NHS SCOTLAND

NORTH OF SCOTLAND PLANNING GROUP

National Delivery Plan for Children and Young People's Specialist Services
Performance Monitoring Framework

1. Aim

The aim of this document is to set out a performance monitoring framework which will support NoS to report on progress in implementing the National Delivery Plan for Specialist Children's services (NDP) during Year 3 (2010/11) to the Scottish Government.

2. Background

NoS have received an NDP allocation of £3,113,058 for Year 3 with funding of £1,914,074 recurring from Year 1 and 2 and £1,198,984 for new Year 3 developments. Table 1, highlights the specialities which have been prioritised in the NoS

Table 1 - NoS NDP Specialties

1. Gastroenterology	7. Child Protection
2. General Surgery	8. Neurology
3. Rheumatology	9. Allergy
4. Cystic Fibrosis/Complex Respiratory	10. Critical Care
5. Oncology	11. Metabolic
6. Psychology	12. Nephrology
	13. PID / HIV

The Scottish Government has stated that NDP funding has been designated as earmarked recurring which will be dependent upon evidenced need and 'additionality' i.e. quantifiable benefit to date. There is no set term to the recurrence and this will be reviewed annually.

The North of Scotland Regional Planning Group, also require evidence that the NDP resources are providing additionality and that the resources are being used efficiently.

During Year 3, the NDP investment will be monitored on a quarterly basis with reports being provided to the Scottish Government and NoSPG.

3. NoS NDP Performance Monitoring Framework

Table 2 below sets out the quarterly reporting timescales in which reports will be requested for and submission expected. This is to provide the NoS Child Health Clinical Planning Group an opportunity to review progress ahead of submission to the Scottish Government and NoSPG.

Table 2 – SEAT NDP Year 3 Reporting Timescales

Quarter	Reporting period	Date request for report will be issued	Date for submission
1	April – June 2010	23 June	8 July
2	July – September 2010	22 September	7 October
3	October – December 2010	22 December	7 January
4	January – March 2011	23 March	7 April

The performance monitoring template which will be used by NoS to report on NDP progress can be found in **Appendix 1**. It is intended to monitor progress in each speciality where investment has been made. It is also intended that the reports be shared with the lead Clinicians and other NHS Boards prior to completion.

Section 2 draws attention to the outcomes and outputs for each specialty. These are the objectives that were submitted as part of the proposals. This section is not expected to be updated for each quarter, but acts as a reminder as to what NoS proposed to the Scottish Government would be achieved with the NDP funding.

Section 3 identifies the Lead Manager that is expected to take responsibility for ensuring submission of the report and would be the first point of contact for a particular speciality from each Board. The NDP funded posts in each of the Boards and date of appointment are also featured. Progress with recruitment to outstanding NDP posts is expected to be updated every quarter where appropriate.

Section 4 describes the activities and outputs completed in each quarter. There are a series of questions which are based on the information requested by the Scottish Government. Pertinent data will greatly support the region's ability to demonstrate 'additionality' and secure NDP funding on a recurring basis. It is expected that this section is updated every quarter with relevant information where available and concise statements can be made regarding the progress made.

Section 5 asks for any patient or family feedback that has been made during the quarter that is directly relevant to the NDP investment made in specialist children's services. Concise statements and data will again greatly support the region's ability to demonstrate 'additionality' and secure NDP funding. Where there is appropriate and available information, it is expected that that the section is updated every quarter.

Section 6 requests that any other relevant improvements, activities or issues that have not been covered by sections 4 or 5 be highlighted. Where there is appropriate and available information, it is expected that the section is updated every quarter.

Section 7 requests that the Lead Manger makes a statement evaluating the progress made in this quarter. It is expected that the section is updated every quarter.

APPENDIX 1

NoS National Delivery Plan for Specialist Services for Children and Young People Performance Monitoring

Reporting Period: Quarter 3, October – December 2010

Frequency of Update: Quarterly

Submission Date:

1.	**Specialist Service - Neurology**

2.	**Outcomes and Outputs**
2.1	**Outcomes**

- Improved integration of clinically effective care
- Meeting published standards of care
- Improving equity of access of services
- Reduction in waiting times, travelling times & costs
- Improved sharing of expertise and resource at "local" level
- Improved multi-disciplinary care
- Increased professional/patient awareness of service
- Improved transition to adult services
- Improved condition management
- Reduce inequalities
- Improved health and well-being of children

2.2	**Outputs**

- Establishment of steering group
- Introduction of audit system
- Development of regional protocols, guidelines & pathways
- Integrated secondary services for children in Highland, Shetland, Orkney and Moray
- Utilisation of telemedicine
- Tertiary support to Orkney, Shetland & Moray
- Visiting clinics with "local" paediatrician
- CPD/Training events
- Transition Clinics
- Patient Information packs

3.	**NoS NDP Inputs**			
3.1	**Grampian**	**Lead Manager - G Thomson**		
Post		**Band**	**WTE**	**Appointed**
Specialist Nursing		7	0.5	Yes
Physiotherapist		7	0.25	Yes
3.2	**Tayside**	**Lead Manager – D Sturrock**		
Post		**Band**	**WTE**	**Appointed**
Paediatrician with an interest		Cons	2pas	Yes
Rehab – Occupational Therapist		7	0.25	Yes
Specialist Nursing		7	0.5	Yes
Admin		4	0.5	Yes
3.3	**Highland**	**Lead Manager - N Summer**		
Post		**Band**	**WTE**	**Appointed**
Consultant paediatrician with an interest		Con	10pas	No
Specialist Nursing		6	0.6	Yes

Physiotherapist	7	0.25	Yes
Admin	4	0.5	Yes

4.	**Activities and Outputs Completed**	
4.1	**Number of patients being seen by specialist service**	
The network has a case load in excess of 2000 children and young people, across the NoS Boards, with a mix of complexity. This includes _ **Highland** 320 patients that are active on the current case load, but this will changes on a daily/frequently basis. On average the service receives 6 new referrals per month. **Grampian** Out-patient physiotherapy has been provided for four children and support given to colleagues who have children with a neuromuscular condition on their caseload		
4.2	**Reduction in waiting times / list**	
Nurse led clinics are being introduced across the network to ensure that families are followed up quicker and they received high quality nursing input/follow up. NHS Highland are currently waiting to get on to i-soft.		
4.3	**Number of new outreach / specialist clinics and number of attendees**	
Grampian Physiotherapy input has been increase to support the specialist Diagnostic Muscle Clinic and Spina Bifida clinic which previously were unsupported by physiotherapy. Nurse-led clinics in Moray, Orkney and Shetland are being introduced; Moray will take place on a monthly basis, with Shetland and Orkney potentially occurring on a quarterly basis. **Tayside** An Adolescent Epilepsy Service has been introduced and is providing support to young people during the transition. This is occurring on a monthly basis at the moment. Tertiary consultants have increased the number of out reach clinics they are supporting in NHS Highland, Moray, NHS Shetland and NHS Orkney. In addition consultations are also being provided via VC in remote and rural areas. Out reach clinics in the various areas are talking place on a weekly basis. **Highland** Epilepsy clinic (Community paediatrician & specialist nurse) Usually around 6 people seen at these specialist clinics every 3 weeks. Epilepsy nurse clinic is in the process of commencing on a weekly basis. 6 children seen on each occasion. Community paediatricians in different areas are requesting our attendance at their clinics, as support and for follow on treatment to assist both children & their families. This is increasing, but currently each of us will attend 6 clinic appointments per month – this is usually in the special needs schools local to Inverness.		
4.4	**Number of agreed standards, protocols and patient referral pathways in place or are being met**	
The following have been introduced across the network: Duchenne Muscular Dystrophy Scottish Multidisciplinary Care Pathway. SIGN guideline being followed for each patient Protocols for their emergency medication issued for each patient Referral pathway followed by all professionals		

