilepsy continue to increase.

The network was delighted to welcome Faye Chappell, Regional Neuromuscular Physiotherapist, replacing Anne Keddie. Faye took up her part-time role in April 2014 and is based at Dr Gray's Elgin. The NDP funded post links with the regional physiotherapists in the East and West of Scotland and work is collaborative to promote best practice and efficacy.

We also welcomed Dr Philip Brink to the team in Dundee as Locum Consultant Neurologist in February 2015.

3.3 Highland-Moray Epilepsy Service

Epilepsy clinics were held every 2 months at Dr Gray's Elgin with input from the Specialist Epilepsy Nurses and Dr Shelagh Parkinson in her role as local paediatrician with an interest in neurodisability. There are currently 21 epilepsy patients in regular follow up and of whom 18 are on treatment. Four patients have transitioned to adult services, one has moved to Grampian and another 4 have been discharged. The bulk of neurophysiology and neuroradiological investigations have been carried out at Raigmore which is generally more convenient than Aberdeen for Moray patients.

Over the next year it is planned that more of the epilepsy with additional needs patients will be seen in the Dr Gray's epilepsy clinic and extra 2 clinics per year may be required. Epilepsy training delivered in Moray is being transferred on a phased basis from Grampian Epilepsy Specialist Nurses to the responsibility of the Highland Epilepsy Specialist Nurses. During the year training was provided in 2 secondary schools, 5 primary schools and 2 nurseries by Highland ESNs. In April 2015, a further planning meeting will take place to discuss and to decide on the Moray epilepsy service configuration moving forward.

Dr Alan Webb, Consultant Paediatrician

3.4 Work Plan

Objectives in the 2013-15 collaborative work plan were progressed during the year (*Appendix 2*). The work plan is continually performance managed with a red/amber/green traffic light system. Objectives included:

- Review the membership of the Paediatric Neurology Steering Group and produce an up-to-date work plan
- Map, develop and agree care pathways to ensure consistency across the network
- Map existing clinics and develop and agree new clinic developments
- Develop information for patients to enhance patient/families' knowledge of the service and of disease information

- Continue to develop education framework and to review the training needs of network staff
 - Implement cross-boundary data collection IT system to have the ability to audit
 - Audit clinical care and to measure performance indicators in children's epilepsy care.
- There has been detailed discussion on producing and adopting a network Continuing Seizures pathway for patients who fail 2 or more drugs and require onwards referral for a tertiary opinion. This pathway was ratified by the Steering Group during the year. Work has also been undertaken with regards a clinical pathway for muscle biopsies in Grampian which was agreed.
- A fit for purpose data collection system and data officer support remain as gaps for our network as well as other NoSPG paediatric networks. It has been recognised for a number of years that there could be clinical governance issues at times regarding access to patient information and the ability to make clinical decisions on patients' outwith their home Board. There is a review ongoing at the North of Scotland Planning Group together with e-Health Leads in the region to investigate the best means of collecting data in future by using existing NHS systems.

SPEN continues to roll out training on the NSD funded Clinical Audit System (CAS) nationally and to collecting data in paper format currently (electronically for the GACE study for under 3s).

Network clinicians have been working with SPEN (and with the national Epilepsy 12 audit team) with regards agreeing epilepsy performance indicators for Scotland. This is a large piece of work which will be progressed further in 2015/16.

3.5 Training & Education

The network is committed to ensuring staff are well trained and highly skilled and there are a number of educational opportunities available to professionals across the network. Monthly multi-disciplinary meetings take place in the 3 main centres i.e.

- Brainwave (Ninewells) – now available across the region by VC
- Neurology Open Day (RACH)
- Raigmore, Inverness lunchtime sessions alongside the visiting Consultant Neurologist clinics.

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

In 2015, a PET1 course – 30th October (Paediatric Epilepsy Training) and a CHaT course, 31st March (Childhood Headache Training) run by the British Paediatric Neurology Association will take place in the Suttie Centre, Aberdeen with several network clinicians providing the teaching.

3.6 Network Study Event – September 2014, Aberdeen

A very interesting study afternoon was organised in the Suttie Centre, ARI on 18th September 2014. There were 2 excellent external speakers as well as network members presenting on themes incorporating topics on neurogenetics and neuromuscular conditions. Dr John Dean, Consultant Geneticist, presented epilepsy insights from the genetics point of view and Dr Callum Duncan, Consultant Neurologist, presented on chronic daily headache.



