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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. <https://doi.org/10.59481/197307>

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Quality Improvement Project to improve access to early screening and physiotherapy for infants at high risk of neuro-developmental disorders.
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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-oesophageal 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 4th 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 1st February 2018 – 31st 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.

Rapid response values (Categorisation Scores)	Difference between pre-pilot and during pilot	Financial Savings
Red (hospital admission avoided i.e., 7 ward days)	64 admissions (average 448 bed days saved)	£201,600.00
Amber (A+E/out of hours appointment avoided)	158 appointments	£15,800.00
Green (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
Total savings to date.		<u>£239,688.32</u>

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.

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

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

Data Set	Cost (£)
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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Quality Improvement Project to improve access to early screening and physiotherapy for infants at high risk of neuro-developmental disorders

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Category: Service Evaluation/Audit

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Ethical and R&D approval N/A

Key points:

- A quality improvement project led to direct referral of all high-risk infants according to NICE guidance from the NICU to a new physiotherapy clinic using evidence-based screening tests.
- Earlier screening and physiotherapy input resulted in parents reporting feeling better supported.

ABSTRACT

Purpose and Setting

Recent international guidelines for Early Diagnosis of Cerebral Palsy (CP) recommend the use of specific evidence-based tools and early therapy intervention for preterm infants at high risk of cerebral palsy. Referrals for physiotherapy and diagnoses of CP in high-risk infants discharged from the Neonatal Intensive Care Unit (NICU) at the Chelsea and Westminster NHS trust were recorded as occurring later than guidance recommends. A

quality improvement project was initiated aiming to enhance identification of CP, increase provision of early physiotherapy and achieve this within the current physiotherapy staffing establishment.

Methods

A quality improvement project was implemented. Physiotherapists received training in using evidence-based assessment tools and early intervention. A new pathway was developed including a schedule of screening assessments and physiotherapy for high-risk infants on discharge from the NICU. This included a 14-month pilot of a new physiotherapy outpatient screening clinic.

Results

Following the pilot, age of referral for physiotherapy reduced from a mean of 11.84 to 4.25 months. All babies were assessed using recommended evidence-based tools including the Hammersmith Infant Neurological Examination, Hammersmith Neonatal Neurological Examination and General Movements. Previously only the Alberta Infant Motor Scales were used. Parent feedback demonstrated that the parents felt supported, valued the relationship with physiotherapists and felt confident to carry out activities suggested by physiotherapists.

Conclusion and Recommendations

The new physiotherapy screening clinic was effective in increasing access to early physiotherapy and evidence based diagnostic assessments and was achieved within current staffing levels. A business case is being considered to increase physiotherapy provision so intervention can be provided consistently at the planned frequency. It is suggested that other Trusts may also find this model of intervention effective.

Introduction

Infants at high risk of a diagnosis of cerebral palsy (CP) or developmental delay benefit from early physiotherapy intervention to enhance their development (Novak et al., 2017; Spittle, Orton, Anderson, Boyd, & Doyle, 2015). Families of these infants benefit from early diagnosis, to understand their child's needs, and enable access to therapies and other services (Novak et al., 2017). The NICE guidelines for developmental follow-up of children born preterm ((NICE), August 2017); CP in under 25 years (NICE, January 2017), and guidance on early diagnosis (Novak et al., 2017) recommend that eligible children born preterm should have enhanced developmental surveillance: evidence-based screening tests should be used to detect possible cerebral palsy (CP) from 3 months, and children with suspected CP should receive early therapy. Developmental support should be provided to empower parents to be involved in decisions about their child's care.

Recommended assessments for predicting future neurological function at different ages include General Movements Assessment (GMA) (Rosendo & Vericat, 2023) and the Hammersmith Infant Neurological Examination (HINE) (Howard et al., 2023). Triangulation with other recommended assessments such as the Alberta Infant Motor Scales (AIMS) (Yildirim, Asalioğlu, Coşkun, Acar, & Akman, 2022), Infant Motor Profile (IMP) (Rizzi et al., 2021) and Bayley Scales of Infant and Toddler Development III (Bayley, 2006) give more information about the infants' functional difficulties.

