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NIHR Service Delivery and Organisation programme

NHS National Institute for Health Research

Evaluating models of care closer to home for children and young people who are ill: main report

Executive Summary

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Executive Summary

Background

Providing care for children who are ill, as close to home as possible, is an objective of health care providers and policy makers nationally and internationally. The existing evidence base to support development of care closer to home (CCTH) is weak in relation to clinical effectiveness, approaches and models, potential costs and benefits to families and the health service, impact on those who use CCTH, and how CCTH is best delivered and organised.

Aims of the project

1. Identify service models currently available to provide CCTH for children who are ill
2. Explore how these models respond to need
3. Explore the benefits, drawbacks and cost implications of a shift to more CCTH for ill children
4. Establish evidence-based good practice for establishing and running CCTH

Methods

This project took a mixed methods approach. We updated and extended a previous systematic review of international evidence on paediatric home care and reviewed UK literature that described models of CCTH. The review is in a separate report, but we used its findings in our health economics analysis. A national survey of English acute and primary care trusts mapped paediatric CCTH services and collected data on their delivery and organisation (e.g. staffing, cover, budgets). We used the survey data to create a typology of CCTH services. Case studies in four PCTs in England, using in-depth interviews with 35 staff who commissioned, organised and delivered CCTH and 22 families who used the services, explored the implications and impact of CCTH. Lastly, we explored the cost effectiveness of providing CCTH. This used survey data on caseloads and costs, compared Hospital Episode Statistics in case study sites with national data, and used the results of these, alongside evidence from the systematic review, to carry out simple economic modelling. Relatively few services provided information about their costs and caseloads, limiting this element of our work.

Key findings

Models of care closer to home

There is a wide range of CCTH services, but community children's nursing teams are predominant. Fifteen children's hospices providing CCTH services also responded, suggesting that this model of end of life care is growing.

There are three main service models: cluster 1 largely provides condition specific services, usually working from acute settings; cluster 2 predominantly provides allied health therapy input; and cluster 3 services are largely community-based and provide both acute and long-term care, usually to children with very complex needs.

Responding to need

Cluster 1 and 3 services focus on preventing hospital admission, providing care for complex health needs out of hospital, reducing length of hospital stay, and supporting early discharge. Cluster 3 services are more likely to provide ongoing nursing care, technical support, drugs administration, and palliative or end of life care. Cluster 1 services are more likely to report training, liaison, health monitoring and social/psychological support, although half also report providing ongoing nursing care, drugs administration and sample taking.

These CCTH models operate as a 'virtual' service system, providing different elements of support to children with differing needs. While their functions and focus overlap somewhat, all are arguably necessary to avoid gaps in care delivery for very vulnerable children.

Benefits, drawbacks and cost implications

Commissioners and providers see CCTH as something that is for the NHS (e.g. preventing hospital admission), and for patients and families. Many feel that CCTH is better for children and families, describing both clinical (e.g. reducing risk of infection) and social (e.g. maintaining 'normality') benefits.

However, we identified difficulties in implementing CCTH at organisational and practice levels.

Organisational level issues

A perceived lack of evidence can impede CCTH development. Inadequate systems, and problems defining and quantifying effectiveness make collecting robust data difficult. Where data are available, this can underpin developing provision.

Good relationships between commissioners and providers are vital, particularly as providers hold the 'expertise'. Some find that competition rules make good relationships more difficult. Others adopt a useful strategy of distinguishing between working with providers to develop existing services, and working with them to commission new ones.

Practice level issues

Capacity – particularly staffing and cover – is sometimes problematic, making it difficult to provide holistic care, including social and psychological support, which both practitioners and families see as important aspects of CCTH.

Working across and within boundaries can create difficulties when there is imperfect understanding in other parts of the health service about the role and purpose CCTH.

Community working can be isolating for staff and raises issues about personal safety when working alone. Good supervision and support structures help to deal with this.

