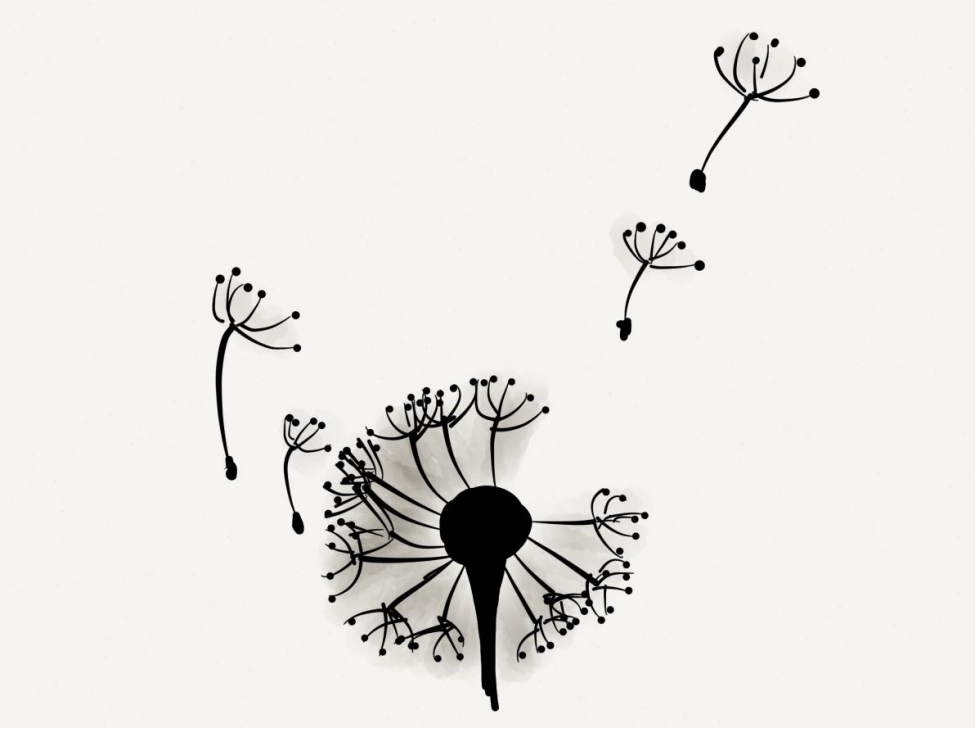
# North of Scotland

# Paediatric Respiratory Network (NOSPRN)

# ANNUAL REPORT 2020/21



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**CONTENTS:**

**EXECUTIVE SUMMARY**

I would like to pay tribute to every member of the network for their resilience and unstinting efforts in maintaining clinical services for children with CF and complex respiratory conditions during the ongoing Covid-19 pandemic. This year's annual report details the many ways in which members of NOSPRN have adapted to the changes at work.

Colleagues have been courageous, creative, and flexible in devising new ways of delivering patient services through the most difficult of times. Lockdown gifted many of our patients a period of unparalleled clinical stability without the risks of recurrent respiratory tract infections acquired from classmates at school and nursery. Staffing levels have been relatively consistent throughout the last two years, which has helped the continuity of patient services. With dire warnings about a rebound surge in RSV and other respiratory viruses in the autumn and winter of 2021/2022, there is little sense that these challenges are dissipating or that services will return to the way they were anytime soon.

We can reflect on numerous successes. The earlier than expected arrival of Kaftrio in 2020, a new CFTR modulator for eligible CF children over 12 years old, delivered incredible benefits to a select number of patients in each centre. We remain optimistic that younger children will soon benefit from this new medicine. Each team has adapted technology to their own needs, whether it's through running clinics and educational sessions online, the introduction of home spirometry monitoring, or by reviewing videos of children demonstrating their inhaler technique submitted by their parents. Researchers have continued to recruit children to clinical trials to help us answer important questions to benefit patient care in the future.

Our key goals for the year ahead include the rollout of Kaftrio to eligible children over 6 years old once approval has been granted, the beginning of a new NOSPRN respiratory clinic in Tayside, further joint working of professionals on network guidelines, further refinements to the delivery of outpatient services, continued work with managers in Dundee to try to create a replacement consultant job, and further work with RACH management to improve the efficiency of the service to cope with the increased demand for sleep and ventilation services. Optimistically, we hope that conditions improve to allow an in person NOSPRN study day in 2022.