Since the inception of the new guidelines for Early Diagnosis and Intervention (Novak et al., 2017), there have been several studies of implementation. Byrne, Noritz, and Maitre (2017) and (Maitre et al., 2020) introduced new screening pathways using new evidence-based screening tools. Both studies demonstrated reductions in age at diagnosis and parents expressed satisfaction with the new clinics. Te Velde et al. (2021) promoted the new guidelines within one existing screening clinic: adherence to using the GMA and HINE, and parent satisfaction, were high and diagnosis of CP was well within the first 12

months. All three studies highlighted the importance of stakeholder engagement and training for the physiotherapists in utilising the evidence-based tools.

Current services:

In 2020, infants in the Chelsea and Westminster Hospital NHS Foundation Trust (CWH Trust) were followed up in a number of ways: (1) surveillance in neonatologist led clinics which included one of the recommended evidence-based screening assessment at two years corrected age. (2) The acute paediatric physiotherapy team provided 3 hours/week on the NICU including developmental therapy to a few of the highest risk infants and attended some neonatology led follow up clinics at 9 and 12 months. Any infants who were showing atypical motor signs were referred to community physiotherapy early intervention clinics. (3) GPs, health visitors and other paediatric physiotherapists also made referrals to the community physiotherapy early intervention clinics and those infants were then followed up until showing age- appropriate skills and/or walking independently.

A preliminary review of age and sources of referral to early intervention clinics at the CWH Trust was undertaken in 2020 to better understand the infant and family journey. Average age of referral for physiotherapy at the early intervention clinics at that time was 11.84 months (range: 24 days to 2y 4m 27 days). Referrals came from GPs, health visitors, paediatricians, neonatologists and the physiotherapists on the NICU. A review of all children with CP on the CWH physiotherapy caseload, showed age of diagnosis varied from birth to 5 years 2 months (mean 20.88 months). Many infants received physiotherapy prior to a diagnosis of neuro-disability, but without a formal diagnosis, access to other therapies, psychological or financial support may have been delayed. Such delays are known to increase parental stress (Williams et al., 2021).

Within the community paediatric physiotherapy service at the CWH Trust, therapists were concerned that infants at high risk of CP or other neuro-disabilities were often referred at

several months corrected age so potentially had missed out on early intervention during a key period of neuroplasticity (Novak et al., 2017), and diagnoses of conditions such as CP were being further delayed. A quality improvement (QI) project thus developed, aiming to (1) enhance identification of possible CP through timely referral of at-risk infants and the use of evidence-based standardised assessments, (2) increase the provision of physiotherapy for all infants at high risk of neuro-developmental disabilities who lived within our catchment area, and (3) improve support for parents of high-risk infants and (4) achieve this from within our current staffing provision.

Methods

Study design

To support access to earlier evidence-based assessments and physiotherapy intervention, a QI project was undertaken: a new pathway was designed and a pilot was planned to run for 6 months. QI was selected as an appropriate approach as it focuses on improving efficiencies in healthcare processes and health care outcomes. QI includes exploring the identified problem to understand its' characteristics and causes, setting improvement goals, proposing changes, objectively measuring data during implementation, and providing a solution which is sustained within normal practice (Backhouse & Ogunlayi, 2020). The project was registered with the CWH Trust QI department in advance. To engage stakeholders and raise awareness of the QI project, including the Early Detection and Diagnosis Recommendations (Novak et al., 2017), and this new physiotherapy pathway, neonatologists, acute and community paediatricians were invited to two presentations by the physiotherapy team.

