

North of Scotland Paediatric  
Respiratory Network  
Annual Report 2011

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# 1) Foreword & Introduction

Welcome to the first annual network report from the North of Scotland Paediatric Respiratory Network (NoSPRN). Over the past 12 months, we have achieved the final building blocks to enable the network to start working towards achieving its ambitions.

The National Delivery Plan (2008-2010) brought significant opportunities for funding for service improvements across Tayside, Grampian and Highland. These have enabled improvements to the tertiary and secondary specialist service for patients with Cystic Fibrosis and chronic respiratory disease. These investments have increased local access for children and young people with complex and rare, respiratory conditions. Specialist multi-disciplinary teams of professionals including medical, nursing, dietetics, physiotherapy, clinical physiology and pharmacy underpin the improvements in quality of care.

Increased capacity in staffing in the service due to NDP funding has helped to supplement already established specialist clinics for complex respiratory and CF in Dundee and Aberdeen. During 2011, over 300 clinics were provided across the network with in excess of 2000 patient appointments met. Specialist Respiratory clinics in Highland will be increased

by 50% in 2012 with a consultant in paediatric respiratory medicine joining the Highland's CF team for their Isle of Skye CF clinic. Biannual complex respiratory clinics commenced in Orkney in 2011 and preparations have been made for analogous clinics to begin in Shetland in 2012. Additional staffing facilitated the remodelling of the RACH outpatient services to offer specialist multi-disciplinary respiratory clinics. The established monthly Flexible Bronchoscopy theatre list in RACH enables diagnostic procedures to be performed for children across the Health Boards by the network's four trained paediatric bronchoscopists.

Video-conferencing is actively used within the network. From fortnightly lunchtime respiratory teaching sessions to monthly patient presentations of Cystic Fibrosis annual reviews, technology is helping the network deliver its vision of one department working across multiple sites. Positively, the quality of the respiratory teaching programme has led to requests to establish new telemedicine links with paediatric centres beyond the boundaries of the network.

The network's main asset is its multidisciplinary staff. They are focused on developing and delivering improved services in line with the work plan over the next year.

Dr Jonathan McCormick  
Clinical Lead for Paediatric Respiratory for the  
North of Scotland

## 2) Background & National Delivery Plan

As a network, NoSPRN is regarded as a regional MCN, managerially accountable to the NoS Regional Planning Group (NoSPG) and the six individual NHS Boards (Grampian, Highland, Orkney, Shetland, Tayside and the Western Isles). A quarter of the Scottish population lives in this region which covers half of Scotland's land mass. NoSPRN's work is predominantly delivered in the two teaching hospitals (RACH and Tayside Children's Hospital, Ninewells) and DGHs and RGHs (particularly Elgin, Perth and Raigmore). NoSPG's key objectives are to sustain services as locally as possible, to support remote and rural services and to work collaboratively where this will add value.

The *National Delivery Plan for Children and Young People's Specialist Services in Scotland: Draft for Consultation* (March 2008) and *Better Health, Better Care: National Delivery Plan for Children and Young People's Specialist Services in Scotland* (January 2009) were officially published by the Scottish Government and recognised Cystic Fibrosis as one of the national priorities for investment and Complex Respiratory as an area suitable for development of a Managed Clinical Network as a matter of priority (MCN). The concept of a MCN was defined in NHS HDL 69 (2002) *Promoting the Development of Managed Clinical Networks in NHS Scotland* as "Linked

groups of health professionals and organizations from primary, secondary and tertiary care, working in a co-ordinated manner, unconstrained by existing professional and health board boundaries, to ensure equitable provision of high quality clinical effective services throughout Scotland".

Investment in new staffing following the *National Delivery Plan* funding in 2008-10 and the development of cross-boundary working enabled the prospect of a NoSPRN to become a reality. This document describes the progress to date and outlines the strategy for fully achieving the objectives in the next phase of the network.



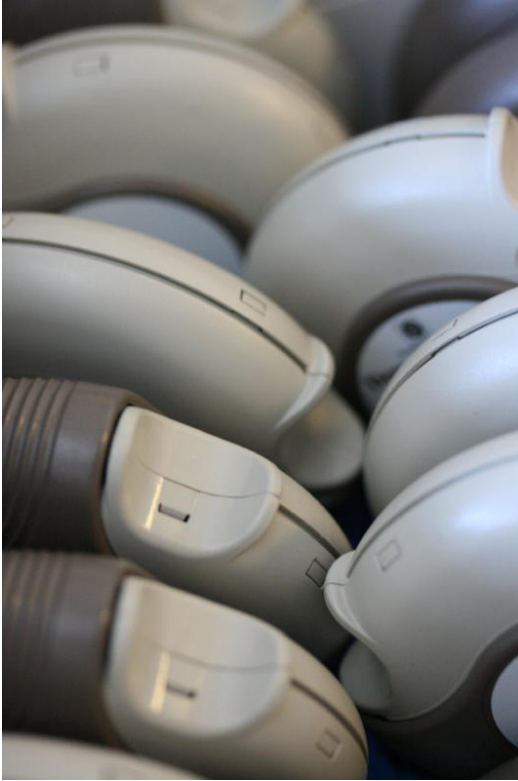
The initial steps in setting up the network involved the establishment of cross-boundary working following the appointment of the first ever NHS Consultant in Paediatric Respiratory Medicine post in NHS Tayside in 2008. Dr McCormick is based in Ninewells but provides a monthly CF clinic and participates in the monthly flexible bronchoscopy lists in RACH as well as providing specialist respiratory and CF clinics in Raigmore, twice a year in collaboration with Dr Alan Webb, Consultant Paediatrician. Dr Brooker is based in RACH and provides both a monthly respiratory and CF clinic in Ninewells as well as providing specialist respiratory and CF clinics in Raigmore, twice a year. He has

established a new respiratory clinic in Orkney in 2011 with the support of Richard Leece, Respiratory Nurse Specialist. Dr Brooker and Dr McCormick aim to provide cross-cover for CF queries across the network and field other enquiries about respiratory patients at a local and regional level.

The network welcomed an additional consultant in 2011, with the substantive appointment of Dr Mustafa Osman. He is providing paediatric services (both general and respiratory) in Elgin and Aberdeen and providing three visits a year to Shetland. He will be establishing a Shetland specialist respiratory clinic, based on the successful pilot work in Orkney.

With the appointment of new specialist nursing and AHP positions boosting respiratory and CF teams, several new telemedicine meetings were established to promote the network, share clinical experience and link the sites and professionals. These included fortnightly teaching, monthly CF annual review meetings and Paediatric Respiratory Inter-Region Service Meetings known as PRISM. This has fostered greater communication and support between professionals with similar roles in different sites within the network. Carolyn Duncan, our network manager has enabled greater progress on the future aims of the network as set out in "Network Activities". The Logic Model guides quality improvements in network activity and can be found in Appendix 1.

### 3) Workforce



The NOSPRN has been successful at attracting and retaining members of staff across disciplines (current staffing levels are set out in Appendix 2). The NDP resource has enabled multi-disciplinary respiratory and CF teams to flourish. For the first time, Aberdeen, Dundee, Perth and Inverness teams now have access to a specialist respiratory nurse. These posts anchor the team and form the first point of contact for most of our families whether it's by letter, phone or text. They are providing nurse-led clinics to

reinforce asthma education, compliance and the provision of written asthma plans which is helping to drive down out-of-hours asthma attendances and unscheduled hospital admissions. The network has allowed the sharing of best practice, discussions on protocols and clinic formats and support for less experienced nurses from those who have been in post for longer. This process is having similar benefits for CF teams where the linking of teams has led to the sharing of clinical experiences and more accessible avenues for clinical advice. Communication has increased such that it is not uncommon for someone from team A to be able to solve a simple problem for team B in another hospital and Health Board during a period of annual leave for one member of team B's staff. The regular opportunities for meeting and discussing services and patients across the month are allowing staff to adopt new strategies and maintain professional development. Patients are benefiting from faster access to tertiary specialist advice and

specialist investigations leading to better patient management and experiences and safer patient care.

There have not been major difficulties with staffing problems impacting on service delivery. However, when each of the three teams commonly have only one person filling a specific role, circumstances will always arise when that post becomes vacant due to factors including sick leave, maternity cover and retirement. Similarly, within small departments, the impact of sick leave, maternity cover and retirement out with the network can negatively affect

the services provided by the network staff (whether NDP funded or otherwise). Whenever these circumstances occur, pragmatic choices can lead to alterations in duties and responsibilities. There have been concerns across Scotland that this has led to examples of posts being down banded or a lack of backfill, cancelling out some of the positive benefits of the NDP funding. Therefore, the NOSPRN takes workforce issues seriously and it remains a standing item on the PRISM agenda.



