

Quality Improvement Project to improve access to early screening and physiotherapy for infants at high risk of neuro-developmental disorders

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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

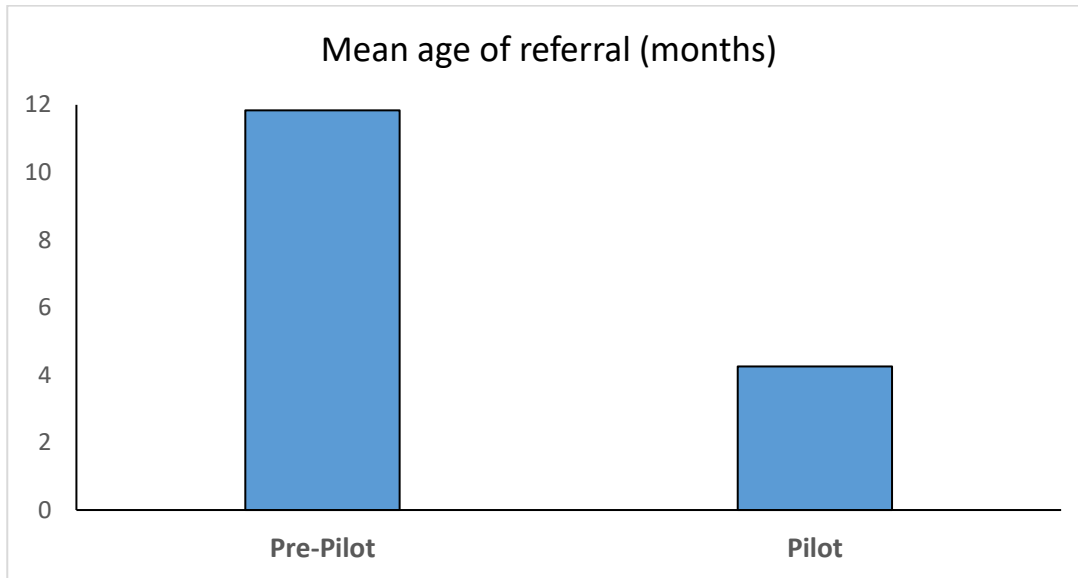
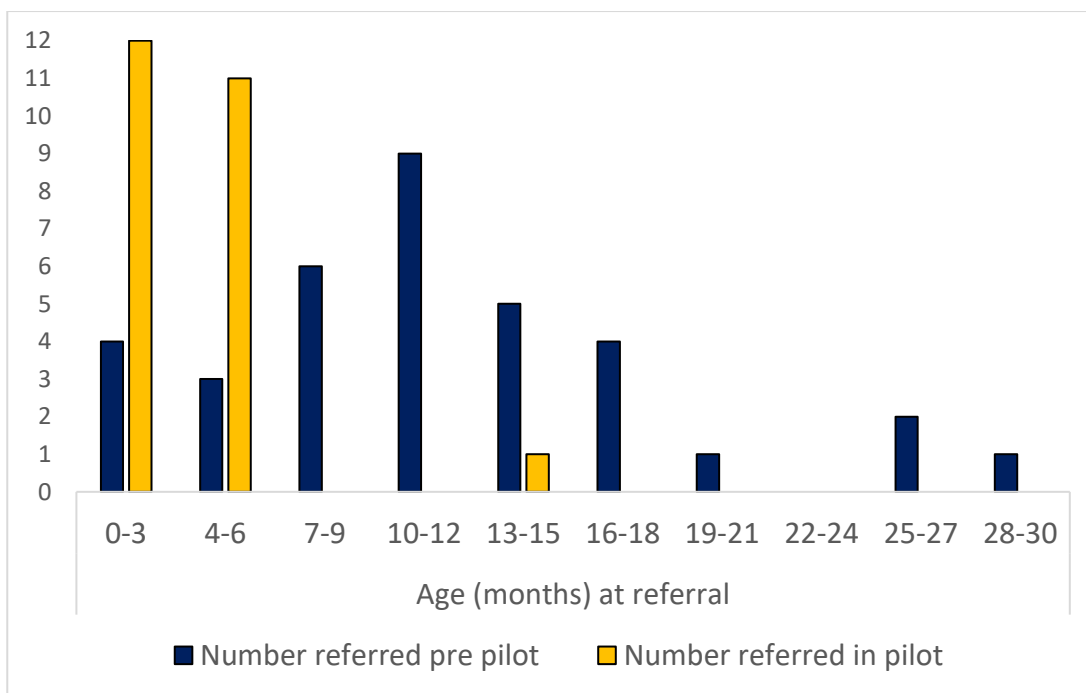


Figure 2: Frequency and age of referral of infants pre-pilot and during pilot



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

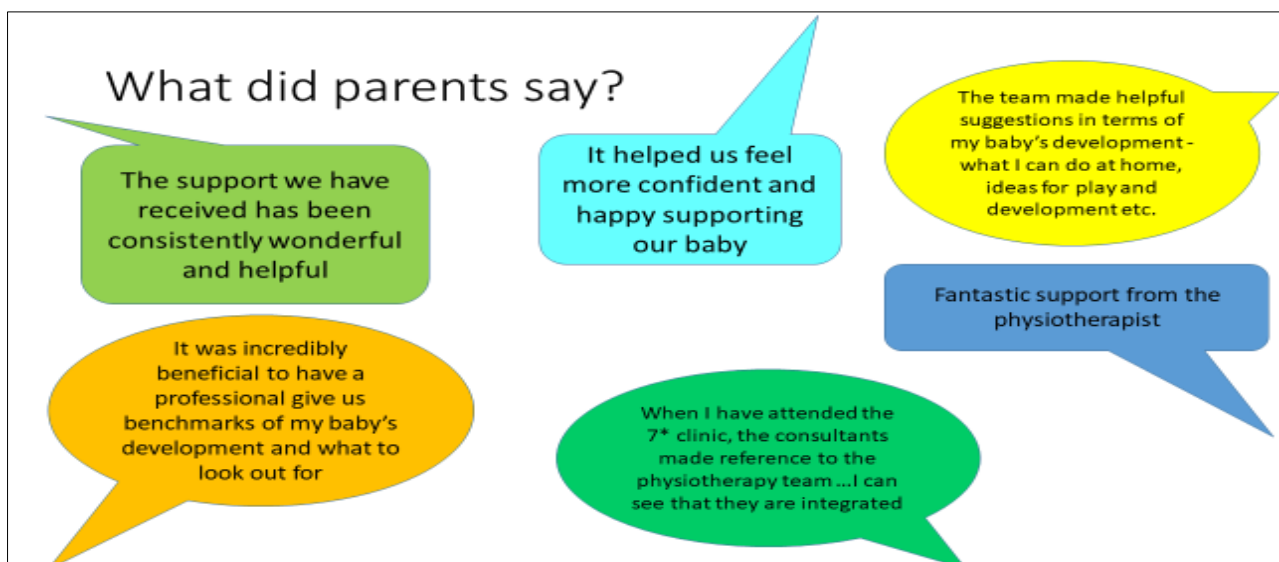
required, could not always be delivered weekly for all those infants deemed to require this, such as those with signs of atypical tone/movement or significant developmental delay.

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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