**PURPOSE OF THE NETWORK**

The NOSPRN is a regional managed clinical network (MCN) covering a quarter of the Scottish population based over half the land mass of Scotland and includes 50% of Scotland's children's hospitals. Our goal is to sustain services for children with respiratory conditions as locally as possible, support remote and rural services, and work collaboratively across the region.

The network was formed following a series of documents published by the Scottish Government during 2008-9, where CF was recognised as a national priority for investment and Complex Respiratory was highlighted as a suitable area for a MCN.

The network endeavours to promote greater communication, professional peer support, training opportunities, cross boundary working, and the sharing of best practice. NOSPRN aims to improve access to specialist respiratory advice and management through frontline specialist respiratory nurses and AHPs, in addition to more traditional consultant-led clinics.

We advocate for improved availability and access of diagnostic services including physiological measurement, ciliary diagnostics, flexible bronchoscopy, and sleep monitoring.

**NETWORK GOVERNANCE**

The advantages of NOSPRN include enhanced training opportunities for staff, more efficient use of resources, an increased capacity for service delivery and the management of complex patients resulting in improved services for children with respiratory conditions.

One of the recognised factors in our success has been a strategic design in network functioning of non-hierarchical partnerships between staff in similar roles which have helped shape the network's distinct identity, rather than a centralist model of specialists providing an outreach service. The integration of teams through shared working in clinics, or through collaborative educational and peer review initiatives such as the CF annual review meetings or network respiratory teaching has helped to negate barriers and promote professional support amongst all grades of staff who might previously have worked in isolation.

The network runs monthly peer review sessions for CF annual reviews and complex respiratory cases on Microsoft Teams. Each of the three main centres contributes to the sessions by preparing and presenting a case and offering constructive ideas in response to others' presentations. The CF teams in each centre contribute data to the national CF registry, registering new patients, and completing data entries around each patient's annual review.

Over recent years, the Aberdeen respiratory team have been developing a vision for their services in the future and reviewing their staff and equipment resources with their management. They recently engaged in a detailed service mapping exercise to identify bottlenecks in the service and clinical governance risks (see appendix).

**NETWORK ACTIVITIES**

Clinic formats evolved out of necessity during the pandemic. General respiratory clinics were initially conducted by phone during the first lockdown, and then gradually, webcams and headsets were distributed to enable Near Me clinics to take place. As time moved on, and lockdowns came and went, face-to-face activity began to return in select patients.

For respiratory teams, this led to a compromise from pre-pandemic outpatient services, but despite necessary adaptations, our patients have still had access to their teams when they need them.

There are advantages and disadvantages to Near Me clinics; appointments times tend to be shorter and less in-depth, but parents could join appointments while working from home, and travel to the hospital was not required thus saving time, fuel, and parking costs. The fear of being exposed to Covid-19 while visiting a hospital during the pandemic was eliminated: a real concern felt by many parents of children with respiratory conditions. Many of the children were initially added to shielding lists, and much of the discussions in Near Me clinics were spent answering questions about their child's risks of Covid-19 infection, mask wearing, parental concerns regarding the return to school, the introduction of school bubbles, travel restrictions, subsequent removal from shielding lists, and the prospect of Covid-19 vaccination for parents and their children. There were some rather obvious disadvantages as far as respiratory teams were concerned, which created their own new set of clinical governance risks; clinical examination was impossible, so despite taking a history, auscultation of the chest with the stethoscope could not occur and inspection of the ears, nose, and throat were not possible, physiological measurements of lung function in the paediatric lung lab ceased, and an appreciable number of children were not seen during their Near Me appointment, only the parent, and some children found it hard to participate due to shyness or distractions from siblings and pets. Non-attendance rates at clinic rose, perhaps because appointments were less memorable if time off work and school did not need to be organised, and appointment systems were chaotic at times as organisations introduced emergency procedures leading to patients becoming lost to follow up. Secretarial support was reduced leading clinicians to type their own clinic letters or not produce a clinic letter for the GP at all. Blending Near Me and face-to-face appointments

within one clinic was difficult to manage due to the lack of flexibility if the face-to-face patient required extra time. Networking between teams during a clinic was hampered by the platform, and joint working in clinic with colleagues in ENT and community became more difficult. Quickly, it became apparent that the reliance on Near Me disadvantaged families from lower socioeconomic backgrounds where access to suitable technology was a challenge in terms of the availability of laptops, tablets, smart phones, and high-speed broadband. Even if the family had one device, it may have been needed by another child for online learning during home schooling, and an increasing number of families do not maintain a landline. Slower internet speeds through old routers and broadband provision in rural areas produced blocky and pixelated images and audio delays making communication difficult. This was even harder for families where English was not their first language or a translator was required.

