

## Paediatrics

# Physiotherapy service provision after cardiac surgery for children with congenital heart disease in the United Kingdom and Ireland: a service evaluation

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### Abstract

#### Background

Congenital heart disease (CHD) is the most common form of congenital abnormality present at birth representing 57.1 per 10 000 live births in England. Many children with CHD will undergo lifesaving surgery, and a proportion will require post operative monitoring in a paediatric intensive care unit (PICU). Physiotherapy in PICU has historically focused on respiratory management. However, newer responsibilities include developmental assessment and rehabilitation of motor-delay and motor-function.

#### Aim

Explore physiotherapy service provision for children with CHD post cardiac surgery in the United Kingdom (UK) and Ireland.

#### Methods

Literature was used to develop a questionnaire, containing 32 questions. This was emailed to physiotherapists at 12 Trusts providing paediatric cardiac surgery in the UK and Ireland in July 2022. This questionnaire was registered and approved by the Trust as a service evaluation.

#### Results

Ten Trusts completed the questionnaire, with a response rate of 84%. There was variety in service provision. Respiratory physiotherapy assessments occurred at all sites (10, 100%). Rehabilitation referral processes, timing of assessments and treatment dosages differed. Sternal precaution advice was provided at eight sites (80%). Referral criteria and practice for outpatient follow-up and community physiotherapy varied.

#### Conclusion

Physiotherapy service provision for children with CHD in the UK and Ireland varied. Routine respiratory assessment is common practice, however, the effectiveness of subsequent interventions in ventilated children remains inconclusive. Routine outpatient physiotherapy is infrequent although the evidence highlights the importance of ongoing specialist rehabilitation. Further research is needed to develop guidelines and standardise care.

## INTRODUCTION

Congenital heart disease (CHD) is the most common form of congenital abnormality present at birth representing 57.1 per 10000 live births in England.<sup>1</sup> In the United Kingdom (UK), approximately 4000 operations for CHD in children are performed annually. Of these, around 75% require a pe-

riod of post-operative recovery on a Paediatric Intensive Care Unit (PICU).<sup>2</sup>

Physiotherapy practice on PICU has historically focused on respiratory management of ventilated patients. The effects of anaesthesia, surgery and mechanical ventilation can lead to reduced lung volume and secretion retention in children post cardiac surgery. This can increase the risk of developing ventilator acquired pneumonia (VAP). Higher

incidences of VAP have been reported in children with CHD post cardiac surgery compared to other patient groups on PICU.<sup>3</sup> Physiotherapists have in-depth knowledge regarding the assessment and management of secretion retention associated with being intubated and ventilated.

Due to increased awareness that a period of critical illness can lead to a loss or delay in motor function, physiotherapy practice on PICU has expanded to include assessment and rehabilitation of motor function.<sup>4</sup> A period of illness requiring a PICU admission can lead to motor delay or a loss of motor function in children.<sup>5</sup> CHD can impact antenatal brain development leading to motor developmental delay.<sup>6</sup> The effects of being critically ill on PICU, in addition to pathological risk factors associated with CHD, mean many children require rehabilitation following surgery. Physiotherapists have specialist skills in the assessment and rehabilitation of motor delay and loss of motor function.

Sternal precaution advice is routinely used in clinical practice for patients who have undergone a sternotomy.<sup>7</sup> However, this advice can impact developmental and rehabilitation activities completed by physiotherapists.

There is a role for physiotherapists in the assessment and management of children with CHD post cardiac surgery. However, there is a lack of literature exploring physiotherapy service provision and practice in this patient group.

This project evaluated physiotherapy practice and service structure for children with CHD post cardiac surgery in the UK and Ireland, in three key areas.

1. Respiratory physiotherapy practice and service provision in children following cardiac surgery.
2. Physiotherapy rehabilitation practice and service provision in children following cardiac surgery.
3. Clinical practice on sternal precaution advice.

