

# A systematic review of the costs and effectiveness of different models of paediatric home care

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## *Executive summary*

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# Executive summary

## Background

Technological developments in care, the impact of hospital admission on children and their families, changing policies for severely disabled children, and the costs of health care have encouraged the development of paediatric home care (PHC). However, despite increased provision, evidence about effectiveness, costs and impact remains elusive.

## Objectives

To establish:

- the range and types of PHC
- the effectiveness and costs of PHC
- if and how cost-effectiveness differs between different groups of children
- the speed of growth of the evidence base
- what recommendations could be made for further research.

## Methods

Guidelines from the Centre for Reviews and Dissemination were followed.

### Data sources

Twenty electronic databases, publications lists and current research registers were searched. Reference lists, handsearching, personal contact with researchers, and forward citation searching were also used.

### Inclusion criteria

#### **For relevance:**

- studies of PHC as an alternative to acute hospital care
- children under 18 years of age
- serious acute or chronic illness
- published since 1985.

#### **For design:**

- randomised or pseudo-randomised trials
- studies with a health economics element
- non-randomised controlled trial (RCT) studies comparing PHC against some other model.

### Data extraction

#### **RCTs:**

mortality; service use; clinical, physical and psychological outcomes; costs; impact on family, social life and education; knowledge of the condition.

#### **Economic studies:**

costs to the health service, family, and other agencies; analysis of costs and benefits.

#### **Other studies:**

clinical outcomes; costs; impact.

Quality criteria were applied to the RCTs and economic studies, but were not used to exclude studies.

### Data synthesis

Analysis was predominantly descriptive, given the heterogeneity of focus, outcome reporting and quality of the studies.

## Results

Almost 15,000 papers were identified. Ten RCTs (24 papers), 16 economic papers and 14 non-RCT studies (15 papers) were eventually included.

Five main types of PHC were evident for the following: very low birth weight or medically fragile babies; asthma or diabetes; technology-dependent children; children with mental health problems; generic models of PHC.

### Very low birth weight babies

There was limited reporting of the clinical or developmental outcomes of earlier discharge, accompanied by home care, for very low birth weight babies. Physical and mental development may be enhanced but sample sizes were too small to be confident about this. PHC may be cheaper than the alternative but the costing methods used were weak. Impact on family members was rarely reported.

### Diabetes and asthma

Whether PHC for children with diabetes or asthma affects clinical or 'social' outcomes or

costs, for children, their families or the health service remained unsure. It was concluded that early discharge with home care after diagnosis may reduce parents' costs, largely by reducing children's initial length of hospital stay.

### Technology-dependent children

Studies of home intravenous therapy, parenteral and enteral nutrition, oxygen therapy, dialysis and nebuliser therapy were identified. Controlled studies were rare, as were studies that measured clinical outcomes, impact on families or children's quality of life. PHC for technology-dependent children may be cheaper for the health service, but little else could be concluded about it.

### Children with mental health problems

Apart from parents' satisfaction with services, few other effects were reported. It was concluded that health service use after home care may be lower, with reductions in health service costs. Admission to residential care may also be lower, with reductions in social care costs.

### Generic paediatric home care

Only one study was identified. No major clinical effects were evident at early follow-up. Very partial follow-up after 5 years suggested that psychological adjustment may be improved by PHC. Family satisfaction with services was higher with home care, although no direct impact on the children's mothers or on the family was detected. No costings have been reported.

## Conclusions

### State of research

The evidence base in this area was weak, as were methods. Common methodological weaknesses included sample sizes, timing of data collection, objectivity, long-term follow-up, accurate description of PHC models, impact beyond the hospital, and the ages of children researched. Narrow ranges of children and parents – in terms of socio-economic status, ethnicity and geographical location – were included in studies, and children's views were largely absent.

### Implications for the health service

With the current state of evidence, it was concluded that no confident messages could be given to the health service about PHC.

### Recommendations for research

1. A controlled, prospective evaluation of the role of generic PHC for very dependent

children and their families, across several sites.

2. A systematic review of the clinical safety of home nebuliser use for children with cystic fibrosis, concentrating on infection rates.
3. Evaluation of services or training programmes that enable families to use nebuliser equipment effectively and safely.
4. A national survey of current practice in paediatric home intravenous therapy.
5. Systematic reviews of outcomes in paediatric home intravenous therapy using case series.
6. Multicentre controlled studies of home versus hospital care for paediatric home intravenous therapy.
7. A systematic review of paediatric parenteral and enteral nutrition (updated in the case of parenteral nutrition) using case series.
8. Non-RCT, empirical evaluation of home dialysis for children, and economic modelling that includes costs falling to other agencies and families.
9. High quality trials of models of home care for children with diabetes and asthma, exploring which children and families would benefit the most.
10. Research to identify what support the most fragile babies and their families need and, if provided, what benefits it delivers at what cost.
11. A national survey to establish current practices and numbers of children receiving home oxygen therapy, to ensure adequate sample sizes for subsequent evaluative research drawn from multiple sites.
12. Rigorous, well-designed, non-RCT research on the effectiveness of different models of care for oxygen-dependent children, the impact that home oxygen therapy has on children and their families, and the ways in which services can enhance positive outcomes.
13. Research about whether children with asthma should have nebulisers at home, rather than using different modes of drug administration; this should include studies of different age groups.
14. A multicentre RCT of home care for children with mental health problems, controlling for different treatment regimes.

## Publication

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# NHS R&D HTA Programme

The NHS R&D Health Technology Assessment (HTA) Programme was set up in 1993 to ensure that high-quality research information on the costs, effectiveness and broader impact of health technologies is produced in the most efficient way for those who use, manage and provide care in the NHS.

Initially, six HTA panels (pharmaceuticals, acute sector, primary and community care, diagnostics and imaging, population screening, methodology) helped to set the research priorities for the HTA Programme. However, during the past few years there have been a number of changes in and around NHS R&D, such as the establishment of the National Institute for Clinical Excellence (NICE) and the creation of three new research programmes: Service Delivery and Organisation (SDO); New and Emerging Applications of Technology (NEAT); and the Methodology Programme.

This has meant that the HTA panels can now focus more explicitly on health technologies ('health technologies' are broadly defined to include all interventions used to promote health, prevent and treat disease, and improve rehabilitation and long-term care) rather than settings of care. Therefore the panel structure has been redefined and replaced by three new panels: Pharmaceuticals; Therapeutic Procedures (including devices and operations); and Diagnostic Technologies and Screening.

The HTA Programme continues to commission both primary and secondary research. The HTA Commissioning Board, supported by the National Coordinating Centre for Health Technology Assessment (NCCHTA), will consider and advise the Programme Director on the best research projects to pursue in order to address the research priorities identified by the three HTA panels.

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