QI Intervention

(i) Training of physiotherapy team

Community physiotherapists and physiotherapists working on the Neonatal Intensive Care Unit (NICU) received training in using evidence-based assessment tools and/or in early

therapy intervention. In total, 5 therapists attended a variety of external courses: GMA (n=2); IMP (n=3); Early Intervention and Assessment course (n=2). In-service training was conducted on the HINE and Hammersmith Neonatal Neurological Examination (HNNE) for infants <3m. Further in-house training took place to cascade skills to other therapists, and to practice scoring assessments to ensure reliability.

(ii) New pathway

Criteria for referral to new clinic: All CWH infants on the NICU were checked prior to time of discharge against NICE criteria for being at high risk of developing CP ((NICE), August 2017) by the NICU physiotherapist and/or community clinic physiotherapists. Infants meeting the criteria listed below were referred into a new community physiotherapy led clinic.

- Children born before 30 weeks gestation
- A brain lesion on neuroimaging which is likely to correspond with abnormal developmental outcomes (i.e. Peri-ventricular Leukomalacia, Intra ventricular Haemorrhage grade 3 or 4)
- Grade 2 or 3 Hypoxic Ischaemic Encephalopathy in the neonatal period
- Neonatal Bacterial Meningitis
- Herpes Simplex Encephalitis
- Severe neonatal sepsis
- Bronchopulmonary dysplasia for which mechanical ventilation is still required at 36 weeks gestational age
- Antenatal steroids not given
- Postnatal steroids given to babies born before 32 weeks gestation

The new community physiotherapy led clinic was staffed within existing service provision. Staff were trained in evidence-based assessment tools (see Table 1) and early intervention therapy as part of the QI project.

Evidence-based assessments provided: Depending on corrected age at referral, infants were assessed with the tools detailed in Table 1.

Table 1: Assessments

Age	Assessment
0-4 months	Prechtl General Movements Assessment (GMA) Hammersmith Infant Neurological Examination (HINE) (or if <3m Hammersmith Neonatal Neurological Examination HNNE) Alberta Infant Motor Score (AIMS) or Infant Motor Profile (IMP)
1 year	HINE, AIMS and/or IMP Bayley III if indicated (global delay)
2 years	Bayley III (unless standardised developmental assessment completed within neonatal follow -up clinics)

Physiotherapy Intervention and Support:

Following referral, infants received assessment, advice on developmental care including play and handling, supporting information such as Early Intervention (EI) Smart leaflets (Hutchon B, 2018) and an initial block of 4-6 physiotherapy sessions to support parents in carrying out developmental activities. If no neurological abnormalities or developmental delays were identified, infants were invited back for further assessment as documented in Table 1.

If infants demonstrated signs of abnormal neurology or early delayed development, families were provided with further physiotherapy within the clinic, with a frequency of up to

weekly sessions depending on degree of delay or atypical signs. Following identification of parents' main concerns and goals, evidence-based principles of early intervention were followed (Baker, Niles, Kysh, & Sargent, 2022; Morgan et al., 2021; Morgan, Novak, & Badawi, 2013; Ulrich, 2010; Ziviani, Feeney, & Khan, 2011). Activities were selected to promote active movements and postural control to facilitate early motor development. Scaffolding was provided as needed to enable infants to maintain postures and move more actively. Simple supports parents would have in the home, such as folded or rolled towels were used, for example, to enable nesting in supine to support shoulder protraction and enable active reaching into the midline. Parent training included demonstration of activities, practice with support and feedback from the therapist and reinforcement by the provision of written home activity programmes with diagrams/photographs. Environmental enrichment including ideas for corrected age-appropriate play and interaction, and ideas on using toys to encourage specific activities was provided.

Communication with multi-disciplinary team: Concerns about infants identified as being at high risk of CP on clinical examination and assessments were communicated to neonatologists if the infant was still under their care or referred on to community paediatricians and child development teams to expedite early diagnosis. Referrals were made to other therapies such as occupational or speech and language therapy as appropriate.