Transition pathway just complete and ratified by the Area Nursing and Midwifery Advisory Committee Medicines at school pathway Guideline for administration of emergency midazolam	
4.5 Number of routine multi disciplinary team meetings, clinics or reviews completed or delivered	
Across the network: • MDT's occur on a weekly basis in the 3 mains centres, with quarterly meetings occurring in rural centres. VC is utilised to ensure input from tertiary consultants • The number of clinics occurring across the network on a quarterly basis is 40-45 • With regard to the number of annual reviews completed there have been difficulties in quantifying this information; however it is estimated that it is between is >45.	
4.6 Number of training / CPD events developed, delivered or received	
Highland Continual! 2 delivered & 2 received **Grampian** Specialist Physiotherapist has attended the Scottish Muscle Network annual conference in Dundee. Epilepsy Awareness Study Day - 10/08/2010 Induction - Pharmacy, Blood Transfusion, Infusion devices, Drug Administration - 23/09/2010 Child/Infant BLS - 08/12/2010 Care of the critically ill Child - 09/12/2010 • Epilepsy training at schools • Database input • Communicating with members of multidisciplinary team • Department meetings • Clinic • Office duties, filing, preparing information, ordering supplies. • Clinical Nurse Specialist meeting • Working in Daycase Unit • Local epilepsy training The Ketogenic Dietitian has visited dietetic departments across the network and is working with colleagues to establish the ketogenic service. Attended international ketogenic diet meeting in Edinburgh in October 2010 and contributed to medical "grand rounds" teaching.	
4.7 Availability of specialist staff – number of informal contacts/advise delivered or received	
Staff involved with the network provide a range of support, which includes: • Support for families at various clinics • Support for families, and colleagues utilising telephone, VC and electronic mail A mechanism is current being introduced across the network to gather accurate figures on the number of contacts made.	

4.8	**Number of new treatments delivered or new ways of working implemented**	
This includes - Ketogenic diet, VNS, Independent Non medical prescribing		
4.9	**Improved compliance to treatment regime**	
Across the network, it has been informally noted that there is a significant improvement compliance & better management of seizures. A number of patient stories are currently being collected and will highlight the impact the NDP investment has had for them.		
4.10	**Reduction in hospital length of stays**	
Across the network it has been reported; That the length of stay is reduced due to the increased access to staff who are available to visit children and young people to give advice/ training/ support & promote early discharge.		
4.11	**Reduction in number of hospital admissions / re-admissions**	
Across the network there is evidence of a significant reduction of paediatric admissions, with some evidence that there has been a decrease in the number of emergency admissions for epilepsy.		
4.12	**Number of children that have made the transition to adult care**	Patient - Centred Effective Equitable Safe
Highland 4 children who have been handed over, but there are 4 in process of following new transition pathway.		
4.13	**Improved functional quality of life or other improved health outcomes**	Patient - Centred Effective
There is some evidence to suggest that children and young people are able to attend school much more readily, due to the increased level support being provided. In turn this gives the children some routine, their siblings some time with their parents, their parents some time to work/socialise & look after their children. Minimal hospital admissions, which causes less disruption to the family as a whole. Maximise time at home, due to support from our team.		
5.	**Patient and Family Feedback**	
As part of the evaluation process the network is undertaking the following feedback approaches: • Questionnaires • Family and patient stories are being gathered		Patient - Centred
6.	**Other Activities, Improvements or Issues**	
Non medical prescribing means that children & families are treated in an efficient prompt manner without having to wait for medical intervention. This is done cautiously & with reference back to correspondence between self/parents & community paediatricians at clinic etc. Epilepsy nurse clinics Link between acute & community No issues detected		
7.	**Evaluation of Progress**	
Highland This post & team is evolving on a frequent basis, but I truly feel that we are meeting the needs of both the children & their families. The logic model from NESCAN identifies that all our requirements are being met. Outputs are being done, which in turn provides good outcomes.		

APPENDIX 1

Tayside
The Highland consultant post will be interviewed for in March
Aberdeen 0.5wte Epilepsy Nurse post is filled
P/T Regional physio posts for Neuromuscular Service and Intra-thecal Balcofen service have now been appointed to.

APPENDIX 1

NoS National Delivery Plan for Specialist Services for Children and Young People Performance Monitoring

Reporting Period: Quarter 3, October – December 2010

Frequency of Update: Quarterly

Submission Date:

1.	**Specialist Service - Gastroenterology**

2.	**Outcomes and Outputs**
2.1	**Outcomes**

- Improved integration of planning, service provision and care
- Meeting published standards of care
- Improving equity of access of services, to provide local care
- Reduction in waiting times, travelling times & costs
- Improved sharing of expertise and resource at "local" level
- Improved multi-disciplinary care
- Increased professional/patient awareness of service
- Improved transition to adult services
- Improved condition management
- Reduce inequalities
- Improved health and well-being of children
- Families supported throughout their child's illness
- Developing a sustainable model of care

2.2	**Outputs**

- Establishment of steering group
- Introduction of audit system
- Development of regional protocols, guidelines & pathways
- Integrated secondary services for children in Highland, Shetland, Orkney and Moray
- Utilisation of telemedicine
- Tertiary support to Orkney, Shetland & Moray
- Visiting clinics with "local" paediatrician
- CPD/Training events
- Transition Clinics
- Patient Information packs
- Development of a training strategy
- Increased access to dietetic services locally
- Increased provision of endoscopy services locally

3.	**NoS NDP Inputs**			
3.1	**Grampian**	**Lead Manager - G Thomson**		
Posts		**Band**	**WTE**	**Appointed**
Consultant Gastroenterologist		Cons	8pas	Yes
Dietician Assistant		3	0.5	Yes
Specialist Nursing		7	0.5	Yes
Admin		4	0.5	Yes
Psychology		8A	0.5	Yes
3.2	**Tayside**	**Lead Manager –D Sturrock**		
Post		**Band**	**WTE**	**Appointed**

Paediatrician with an interest	Cons	2pas	Yes
Consultant Anaesthetist	Cons	1pa	Yes
Dietician	7	0.7	Yes
Admin			
3.3 Highland	**Lead Manager - N Summer**		
Post	**Band**	**WTE**	**Appointed**
Dietician	7	0.5	Yes

4.	**Activities and Outputs Completed**	
4.1	**Number of patients being seen by specialist service**	

During this reporting time period the network has seen approximately:

- 120 new pts
- 370 return pts
- Undertaken 75 endoscopes

4.2	**Reduction in waiting times / list**	

4.3	**Number of new outreach / specialist clinics and number of attendees**	

Grampian

The first nurse-led transition clinic was held by the Paediatric Gastroenterology Nurse Specialist along with the Adult IBD Nurse Specialist in RACH. Another nurse-led transition clinic is planned for June 2011 with a total of nine young people attending.

The first Gastroenterology clinic was planned for December 2010 in Shetland, but the poor weather intervened and closed the airport. A video conference clinic was held for five patients who prevented them having to travel to Aberdeen.

During recent bad weather, staff were able to carry out the Inverness clinic with videoconference links between Aberdeen, Inverness, Thurso and Fort William. Contacted medical staff, specialist nurses and families in the centres.

Dietitian now attending weekly gastroenterology clinics and providing cover for Kathleen Ross. Hazel Edward completed third paediatric dietetic module which has gastroenterology bias.

4.4	**Number of agreed standards, protocols and patient referral pathways in place or are being met**	

Across the network the following have been achieved;

- Information pathway for families regarding endoscopy procedures.
- DoH (Improving the Health and Wellbeing of People with Long-Term Conditions 2010) recommendations are now being met in NHS Tayside and NHS Grampian.
- NICE guidelines for Coeliacs to be seen on diagnosis and follow up are now being achieved in the 3 main sites.
- Protocols for TPN are currently being developed
- Developing ICP for gastrostomies with nurse specialists.
- Common discharge policies for NG feeds are currently underway.
- CMPA protocol and guidance developed.
- Common referral protocols are currently being reviewed.

4.5	**Number of routine multi disciplinary team meetings, clinics or reviews completed or delivered**	

Across the network:

- MDT's occur on a weekly basis in the 3 mains centres, with quarterly meetings occurring in rural centres. VC is utilised to ensure input from tertiary consultants

4.6 Number of training / CPD events developed, delivered or received

The North of Scotland PGHN network organised a two day residential meeting at Crieff Hydro on behalf of the three Scottish networks. 85 delegates attended to hear a mixture of Scottish and UK speakers. Feedback from delegates was excellent.

