

2024

Supporting Children's Community Respiratory Physiotherapy Services



Written and compiled by the
APCP Respiratory Committee

Supporting Children's Community Respiratory Physiotherapy Services: A guide to commissioning and evaluation

Contents:

List of abbreviations:

Active cycle of breathing technique (ACBT)
Airways clearance technique (ACT)
Association of Paediatric Chartered Physiotherapist (APCP)
Cerebral palsy (CP)
Child or young person / Children and young people (CYP)
Children's community respiratory physiotherapy service (CCRPS)
Emergency department (ED)
Expiratory flow acceleration (EFA)
Gross motor function classification system (GMFCS)
High frequency chest wall oscillation (HFCWO)
Intermittent positive pressure breathing (IPPB)
Intrapulmonary percussive ventilation (IPV)
Length of stay (LOS)
Manual assisted cough (MAC)
Mechanical Insufflation Exsufflation Device (MI:E)
Multidisciplinary team (MDT)
Non-invasive ventilation (NIV)
Out of hours (OOH)
Outpatients (OP)
Paediatric Early Warning System (PEWS)
Paediatric Intensive Care Unit (PICU)
Positive expiratory pressure (PEP)
Therapy outcome measure (TOM)
Whole time equivalent (WTE)

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Introduction

This guide has been developed by the Association of Paediatric Chartered Physiotherapists (APCP) Respiratory Committee to support members to develop and evaluate community paediatric respiratory physiotherapy posts.

The guide gives some brief information on the causes of respiratory morbidity in children and young people with profound neurodisability. A summary of evidence supporting prevention and treatment and some data from UK community paediatric respiratory services. It then goes on to give suggestions of key metrics to collect to demonstrate the need for services and to audit proposed or existing services. Examples of successful services are provided. Users are free to use the information included in this guide to support local business cases or service improvement projects provided that the source is referenced.

An APCP risk identification matrix which aims to help identify children who have or are at risk of respiratory morbidity is due for publication in 2024 and will be a useful resource to use alongside this guide.

This document has been developed to be used in conjunction with the CSP information paper: [Making the business case: It's your business](#), July 2012. There are also further business case tools available on the CSP website.

Background

Many children and young people (CYP) with profound neurodisability experience significant respiratory morbidity and reduced life expectancy as a result of respiratory dysfunction (Trinick et al., 2012, Meštrovi et al., 2006, O'Loughlin, Somerville and Somerville 2009, McCrea, O'Donnell and Brown 2013, Toder, 2000, Mahon and Kibirige, 2004), but their needs have not historically been a focus from those who plan and commission healthcare services.

In recent years there have been two significant publications to support respiratory care for these (CYP), providing an ideal time for physiotherapists to do their part to drive positive change for this vulnerable cohort. In 2021 a research group in Australia (Gibson et al., 2021) published 'Prevention and management of respiratory disease in young people with cerebral palsy: consensus statement' which identifies risk factors for respiratory morbidity and identifies prevention and treatment strategies to guide proactive care. Crucially, they also produced a plain language version designed to inform and empower parents and caregivers.



In 2023 the British Thoracic Society (BTS) published 'Clinical Statement on the prevention and management of community-acquired pneumonia in people with learning disability' (Legg et al., 2023) which further provides guidance on risk assessment, prevention, and management with this cohort. While the paper does not exclusively focus on children, it states that it applies to people with learning disabilities across all age ranges. Aligning with the Consensus statement, it identifies risk factors and advocates for proactive intervention rather than reactive treatment. Both papers support the role of physiotherapists in preventing and treating respiratory morbidity in this patient group. In order to support proactive assessment and management and prevent acute admissions, respiratory physiotherapy needs to be accessible in the community.

Evidence Summary

The following evidence summary is designed as a succinct synopsis of the literature that may be extracted and used, for example, to support business cases. It is not a detailed literature review. The increasing demand for specialist paediatric respiratory care in the community is being driven by a variety of factors:

- There are increasing numbers of (CYP) surviving with multiple and profound impairments in whom respiratory pathology is a major contributing factor to reduced quality of life, morbidity, and mortality (Blucker et al., 2011; Cohen et al. 2012; Meehan et al. 2017; NCEPOD 2018; Carter et al. 2021).
- Increasing numbers of (CYP) with severe disability and complex needs living in the community are aided by technologies such as gastrostomy feeding, tracheostomy and home ventilation (Cohen et al., 2011). The current economic and political climate has also propelled a drive toward community-based care for long term conditions (NHS, 2020)
- (CYP) with severe disability and complex needs often have problems with abnormalities of swallow, gastro-oesophageal reflux, scoliosis, restrictive lung disease, impaired cough, and chronic bacterial colonisation which puts them at risk of recurrent chest infections (Seddon and Khan, 2003, Kansra and Ugonna, 2016, McCrea, O'Donnell and Brown, 2013).
- Respiratory infections in these (CYP) lead to frequent emergency department attendances and hospital admissions which are often prolonged and may involve paediatric intensive care (Meehan et al, 2017, Mahon and Kibirige, 2004, O'Mahony et al., 2013). They utilise considerable primary care, emergency and acute paediatric health resources (Newacheck, Inkelas and Kim, 2004, Meehan et al., 2015)
- (CYP) with conditions such as Cystic Fibrosis, Primary Ciliary Dyskinesia and neuromuscular disease are typically seen in specialist clinics with respiratory physiotherapy input, with access to proactive monitoring and long-term treatment plans to optimise respiratory health. Children and young people with severe and complex neurodisability are generally not seen in specialist clinics that include respiratory physiotherapy and may only get input from respiratory physiotherapy during acute admissions to hospital.