Measurement and Evaluation

Data pertaining to the aims of the QI project were collected from patient records (for 12 months before and after the QI intervention), therapist training records and parent feedback. To address the first aim of the QI project (enhance identification of possible cerebral palsy CP through timely referral of at-risk infants and the use of evidence-based standardised assessments), the child's age at referral, and assessments used, were

extracted from patient and clinic records for the 12 months pre pilot and from the new pilot clinic.

To address the second aim of increasing provision of physiotherapy for high-risk infants within the catchment area, data on the number of therapists attending training courses on evidence-based tools and early physiotherapy intervention were recorded. Data on the age at which infants first received physiotherapy was extracted from patient records. At the end of the pilot, it was determined if the increased provision had been met within the existing staffing level (project aim four).

The third aim of improving support for parents was evaluated through parent feedback collected post pilot through an online survey (see Appendix 1) and a standardised tool for Early Intervention Clinics (EIC), the Modified European Parent Satisfaction Scale about Early Intervention (EPASSEI) (Ziviani et al., 2011). The EPASSEI is arranged in 7 domains including: Assistance or care for parents, assistance or care for children, social environment, relationship between parents and service providers, model of assistance or care, parents' rights and services of other community agencies. It is rated on a 5-point Likert scale: 1=strongly agree or very good to 5=strongly disagree or very bad.

Results

Implementation of new clinic and pathway

A screening clinic was set up and run as a pilot from October 2020 with the original aim of evaluating the impact after 6 months, however this was extended to 12 months due to the effects of the Covid-19 pandemic affecting staffing of the clinic and attendance at the clinic by families. The evaluation period was then extended by a further 2 months to allow for more time to collect parent feedback. All infants within the CWH trust catchment area who were discharged from the NICU were screened against the NICE guidelines to determine if

they were at high risk of neurodevelopmental conditions. Twenty-five infants were within this group and immediately referred into the clinic for screening and early physiotherapy. The clinic succeeded in being delivered within existing staffing.

Enhanced identification of CP:

It was not possible to measure the effect of the pilot clinic on achieving earlier diagnoses as, of the 25 infants attending, only one received a diagnosis of CP. The diagnosis was confirmed at six months corrected age.

Timely referral and physiotherapy provision:

In the 12 months preceding the set-up of the new clinic (pre-pilot), the majority of referrals were received via paediatricians, health visitors and general practitioners as opposed to from the CWH Trust NICU. Following the set-up of the new clinic (post-pilot), all referrals came directly from NICU via physiotherapists, neonatologists and paediatricians. Pre-pilot, the mean referral age was 11.84 months chronological age (range: 24 days to 2y 7m 27 days) whereas during the pilot the mean referral age was 4.25 months chronological age (range: 14 days to 5m 26 days) for the n=25 infants referred (see Figure 1). Physiotherapy started immediately on receipt of the referral (Figure 2). Infants therefore received physiotherapy a mean of 7.6 months earlier than pre-pilot.

