

## Evaluating models of care closer to home for children and young people who are ill

Gillian Parker, Gemma Spiers, Kate Gridley, Karl Atkin<sup>1</sup>, Linda Cusworth, Suzanne Mukherjee, Yvonne Birks<sup>1</sup>, Karin Lowson<sup>2</sup>, Dianne Wright<sup>2</sup> and Kate Light<sup>3</sup>

Standard six of the National Service Framework (NSF) for Children, Young People and Maternity Services recommends that care for ill children should be delivered as close to home as possible. This research aimed to find evidence about delivering care closer to home (CCTH) for ill children, particularly in relation to:

- the range and extent of provision
- the implications of CCTH for those who plan, deliver and use such services
- cost effectiveness.



## Key findings

- Through a national survey of English Primary Care Trusts, Acute Trusts and Children's Hospices, we identified three relatively distinct 'clusters' of services: specialist, hospital-based services; generic, community-based services; and a third cluster of mainly therapy-type services.
- Using four case studies, we found that a number of factors influenced the development and delivery of CCTH.
- At an organisational level:
  - A lack of evidence made it difficult to develop CCTH. Problems defining and quantifying its effectiveness made collecting robust data difficult.
  - Good relationships between commissioners and providers were important in developing CCTH services. Competition rules had, however, made this more difficult for some.

<sup>1</sup> Department of Health Sciences, University of York

<sup>2</sup> York Health Economics Consortium, University of York

<sup>3</sup> Centre for Reviews and Dissemination, University of York

- At a practice level:
  - Capacity could influence the amount and quality of care provided.
  - Working across and within boundaries created difficulties, and appeared to be linked to an imperfect understanding about the role and purpose of CCTH among staff in other parts of the health service.
  - Working in community settings could be isolating for staff and raised issues about personal safety when working alone.
- For parents using CCTH services:
  - They usually preferred receiving care at home where possible.
  - Being supported by community staff was seen to be important, especially when parents played an increased role in their child's care.
- Economic analysis suggests CCTH may offer a cost saving when compared to hospital-based care, but a number of factors influence this.

## Background

Standard six of the National Service Framework (NSF) for Children, Young People and Maternity Services recommends that care for ill children should be delivered as *close to home* as possible.

The evidence base to support development of care closer to home (CCTH) is, however, relatively weak in relation to several issues, such as: clinical effectiveness; the merits of different approaches and models; potential costs and benefits to families and the health service; and the implications of CCTH for those who plan, deliver and use CCTH services.

Our study aimed to:

- map the extent of CCTH provision and the types of models providing this care
- explore the implications of CCTH for those who plan, deliver and use such services
- explore the cost implications of CCTH.

## Findings

### National Survey

We identified 417 NHS services providing CCTH, and received completed questionnaires from 296 of these, plus 15 children's hospices providing hospice care in the home. A wide range of services was reported, but the most common service type was generic home care and community children's nursing teams. This suggests that this is the most common model of CCTH delivery.

Using cluster analysis, we identified three relatively distinct 'clusters' of services: specialist, hospital-based services (e.g. teams providing outreach, or specialist units that aim to prevent hospital admission); generic, community-based services; and a third cluster of mainly therapy-type services.

Further analysis demonstrated that specialist hospital-based services and community-based services offered and performed different activities. For example, more than 90% of community-based services reported providing ongoing nursing care, technical support, drugs administration, palliative or end of life care, and training and liaison. By contrast, around half of specialist hospital-based services reported providing ongoing nursing care, drugs administration and sample taking. Specialist, hospital-based services were more likely to report training, liaison, health monitoring and providing social/psychological support compared to other activities.

### Case Studies

We studied five CCTH services across four Primary Care Trusts (see figure 1). These services were: a generic community children's nursing team, a team of nurse practitioners, two teams of specialist outreach nurses (both oncology) and a children's assessment unit. Interviews with staff in these sites highlighted a number of factors that influenced the development and delivery of CCTH at both an organisational and practice level.

#### Organisational Level

For those working at a strategic level in their organisation (this was typically commissioners, and senior strategic managers), various factors played a role in developing CCTH services. A lack of evidence was felt to impede the development of CCTH services. For some, insufficient systems and problems defining and quantifying effectiveness of CCTH made collecting robust data difficult. Where data was available, this was important in developing provision.

Good relationships between commissioners and providers were also important in developing CCTH services, particularly as providers held 'expertise'. Competition rules had made this more difficult for some. Others, however, sustained a distinction between working with providers to develop existing services, and working with them to commission new ones, which offered a useful strategy for negotiating this problem. Finally, a lack of money and performance mechanisms to accompany the NSF meant that developing CCTH services was not a priority for some.

