

This is a repository copy of *Provision of services for rehabilitation of children and adolescents with congenital cardiac disease: a survey of centres for paediatric cardiology in the United Kingdom.*

White Rose Research Online URL for this paper:

<https://eprints.whiterose.ac.uk/1815/>

---

**Article:**

Lewin, R.J.P., Kendall, L. and Sloper, P. (2002) Provision of services for rehabilitation of children and adolescents with congenital cardiac disease: a survey of centres for paediatric cardiology in the United Kingdom. *Cardiology in the Young*. pp. 408-410. ISSN 1047-9511

---

**Reuse**

Items deposited in White Rose Research Online are protected by copyright, with all rights reserved unless indicated otherwise. They may be downloaded and/or printed for private study, or other acts as permitted by national copyright laws. The publisher or other rights holders may allow further reproduction and re-use of the full text version. This is indicated by the licence information on the White Rose Research Online record for the item.

**Takedown**

If you consider content in White Rose Research Online to be in breach of UK law, please notify us by emailing [eprints@whiterose.ac.uk](mailto:eprints@whiterose.ac.uk) including the URL of the record and the reason for the withdrawal request.

## Brief Report

# Provision of services for rehabilitation of children and adolescents with congenital cardiac disease: a survey of centres for paediatric cardiology in the United Kingdom

Robert J. P. Lewin,<sup>1</sup> Lynne Kendall,<sup>2</sup> Patricia Sloper<sup>3</sup>

<sup>1</sup>British Heart Foundation Rehabilitation Research Unit, University of York, York; <sup>2</sup>Paediatric Cardiac Unit, Yorkshire Heart Centre, Leeds General Infirmary, Leeds; <sup>3</sup>Social Policy Research Unit, University of York, York, UK

**Abstract** A postal questionnaire survey of the 17 centres for paediatric cardiology in the UK investigated the attitudes of staff towards rehabilitation and the current level of provision. The majority of respondents (82%) believed they should provide rehabilitation for their patients, but only one centre had a programme for rehabilitation. Few respondents (18%) believed they were meeting the needs of their patients' for rehabilitation. Major barriers to providing rehabilitation were funding and the wide geographical catchment areas.

Keywords: Congenital cardiac disease; survey; children; grown-up congenital heart disease

**D**RAMATIC IMPROVEMENTS IN THE MEDICAL CARE for children with congenital cardiac disease have meant that many of those who would have died are now surviving. A number of patients display symptomatic and psychosocial problems that rehabilitation, appropriate to age, might help to ameliorate.<sup>1–4</sup> The Report of the Inquiry into the Care and Management of Children Receiving Complex Heart Treatment at the Bristol Royal Infirmary<sup>5</sup> highlights the fragmentation and lack of coordination of services providing healthcare for children. It notes that existing guidance<sup>6</sup> states that such services should provide for “the child as a whole, for his or her complete physical and emotional well being”. Cardiac rehabilitation programmes aim to provide just such a holistic approach.<sup>7</sup>

We undertook a survey to establish the opinions of the staff working in centres for paediatric cardiology centres as to the value of providing a rehabilitation service, the extent to which such services are already being provided, the extent to which the children's needs for rehabilitation are routinely assessed,

and the extent of multidisciplinary case work in that centre.

## Subjects, methods and results

The survey included all 17 centres providing paediatric cardiology services in the United Kingdom. A questionnaire was sent to one named paediatric cardiologist, liaison nurse and physiotherapist in each centre. If a response was not received within four weeks, a written reminder was sent. Between February and July 2001, questionnaires were returned by 34 (100%) of the nurses and physiotherapists. Two physiotherapists returned the questionnaires without completing them, as their centres had recently stopped doing paediatric cardiac surgery. Only two cardiologists (12%) returned questionnaires, their views could not be assumed to be representative and these returns were therefore omitted from the analysis. There were no significant differences between the frequency of answers endorsed by the physiotherapists and the nurses, and their responses were pooled. We asked if there was a need for services providing rehabilitation for children and adolescents with congenital cardiac disease. The great majority, 28 (82%) answered “yes”. One nurse replied that she was “not sure”, and one nurse and two physiotherapists did not answer the question. We asked “Do you run a rehabilitation

Correspondence to: Prof. Bob Lewin, British Heart Foundation Rehabilitation Research Unit, Genesis 6, York Science Park, University of York, Heslington YO10 5DG, UK. Tel: 01904 434127/434106; Fax: 01904 434102; E-mail: rjpl1@york.ac.uk

Accepted for publication 1 March 2002

programme for children and adolescents?" One nurse responded "yes" but the physiotherapist from that centre replied "no". We asked staff if they thought that their "... current rehabilitation services meet the need of patients and their families?". Only six (18%) answered "yes".

We asked which of five professions were available, either as a member of the paediatric cardiology team, or through an "ad hoc" referral to that discipline. All centres had at least one liaison nurse and a physiotherapist, and access to a dietician, while 15 (88%) centres had access to both a clinical psychologist and an occupational therapist. We asked if any other professions were available. Four (24%) centres reported a paediatric cardiac social worker, four (24%) a play specialist and two (12%) a speech therapist. One centre reported having a clinical nurse specialist and a parent support nurse. Another reported that a pharmacist was available.

