

## **The Impact of a new Rapid Response Children's Respiratory Physiotherapy Service for Children with Long Term Complex Physical Disabilities – A Service Evaluation of a 12-month pilot**

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### **Abstract**

#### **Background:**

Severely disabled children are at increased risk of hospitalisation because of chest infections. Providing specialist respiratory care to these children may help to reduce morbidity, mortality, and rates of hospitalisation. The Children's Rapid Response Respiratory Service aims to provide early specialist assessment and rapid treatment within 24 hours of onset of respiratory concern in the community as well as provision of a chest care plan, regular review, and parent/carer training throughout the year. The aim of this service evaluation was to examine the impact of a 12-month pilot Children's Rapid Response Respiratory Service on children and young people with complex physical disabilities.

#### **Methodology:**

Children and young people aged 0-19 years of age, with long-term physical disabilities, who were registered with a Lincolnshire GP practice, were eligible for the service. The Gross Motor Function Classification Scale (GMFCS) was used to classify physical disability eligibility (Palisano et al. 2007): all children classified as GMFCS level V as well as those classified as GMFCS level IV who incurred repeated chest infections were included. The number and length of hospital admissions over 12 months were collected retrospectively 12 months prior to the pilot start date and prospectively for 12 months after the start date. Additional data collection included: number of out of hour attendances with general practitioners (GP) and at Accident and Emergency departments (A&E), number and graded impact of rapid response interventions, anticipated cost savings and service user feedback.

#### **Results:**

127 children and young people in Lincolnshire were eligible for the service. Comparison of data before and after the 12-month pilot revealed an 80% reduction in hospital admissions, reducing inpatient days from 123 to 25 days. In addition, the total cost of admissions, GP Out of Hour, and A&E appointments reduced by 56.1%. Rapid response interventions resulted in avoidance of 64 hospital admissions, 64 ambulance callouts, 158 A&E/urgent GP appointments and 165 routine GP appointments - resulting in a total cost saving of £239,688.32. Of the 127 cases included, 96 feedback questionnaires were returned: 100% of parents felt the service had been critical to keeping their child out of hospital, had a positive impact on their child's and family's life; and helped them to be more equipped to manage their child at home (improvement from their rating of 2.7/10 to 8.1/10 on average). Parents/carers highlighted that their child's respiratory management had improved from their rating of 5.1/10 to 9.3/10.

**Conclusion:**

A Rapid Response Respiratory Service based in the community of Lincolnshire, that is both proactive and reactive in design, was effective in reducing hospital admissions and associated costs, whilst improving service user satisfaction and parent/carer perceived respiratory management of children with complex physical disabilities

**Introduction:**

Children and young people with neurodisabilities such as cerebral palsy are more likely to recurrently attend hospital for respiratory illness than for any other reason (Meehan et al, 2015) and it has been suggested that pneumonia accounts for as many as 40% of all deaths in this cohort of patients (Reid et al, 2004). This is linked to these children often experiencing problems with coordination of swallow, gastro-esophageal reflux, scoliosis, restrictive lung disease and respiratory secretion clearance due to ineffective cough, which increases their risk of recurrent chest infections (Seddon et al., 2003).

The National Confidential Enquiry into Patient Outcome and Death review (NCEPOD, 2018) shows that respiratory care for children and young adults with cerebral palsy is significantly lacking across the country. One of its principal recommendations for improved care was the need for proactive respiratory assessment and management. Winfield et al (2014) also suggest that when trained staff are available to provide proactive respiratory care and treatment of subacute and chronic respiratory conditions in the community, hospital admissions and readmissions can be avoided whilst also facilitating timely discharge. Analysis of local data from hospital admissions between February 2018 and 2019, highlighted that there was an increasing number of severely disabled children having frequent and prolonged hospital admissions for respiratory tract infections. Their discharge was often delayed by the need for chest physiotherapy to aid secretion clearance after an acute illness at an estimated cost of over £400,000 to Lincolnshire Clinical Commissioning Group (CCG).