### Practice Level

For frontline staff, a number of factors influenced the day-to-day delivery of CCTH. Team capacity was seen to be problematic, and could influence the amount and quality of care provided. This was particularly the case in relation to staffing and service cover. For staffing, some teams experienced recruitment and retention difficulties, and even when at full complement could not always meet the demand for their service. For service cover, practitioners felt that 'office hours' were not compatible with normal family routines. Limited team capacity created difficulties in providing holistic care, including social and psychological support, which practitioners saw as important aspects of CCTH. Working across and within service boundaries was another factor that created difficulties. This was related to an imperfect understanding of the role and purpose of CCTH among staff in other services or agencies. Such imperfect understanding, for example, could mediate the extent and appropriateness of referrals. Finally, working in community settings could be isolating for staff and raised issues about personal safety when working alone. There was thus a need for good supervision and support structures. Despite the difficulties of providing CCTH, practitioners were passionate about this form of care and felt it offered benefits to the family, such as facilitating the continuation of normal family routines.

### Parents' experience of CCTH

While parents in our study recognised that sometimes their child needed to be in hospital, they tended to prefer care provided at home when it was possible to do so. When care was provided at home, it was seen to counter the logistical (e.g. travelling) and financial (e.g. parking costs, loss of hours of work) difficulties of attending hospital for care.

When care was provided closer to, and at home, parents often had good relationships with staff. It was through these relationships that parents were supported both socially and psychologically. Being supported in this way was important to parents in our study, and for some, there was a need for increased support. Being supported was especially important when parents took on increased responsibility for caring for their ill child at home. For example, parents could be involved in technical nursing procedures, or administering complex regimens of medicine. The extent to which parents were willing to take on technical and nursing responsibilities varied across our sample. Some felt able to take on more responsibility, whereas others did not want this.

### Health Economics

CCTH may offer a cost saving when compared to hospital-based care, particularly for children with complex and long-term needs. This appears largely due to days of hospital care saved. The opportunities for cost saving may be affected by case mix, skill mix and financial incentives that might encourage or discourage acute hospitals from moving care closer to home.

Figure 1. Summary of the case study sites

	<i>Urban</i>	<i>Urban/Rural Mix</i>
<b>High to moderate ethnic diversity</b>	<b>Site W</b> <i>Deprivation: High</i> <i>Model: Generic Children's Community Nursing Team</i> <i>Provider Trust: PCT</i>	<b>Site Xa</b> <i>Deprivation: Low</i> <i>Model: Nurse Practitioners</i> <i>Provider Trust: PCT</i>  <b>Site Xb</b> <i>Deprivation: Low</i> <i>Model: Oncology Specialist Outreach Nursing</i> <i>Provider Trust: Acute</i>
<b>Moderate to low ethnic diversity</b>	<b>Site Y</b> <i>Deprivation: High</i> <i>Model: Oncology Specialist Outreach Nursing</i> <i>Provider Trust: Acute Trust</i>	<b>Site Z</b> <i>Deprivation: Low</i> <i>Model: Children's Assessment Unit</i> <i>Provider Trust: Acute Trust</i>

# Implications for policy and practice

Our research demonstrates that a wide range of services in England are providing CCTH, but are doing so within distinct models of care. This suggests that CCTH is a feasible service option for NHS organisations. Moreover, interviews with parents suggest it is a valued service option when possible. Our case studies, however, show that a number of factors are important for the development of CCTH services:

## Important factors for the development of CCTH Services

- Effective working relationships between commissioners and providers are important.
- Better or more readily available data on costs, caseload and contacts would improve the evidence base for CCTH. This evidence, in turn, would help facilitate further service development.
- Sufficient and holistic support for families should be an integral aspect of CCTH services. This is especially the case where parents take on responsibility for nursing tasks as part of their child's care.
- Sufficient service capacity is important for delivering the holistic care needed for CCTH provision.
- CCTH involves isolated working on the part of the practitioner, and adequate support structures should be in place to address this.

## Methods

This research was funded by the National Institute for Health Research Service Delivery and Organisation programme, and was carried out between 2007 and 2010. We conducted the research in four stages:

- 1 A systematic review of the evidence for paediatric home care, and a descriptive review of UK models of CCTH
- 2 A national survey of English PCTs and Acute Trusts, as well as children's hospices, to map the extent and range of service provision. We used a two-stage approach for this. We initially asked key people in each trust to tell us what CCTH services they currently provided. In the second stage, we contacted each of the identified services to collect data on service delivery and organisational features (e.g. staffing, cover, budgets). We achieved a 71% response rate for identified services.
- 3 Four in-depth case studies covered five CCTH services. Each case study site represented different demographic profiles and models of CCTH provision. Figure 1 gives a summary of the sites. Across the sites, we conducted in-depth interviews with 36 staff involved in commissioning, planning and delivering CCTH. We also conducted face-to-face interviews with 22 families of children using the CCTH services in the case study sites.
- 4 Some limited economic analysis was carried out to explore the cost effectiveness of providing CCTH. This used survey data on caseloads and costs, explored some Hospital Episode Statistics in our case study sites and compared them with national data; and used both of these, alongside evidence from the systematic review, to carry out simple economic modelling.

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Social Policy Research Unit  
The University of York, Heslington  
York YO10 5DD, United Kingdom.  
Telephone: +44 (0)1904 321950  
Fax: +44 (0)1904 321953  
E-mail: [spru@york.ac.uk](mailto:spru@york.ac.uk)