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

G Parker
P Bhakta
CA Lovett
S Paisley
R Olsen
D Turner
B Young

Health Technology Assessment 2002; Vol. 6: No. 35
How to obtain copies of this and other HTA Programme reports.
An electronic version of this publication, in Adobe Acrobat format, is available for downloading free of charge for personal use from the HTA website (http://www.hta.ac.uk). A fully searchable CD-ROM is also available (see below).
Printed copies of HTA monographs cost £20 each (post and packing free in the UK) to both public and private sector purchasers from our Despatch Agents.
Non-UK purchasers will have to pay a small fee for post and packing. For European countries the cost is £2 per monograph and for the rest of the world £3 per monograph.
You can order HTA monographs from our Despatch Agents:
– fax (with credit card or official purchase order)
– post (with credit card or official purchase order or cheque)
– phone during office hours (credit card only).
Additionally the HTA website allows you either to pay securely by credit card or to print out your order and then post or fax it.

Contact details are as follows:
HTA Despatch Email: orders@hta.ac.uk
c/o Direct Mail Works Ltd Tel: 02392 492 000
4 Oakwood Business Centre Fax: 02392 478 555
Downley, HAVANT PO9 2NP, UK Fax from outside the UK: +44 2392 478 555

NHS libraries can subscribe free of charge. Public libraries can subscribe at a very reduced cost of £100 for each volume (normally comprising 30–40 titles). The commercial subscription rate is £300 per volume. Please see our website for details. Subscriptions can only be purchased for the current or forthcoming volume.

Payment methods
Paying by cheque
If you pay by cheque, the cheque must be in pounds sterling, made payable to Direct Mail Works Ltd and drawn on a bank with a UK address.

Paying by credit card
The following cards are accepted by phone, fax, post or via the website ordering pages: Delta, Eurocard, Mastercard, Solo, Switch and Visa. We advise against sending credit card details in a plain email.

Paying by official purchase order
You can post or fax these, but they must be from public bodies (i.e. NHS or universities) within the UK. We cannot at present accept purchase orders from commercial companies or from outside the UK.

How do I get a copy of HTA on CD?
Please use the form on the HTA website (www.hta.ac.uk/htacd.htm). Or contact Direct Mail Works (see contact details above) by email, post, fax or phone. HTA on CD is currently free of charge worldwide.

The website also provides information about the HTA Programme and lists the membership of the various committees.
A systematic review of the costs and effectiveness of different models of paediatric home care

G Parker\textsuperscript{1}\textsuperscript{*}
P Bhakta\textsuperscript{1}
CA Lovett\textsuperscript{1}
S Paisley\textsuperscript{2}
R Olsen\textsuperscript{1}
D Turner\textsuperscript{3}
B Young\textsuperscript{3}

\textsuperscript{1} Nuffield Community Care Studies Unit, University of Leicester, UK
\textsuperscript{2} School of Health and Related Research, University of Sheffield, UK
\textsuperscript{3} Department of Epidemiology and Public Health, University of Leicester, UK

\textsuperscript{*} Corresponding author

Declared competing interests of the authors: none

Published January 2003

This report should be referenced as follows:


Health Technology Assessment is indexed in Index Medicus/MEDLINE and Excerpta Medical EMBASE. Copies of the Executive Summaries are available from the NCCHTA website (see opposite).
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.

The research reported in this monograph was funded as project number 98/05/03.

The views expressed in this publication are those of the authors and not necessarily those of the HTA Programme or the Department of Health. The editors wish to emphasise that funding and publication of this research by the NHS should not be taken as implicit support for any recommendations made by the authors.

Criteria for inclusion in the HTA monograph series
Reports are published in the HTA monograph series if (1) they have resulted from work commissioned for the HTA Programme, and (2) they are of a sufficiently high scientific quality as assessed by the referees and editors.

Reviews in Health Technology Assessment are termed ‘systematic’ when the account of the search, appraisal and synthesis methods (to minimise biases and random errors) would, in theory, permit the replication of the review by others.
## Contents

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>List of abbreviations</td>
<td>i</td>
</tr>
<tr>
<td>Executive summary</td>
<td>iii</td>
</tr>
<tr>
<td><strong>1 Background</strong></td>
<td>1</td>
</tr>
<tr>
<td>What is paediatric home care?</td>
<td>1</td>
</tr>
<tr>
<td>The need for evaluation</td>
<td>2</td>
</tr>
<tr>
<td>Research question</td>
<td>3</td>
</tr>
<tr>
<td><strong>2 Review methods</strong></td>
<td>5</td>
</tr>
<tr>
<td>Preliminary searching</td>
<td>5</td>
</tr>
<tr>
<td>Main search strategy</td>
<td>5</td>
</tr>
<tr>
<td>Additional strategies</td>
<td>7</td>
</tr>
<tr>
<td>Inclusion and exclusion criteria for selection of studies</td>
<td>8</td>
</tr>
<tr>
<td>Final selection of studies for review</td>
<td>10</td>
</tr>
<tr>
<td>Data extraction</td>
<td>12</td>
</tr>
<tr>
<td>Quality of studies</td>
<td>12</td>
</tr>
<tr>
<td>Analysis of data</td>
<td>13</td>
</tr>
<tr>
<td><strong>3 Trial results</strong></td>
<td>15</td>
</tr>
<tr>
<td>Home care for very low birth weight or medically fragile babies</td>
<td>15</td>
</tr>
<tr>
<td>Home care for children with asthma or diabetes</td>
<td>21</td>
</tr>
<tr>
<td>Home care for children with mental health problems</td>
<td>26</td>
</tr>
<tr>
<td>Paediatric home care</td>
<td>33</td>
</tr>
<tr>
<td><strong>4 Studies including some element of health economics</strong></td>
<td>37</td>
</tr>
<tr>
<td>Early discharge for very low birth weight babies and/or those who have received neonatal intensive care</td>
<td>37</td>
</tr>
<tr>
<td>Early discharge and home care for oxygen-dependent babies</td>
<td>39</td>
</tr>
<tr>
<td>Home care for children with newly diagnosed diabetes</td>
<td>42</td>
</tr>
<tr>
<td>Home chemotherapy for children with cancer</td>
<td>46</td>
</tr>
<tr>
<td>Home intravenous antibiotic treatment</td>
<td>48</td>
</tr>
<tr>
<td>Home haemodialysis</td>
<td>49</td>
</tr>
<tr>
<td>Home care for oxygen-dependent children</td>
<td>52</td>
</tr>
<tr>
<td>Home-based treatment for children with mental health problems</td>
<td>54</td>
</tr>
<tr>
<td><strong>5 Other comparative studies of paediatric home care</strong></td>
<td>61</td>
</tr>
<tr>
<td>Home care for very low birth weight/ NICU babies</td>
<td>61</td>
</tr>
<tr>
<td>Home care for children with insulin-dependent diabetes</td>
<td>63</td>
</tr>
<tr>
<td>‘Technological’ care at home</td>
<td>65</td>
</tr>
<tr>
<td>Home care for children with mental health problems</td>
<td>67</td>
</tr>
<tr>
<td>Discussion</td>
<td>68</td>
</tr>
<tr>
<td><strong>6 Integration and discussion of findings</strong></td>
<td>71</td>
</tr>
<tr>
<td>Home care for very low birth weight or medically fragile babies (including oxygen-dependent babies)</td>
<td>71</td>
</tr>
<tr>
<td>Home care for children with asthma or diabetes</td>
<td>71</td>
</tr>
<tr>
<td>Home care for technology-dependent children</td>
<td>72</td>
</tr>
<tr>
<td>Home care for children with mental health problems</td>
<td>73</td>
</tr>
<tr>
<td>Generic models of paediatric home care</td>
<td>74</td>
</tr>
<tr>
<td>Methodological and interpretive issues</td>
<td>74</td>
</tr>
<tr>
<td><strong>7 Conclusions, implications and recommendations</strong></td>
<td>77</td>
</tr>
<tr>
<td>Implications for health care</td>
<td>77</td>
</tr>
<tr>
<td>Recommendations for research</td>
<td>78</td>
</tr>
<tr>
<td>Rate of growth of research base</td>
<td>82</td>
</tr>
<tr>
<td>Acknowledgements</td>
<td>85</td>
</tr>
<tr>
<td>References</td>
<td>87</td>
</tr>
<tr>
<td>Appendix 1 Other sources consulted</td>
<td>93</td>
</tr>
<tr>
<td>Appendix 2 Electronic search strategies</td>
<td>95</td>
</tr>
<tr>
<td>Appendix 3 Details of all papers included</td>
<td>103</td>
</tr>
<tr>
<td>Health Technology Assessment reports published to date</td>
<td>109</td>
</tr>
<tr>
<td>Health Technology Assessment Programme</td>
<td>115</td>
</tr>
</tbody>
</table>
# List of abbreviations