Preventing lower respiratory tract infections in children from becoming serious, is a recommended outcome in the NHS (National Health Service) Outcomes Framework 2015-16 (NHS Group, Department of Health, 2014) and a priority for the NHS Long Term Plan (NHS, 2019). This means it is essential that alternative, safe, and effective models of care are developed to reduce unnecessary acute hospital admissions and Accident and Emergency (A&E) department attendances, whilst providing patients and carers with the appropriate professional support and education to facilitate effective self-management at home (APCP, 2017).

Rapid Response Respiratory Services are emerging nationally to meet these recommendations and are beneficial at managing acute respiratory symptoms within the community for this cohort of children (APCP, 2017). Lincolnshire is one of the largest emerging services in the UK. At the start of this project there were 127 children living in Lincolnshire with severe complex physical disabilities, (classified as level IV or level V using the Gross Motor Function Classification Scale (GMFCS; Palisano et al, 2007), including 30 children with long term ventilation needs.

The Lincolnshire children's rapid response respiratory service launched on 4<sup>th</sup> February 2019 for a 12-month proof of concept period to provide specialist assessment, treatment, and management of children with complex physical disabilities with additional respiratory problems in the community. The service comprised of two parts: one proactive, and one reactive. The proactive arm to the service focused on prevention. This involved early specialist respiratory physiotherapy assessment, preventative daily chest management plans and training in chest physiotherapy management strategies for families, carers, and school staff so they became the experts in day-to-day management of the child's chest problems. The reactive arm of the service involved rapid response to children when they were acutely unwell with a chest infection.

This paper describes the evaluation of the children's rapid response respiratory service. Specifically, we sought to address the following objectives:

- Estimate the number of planned and unplanned hospital admissions and GP out-of-hour appointments avoided as a result of the new pilot service.
- Estimate the cost savings in respect of objective 1.
- Compare hospital admission data for respiratory infections, for the 12 months pre and post pilot service implementation and estimate any cost savings.
- Gather parent/carer feedback on the new pilot service.

### **Methodology:**

**Study design:** A service evaluation approach was employed. Retrospective data from medical records 12 months prior to the pilot start date was gathered and compared to prospective data collected 12 months after the pilot start date.

**Ethics and governance:** No ethical or research and development approvals were required for this service evaluation; however, all participants included in the study were screened against the national data opt-out service to make sure parents had not withdrawn consent for their child's data to be used in health research (NHS Digital, 2022).

**Participants:** Patients aged 0-19 years who were classified as GMFCS level V, or IV with repeated chest infections, and either lived, had a GP surgery, or schooled within Lincolnshire, were eligible for the pilot service. Repeated chest infections were defined as two or more separate respiratory infections within a year. Eligibility for the pilot study was irrespective of underlying medical diagnosis.

Retrospective data from medical records 12 months prior to the pilot start date was gathered and compared to prospective data collected 12 months after the pilot start date. The following data categories were used:

#### ***Managing acute episodes at home***

Prospective data was collected following every rapid response intervention when the child was acutely unwell with respiratory symptoms. The intervention was categorised based on who the parent/carer would have contacted for help had the service not been available. Namely, red (avoiding hospital admission – 7 ward days), amber (avoiding A&E admission), or green (avoiding routine GP appointment). Previous hospital admissions data for the cohort of children accessing the service, indicated that the average hospital stay for respiratory illness was 7 days therefore, if an intervention were categorised as 'red,' interventions were not categorised again for 7 days to ensure no double counting of figures. Benchmarking exercises were completed with all team members to ensure reliability of categorisation scores.

Financial costs for each of the categorisation scores were acquired by Lincolnshire Community Health Service (LCHS) Finance department (see Appendix 1) and used to calculate the savings made across the Health System. For the purposes of this service evaluation, it was assumed that every admission would require transfer via ambulance.