Figure 1: Mean age of referral of infants pre-pilot and during pilot

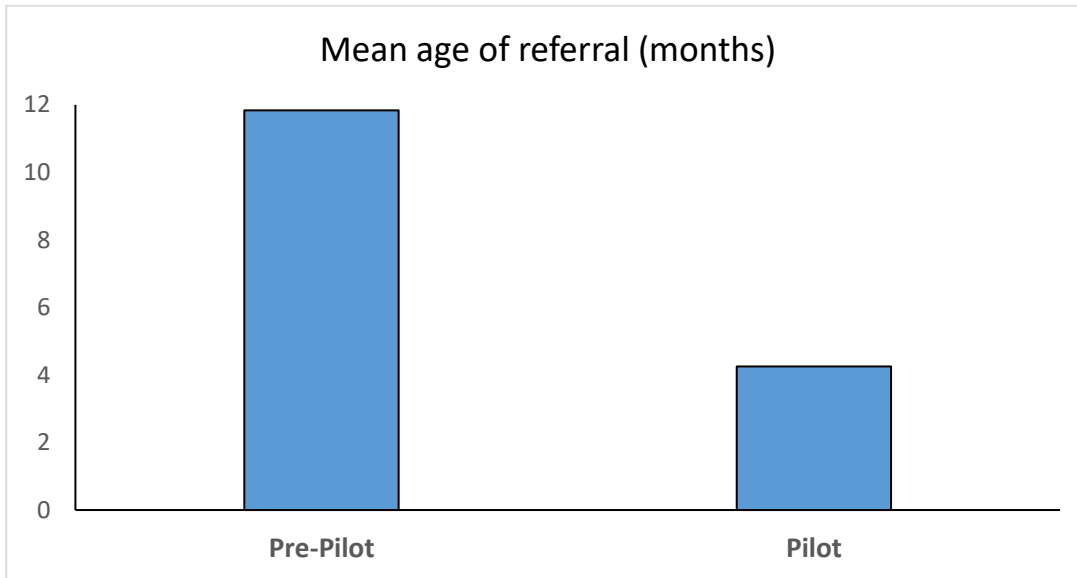
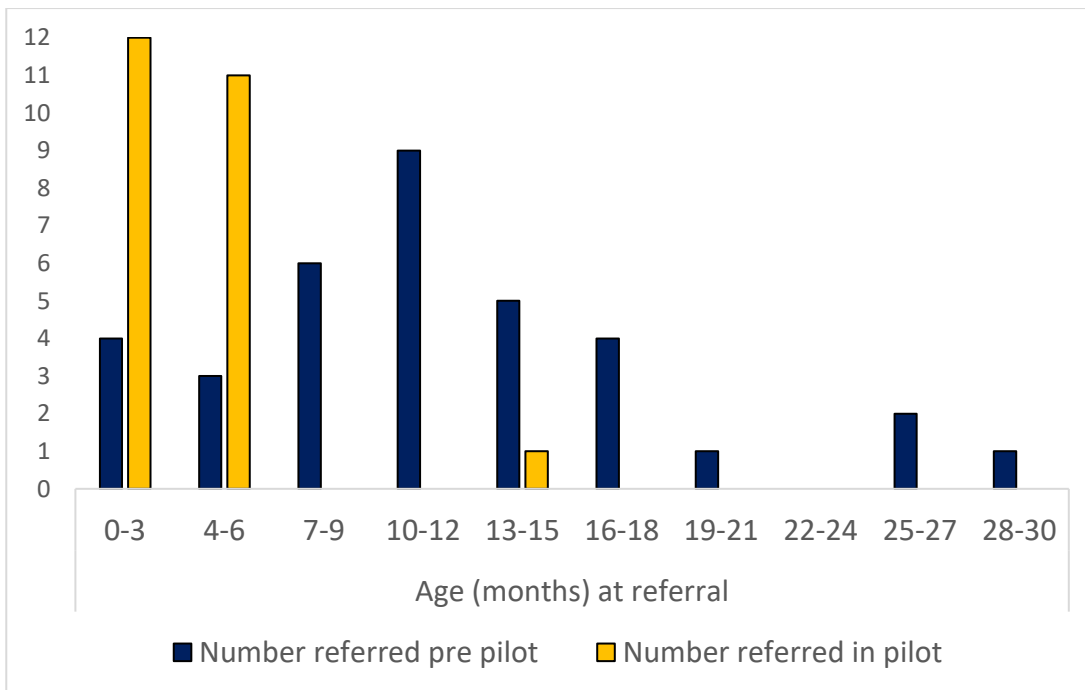


Figure 2: Frequency and age of referral of infants pre-pilot and during pilot



More referrals were taken during the pilot period, compared to pre-pilot, but provision of appointments for the schedule of screening tests and new appointments for therapy was available within the existing staffing establishment. However, the clinic could not always provide the desired frequency of follow-up appointment, i.e. the aim of an initial block of 4-6 weekly sessions sometimes had to be delivered fortnightly and further physiotherapy, if