Proactive respiratory care, improved access to specialist equipment and the availability of trained staff supports treatment of subacute and chronic respiratory conditions in the community, while facilitating timely discharge and preventing hospital readmissions (Kettle and Clements, 2024, Wolff et al., 2015 and Smith et al., 2022).

Prevention and management of respiratory morbidity

The following section provides a summary of recommendations from ‘Prevention and management of respiratory disease in young people with cerebral palsy: consensus statement’ (Gibson et al., 2021) and ‘Clinical Statement on the prevention and management of community-acquired pneumonia in people with learning disability’ (Legg et al., 2023). It is intended as a quick reference guide. Users should read both documents in full before considering any changes to clinical practice.

The 2021 Consensus statement: Prevention and management of respiratory disease in young people with cerebral palsy’ by Gibson et al. (2021) was produced by an international multidisciplinary group with expertise in the management of respiratory illness in children with Cerebral Palsy (CP). Recommendations were developed using a modified Delphi method. The recommendations are applicable to children with CP and CP like conditions, which is defined as ‘conditions where there is a disturbance of movement and posture because of genetic and metabolic causes’. This includes syndromes, brain disorders that do not change, or brain injuries that occur in early childhood’.

Part one of the consensus statement is about recognising and managing risk. Nine risk factors are identified; the first three are considered reg flags, the following six ‘modifiable’, please see below (Table 1) .



Table 1: Risk factors for respiratory hospital admissions for young people (1-26 years) with CP (Gibson et al., 2021)

Gross motor function classification system (GMFCS) level V
At least one hospital admission for respiratory illness in the past year
At least two courses of antibiotics for chest infections in past year
Current seizures (during a seizure a person may vomit, drool or stop breathing. The vomit or excess saliva can be aspirated. Seizure medications can cause sedation which leads to increased drooling and further aspiration).
Frequent respiratory symptoms (daily cough, weekly wheeze, phlegm or gurgly chest)
Gastro-oesophageal reflux disease (now or previously)
Oropharyngeal dysphagia (swallowing difficulties)
Mealtime respiratory symptoms (gurgle voice, wheezing, coughing, sneezing, choking)
Snoring every night

Recommendations for reducing risk are made in the form of a series of consensus-based recommendations for assessment, prevention and treatment. The infographics below detail some of the key recommendations (reproduced from Gibson et al., 2021 with permission).





QUICK REFERENCE Recommendations for the prevention and management of respiratory disease in young people with cerebral palsy: Standards of care



Family centred care is at the forefront of application of the recommendations

PREVENTION

- Respiratory review annually and when there has been
- A respiratory related hospital admission
 - Any change in **Red Flags** and **Potentially Modifiable Risk Factors**
 - Loss of weight



- Good personal hygiene and hand hygiene of carers



- Good dental hygiene and regular dental reviews



- Optimise nutrition



- Vaccinate against influenza



- Reduce exposure to tobacco smoke



- Encourage physical activity

Recognizing respiratory risk in young people with cerebral palsy is everyone's role.



The Multidisciplinary Team

- Doctor
 - Treat asthma
 - Manage upper airway obstruction
 - ? Snoring/apnoea → refer to Ear, Nose, Throat Doctor/or refer for overnight oximetry
 - Review tone and treatment
- Physiotherapist
 - Prescribe chest physiotherapy as required and educate carers in recommended chest physiotherapy regimen

Potentially Modifiable Risk Factors



Dysphagia



Gastro-oesophageal reflux



Frequent respiratory symptoms



Mealtime respiratory symptoms



Current seizures



Snoring every night

Red Flags

- GMFCS level V, or
- Hospital admission/antibiotics for respiratory illness over the last year



- Speech pathologist
 - Assessment swallowing problems
 - Prescribe mealtime management plan
 - Conduct video fluoroscopy swallow study as needed
- Doctor
 - Treat
 - Drooling
 - Gastro-oesophageal reflux disease
 - Seizures

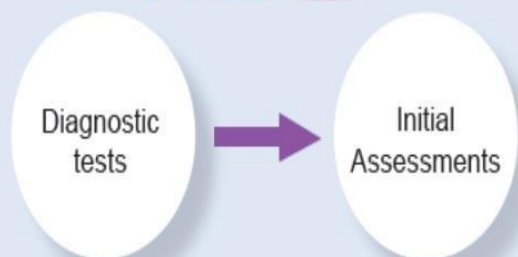


ASSESSMENT

Multidisciplinary assessment is essential (Family, Speech Pathologists, Occupational Therapists, Physiotherapist, Doctor, Nurse Consultant).