## METHODS

A self-completed questionnaire of physiotherapy departments in UK and Ireland level 1 centres providing paediatric cardiac surgery, was conducted. This method was chosen as it captured quantifiable data from individuals at a single point in time.<sup>8</sup> Although not a web-based questionnaire the project was designed using the CHERRIES guidelines.<sup>9</sup> As a service evaluation, this project was not classed as research, therefore formal ethical approval was not required, as per UK Health Research Authority guidance. It was registered and approved by the Trust (CARMS 31431).

The questionnaire content was derived from relevant literature and clinical experience of authors SC and NM (*supplementary material 1*). The questionnaire took approximately 15 minutes to complete and included 32 multiple-choice and open-ended questions. An e-link to the questionnaire was shared in July 2022. To ensure a variety of Trusts were represented nationally, demographic information collected was limited to the location of the responding Trusts. No identifiable personal information was collated. Face and content validity was achieved by pilot testing the questionnaire using physiotherapists from two

Trusts. Following pilot testing, the introductory wording was modified, seven questions were rephrased, and the layout was altered.

The physiotherapy UK extracorporeal membrane oxygenation (ECMO) specialist interest group were approached regarding the project as this group had representatives in level 1 cardiac Trusts. A verbal explanation of the project was completed and an email mailing list of individuals within the specialist interest group was obtained. The questionnaire could be distributed to other physiotherapists within their organisation if these individuals were best placed to complete the questionnaire. The results were stored on a secure NHS drive. Descriptive statistics were used to analyse and report results.

## RESULTS

Ten sites completed the questionnaire, with a response rate of 84%. All questionnaires were completed in full. Responses were from sites in the UK and Ireland.

All 10 sites provided physiotherapy input as part of their service provision. Four sites (40%) reported ring-fenced monies for physiotherapy staffing for post-surgical cardiac patients; of these, two (50%) reported one or more dedicated Whole Time Equivalent (WTE) (37/5 h/week) physiotherapists. All sites reported having other member(s) of the multidisciplinary team as part of their work force establishment in post-surgical cardiac patients (*supplementary material 2*).

Post cardiac surgery, eight sites (80%) reported all new patients were automatically referred for respiratory physiotherapy assessments. Seven sites (70%) stated a respiratory assessment was completed for all patients post operatively, two sites (20%) completed assessments on specific patient groups and one site (10%) only completed assessments on patients that were referred.

Clinical practice when conducting a respiratory assessment varied. Five sites (50%) reported their assessment process included a full bedside assessment, bedside discussions, and chest radiography screening practice. Two sites (20%), used chest x-ray screening and bedside discussions, and a further two sites (20%) completed a full bedside assessment and one site (10%) used full bedside assessment and discussion.

Nine sites (90%) reported that, post cardiac surgery, routine assessment of motor delay and motor function were not completed on all new patients. Four sites (40%) used a formal referral criterion for assessment of motor delay and motor function. Other methods of referral included physiotherapy screening of patients (70%), members of the multidisciplinary team (50%) and parents (30%).

The timing of initial assessment of motor delay and motor function post operatively varied. Sites reported patients were commonly assessed either intubated or extubated on PICU (50%). One site (10%) reported assessment occurred on the cardiac ward and one site (10%) stated it was not part of their service provision (*Table 1*).

Seven sites (70%) used standardised outcome measures as part of their assessment process; amongst these sites,

**Table 1. Completion of initial developmental and motor assessment**

Completion of initial assessment	Sites n (%)
Stable intubated or extubated on PICU	5 (50)
Stable intubated on PICU	2 (20)
Stable extubated PICU	1 (10)
Stable ward	1 (10)
Not part of service	1 (10)

PICU, paediatric intensive care unit.

the Alberta Infant Motor Scale (AIMS) was the most reported measure (n=5, 71%), followed by the Bayley Scale of Infant Development (n=4, 58%). Other measures reported included Peabody Developmental Motor Score, Hammer-smith Infant Neurological Examination, and Prechtal’s General Movement Assessment (each at 1 site, 14%).