4.7 Availability of specialist staff – number of informal contacts/advise delivered or received

Grampian
Nurse – provides specialist information to Education and Social Work staff to support children in school. This did not happened before this post was created. Gastro Nurse receives 15-20 calls over a four day week from parents and professionals. Nurse empowers parents to manage their child's condition at home

Daily advice provided by all team members to parents and GPs via phone contact.

Psychologist has provided clinical advice on 92 occasions about GI patients not referred to her service. She has conducted 10 joint appointments with MDT colleagues in the GI team. She offers informal consultancy of course at all MDT meetings.

Dietetic Asst - giving support to home enteral feeding service(145 children) including maintaining data base

Tayside
Regular telephone contact and out of clinic reviews of gastro patients by team. No way of formally recording these at present due to lack of network manager

Highland
Daily cover is available; even during staff absence, since new funding has increased dedicated paediatric staffing. Able to respond within 24 hours to enquiries from other healthcare professionals and parents (previously not possible).

4.8 Number of new treatments delivered or new ways of working implemented

Grampian
Greater use of videoconferencing for patient follow-up.

Psychologist – this is a new service, therefore every attendance at MDTs, on RACH wards, at outpatient clinics and every patient seen with colleagues is a new way of working.

Tayside
Hepatitis C treatment delivered locally (Previous required travel to London, high intensity follow up and monitoring required)
Increasing numbers of home visits by dietician
Continued home visits by specialist nurse
Due to MDT meeting better implementation of care plans

Highland
The children's home care nurses and the paediatric dietician reviewed the way that children requiring home enteral feeding, were cared for on discharge. There are now 2 dietician-led clinics for home enteral feeding patients/ year. Patients come to the

children's ward to have bloods taken the week before clinic so that a complete clinical picture is available. There is a protocol in place for the new constipation clinics to start. Malnutrition screening, using a validated tool is to start on the children's ward. Patients requiring follow up are to be offered telephone reviews where appropriate, to minimise travel and inconvenience to the wider family.	
4.9 Improved compliance to treatment regime	
4.10 Reduction in hospital length of stays	
Within the network there is no system of recording this but improved availability of staff is optimising out of hospital care, which should lead to reduction in length of hospital stays. In addition the improved managing of enterally fed patients at home should mean that they do not have to be on the ward and having time to train carers and organise home delivery of feeds enables patients to go home quicker. Rapid access to dietician at admission has led to reduction in hospital length of stay for a number of patients, particularly those suffering from Crohn's disease and requiring commencement of Exclusive Enteral Nutrition (EEN). Increased liaison with primary care services by dietician has allowed earlier discharge even for some patients from remote areas.	
4.11 Reduction in number of hospital admissions / re-admissions	
4.12 Number of children that have made the transition to adult care	Patient - Centred Effective Equitable Safe
Grampian Nine young people with inflammatory bowel disease will be transitioned to adult services over the next 6 months.	
4.13 Improved functional quality of life or other improved health outcomes	Patient - Centred Effective
The higher availability of staff has ensured better adherence to treatment and early advice and intervention have prevented worsening of symptoms. This is giving better quality of life and better school attendance.	
5. Patient and Family Feedback	
As part of the evaluation process the network is undertaking the following feedback approaches: • Questionnaires • Family and patient stories are being gathered	Patient - Centred
6. Other Activities, Improvements or Issues	
7. Evaluation of Progress	
The evaluation of the NDP investment is currently underway and is due to be concluded by February 2011.	

APPENDIX 1

NoS National Delivery Plan for Specialist Services for Children and Young People Performance Monitoring

Reporting Period: Quarter 3, October – December 2010

Frequency of Update: Quarterly

Submission Date:

1.	**Specialist Service - Metabolic**			
2.	**Outcomes and Outputs**			
2.1	**Outcomes**			
• In line with Nationally agreed outcomes				
2.2	**Outputs**			
• In line with Nationally agreed outputs				
3.	**NoS NDP Inputs**			
3.1	**Grampian**	**Lead Manager - G Thomson**		
Posts		**Band**	**WTE**	**Appointed**
Dietician		7	1	Yes
3.2	**Tayside**	**Lead Manager –D Sturrock**		
Post		**Band**	**WTE**	**Appointed**
Consultant		Cons	5pas	Yes
A&C Support		4	0.3	Yes
Dietician (remaining 0.3 wte Band 7 used to employ part time Band 3 Dietetic Assistant)		7	0.7	Yes
Specialist Nurse		7	0.5	Yes
Psychology		7	0.2	Yes
3.3	**Highland**	**Lead Manager - J Veasey**		
Post		**Band**	**WTE**	**Appointed**
Funding to date has been used to appoint: 1wte band 6 dietician, 0.5wte dietetic assistant; 0.5wte admin support		7	1	Yes

4.	**Activities and Outputs Completed**	
4.1	**Number of patients being seen by specialist service**	
Grampian Two clinics per month held in Aberdeen with twice yearly clinics held jointly with a specialist metabolic consultant.		
4.2	**Reduction in waiting times / list**	
Tayside Not applicable. All new/review urgent metabolic patients require to be seen promptly out with clinic or added onto end of next clinic list. **Highland** We have minimal waiting times for any paediatric patients and are accessible by phone		

each day during working hours as there is always someone to answer the phone now. **Grampian** Not applicable. All new/review urgent metabolic patients require to be seen promptly out with clinic or added onto end of next clinic list.	
4.3 Number of new outreach / specialist clinics and number of attendees	
Grampian A family day involving hands on low protein cookery and eating lunch together for our PKU families was held in August 2010 with 15 attendees including one family from Shetland.	
4.4 Number of agreed standards, protocols and patient referral pathways in place or are being met	
Grampian Developed local protocol for the implementation of the national screening programme for MCAD which was introduced in Scotland on 1st October 2010.	
4.5 Number of routine multi disciplinary team meetings, clinics or reviews completed or delivered	
Tayside • The metabolic team are now undertaking monthly multi-disciplinary team meetings/clinical updates in addition to weekly metabolic clinics within Ninewells Hospital (includes nursing and medics) **Highland** • There are none specifically for metabolic patients. However the use of support staff has freed up other resource to have a greater presence within other paediatric team meetings and clinics **Grampian** • 2 clinics per month by local staff. Twice a year clinic supported by Yorkhill	
4.6 Number of training / CPD events developed, delivered or received	
4.7 Availability of specialist staff – number of informal contacts/advise delivered or received	
Grampian • Specialist support is provided to colleagues in Inverness in how to deal with patients with metabolic issues. • Increased involvement with MCN activities. • Dietetic input to local neonatal screening group re implementation of MCADD screening. • Nurse attended meeting for implementation of MCADD screening. **Tayside** • Nurse and Dietician provide invaluable links and co-ordination of team, with rapid and effective communication with the outreach Specialist consultant. **Highland** • Now easily available to any healthcare professional and patients.	
4.8 Number of new treatments delivered or new ways of working implemented	
Grampian Metabolic Nurse has been involved with administering Enzyme therapy via a port for a child in Aberdeen.	

4.9	**Improved compliance to treatment regime**	
• This is an area which requires further auditing		
4.10	**Reduction in hospital length of stays**	
Not applicable		
4.11	**Reduction in number of hospital admissions / re-admissions**	
• This is not applicable as the service is predominately an out patient service		
4.12	**Number of children that have made the transition to adult care**	Patient - Centred Effective Equitable Safe
Tayside - Not applicable. • Care for children and adults is provided by the same team. Team have been working with adult medical service to facilitate the introduction of a direct access service for adults with IMD requiring urgent hospital admission, with direct admission to the acute ward at Ninewells. **Highland –** None at this stage **Grampian -** Not applicable		
4.13	**Improved functional quality of life or other improved health outcomes**	Patient - Centred Effective
5.	**Patient and Family Feedback**	
As part of the NoS evaluation process the work is being progressed in gathering feedback from families, it is envisaged that the approaches can be utilised to support other networks. The approaches being utilised include: • Questionnaires • Family and patient stories are being gathered		Patient - Centred
6.	**Other Activities, Improvements or Issues**	
7.	**Evaluation of Progress**	
The evaluation of the NDP investment is currently underway and is due to be concluded by February 2011.		