Our aim is to understand the individual's unique risk factors for aspiration (when well and unwell)

- In certain instances consider**
- Videofluoroscopy swallow study
 - Overnight oximetry if indicated
 - Sputum culture
 - Chest x-ray
 - Chest CT
 - Sleep study



Individuals at risk of respiratory illness need their respiratory health assessed regularly

Screen for

Red Flags and Potentially Modifiable Risk Factors

History:

Concerns, care, comfort, goals
Episodes of aspiration, wheeze
Details of hospital admissions

Physical Examination:

(when well and unwell)
Breathing pattern (rhythm, depth, pattern of chest wall movement), oxygen saturation level, respiratory rate
heart rate, work of breathing, colour, chest wall shape, palpation, auscultation, visualisation of tonsils and other turbinates

- **Assessment of eating and drinking abilities** (when well and unwell)

- **Nutritional status**

- **Ability to manage secretions** (when well and unwell)

- **Assessment of musculoskeleton deformities**



TREATMENT

Effective treatment of respiratory illness must be a partnership between individuals with CP, their parents, carers, team.

Speech Pathologist

- Conduct a swallow assessment
- A video fluoroscopy swallow study as is needed
- Prescribe a mealtime management plan for well and unwell days
- Educate individual/parent/carer in strategies to optimize meal time management
- Discuss with individual, family and team including dietitian and doctor if alternatives to oral intake are indicated

Physiotherapist

- Assess
 - Strength and effectiveness of cough
 - Is cough productive i.e. wet, or are there signs of mucous retention?
- Prescribe
 - Airway clearance therapy
 - Suction if cough too weak to bring up mucous and secretions
 - Long term plan for chronic wet cough
- Educate individual/parent/carer
 - Manual techniques to get the best cough and clear secretions
 - Positional changes to maximise lung and chest movement
 - Plan for when well and when unwell
- Monitor and review
 - Any positive or negative responses to airway clearance therapy



- Continue to screen for Red Flags and Potentially Modifiable Risk Factors

Potentially Modifiable Risk Factors

- Dysphagia
- Gastro-oesophageal reflux
- Frequent respiratory symptoms
- Mealtime respiratory symptoms
- Current seizures
- Snoring every night

Doctor

- Investigate and treat infections early with antibiotics
- Manage drooling
 - If using medication for drooling, ensure secretions do not become too thick (from treatment or during a chest infection)
- Treat asthma
 - Consider a trial medication
- Allocate a clinical lead
 - Refer to other teams as needed: Nurse Consultant, Surgeon, Anaesthetist, Neurologist, Gastroenterologist, Palliative Care Physician, Ethicist, Allied Health Professionals

Reference: Gibson N, Blackmore AM, Chang AB, Cooper MS, Jaffe A, Kong W, Langdon K, Moshovis L, Pavleski K, Wilson AC. (2020) Prevention and management of respiratory disease in youngpeople with cerebral palsy: consensus statement. Dev Med Child Neuro. <https://onlinelibrary.wiley.com/doi/epdf/10.1111/dmcn.14640>

This infographic is based on a systematic review, Delphi informed clinician expert consensus and consumer review process conducted by the researchers between Feb 2018 to Feb 2020. Disclaimer: The advice and information contained herein is provided in good faith as a public service. However the accuracy of any statements made is not guaranteed and it is the responsibility of readers to make their own enquiries as to the accuracy, currency and appropriateness of any information or advice provided. Liability of any act or omission occurring in reliance on this document or for any loss, damage or injury occurring as a consequence of such act or omission Ref:M20000062 Freepik images



The BTS Clinical Statement (2023) on the prevention and management of community acquired pneumonia in people with learning disability was developed by a multidisciplinary group of experts in the field of respiratory medicine, and identifies modifiable and non-modifiable risk factors, in this case specifically for community acquired pneumonia (CAP) (Legg et al., 2023). Table 2 summarises these. Potentially modifiable risk factors are highlighted in purple.

Table 2 Risk Factors for CAP in people with learning disability (Legg et. al., 2023)

Sleep disordered breathing	Smoking / environmental tobacco exposure
Reduced mobility / impaired motor function	Sialorrhoea
Poorly controlled epilepsy	Bacterial colonisation
Oral health	Nutritional status
Gastro-oesophageal reflux disease (GORD)	Immunodeficiency
Previous history of respiratory	Eating, drinking and swallowing difficulties infections
Tracheostomy	Comorbid conditions



Table 3 Respiratory physiotherapy options for patients with learning disability and retained secretions (Legg et al., 2023)

Inability to cooperate and/ or severe bulbar impairment, with proximal secretions	Retained proximal secretions due to weak cough without severe bulbar involvement	Retained peripheral secretions and fatigue	Retained peripheral secretions	Retained peripheral secretions and unable to participate in treatment
Suction Inspiratory assistance: single breath insufflation with resuscitation bag or IPPB device	Inspiratory assistance: breath stacking, single breath insufflation with resuscitation bag or IPPB device	If severely fatigued consider supporting deep breaths with either NIV or IPPB	Postural drainage with ACBT	Suction should be available in the event of moving significant amounts of secretions and not stimulating a cough
	MAC MIE MIE + MAC	With or without manual techniques Metaneb*	Exercise PEP Oscillatory PEP device HFCWO	HFCWO Positioning Manual techniques
		NIV and HFCWO IPV*	IPV* EFA	MIE with care as may produce an overwhelming amount of secretions that the patient can not clear