Rehabilitation of motor delay and loss of motor function in children post cardiac surgery varied. Five sites (50%) did not offer a standardised treatment frequency or length, and eight sites (80%) did not have a standard duration of treatment (Table 2).

The practice of providing families formal developmental advice prior to discharge also differed. Six sites (60%) gave developmental advice prior to discharge, either on PICU or the wards, via a combination of verbal advice, written literature or by individual treatment plans (Table 3).

Eight sites (80%) did not offer outpatient physiotherapy follow up after discharge. At the two sites where outpatient follow up occurs, referral practice and follow up format varied (Table 4).

Seven sites (70%) referred patients to community physiotherapy services however, referral criteria differed (supplementary material 3)

Eight sites (80%) provided advice on sternal precautions. Advice was delivered to families on the cardiac ward at seven sites (n=7, 87%). Four sites (n=4, 50%) also reported providing advice on sternal precautions on PICU, and one site (12%) prior to admission. Sternal precaution advice was shared verbally or via written literature. Four sites (50%) used written literature, two sites (25%) a combination of written literature and verbal advice, and two sites (25%) provided verbal advice only. Physiotherapists commonly delivered sternal precaution advice to families (n=7, 87%). Other professionals included cardiac nurse specialists (n=4, 50%), occupation therapists (n=2, 25%) and therapy assistants (n=1, 12%). Sternal precaution advice varied across each site (Table 5).

**DISCUSSION**

To our knowledge, this is the first project to evaluate UK paediatric physiotherapy practice, and service provision, for children with CHD post cardiac surgery. All responding sites reported providing postoperative physiotherapeutic intervention to children with CHD but clinical practice and service delivery varied.

Adult intensive care guidelines recommend one WTE physiotherapist for every four, level three ICU beds.<sup>10</sup> This is a higher staffing ratio compared to paediatric critical care quality standards, which recommend one physiotherapist five days a week.<sup>11</sup> Protected funding and recommendations regarding physiotherapy staffing ratios for specialist service provision including CHD are currently lacking in the UK. This is reflected in our findings.

**Table 2. Rehabilitation frequency, duration and length of treatment**

How often is treatment	Sites n (%)	How long are treatment sessions	Sites n (%)	Standard number of treatment sessions	Sites n (%)
Daily	0	<30mins	2 (20)	Yes	1 (10)
X1 a week	3 (30)	30-60mins	2 (20)	No	8 (80)
X2 a week	0	>60mins	0	Not part of service	1 (10)
X3 a week	1 (10)	Not part of service	1 (10)		
Monthly	0	Other- variable	5 (50)		
Not part of service	1 (10)				
Other- variable	5 (50)				

**Table 3. Information provision on motor development**

Development advice provided on discharge	Sites n (%)	When is advice provided	Sites n (%)	What format in advice given in	Sites n (%)
Yes	6 (60)	PICU	5 (83)	Verbal	5 (83)
No	4 (40)	Ward	6 (100)	Literature	6 (100)
				Treatment plans	5 (83)

PICU, paediatric intensive care unit.

**Table 4. Outpatient service provision**

Outpatient referrals completed by	Sites n (%)	Outpatient follow up format	Sites n (%)
AHP	2 (100)	Face-to-face single therapist clinic	2 (100)
CNS	1 (50)	MDT virtual clinic	1 (50)
Medical team	1 (50)	MDT face-to-face clinic	1 (50)
Ward staff	1 (50)	Single therapist outpatient appointment	1 (50)

AHP, allied health professional; CNS, cardiac nurse specialist; MDT, multi-disciplinary team.

This project demonstrated that respiratory physiotherapy was the most reported service provision. However, the effectiveness of ongoing respiratory physiotherapy treatment in ventilated children remains inconclusive.<sup>12</sup> Furthermore, the completion of prophylactic chest physiotherapy in patients post cardiac surgery failed to prevent pneumonia or reduce episodes of atelectasis.<sup>13</sup> Further evidence is needed to guide respiratory physiotherapy service provision in this patient group. This is emulated in this project as a variety of clinical assessment processes and service provision were demonstrated.