Above: Dr John Dean presenting

Below: Jo Campbell presents the findings from the network epilepsy monitoring audit.



3.7 Allied Health Professionals

3.7.1 Intrathecal Baclofen (ITB) Service Update - Jo Armstrong, Physiotherapist

Following on from last year's report Dr Martin Kirkpatrick and I successfully held a tone management/ITB assessment clinic in Inverness in March with Dr Lesley Henderson and Dr Linda MacLellan. We continue to hold joint tone management clinics in Tayside and are still working to replicate this in Highland and Grampian. We have had a further 2 successful pump implants this year.

I was fortunate to attend the National ITB Physio Meeting and National ITB Forum in Birmingham on 3rd & 4th July 2014. ITB physiotherapists across the UK are looking to complete a competency document for physiotherapists working in ITB services, as well as looking at service standards. The National Forum topic was mainly focused on ITB therapy in Spinal Injuries and there were also presentations from those working in paediatrics, with a very interesting presentation on gastrointestinal problems and tone management medications.

We are currently planning a Scottish ITB Seminar entitled 'Sharing Practice in Intrathecal Baclofen Management' on the 22nd May 2015 and are inviting representatives working in paediatric and adult ITB services across Scotland. The aim of the day is to provide a forum for networking and sharing practice in ITB management for children and adults and to examine issues of transition between adult and paediatric services.

I have now completed the Non-medical Prescribing Module at the University of Dundee and am awaiting results. It has been a very interesting module to complete and I hope to use my prescribing abilities initially working closely with patients commencing and titrating tone medications. In the future I plan to develop my role in the ITB service to perhaps include pump dose changes and refills.

3.7.2 Ketogenic Diet Service update

The Ketogenic Diet Service continues to make strides in providing a very good service for patients throughout the North of Scotland.

Joint clinics continue to be held in Ninewells Hospital, RACH and Raigmore Hospital with Dr Martin Kirkpatrick, Dr Alice Jollands and Dr Linda MacLellan along with the Epilepsy Specialist Nurses.

Helen Grossi, Ketogenic Diet Co-ordinator has been involved with providing local teaching sessions throughout the North to health, education and social care staff to increase awareness and knowledge of the ketogenic diet. She also presented and chaired sessions at the International Conference on the Ketogenic Diet for Epilepsy and other Disorders in October 2014.

Helen is currently leading the Scottish Ketogenic Diet Group where work is being carried out to streamline documentation that is used throughout Scotland for the ketogenic diet. This also provides a forum for networking and collaborative working nationally.

3.7.3 Regional Paediatric Neuromuscular Physiotherapist

Faye Chappell took up this part-time role in April 2014. The NDP funded post links with the regional physiotherapists in the East and West of Scotland and work is collaborative to promote best practice and efficacy.

Faye actively participates within the Scottish Muscle Network (SMN) and is a member of the steering group and physiotherapy, transition and paediatric sub groups. The work within these sub groups is shared and made specific to the needs within the north through discussion at the North of Scotland neuromuscular steering group and within NESCANN.

A scoping exercise has been completed establishing current provision and identifying variations and/or inequalities across the region. Following on from this, a defined physiotherapy structure has been established within the north; with named link neuromuscular physiotherapists being identified in Tayside, Grampian and Highland. The establishment of this core group of physiotherapists provides a tiered problem solving/supervision pathway and a forum to discuss both clinical issues and service developments.

Faye provides specialist physiotherapy input into the muscle clinics in Highland and Tayside. Patients in Grampian are mainly seen in the community following diagnosis. New standardised assessment forms have been developed for use across the region and new paperwork introduced to improve communication between the treating local therapist and the clinic staff. The format and structure of the clinics are being reviewed

on an ongoing basis to ensure maximum efficacy and benefit for the patients and their families.

Newsletters have been introduced to disseminate relevant information from conference, the SMN and NEScANN and also to signpost therapists to new information, advice and fact sheets on the Muscular Dystrophy campaign website. A half day training session has been completed for the physiotherapists in Highland and further training needs are being identified and addressed.

Faye Chappell

3.8 Neuropsychology

The neuropsychologist in Grampian, Dr Bruce Downey, is a paediatric work stream steering group member of the Scottish Acquired Brain Injury National Managed Clinical Network (otherwise known as SABIN). Over the past six months, this group has been involved in developing a set of NHS clinical service standards for paediatric ABI; with the standards produced providing statements on the level of performance that service users and their families can expect from relevant NHS Scotland paediatric ABI services. A draft of those standards produced has recently been circulated for consultation and peer review. It is anticipated that the final document will be published and publicly available by the summer of 2015.