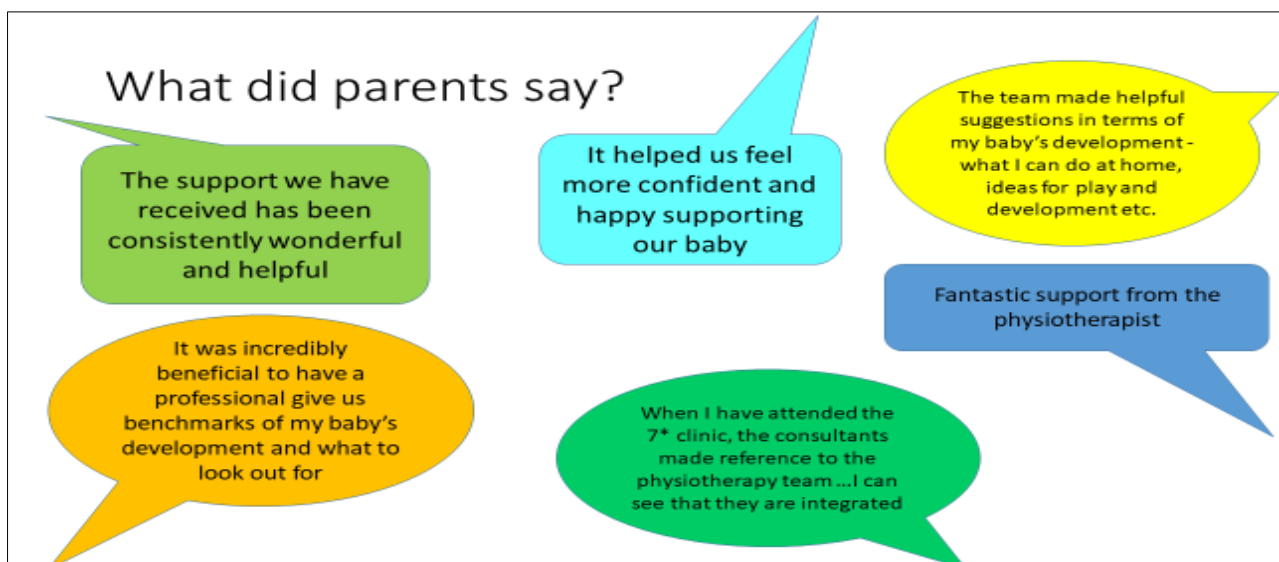
required, could not always be delivered weekly for all those infants deemed to require this, such as those with signs of atypical tone/movement or significant developmental delay.

Parent feedback:

Ten out of the twenty-five pilot families received an EPASSEI feedback form and six responded. In all areas except social environment, parents rated items as good/very good and highest scores were for “relationship between parents and service providers / professionals” and for “model of assistance/care”. Social environment included the most “not applicable” responses as it covered “addressing issues of siblings” and for many of the families, this was their first child. Other items receiving high numbers of ‘non applicable’ responses were for services not provided in this clinic, e.g. financial assistance; groups; meetings with other parents. Additional feedback from five families was received from an online Survey Monkey (see Appendix 1).

Parents strongly agreed or agreed that the sessions were helpful, appropriate for their babies and helped them develop; physiotherapists were approachable and addressed their concerns; and they felt confident to carry out activities suggested by the physiotherapist. Parents also considered the number of physiotherapy sessions received to be just right. A sample of parent comments are provided in Figure 3.

Figure 3: Parent feedback comments



Discussion

A new physiotherapy screening and intervention pathway was developed and a pilot clinic was conducted for 14 months. Infants at high risk of CP or developmental delay were referred for physiotherapy a mean of 7.6 months earlier compared to pre-pilot, and all were referred directly from the NICU in comparison to a mixture of NICU and later community referrals pre-pilot. Feedback was challenging to collect as families were often coping with an infant with many medical problems, frequent hospitalisations, caring for other siblings and/or experienced issues related to the pandemic. In spite of this, parents who attended the pilot clinic reported feeling supported and having increased confidence in carrying out home activities with their infants. One infant received a diagnosis of CP at six months CA and received earlier physiotherapy intervention than typically provided pre-pilot.