## 4) Network Activities

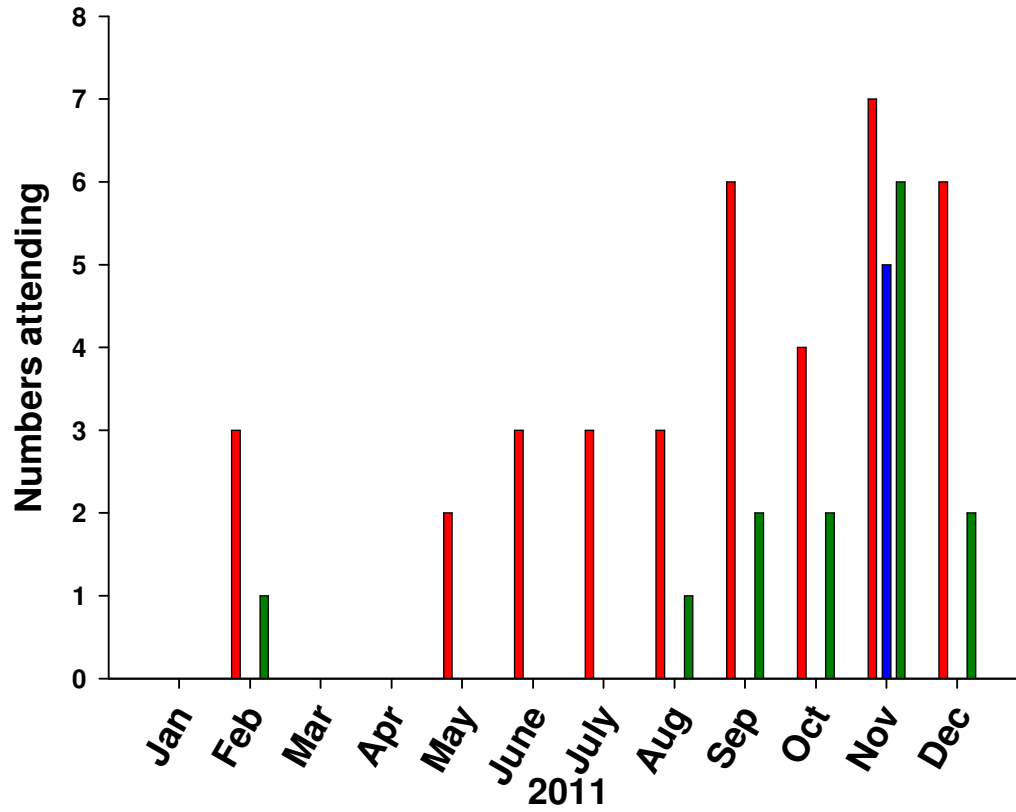
### 4i) Steering Group/Membership

Within the last year, monthly network service meetings have been established: the Paediatric Respiratory Inter-Regional Service Meetings known as PRISM. The purpose of these meetings was manifold: as a tangible presence of the network, the integration of departments (“networking” in the old-fashioned sense of the word), to provide an accessible forum for developing the network, to be inclusive to all members of the multidisciplinary teams, to share best practice and to build better respiratory services for patients in the network overcoming remote and rural challenges. Steering Group meetings have been proposed as a quarterly function of PRISM. The

core membership has been proposed to overlap with PRISM as each professional attending usually represents the only representative of their discipline for their hospital. Lay involvement has been considered and this has been recognised as a common issue at the Clinical Leads meeting under NoSPG. Parents of respiratory patients often have very specific experience about their own child’s illness but find it difficult to engage with equal vigour on topics related to other illnesses. Respiratory Charity representatives could be a solution, but a number would need to be invited for balance, whilst keeping the group as a manageable and functional unit.



## PRISM Attendance by Centre 2011



**Figure 1** – PRISM meetings commenced in the Spring/Summer of 2011 and attendance has grown throughout the year with a peak attendance in November. (Key: Red = RACH, Blue = Ninewells, Green = Raigmore)

## 4ii) Clinical Activity Bed Occupancy (Cystic Fibrosis)

Cystic Fibrosis patients are most commonly admitted for intravenous (IV) antibiotics for acute exacerbations or for elective courses of IV antibiotics, or for operative procedures such as Portacath insertion, gastrostomy insertion or flexible bronchoscopy, many of which are suitable as day case procedures. IV antibiotics courses usually last two weeks and elective patients may receive this treatment four times per year. Many families are willing to be taught the technique and can deliver IV antibiotics at home which can be less disruptive to family life but places the onus of this additional aspect of delivery of care on the parents.

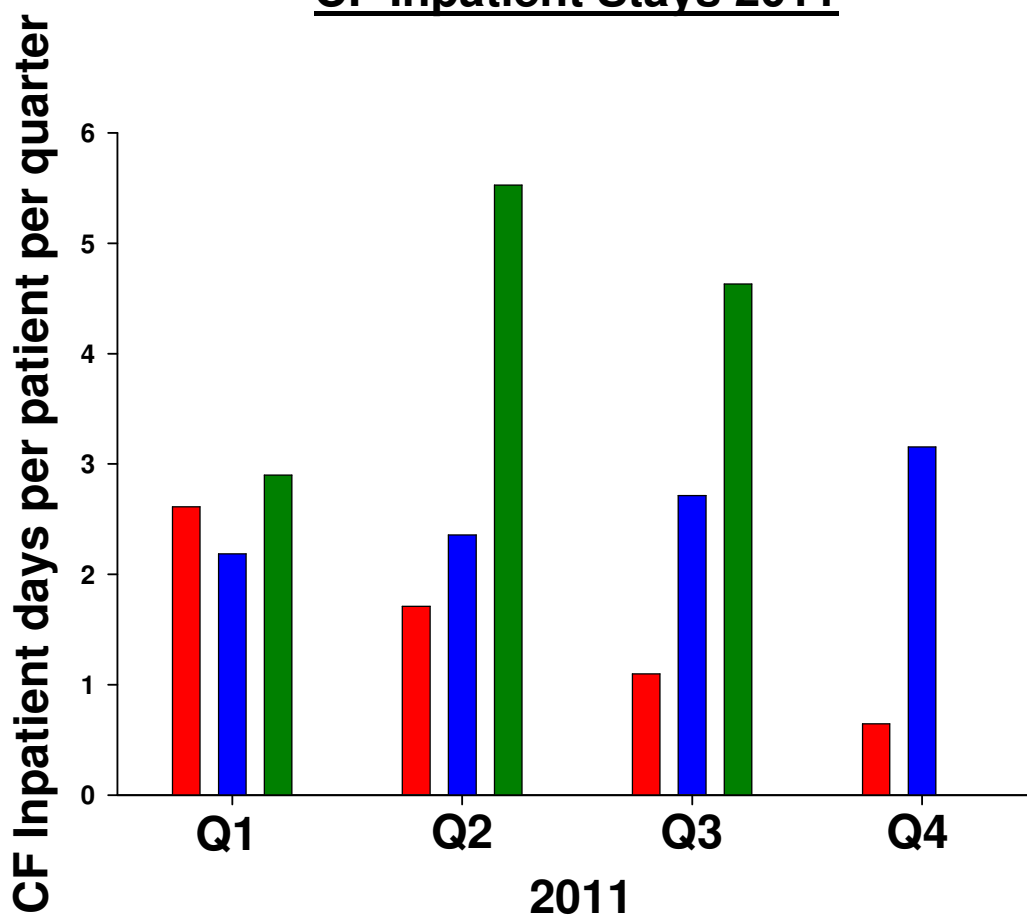
Depending on the quarter, there were 76-78 paediatric CF patients in the network in 2011 and collectively, CF patients spent a total of 722 nights in hospital. Each night a child with cystic fibrosis spent in hospital was determined and plotted over a denominator of the known paediatric

CF population for that service, giving a monthly value for bed occupancy nights per patient.



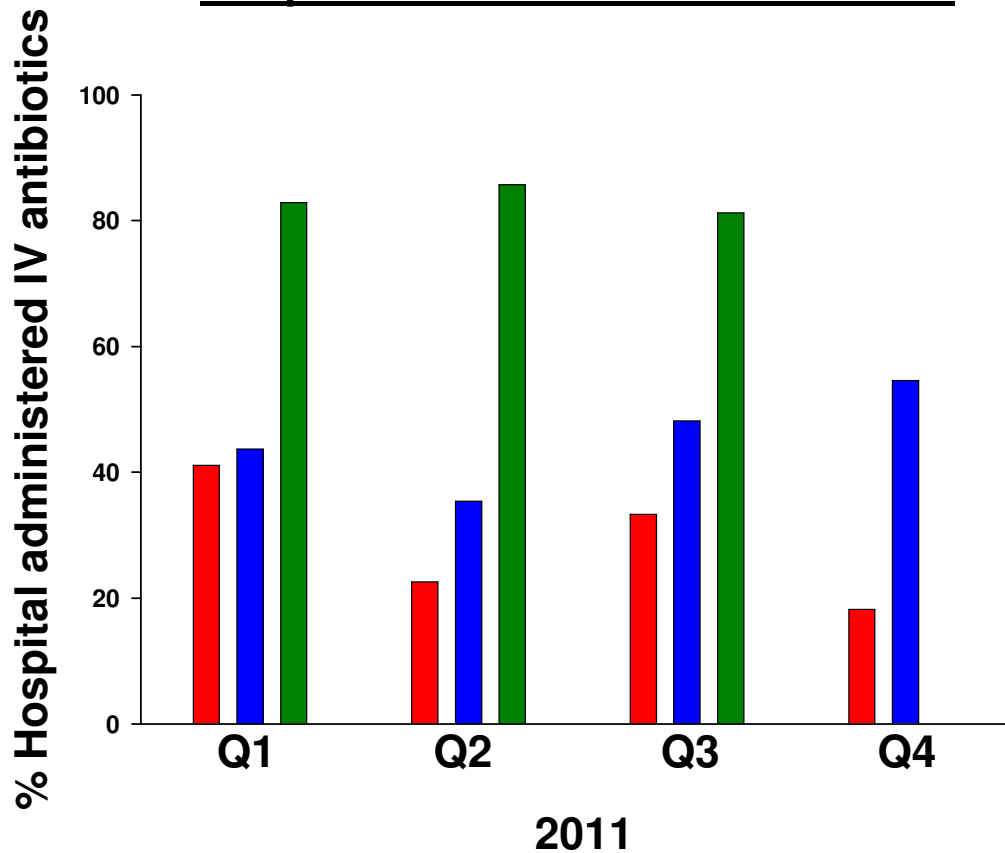
In reality there are many paediatric CF patients who seldom need hospital admission, so this does not provide a means of interpreting differences, merely a means of comparing admission rates between centres. Comparison rates of IV antibiotics delivered at hospital and home for CF are also shown.