High quality services and delivering a high standard of care should be paramount in the development of new ways of working. For multidisciplinary clinics like CF, running clinics to the same high standards as before was even more challenging. CF clinics are set up differently from most other clinics to reduce the risk of cross infection. Families are allocated to individual rooms and have individual assessments and reviews with their doctor, specialist nurse, physiotherapist, dietitian, psychologist, pharmacist, and physiologist (depending on the available team members in different locations). During the initial lockdown with its inherent travel restrictions, face-to-face CF clinics were halted and home visiting was curtailed, and some members of the MDT were redeployed to help with the pandemic response. Once the initial phase of consultant-only phone clinics had passed, two models emerged to meet the challenge of providing multidisciplinary CF outpatient services.

Firstly, the interview style online clinic: the clinician runs a Near Me appointment from the computer in a large room while a panel of multidisciplinary team (MDT) members listen in and contribute in the background. The advantages are speed and the avoidance of repetition of information as the appointment takes the form of a single clinical encounter. The disadvantages are that it requires a large, well-ventilated room, the MDT (including the consultant speaking) need to wear face masks and sit socially distanced, and contributions from the rest of the MDT are either shouted from the back of the room or require an

awkward change of speaker. The whole team can only see one patient at a time, which creates certain built-in inefficiencies as less participation is required from MDT members if the discussions are not focused in their area. This format doesn't deliver any one-to-one time between the child and their physiotherapist, dietitian, or other MDT members to help maintain and build the long-term therapeutic relationship. It also favours the consultant as the main communicator to the detriment of other disciplines. Children and young people could feel inhibited to raise difficult topics or answer questions about incontinence, puberty, relationships, fertility, needle phobia, and pandemic-associated anxieties when they can only see a room of multiple masked adults behind the speaker who they may not be able to identify on a small screen. The gains in the appointment's brevity need to be offset against the quality of interaction taking place between the child and the full CF MDT.

The second model is a dual channel online clinic: the child and their family join a Near Me appointment and have a series of consecutive one-to-one MDT reviews from their CF clinician, specialist nurse, physiotherapist etc. Meanwhile, a Microsoft Teams channel is open for the professionals to exchange confidential information during the clinic between patients, make strategies and find solutions to issues outside of the consulting room, and coordinate the review while multiple patients are seen simultaneously by the team. In general, the family only see unmasked faces from their CF team as the clinic runs from separate areas, and the one-to-one encounters help to foster long-term therapeutic relationships. This is important in chronic disease management and builds confidence in order to enable young people to broach difficult topics during clinic. It also lowers the risk of the whole CF team needing to self-isolate if one of them tests positive shortly after a clinic. The disadvantages with this format include the process being more time consuming for families than an interview style online clinic (though still shorter than a face-to-face clinic), though it is not necessarily more time consuming for the team due to the running of simultaneous appointments. In maintaining the bonds between each CF team member and the CF family, there will be repetition of pleasantries at the start of every encounter and some duplication of information sharing. Neither method is superior to the other, with both formats offering different positives and negatives aspects.

While it is clear that there was a greater reliance on technology to run outpatient services, technological adaptations also provided various new solutions to respiratory teams. Zoom

was quickly superseded by Microsoft Teams for professional communication, before Near Me was introduced as purpose built software for clinics: the NHS Scotland video conferencing network, which we had used for many years for our network meetings, was effectively rendered obsolete in early 2020.