Key

IPPB - intermittent positive pressure breathing MAC - Manually assisted cough

MIE - Mechanical Insufflation Exsufflation Device NIV - Non-invasive ventilation

HFCWO - high frequency chest wall oscillation, IPV - Intrapulmonary percussive ventilation ACBT - Active cycle of breathing technique PEP - positive expiratory pressure

ACT - airways clearance technique EFA - Expiratory flow acceleration

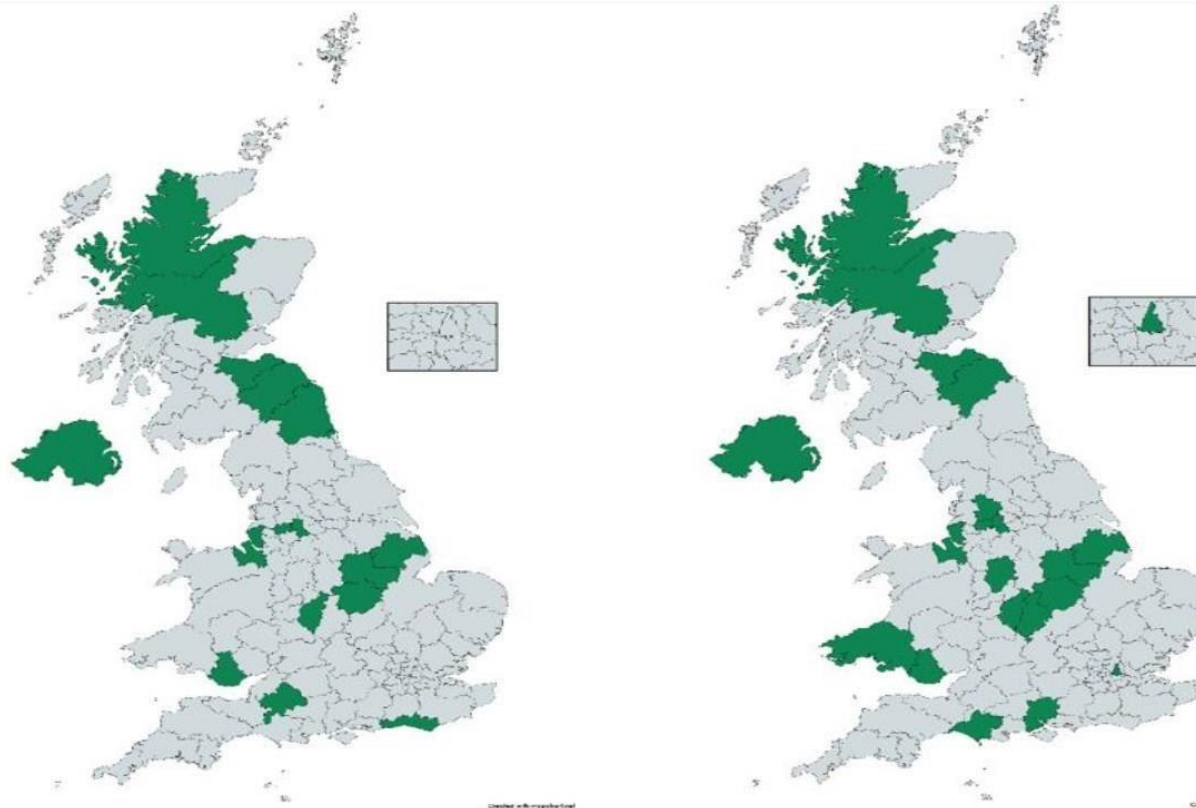
*acute settings only

Techniques highlighted in blue are proximal ACTs, red peripheral ACTs

Children's Community Respiratory Physiotherapy Services (CCRPS) in the UK

There is no comprehensive database of Children's Community Respiratory Physiotherapy Services in the UK and existing services have significant variation in their service design and provision.

The maps below indicate areas of the UK served by a children's community respiratory physiotherapy service in 2020 and 2022 (results based upon web-based survey). Please note the areas highlighted are postcode areas rather than healthcare trusts and therefore a highlighted area does not necessarily indicate the whole region has a CCRPS.



CCRPS Services 2020 (data from Jones, Winfield and Douglas, 2021)

CCRPS Services 2022 (data from APCP Resp scoping survey)



Evidence for effectiveness of children's community respiratory physiotherapy services (CCRPS)

There are currently several examples of children's community respiratory physiotherapy services across the UK that have been successful in reducing hospital admissions, length of stay, and emergency department (ED) presentations (Smith et al. 2015; Wolff et al. 2015) . Not only does this result in significant healthcare cost savings, but it can reduce the illness burden and improve quality of life in children with disabilities (Elema et al. 2016).

The APCP respiratory committee completed a scoping exercise of current CCRPS across the UK in 2022. There were 25 responses, of which 3 were discounted due to being incomplete, duplicate, and an adult only service.

Of the remaining 22 responses, 7 were mixed community caseloads but had a respiratory community element, 13 were specialist respiratory community services, 1 was a hospice providing respiratory physiotherapy care and 1 was a specialist respiratory service that covered inpatients, outpatient and community. It is worth noting that 3 of these responses were pilot services, demonstrating that while there are not many of these services, there is a growing demand and interest in establishing such services.