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Meaning</th>
</tr>
</thead>
<tbody>
<tr>
<td>A&amp;E</td>
<td>Accident and Emergency</td>
</tr>
<tr>
<td>ANOVA</td>
<td>analysis of variance</td>
</tr>
<tr>
<td>AV</td>
<td>arteriovenous</td>
</tr>
<tr>
<td>BNI</td>
<td>British Nursing Index</td>
</tr>
<tr>
<td>CAPD</td>
<td>continuous ambulatory peritoneal dialysis</td>
</tr>
<tr>
<td>CCA</td>
<td>corrected chronological age</td>
</tr>
<tr>
<td>CCN</td>
<td>community children’s nurse</td>
</tr>
<tr>
<td>CCPD</td>
<td>continuous cyclic peritoneal dialysis</td>
</tr>
<tr>
<td>CCTR</td>
<td>Cochrane Controlled Trials Register</td>
</tr>
<tr>
<td>CDSR</td>
<td>Cochrane Database of Systematic Reviews</td>
</tr>
<tr>
<td>CI</td>
<td>confidence interval</td>
</tr>
<tr>
<td>CPN</td>
<td>community psychiatric nurse</td>
</tr>
<tr>
<td>CRD</td>
<td>[NHS] Centre for Reviews and Dissemination</td>
</tr>
<tr>
<td>CRIB</td>
<td>Current Research in Britain</td>
</tr>
<tr>
<td>CRIW</td>
<td>Current Research Worldwide</td>
</tr>
<tr>
<td>CV</td>
<td>central venous</td>
</tr>
<tr>
<td>CVC</td>
<td>central venous catheter</td>
</tr>
<tr>
<td>DARE</td>
<td>Database of Abstracts of Reviews of Effectiveness</td>
</tr>
<tr>
<td>DoH</td>
<td>Department of Health</td>
</tr>
<tr>
<td>POINT</td>
<td>Publications on the Internet</td>
</tr>
<tr>
<td>DQ</td>
<td>Battelle Development Quotient</td>
</tr>
<tr>
<td>EPOC</td>
<td>Effective Practice and Organisation of Care (Cochrane Review Group)</td>
</tr>
<tr>
<td>GP</td>
<td>general practitioner</td>
</tr>
<tr>
<td>HbA1c</td>
<td>glycosylated (glycated) haemoglobin</td>
</tr>
<tr>
<td>HETF</td>
<td>home enteral tube feeding</td>
</tr>
<tr>
<td>HH</td>
<td>home health care</td>
</tr>
<tr>
<td>HMIC</td>
<td>Health Management Information Consortium</td>
</tr>
<tr>
<td>HOME</td>
<td>Home Observation for Measurement of the Environment</td>
</tr>
<tr>
<td>HPN</td>
<td>home parenteral nutrition</td>
</tr>
<tr>
<td>HV</td>
<td>home visiting</td>
</tr>
<tr>
<td>IDDM</td>
<td>insulin-dependent diabetes mellitus</td>
</tr>
<tr>
<td>ISI</td>
<td>Institute of Scientific Information</td>
</tr>
<tr>
<td>ISTP</td>
<td>Index of Scientific and Technical Proceedings</td>
</tr>
<tr>
<td>IVI</td>
<td>intravenous infusion</td>
</tr>
<tr>
<td>IVP</td>
<td>intravenous push</td>
</tr>
<tr>
<td>MDI</td>
<td>Bayley Mental Development Index</td>
</tr>
<tr>
<td>MST</td>
<td>multisystemic therapy</td>
</tr>
<tr>
<td>N/A</td>
<td>not available</td>
</tr>
<tr>
<td>NHS EED</td>
<td>NHS Economic Evaluation Database</td>
</tr>
<tr>
<td>NICU</td>
<td>neonatal intensive care unit</td>
</tr>
<tr>
<td>NRR</td>
<td>National Research Register</td>
</tr>
<tr>
<td>NS</td>
<td>not significant</td>
</tr>
<tr>
<td>PDI</td>
<td>Bayley Psychomotor Development Index</td>
</tr>
<tr>
<td>PHC</td>
<td>paediatric home care</td>
</tr>
<tr>
<td>RCT</td>
<td>randomised controlled trial</td>
</tr>
<tr>
<td>SCI</td>
<td>Science Citation Index</td>
</tr>
<tr>
<td>SD</td>
<td>standard deviation</td>
</tr>
<tr>
<td>SMD</td>
<td>standard mean difference</td>
</tr>
<tr>
<td>SSCI</td>
<td>Social Sciences Citation Index</td>
</tr>
<tr>
<td>TPN</td>
<td>total parenteral nutrition</td>
</tr>
<tr>
<td>WOS</td>
<td>Web of Science</td>
</tr>
</tbody>
</table>

All abbreviations that have been used in this report are listed here unless the abbreviation is well known (e.g. NHS), or it has been used only once, or it is a non-standard abbreviation used only in figures/tables/appendices in which case the abbreviation is defined in the figure legend or at the end of the table.
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

© Queen’s Printer and Controller of HMSO 2002. All rights reserved.
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.
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.

---

**Executive summary**
Chapter 1
Background

Where children are cared for when they have acute or chronic health needs has become an important issue for a number of interrelated reasons: technological developments which ensure that children survive with conditions that would previously have been fatal; technological developments that allow children to be cared for at home where once there would have been little option but hospital care; the often negative impact of hospital admission on children and their families; changing policies for the care of children with severe impairments and costs for healthcare providers, including increased hospital admission rates. These factors combine to create a powerful incentive to recommend or promote the care of ill children at home under most circumstances.

What is paediatric home care?

Home care for sick children has been on the policy agenda for many years. As long ago as 1959 the Platt Report on the health and welfare of children in hospital recommended that “children should not be admitted to hospital if it can possibly be avoided” and that “special facilities for looking after sick children at home should be extended” (cited in House of Commons Health Committee, para.29). The first team of community children’s nurses (CCNs) was established in Rotherham in 1948, followed by another in Birmingham in 1954. However, there was little further development until the 1970s, and only a slow growth in the number of schemes up to the early 1990s. The Health Committee reported that by 1976, six CCN teams were in existence but that the original Rotherham team had been disbanded; in 1981 there were still only eight teams in the whole of the UK. In 1991, however, 54 ‘general’ paediatric home care (PHC) schemes and 105 ‘specialist’ schemes were identified across the UK and by 1995 these numbers had risen to 62 and 124, respectively. Substantial geographical variation was evident, with five regions having only specialist services and only 30% of children living in a district that had a generic scheme.

Two surveys of PHC services carried out in the 1990s paint a similar picture.

First, general PHC services are more likely to work from a community base, in a single district, and accept referrals from general practitioners (GPs), community health staff and parents. By contrast, specialist services are predominantly hospital-based and are more likely to provide services for more than one district. Such ‘out of district’ services are less likely than others to provide practical care and more likely to provide advice only.

Secondly, specialist services are more likely to be focused on a single condition or group of conditions. Tatman and Woodroffe’s survey found that 25% dealt with children with cancer, 22% with cystic fibrosis and other severe respiratory disorders and 20% with neonatal disorders. Very few provided specialist diabetes or asthma services (7% and 2%, respectively). General services were, by definition, more eclectic, providing services for a wide range of conditions – the main ones covered were cancer (74% of services), asthma (74%), cystic fibrosis and other severe respiratory disorders (70%), post-surgical care (72%), diabetes (51%) and ‘other’ medical care (88%). By contrast, only 33% of general services provided neonatal care and 30% orthopaedic care.

Thirdly, few services provided 24 hour cover on a regular basis, with the community-based services providing more extensive hours of service overall.

Fourthly, there was substantial variety in funding sources for the services – hospital trusts, community health services trusts, charities, local fund-raising and specialist ‘inner city’ grants were all identified.

The functions of individual PHC services might thus be very diverse, depending on the particular model, but have been summarised as:

- direct services such as dressings and drug administration, including chemotherapy, tracheostomy care, general nursing care and counselling
- education of the family and patient
- coordination of services between the hospital, GP and the community
- patient advocacy.
The children who particularly benefit from PHC are said to be “those with complex problems who need a coordinated, multidisciplinary approach, those whose condition has not been stabilised in hospital, and children who are at risk in a hospital environment such as those who are immunocompromised” (Lessing and Tatman, 3 p.994).

The need for evaluation

The Audit Commission 6 argued in 1993 that as well as “striving to offer only effective treatments [to children], it is necessary to ensure that they are delivered in the most appropriate setting, and in particular that hospital care is only used when it offers a therapeutic advantage over care at home” (para.112). The Commission’s report claimed that “detailed studies…have shown that home care is much more cost effective…or at least as good” (para.114) as hospital care. However, it is not clear that research currently does show this.

Before embarking on this review, a preliminary scoping search in MEDLINE, using the terms child$ or paediatric$ and home care, for the years 1966–1998, identified 432 titles, some 142 of which seemed possibly relevant to the review. Only seven were described as meta-analyses, controlled studies or randomised controlled trials (RCTs) and four of the latter referred to the same study (of the Paediatric Ambulatory Care Treatment study). 7 This dearth of evaluative literature was particularly evident for new models of service organisation. The evidence base for either clinical or organisational decision-making thus seemed weak. However, the recent growth in this largely descriptive literature suggested, as had the surveys described above, that home or community-based services were being developed with some speed; half of the 142 relevant titles from this preliminary search had been published since 1990.