## CF Inpatient Stays 2011



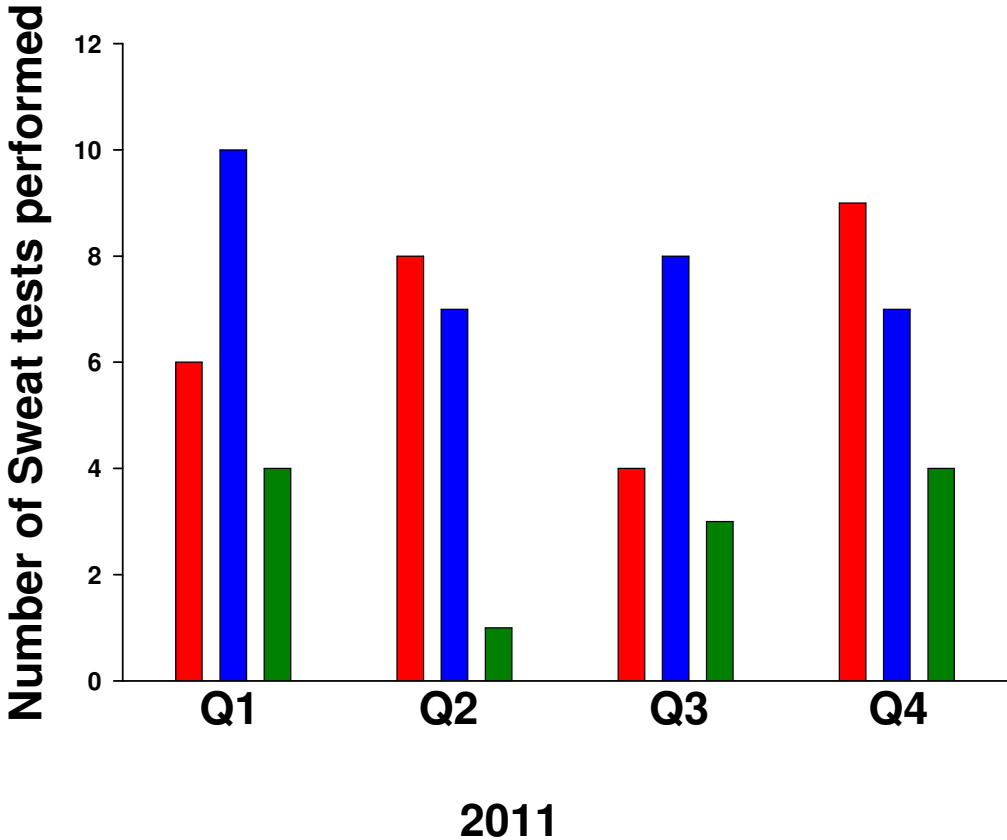
**Figure 2** – CF patient numbers were stable throughout the year, but clinical activity requiring inpatient facilities can vary when new patients are diagnosed or older patients require hospitalization for acute exacerbations. Total number of inpatient nights = 722. 2011 totals for each unit: RACH 188 nights (1.52 nights/patient/year), Ninewells = 283 (2.60 nights/patient/year), Raigmore = 251 (3.26 nights/patient/year). (Key: Red = RACH, Blue = Ninewells, Green = Raigmore).

## Hospital versus Home IV antibiotics



**Figure 3** – Certain patients will only receive IV antibiotics in hospital as home IVs are not an option. Individual centres results can vary due to acute exacerbations and patients entering or leaving the paediatric service with different clinical needs. Total number of days on IV antibiotics = 967. 2011 totals per centre: RACH = 296 days (9.55 days on IVs/patient/year), Ninewells = 439 days (16.26 days on IVs/patient/year), Raigmore = 232 days (12.21 days on IVs/patient/year). (Key: Red = RACH, Blue = Ninewells, Green = Raigmore).

# Sweat Testing 2011



**Figure 4** – In 2011, there were 71 sweat tests performed across the region (RACH 27, Raigmore 12, Ninewells 32). Regular performance of sweat tests are important to maintain technical skills and for quality control purposes (Key: Red = RACH, Blue = Ninewells, Green = Raigmore).

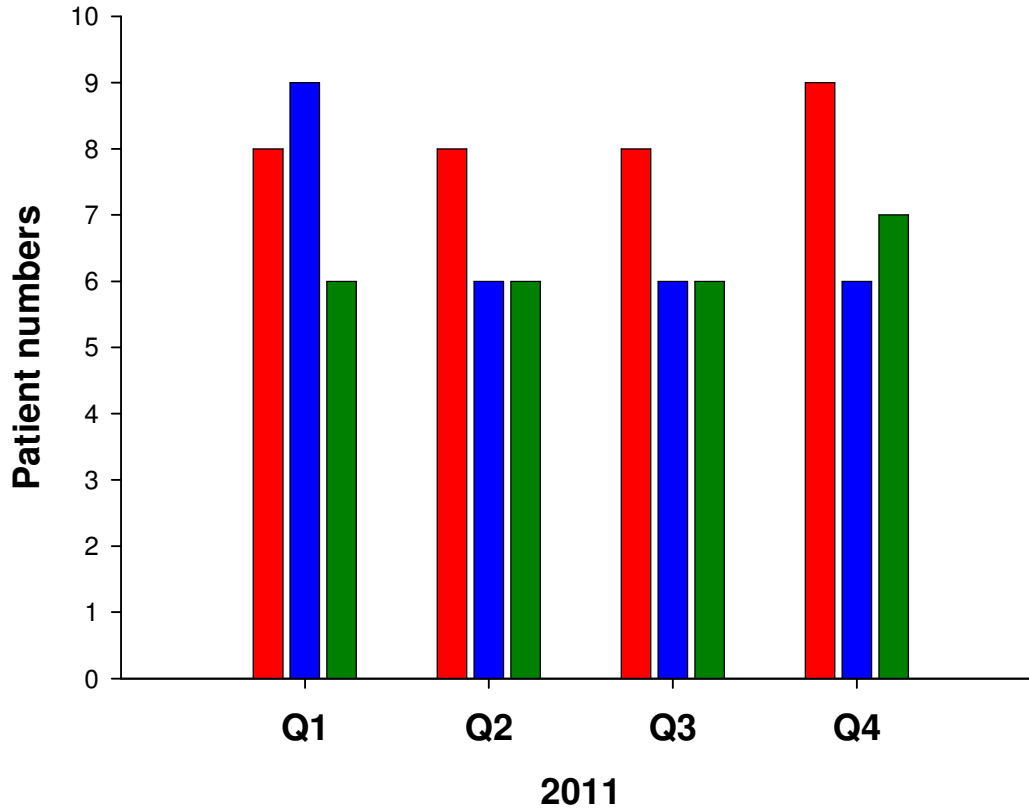
## Flexible Bronchoscopy

RACH theatres are the only location where flexible bronchoscopy services are provided within the NoSPRN. A monthly elective theatre list was established in 2009 (first Thursday of every month) and patients have been referred for bronchoscopy and bronchoalveolar lavage from clinics in Perth, Dundee, Elgin, Inverness,

Orkney and Shetland. There were 22 flexible bronchoscopies undertaken during 2011 (Q1 - 8, Q2 - 3, Q3 - 10, Q4 - 1). Dr Brooker undertook an audit of flexible bronchoscopy practice at RACH which reported the increasing numbers of procedures, the diversity of clinical indications and the low number of complications.

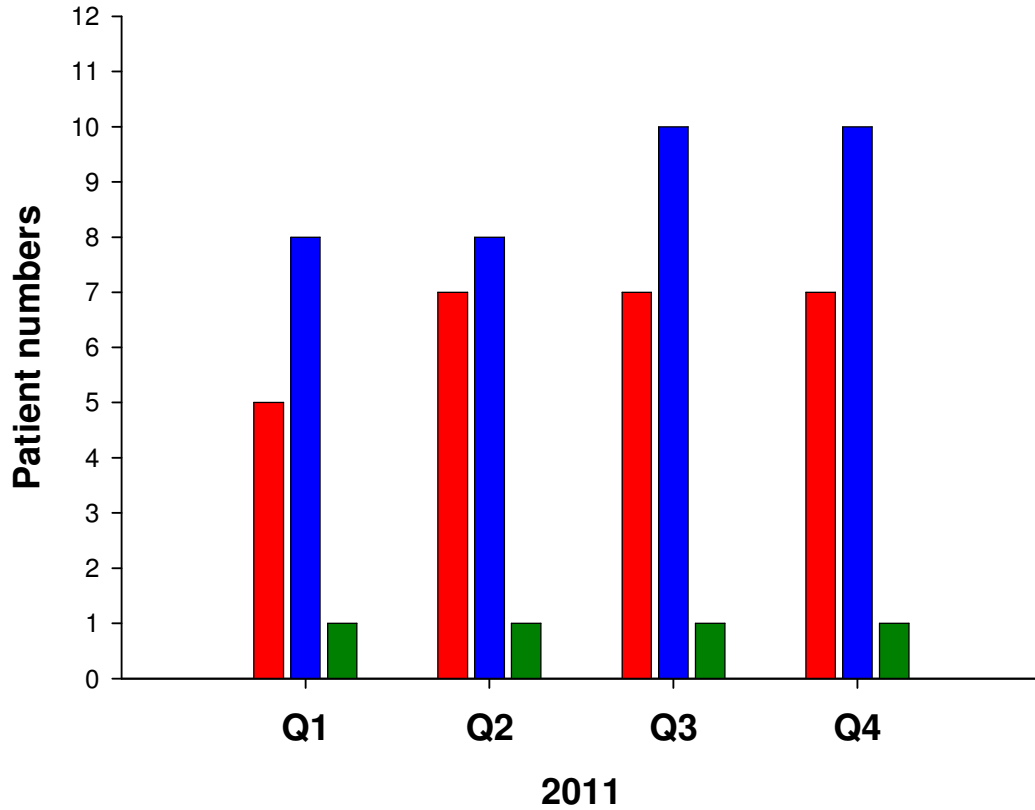


## Patients requiring Long Term Oxygen 2011



**Figure 5** – In 2011, numbers of children prescribed long-term supplementary oxygen were stable in the range of 20-23 families. Initiation of long term oxygen is usually the decision of a paediatric respiratory consultant or consultant neonatologist. (Key: Red = RACH, Blue = Ninewells, Green = Raigmore).