#### ***Preventing acute admissions***

For each patient, respiratory-related admissions (days) to a ward, high dependency/intensive care unit, as well as the number of Out of Hours and A&E attendances, and ambulance callouts for the period 1<sup>st</sup> February 2018 – 31<sup>st</sup> January 2019 inclusive were extracted from medical records by the team using a standardised data collection form. The same data were collected prospectively during the 12-month pilot. Any non-respiratory related admissions data were excluded. Related financial costs were again acquired by LCHS Finance department (Appendix 1).

**Parent/carer feedback**

Parent/carer feedback about the impact of the new service and their confidence to manage their child's respiratory problems day-to-day was collected via an online survey, emailed to all families after the 12-month pilot period. The survey consisted of both closed and open questions and was hosted on SurveyMonkey. Responses were returned anonymously.

**Results:**

One hundred and twenty-seven children (52 girls, 75 boys; mean age 8 years and 1 month) were eligible for the pilot. Of these, 46% had a confirmed diagnosis of Cerebral Palsy and 8% had a diagnosis of a neuromuscular condition such as Duchenne Muscular Dystrophy. The remaining 46% had a range of neurological or genetic diagnoses that predisposed them to significant complex physical disabilities.

**Managing Acute Episodes at Home**

A total of 643 rapid response visits were completed for 79 children (62% of the cohort) during the pilot year, equating to an average of approximately 53 visits per month or 8 visits per patient per year.

Table 1 displays the direct savings (in terms of admissions/appointments, and in financial terms) from February 2019 –January 2020 for the rapid response element of the service. These savings were made when a child, with an acute chest infection, was seen by the rapid response service instead of attending a Primary or Secondary Care setting.

*Table 1 - Admission/appointment and associated financial savings where rapid response service involvement directly avoided a hospital admission/A&E attendance/out of hours G.P. appointment.*

<b>Rapid response values (Categorisation Scores)</b>	<b>Difference between pre-pilot and during pilot</b>	<b>Financial Savings</b>
<b>Red</b> (hospital admission avoided i.e., 7 ward days)	64 admissions (average 448 bed days saved)	£201,600.00
<b>Amber</b> (A+E/out of hours appointment avoided)	158 appointments	£15,800.00
<b>Green</b> (routine GP appointment avoided)	165 appointments	£6,600.00
Ambulance call outs prevented (cost based on the East Midlands Ambulance Service 'see and convey' flat rate tariff of £245.13)	64 call outs	£15,688.32
<b>Total savings to date.</b>		<b>£239,688.32</b>

*Data included in the table represent n=77 cases that used the rapid response service during the 12 months pilot period.*

Most rapid response visits avoided attendance at a GP surgery (n=165, 42.6%) and A&E attendance (n=158, 40.6%). Only 16.5% of rapid response visits avoided hospital admission (n=64). However, converse to these frequency data, the greatest financial savings occurred because of avoidance of hospital admissions and ambulance callout (n=£217,288.32, 90.7%). Only a small percentage of savings were credited to avoidance of A&E and GP attendances (6.6% and 2.8% respectively).

**Preventing Acute Episodes**

Table 2 compares the number of respiratory-related hospital admissions for all 127 children eligible for the service in the 12 months prior to pilot year (2018-2019), with the 12 months of the pilot year (2019-2020). The data shows that respiratory-related hospital admissions reduced by 80% (n=95), and the number of hospital bed days reduced by 61.8% (n=309) resulting in financial savings of £204,000 (55.5%). However, an increase in average number of bed days per admission from 4 days to 7.6 days was noted at the end of the pilot.

Additional financial savings were made when comparing cost of ambulance callouts/transfers and cost of Out of Hours and A&E attendances (55.2% and 76.4% respectively). The total financial savings from pre-pilot to the end of the pilot period were £214,582.08 (56.1%).