Further, messages from this early look at the literature about some clinical interventions delivered at home were mixed: increased infections in children with cancer cared for at home, 8 but cheaper and equally effective chemotherapy at home; 9 infected nebulisers used for treatment of cystic fibrosis at home; 10–12 poorly controlled asthma with home nebulisers, 13 sometimes associated with incorrect use, 14 yet lowered emergency hospital visits and admissions when using home nebulisers for asthma; 15 higher rates of catheter infection in total parenteral nutrition (TPN) at home for children compared with adults, 16 yet less infection in central venous catheters at home than in hospital, 17 and long-lasting and safe lines; 18 embolism and septicemia 19 in parenteral nutrition; higher rates of contamination in enteral feeds at home than in hospital 20 and poor standards of care for enteral nutrition. 21 By contrast, home ventilation therapy seemed to have a somewhat better ‘press’ 22,23 with suggestions that, compared with prolonged hospital care, it was both safer and cheaper. 24

It was clear from these papers that a number of factors might affect the ‘success’ or otherwise of these interventions: selection of children for the intervention; 25 different policies for life-supporting interventions for different conditions and in different healthcare systems; 26 parents’ ability to cope with 27,28 and their motivation to provide, technologically complex interventions, 29,30 urban or rural location 31 and the organisational and supportive structure within which these interventions were delivered at home. 32,33

A supportive organisational structure was a key feature of many of the service innovations described – support systems for families with a child in home dialysis, 33,34 home care for children with diabetes, 35,36 ‘hospital at home’, 37 condition-specific, specialist home care nursing services, 38 and ‘outreach’ services for children with complex healthcare needs. 7 With an even lower proportion of evaluation studies for such models of care than for clinical interventions, messages were again either mixed, or simply non-existent. The exceptions found included an RCT of home-based care for children newly diagnosed with insulin-dependent diabetes, 35 a literature review of 20 economic appraisals of asthma management, (which subsequently turned out to be predominantly about adults), 39 and an RCT of home and ambulatory models of care for asthma. 40 All of these suggested some advantages to certain models of home-based care, but with considerable provisos.

The surveys of PHC in the UK, referred to earlier, also concluded that there is inadequate evidence about the costs and effects of PHC services and the effects that they might have on families, particularly the impact of providing high levels of care at home. Evidence on the numbers of children who could be kept at home rather than admitted or who could be discharged ‘early’, on the comparative costs of hospital and home care, and on satisfaction with services were all said to be needed. While and Dyson 5 concluded that:
“a diverse pattern of provision has developed on an ad hoc basis determined by local circumstances and inspired by enthusiastic individuals rather than strategic planning based on evidence. Research is urgently needed to identify the strengths of the different models and their effectiveness” (p.273).

There is, then, a clear need for a systematic review of the evidence available in this field, an indication of where research is (still) needed, and a discussion of the policy and practice messages that have emerged from the evidence.

**Research question**

The aims of the review reported here were thus to:

- establish the range and types of ‘home-based’ models of paediatric care and interventions for children with acute or chronic illness
- evaluate the effectiveness and costs of these different models across the service system and for children, their families and carers
- explore how, if at all, cost-effectiveness differs between children with different needs and between children with similar needs but from different populations
- gauge the speed with which the evidence base in this area is growing and make recommendations for further research (if necessary).

The objectives of the project were to produce:

- a systematic review of the literature in the area of paediatric home care, using CRD4 guidelines*
- a final report which outlines the evidence on cost-effectiveness, evaluates its strength, makes suggestions for future research, and considers policy options for the further development of children’s services, in the light of the evidence.

---

*NHS Centre for Reviews and Dissemination. Undertaking systematic reviews of research on effectiveness. CRD guidelines for those carrying out commissioning reviews. CRD Report No. 4. York: University of York; 1996.
Chapter 2

Review methods

Preliminary searching

Prescoping exercise
The first part of the project was taken up with preliminary hand and electronic searching of the literature. This included a prescoping search in MEDLINE using terms such as: asthma + nursing, home care + nursing, early discharge and apnoea monitoring. Specific author searches (Jessop and Stein, Tatman, Hughes, Koh, Marks, Madge, McConochie) and scanning of reference lists of specific articles helped to identify other possibly useful studies. The Cochrane Database of Systematic Reviews (CDSR) was also searched for relevant trials.

The prescoping exercise aided in further development of the inclusion and exclusion criteria. This information was discussed at the first team review meeting. The range of outcomes, search terms, and databases to be searched was also discussed. It was decided that the first electronic scoping search would concentrate on RCTs to assess the range and type of studies available and subsequently focus on other comparative study designs.

Scoping exercise
The first electronic scoping search comprised seven files from MEDLINE (four files) and CINAHL (three files). Each file contained an average of just over 100 records. Some adjustments of the files had to be made to facilitate electronic transfer to the configuration file and subsequently to the appropriate Procite® database. Adjustments to electronic search files were made for the majority of searches.

The scoping searches generated a total of 817 records; 29 duplicates were initially identified across sets, leaving 788 records. After importing into Procite the database was searched again, using separate search terms, in order to group material into three sets, according to design:

Set 1 – 113 records identified by the terms 
randomised, randomized and RCT
Set 2 – 118 records identified by the terms 
controlled, trial, clinical and trial, cohort,

observation/ al and study, evaluation, experimental and intervention
Set 3 – 557 records making up the remainder.

The three sets were treated differently. Set 1 and Set 2 records were printed with abstracts. Two reviewers read these abstracts and identified those records that definitely fell into the scope of the review (16 records) those that might be useful (35 records) and those that definitely did not fall into the review (187 records). Set 3 records were initially printed with the title only. The titles were scanned for relevance using two reviewers and marked for inclusion and possible inclusion. Abstracts were then printed for these selected titles and read to identify studies to be included (23 records), for possible inclusion (107 records) and those that clearly fell outside the review (427 records). In all, 181 records from the original 788 were identified as being of definite or possible relevance to the review. Of these, 14 further duplicates and 20 non-RCT foreign language studies (see below) were identified, leaving a total of 147.

In all cases, two reviewers worked to agreement – discussing and resolving any disagreements identified after each had independently reviewed each list. If a disagreement could not be resolved by the two reviewers, the relevant paper was passed on to a third reviewer. This method of searching, creation of sets and identifying references in pairs was subsequently used throughout the review, although the terms for identifying RCTs were expanded (see below).

Refinement of the search strategy was an ongoing process and output from the scoping stage, along with lists of selected studies, informed the next, more formal, stage of the search.

Main search strategy
The aim of the main searches was to provide as comprehensive a retrieval as possible of published and unpublished studies relating to interventions which could be classed as models of paediatric home care.
Twenty bibliographic and other electronic databases were searched, providing coverage of health and social sciences literature, grey literature and current research. A list of the databases searched is given in Box 1.

<table>
<thead>
<tr>
<th>BOX 1 Databases searched</th>
</tr>
</thead>
<tbody>
<tr>
<td>BNI (British Nursing Index)</td>
</tr>
<tr>
<td>CINAHL (Cumulative Index of Nursing and Allied Health Literature)</td>
</tr>
<tr>
<td>CDSR (Cochrane Database of Systematic Reviews)</td>
</tr>
<tr>
<td>CENTRAL/CCTR (Cochrane Controlled Trials Register)</td>
</tr>
<tr>
<td>CRIB (Current Research in Britain)</td>
</tr>
<tr>
<td>CRIW (Current Research Worldwide)</td>
</tr>
<tr>
<td>DoH POINT (Department of Health Publications on the Internet)</td>
</tr>
<tr>
<td>EMBASE</td>
</tr>
<tr>
<td>HealthSTAR</td>
</tr>
<tr>
<td>HMIC (Health Management Information Consortium)</td>
</tr>
<tr>
<td>Index to Theses</td>
</tr>
<tr>
<td>ISTP (Index of Scientific and Technical Proceedings)</td>
</tr>
<tr>
<td>MEDLINE</td>
</tr>
<tr>
<td>NHS CRD DARE (Centre for Reviews and Dissemination Database of Abstracts of Reviews of Effectiveness)</td>
</tr>
<tr>
<td>NHS CRD NHS EED (NHS Economic Evaluation Database)</td>
</tr>
<tr>
<td>NHS CRD HTA (Health Technology Assessment) database</td>
</tr>
<tr>
<td>NRR (National Research Register)</td>
</tr>
<tr>
<td>PsycINFO</td>
</tr>
<tr>
<td>SCI (Science Citation Index – expanded)</td>
</tr>
<tr>
<td>SSCI (Social Sciences Citation Index)</td>
</tr>
</tbody>
</table>

In addition, the publications lists and current research registers of fifty health services research-related resources were consulted via the Worldwide Web. These included health economic and health technology assessment organisations, child health and welfare research bodies and charities, guideline-producing agencies and generic current research registers or databases. The list was compiled using an internal core checklist of sources, through the identification of relevant bodies from the results of database searching and through the following up of links pages of key internet resources until no further useful links were found. A list of the sources is given in appendix 1.

**Keyword strategy**

Keyword strategies, using freetext and, where available, thesaurus terms were developed to search the twenty databases included in the review. Given the breadth of the range of relevant interventions, the diversity of definitions or descriptions of such interventions and the lack of consistency in indexing them, search strategies for MEDLINE and EMBASE were developed iteratively in order to achieve an acceptable balance of sensitivity and specificity. Preliminary, specific searches were undertaken, as described above, and the indexing and titles and abstracts of relevant studies were used to identify additional terms to extend the initial strategy. The search strategy for these two databases was then transposed to the remaining databases. The strategies are listed in appendix 2.