Bruce has recently been awarded an NHS Research Scotland (NRS) Career Research Fellowship - to run from April 2015 to March 2018. The overarching theme of the programme of research proposed is concerned with the procedure of neuropsychological assessment in clinical practice and the evaluation of both medical and neuropsychological interventions on an individual's cognitive functioning. Aligned to this, the development and evaluation of interventions designed to improve psychosocial outcomes in neuropsychology populations is also a designated topic of interest.

Aligned to the above, Bruce and Epilepsy Specialist Nurses have been actively involved in collaborating on a large multi-centre national research project which is aimed at improving psychosocial functioning in children with epilepsy. Utilising principles of cognitive behavioural therapy (CBT), it is anticipated that this group intervention programme will help increase children's knowledge of their condition, while also enhancing their psychological health and their ability to cope with their condition. Positive effects on specific quality of life indicators are also expected.

Dr Bruce Downey, Neuropsychologist

4.1 'Epilepsy 12' national audit, Round 2

We have continued to participate in the second round of this national audit and three audit units in Aberdeen, Dundee and Highland have contributed data to this. The results for the performance indicators demonstrate that NEScANN fairs well in comparison to the rest of the UK and in many of the 12 Performance Indicators we are at the top of the range of data results.

Another part of this audit involved gathering data from a "patient reported experience measure" and there are still some 2,500 different questionnaires to examine in more detail. Two out of the three audit units in the north of Scotland had the best return rates across the UK and we are grateful to everybody, staff and parents and young people alike who contributed to this.

Our ambition is to move to a system whereby the performance indicators are collected prospectively and this will enable us to continue to demonstrate that we are providing high quality care to children with epilepsy and their families.

The summary and national reports both for professionals and for parents and children can be found on this website www.rcpch.ac.uk/epilepsy12.

Martin Kirkpatrick, Consultant Neurologist

4.2 Network Epilepsy Monitoring Equipment audit

The network qualitative audit on the use of monitoring devices by families was carried out across the network from November 2013 to May 2014 and the results analysed by NHS Grampian's Clinical Effectiveness team. The audit was led by Dr Ann O'Hara and Epilepsy Specialist Nurse, Jo Campbell. Epilepsy Specialist Nurses across the network in RACH, Ninewells and Raigmore were instrumental in encouraging families to become involved and were asked to distribute the audit questionnaire to 25 of their team's caseload.

Jo presented the findings at the SPEN Members' Day in November which was very well received. The results and analysis identified the range of monitoring devices families use and also gave a great insight from the parents' and carers' perspective as to how they are monitoring their children.

During the year Scottish Government also commissioned a survey for families to try to help them understand patient and carer experiences of epilepsy alarms (this was different to our network audit which looked at all types of monitoring devices). The survey results have yet to be published.

4.3 GACE (Genetic & Autoimmune Childhood Epilepsy) Study

This national Scottish study 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. This 3 year study will use a panel of some 80 different genes linked to childhood epilepsy and also look for possible auto-immune causes. Families are being asked if they wish to participate. Dr O'Hara, Dr Webb and Dr Kirkpatrick are the local leads for the study in Grampian, Highland and Tayside respectively. This will be a valuable study for a group of children who are often difficult to manage and difficult to get a correct diagnosis for.

4.4 Academic Presentations and Publications

Scientific Presentations

Gardella E, Larsen J, Wolff M, Schmiedel G, Kirkpatrick M, Barisic N, Depienne C, Troncoso M, Jepsen B1, Nikanorova M, Troncoso L, Bevot A, Hjalgrim H, Benikzky S, Møller RS. Peculiar interictal and ictal video-EEG features of SCN8A-related epileptic encephalopathy. Accepted for presentation to the International League Against Epilepsy meeting, Stockholm, June 2014.

Tharwat N, Henderson L, Stone J, Kirkpatrick M. The role of a controlled Propofol infusion in the rehabilitation of functional dystonia in a teenage girl. *Developmental Medicine and Child Neurology* 2015;57(suppl no.1):25
Presented to the British Paediatric Neurology Association, Newcastle, January 2015.