Whole Time Equivalent (WTE) to caseload size data was received from 16 services.

There were significant differences between services, with a median of 45.5 patients per WTE.

Within the survey, services were asked if they had referral criteria or audit data that they were happy to share. Four CCRPS; Alderhey, Lincolnshire, Nottingham and Lothian, shared their audit data or publications, which is discussed below. These services vary in caseload size, geography, socioeconomics, referral criteria and wider multidisciplinary involvement, however, these services have two key components in common:

1. **A preventative pro-active model** of regular patient review, targeting those at high risk of acute respiratory illness through regular physiotherapy assessment, preventative airway clearance plans and training for families, carers, schools and care centres in airway clearance plans.
2. **A Rapid Response Service** that supports community review within a 24-48hr time frame when CYP are unwell, facilitating review and modification of airway clearance advice, collection and sending of sputum samples to support accurate prescription (if indicated) and liaison with relevant teams.

Both of these components aim to proactively treat respiratory illness to prevent deterioration or reduce severity, reduce unnecessary ambulance call outs, ED or paediatric assessment unit presentations, hospital admission and Length of Stay (LOS), resulting in cost savings and reduced illness burden for children with neurodisabilities and their families.



The data from Lothian and Alderhey is unpublished audit data that these services gave permission to share. Lincoln (Kettle and Clements, 2024) and Nottingham (Wolff et al 2015 and Smith et al., 2022) have published peer reviewed data. A brief description of each service is included in Appendix 1.

The following section summarises the outcomes from the four services.

Service Outcomes

A lack of standardised outcomes and reporting methods presented challenges in pooling data for synthesis. Services reported a variety of outcomes, and also reported similar outcomes in different ways, for example, reduction of LOS presented in days or percentage reductions.

To ease interpretation, data has been converted to percentages, allowing more standardised reporting of results.

Table 4 summarises the characteristics of each service; please note Alderhey and Nottingham each completed audits at two time points. Service descriptors are included in Appendix 1 and details of service reviews in Appendix 2.

Table 5 summarises the common outcome data from the four services.

Each service used different methods of collation as displayed in Table 4 and further described in Appendix 2.

The Nottingham service collated different information between their first and second publication, which is why the evidence is a mixture of the two reviews (Wolff et al., 2015 and Smith et al., 2022).

Common Themes Reported by Services

Some of the other information reported in these audits were: Critical care vs ward level bed days, bacterial vs viral infections, school attendance, ambulance call outs and Therapy Outcome Measure (TOM). This data is not presented here but can be found in the appendices or published data.

It was not possible to standardise the qualitative data that each service reported, but all had high satisfaction, with key themes reported by families and carers:

- Improved ability to keep CYP at home
- Feeling supported and empowered to manage their CYP in the community with awareness of when to contact the appropriate services
- School staff feeling more confident and noting increased attendance

Of note, negative feedback was minimal and all negative comments related to services not being available over the weekend or 24/7, and that they stopped between age 16-25 depending on area. There are other outcome measures beyond morbidity and healthcare use, which could be considered, related to body structures and functions, activity and participation, and health related quality of life (Knight Lozano et al 2024).

Table 4	Duration date of collection	WTA	Caseload Size	Effectiveness comparator e.g. pre vs post service, admission avoidance indicator
Alderhey 1	2 years (2010-2012)	0.6 WTE Band 7	38	Pre vs post service comparison
Alderhey 2	3 years (2015-2017)	1 WTE Band 8A and 0.75 WTE Band 7	107	Pre vs post service comparison
Lincoln (Kettle and Clements, 2024)	2 years (2018-2020)	2 WTE Band 7	127	Pre vs post service, and RAG rating of rapid response visits grading likely outcome without service: Green - routine OP appt, Amber - Urgent GP/ED/OOH, Red-hospital admission
Nottingham 1 (Wolff et al., 2015)	2.3 years (2010-2013)	1 WTE Band 7	34 (increased from 20 during the audit period)	28 months of data collection, but the audit was based on each CYP first 12 months in the service, Pre vs post service comparison
Nottingham 2 (Smith et al., 2022)	1 year (2019-2020)	3 WTE (1 x Band 8A, 2x Band 7)	120	Service well established so pre vs post service not used. Hospital admission prevention identified if 3 out of 5 PEWS indicators present. Bed days assumed an average LOS of 9 days
Lothian	3 years (2009-2012)	1 WTE Band 6	34 (only 14 included in the audit)	Pre vs post service comparison

Key:

RAG - Red/amber/green, LOS - length of stay, WTE - whole time equivalent, PEWS - paediatric early warning score, ED - emergency department, OP - outpatient, OOH - out of hours, vs – versus



Table 5 - Summary of common outcome data

Service	ED presentations	No of admissions	LOS	Cost Savings
Alderhey	↓74%	↓80%	↓52%	£673738 p.a. avg
Lincoln	↓76%	↓80%	↓61.8%*	£214582 p.a avg
Nottingham	↓31% (Wolff et al., 2015)	↓33% (Wolff et al., 2015)	↓38% ** (Wolf et al., 2015)	£751 728 to £1009986 p.a. (Smith et al., 2022)
Lothian	↓40%	↓62.5%	↓80%	£116289 p.a.