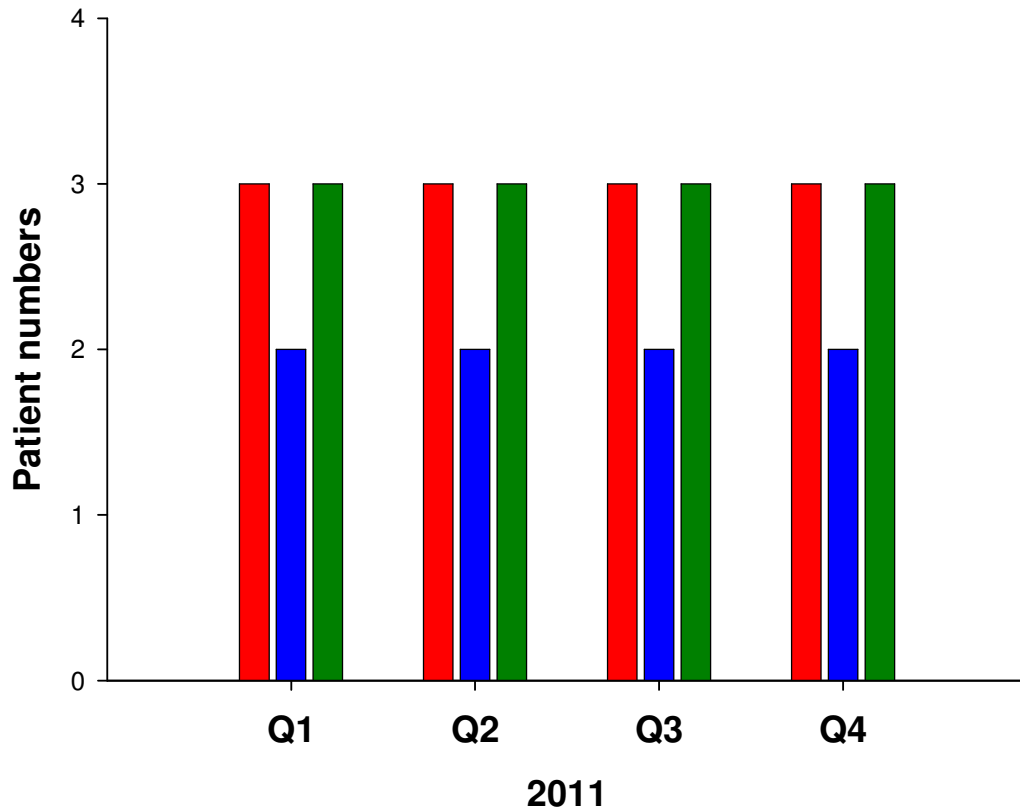
## Patients requiring Non-Invasive Ventilation 2011



**Figure 6** – In 2011, the number of children receiving non-invasive ventilation climbed by nearly 30% over the year, reaching a peak of 18 patients. This method of respiratory support is becoming more widespread and has cost implications due to equipment purchase, maintenance and training and support of parents, staff and carers. (Key: Red = RACH, Blue = Ninewells, Green = Raigmore).



## Patients requiring Invasive Ventilation 2011



**Figure 7** – In 2011, the number of children receiving invasive ventilation remained stable over the year. Many of these patients have shared care arrangements with Scotland’s two ventilation centres in Edinburgh and Glasgow. (Key: Red = RACH, Blue = Ninewells, Green = Raigmore).

### iii) Work Plans

## Strategic Aims and Challenges

### Aims

- 1) Formation of a Regional Work Plan
- 2) Implement quarterly Steering Group meetings interspersed between the Operational PRISM meetings
- 3) Establishment of a Specialist Respiratory Clinic in Shetland and explore telemedicine clinics
- 4) Establish audit across NoSPRN sites
- 5) Develop clinical protocols and care pathways
- 6) Develop links with other networks
- 7) To ensure assessment of NoSPRN demonstrates improvement and benefit for region's population
- 8) Develop NoSPRN website
- 9) Develop NoSPRN Patient Information Leaflets
- 10) Determine training needs of NoSPRN staff
- 11) Determine network user's experiences

### Challenges

- 1) Rural and Remote Populations
- 2) Sustainability of general paediatric services

The progress with the current work plan is included in Appendix 3.

## iv) Training and Education Framework

In general, staff training is arranged by individual staff members in conjunction with their line managers rather than being a direct responsibility of the network. At present, the network has not undertaken a network wide scoping exercise into training needs of staff however it is recognised that there are members of staff with different levels of experience. Recently appointed members of staff are paired with more experienced colleagues in other parts of the network for support. Members of the network are encouraged to attend, participate and lead on fortnightly network-wide teaching sessions and monthly CF annual review meetings. Most allied health professionals have

their own specialty groups and meetings which members are encouraged to attend. Through the Scottish Paediatric Respiratory Interest Group, members of network staff were encouraged to attend or present at the Paediatric Respiratory Education Day held in Stirling Management Centre in September 2011. The current lack of resources for study leave and training budgets have made it very difficult for the majority of staff to attend courses and meetings nationally and internationally with many members of staff commendably attending in their own time and at their own expense.

### **Four examples of good local respiratory training:**

**Undergraduate Training:** 7 x 4 week Student Selected Components (SSC) in Phase 3 and 2 x 4 week SSCs in Phase 2 are offered for University of Dundee undergraduate medical students. Students have the opportunity to participate in all aspects of departmental activity including attending network clinics and traveling to RACH to observe the flexible bronchoscopy lists.

**Video-Conference Network Teaching:** Twice monthly 1 hour sessions are held between RACH, Ninewells and Raigmore Hospitals using the telemedicine link. This has become a useful forum for offering in-depth respiratory topics, case presentations, training, research updates, audit presentations and journal clubs.

**Scottish Cystic Fibrosis Group Annual Educational Meeting:** Network members are encouraged to attend this useful meeting held in Stirling each May. Dr Brooker, Clinical Lead for the Paediatric CF MCN, formally launched that network at this meeting in 2010.

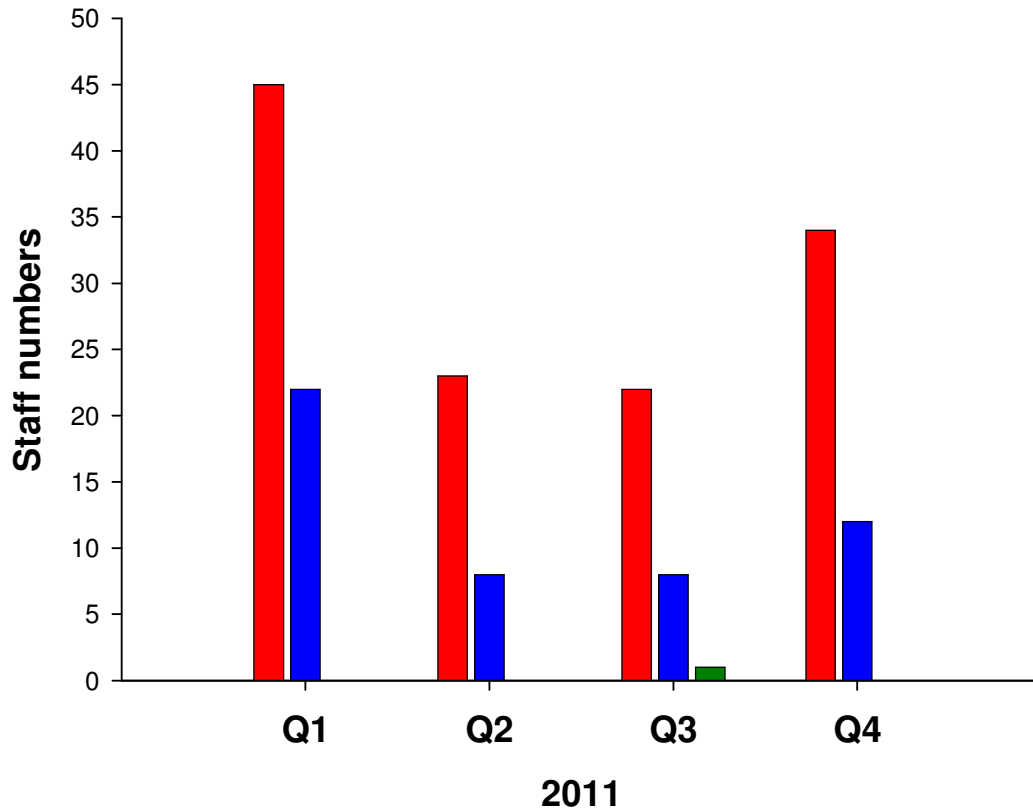
**PRED:** Paediatric Respiratory Education Day organized under the auspices of SPRING (Scottish Paediatric Respiratory Interest Group) held in Stirling in September. This meeting is organized by Dr Jonathan McCormick, Chairman of SPRING.

## v) Teaching Sessions

A fortnightly paediatric respiratory network teaching session has been established across the network. During the first year, the sessions were predominantly led by the Consultants and featured audits, journal clubs, topic reviews, recent cases and research presentations. Dr Steve Turner coordinates the programme which has

been widened out to include presentations by a wider range of the multi-disciplinary team. The use of the video-conference facilities has enabled greater collaboration between sites, and facilitated discussions on future topics for clinical care pathways, audits and research.