We asked two questions about multidisciplinary working, and one about the use of assessment measures. The questions and the responses are shown in Table 1.

Table 1. Questionnaire items about multidisciplinary working and assessment.

Questions	Yes	No
Do you discuss the rehabilitation needs of each patient as a team?	7 (41%)	9 (53%)*
Do you have regular rehabilitation meetings or case discussions?	6 (35%)	11 (65%)
Do you use any standardised tests or questionnaires to assess needs or measure outcomes?	0	16 (94%)*

In each case out of 17 British centres. \*1 no reply.

We also asked a series of open-ended questions, the responses are summarised in Table 2.

### Comment

Cardiac rehabilitation has been shown to reduce morbidity both psychological and physical as well as mortality in adults with heart disease, and the great majority of nurses and physiotherapists working in paediatric cardiology believed that they should provide a similar programme for rehabilitation of children and adolescents with cardiac disease. Only one centre appears to provide such a service. Most centres have access to the disciplines required to provide such a service, but there appeared to be little use of valid measures of assessment to ascertain the psychosocial, lifestyle, or educational needs of the children and adolescents. Only a minority of centres have regular multidisciplinary meetings or multidisciplinary discussions, and such help is mostly restricted to the acute in-hospital phase. Any help for outpatients is supplied in a reactive rather than proactive manner. The findings of the survey, therefore, concur with the findings of the Bristol Royal Infirmary Inquiry that services for children are poorly coordinated, and do not provide for the child as whole.

The views of paediatric cardiologists on these topics remain unknown, but a similar survey of cardiac rehabilitation for adults in the United Kingdom found cardiologists had little active involvement in programmes for rehabilitation.<sup>8</sup> Other surveys<sup>9</sup> have shown that, despite an established evidence base, it has mainly been nurses and physiotherapists who have initiated programmes for rehabilitation in the United Kingdom.

Table 2. Categorised responses of nurses and physiotherapists to open ended questions about the need for improvement, common problems and barriers to implementing rehabilitation showing the combined response rate for each question.

Questions	Summarised responses
Which areas of rehabilitation you would like to improve? Response rate (20/34, 59%)	<ul style="list-style-type: none"> <li>• More multidisciplinary input and follow-up, especially for older children, teens and young adults (20)</li> <li>• Improved staffing levels and facilities (9)</li> <li>• Measurement tool to assess outcome/identify needs (1)</li> </ul>
List the 3 most common rehabilitation problems you encounter in your unit. Response rate (26/34, 77%)	<ul style="list-style-type: none"> <li>• Acute in-patient problems, especially neurodevelopmental problems (11); weakness &amp; debility with long term patients (8); respiratory &amp; feeding problems (7)</li> <li>• Exercise &amp; activity related issues (returning to exercise/school/college/work; knowing how much exercise to do; management of exercise tolerance) (9)</li> <li>• Lack of professionals time and facilities (3)</li> </ul>
Identify the main barriers to the development of rehabilitation services in your unit. Response rate (28/34, 82%)	<ul style="list-style-type: none"> <li>• Lack of funding (staffing and/or facilities) (28)</li> <li>• Wide geographical catchment area (9)</li> <li>• Relatively small number of patients needing rehabilitation (2)</li> </ul>

## Acknowledgements

Work supported by a grant from the Research Capacity Committee of the NHS Northern and Yorkshire Region.

## References

1. Fredriksen PM, Kahrs N, Blaasvaer S, et al. Effects of physical training in children and adolescents with congenital heart disease. *Cardiol Young* 2000; 10: 107–114.
2. Gupta S, Mitchell I, Giuffre, RM, Crawford S. Covert fears and anxiety in asthma and congenital heart disease. *Child: Care, Health and Development* 2001; 27: 335–348.
3. Kendall L, Lewin RJP, Quirk J, Parsons JM, Veldtman GR, Hardman GF. Factors associated with self-perceived state of health in adolescents with congenital cardiac disease attending paediatric cardiologic clinics. *Cardiol Young* 2001; 11: 431–438.
4. Galioto FM, Tomassoni TL. Exercise rehabilitation in congenital heart disease. *Prog Pediatr Cardiol* 1993; 2: 50–54.
5. The Bristol Royal Infirmary Inquiry, July 2001.
6. Department of Health. *The Welfare of Children and Young People in Hospital*. HMSO, London, 1991.
7. NHS Centre for Reviews and Dissemination. *Cardiac Rehabilitation*. *Effective Health Care* 1998; 4 (4).
8. Lewin RJP, Ingleton R, Newens AJ, Thompson DR. Adherence to cardiac rehabilitation guidelines: a survey of rehabilitation programmes in the United Kingdom. *BMJ* 1998; 316: 1354–1355.
9. Thompson DR, Bowman GS, Kitson AL, de Bono DP, Hopkins A. Cardiac rehabilitation in the United Kingdom: guidelines and audit standards. *Heart* 1996; 75: 89–93.