Peer Reviewed Papers

Kirkpatrick M, Dunkley C, Ferrie C, Flower D, Waldron B, Whitehouse WP, Helen Cross J, Rodie P, Appleton R. Guidelines, training, audit, and quality standards in children's epilepsy services: Closing the loop. *Seizure: Eur J Epilepsy* 2014;23:864-8

Larsen J et al. The phenotypic spectrum of SCN8A encephalopathy. *Neurology*. 2014 /595553 (in press).

-Hamilton MJ, Longman C, O'Hara A, Kirkpatrick M, McWilliam R. Growing up with spinal muscular atrophy with respiratory distress (SMARD1). *Neuromuscular Disorders* 2014 (in press).

-Shetty J, Greene SA, Kirkpatrick M. Adherence to anti-epileptic drugs in children with epilepsy in a Scottish population cohort. *Archives of Disease in Childhood* (accepted pending minor revision) 2015.

5. Key Issues

There have been a number of challenges for the network over the past year.

- The network maintains a risk register which is reviewed at every steering group meeting and when relevant we engage with Boards' child health management staff to try to resolve these issues. Ongoing issues include IT/data collection as indicated below, Moray local medical staffing responsibilities with regards epilepsy patients and lack of a Tayside neurophysiology service and a potential similar situation in the Grampian following retirements of single-handed posts.
- A fit for purpose data collection system and data officer support remain as gaps for our network (as well as for other North of Scotland child health networks). It has been recognised for a number of years that there are clinical governance issues at times regarding access to patient information and the ability of Consultants to make clinical decisions on patients' out with their home Board. There is a review ongoing at the North of Scotland Planning Group together with e-Health Leads in the region to investigate the best means of collecting data in future by using existing systems such as Trakcare.

A large piece of work will be progressed with SPEN and Epilepsy 12 during the coming year by network clinicians looking at national epilepsy performance indicators that should be embedded into any future IT data systems. Data collection on epilepsy and neurology patients needs to be embedded into everyday practice therefore this will remain a major network priority in the coming year.

6. Looking Ahead

We have had an extremely busy year but remain well positioned to take the network forward positively. Members of the network continue to work extremely hard to deliver the best quality service to their patients across the region in spite of challenging economic times. NeSCANN will continue to develop services where possible and to build on the good collaborative work carried out across the region over the past 11 years.

Our multi-disciplinary teams of conscientious, hardworking, well trained staff continue to make a big difference and we will continue to drive service improvements to improve standards of care for patients with a neurological condition across the North of Scotland.

We wish to ensure the right knowledge and skills are available throughout the network to meet the specific needs of the patients and we will continue to make available to staff many learning and educational opportunities within the network and alongside the Scottish Paediatric Epilepsy Network, the British Paediatric Neurology Association and other relevant organisations.

Appendix 1 –

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 Ayaz Shah | Consultant Paediatrician | |
| Dr Elma Stephen | Consultant Paediatrician | Neurology/Dr Gray's, Elgin |
| Dr Ann O'Hara | Associate Specialist | Also Clinical Lead for Scottish Paediatric Epilepsy Network until December 2014 |
| Diane Honeyman | Medical Secretary | |
| Jo Campbell | Specialist Epilepsy Nurse | |
| Ena Cromar | Specialist Epilepsy Nurse | Part-time |
| Dr Bruce Downey | Neuro-Psychologist | |
| Hilary Rennie | Dietitian | |
| Winnie Taylor | Lead Speech & Language Therapist | |
| Jo Thomas | Occupational 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 working in Grampian, Highland & Shetland |
| Dr Alice Jollands | Consultant Paediatric Neurologist | Also working in Grampian, Highland & Orkney |
| Dr Philip Brink | Locum Consultant Paediatric Neurologist | Commenced February 2015 |
| Dr Linda Clerihew | Consultant Paediatrician | |
| Sheila Kerr | Medical Secretary | |
| Karen Berry | Specialist Epilepsy Nurse | |
| Pauline McEachen | Specialist Epilepsy Nurse | |
| Aileen McCafferty | Neuropsychologist | |
| Faye Chappell | Regional Neuromuscular Physiotherapist | |
| Jo Armstrong | Physiotherapist – Intrathecal Baclofen | Based in Dundee |
| Helen Grossi | Ketogenic Diet Co-ordinator | |
| Heather Mitchell | Dietitian | |
| Zoë Whyte | Occupational Therapist | |
| INVERNESS | | |
| Dr Alan Webb | Consultant Paediatrician with a Special Interest in Epilepsy | 5 PAs for epilepsy service |
| Mandy Craib | Medical Secretary | |
| Lis Jackson | Medical Secretary | Retiring April 2015 |
| Dr Linda MacLellan | Consultant Paediatrician | |
| Dr Lesley Henderson | Consultant Paediatrician | |
| Kelly McBeath | Specialist Epilepsy Nurse | 4 days, part-time |
| Kirsteen Mackintosh | Specialist Epilepsy Nurse | 3 days, part-time |
| Nikki Strachan | Dietitian | |
| Judy Shalcross | Dietitian - Wick | |
| Dr Tracy McGlynn | Psychologist | Maternity leave from March 2014 |
| Dr Rachel Smith | Psychologist | |