APPENDIX 1

NoS National Delivery Plan for Specialist Services for Children and Young People Performance Monitoring

Reporting Period: Quarter 3, October – December 2010

Frequency of Update: Quarterly

Submission Date:

1.	**Specialist Service - Oncology**			
2.	**Outcomes and Outputs**			
2.1	**Outcomes**			
• In line with Nationally agreed outcomes				
2.2	**Outputs**			
• In line with Nationally agreed outputs				
3.	**NoS NDP Inputs**			
3.1	**Grampian**	**Lead Manager - G Thomson**		
Posts		**Band**	**WTE**	**Appointed**
Nurse Specialist – Outreach		7	1	Yes
Consultant Oncologist		Cons	5pas	No
Speech & Language Therapist		7	0.3	Yes
Health Psychologist		8A	0.5	Yes
Pharmacist		8A	0.5	Yes
3.2	**Tayside**	**Lead Manager –D Sturrock**		
Post		**Band**	**WTE**	**Appointed**
Consultant Oncologist		Cons	2pas	Yes
Occupational Therapist		7	0.1	Yes
Speech & Language Therapist		8	0.3	Yes
Outreach Nursing		6	0.5	Yes
Health Psychologist		8A	0.5	Yes
Pharmacist		8A	0.5	Yes
3.3	**Highland**	**Lead Manager - J Veasey**		
Post		**Band**	**WTE**	**Appointed**
Nurse Specialist		7	0.2	Yes
Staff Nurse		5	0.3	Yes
Admin		4	0.5	yes
4.	**Activities and Outputs Completed**			
4.1	**Number of patients being seen by specialist service**			
Highland 25 non-malignant haematology. 54 oncology of which 17 on treatment, 2 post bone-marrow transplant, 1 palliative, 1 relapse **Grampian** December 2010 has been a particularly busy time with five new chemotherapy patients. Increased staffing has allowed us to provide the specialised clinical pharmacy cover required to accommodate this workload.				

4.2 Reduction in waiting times / list	
Highland No waiting time for clinic attendance or referral. Time spent by families waiting in clinic for blood results/chemotherapy prescribing and receipt of mediation increased at present due to current patients on treatment. Re-evaluating blood sampling process at clinic to speed up clinic time	
4.3 Number of new outreach / specialist clinics and number of attendees	
Highland 14 non-malignant haematology clinic attendees/ quarter, 74 oncology clinic attendees/ quarter No new clinics developed but current 0.5 day/week clinic stretched to capacity and overrunning by 1-2 hrs weekly. Attempting to restructure clinic to improve efficiency but nature of CNS input changed due to increased need for a clinical role reducing the opportunity for psychosocial input. New appointment of band 6 should rectify this by next quarter	
4.4 Number of agreed standards, protocols and patient referral pathways in place or are being met	
Highland Febrile neutropenia, blood product and immunisation protocol, referral pathways, protocols for clinical trials, mouthcare policy – all being met In conjunction with CATSCAN – developing long-term/late effects follow up protocol **Grampian** Nurse - we now have various Information sheets and resources available at Outpatient Clinic for families / staff to freely access.	
4.5 Number of routine multi disciplinary team meetings, clinics or reviews completed or delivered	
Highland Weekly clinic and MDT (no exceptions). Monthly 5-centre haematology MDT. Twice yearly visits from paed oncology consultants and thrice yearly from paed haematologist from principle centres **Tayside** Weekly MDT locally: weekly MDT for solid tumours via telemedicine with RHSCE – attended by medical staff and nursing staff. Neuro-oncology MDT via telemedicine with RHSCE – attended by medical staff – every week except first week of the month. Monthly national BMT MDT via telemedicine – attended nursing and medical staff.	
4.6 Number of training / CPD events developed, delivered or received	
Highland FY2 training delivered. Informal training to staff nurses on acute ward. Recent appointment of band 6 nurse will mean training/upskilling of ward staff can commence GIRFEC training received. Nurse specialist completing MSc Paediatric Palliative Care. Training on sarcomas given by oncologist. IT chemo therapy training received **Tayside** Delivered study day for AHPs, nurses and junior medical staff. Consultants have also been involved in formal teaching programme for Specialist Trainee Doctors – they have provided 2 afternoon teaching sessions 3 nurses have successfully completed chemotherapy course at Robert Gordon University **Grampian** The pharmacy service at RACH has continued to benefit from NDP funding. The main advantage is being able to provide a more sustainable safe service in the highly specialised area of paediatric chemotherapy. We are no longer dependent on a single pharmacist.	

A pharmacist has also prepared paediatric information on medicines included in the "Just in Case" boxes for palliative care children.

Pharmacist also attended a CATSCAN pharmacy meeting.

Nurse – attended Scottish Paediatric Oncology Outreach Nurse update meeting. This means nurses can support each other and share information about ways of improving their services. Aberdeen will be hosting the next meeting.

4.7 Availability of specialist staff – number of informal contacts/advise delivered or received

Highland
Consultants cover 5 days/week with extra on-call weekend. Paediatric Oncology Nurse Specialist available 5 days/week. Band 6 link nurse to cover outreach and clinics whilst band 7 on A/L. Band 6 supporting ward 11 -12 hrs/week
Specialist nurse contacts: – 2 weeks A/L which reduces potential for contacts
Haematology – 4 family phone calls , 4 professional contact , 1 ward visit
Oncology – 85 family phone calls , 20 ward visits , 68 home visits , 145 professional contact , school reintegration x 2, primary health care team meeting x 3

Tayside
There is now a chemotherapy trained nurse available to check chemo in working hours, Monday to Friday.

Grampian
Nurse – this investment has allowed increased resource to provide more equitable service to families. Additional nursing means there is an outreach nurse available at Oncology clinics for advice.

4.8 Number of new treatments delivered or new ways of working implemented

Highland
1 child on phase 2 trial conducted through Glasgow but supported closely through Raigmore, no other new protocols. About to implement draft long-term follow-up forms

Grampian
Nurse - increased number of home visits, 25 in last quarter, enabling families to stay at home, reducing disruption to family life, increasing school attendance. Nurse now administers outpatient chemotherapy at clinic. This improves pathway of care and continuity for child and family.

Nurse visited CLAN and met with Family Support Worker

4.9 Improved compliance to treatment regime

Highland
Patients/parents appear to be fully compliant with oral chemotherapy. All patients receiving admission for acute illness appropriately. Compliance with mouthcare difficult to assess without formal research

Grampian
Nurse – increased investment allows time to provide greater level of support and education to families and professionals both in community and hospital, especially to adolescent group who are more at risk of non compliance.

4.10 Reduction in hospital length of stays

Highland

Nursing outreach services possibly allowing for earlier discharge and follow up (1 day early) **Grampian** Nurse – more nursing time available to support families at home, able to offer increased numbers of home visits, also increased telephone contact to empower families to look after children with cancer at home. Liaison with community nurses and training of community nurses to empower them to support families at a distance ie in last quarter on average 14 telephone contacts with families per week. These phone calls can be difficult, emotional and lengthy at times. 25 telephone contacts per week on average to MDT. The recording of telephone calls and home visits etc is a new development and will be more accurate as staff get used to doing this.	
4.11 Reduction in number of hospital admissions / re-admissions **Highland** ? reduction in admissions x2, but evidence of 5 occasions where attendance for review on ward averted. Non-medical prescribing ensuring earlier access to drugs, preventing attendance at GP and ward attendance	
4.12 Number of children that have made the transition to adult care **Highland** 1 oncology, 1 haematology, 1 long-term palliative being shared with adult services as a process of transition, 1 relapse being shared with adult services as part of a staged transition **Tayside** One young person is in the process of being transitioned to the adult neuro-oncology team.	Patient - Centred Effective Equitable Safe
4.13 Improved functional quality of life or other improved health outcomes **Highland** Reduced hospital attendance through a reactive nursing/advisory service and increased outreach causes less disruption to the family, maximising time at home and improving integration with peers Increased support of teenage siblings Improved school attendance through school staff being directly supported with reintegration meetings. Increased academic and school social input received from schools when the children are receiving care in tertiary services. Increased use of internet/phones Increased use of more appropriate written and verbal information for parents, siblings and grandparents Working increasingly closely with adult services to develop appropriate care and support for teenagers (16-18) cared for out with the paediatric setting – mainly through school and psychosocial/emotional support **Tayside** The team have used a video link to assist in terminal care by contacting the patient and family at home – thus reducing visits to and stays in hospital and allowing staff to judge if a home visit was required.	Patient - Centred Effective
5. Patient and Family Feedback	
Highland Verbal only - +ve feedback re support from service. Families expressing their enthusiasm at appointment of band 6	Patient - Centred
6. Other Activities, Improvements or Issues	
Highland Reviewing ward-based information & advice folder for staff and developing a learning-needs analysis questionnaire for staff prior to developing a learning package - all with assistance of band 6 nurse Nurse specialist involved in implementing LDW for paediatrics, with especial interest in staff education	

programmes – developing links with education champion at Highland Hospice
Involved in responses to draft documents on nursing standards for cancer services, DNR policies, assisted suicide bill, bereavement guidelines, CATSCAN docs.