Parents recognise that sometimes their child needs to be in hospital but prefer care to be at home where possible. This reduces disruption for the child and family, and sometimes the financial impact of caring for an ill child. Some parents have good relationships with staff, receiving social and psychological support, which they value. Others feel a need for increased support. Parents' willingness to take on technical and nursing responsibilities varies. The support of CCTH services is important for those who play an enhanced role in technical care for their child.

Our health economics work used all elements of the study, including the systematic review (see separate report). The conclusion was that CCTH might 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. Case mix, skill mix and financial disincentives for acute providers may affect the opportunities for cost saving. The inability of most survey respondents to provide information about caseload and costs for their services restricted the health economics analysis we could carry out.

Evidence-based good practice

Descriptive accounts of CCTH rarely describe service delivery and organisational characteristics of services. This made it impossible to produce advice about good practice in establishing and running CCTH services from the systematic review (see separate report). However, other elements of the project threw some light onto these issues, outlined above. We build on these below, where we bring findings from the different elements of the project together.

Implications for health care

CCTH can provide safe and effective care for a wide range of children who would previously have been in hospital, and may do so with reduced costs to the health service, and to families too. Areas that commissioners and providers will need to consider in developing CCTH include:

- **The need for negotiated and agreed care protocols**, between acute and community-based providers, and between CCTH services and primary care.

- **Good working relationships between acute and community-based health care providers to ensure continuity of care.** These relationships are also important to ensure that savings from reduced length of stay in one part of the health care system are applied in the parts that support the reduced lengths of stay.
- **Understanding among general practitioners about CCTH and its potential**. Even when care protocols are agreed, it takes time to build the trust of GPs in referral to CCTH. A sustained period of negotiation and confidence building among GPs may be necessary to help realise the full gains of CCTH.
- **The right skill mix in CCTH teams**. Having a range of nursing bands in a team, including health care assistants, may influence cost-effectiveness.
- **The importance of case mix in determining the costs and flexibility of CCTH services**. Generic teams that can deal with both short-term acute illnesses and longer-term, more complex care may be more cost-effective and find it easier to manage fluctuations in demand. Embedding nurse practitioners within generic CCTH teams seems a promising model, because it addresses both skill mix and case mix.
- **The nature of contracting with CCTH services**. Block contracts offer less flexibility to CCTH services dealing with fluctuating levels of need, while competition rules may impede planned innovation. However, given variability of caseloads in most CCTH services, setting a tariff is challenging. Cost per case seems to work well in continuing care provision and may be worth experimenting with in other types of CCTH.
- **The need to provide psychosocial support within CCTH**. This is not a luxury; it is a vital part of supporting ill children and their families, particularly those dealing with very complex health needs.
- **The need for robust data systems on activities and costs**. Using HES data to examine length of stay might be a useful starting point for many health economies that do not yet have robust systems in place.
- **Supervision and support in CCTH**. CCTH involves lone-working; good supervision and support structures within teams are essential to safe practice.
- **24 hour, seven day a week support**. For some CCTH services, this can be provided effectively through telephone support systems. For services intended as immediate alternatives to acute hospital care, it is counterproductive, for children, families and the health care system, to limit them to 'office hours'.
- **The availability of training for paediatric community nursing**. Local availability of appropriate training for nurses working in the community with ill children seems to affect recruitment and retention.

Addendum:

This document is an output from a research project that was commissioned by the Service Delivery and Organisation (SDO) programme whilst it was managed by the National Coordinating Centre for the Service Delivery and Organisation (NCCSDO) at the London School of Hygiene & Tropical Medicine. The NIHR SDO programme is now managed by the National Institute for Health Research Evaluations, Trials and Studies Coordinating Centre (NETSCC) based at the University of Southampton.

Although NETSCC, SDO has managed the project and conducted the editorial review of this document, we had no involvement in the commissioning, and therefore may not be able to comment on the background of this document. Should you have any queries please contact sdo@southampton.ac.uk.