Implementation of the new guidelines for Early Diagnosis and Intervention (Novak et al., 2017) have been investigated in other studies. Significant increases in clinic attendance for evidence-based assessments at 3-4 months corrected age and reductions in age of diagnosis from 19.5 to 5 months and 18 to 13 months were demonstrated by Maitre et al. (2020) and Byrne et al. (2017). Both studies included far larger cohorts (5000 and over 7000 high risk clinic visits per year respectively) which allowed more robust analysis of diagnostic age data than in this small study. Te Velde et al. (2021) promoted the new guidelines within one existing screening clinic and diagnosis of CP was typically provided well within the child's first 12 months. In addition, Te Velde et al. (2021) recorded infants as being referred on average for physiotherapy at 4.7 months, similar to this study, although their screening clinic and intervention services were separate.

Strengths and limitations

Strengths of this study include fidelity with the QI intervention: the early intervention guidelines regarding evidence-based assessments were implemented exactly as recommended during this study and earlier referral for physiotherapy direct from the NICU

was achieved. Due to the size of the NICU, catchment area and length of pilot, the sample of infants was small, and it was not possible to definitively conclude if it had influenced age of diagnosis. Limited feedback was obtained from parents, despite several email and phone reminders and it is not possible to know the views of non-responders.

Recommendations

Following the pilot, the physiotherapy screening and intervention clinic is continuing in our trust. This QI project has demonstrated that a package of training and new clinical pathway achieved within current staffing, resulted in reduced times waiting for physiotherapy and increased use of evidence-based assessments. We thus recommend that similar models are introduced in other trusts.

Following concerns raised about the quality and outcomes of maternity and neonatal care, two important reports were recently commissioned by the House of Commons, NHS England and NHS Improvement: East Kent (Kirkup, 2022) and Ockenden (Ockenden, 2022). Both recommended increased staffing, and, as a result, therapist provision has now been increased on our NICU to include physiotherapy, occupational therapy and speech and language therapy. If it continues to be challenging to provide physiotherapy at the desired frequency consistent with the pathway on further reviews of the clinic, it is recommended that a business case also be put forwards for more community physiotherapy. In addition, following conclusion of the pilot project, it was recommended that physiotherapy early intervention services are reviewed in the neighbouring trusts, to ensure CWH is providing an equitable service.

Conclusion

This quality improvement project aimed to implement evidence-based international guidance on early diagnosis and intervention by offering evidence-based recommended assessments, earlier physiotherapy and improved parent support to all infants at high risk of neuro-developmental disabilities who lived within our catchment area. As a result of piloting a new care pathway and screening clinic, age at referral for physiotherapy reduced, all infants received evidence-based screening and parents who gave feedback reported high levels of satisfaction with the service. This model could be adopted by teams in other regions to optimise care for high-risk infants.

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Appendix 1: Parent Survey

1. The sessions with the physiotherapist were helpful.

Strongly Disagree to Strongly Agree (5-point scale)

2. The sessions were appropriate for my baby.

Strongly Disagree to Strongly Agree (5-point scale)

3. The physiotherapist addressed any concerns I had about my baby's physical development

Strongly Disagree to Strongly Agree (5-point scale)

4. The sessions supported me to help my baby develop

Strongly Disagree to Strongly Agree (5-point scale)

5. The number of physiotherapy sessions I received were:

Too few/just right/not enough

6. I feel confident to carry out the activities suggested by the physiotherapist on my own

Strongly Disagree to Strongly Agree (5-point scale)

7. The physiotherapist was approachable and able to answer my questions.

Strongly Disagree to Strongly Agree (5-point scale)

8. How would you like your sessions?

Mainly face to face/ mainly virtual via video/a mixture of face to face and virtual via video.

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