## Network Respiratory Teaching Attendance 2011



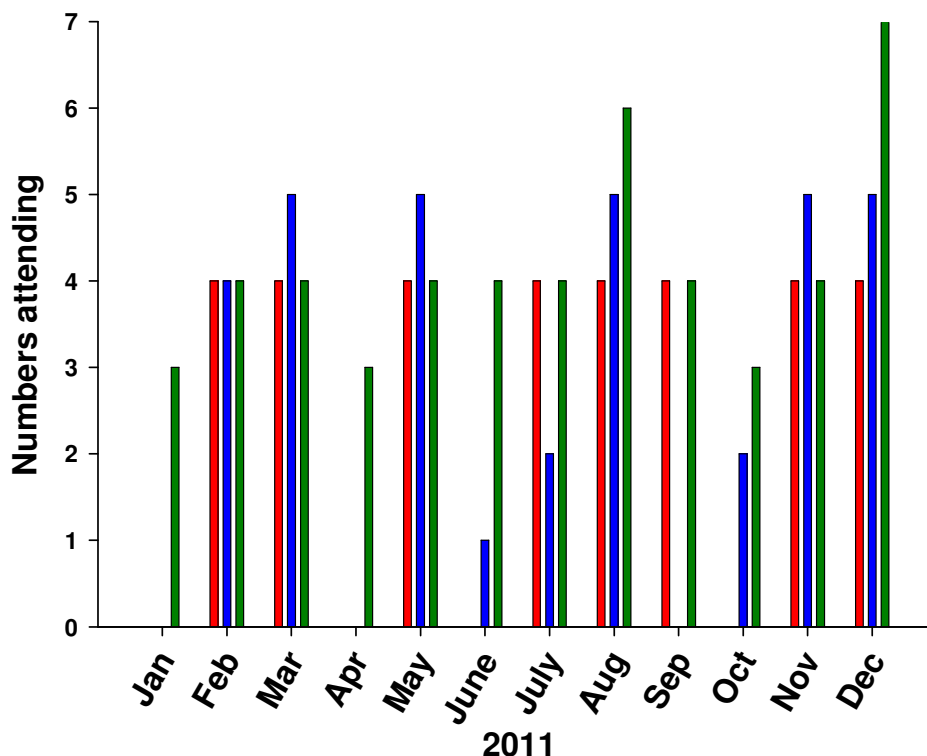
**Figure 8** – Network teaching attracts all members of the multi-disciplinary team and is open to medical students and junior doctors in training, even if they are not specifically attached to a respiratory team. It is acknowledged that the timing of teaching clashes with other clinical activities in Raigmore. (Key: Red = RACH, Blue = Ninewells, Green = Raigmore).

## vi) Telemedicine & Videoconferencing

The network has been active in embracing the video-conferencing facilities available at RACH, Raigmore and Ninewells. Most regularly these are used to link the centres for the monthly CF annual review meetings and the fortnightly network respiratory teaching. However, patients have also

been reviewed by videoconference. During a heavy snowfall, Dr Brooker was unable to travel to Raigmore for the specialist respiratory clinic. Clinical histories were taken over the live video link by Dr Brooker with examination performed by Dr Alan Webb, the local consultant paediatrician at Raigmore.

### CF Annual Review Videoconference Meeting Attendance by Centre 2011



**Figure 9** – Video-conference facilities have allowed shared discussions across the network between the multi-disciplinary CF teams in the three sites. This provides support and a mutual exchange of ideas with regard to complex management situations and the sharing of best practice. (Key: Red = RACH, Blue = Ninewells, Green = Raigmore).

## vii) Liaison with national/regional MCNs and other bodies

Scotland has paediatric respiratory networks in the North and West but not in the East.

Our network has close working relationships with many of the other networks, frequently due to dual membership. Networks collaborate to help individual patients and this has been particularly the case with our colleagues

in neurology and gastroenterology. Clinical Lead meetings have enabled discussions around shared challenges of data collection, cross-boundary working, IT access, recruitment, continuity, responsibility and governance. Networks and groups that NOSPRN liaise with regularly include:

- National Cystic Fibrosis MCN
  - Clinical Lead: Dr RJ Brooker, RACH, Aberdeen
- West of Scotland Paediatric Complex Respiratory MCN
  - Clinical Lead: Dr JY Paton, RHSC, Yorkhill, Glasgow
- CLEFTSiS MCN for Cleft Lip and Palate in Scotland
- SPRING (Scottish Paediatric Respiratory Interest Group)
  - Chair: Dr J McCormick, Ninewells Hospital, Dundee

## 5) Key Service Developments

### i) Specialist Clinics

Specialist respiratory and CF outpatient clinics occur across the network bringing specialist advice close to patients by delivering services in their local hospitals. This can shorten the time to a diagnosis by offering quicker access to specialist investigations such as flexible bronchoscopy. In 2011, the network delivered in excess of 300 clinics and more than 2000 appointments were met. Specialist clinics facilitate access to the many disciplines that support the care of children with respiratory disorders including respiratory physiotherapy, dietetics, clinical psychology,

pulmonary physiology and specialist nursing. In the past year, specialist respiratory clinics have commenced in Orkney with a visiting Consultant in Paediatric Respiratory Medicine and a NDP-funded Respiratory nurse Specialist. Joint clinics for Highland are set to increase by 50% in 2012, including undertaking a CF clinic on the Isle of Skye. Nurse-led asthma clinics are delivering additional opportunities to reinforce inhaler technique, written asthma plans and emergency advice as well as offering further opportunities for clinic review.



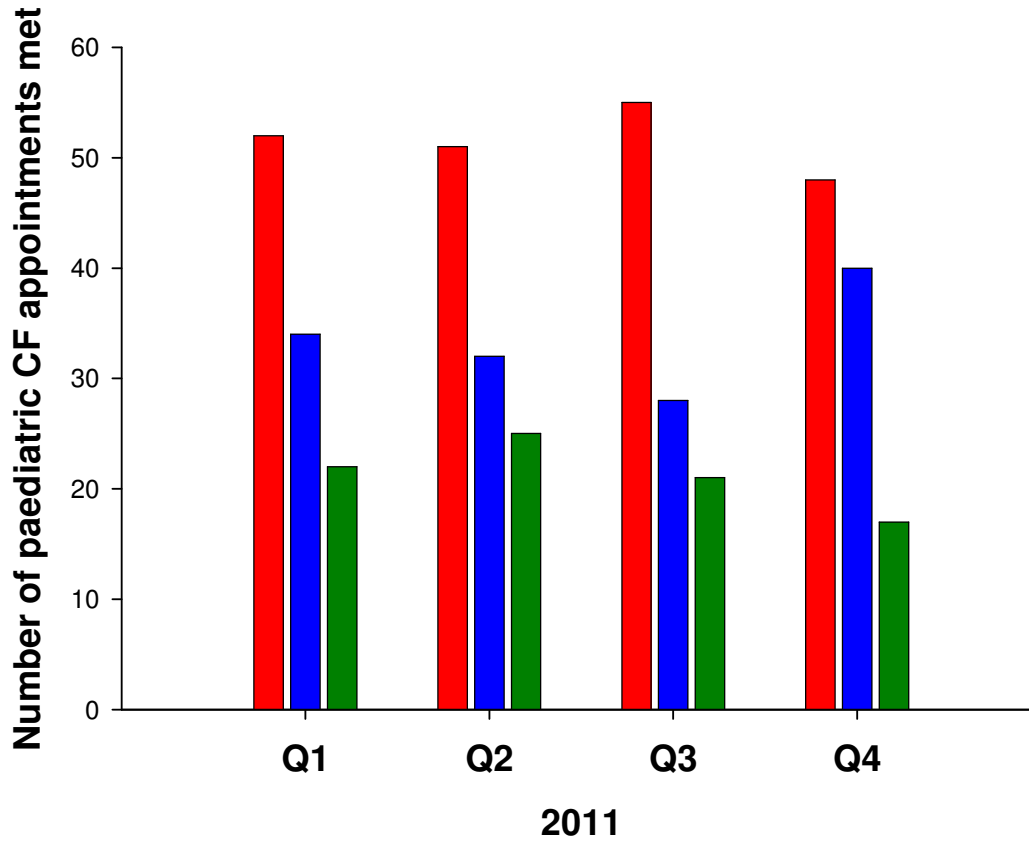


## **Paediatric Respiratory Clinics**

Attendance data were recorded from the following Paediatric Respiratory Clinics:

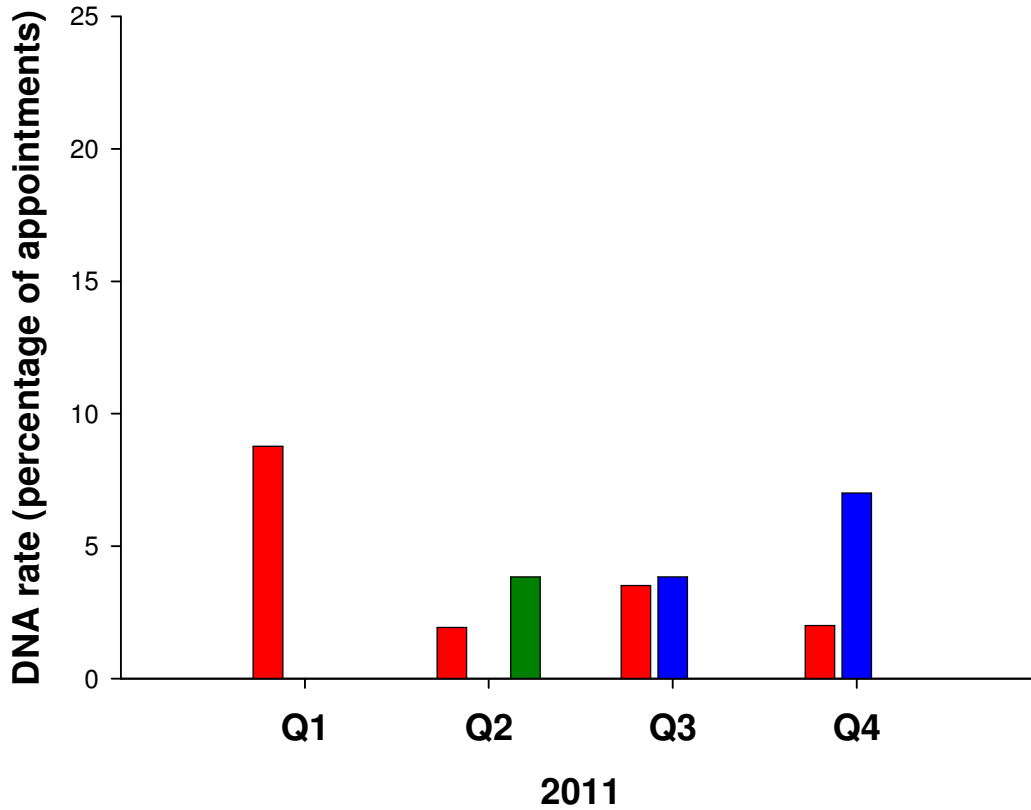
- RACH Nurse-led Respiratory Clinic
- RACH Respiratory Clinic
- RACH CF Clinic
- Orkney Respiratory Clinic
- Raigmore Complex Respiratory Clinic
- Raigmore CF Clinic
- Raigmore Allergy Clinic
- Raigmore Nurse-led Respiratory Clinic
- Ninewells General Respiratory Clinic
- Ninewells Chronic Respiratory Clinic
- Ninewells Nurse-led Asthma Clinic
- Ninewells Neuromuscular Respiratory Clinic
- Ninewells Respiratory Transition Clinic
- Ninewells CF Clinic
- Ninewells CF Transition Clinic
- Perth Royal Infirmary Respiratory Clinic
- Perth Nurse-led Asthma Clinic

## Paediatric CF Clinic Attendances 2011



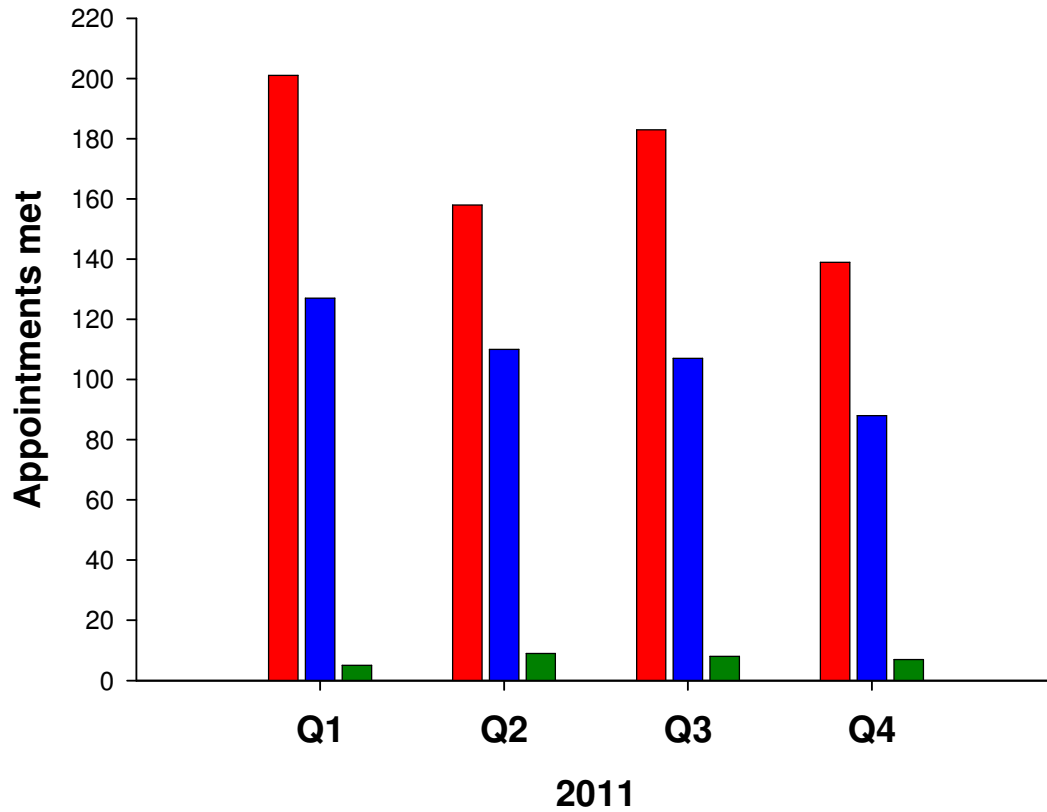
**Figure 10** – In 2011, there were 97 paediatric CF clinics across the network and 424 CF appointments were met. Attendance was excellent with only 15 appointments where the patient did not attend (3.4%) (Key: Red = RACH, Blue = Ninewells, Green = Raigmore).

## Paediatric CF Clinic DNA rates 2011



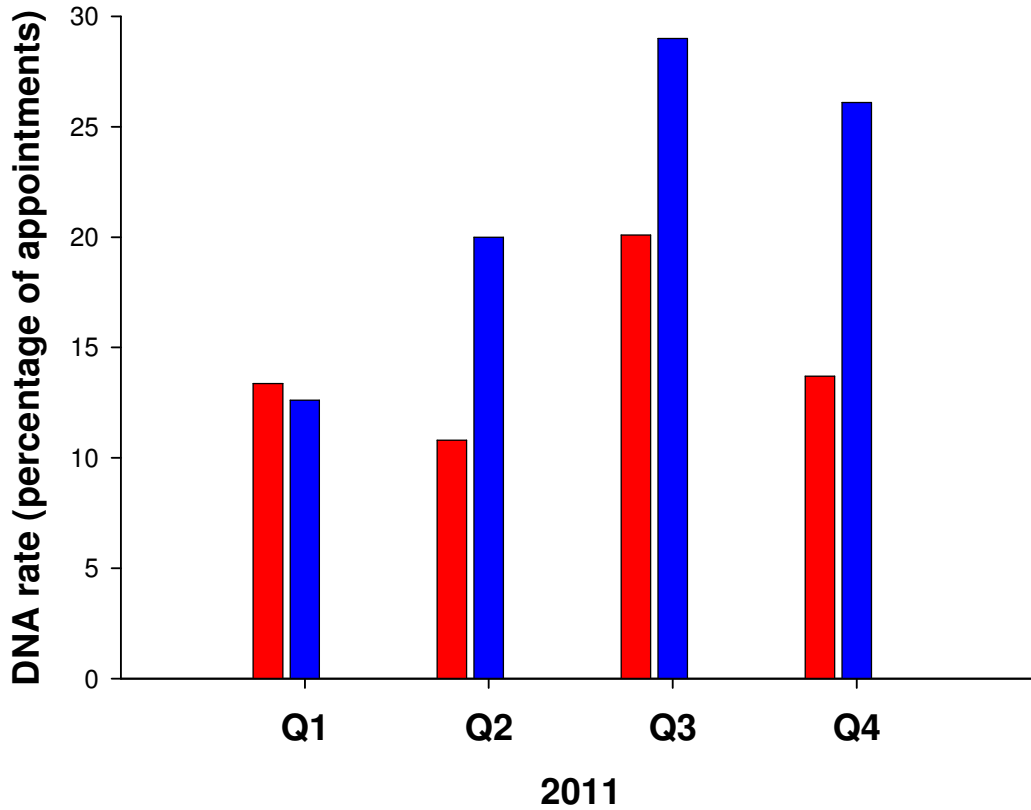
**Figure 11** – In 2011, there were 97 paediatric CF clinics across the network and 424 CF appointments were met. Attendance was excellent with only 15 appointments where the patient did not attend (3.4%) and the percentage of missed appointments did not favour any individual clinic (Key: Red = RACH, Blue = Ninewells, Green = Raigmore).

## Paediatric Respiratory Clinic attendance 2011



**Figure 12** – There were 142 paediatric respiratory clinics and 82 nurse-led clinics across the network and 1629 appointments were met. Overall, there were 266 missed appointments in the respiratory clinics (16.1%) and 67 missed appointments in the nurse-led clinics (21.8%). (Key: Red = RACH, Blue = Ninewells, Green = Raigmore).

## Paediatric Respiratory Clinic DNA rates 2011



**Figure 13** – There were 142 paediatric respiratory clinics and 82 nurse-led clinics across the network and 1629 appointments were met. Overall, there were 266 missed appointments in the respiratory clinics (16.1%) and 67 missed appointments in the nurse-led clinics (21.8%). Individual “DNA” rates across these clinics were 18.2% for Ninewells Respiratory Clinic, 25.5% for the Ninewells Nurse-led clinic, 14.8% for the RACH Respiratory Clinics, 36.5% of the RACH Nurse-led clinic and the Raigmore Specialist Respiratory Clinic had a DNA rate of 0% reported. (Key: Red = RACH, Blue = Ninewells, Green = Raigmore).

## ii) Transition Clinics

Transition of CF patients to adult services is widely seen as an exemplar of how transition should be approached. Joint working with the adult multi-disciplinary team exists for patients seen in Raigmore, RACH and Ninewells. Each centre has a slightly different method of accomplishing transition and therefore there is no commonly agreed age for transition (usually this is tailored to the individual young person's situation, maturity and readiness for transition), nor is there a specified duration of the transition process. However, this is understandable for these services have developed in isolation rather than as a result of network activity and each service has built the service that works best for their locality, staffing and patient population. The Raigmore CF team is joined by the outreach service of adult CF physicians from Edinburgh, although there is excellent continuity with specialist nurses and other allied health professionals caring

for both the paediatric and adult CF populations in Highland. RACH patients transfer to the adult service at Foresterhill in general. The Ninewells adult CF team has a full team based in the hospital as part of a shared care arrangement with Edinburgh and Dr Helen Rodgers travels up to Dundee on a weekly basis and joins the transition clinic with the paediatric team.