Key:

* Bed days rather than LOS

**Bed days rather than LOS as they combined admission and LOS data together and did not present separate LOS



Supporting Services

Service Design Variation

It is important to note that an effective respiratory physiotherapy service for children with complex needs is not one size fits all. Every NHS Trust and local community will have different service requirements and limitations.

Service designs may include...



Specialist physio training parents/care team in chest care



Community neurodisability physio with respiratory expertise providing chest care advice and support

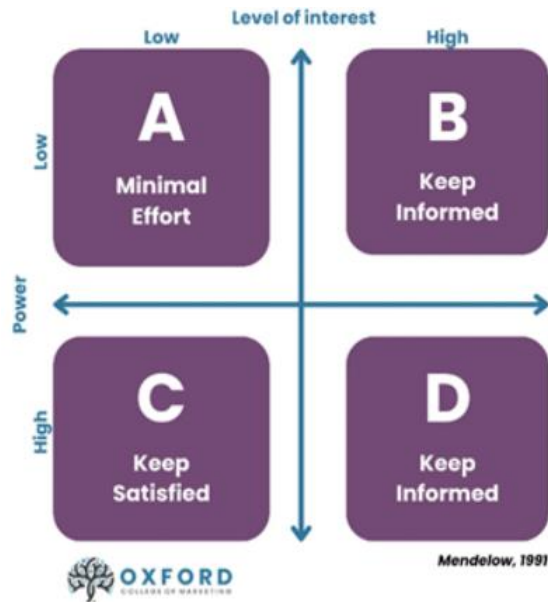


Specialist respiratory physiotherapy outpatient clinic, providing assessment and advice



Whilst there is no published evidence to support the efficacy of the services that do not provide a rapid response service, we encourage those with services described, to collect data using the tools in the appendix and to share these outcomes to support future service development.





Top Tips for Starting Service

Know your Stakeholders

Creating a Mendelow's Matrix (Mendelow, 1991) will help you in the first instance to identify the stakeholders you will need support from to get your business case off the ground and how you are best to manage them. It is expected that stakeholders will move around the matrix as your business case progresses.

Conduct a Pilot

Identify up to 5 patients who are regularly admitted to hospital due to respiratory concerns and deliver a service for them within your current work capacity for 6 months, in order to gather initial quantitative and qualitative data about the service's impact. This gives you some evidence and reasoning to support your business case.

Please discuss any data collection plans with your local research governance, such as your Research and Development Department, in advance of collecting data (HRA, 2017).

Know your Referral Criteria

Establishing your referral criteria will enable you to identify how many children are currently eligible for the service in your area – which in turn will help you identify how many therapists you require to manage the workload. Speaking to your community physiotherapy teams may help you to establish the number of eligible children as they are likely to be known to their teams.



Give Options

When presenting your business case to leaders in your Trust or those who fund your services, it can be beneficial to present them with different options (Bronze, Silver, Gold for example). These different options could reflect growing caseload numbers (and therefore therapist numbers) or referral criteria. If you're struggling, the option of a proof-of-concept/pilot year can give you the chance to try out the service, gather data and prove its worth. Rapid Response Respiratory Services can also fit well within the 'Virtual Ward' projects which are becoming more prevalent in NHS Trusts and can be a good source of funding.



Gather Initial Data

Establishing the number of respiratory-related hospital admissions that have occurred within your caseload over the past 12 months and the associated costs is a good place to start. Don't forget to look at existing services in geographically similar locations to demonstrate how a service could impact on these admissions / costs.



Top Tips for Existing Services

Evidencing Your Work

Whether you have been granted a proof-of-concept/pilot year or are a fully funded service, continuing to evidence the amazing work that your service does remains important.

It's time to gather quantitative and qualitative information to showcase the impact that your service is having on your patients and their families. Examples of key performance indicators may include but are not limited to:

- **Hospital admissions / LOS / ED attendances / GP appointments avoided**
- **Courses of antibiotics prescribed**
- **School / nursery attendance**
- **Parent / Carer reported confidence to self-care Quality of life questionnaires**
- **Patient case studies**
- **Service evaluation feedback forms from stakeholders**



Please discuss any data collection plans with your local research governance, such as your Research and Development Department, in advance of collecting data (HRA, 2017).



Well Established Services

The longer the service is established the harder it will be to show such dramatic savings with a pre vs post service analysis. This is due to patients already having optimal preventative plans and families/carers being trained and empowered in effective management. Additionally, new patients will be referred appropriately earlier to your service, as awareness of the service increases and the benefits of the prevention/early intervention are more widely known.

If you are unable to evidence the effects with pre vs post service analysis then you can look at the Nottingham or Lincolnshire methods of data collation where the therapist or family/carers assess what the outcome would have been if the rapid response service was not available.

Build A Reputation

Now is the time to create a 'buzz' about what you're doing. Create yourselves a communications strategy, present your feedback and data to leaders in your trust and nominate your service and therapists for awards – you're doing an amazing job, make sure everybody knows!