Tayside
Contact with AHPs now easier and more readily available

Grampian
Nurse set up 'Look Good Feel Better 'for our adolescents. This is the first time it has been implemented in RACH and was a great success. Has attended video conferencing training as this is becoming an important method of communicating with other centres. Nurse able to attend video conference with family to discuss future surgery at distant hospitals, thus saving the family further travel and disruption and enabling them to be fully informed and supported.

7.	**Evaluation of Progress**

Gradual evolvement of service with a recognised need for emphasis on staff education
Limitations on role and service development due to restricted travel to central belt for network meetings and peer support, which is included in job description. Paediatric oncology is a very specialised field that requires national agreement and collaboration. The types of peer support meetings held are not amenable to telemedicine and, in any case, this format is often limited due to the increased use of this form of communication (budgetary constraints) without increased venues and resources.
Concerns re recent proposal by Joint NHS Highland and Highland Council to transfer paeds community staff to Highland Council management, which may/may not include band 7 nurse specialist (consultation for method of rolling out proposal to start next month)

APPENDIX 1

NoS National Delivery Plan for Specialist Services for Children and Young People Performance Monitoring

Reporting Period: Quarter 3, October – December 2010

Frequency of Update: Quarterly

Submission Date:

1.	**Specialist Service - Rheumatology**			
2.	**Outcomes and Outputs**			
2.1	**Outcomes**			
• In line with Nationally agreed outcomes				
2.2	**Outputs**			
• In line with Nationally agreed outputs				
3.	**NoS NDP Inputs**			
3.1	**Grampian**	**Lead Manager - G Thomson**		
Posts		**Band**	**WTE**	**Appointed**
Nurse Specialist		7	1	Yes
A&C Support		4	0.3	Yes
Physiotherapist		7	0.5	Yes
Occupational Therapist		7	0.5	Yes
3.2	**Tayside**	**Lead Manager –D Sturrock**		
Post		**Band**	**WTE**	**Appointed**
Consultant Outreach Time		Cons	1pa	Yes
Nurse Specialist		7	0.5	Yes
A&C Support		4	0.2	Yes
Physiotherapist		7	0.5	Yes
Occupational Therapist		7	0.5	Yes
3.3	**Highland**	**Lead Manager - J Veasey**		
Post		**Band**	**WTE**	**Appointed**
Physiotherapist		7	0.25	Yes

4.	**Activities and Outputs Completed**	
4.1	**Number of patients being seen by specialist service**	
Tayside 44 children and young people diagnosed with Rheumatological disorder in Tayside under the care of the paediatric rheumatology service 26 return patient contacts by physiotherapist outwith clinics and 3 new patients		
4.2	**Reduction in waiting times / list**	
Tayside No waiting times		
4.3	**Number of new outreach / specialist clinics and number of attendees**	
Tayside		

Last year Nov 2009 to Nov 2010 by tertiary Consultant Paediatric Rheumatologist 5 new patients and 49 returns patients over 4 all day clinics (previously 4 half day clinics). 8 half day clinics by Consultant paediatrician with an interest in Rheumatology: 8 new patients and 63 return patients seen.		
4.4	**Number of agreed standards, protocols and patient referral pathways in place or are being met**	
Grampian OT has devised an advice sheet for children suffering from Reynaud's disease. The OT continues to work on other paperwork on assessment for children with JIA. OT and physiotherapy are looking at suitable paperwork for recording the assessment of children with hyper mobility. Teenage transition pathway SPARN document agreed and implemented November 2010 into teenage clinics in RACH and Woolmanhill transition clinic.		
4.5	**Number of routine multi disciplinary team meetings, clinics or reviews completed or delivered**	
Tayside 2 peer support meetings held by nurse and physio with patient updates, discussions on service development and education session. Decembers cancelled due to adverse weather. **Grampian** The nurse, physiotherapist and OT meet on a weekly basis to discuss patients' progress and plan interventions, as well as service improvements. The managed clinical net work team meet once a month to discuss individual patients. Each member of the team has agreed to present a paper to the Rheumatology MCN team to enhance learning opportunities for the team as a whole.		
4.6	**Number of training / CPD events developed, delivered or received**	
Tayside SNAC (Scottish Network of Arthritis in Children) held annual parent education day supported by education sessions from Consultant, Physiotherapist and Nurse. Post graduate update by Dr Fowlie in early 2011 **Grampian** The nurse and OT attended the parent's day organised by SNAC in November 2010 in Dundee. They both participated in workshops organised for parents and were part of a panel to which parents could direct questions. OT and physiotherapy have visited schools as appropriate to observe children, talk with class and PE teachers and advise about the child's capabilities and give general information about JIA. They intend to send a questionnaire to staff following these visits to assess the value of these visits.		
4.7	**Availability of specialist staff – number of informal contacts/advise delivered or received**	
Tayside October to November Nurse contacts – 168 text contacts 15 emails contacts 30 telephone contacts 3 episodes of parent/child/young person attending out with clinic for support/education (2 new patients) 2 training sessions with Practice nurses to administer biological therapies 15 home visits		

Physiotherapist contacts – 28 telephone contacts 10 text contacts 3 email contacts Weekly team contacts via Email/telephone locally and with tertiary centre. **Grampian** The specialist nurse works every day apart from Thursday and continues to lead an advice helpline for parents and children.	
4.8 Number of new treatments delivered or new ways of working implemented	
Tayside Biological and immunosupression therapy Infliximab – 1 patient Adalulimumab – 3 patients Anakinra – 1 patient Etanercept – 6 patients Methotrexate – 14 patients Education of 3 children and their family on changes in treatment regime. Pathway for children requiring joint injections – local orthopaediac team carry out injections, more complex joint injections go to Glasgow or Edinburgh. Blood monitoring Pathway for biological therapies and Methotrexate. **Grampian** OT and physiotherapy continue to work on the proposal to set up an AHP led clinic for children with hyper mobility. They also assess and treat some children jointly, thus more effectively using therapy time and cutting down the time children spend in clinic. The physiotherapist has supported community physiotherapy staff in the treatment of complex children with rheumatology conditions. The specialist nurse and physiotherapist are continuing to improve the service available to patients through emergency appointments. Good verbal feedback has been given by users of this service. The MDT team are to carry out annual reviews of all patients in line with network standards.	
4.9 Improved compliance to treatment regime	
Tayside Nurse working in conjunction with Play Specialist with 3 children who were struggling with their treatment, all three now compliant with treatment.	
4.10 Reduction in hospital length of stays	
Tayside No in-patients except day case for Infliximab infusion	
4.11 Reduction in number of hospital admissions / re-admissions	
Tayside No in-patients except day case for Infliximab infusion	
4.12 Number of children that have made the transition to adult care	Patient - Centred Effective
Tayside Introduction of Transition pathway with 3 young people	