| <i>NAME</i> | <i>POST</i> | |
|-------------------|----------------------------|----------------------------------|
| SHETLAND | | |
| Dr Susan Bowie | GP with a Special Interest | Based at Hillswick Health Centre |
| ORKNEY | | |
| Catriona McCallum | Dietitian | |
| Penny Martin | Physiotherapist | |

**North Scotland Child & Adolescent Neurology Network
(NeSCANN) Work Plan 2014-2015**

| Objectives | Outcome | Tasks | Timescales | Lead Professionals | Progress at March 2015 |
|--|--|---|------------|---|--|
| Review the membership of the Paediatric Neurology Steering Group (RAG: Green) Efficient, Effective, Equitable | Review the group membership and produce an up-to-date work plan | <ul style="list-style-type: none"> Produce a network mission statement Update annual work plan | 2014 | M Kirkpatrick C Duncan | Mission statement and Terms of Reference completed with NoSPG Framework for Tertiary Paediatric clinics now included |
| Map, develop and agree care pathways (RAG: Amber) Patient-centred, Efficient, Safe | Develop North region care pathways to ensure consistency across the network, enhancing links to national/other regional networks | <ul style="list-style-type: none"> Identify existing care pathways and any gaps Link with national/regional groups to inform existing or new network protocols, standards and referral pathways Develop neurology and epilepsy care pathways for western Grampian/Moray area | 2014-15 | A Jollands H Grossi J Campbell J Armstrong A Webb | |
| Map existing clinics and develop and agree new clinic developments (RAG: Green) Patient-centred, Efficient, Safe | Agree and establish new clinics according to local needs | <ul style="list-style-type: none"> Map existing cross-boundary clinics Agree with multi-disciplinary colleagues proposed new clinic requirements Identify local lead clinician(s) to be responsible for organising new clinics within individual Health Boards, for example, Baclofen clinics in Inverness, Elgin and Aberdeen | 2014-15 | M Kirkpatrick A Shah A Webb A Jollands ESNs | New Baclofen clinic commenced in Inverness March 2014 |
| Develop information for patients (RAG: Green) Patient-centred, Efficient | Enhance patient/families' knowledge of service and of disease information | <ul style="list-style-type: none"> Develop patient information and involvement leaflets Investigate Web possibilities to develop network website | 2014-15 | A Jollands H Grossi J Campbell J Armstrong | Patient network information leaflet to be piloted late Spring 2015 |

| Objectives | Outcome | Tasks | Time-scales | Lead Professionals | Progress at March 2015 |
|--|---|--|-------------|--|---|
| Continue to develop education framework (RAG: Green) Efficient, Safe | Continue to review the training needs of network staff and describe a planned curriculum of Continuing Professional Development | <ul style="list-style-type: none"> Identify service and staff needs Review educational opportunities – local/ regional/national | 2014-15 | A Jollands C Duncan J Campbell E Cromar | 2015 Educational Opportunities List distributed in region |
| Implement cross-boundary data collection IT system (RAG: Amber) Patient-centred, Safe, Equitable | Improve clinical data collection by means of a Clinical Audit System to have ability to audit and provide high quality care to patients | <ul style="list-style-type: none"> Gain NoSPG agreement to develop and to provide funding so that NeSCANN can input to a North of Scotland version (which includes the SPEN version with NoS neurology data sections) | 2014-15 | M Kirkpatrick A Jollands C Duncan | SPEN training took place in Aberdeen and Dundee, May 2014. However discussion ongoing in NoSPG e-Health Leads group with regards future most appropriate systems for use in NoS networks. |
| Audit clinical care (RAG: Green) Efficient, Safe | Measure performance indicators in children's epilepsy care and review parents' and carers' experiences of service provided | <ul style="list-style-type: none"> Participation in and collation of data for the Epilepsy 12 extension national audit during 2014 Each unit to produce local action plans for Round 2 of Epilepsy 12 | 2014-15 | M Kirkpatrick A Shah A O'Hara A Webb | Data submitted & PREM questionnaires returned to Epilepsy 12 from Grampian & Tayside. Round 2 Tayside action plan produced. Updates being worked on from NHSG & NHSH. |