Share Your Work

Finally, once you're up and running, share what you're doing. Write up your service in a service evaluation, do some research and don't forget to get in touch!



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APPENDICES

Appendix 1- Summary of four services evaluated- Lothian, Alderhey, Lincolnshire and Nottingham

Lothian- Paediatric Community Respiratory Team (PCRT). The service was setup in 2009. The audit data is from an initial service review covering 3 years: 2010-2012. There were 34 patients in the service but the audit focused on 14 patients, with 1 WTE Band 6. It was a direct comparison of outcomes pre service vs post service.

The team has since expanded to include Band 7 0.3WTE, Band 6 1.4WTE covering a caseload of 132 patients.

Alderhey- Liverpool Children's Respiratory Team-

The Liverpool team completed two audits. The initial audit was pre service to post service comparison over 2 years May 2010- June 2012 with 38 children by 0.6WTE Band 7 Physiotherapist.

The second audit was over 3 years, 2015-2017, with 1 WTE Band 8A and 0.75 WTE Band 7 for 107 CYP, and compared data of these 3 years against pre-pilot data.

Lincolnshire- Rapid Response Children's Respiratory Service

The service was setup in Feb 2019 and they kindly shared their data from their 3-year study (Feb 2019 to Feb 2022) of 0-19 yrs old (they have extended service to 25yrs old but not covered in this audit), and the caseload increased from 127 to 140 in this time.

They looked at 2 ways of outcome and cost analysis:

1. Direct comparison of pre vs post service of ED presentations/ambulance call outs/ward admissions and critical care admissions.
2. They assessed the rapid response aspect of their service by RAG rating the rapid response calls- the therapist assessed if they hadn't attended what would have been the outcome- 1- routine GP/Consultant appt 2- Urgent GP/ED/OOH appt or 3-hospital admission. They worked out the number of bed days saved as number of admissions vs average length of stay of 7 days. This average of 7 days was selected based on pre service data and is recognised to be a likely underestimation with the national average for this cohort as 9 days.



Nottingham- Children's Community Respiratory Physiotherapy Service (CCRPS)

Nottingham set up their service in 2010 and have since published two papers so further details are available in the publication. Below is a summary:

The 2015 publication had a caseload of 20 CYP that increased to 34 CYP 0-19yr olds. The actual number referred was 68 but they hadn't been in the service for 1 year and/or had their condition for 1 year before referral to service so couldn't be part of the comparison. They completed a comparison of the 12 months pre service to 12 months post service (over a 28-month period of individual patient case comparison). They used ED presentations, number of admissions and LOS as outcomes.

Each child acted as their own control and Wilcoxon signed ranked matched pairs statistical test used to compare performance indicators before and after introduction of the service for each individual child (Wolff et al 2015).

The second paper was published in 2022 (Smith et al 2022). This focused on satisfaction and effectiveness/cost analysis. The caseload had increased to 120 CYP up to 25yrs old, covered by 3 WTE physiotherapists (1x Band 8A and 2 x Band 7). It wasn't a comparison study. Instead, the number of admissions prevented was worked out by indicators from the physiotherapists assessment (3 out of 5 indicators were present at the physiotherapy assessment at the time of the emergency call out visit: fever, respiratory distress, chest auscultation changes, tachycardia or bradycardia and reduced arterial, oxygen saturation).

LOS was assumed at 9 days. This was based on the UK NHS Improvement 2020 National tariff, which uses an expected average length of stay of 9 days for a child with long-term conditions and comorbidity admitted with an LRTI, and this also was what the average LOS was for the cohort previous to this physiotherapy service provision.



Appendix 2- Outcome Measure background

ED attendances

Reduced ED presentations have been evidenced by all four services.

Alderhey demonstrated a reduction of 3.2 ED presentations (from 4.3 to 1.1) on average per patient before the service vs one year after service was established. This equates to a **74%** reduction in ED attendances.

This benefit was sustained when reviewed again in 2015-2017.

In Lincoln they RAG rate all 'rapid response' calls when a patient calls with an acute issue such as chest infection. (See service description for details). They assessed that 128 ED presentations and 68 ambulance call outs were avoided in 1 year.

There was no raw data available to compare this to pre-service levels, but they calculated that the cost reduction of OOH & ED presentation was **58%** after 3 years of service (£8720 to £3640).

Nottingham piloted their service with 20 children, and reduced ED attendance from 48 pre service to 33 after 1 year of service (31% reduction) (Wolff et al., 2015).

In Lothian there was a **40%** decrease in ED attendances demonstrated over 3 years when comparing pre-service ED attendances to service having been established for 3 years.

All have shown a 31% to 76% reduction in ED presentations.

Number of admissions

Four services evidenced reduction in admission rate for this cohort of patients.

Alderhey noted a reduction from 3 to 0.6 admission per patient on average during their 2-year pilot, showing an **80%** reduction, and this has been sustained in repeat evaluation.