The vocabulary included in the search strategies focussed on terms relating to home care (combined terms relating to children). That is, the search strategies focussed on the setting or delivery of the intervention. This relied on interventions being identified explicitly by authors or indexers as comprising some form of home care. Interventions not defined as ‘home care’ but which by their nature might result in a form of home care, would not necessarily be retrieved by such strategies. For example, a patient education intervention might result in patients treating themselves at home rather than having to be admitted to or attend a clinic at a hospital. In order to assess the extent to which such evidence was not being retrieved, test searches restricted to a single publication year (1998) were undertaken on MEDLINE. The searches focussed on five conditions (AIDS, asthma, cystic fibrosis, diabetes, epilepsy), which, from the evidence already identified, could be commonly associated with home care interventions. Terms relating to the five conditions were combined with the terms relating to children. References already identified by the home care strategies were then excluded. The yield of the test searches in terms of additional relevant studies was extremely low and it was decided not to extend the condition-specific searches to other years or databases.

The range and lack of consistency in vocabulary used to describe models of home care exacerbated the problems associated with achieving a balance of sensitivity and specificity when searching the Internet. As a result it was not possible to undertake effective keyword searches of the Worldwide Web using general search engines. Searches of the web were therefore restricted to the iterative identification and consultation of relevant sources as described above.
**Search restrictions**

Search strategies did not include methodological filters to restrict search results to specific study designs. Language restrictions were not used. In accordance with the review protocol, inclusion criteria date limits were used to restrict the publication dates of retrieved studies to 1975 onwards. The MEDLINE and EMBASE search strategies were developed from December 1999 onwards with final full searches being undertaken in July 2000. The remaining databases and other sources were searched after this date.

**Additional strategies**

**Contact with experts**

Databases of researchers working in a similar field were scanned as part of an ongoing process. Researchers who were thought to have carried out projects that might be useful to the review were contacted and requests for information and published reports made. Authors of studies selected where further clarification was needed were also contacted. In a number of instances, projects were ongoing and these researchers were contacted again later.

In one case, lack of clarity in a published trial carried out outside the UK made it impossible to judge whether or not the intervention being described had actually been delivered in children’s own homes. Various attempts at contact via academic addresses were unsuccessful. We then tried to locate the authors via the Internet, only to discover that the lead author was currently under suspicion of committing a serious crime. Given these circumstances, we decided not to pursue contact any further and left the trial out of the review.

Requests for researchers to contact us about projects or information they felt might be useful to us were also made. The Royal College of Nursing’s Research and Development centre reported the project in their newsletter. The NHS R&D HTA Programme website, which described the project, was also useful as those that had read about the project there contacted us directly. Two ongoing trials of generic PHC were identified – one in the UK and one in the USA – as well as a descriptive study of a paediatric hospital at home (Wilson A, University of Leicester: personal communication, 2001).

**Handsearching**

Handsearching, using a variety of approaches, was an ongoing process throughout the project. The methods used are described below.

Reference lists of studies that were data-extracted were scanned to identify other studies of relevance that had not been identified before. Sixteen relevant papers were found, of which three had not previously been identified. All three were related to trials subsequently selected for the review.

Two members of the team also scanned reference lists from reviews and systematic reviews in related areas. One hundred and thirty-nine apparently relevant references were identified. Abstracts for these were then identified via MEDLINE and printed. Thirteen were followed up after discussion. Seven studies were added to the review database (of which two were subsequently classed as relevant, four were for possible inclusion, and one was kept as background) and six were rejected.

Tables of contents for the *British Medical Journal* (weekly), *Pediatrics* (monthly) and *The Lancet* (initially) were searched regularly to identify new studies. Five apparently relevant papers were identified using this process, but none subsequently entered the review.

**Final searching**

In order to be certain that we had identified all possible references from within our searches, a combination of approaches was used. First, a final rerun using selected search terms in our all references database of records was carried out. This was to check against our instinctive feeling that we might not have identified all relevant trials related to diabetes and asthma. Some 216 records were identified via these searches (*Table 1*), only one of which was ordered and subsequently excluded.

**TABLE 1** Checking searches run against all references database

<table>
<thead>
<tr>
<th>Search term</th>
<th>Number of references identified</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diabetes and Randomly</td>
<td>16</td>
</tr>
<tr>
<td>Diabetes and Randomized</td>
<td>17</td>
</tr>
<tr>
<td>Diabetes and Randomised</td>
<td>6</td>
</tr>
<tr>
<td>Diabetes and Random</td>
<td>0</td>
</tr>
<tr>
<td>Asthma and Randomly</td>
<td>32</td>
</tr>
<tr>
<td>Asthma and Randomized</td>
<td>68</td>
</tr>
<tr>
<td>Asthma and Randomised</td>
<td>23</td>
</tr>
<tr>
<td>Asthma and Random</td>
<td>25</td>
</tr>
<tr>
<td>Self management</td>
<td>4</td>
</tr>
<tr>
<td>Self-management</td>
<td>25</td>
</tr>
<tr>
<td><strong>Total references identified</strong></td>
<td><strong>216</strong></td>
</tr>
<tr>
<td><strong>Total selected</strong></td>
<td><strong>1</strong></td>
</tr>
</tbody>
</table>
A late search on DARE was also carried out which identified eight references, five of which we had already identified and three of which were reviews that were selected and ordered. One of these was by Marco and co-workers.44 This had previously been identified as part of the electronic searches but was at the protocol stage at that time. By the time the quick search was carried out, the review had been completed. In a second case, the full report of a review45 was in Swedish. We were able to obtain a summary in English via the Internet and made a formal request for the reference list from the review. Ten apparently relevant references were identified and checked against our list of selected studies; all of them had been identified already.

Also at a late stage of the review process, the table of contents in the journal Pediatrics was handsearched from 1985 onwards. This journal was chosen as it was the one in which the majority of selected studies had been identified. In total, 11 papers were found, five of which had already been identified. However, six new papers were found, five of which were kept for background information and one of which was entered into Set 3 (i.e. none were trials or other comparative designs).

The final stage of searching was the forward citation searches, carried out on the trials eventually included in the systematic review. This was done via the Web of Science (WOS) Institute of Scientific Information (ISI) Citation Database. Each main results paper was entered separately and all citations to that paper since publication identified. Titles and, where available, abstracts of the papers that had cited the selected trials were downloaded. The results of this process are summarised in Table 2. As the table shows, some papers appeared to generate no citations at all. In three cases, citations for any articles for that author since the date of the paper in question were searched for. Despite this process, two trials generated no citations. Five apparently relevant papers were identified from the 264 citations, four of which had already been identified through earlier processes and the fifth of which was a letter commenting on a trial that had been included in the review.

### TABLE 2 Results from forward citation searches for selected trials

<table>
<thead>
<tr>
<th>Trial</th>
<th>Number of citations</th>
</tr>
</thead>
<tbody>
<tr>
<td>Brooten et al., 198653</td>
<td>74</td>
</tr>
<tr>
<td>Casiro et al., 199359</td>
<td>23</td>
</tr>
<tr>
<td>Gillette et al., 199158a</td>
<td>0</td>
</tr>
<tr>
<td>Finello et al., 199851a</td>
<td>41</td>
</tr>
<tr>
<td>Dougherty et al., 199964</td>
<td>0</td>
</tr>
<tr>
<td>Mitchell et al., 198665</td>
<td>19</td>
</tr>
<tr>
<td>Hughes et al., 199140</td>
<td>41</td>
</tr>
<tr>
<td>Harrington et al., 199869</td>
<td>20</td>
</tr>
<tr>
<td>Henggeler et al., 199967</td>
<td>2</td>
</tr>
<tr>
<td>Stein and Jessop, 19847</td>
<td>44</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>264</strong></td>
</tr>
</tbody>
</table>

*All citations for these authors since publication of original trial*

The first stage was to identify all material that was actually about paediatric home care (i.e. selection for relevance). The point of this stage was thus not simply to identify papers that would eventually find their way into the review but also to allow us to determine the range of models of paediatric home care being described in the literature.

The second stage was to identify material that, because of its design, would allow us to say something about the comparative merits of paediatric home care against those of other models of care.

### Relevance

As we have discussed elsewhere,46 we believe that it is almost impossible to define inclusion and exclusion criteria for relevance in systematic reviews of complex models of care *ab initio*. This is particularly the case here where there is no universally agreed definition of what constitutes ‘paediatric home care’. In our original research proposal we suggested a number of criteria for inclusion and exclusion. Suggested inclusion criteria were: children (18 and under); ‘home’ or ‘community’-based interventions or models of care for children with acute or chronic illnesses who might otherwise be in hospital; and material published since 1975. By contrast, we argued that exclusion criteria would have to be finalised after the scoping searches proper had been carried out, but did suggest that models of palliative (terminal) care for children should be excluded from the outset. In doing this we wanted to distinguish between services for children whose life expectancy might (or might not) be less than average because of their condition, and services for those who were in the terminal

### Inclusion and exclusion criteria for selection of studies

Decisions about inclusion and exclusion of papers were taken in two stages:
stages of disease and/or who were expected to die within the near future. While this distinction may sometimes be difficult to make in terms of the individual patient, we felt that models of appropriate services and the desired outcomes for children in these two groups were so distinct that they should not be covered in a single review.

We also suggested at the outset that foreign language literature should be excluded unless it was reporting a controlled evaluation of models of paediatric home care. Experience of a review in a similar area had suggested that the effort and expense of obtaining foreign language articles and having them translated was usually worthwhile only when they described good quality evaluative research. English language abstracts usually give a good enough idea of the content of an article to distinguish between those that are evaluative and those that are not.

Additional inclusion and exclusion criteria were developed as the project proceeded, with the review team making decisions over a number of meetings, as issues arose from the study selection process. The most complex discussions were around the following issues:

**Low birth weight**

The team decided that only studies of models of home care for very low birth weight babies (<1500 g) should be included. The literature and professional experience suggest that low birth weight above this level tends to resolve satisfactorily in most cases, where below this weight there are often significant, long-term effects on physical and intellectual development.