Table 2 – A comparison of inpatient stay and A&E costings pre and during pilot service provision.

	<b>Number/Cost Pre-Pilot (Feb 2018 – Jan 2019 inclusive)</b>	<b>Number/Cost 12 months During Pilot (Feb 2019 – Jan 2020 inclusive)</b>	<b>Raw Difference between Pre and During Pilot</b>	<b>% Reduction</b>
<b>Number of admissions (n=)</b>	123	25	98	80%
<b>Number of hospital bed days (n=)</b>	500	191	309	61.8%
<b>Cost of inpatient stay on children's ward (£)</b>	£174,600.00	£60,300.00	£114,300.00	65.5%
<b>Cost of stay in HDU/ITU (£)</b>	£193,200.00	£103,500.00	£89,700.00	46.4%
<b>Cost of Ambulance call outs and transfers (£)</b>	£7,108.77	£3,186.69	£3,922.08	55.2%
<b>Cost of OOH (Out of Hours) and A&amp;E attendances (£)</b>	£8,720.00	£2,060.00	£6,660.00	76.4%
<b>Total savings pre and post service (£)</b>	£382,648.25	£169,406.69	<b><u>£214,582.08</u></b>	<b><u>56.1%</u></b>

**Patient/Carer feedback**

All 127 families involved in the service were invited to complete the survey; 96 responses were received. (75.6%). The mean score and range for each question are presented in Table 3.

Table 3 – Parent/Carer Feedback Questionnaire

Question	Response	
	Mean Score	Range
How would you rate your child's respiratory care before this service was launched? (1= very poor, 10 = outstanding)	6.2	5 – 7
How would you rate your child's respiratory care since the service has been launched? (1 = very poor, 10 = outstanding)	8.4	7 - 10
On a scale of 1-10 how much would you agree with the following statement? "The Children's Rapid Response Service has made a positive impact on me, my child and my family" (1= strongly disagree, 10 = strongly agree)	9.8	9 - 10
How important is this service to you and your child in helping to manage their respiratory problems at home to help them stay out of hospital? (1 = not important, 10 = very important)	10	10
On a scale of 1-10 how confident were you to manage your child's respiratory problems at home before the service started? (1= not confident at all, 10 = very confident)	2.7	1 - 4
On a scale of 1-10 how confident are you now at being able to manage your child's respiratory problems at home? (1= not confident at all, 10 = very confident)	8.1	6 - 9
If you called the Rapid Response Service, have you always been seen within 24 hours?	Yes = 100%	
How would you rate the care provided to your child by the Rapid Response Service? 1 = very poor, 10 = outstanding	9.7	9 - 10

When asked for recommendations and improvements for the service, common themes were to extend the service to include provision for those aged over 19 years and to provide weekend cover.

**Discussion:**

This service evaluation investigated the impact of the Children's Rapid Response Respiratory Service on 127 children with complex physical disabilities and their families in Lincolnshire. Early implementor services provided data based on a sample of their populations (APCP Commissioning Tool for Community Paediatric Physiotherapy Posts, 2017) however, this service evaluation provides data for an entire geographical region which enables us to accurately describe and understand the local needs.

Results of the service evaluation demonstrate that in relation to ‘managing acute episodes at home,’ our pilot service reduced hospital days, aligning with findings of Winfield et al. (2014) and other Rapid Response services reported in the APCP Commissioning Tool for Community Paediatric Physiotherapy Posts (2017). The financial savings associated with the reduction in hospital days supports a sustainable future healthcare model, in line with the UK NHS agenda (NHS England, 2019). Furthermore, this has potential to improve quality of life for patients and their families (Elema et al, 2016).

Although the number of hospital admissions reduced, the mean cost of an admission increased. This suggests that those that were admitted required higher healthcare resources, indicative of high-level respiratory illnesses. Those with low level respiratory problems were successfully treated outside of hospital care. It is also important to note, that the indicative savings could be a conservative estimate as they are based on a paediatric ward stay where the cost per day is significantly lower than a HDU/ITU stay (see appendix 1).