	Equitable Safe
4.13 Improved functional quality of life or other improved health outcomes **Tayside** Use of Childhood Health Assessment Questionnaire (CHAQ) for all JIA children at the clinic.	Patient - Centred Effective
5. Patient and Family Feedback	
Tayside SNAC parents day very positive feedback from the day:- 'Having so much support from the medical profession.' 'Enthusiasm from clinical staff who take time to attend information day, enthusiasm from SNAC committee who are all easily identified! Large venue easily accessed. ' 'Talks and meeting other parents.' presenters', 'Networking and personal experience's 'Research update, speaking to other parents' Physiotherapy evaluation questionnaire of rheumatology service (comparison between service pre-introduction of specialist rheumatology physiotherapist and post introduction). Results included: 20% of parents/carers felt the amount of physiotherapy they received was 'just right' prior to the introduction of the specialist post compared to 80% reporting it was 'just right' after the introduction of the specialist post. 100% of parents/carers of new children to physiotherapy service felt amount of physiotherapy was 'just right'. Additional comments received included: "This service is long overdue. I wish it had been available 10 years ago when we first dealt with this as it could have had a more improved impact on my child's joints…." "Excellent service with phone calls and letters to keep in touch and excellent face to face where I get all the information." "I am really pleased with the service that my daughter has received and it's good to know that help and advice is only a phone call away if required. I also feel that the joint home visit by the physio and OT was really good as it let them see how my daughter was in her own environment."	Patient - Centred
6. Other Activities, Improvements or Issues	
Tayside Teenagers Christmas bowling day – cancelled due to adverse weather conditions – try to reschedule early next year. Christmas ice-skating show for all the family – helps siblings to be involved and reduce their isolation when they have a sibling with chronic illness (tickets donated locally). Physiotherapist completed Orthopaedic Medicine peripheral course as pre-cursor to injection therapy course due to commence March 2011. **Grampian** OT has given a presentation to colleagues on some aspects of the service being offered to children with rheumatology conditions. Nurse presented an audit on Blood Monitoring for Children with JIA on biologic and methotrexate therapy to medical and AHP colleagues in RACH	
7. Evaluation of Progress	
We are very pleased with the development of this service, which will ensure the provision of a much	

more comprehensive service to our children and young people with rheumatological conditions.

NoS National Delivery Plan for Specialist Services for Children and Young People Performance Monitoring

Reporting Period: Quarter 3, October – December 2010

Frequency of Update: Quarterly

Submission Date:

1.	**Specialist Service – CF/Complex Respiratory**
2.	**Outcomes and Outputs**
2.1	**Outcomes**

- Improved integration of planning, service provision and care
- Meeting published standards of care
- Improving equity of access of services, to provide local care
- Reduction in waiting times, travelling times & costs
- Improved sharing of expertise and resource at "local" level
- Improved multi-disciplinary care
- Increased professional/patient awareness of service
- Improved transition to adult services
- Improved condition management
- Reduce inequalities
- Improved health and well-being of children
- Families supported throughout their child's illness
- Developing a sustainable model of care

2.2	**Outputs**

- Establishment of steering group
- Introduction of audit system
- Development of regional protocols, guidelines & pathways
- Integrated secondary services for children in Highland, Shetland, Orkney and Moray
- Utilisation of telemedicine
- Tertiary support to Orkney, Shetland
- Visiting clinics with "local" paediatrician
- CPD/Training events
- Transition Clinics
- Patient Information packs
- Development of a training strategy

3.	**NoS NDP Inputs**			
3.1	**Grampian**	**Lead Manager - G Thomson**		
Posts		**Band**	**WTE**	**Appointed**
Outreach Provision for NHS Highland		Cons	2pas	Yes
Specialist Nursing		7	0.6	Yes
Physiotherapist		7	0.5	Yes
3.2	**Tayside**	**Lead Manager –D Sturrock**		
Post		**Band**	**WTE**	**Appointed**
Consultant Respiratory Paediatrician		Cons	10pas	Yes
Dietician		7	0.5	Yes
A&C Support		4	0.5	Yes

3.3	Highland	Lead Manager - J Veasey		
Post		**Band**	**WTE**	**Appointed**
Dietician (returned from maternity leave Jan 2011)		6	0.5	Yes
Complex respiratory/CF paediatric link nurse		6	0.4 (until march 2011 then 0.5)	Yes

4.	Activities and Outputs Completed	
4.1	**Number of patients being seen by specialist service**	

Highland
No new CF patients diagnosed this quarter- 21 Cystic Fibrosis patients
CF patients are reviewed every 3 months or sooner if indicated or under 1 year of age 6 CF patients each clinic - Number attended this quarter 18
Joint clinics with visiting consultants from Dundee and Aberdeen.
Clinics will be ongoing in 2011 6 CF patients each clinic
All CF annual review to be carried out by fully funded MDT and reviewed at CF MDT meeting.
No of annual review this quarter 6

Complex respiratory clinics 3 monthly again joint with Aberdeen and Dundee visiting consultant. 4-6 patients each clinic.
Sweat tests/skin prick tests to start feb 2011 3 patients each clinic

Tayside
Ninewells CF
No of new CF patients this period = 0
NW CF Clinic – 7 clinic held, 35 appointments met, DNA rate = 7.9%
NW NDP funded CF Dietician – 6 clinics attended, all pts seen at each clinic
Ninewells Respiratory
NW Resp Clinic – 11 clinics held, 90 appointments met, DNA rate = 21.7%
NW Respiratory clinic includes General Respiratory, Joint ENT/Resp, Joint Neuromuscular/Resp, Chronic Respiratory clinics, outreach clinic at Armistead Child Development Centre
PRI Resp Clinic –6 clinics held, 47 appointments met, DNA rate = 19.0%
NW Nurse led asthma clinic – 9 clinics held, 16 appointments met, DNA rate = 40.0%
PRI Nurse led asthma clinic – 3 clinics held, 7 appointments met, DNA rate = 22.2%
NW BCG clinic – 3 clinics held, 5 appointments met, DNA rate = 37.5%

4.2	**Reduction in waiting times / list**

Highland
No waiting list for CF patients
referrals from new born screening are dealt with in 24 hours and sweat test carried out and analysis results on day of test.
Routine sweat test referrals are dealt with within 3 weeks.

Tayside
At end of December 2010, waiting time for the NW Respiratory clinic was 8 weeks for a new patient and 11 weeks for a return appointment. In PRI, the new patient appointment wait was 6 weeks and a return appointment was 8 weeks.
No waiting time for NW CF clinics.

4.3	**Number of new outreach / specialist clinics and number of attendees**

Highland
6 patients at CF clinics
4-6 at patients
3 patients monthly for sweat test or skin prick testing to start Feb 2011

Tayside
Number of outreach Respiratory clinics = 0 (zero planned in Q3)
Number of Aberdeen CF Clinics attended during period = 3
Number of Aberdeen flexible bronchoscopy lists attended during period = 1
Number of Inverness CF Clinics attended during period = 0 (zero planned in Q3)
Number of Inverness Resp Clinics attended during period = 0 (zero planned in Q3)

Grampian
Nurse - plans to go to Elgin in early 2011 with academic colleague to attend his clinic and meet the team up there.

4.4	**Number of agreed standards, protocols and patient referral pathways in place or are being met**	North Scotland CF MCN developing Scotland wide CF protocols all MDT staff involved

Highland

- CF standards of care for Cystic Fibrosis (2001)
- European Cystic Fibrosis Society Standards of Care 2005
- NHS QIS Clinical Standards for Asthma Services for Children and Young People, March 2007.
- Department of Health, National Services Framework for Children, Young People and Maternity Services, June 2005: Guidance on discharge management and community support for children on long term ventilation and the care pathway for the discharge and support of children requiring long term ventilation in the community
- SIGN guideline 101 Asthma May 2008
- SIGN guideline 91 Bronchiolitis in children Nov 2006
- NHS QIS. Best practice statement. Caring for a child with a tracheostomy. 2008
- NHS QIS. Best practice statement. Home oxygen. 2002
- BTS guidelines for home oxygen in children. 2009
- NICE Guidance November 2007 for omalizumab for treatment of severe persistent allergic (IgE mediated) asthma
- NHS Highland CF transition pathway
- NHS highland medicines in schools policy

Tayside
There are a number of quality standards and guidelines to inform specialist respiratory service delivery; these support the proposed models of care:

- Cystic Fibrosis Trust Standards of Care 2001
- European Cystic Fibrosis Society Standards of Care 2005
- NHS QIS Clinical Standards for Asthma Services for Children and Young People, March 2007.
- Primary Ciliary Dyskinesia: Standards of care 1998
- Department of Health, National Services Framework for Children, Young People and Maternity Services, June 2005: Guidance on discharge management and community support for children on long term ventilation and the care pathway for the discharge and support of children requiring long term ventilation in the community
- SIGN guideline 101 Asthma May 2008
- SIGN guideline 91 Bronchiolitis in children Nov 2006
- RCPCH Standards for Services for Children with Disorders of Sleep Physiology. 2009
- NICE Tuberculosis: Clinical diagnosis and management of tuberculosis, and

measures for its prevention and control April 2006
- Respiratory Care of the Patient with Duchenne Muscular Dystrophy – ATS Consensus Statement, AJRCCM 2004;170:456-465
- Consensus Statement for Standard of Care in Spinal Muscular Atrophy, J Child Neurology 2007; 22:1027-1049
- RCPCH Working Party on Sleep Physiology and Respiratory Control Disorders in Childhood. Standards for Services for Children with Disorders of Sleep Physiology Feb 2009
- CLEFSIS. Standards for cleft lip and palate. 2001
- NHS QIS. Best practice statement. Caring for a child with a tracheostomy. 2008
- NHS QIS. Best practice statement. Home oxygen. 2002
- BTS guidelines for home oxygen in children. 2009

NICE Guidance November 2007 for omalizumab for treatment of severe persistent allergic (IgE mediated) asthma

4.5 Number of routine multi disciplinary team meetings, clinics or reviews completed or delivered

Highland
CF clinics every 4 weeks. (3 x 6 patients each clinics)
CF/ complex resp every 3 months (1). Facilitated with visiting consultant.
Telelink with Aberdeen and Dundee monthly (3)
MDT CF meeting monthly (3)

Tayside
Ninewells
Ninewells CF/Resp Ward rounds = 21, NW CF Team Meetings = 11, NW CF Annual Review Meetings = 5, NW CF Clinics = 7, NW Respiratory Clinics = 11, Embletta studies performed = 0, MDT (Complex Resp) Patient Meetings = 0, Difficult Asthma Meetings = 0.
NW NDP funded CF Dietician attended 5 CF team meetings 5 and 4 annual review meetings.
Inverness
No visit in Q3
Network activity (all units)
Fortnightly VC Network Respiratory Teaching = 4, VC CF Annual Review Meetings = 3

Grampian
Nurse - attended a primary care asthma clinic and have now been invited to their team meeting which takes place every second month.

4.6 Number of training / CPD events developed, delivered or received

Highland
CF Nurses and Physiotherapist to attend spirometry course in March 2011-01-05 Link Nurse attended national allergy and asthma conference in London November 2010

Tayside
Dr McCormick presented a clinical update on new treatments in Cystic Fibrosis on 14/10/10 and presented a round-up of interesting new papers published in Thorax on 28/10/10 at the videoconference network respiratory teaching.
Dr McCormick attended the Scottish Paediatric Society St Andrew's Day Symposium in Glasgow on 19/11/10.
Dr McCormick gave a presentation on Quality Indicators of Health in Cystic Fibrosis at the European Union Committee of Experts on Rare Diseases in Paris on 25/11/10.

Grampian Nurse - data audits requested from health intelligence. Looking at the number of children either presenting to A&E and/or being admitted to RACH with asthma symptoms. This will be looked at this over a 12 month period and will examine the figures as follows; what % of total A&E attendees and admissions to RACH are those with asthma symptoms? Age. Gender. GP Practice – to see if there are any clusters of patients from a particular area. If there are any clusters this may aid a targeted approach to any interventions in primary care. Those re-attending/re-admitted within a month of their previous admission as this is a good indicator of poor asthma control. This audit will act as a bench mark for the number of asthmatic children seen at RACH and will aid in measuring the effectiveness of any new interventions. The nurse is examining the number of children who did not attend their asthma clinic over the past 12 months. These figures will also be broken into age, gender and GP practice. Again if there are clusters of non-attendees it may indicate the need for the development of a local clinic for these children and providing a more accessible service for these children. It will be interesting to see if there is a link between those children who frequently miss their clinic appointments and those who frequently attend A&E or are admitted to RACH with their asthma as this will highlight particular children who are a cause for concern. The nurse is in the process of developing an audit to examine parent/child's views of the current asthma service. The aim of this will be to look at their views on what is currently offered by the service such as; asthma education, inhaler technique, self management plans, point of contact, primary care, waiting times, access to service, do they feel supported etc. Support will be provided from the clinical effectiveness team. The nurse has been in touch with RGU and they are interested in her assistance with some teaching for nursing students in February 2011. Nurse - through discussions with primary care, there is a recent audit surrounding the training needs of primary care teams involved in the management of asthma in children and young people. This audit has identified a lack of education and training for nurses on the topic of paediatric asthma and highlights the willingness of primary care teams to attend study sessions. This has been brought to the attention of the respiratory team within RACH and we have agreed the need to develop a coordinated approach to meeting the educational requirements of the primary care teams between ourselves within secondary care and primary care. We will take this forward in early 2011. Nurse education - applied to commence the non-medical prescribers course in March 2011. Also aim to then apply for the asthma diploma. Nurse clinic - investigating how annual reviews of asthmatic patients work in the other centres and will report these findings back to the team such that we can see how to best to implement this locally. There are a range of various asthma self management plans in use with children across the UK. These are being collated for discussion with the respiratory team at RACH such that we decide on a format for local use.	
4.7 **Availability of specialist staff – number of informal contacts/advise delivered or received**	
Highland 9-5 Monday to Friday Cf nurse availability 9-5 Wed, Thursday, Friday CF Dietitian 0.4 WTE link nurse days vary to meet the need of the service and clientele.	

Email contact available for patients to contact team. CF Newsletter now electronically emailed to families x 16 (5 have either no access to computers or prefer paper copy)

Tayside

Number of potential M-F working days during October – December (excluding PH): 63 (+3 PH). Days worked – 58 (including 2 weekend days worked). Study Leave – 2 days. Sick Leave – 2 days. Annual Leave – 5 days.
Regular discussions taking place by email, phone and during video-conference between members of nursing and medical staff. Links made between the new specialist respiratory nurses.

NW NDP funded CF Dietician

Potential days – (excluding PH) – 36 days (+3 PH), Days worked – 19, Study Leave - 2 days, Sick leave – 0, Annual leave -13 days
Regular discussions took place by email. Phone and sms between nursing & medical staff, CF team and patients

NDP funded Respiratory Nurse

Potential days (excluding PH) – 45 days (+3 PH) Days worked – 30, Annual leave – 8 days
Number asthma training sessions - Dundee schools x 2 12th November & Moncrieffe Primary school Perth - for pupils with asthma 23rd November
Number of home visits – 1 x post admission to HDU, 2 x referral from general medical clinic
Clinics attended - all PRI (nurse led x 3 and PRI Resp x 6 clinics)
Clinics attended - NW Resp = 4 (2 to cover annual leave & 2 due to increased clinic numbers visiting consultant from Aberdeen also attending) one nurse led due to increased clinical activity

Grampian

Nurse – has been in contact with respiratory nurse colleagues around Scotland.
Visits arranged to Dundee and Glasgow and plan to visit Edinburgh in early 2011. Met with Dr Jonathan McCormack (respiratory lead for the North of Scotland) and Mary Malone while attending a bronchoscopy list here at RACH and plan to meet with Dr McCormack again while in Dundee on the 16th of December. Plan to go to the Balfour Hospital in Orkney in February with Dr Brooker to meet the team there. Been in touch with Eileen Cornfield who heads the asthma team at ARI and will meet with her in early 2011 to discuss transitional care of asthmatic patients from RACH to adult services.