**Neonatal jaundice**

There is a large body of literature on sending jaundiced babies home with a range of equipment to treat the condition, rather than keeping them in hospital. Again, the team felt that the literature and professional experience suggest that most of these babies suffer no long-lasting effects and that this area, though possibly worthy of systematic review, should not be included here.

**Home diagnosis and monitoring**

A number of articles about home diagnosis of conditions such as sleep apnoea were found in the first searches. We chose to exclude these, after discussion, on the basis that the ‘intervention’ precedes the point at which definite diagnosis is available and therefore could not really be characterised as paediatric home care.

Difficulties in deciding whether or not to include home monitoring of long-term conditions arose partly because of the rapid pace of technological development in some disease areas. For example, home monitoring of urine or blood in diabetes and respiratory function in asthma have become routine rather than innovative. As a result, some of the earlier studies we identified described procedures that have now become part of ‘normal’ practice for children with these conditions but which, at the time they were carried out, were real alternatives to hospital admission or clinic visits. For example, it would now be unusual for a child to be admitted to hospital simply to monitor his or her glucose levels. Issues about the best techniques for home monitoring remain to be resolved but the place of home monitoring, *per se*, is now very well established in the UK. The decision to exclude studies of home monitoring in asthma and diabetes was thus relatively easy to make.

By contrast, home monitoring of something like a heart condition was more difficult to deal with. While children would not be kept in hospital all the time just to enable monitoring, if they were more likely to die at home without such monitoring then perhaps it would fall legitimately into the remit of paediatric home care. As it happened, no RCTs or comparative studies of this type of home monitoring were identified, despite a substantial literature, especially related to home apnoea monitoring. Much of the latter was either descriptive, or compared the effectiveness of different types of monitoring equipment.

**Home-based developmental interventions**

There is a large body of literature on home-based interventions intended to improve developmental outcomes for disabled children. The best known of these is, perhaps, Portage*, but there are many other models with broadly similar aims. After discussion, the team decided to exclude these from the review on the basis that they are primarily educational interventions rather than ones that deliver any aspect of clinical care for children. Again, however, we felt that the volume of the literature suggested that this area might be a candidate for systematic review elsewhere.

---

**Review methods**

**Non-organic failure to thrive and child abuse**
Many studies about home-based interventions to prevent or address non-organic failure to thrive and child abuse were identified. Again we felt that, while of interest to the health service, the focus of such interventions was significantly different from that of paediatric home care and therefore should be excluded.

**Postsurgical care**
This area was excluded on the basis that, although interventions such as home intravenous therapy might allow early discharge, they did not have implications for the delivery of health care beyond the immediate postoperative period. In the event, no trials or comparative evaluations of home care services specifically for postsurgical care of children were identified in the full searches.

**Date of publication**
As outlined earlier, formal searching was carried out back to 1975, as originally proposed. However, after discussion in the review team it was decided to limit inclusion in the review itself to material published since 1985. This decision was taken on the basis of the very substantial changes that have happened in the past 15 years or so in the organisation and delivery of services for sick children, whether as a result of technological or policy innovations. We felt that any messages from evaluations of services that had taken place before this time would be of only very limited application in the early years of the 21st century.

**Design**
The aim of the review was to establish the range and types of ‘home-based’ models and interventions, as well as to come to some judgement about what was known about the effectiveness and costs of different models and services. The original proposal therefore suggested that we should include study designs that allowed comparisons of models or interventions or that included information which could be used to address issues of costs and effectiveness. It was always intended, then, that the review should not exclude any particular design. However, after the first electronic search, it became apparent that there was a large volume of studies that were purely descriptive, as opposed to comparative or evaluative. The review group therefore decided that after material had been identified as relevant, the final review process would be restricted to: randomised and quasi-randomised trials; evaluative studies that compared a model of home care against some alternative form of care; and studies of home care that could be considered as economic studies, widely defined.

The final inclusion and exclusion criteria were, therefore, as follows:

**Inclusions for relevance**
- models of home-based care which prevent immediate admission to hospital
- models which provide care within the home rather than in hospital
- children under 18 years of age
- acute or chronic illness
- published since 1985.

**Inclusions for design**
- randomised or pseudo-randomised trials
- studies with a health economic element
- non-RCT studies comparing home-based care against some other model.

**Exclusions for relevance**
- terminal or palliative care
- ‘Portage’ type schemes
- job satisfaction studies
- parenting skills
- child abuse and/or non-organic failure to thrive
- service standards
- normal child bearing/pregnancy/neonatal period
- comparisons of different forms of equipment
- postsurgical home care
- ‘routine’ home monitoring.

**Exclusion for design**
- letters/editorials
- single case studies
- foreign language (unless RCT).

**Final selection of studies for review**

**Formal search stage**
The first electronic search was carried out using the MEDLINE database. A total of 3629 records were identified. Both electronic and paper searches generated a large number of records (see Tables 3 and 4). A combined total of 14,658 records were received, of which 11,487 were in electronic form and 3171 in paper format.

All electronically received records went through the method described earlier for selection for relevance.

Having received the EMBASE search, it became apparent that the additional grouping done after the records were received was not placing some
references in the appropriate sets, as some RCTs were found in Set 2. It was recognised that the words ‘RCT’, ‘randomised control trial’, ‘randomised’, or ‘randomized’ were not sufficient to identify all the randomised controlled trials; the terms ‘random’ and ‘randomly’ were therefore added to this secondary strategy. The previous searches were rerun to identify possible missed trials and then regrouped, if necessary. All subsequent searches were carried out using these additional terms.

Not all references could be imported into the Procite database. These files were converted into Word files and the text files printed. This meant that the records could not be grouped into the three sets as with the electronic searches, however, they still went through the same process whereby two people worked independently, identified those that were ‘in’, ‘out’ or for ‘possible inclusion’, and then worked to agreement.

Selection of studies was a two-part process, as described above. Two members of the team made independent decisions about which studies proceeded to data extraction.

Tables 3 and 4 outline the number of references identified through the electronic and paper searches, and the number that proceeded to data extraction.

Ten trials reported in 24 papers (see appendix 3) are included in the review. Health economics papers from trials are also included in chapter 4.
Non-RCT evaluative studies

The review also includes a chapter based on non-RCT evaluative studies (chapter 5). These studies were selected from the total selected list of 1579 studies selected for relevance in Sets 2 and 3 (1367 electronic and 212 ‘other’). Three members of the review team scanned titles and abstracts. This achieved two goals. First, it allowed us to gauge the scope and nature of this substantial literature. Secondly, it enabled us to filter studies that, although not RCTs, indicated that they might report data on the comparative effectiveness of PHC. We therefore restricted selection to studies that involved a clear comparative component and which could consequently inform our understanding of the merits of care delivered at home as opposed to some other setting.

The vast majority of papers in Sets 2 and 3 were, in fact, descriptions of services from which little or no information about relative costs or effectiveness could be gained. In total, 77 papers were initially selected, of which 15 were duplicates and 1 was not in English. The 61 remaining papers were ordered. These studies were then further filtered and 15 papers (14 studies) finally included.

Some papers from this section were also included in chapter 4 if they included an economics element.

Economic evaluation

Economic evaluation of the costs of PHC services, broadly defined, also formed part of the review. However, few of the RCTs included anything that could be described as economic evaluation. We decided, therefore, to include a broader range of designs in this element.

Using the entire reference database, the search terms ‘cost’, ‘cost and home’ and ‘cost effectiveness’ were used to identify studies that might be characterised as economic evaluations. Four hundred and fifty-five studies were identified across the databases, of which 248 were duplicates. Abstracts were printed for the remaining 207 studies and read initially by the health economist on the team who judged whether or not the papers did indeed include anything that could be described as economic information. Studies were then further filtered by two members of the team, independently and then to agreement, to include only those papers reporting an economic analysis (cost-minimisation, cost-effectiveness, cost-utility or cost–benefit) or a cost study (where there was an estimate of the cost of the intervention but no attempt to combine this with measures of effectiveness). Fifteen studies were finally included.

Data extraction

The main outcomes of interest for the review were costs, quality and effectiveness, but broadly defined in order to include impact on families and carers and on the service system beyond the NHS.

Data extraction for the RCTs covered the following areas:

- publication details
- details of the intervention or model of care
- study details
- study participants
- Jadad and EPOC quality criteria (see below)
- mortality
- length of stay and readmission
- clinical, physical and psychological outcomes
- costs to the health service, social services and the family
- impact on the family, social life and education
- knowledge of the condition.

The data extraction form was developed, piloted and then ratified at the third review team meeting. The form was created using Microsoft Excel and information was entered directly onto the worksheets. A second researcher checked data prior to analysis.

A separate, specially designed, Excel database was used for the economics studies. This covered costs to the health service of the intervention, costs of health care during any follow-up period, costs to the family, costs to other agencies, and analysis of costs and benefits.

Data for the other evaluative studies were extracted onto an evidence table and further checked at analysis stage.