The Children’s Rapid Response Respiratory Service provided proactive assessments and education for all 127 children within the service regardless of their current respiratory requirements. Forty-six children (36%) had not previously had any hospital admissions for chest infections; however, their chest health had deteriorated requiring support to better manage them at home. There were also 48 children (38%) who were in good respiratory health before commencement of the Rapid Response Respiratory Service: they had no respiratory admissions and remained in good health throughout the pilot period. It is difficult to evidence the impact of the proactive arm of the service on these children or determine whether their chest health would have deteriorated further without the support and advice provided from the service.

Parent feedback was overwhelmingly positive, with all parents highly valuing this new service. This was due to the service enabling children and families to stay at home during an acute chest infection, positively impacting on both the child’s and the family’s health and wellbeing. It is important to highlight potential biases in parents/carers’ views as all parents/carers were aware that the service was only initially commissioned for 12 months and that their views would be influential in supporting the service in a bid to achieve recurrent commissioning (Sedgwick and Greenwood, 2015). Nonetheless, the positive feedback from parents/carers suggests strong support for continuation of the service. Feedback on the service will be continuously sought.

Results of the survey showed that parents and carers now felt more empowered and confident to manage their child’s respiratory problems day to day with many reporting that they now feel part of the multidisciplinary team around their child. This is significant as it reframes the physiotherapist/parent relationship to one that encourages and supports self-management in the first instance. Prior to this service, care was typically reactive, provided at a time when the child was unwell. Indeed, parents reported that pre-emptive activity around chest clearance and management was lacking. Parents now report that this service has taken on a coordination role around the child and has guided a more proactive management strategy. This is helping to prevent chest infections and manage any problems earlier, thus preventing hospital admission.

Strengths of this service evaluation include that red/amber/green categorization scores were gathered using a ‘shared decision making’ model which, although subjective, improves the validity of the resultant cost-savings (Elwyn et al, 2012). A potential limitation of this service evaluation is author bias as both authors were involved in the service which may undermine the conclusions reached. We have tried to minimise bias by including the entire case load in this service evaluation, extracting objective clinical data (e.g. days, costs etc) and using online questionnaires, as opposed to interviews, to collect parent/carer reflections (Healthwatch, 2020).



**Conclusion:**

In conclusion, results from this service evaluation provide evidence that a pilot, home-based, rapid response service based in Lincolnshire, that is both proactive and reactive at a time when the child is unwell, has significantly improved the respiratory management of a cohort of children with severe complex physical disabilities. This evaluation demonstrated that the rapid response service helps to keep this population healthier, and effectively manages these children at home when they do become unwell with a chest infection, thus keeping the family unit together. Evidence from this one-year pilot demonstrates that the service is financially viable: an 80% reduction in hospital admissions was achieved with financial savings across the health system of well over £239,000. Given the service cost of £190,000, this evaluation clearly supports provision of recurrent funding for the service.

**Implications for practice**

- Rapid response respiratory services with both proactive and reactive models should be considered.
- Further service evaluations and research are recommended to investigate the longer-term impact of rapid response respiratory services.
- Further research investigating the impact of rapid response home-based services on children and their family's health and wellbeing is warranted. This will aid our understanding of families' experiences and may be useful in the development of business cases to support long term commissioning of such services.

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**Ethical and R&D approval:** Not required.

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### **Appendix 1 – 2019/20 Lincolnshire NHS System Costs**

<b><u>Data Set</u></b>	<b><u>Cost (£)</u></b>
G.P. appointment	40
Out of Hours Attendance	80
A&E Attendance	100
Ambulance Call-Out	245.13
One Paediatric Ward Day	450
One Paediatric High Dependency Unit Day	1300
One Paediatric Intensive Care Unit Day	2000

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