With greater networking, additional transition services are developing. In Ninewells, the first Respiratory transition clinics took place in 2011, predominantly for young asthmatic patients and for a number of patients with chronic respiratory problems.

These were in response to the recognition that many adolescent patients were being referred back to the adult respiratory physicians after discharge from the paediatric team and often only required a single visit. Additionally, complex patients that clearly required follow-up in the adult clinic had previously been transferred by a single referral letter, and a new transition clinic offered the prospect of a detailed handover of medical and nursing information. Clinics were

initially offered monthly in Dundee, and then rationalized to quarterly based on the volume of referrals. There are plans to replicate this service in Perth in 2012. Members of the NoSPRN attend twice yearly neuromuscular/respiratory clinics in Dundee and have attended a new neuromuscular/respiratory transition clinic held jointly with the adult team led by Dr Bateman from Edinburgh.

### iii) Quality Improvements: IT, Administration and Finance

At present, NoSPRN does not have its own website or IT support, however, network activity can be shared on the NOSPUG website. There is not an

appropriate data management system linking all centres and accessible by all members of NoSPRN.

## 6) Key Challenges

### i) Recruitment to Vacant Posts

The Exception reporting chart for staffing during 2011 is included in Appendix 2. As can be seen, there are no vacant posts in the NDP-funded network posts but there has been good

provision of cover for the small number of staff away on maternity leave or sick leave. Currently, the only vacant post is the RACH Pulmonary Function Technician.

### ii) Workforce challenges – Doctors in Training

There are significant training opportunities for doctors in training through engagement with the network. It is commonplace for members of the multidisciplinary team to bring students from their own disciplines to clinic visits, teaching or home visits. Optional undergraduate special study components in Paediatric Respiratory Medicine are popular choices and students have taken advantage of the teaching available across the network (for example, Dundee medical students attending the flexible bronchoscopy list in Aberdeen, or attending the network respiratory teaching by videoconference).

There are significant workforce pressures at present with a falling number of middle grade doctors in paediatrics across Scotland and considerable debate about the sustainability of the middle grade system and the provision of safe out of

hours cover. In Dundee, the respiratory team is not always allocated a middle grade doctor but in 2011, the team was allocated a ST6 doctor working less than full time (LTFT) trainee at 0.6 whole time equivalent (WTE). She was replaced from August 2011 by an ST1 post rotating on a 4 month attachment. RACH did not have an individual middle grade doctor on the respiratory team in 2011. Raigmore do not have an individual junior doctor as named part of the paediatric respiratory service. Attracting the next generation of staff of all disciplines requires engagement with students and those qualified but in the early years of their careers. Maintaining the presence of junior doctors in the respiratory team in Ninewells and exploring options of attracting trainees in Aberdeen to the specialty should be pursued.



## 7) Research & Audit Research

Only one member of the network has any permanent academic sessions for research in their job plan (Dr Steve Turner) but the network was successful in collaborating in a number of multi-centre studies. When new approaches are made, the centres are more likely to discuss participation at a network level rather than at an individual unit level. The multi-centre studies that the network participated in during this year were:

1) **TIDES** – Ninewells and RACH CF teams have participated in data collection for this multi-centre study on anxiety and depression amongst CF patients and their caregivers. The local Principal Investigators are Dr Jonathan McCormick (Ninewells) and Dr Richard Brooker (RACH).

2) **BIDS** – Ninewells and RACH teams participated in this HTA-funded Scottish multi-centre study over winter 2011-12 and 2012-13 which aims to assess whether therapeutic oxygen makes any difference to how quickly infants recover from bronchiolitis. The local Principal Investigators are Dr Jonathan McCormick (Ninewells) and Dr Steve Turner (RACH).

## Audit

Audits have been conducted into clinical practices in individual centres and the results of these have been disseminated through the video-conference respiratory teaching sessions. With the establishment of the network, further network wide audits are planned.

- **Tobramycin levels in Cystic Fibrosis** – Dr Helen McPherson, FY2, Ninewells Hospital.
- **Short Synacthen test audit** – Dr Helen Dunne, SpR, Ninewells Hospital
- **Flexible Bronchoscopy audit** – Dr Richard Brooker, RACH
- **CF Annual Review Patient Satisfaction Questionnaire** – Eilidh Brown, 4<sup>th</sup> Year Project, Medical Student, University of Dundee

## 8) Views from the Network

### **Views from the Network**

*“Grampian physiotherapy department was fortunate in obtaining a 0.5wte staff member for the Cystic Fibrosis / Specialist Respiratory services from the NDP funding. We have a 12 year old girl who has non-CF bronchiectasis and is in total denial of having a chest problem. Prior to the set up of the RACH specialist respiratory clinic, she had only been seen twice by physiotherapy in her twelve years. She is able to take part in gym, keep up with her peers and is a competitive swimmer – why bother with regular Airway Clearance Techniques?! Her mum is the one concerned as to why her daughter coughs throughout the night and isn’t able to hold her breath under water for as long as others in the swimming club!*

*Since being referred (through our team discussions) she has been seen on a regular basis and is now undertaking regular chest management resulting in her coughing less and breath holding more!!*

*The dedicated time offered by this post has resulted in an integrated service which has had greater impact than ‘the sum of parts’ which was previously offered.” – **Maureen Ryles, Head of Paediatric Physiotherapy, RACH***

## **Views from the Network**

*“Since I started my post as the Cystic Fibrosis paediatric dietitian in late October, I have had a lot of regular input into the family of a 9 month old baby and her care. She has had ongoing problems in her feeding and growth and she has required quite intense dietetic input. Apart from pancreatic insufficiency and the need for enzymes, she has had issues with reflux, tolerating high calorie formula, painful oral thrush, weaning setbacks and tube feeding. I have been able to provide home visits, consultations at each clinic appointment and up to daily assessments on the ward when she has been an inpatient. As her needs have changed so rapidly and so often, it would have been extremely difficult for me to provide her with the nutritional care she has needed without have dedicated time for my CF patients. I have been able to liaise with speech and language therapy for joint assessments, the paediatric CF specialist nurse for home visits and regular meetings with the complete CF team (which includes physiotherapists, pharmacist, consultant, physiologist and clinical psychologist). I have been able to identify a number of issues and address them as well as support her family, who have been understandably concerned about her nutritional status, which will have impacts on her growth, lung function and immune function. She has been showing improvements in her growth, her social skills and her overall development with her complex dietetic care. I have developed a guideline document for maximum doses of pancreatic enzymes as a result of our interaction, which has been used on the ward for our CF inpatients to ensure they are receiving appropriate doses for absorption. This has lead to my involvement in a nursing training day, where I will be providing more information on the nutritional care of CF patients and the use of enzymes in their treatment.” – Emma Crowley, CF Dietician, Ninewells Hospital*

## Views from the Network

*“Covering the wide geographical area of the Highlands and Islands poses its challenges both in terms of the landscape and proving equity of service to those living more remotely. The enhanced funding provided by the NDP has facilitated the complete multidisciplinary team being able to travel quarterly for CF clinics on the Isle of Skye. Families are therefore given the opportunity to meet with the specialist team closer to home.*

*The NDP funding has also resulted in clinical psychology hours dedicated for CF. Every family now has the opportunity to meet with the psychologist at annual review and those requiring support are offered this in a timely manner.*

*The advent of the wider North of Scotland Paediatric Respiratory Network has improved and enhanced working relationships between the multidisciplinary teams. Monthly telemedicine links provide education and network opportunities for the whole team as well as excellent teaching opportunities for students.” – Lesley Blaikie, Senior Cystic Fibrosis Clinical Nurse Specialist, Raigmore Hospital*



## **Views from the Network**

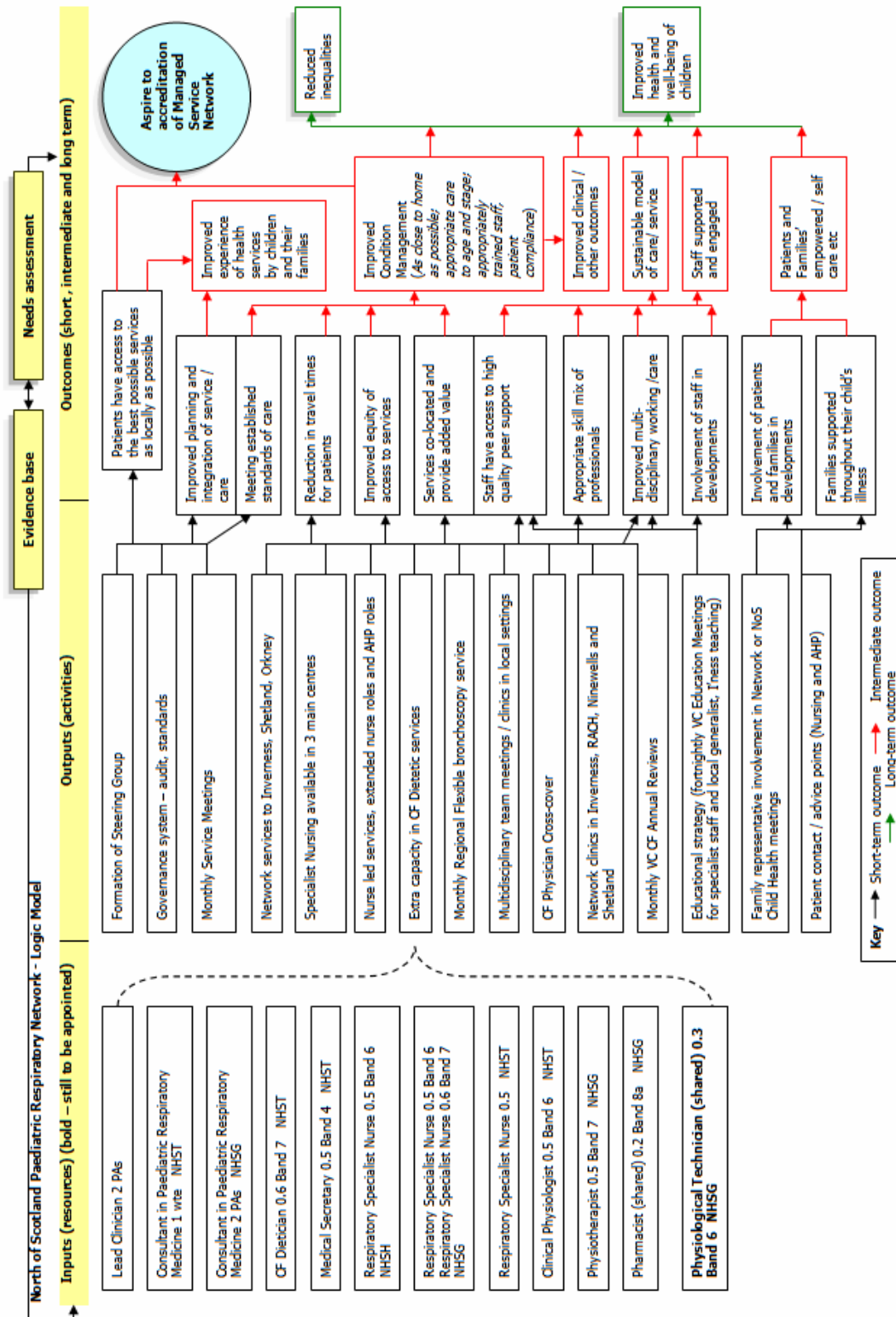
*“As part of my post as paediatric respiratory clinical physiologist at Ninewells, I have been responsible for setting up and developing hypoxic challenge tests often known as “fitness to fly” assessments.*