4.8 Number of new treatments delivered or new ways of working implemented

Highland

3 centre telelink now established and dates for 2011

Tayside

Domiciliary oximetry studies performed, edited, analysed and reported = 61
Embletta sleep studies performed = 0
Short Synacthen tests performed = 5
NW NDP funded CF Dietician Home Visits = 4
Omalizumab anti IgE antibody asthma treatment = 1 new patient commenced Oct – initial treatment Children's Hospital Ninewells, follow on 2 weekly injections CACU Perth Royal Infirmary

4.9 Improved compliance to treatment regime

Highland

Patients are offered individual self-management plans. Young people are encouraged to be full partners to their plan of care regimens. The dietitian individually reviews their diet history and adjusts accordingly. Review of patients height and weight at every clinic

plotted onto growth Charts **Tayside** NW NDP funded CF Dietician: More time spent with in-patients, enabling a greater understanding of their requirement of nutrition, resulting in improved compliance with medications	
4.10 Reduction in hospital length of stays	Patient centred, safe, quality
Highland CF admissions x 2 (all due to port a cath insertion) Patients are transferred home to self-manage when and where appropriate. Admissions are for the minimal safe and effective time/duration. Regular courses of home intravenous antibiotics are facilitated by the CF nursing team. Senior Cf nurse is an independent nurse prescriber and able to request x rays, scans and dexa scans. Dietitian is able to facilitate discharge for home enteral feeders. Respiratory link nurse aims to reduce the number of asthma re-admissions and promote self-management plans in this group of patients by providing education and support. An audit of admissions and treatment plans is currently being undertaken. **Tayside** **Ninewells** Inpatient bed occupancy by CF patients = 137 patient nights (increased due to one long-term patient who was in for 66 days of this period) The increased availability of dietetic time allowed home visits of the long term patient, enabling an earlier discharge.	
4.11 Reduction in number of hospital admissions / re-admissions	Patient centres, safe , quality, effective, efficient, equitable
Highland CF patient regularly administer intravenous antibiotics at home. Full MDT support review of patients in their home. **Tayside** Number of CF patients with hospital admission = 8	
4.12 Number of children that have made the transition to adult care	Patient - Centred Effective Equitable Safe
Highland This year 2 paediatric patients will transfer to adult service. They are seen 3-4 times and transferred up when family and medical agree readiness to transition. Established transition referral pathway in place **Tayside** CF patients completing transition process = 2 CF patients currently in transition = 1 Complex Respiratory patients transitioned = 0	
4.13 Improved functional quality of life or other improved health outcomes	Patient - Centred Effective
Highland MDT working across region working well. Good links established within the disciplines and across disciplines Ongoing support from CF dietitian in Aberdeen. Visiting consultant at Resp clinic provided lunchtime discussion/training	
5. Patient and Family Feedback	
Highland Families have verbally given positive feedback from clinics. Need for formal evaluation now clinics are established. Clinical effectiveness team in liaison with Cf team to devise a proforma	Patient - Centred

Tayside
NW NDP funded CF Dietician: Home visit to newly discharged and/or diagnosed patients to provide vital ongoing dietetic support in their own home, which the families report as being a greatly valued improvement in service.
No formal feedback process undertaken during this period, however, families concerned about the lack of lung function availability at outpatient clinics and the gaps accumulating in their long-term records.
Positive comment from a parent after support and involvement from Hospital Play specialist before her daughter's CT scan

6.	Other Activities, Improvements or Issues

Tayside
Status of Ninewells Respiratory staffing during period October - December 2010

- NDP funded Consultant in Paediatric Respiratory Medicine = Dr McCormick
- Consultant Paediatrician = Dr MacGregor (PRI & NW Resp Clinics)
- Registrar – Post Vacant from August 2010 – February 2011 due to staff shortages
- CF Specialist Nurse – Gail Milne
- NDP funded CF Dietician – Rachel Joensen working 0.5WTE
- CF Physiotherapist - Hannah Forbes
- CF psychologist – Dr Eve Wilson – returned from sick leave, mid December 2010
- Pulmonary Function Technician – Post vacant since March 2010 and not advertised due to financial pressures (Emergency Cover only)

Asthma Liaison Nurse – Mary Malone & Helen Donald (0.5WTE NDP funded)

7.	Evaluation of Progress

Highland
As above

Tayside
Dr McCormick arranging start date for Lead Clinician for Paediatric Respiratory for the North of Scotland.

APPENDIX 1

NoS National Delivery Plan for Specialist Services for Children and Young People Performance Monitoring

Reporting Period: Quarter 3, October – December 2010

Frequency of Update: Quarterly

Submission Date:

1.	**Specialist Service – Paediatric General Surgery**			
2.	**Outcomes and Outputs**			
2.1	**Outcomes**			
• Under-graduate education • Post-graduate education • Local governance and committees • Ward consultations on in-patients • Out-patient Clinic • Operating Theatre List • Equipment Review and Acquisition (Clinical Standard Setting) • Multi-disciplinary Care • Local Community Care (Access for Specialist Community Nurses) • Local Follow-up following Tertiary Care				
2.2	**Outputs**			
• Provision of Tertiary Services for Highland, Orkney and Shetland in Specialist Paediatric Surgery, Paediatric Urology and General Surgery of Childhood. • Integration of Services across geographic spread • Supporting local clinicians/supporting local paediatric nephrology • CPD/Training Events • Developing/Consolidating Paediatric Patient Safety Systems in Surgery • Maximising local facilities • Minimising travel time/employment loss				
3.	**NoS NDP Inputs**			
3.1	**Grampian**	**Lead Manager - G Thomson**		
Posts		**Band**	**WTE**	**Appointed**
Consultant Paediatric Surgeon		Cons	10 pas	Yes
Admin		4	0.5	Yes
3.2	**Tayside**	**Lead Manager –D Sturrock**		
Post		**Band**	**WTE**	**Appointed**
3.3	**Highland**	**Lead Manager - N Summer**		
Post		**Band**	**WTE**	**Appointed**
4.	**Activities and Outputs Completed**			
4.1	**Number of patients being seen by specialist service**			
Inverness General Surgery – 30 / month OPD				

Inverness Urology – 100 patients / year Shetland General Surgery – 70 patients / year Orkney General Surgery – 60 patients / year Elgin General Surgery and Urology – 180 patients / year Dundee Urology – 80 patients / year	
4.2 Reduction in waiting times / list	
Consultant has one or two operating lists per week in Aberdeen Theatre sessions are being provided in Inverness twice a month. Theatre sessions are being provided in Shetland four times a month Plans to develop theatre sessions in Orkney (December2010)	
4.3 Number of new outreach / specialist clinics and number of attendees	
Consultant has two clinics per week in RACH with 15 patients at each clinic. Clinics are being provided in Inverness twice a month. Clinics have been held in Orkney, Shetland and Elgin, plus specialist Urology in Elgin, Dundee and Inverness.	
4.4 Number of agreed standards, protocols and patient referral pathways in place or are being met	
Emergency care plans implemented as set out in Specialist Services Review. Referral pathway for advice and referral from Adult Surgeons to Consultant Paediatric Surgeon formalised	
4.5 Number of routine multi disciplinary team meetings, clinics or reviews completed or delivered	
MDT meetings have been introduced in Inverness and Shetland.	
4.6 Number of training / CPD events developed, delivered or received	
Grampian Nurse – has devised a proforma for the spina bifida clinic which has been used in clinic which makes the clinic run more smoothly. Have carried out Non Invasive Urodynamics on three patients. This was previously done in another area. Have rearranged rotas for nurse led UTI clinic. Currently revising patient information. Have taken referrals from community based staff for non invasive dynamics instead of referrals going through consultant.	
4.7 Availability of specialist staff – number of informal contacts/advise delivered or received	
The appointment of this consultant post has allowed all four members of the surgical team to undertake regional duties in relation to providing clinics and surgery in the North of Scotland.	
4.8 Number of new treatments delivered or new ways of working implemented	
4.9 Improved compliance to treatment regime	
As above through local post-graduate education/MDT discussions, improved compliance with Emergency Care Guidance and with specialist guidance on urinary tract infection. Our activity improvements are all issues. Support for engagement with Scottish Paediatric Patient Safety Programme obviously has substantial benefits for reduced travel for patients from the islands and Highland.	
4.10 Reduction in hospital length of stays	
4.11 Reduction in number of hospital admissions / re-admissions	

4.12	**Number of children that have made the transition to adult care**	Patient - Centred Effective Equitable Safe
4.13	**Improved functional quality of life or other improved health outcomes**	Patient - Centred Effective
5.	**Patient and Family Feedback**	
		Patient - Centred
6.	**Other Activities, Improvements or Issues**	
7.	**Evaluation of Progress**	
This is an excellent extension of this specialist service to the North of Scotland and in particular is supporting the sustainability of the General Surgery of Childhood across the region.		