Red/Amber/Green status

| | |
|--|--|
| | red - not on target/little or no progress |
| | amber - satisfactory, significant progress to date but further work required |
| | green – the network has been successful in achieving the objective |

Audit on the Use of Epilepsy Monitoring Equipment



Q1 What age range is your child in?
 Pre-school..... Primary school Secondary school

Q2 Has your child ever been diagnosed with any of the following conditions?
 Learning difficulties/developmental delay
 Cerebral palsy
 Autism or autistic spectrum disorder
 Attention Deficit Hyperactivity Disorder (ADHD)
 None of the above.....
 Other
 If 'other', please specify:

Q3 Do you know the type of seizures your child has?
 Yes..... No
 If 'yes', which type?

Q4a Are your child's seizures well controlled?
 Yes..... No

Q4b How many seizures per month does your child have?

Q5a Does/did your child have seizures in sleep?
 Yes, my child **currently** has seizures in sleep..
 Yes, my child **used to** have seizures in sleep..
 My child **never** had seizures in sleep

Q5b How worried do / did you feel about your child having seizures during sleep or at night?
 Not worried .. Go to Q6a Worried Very worried.

Q5c If 'worried' or 'very worried' to Q5b, have you discussed this or received counselling?
 Yes..... No Go to Q6a

Q5d If Yes to Q5c, who have you discussed this with or received counselling from....? (Tick all that apply)
 Doctor Epilepsy Nurse
 Field worker Other
 If 'other', please specify?

Q5e If 'worried' or 'very worried' to Q5b, do/did you sleep in the same bed /bedroom as your child?
 Yes, I **currently** sleep in the same bed /bedroom as my child..... Go to Q6a
 Yes, I **used to** sleep in the same bed / bedroom as my child..... Go to Q5f
 I have **never** slept in the same bed / bedroom as my child..... Go to Q6a

Q5f If you **used to** sleep in the same bed / bedroom as your child' (Q5e), approximately how long did you do this in the past?

Q6a Do you use any monitoring equipment that would indicate if your child is having a seizure at night?
 Yes Go to Q8
 No **Thank you for completing this questionnaire**
 I used to, but have now stopped..... Go to Q6b, Q6c and Q6d

Q6b If 'I used to, but have now stopped' to Q6a, what did you use? (Tick all that apply)
 Used a Baby monitor Used an Epilepsy alarm
 Used an Apnoea alarm Used a Saturation monitor
 Other
 If 'other', please specify?

Q6c If 'I used to, but have now stopped' to Q6a, what were your reasons for stopping?

Q6d Please explain why you used to use monitoring equipment in as much detail as you can in the box below:

Q7 Would you be willing to be contacted again to further discuss 'monitoring' ?

Yes..... No

If 'Yes', please provide contact details below:

Thank you for completing this questionnaire.

If you 'currently use' monitoring equipment, please complete the following questions:

Q8 Do you currently....? (Tick all that apply)

Use a baby monitor Use an Epilepsy alarm.....

Use an Apnoea alarm..... Use a Saturation monitor.....

Other.....

If 'other', please specify?

Q9 Who is responsible for its maintenance of the monitoring equipment?

I am..... Social Services The manufacturer

Q10 Where did you get the monitoring equipment from?

Occupational Therapist..... Social Services

Charitable Organisation Epilepsy Specialist Nurse.....

Purchased by parent/guardian

If 'Charitable Organisation', please specify?

Q11 Please explain why you use monitoring equipment in as much detail as you can in the box below:

Q12 How would you rate the reliability of the monitoring equipment you use?

Very good..... Good..... Average . Poor Very poor

Q13 If you have any other comments about Epilepsy monitoring equipment, please write in the box below:

Q14 Would you be willing to be contacted again to further discuss 'monitoring' ?

Yes..... No

If 'Yes', please provide contact details below:

Thank you for taking the time to complete this questionnaire

Continuing Epileptic Seizures
NeSCANN Care Pathway (Incorporating SPEN care pathway)

January 2014

Appendix 4