Quality of studies

Jadad and co-workers’ quality of trials algorithm and the Cochrane Effective Practice and Organisation of Care (EPOC) Group’s quality criteria for RCTs and controlled clinical trials were used to assess the quality of the selected trials. We used these assessment tools to allow the findings to be considered alongside quality of the trials and not to further eliminate trials from the review.
As with a previous review in a similar area,\textsuperscript{46} we excluded Jadad and co-workers\textsuperscript{50} criterion of double-blinded assessment of outcomes on the basis that such a criterion is almost impossible to achieve in research where a model or place of care is being evaluated. Interpretation of the EPOC criteria of blinded assessment of outcome and use of ‘reliable’ outcome measures is difficult because it is not clear whether the application of a well-validated scale, for example, is equivalent to a standardised test of a drug (the example used in the EPOC guidance). As before, we decided to score these elements ‘done’ if well-validated measures of outcome had been used. As we used the EPOC criteria to describe but not to exclude, this decision does not have major interpretive implications. Avoidance of ‘contamination’ (another EPOC criterion) is also a problematic concept in research of the type reviewed here, where children may receive care in different settings during the ‘experimental’ phase but then receive similar community health and social care services.

Quality of the economics studies was assessed using an adapted version of the Drummond and Jefferson\textsuperscript{52} criteria. As with the trials included in the review, quality assessment was not used to exclude papers. However, given the wide variation in design and methods used in the papers included in chapter 4, quality assessments are reported only for those papers associated with RCTs.

No formal assessment of quality is reported for the non-randomised studies reported in chapter 5 because of the very substantial diversity in their design and methods. A descriptive account of methodological weaknesses is, however, given.

**Analysis of data**

The RCT papers that had been data extracted fell into four main sections:

- early discharge of very low birth weight or medically fragile babies
- home care for children with asthma or diabetes
- home care for children with mental health problems
- paediatric home care, so described by the authors.

The economics papers also fell into coherent groupings:

- early discharge of very low birth weight babies and/or those who had received care on a neonatal intensive care unit (NICU)
- early discharge and home care for oxygen-dependent babies
- home care for oxygen-dependent children
- home chemotherapy
- home intravenous antibiotic treatment
- home haemodialysis
- home care for children with newly diagnosed insulin-dependent diabetes mellitus (IDDM)
- home care for children with mental health problems.

Finally, the other comparative studies fell into four sections:

- home care for very low birth weight or NICU babies
- home care for children with IDDM
- ‘technological’ care at home: dialysis, intravenous drug administration, parenteral and enteral feeding, and nebuliser therapy
- home care for children with mental health problems.

The analysis of all the RCT material is predominantly descriptive. No subsection in the trials chapter (chapter 3) contains more than three trials and, even within subsections, the trials are varied in their target patient groups, outcome assessment and methodological quality. The opportunities for meaningful meta-analysis were thus very limited. In one or two places, however, pooled standard mean differences (SMDs) are reported. These were calculated using the ‘metan’ procedure in the Stata\textsuperscript{TM} statistical package to produce I–V pooled SMDs.

Analysis of the economics and non-randomised studies is entirely descriptive. For the latter, only three major outcomes domains are analysed – clinical outcomes, however reported; health service use; and any assessment of impact on children or families.
Chapter 3

Trial results

In this chapter we report findings from the randomised or pseudo-randomised trials in a number of subsections. These deal with: home care for very low birth weight or medically ‘fragile’ babies; home-based outreach for asthma and for diabetes; outreach services in mental health; and paediatric home care, so described.

Details of all the papers associated with these trials are given in appendix 3 while the main paper for each trial is described in separate tables in each subsection.

Home care for very low birth weight or medically fragile babies

Four trials, reported in nine papers (one a reprint), were included in this section (Broonen and co-workers, Gillette and co-workers, Casiro and co-workers, and Finello and co-workers. Table 5 gives publication details for the main results paper of each trial, which will be referred to hereafter by the name of the first author. Three of the trials were in the USA and one in Canada. The details of the interventions and the treatment with which they were being compared are outlined in Table 6. The Finello trial included four arms – home health care with home visiting (HH/HV); home health care alone (HH); home visiting alone (HV) and controls.

Inclusion and exclusion criteria

As might be expected, all the services evaluated here were tied in to particular hospital settings. Two also specified residential eligibility criteria, mainly, one assumes, to facilitate visiting services. The definition of low birth weight differed for the three trials, with two having only upper weight limits but one also a lower limit. Babies in the trial about ‘medical fragility’ were defined as those with moderate to severe bronchopulmonary dysplasia (oxygen-dependent and/or needing two or more pulmonary drugs after discharge) or those with moderate to severe neurological dysfunction (defined as Grade III/IV intracranial haemorrhage and/or evidence of other neurological pathology and dysfunction).

<table>
<thead>
<tr>
<th>Authors and title of main paper</th>
<th>Publication details</th>
<th>n subjects</th>
<th>n controls</th>
<th>Jadad score (max 3)</th>
<th>EPOC score (max 7)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Casiro et al., 1993</td>
<td><em>Pediatrics</em> 1993;92:129–34</td>
<td>50</td>
<td>50</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Total randomised</td>
<td></td>
<td>169</td>
<td>129</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Exclusions were also varied. Brooten excluded both children with grade 4 intraventricular haemorrhage and those who were oxygen-dependent for longer than 10 weeks. Similarly, this trial excluded children with life-threatening congenital anomalies, while Casiro excluded children with congenital anomalies that were likely to have a negative impact on neuro-developmental outcomes and Finello excluded any children with ‘gross abnormality’ at discharge. The children in the Gillette trial, then, were likely to be significantly more impaired than were those in the other trials.

The impact of exclusion criteria for trials is, of course, that they limit the extent to which the results can be generalised to the population on which the intervention of model of care was targeted. Table 7 shows the proportion of very low birth weight or medically fragile babies these trials actually included and followed up.

**TABLE 7** Proportion of patient population randomised to trials of home care for very low birth weight and/or medically fragile babies

<table>
<thead>
<tr>
<th>Study</th>
<th>Size of patient ‘population’ if given</th>
<th>Total number of patients randomised</th>
<th>% of patient population randomised</th>
<th>% of patients randomised included at final follow-up</th>
</tr>
</thead>
<tbody>
<tr>
<td>Brooten et al., 1986&lt;sup&gt;53&lt;/sup&gt;</td>
<td>136</td>
<td>79</td>
<td>58</td>
<td>99</td>
</tr>
<tr>
<td>Gillette et al., 1991&lt;sup&gt;58&lt;/sup&gt;</td>
<td>58</td>
<td>50</td>
<td>86</td>
<td>76</td>
</tr>
<tr>
<td>Casiro et al., 1993&lt;sup&gt;59&lt;/sup&gt;</td>
<td>356</td>
<td>100</td>
<td>28</td>
<td>92</td>
</tr>
<tr>
<td>Finello et al., 1998&lt;sup&gt;61&lt;/sup&gt;</td>
<td>Not given</td>
<td>81</td>
<td>–</td>
<td>82</td>
</tr>
</tbody>
</table>
Quality of the trials
As reported in Table 5, only one trial met all three Jadad criteria (excluding the blinding criterion) for quality of trials. Two met six of the seven EPOC criteria. The other two trials met only two and three criteria. The most common problem was the failure to demonstrate equivalence between the subjects and controls.

Across all four trials, 169 babies were randomised to the intervention and 129 to the control conditions.

Outcomes reported
All four trials reported clinical outcomes of some sort, length of stay and impact on the family and/or carers. No trial reported family costs, quality of life measures (for parents), satisfaction with services, subsequent educational achievement, or parents’ knowledge of their child’s condition. Brooten and Casiro report mortality, Gillette and Casiro mental function outcomes, Brooten and Casiro cost to the health service, Casiro costs to the social care system, and Gillette social outcomes (for mothers).

Mortality
Two babies in the Gillette study died after randomisation but it is not clear to which group these belonged. Further, the reported results excluded these babies from the sample. No babies died in the Casiro study and none were reported to have done so in the Finello study. Only Brooten reports any deaths within the study – one (2.6%) in the intervention group during 12 months of follow-up. These low death rates in both subjects and controls probably reflect the careful selection of children into the early discharge groups. As Brooten and co-workers themselves report in their main paper, in the first year of life, very low birth weight children have a postnatal death rate five times as high as that of babies who weigh more than 2500 g at birth.

Length of hospital stay and readmission
Earlier discharge was, of course, an explicit aim of three of the trials reported here. As Table 8 shows, it does seem that it was achieved in two of them. Statistical significance for the difference in length of stay was achieved in only one trial, however.

One of the anxieties about earlier discharge is that it ultimately leads to equivalent or even greater use of health services because children are readmitted or make additional use of emergency care after discharge. Only Casiro and Finello report readmissions or use of emergency care in any detail. Gillette does not report it at all while Brooten reports numbers of readmissions but not length of stay. The reporting of readmissions is difficult to interpret in the Finello trial and has been recalculated by us (Table 9).

Our reanalysis of some of the figures reported in the papers gives a somewhat less sanguine view of the impact of early discharge on readmissions and emergency care than given in the papers themselves. Casiro, for example, reports the number of children who were readmitted for medical or surgical reasons (eight and seven, respectively) and the number of readmissions in

<table>
<thead>
<tr>
<th>TABLE 8 Length of initial stay</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Days of initial hospital stay</strong></td>
</tr>
<tr>
<td>Mean (SD) or median*</td>
</tr>
<tr>
<td>Study</td>
</tr>
<tr>
<td>Brooten et al., 1986</td>
</tr>
<tr>
<td>Gillette et al., 1991</td>
</tr>
<tr>
<td>Casiro et al., 1993:</td>
</tr>
<tr>
<td>All</td>
</tr>
<tr>
<td>≤ 1500 g</td>
</tr>
<tr>
<td>1501–2000 g</td>
</tr>
<tr>
<td>Finello et al., 1998:</td>
</tr>
<tr>
<td>All</td>
</tr>
<tr>
<td>HH/HV</td>
</tr>
<tr>
<td>HH</td>
</tr>
<tr>
<td>HV</td>
</tr>
</tbody>
</table>

* Calculated by us
NS, Not significant; SD, standard deviation
total. When we examine the mean readmissions, however, we see that the intervention mean was actually higher than that for the controls.