Rehabilitation practice and service provision differed within this project. Most sites used screening methods to highlight at-risk patients. Practice recommendation guidelines for early rehabilitation and mobilisation in children endorsed the process of screening for eligibility within 24 hours of admission.<sup>14</sup> This may explain why sites are adopting this practice. The positive impact of early rehabilitation and mobilisation during a period of critical illness is documented in adult literature.<sup>15</sup> There is a lack of evidence establishing the impact of early rehabilitation and mobilisation, and what dosage of rehabilitation is optimal in children.<sup>16</sup> This is reflected in this project with many sites

offering different frequencies, duration and lengths of treatment sessions.

Sternal precautions are utilised within many hospitals with the aim of minimising complications such as wound dehiscence, and poor sternal healing following median sternotomy.<sup>7</sup> Local sternotomy protocols, as shown in this project, vary and can be based on institutional preference, adult literature, and historical practice.<sup>7</sup> The development of an evidence-based national guideline could be used to support the standardisation of sternal precaution practice in children.

The importance of, and need for, ongoing developmental screening and referral for specialist rehabilitation in children with CHD is recognised in the literature.<sup>17</sup> Multiple small studies have demonstrated improvements in motor function, strength, and developmental milestones in children with CHD who access ongoing outpatient physiotherapy.<sup>18,19</sup> This project highlights that outpatient physiotherapy service provision is lacking and referral to community physiotherapy services varies.

The variances in clinical practice and service provision demonstrated in this project may be due to a lack of clinically impactful literature and guidelines. Research to evaluate the impact of physiotherapy in children with CHD could aid standardisation of care, although the heterogeneity of this population may make this challenging.

**LIMITATIONS**

Limitations of this project include obtaining responses from only one physiotherapist per site, as this assumes everyone follows the same clinical practice. The use of the ECMO paediatric physiotherapy specialist interest group relied on therapists disseminating the questions. Asking physiotherapists to comment on clinical practical and service provision across a heterogeneous population may have diluted differences in service provision across conditions, ages, and types of surgery.

**Table 5. Sternal precaution recommendations**

Recommendation(s)
To avoid tummy time for 6 weeks To avoid picking up under arms - bottom scoop instead for 6 weeks
Two weeks of caution to allow wound healing. After two weeks can progress as able. Tummy time two weeks, return to nursery / school 4-6 weeks, rough play / lifting under arms / swimming / cycling 6 weeks.
No tummy time for 2 weeks, closer caution with or suspected wound infection
No tummy time for 6 weeks No pulling/ lifting under the arms for 6 weeks No lifting/carrying heavy objects for 6 weeks, adapted to individual needs depending on age. No contact sport, scooters, riding bike for 8-12 weeks
Scoop lift for 6 weeks Not allowed tummy time for 6 weeks (unless tummy time on parent's chest) however if crawling or rolling then do not worry too much if they get themselves into this position.
Tummy time can commence as pain allows - usually 1-2 weeks post operative, Not lifting under the arms for 3 months

## CONCLUSION

This service evaluation indicates children with CHD have access to physiotherapists following cardiac surgery but there is a disparity of service provision and a variety of clinical practice. The results of this project highlight that certain sites offer a more comprehensive level of service provision. These sites could be used for benchmarking in local service development projects thus aiding standardisation of care.

### Key Points

1. Children with CHD commonly access respiratory physiotherapy post-operatively.
2. Rehabilitation practice post-operatively and on discharge varies between sites.
3. Further development of guidelines may lead to standardisation of care.

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## ETHICAL AND R&D APPROVAL

As a service evaluation, formal ethical approval was not required as this project was not deemed as research, as per UK Health Research Authority guidance. The project was registered and approved by Birmingham Women's and Children's NHS Trust (CARMS 31431).

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