Lincoln prevented 68 admission based on their RAG rating, where the therapist assessed if the outcome would have been GP review, ED presentation or admission. This equated to a **73%** reduction in hospital admissions

The first evaluation completed by Nottingham reduced admissions from 36 pre-service to 24 one year after service, a **33%** reduction (Wolff et al., 2015). The follow up evaluation in 2019/2020 (Smith et al., 2022), did not compare to pre service and instead used indicators from the Paediatric Early Warning Score (PEWS) of fever, respiratory distress, chest auscultation changes, tachycardia or bradycardia and reduced arterial oxygen saturation. If three were present on physiotherapy assessment and admission was avoided then this counted as a prevented admission. The authors identified 182 admissions were prevented. We cannot identify a percentage reduction as this was not a comparison study.

Lothian had a **62.5%** decrease in the number of admissions comparing pre-service to 3 years of service being established.

Length of Stay (LOS)

Alderhey had positive results from their initial two-year pilot study. It showed an improvement of **52%** LOS (pre-pilot LOS average 15.1 days vs 2-year pilot LOS 7.3 days). A 3 year follow up audit was completed with increased patient numbers and further reductions were noted in LOS resulting in a **73%** reduction in LOS when comparing pre pilot data to the follow up audit data. (pre-pilot average 15.1 days vs 4.06 days average over the 3 year follow up).

Lincoln did not collect data directly pertaining to LOS but instead collected data regarding the total number of bed days for respiratory tract infection. Pre-service this was 500 bed days, compared with 191 in the year post-service provision. This equates to a **61.8%** reduction in bed days.

Nottingham's initial evaluation (Wolff et al., 2015) was reported differently from the other services and instead looked at the total number of bed days for respiratory tract infection. Pre-service this was 383 bed days, compared to 236 in the year post service. This equates to a 38% reduction in bed days. The follow up evaluation in 2019/2020 and published in 2022 did not examine LOS and instead assumed LOS at 9 days as this is what the 2015 study averaged at, and the UK NHS Improvement 2020 National Tariff used as the average expected LOS for respiratory tract infections in CYP. While this doesn't evidence any improvement in LOS, it may be helpful for established services to be aware of in ongoing auditing of their services (Smith et al., 2022).

Lothian - A 3-year pilot showed a reduction of total hospital bed days from 220 pre service to 43 in the pilot year, resulting in an **80%** reduction in bed days. The separate number of hospital admissions and LOS was not available.



Cost Savings

Alderhey compared the cost based on pre pilot data (No of hospital admission 4.3 episodes and LOS average 15.1 days) compared to current admission data (reduced hospital admission to 1.1 episodes and LOS 7.3 days). The initial pilot was based on 38 children so the cost saving was £129,485 per year (average of the 2-year pilot). A 3 year follow up audit was completed with increased patient numbers and further reductions in LOS (average of 4.06-day LOS over the 3-year evaluation). This equated to a saving >£650,000 per year with an additional saving of >£16,000 per year in ED presentations. When averaged out over the follow up 3-year audit period this was £673,738.33 per year saving, with the service cost at only £78,298, making a **760%** return on investment of the service.

Lincoln costed the bed days in hospital for ward level care, HDU/ITU level care, ambulance call outs and ED attendances. This equated to £213241.56 1st year saving, £335517.21 2nd year savings and £220241.04 3rd year = Average £256333.27 savings per year.

The first Nottingham evaluation (Wolff et al., 2015) showed the improvement in ED presentations and non-elective hospital admissions led to cost saving of £78,155, that once the service costs were subtracted equated to a total cost saving of £19,624.

A follow up evaluation was completed in 2019/2020 and published in 2022. The service had grown to 120 CYP. The costs of running the service was £250000 including staff, travel and equipment. With 1638 bed days saved over one year the cost saving was estimated as ranging between £751 728 and £1009986 for one year from April 2019 to March 2020. This is noted to be a potential significant underestimation as this was priced on ward level bed savings instead of critical care beds, and on the average LOS of 9 days. But it is recognised that many complex neurodisability patients have an increased risk of LOS >15 days which again would increase the cost saving if admission was prevented (Smith et al., 2022).

Lothian calculated cost savings based on the reduction of bed days in hospital pre service vs 3rd year of service and showed a saving of £116,289. This didn't include ED attendances savings and was based on ward level care, so is likely to be an underestimation.

Patient/Carer Satisfaction

Alderhey- 5-point scale poor to excellent for 10 questions focusing on quality of empathetic, educational and empowering role with >95% rating very good or excellent during the pilot of service in 2014 and follow up in 2016. There was further informal feedback from parents and carers stating they value the service and see the reduction in hospital admissions. Nottingham's first evaluation (Wolff et al., 2015) showed parents and carers were 100% satisfied. Parents and carers reported increased confidence perceived the service prevented hospital admission.

Smith et al (2022) had a 66% response rate for Picker survey which identified very high percentages of satisfaction with service offered, support and outcomes.

Appendix 3 – Audit Tools

Events Occurred

	No. OOH/A+E Attendances	No. Ambulance Callouts	No. Hospital Admissions	No. Ward Bed Days	No. HDU Bed Days	No. ICU Bed Days
Pre-Service						
Post-Service						
Events Saved						



Events Avoided

	Hospital Admissions Avoided	A+E Attendances Avoided	G.P. Appointments Avoided
Number			
Cost Saving (£)			

Quality of Life Indicators

	Pre-Service	Post-Service	Saving/Improvement
School Attendance			