Similarly, Finello\(^61\) reports readmissions of less than and more than 24 hours separately, and for discharge to 6 months and for 6–12 months separately, for each of the four arms of the trial. However, the paper reports means and standard deviations only for the four groups combined. Significant group differences were found for only one set of comparisons – for readmissions greater than 24 hours between discharge and 6 months. What this does not make clear is that it was one of the intervention arms (HH alone) that had the highest number of readmissions. Further, when all readmissions over the 12 months of follow-up were summed, as was done in Table 9, it became clear that two of the intervention arms had mean readmissions higher than the control group and that the mean total for all intervention arms was consequently higher than that of the controls. The interpretive complexities of findings that suggest that, by themselves, two different sorts of interventions produce worse results than the control condition, but in combination produce a better outcome, are not discussed in the paper.

### Clinical outcomes

The reporting of anything that might be considered a clinical outcome was limited in all trials. Brooten\(^53\) and Casiro\(^59\) report only failure to thrive at 18 and 12 months after discharge, respectively, while Finello\(^61\) reports only immunisation status at 6 and 12 months after discharge. Gillette\(^58\) reports outcome measures relating to overall development (Battelle Development Quotient; DQ) and neurological status as measured by the Infant Neurological Battery, standardised infant tone and reflex scale. Both were reported at 2 weeks after discharge and the neurological outcome was also reported at 6 months corrected chronological age (CCA).

As Table 10 shows, there were few differences between intervention and control babies in relation to the limited clinical outcome measures used. Further, it is clear from reanalysis of the Finello data\(^61\) that it is home (health) visiting involvement that is related to up to date immunisation status, as one might expect.

### Physical function

Two trials (Gillette\(^58\) and Casiro\(^59\)) report physical function as an outcome, using the Bayley Psycho-

### TABLE 9 Readmission and emergency care use after discharge

<table>
<thead>
<tr>
<th>Study</th>
<th>Measure used</th>
<th>Period of follow-up</th>
<th>Subjects</th>
<th>Controls</th>
<th>Reported statistical significance</th>
<th>More or fewer readmissions/emergency care for subjects</th>
</tr>
</thead>
<tbody>
<tr>
<td>Brooten et al., 1986(^53)</td>
<td>Number (% of babies readmitted)</td>
<td>18 months</td>
<td>10 (26)</td>
<td>10 (25)</td>
<td>NS</td>
<td>Same</td>
</tr>
<tr>
<td></td>
<td>Number (% of babies with acute care visits)</td>
<td></td>
<td>29 (74)</td>
<td>36 (90)</td>
<td>NS</td>
<td>Fewer</td>
</tr>
<tr>
<td></td>
<td>Number of acute care visits</td>
<td></td>
<td>163 (mean (^4) 4.18)</td>
<td>186 (mean (^4) 4.65)</td>
<td>NS</td>
<td>Fewer</td>
</tr>
<tr>
<td>Casiro et al., 1993(^59)</td>
<td>Readmission or use of ambulatory care for illness</td>
<td>12 months</td>
<td>Mean 20 (SD 14)</td>
<td>Mean 20 (SD 14)</td>
<td>NS</td>
<td>Same</td>
</tr>
<tr>
<td></td>
<td>Number of readmissions for medical or surgical reasons other than hernia repair</td>
<td></td>
<td>17 (mean (^o) 0.41)</td>
<td>11 (mean (^o) 0.25)</td>
<td>Not reported</td>
<td>More</td>
</tr>
<tr>
<td>Finello et al., 1998(^61)</td>
<td>Mean total readmissions(^a)</td>
<td>12 months</td>
<td>HH/HV 0.20</td>
<td>HH 1.33</td>
<td>HV 0.90 All intervention 0.82</td>
<td>0.50 More</td>
</tr>
</tbody>
</table>

All means are per child followed up

\(^a\) Calculated by us
motor Development Index (PDI) at 6 months CCA in the former and at 12-month follow-up in the latter. In both trials, outcomes were marginally better for intervention subjects but in neither case did the difference reach statistical significance (Table 11). Meta-analysis confirms that, while there is evidence of home care conferring a slight advantage in relation to physical developmental outcomes, this does not reach statistical significance (I–V pooled SMD = 0.238, 95% confidence interval (CI), −0.097 to 0.573, \( p = 0.164 \)).

**Mental function**

Similarly, only the Gillette\(^58\) and Casiro\(^59\) trials report mental function as outcomes (Table 12), both using the Bayley Mental Developmental Index (MDI). Again there is some evidence of better outcomes for intervention babies in both trials, but not at a level that reaches statistical significance. Meta-analysis suggests that this may be a real effect, with a result that approaches conventional levels of statistical significance (I–V pooled SMD = 0.327, 95% CI, −0.009 to 0.663, \( p = 0.056 \)).

### Healthcare costs

Only the Brooten\(^53\) and Casiro\(^59\) trials report any kind of cost comparison between the intervention and control models of care. These are described in detail in chapter 4. Both showed an apparent reduction of costs to the healthcare

---

**TABLE 10** Clinical outcomes in home care for very low birth weight and/or medically fragile babies

<table>
<thead>
<tr>
<th>Study</th>
<th>Measure used</th>
<th>Period of follow-up</th>
<th>Subjects</th>
<th>Controls</th>
<th>Reported statistical significance</th>
</tr>
</thead>
<tbody>
<tr>
<td>Brooten et al., 1986(^53)</td>
<td>Number of babies failing to thrive</td>
<td>Not clear, possibly 18 months</td>
<td>0</td>
<td>1</td>
<td>NS</td>
</tr>
<tr>
<td>Gillette et al., 1991(^18)</td>
<td>Mean (SD) Battelle DQ Neurological status</td>
<td>2 weeks after discharge</td>
<td>77 (10.8)</td>
<td>76 (8.7)</td>
<td>( p = 0.74 ) Not reported</td>
</tr>
<tr>
<td>Casiro et al., 1993(^59)</td>
<td>Number of babies failing to thrive</td>
<td>12 months</td>
<td>0</td>
<td>0</td>
<td>N/A</td>
</tr>
<tr>
<td>Finello et al., 1998(^61)</td>
<td>Number (%) with up to date immunisation status</td>
<td>6 months HH/HV</td>
<td>19 (95%)</td>
<td>16 (80%)</td>
<td>( p = 0.196 )</td>
</tr>
<tr>
<td></td>
<td></td>
<td>12 months HH/HV</td>
<td>19 (95%)</td>
<td>14 (70%)</td>
<td>( p = 0.038 )</td>
</tr>
</tbody>
</table>

---

**TABLE 11** Physical function outcomes in home care for very low birth weight and/or medically fragile babies

<table>
<thead>
<tr>
<th>Study</th>
<th>Measure used</th>
<th>Period of follow-up</th>
<th>Subjects</th>
<th>Controls</th>
<th>Reported statistical significance</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gillette et al., 1991(^18)</td>
<td>Mean (SD) Bayley PDI</td>
<td>6 months CCA</td>
<td>78.6 (22.0)</td>
<td>74.3 (2.5)</td>
<td>( p = 0.50 )</td>
</tr>
<tr>
<td>Casiro et al., 1993(^59)</td>
<td>Mean (SD) Bayley PDI</td>
<td>12 months</td>
<td>94 (13)</td>
<td>90 (18)</td>
<td>NS</td>
</tr>
</tbody>
</table>
system of early discharge for very low birth weight babies of around one-quarter. However, for the reasons reported in chapter 4, these findings need to be interpreted with some caution, especially in the UK context.

The Gillette trial\textsuperscript{58} reports differences in intervention and control children’s access to and use of a range of community health and other services. This showed that more children who had received the new service had access to a community-based, coordinated and comprehensive health and development programme 6 months after discharge than did control children (12/19 compared to 2/19, $\chi^2 = 11.31$, degrees of freedom = 1, $p < 0.001$). Details are given about the ingredients of these programmes, for example the hours of home nursing services received, number of referrals for developmental services, and so on. This largely shows increased access to multi-disciplinary services for intervention families, while control families more often received ‘single’ services. However, none of this detail is costed.

Finello simply claims a “minimum of [US$]500,000 savings…realised from the average 2 days that the study infants were discharged early from standard practice”\textsuperscript{61} (p.371). This conclusion is based, apparently, on some estimate of the daily costs of NICU care, but with no reference to the costs of the services provided in the intervention arms.

Costs to other services

Only one trial (Casiro\textsuperscript{59}) makes any reference to costs to other agencies, by including ‘home maker’ costs in the overall costing of the trial – see chapter 4.

Impact on family and/or carers

The babies included in these studies had needed very high levels of care before hospital discharge, and the authors of these papers themselves refer to the ongoing fragility of very low birth weight babies. One might, then, have expected some measure of the impact of home care on family members, particularly mothers, to be included in the studies. However, as reported earlier, there was no attempt to look at parents’ quality of life or satisfaction with services.