Parents were willing to send videos of their child taking their inhalers to their specialist nurse so that their technique could be reviewed and suggestions made on improvements. Likewise, parents were able to submit videos for review of their child's cough, snoring, or noisy breathing. Home spirometry was used to record the lung function in CF patients, with online sessions provided by the physiologist to guide them to the correct technique and obtain the best result from each child. Raigmore's pre-pandemic investment in Nuvoair devices appeared superior to the results with Spirobank devices used in Aberdeen, Glasgow, and Dundee, but all of the options relied on accurate home measurements of height and were dependent on the child's technique.

The regular flexible bronchoscopy list in Aberdeen was halted during the pandemic, and procedures continue to be offered on an ad-hoc basis on the plus lists as the theatres struggled to cope with the backlog of routine procedures and the extra measures required to staff and run the operating theatres safely.

Cross-boundary working was limited in the initial phases of the pandemic, but by the summer of 2020, network clinics were rescheduled for Raigmore and have continued ever since. The Skye CF clinic has yet to return in person as NHS Highland team members cannot travel in the same car, room capacity is limited in Portree, though the clinical input required for Skye patients has increased even if patient numbers are slightly lower: these families have to rely more on Near Me or make additional trips to Inverness and should continue to expect the same level of outpatient services on the island that families have had in the past. Reciprocal clinics between Aberdeen and Dundee have taken longer to get re-established, but are returning slowly. The lung function labs are performing more testing on more children than was possible in 2020, with CPET returning in Dundee by summer 2021. Monitoring and diagnostic work on sleep and ventilation returned relatively quickly and has continued throughout most of the pandemic.

**STAFFING**

Staffing has been relatively stable over the past two years, with turnover and major issues summarised below.

*Consultants*

Dr Cat Middleton commenced her consultant job in RACH during the first weeks of lockdown, which was incredibly challenging. Dr James Stewart worked as a locum consultant during Dr Osman's sabbatical to Bristol and was later appointed to a substantive post in general paediatrics in Aberdeen: his job includes sessions with the respiratory team. In Dundee, Dr Macgregor retires in September 2021 and negotiations are ongoing as to whether there are sufficient sessions to advertise a replacement general paediatric post which includes some allergy and respiratory sessions. No changes at Raigmore, although Dr Ghayyda took on the extra duties of being Clinical Lead for the paediatric department in NHS Highland.

*Specialist Nursing*

There have been a number of absences in specialist nurse posts due to maternity leave and sick leave, but teams have worked hard to maintain cover during these absences. Some staff were redeployed to help with the pandemic response while trying to continue their specialist nursing responsibilities.

*AHPs, Pharmacy, Psychology*

The network physiotherapy group have been meeting online to work on an induced sputum protocol. Natalie McKaig joined the Dundee CF team as the new CF dietitian. Anna Cudmore left the physiotherapy position within the Highland CF team in 2021. Departmental issues made it difficult for April Sutherland, CF dietitian in Highland, to attend some CF clinics which had an impact on families who were asked to attend separate, additional appointments outside of clinic.

*Physiology*

No change in lung lab personnel, but Steph Menzies was redeployed to help with the pandemic response in Tayside. There is an increase in testing requests in adult services and a reduction in face-to-face clinics in paediatrics in Tayside. Staff have been helping families with home monitoring using the Spirobank. Demands for sleep and ventilation services have put pressure on the delivery of other physiology services in Aberdeen.

**NETWORK EDUCATIONAL ACTIVITIES**

The annual NOSPRN study day in 2020 was cancelled due to the pandemic. Due to the ongoing situation with Covid restrictions, the network agreed to continue with educational and peer support activities but not plan a whole study day until conditions improved to the point that we could safely meet again in person. Experience with whole day conferences delivered online has shown the shortcomings in this format for attendees compared with in person events.

The network has continued to provide monthly CF annual review meetings and complex respiratory cases meetings for peer support via Microsoft Teams. The annual programme of twice monthly respiratory teaching has continued via Microsoft Teams. This has maintained the viability of these sessions, but attendance has been more variable, especially from students, trainees, specialist nurses, and AHPs as teams are no longer congregating to present cases and face other service pressures.

Network members have been directed towards educational opportunities at the monthly PRISM which acts as the operational and strategic meeting of the network. Many free educational sessions were held at the onset of the pandemic as teams from other parts of the world shared their knowledge. A further welcome development was the launch of the Scottish Lung in Childhood programme, a national monthly session with prominent specialists in respiratory medicine around the world invited to present.