*The introduction of this service has enabled us to assess if a child may experience respiratory symptoms or complications during a flight and therefore make recommendations on the need for supplementary oxygen.*

*The implementation of this test has allowed several patients with degenerative neuromuscular diseases to safely go on a dream flight to Disney World in Florida, giving the children a fantastic holiday and the parents a much needed break.*

*This test has also enabled us to assess how a young child with cystic fibrosis, who has significant lung damage and is on supplementary oxygen, will cope during a flight and any additional needs they may have. As a result of this test, the family were able to safely fly to visit grandparents and the child’s parents are now planning to fly abroad later in the year to get married with the whole family present.”* – **Lyndsey Schaller, Paediatric Respiratory Clinical Physiologist, Ninewells Hospital**

# Appendix 1 – Logic Model



## Appendix 2 - NoSPRN Staffing 2011

<i>NAME</i>	<i>STATUS</i>	<i>POST</i>	<i>HRS</i>	<i>Band</i>	<i>NDP</i>	
<b>ABERDEEN</b>						
Connie Durno		Medical Secretary	p/t			
Dr Richard Brooker		Consultant Paediatric Respiratory Medicine	f/t		√ 0.2	Clinical Lead for CF National MCN
Dr Mustafa Osman		Consultant Paediatrician	f/t			Clinical Lead for Elgin
Dr Steve Turner		Consultant & Senior Lecturer in Child Health	f/t			
Dr Pat Charleton		Associate Specialist	f/t			0.2 WTE for CF
Nicola Hough		Clinical Nurse Specialist – Cystic Fibrosis	f/t	7		
Richard Leece		Clinical Nurse Specialist – Complex Respiratory	f/t	7		
Elsie Thomson		Advanced Dietitian		7		0.25 WTE for CF
Tamara Taylor		Clinical Nurse Specialist – Community Children's Nurse	28	7		
Kirsteen Williams		Cleft Lip & Palate/Complex Respiratory Nurse	37.5	6	√	0.5 for each
Dr Julie Strachan		Psychologist			√	0.1 WTE for CF
Maureen Ryles		Head of Paediatric Physiotherapy		8c		0.2 WTE for CF
Laura Angus		Physiotherapist	18.75	7	√ 0.5	Maternity leave. Cover from RACH Physiotherapy department
Paula Thomson		Pharmacist – CF		8a	√	0.2 WTE for CF Maternity leave. Ward and Clinic Cover from Jenny Mosely and Alison Copeland

<b>DUNDEE</b>						
Karen Archibald		Medical Secretary			√ 0.5	
Dr Jonathan McCormick		Consultant Paediatric Respiratory Medicine – Clinical Lead	f/t		√	NoSPG Clinical Lead
Dr Donald McGregor		Consultant Paediatrician	f/t			Responsibilities in Dundee and Perth
ST1		Junior Doctor	f/t			4 monthly rotations 2011-2012
Dr Nick		Junior Doctor	f/t			Attends Respiratory



Connolly						clinic weekly and CF clinic monthly
Helen Donald		Respiratory/Research Nurse – Asthma	21.5		√ 0.5	Perth base
Gail Milne		Clinical Nurse Specialist – Cystic Fibrosis	f/t			
Mary Malone		Respiratory Nurse – Asthma	f/t			
Dr Eve Wilson		Psychologist	f/t			0.1 WTE for CF
Rachel Joensen		Dietitian (CF)	21	7	√ 0.6	Maternity leave. Cover provided by Emma Crowley Band 6.
Lyndsey Schaller		Clinical Physiologist	f/t	6	√ 0.5	
Hannah Forbes		Physiotherapist	0.6 WTE			Sick Leave
Anya Farnan		CF Data Clerk				
Catriona Don		Community Children's Nurse				
Shona Lee		Community Children's Nurse				

<i>NAME</i>	<i>STATUS</i>	<i>POST</i>	<i>HRS</i>	<i>Band</i>	<i>NDP</i>	
<b>INVERNESS</b>						
Debbie MacKay		Medical Secretary				
Dr Alan Webb		Consultant Paediatrician				
Jodie Hughes		Respiratory Nurse Specialist	22.5	6	√ 0.5	
Lesley Blaikie		CF Nurse Specialist				
Catherine MacKay		CF Nurse Specialist				
Sheila Gibson		CF Physiotherapist				
Suzanne Offer		Senior Paediatric Physiotherapist				Maternity leave starting in 2012
Gail MacKay		Paediatric Dietician	0.5 WTE	6	√	

#### **Vacant Posts**

<i>Location</i>	<i>Post</i>	<i>WTE</i>	<i>Band</i>	<i>Vacant from</i>	<i>Expected recruitment date</i>	<i>Slippage £</i>
RACH	Pulmonary Function Technician	0.3	6			

## Appendix 3 - Work Plan

Objectives	Outcome	Tasks	Time-scales	Lead Professionals
Formalise a Paediatric Respiratory Network Steering Group	Identify membership across all North of Scotland Health Boards and ensure regional priorities for the network	<ul style="list-style-type: none"> <li>Develop role and remit of group</li> <li>Agree schedule of meetings (3-4 per year)</li> <li>Agree upon annual work plan</li> <li>Develop a performance monitoring framework to monitor the implementation of the work plan</li> <li>Collate twice yearly Exception Reporting for Scottish Government Health Department</li> </ul>	2011-2012	J McCormick R Brooker C Duncan/
Produce a network Annual Report	Description of network improvements and progress using data collected e.g. in-patient and out-patient data, education and training, care pathways/protocols	<ul style="list-style-type: none"> <li>Agree data to be collected – network staff to record on an ongoing basis</li> <li>Collect patient stories from network staff (minimum 4)</li> <li>Draft annual report by February/March 2012</li> </ul>	2011-2012	J McCormick M Osman A Webb C Duncan
Implement planned outreach out-patient clinics across the North	Ensure patients have access to a local, safe sustainable, high quality service	<ul style="list-style-type: none"> <li>Increase tertiary Inverness clinics from 4 to 6 per year</li> <li>Discuss development of Islands' specialist respiratory clinics</li> <li>Introduce RACH Asthma education clinics</li> <li>Develop monthly VC Cystic Fibrosis annual reviews</li> </ul>	2011-2012	J McCormick R Brooker M Osman A Webb R Leece
Map, develop and agree care pathways/protocols/guidelines	Develop care pathways, protocols and guidelines to ensure consistency across the network, enhancing links to national/other regional networks	<ul style="list-style-type: none"> <li>Set up a Care Pathways/Protocols sub-group</li> <li>Identify existing care pathways and any gaps</li> <li>Link with national/regional groups to inform existing or new network protocols, guidelines, etc</li> </ul>	2011-2013	J McCormick R Brooker M Osman A Webb
Develop information for patients and families	Enhance patient/families' knowledge of service and of disease information	<ul style="list-style-type: none"> <li>Develop patient information and involvement leaflets</li> <li>Investigate Web possibilities to develop network website</li> </ul>	2011-2014	J Hughes R Leece G Milne

Continue to develop education framework	Scope current training provided, training needs of network staff and develop a planned curriculum of Continuing Professional Development	<ul style="list-style-type: none"> <li>• Build on fortnightly network teaching sessions by VC</li> <li>• Identify service and staff needs</li> <li>• Map educational opportunities – local/regional/national</li> </ul>	2011-2012	J McCormick C Duncan S Turner
Set up VC consultations with patients in remote locations	Increase tertiary support to improve local access and to reduce staff/patient/family travel time and reduce costs	<ul style="list-style-type: none"> <li>• Review functioning of existing infrastructure and of gaps in current service</li> </ul>	2011-2012	
Implement cross-boundary data collection IT system	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"> <li>• Gain agreement at NoSPG to develop and to provide ongoing funding</li> <li>• Further discussions with NSD in order to tailor the system to meet service need</li> </ul>	2011-15	
Audit clinical care	Measure performance indicators in children's care and review parents' and carers' experiences of service provided			