**RESEARCH**

While conducting and recruiting to clinical trials was difficult during the pandemic, progress continued in existing and new research trials.

**CF START**: anti-staphylococcal antibiotic prophylaxis trial in cystic fibrosis.
https://www.cfstart.org.uk/

**PARROT**: Can azithromycin reduce how often children with neurological impairment have to stay in hospital with chest infections.
https://parrot-trial.org.uk/

**BLIPA**: Oral bacterial lysate to prevent persistent wheeze in infants after severe bronchiolitis; a randomised placebo controlled trial.
https://fundingawards.nihr.ac.uk/award/NIHR128778

**SPIROMAC**: Spirometry to manage asthma in children.
https://fundingawards.nihr.ac.uk/award/NIHR129819

**BronchStart**: a study into bronchiolitis cases admitted through paediatric A&E units.
https://wellcomeopenresearch.org/articles/6-120

**RAACENO**: Study was completed and publication of results is pending.
https://www.raaceno.co.uk/Public/Public/index.cshtml

**ALPINE 2**: This Pseudomonas aeruginosa eradication trial in CF concluded with the network meeting its recruitment target.
https://www.ecfs.eu/ctn/alpine

**APPENDIX**

## i) Work Plan 2021/2022

| Objective | Outcome | Tasks | Timescale |
|---|---|---|---|
| Introduction of Kaftrio to eligible CF patients aged 6-11 years | Improved patient outcomes by starting highly effective CFTR modulators earlier in the clinical course | Await announcement of confidential deal between Vertex Pharmaceuticals and Scottish Government and other regulators in the approvals process.<br>Ensure managers and pharmacy are aware of the patient numbers and plan the finances during horizon scanning for next financial year in each centre<br>Plan coordinated programme of initiation and monitoring of new patients on this modulator | Forecasts early in 2021 predicted an announcement on availability for this age group by the end of 2021 |
| New NOSPRN Respiratory Clinic in Tayside | New respiratory clinic on a new day will improve capacity, increase cross boundary working, improve continuity of care, and take pressure off the Tayside allergy service | Identify new clinic slot and obtain permission and availability of personnel (Dr McCormick, Dr Middleton, Mary Malone, Stephanie Menzies)<br>Dr Middleton will require induction and honorary contract, IT access to Intranet, Winscribe, PACS, Trakcare, Clinical Portal, ICE, and staff badge | From 2022 onwards |
| Guideline development by joint Professional Groups | Meetings of different disciplines by Microsoft Teams to work on network guidelines | Network Manager to facilitate group meetings, monitor progress, and assist in delivering objectives | Physio group close to completing induced sputum protocol, other groups to set topics and deliver their documents |

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|---|---|---|---|
| Outpatient service recovery | Improving access to face-to-face appointments and reducing Near Me appointments | Keep up to date with advice and advise teams accordingly | Ongoing depending on pandemic, keeping within guidance from Scottish Government, NHS Scotland, and local health boards |
| Re-establish the monthly flexible bronchoscopy list in RACH | Improve access and capacity in flexible bronchoscopy and reduce waiting times to a definitive diagnosis | Work with RACH theatre on recovery plans, acknowledging the current backlog for elective work | Ongoing depending on pandemic, keeping within guidance from Scottish Government, NHS Scotland, and local health boards |
| Succession planning for retirement of Dr Macgregor in Tayside | Loss of capacity for respiratory and allergy outpatients in Perth & Dundee [in addition to other duties] | Identification of sufficient sessions to fund a replacement post<br>Contribute to job specification and recruitment process | Dr Macgregor retires in September 2021 |
| RACH Service Mapping Exercise | Identification of service bottlenecks and areas requiring improvement, or investment in resources, time, and personnel | Dissemination and discussion around service mapping exercise to help identify future goals and objectives to improve team efficiency | Service Mapping exercise undertaken in July 2021<br>Ongoing regular meetings with respiratory team and managers |
| NOSPRN Study Day | Return of an in person educational away day interrupted by the pandemic<br>Meeting suspended in 2020 with support of the network until an in person event can be delivered safely | Need to ensure safety of a full day indoor event comprising up to 30-40 highly specialised individuals from different teams before setting a date | Monitor guidance from Scottish Government, NHS Scotland, and local health boards |