Gillette\textsuperscript{58} did examine mothers’ perceptions of the social support that they had available to them, measured by the Family Support Scale. This suggested that those who had gained access to early intervention programmes (mothers in the trial intervention group and in the controls) reported higher levels of social support than those who had not.

Brooten\textsuperscript{53} and Finello\textsuperscript{61} report the incidence of child abuse, neglect or admission to foster care, which could, in a negative way, be seen as indicators of family impact. Finello reports these figures for the whole sample only (one neglect case between discharge and 6 months and one between 6 and 12 months, and one child abuse case between 6 and 12 months). Brooten reports two intervention and four control children with reported abuse during 18 months of follow-up and two control children in foster care. These differences are said not to reach statistical significance.

Finally, Casiro\textsuperscript{59} reports the quality of the home environment, measured by the Home Observation for Measurement of the Environment (HOME) scale. This assesses mothers’ emotional and verbal responsiveness, avoidance of restriction and punishment, organisation of the home environment, provision of appropriate play materials, involvement with the child and opportunities for variety in daily routine. A psychometrist, who was blinded to group assignment, evaluated these at 12 months CCA. Scores are said to have been analysed using “simple regression and by multiple regression adjusting for significant confounding variables” (p.130). These variables are reported, at the foot of the results table,

<table>
<thead>
<tr>
<th>Study</th>
<th>Measure used</th>
<th>Period of follow-up</th>
<th>Subjects</th>
<th>Controls</th>
<th>Reported statistical significance</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gillette et al., 1991\textsuperscript{58}</td>
<td>Mean (SD) Bayley MDI</td>
<td>6 months CCA</td>
<td>86.3 (31.6)</td>
<td>75.6 (22.2)</td>
<td>$p = 0.24$</td>
</tr>
<tr>
<td>Casiro et al., 1993\textsuperscript{59}</td>
<td>Mean (SD) Bayley MDI</td>
<td>12-month follow-up</td>
<td>105 (16)</td>
<td>100 (17)</td>
<td>NS</td>
</tr>
</tbody>
</table>
to be mother’s educational level, family income and marital status.*

There was an overall difference in total score between the two groups and differences in the subscales related to avoidance of restriction and punishment and to provision of appropriate play materials, both of which favoured the intervention group. These persisted even when the confounding variables had been controlled for. Given the differences in family circumstances at the outset, and the nature of the intervention being evaluated, change in the home environment from discharge to follow-up would possibly have been a more appropriate measure of effectiveness.

**Knowledge of the child’s condition**

None of the trials reports the level of parental knowledge of their child’s condition or treatment although, as seen above, home environment, which included the use of appropriate play materials, was assessed in the Casiro trial.59

**Home care for children with asthma or diabetes**

This was one of the most difficult areas in the review to define, given the substantial overlap between programmes of education and training for asthma and diabetes with programmes that also attempt to deliver some element of care, alongside education and training. There is a relatively large body of literature on educational interventions for children who present with asthma as an emergency and this has been systematically reviewed recently.62 Similarly, psychosocial interventions which aim to improve control in diabetes have also been systematically reviewed very recently.63 The intention of this section of our review was to examine models that offered some element of care, with or without education or training.

Three trials were identified in this category (Table 13), reported in four papers (Dougherty and co-workers,35,64 Mitchell and co-workers,65 and Hughes and co-workers40). These reports will be referred to hereafter by the name of the first author. All were of forms of assertive, home-based outreach programmes for children with IDDM35 or asthma,40,65 which delivered some element of care (for example, monitoring or drug compliance checking). Dougherty64 in addition, included an element of ‘early discharge’ in that diabetes nurses accompanied newly diagnosed children home from hospital in order to continue the training and monitoring that otherwise would have taken place during a continued hospital stay. Details of the interventions and the models of care with which they were being compared are included in Table 14.

Two of the trials were carried out in Canada35,40 and one in New Zealand.65

<table>
<thead>
<tr>
<th>Authors and title of main paper</th>
<th>Publication details</th>
<th>n subjects</th>
<th>n controls</th>
<th>Jadad50 score (max 3)</th>
<th>EPOC51 score (max 7)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dougherty et al., 199964</td>
<td>Pediatrics 1999:103:122–8</td>
<td>32</td>
<td>31</td>
<td>2</td>
<td>4/5</td>
</tr>
<tr>
<td>Home-based management can achieve intensification cost-effectively in type 1 diabetes</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mitchell et al., 198665</td>
<td>Archives of Disease in Childhood 1986:61:1184–9</td>
<td>178</td>
<td>190</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Asthma education by community child health nurses</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hughes et al., 199140</td>
<td>Pediatrics 1991:87:54–61</td>
<td>47</td>
<td>48</td>
<td>2</td>
<td>6</td>
</tr>
<tr>
<td>Controlled trial of a home and ambulatory program for asthmatic children</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Total randomised</strong></td>
<td></td>
<td><strong>257</strong></td>
<td><strong>269</strong></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*This is the only place in the paper where there is any reference to the impact of such confounding factors. An earlier table shows that intervention mothers were more likely to be educated beyond high school, more likely to be married, were somewhat older and were more likely to have an annual family income greater than US$35,000. However, only one of these differences is reported in this table to be statistically significant.
Inclusion and exclusion criteria
All three trials were limited to children living within a defined geographical area, usually related to what was seen as the hospital’s ‘catchment’ area. Dougherty\(^64\) and Mitchell\(^65\) included children aged two or over, while Hughes’ study\(^40\) was limited to those aged between 6 and 16. Dougherty excluded children with a sibling with IDDM, while Mitchell excluded children who had had a previous life-threatening attack of asthma and Hughes excluded children who had other major medical problems or who had previously been treated by the study authors. The Mitchell trial, which was in New Zealand, further excluded children who were not of either ‘European’ or ‘Polynesian’ ethnic origin.

The impact of these criteria varied substantially between trials – while Dougherty randomised 86% of the patient population, Hughes randomised only 4%. Mitchell gives no information about the size of the patient population from which the trial sample was drawn but this was the largest of the three trials.

Quality of the trials
Two trials (Dougherty\(^64\) and Hughes\(^40\)) met two of the three achievable Jadad quality criteria,\(^50\) while Mitchell\(^65\) achieved only one. Hughes scored well using the EPOC quality criteria\(^51\) (6) while Dougherty achieved four or possibly five criteria and Mitchell only two (see Table 13). There were particular problems in the Mitchell trial with questionnaire follow-up, which was as low as 54% for some elements of the study, and significantly lower for parents of controls than for subjects in the ‘European’ subgroup.

Across all three trials, 257 children were randomised to the intervention and 269 to the control condition.

Outcomes reported
All three trials report aspects of length of hospital stay, clinical outcomes of some sort, impact on the children’s education and knowledge of the condition. None report any deaths during the period of the studies and none
included physical function, mental function, costs to agencies other than the health service, quality of life, or impact on social life as outcomes. Dougherty’s was the only trial to report costs to the health service and to families themselves and impact on families and/or carers. In addition, the Dougherty and Hughes trials report satisfaction with services.

**Length of hospital stay and readmission**

Dougherty’s was the only trial to report initial hospital stay. While the Mitchell trial also recruited children at discharge from hospital this was not necessarily their first episode of care.

As would be expected, given the nature of the model of care in the Dougherty trial, children in the intervention group had lower mean length of initial hospital stay (2.2 days, SD 1.6) than did control children (4.7 days, SD 1.6). Statistical significance was not reported. Another paper from the trial, which attempted to cost the intervention, reports slightly different mean lengths of stay (2.22 and 5.00, respectively) and the difference is stated not to reach statistical significance.

The impact on subsequent admission to hospital of the forms of care evaluated in these three trials is not entirely clear (Table 15). Hughes alone suggests any long-term effect. A particularly interesting finding in the Hughes trial is the substantial reduction in the proportion of intervention children with physical evidence of airways obstruction during the intervention period, which was not maintained during the 12 months after the end of the study; indeed, there is some evidence of a ‘rebound’ effect.

The Hughes trial also carried out a range of other clinical measurements before, during and after the trial – forced expiratory volume in one second (FEV1), ratio of FEV1 to vital capacity, ratio of residual volume to total lung capacity, and expiratory flow (litres per second) at 50% and 25%. Only the two measures of expiratory flow at 12 months are reported as being significantly better for the intervention group ($p = 0.0001$ and $p = 0.001$, respectively). Again, some possible ‘rebound’ effect was evident in these two measures after the end of the study.

Mitchell found some difference between the two ethnic groups included in the trial. ‘European’ children in the intervention group were taking more drugs 6 months after recruitment than ‘European’ controls; this effect was not evident among ‘Polynesian’ children.

**Clinical outcomes**

A number of clinically related outcomes are reported in the three trials (Table 16). In all cases, the intervention children showed improvements over control children but not always to such an extent that statistical significance was achieved. Dougherty alone suggests any long-term effect.

### Table 15 Readmissions in home care for children with diabetes and asthma

<table>
<thead>
<tr>
<th>Study</th>
<th>Period of follow-up</th>
<th>Days of (re)admission</th>
<th>Mean (SD)</th>
<th>Reported statistical significance</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dougherty et al., 1999</td>
<td>Discharge</td>
<td>Subjects: 2.2 (1.6)</td>
<td>Controls: 4.7 (1.6)</td>
<td>Not reported</td>
</tr>
<tr>
<td></td>
<td>24 months</td>
<td>0.94</td>
<td>1.03</td>
<td>NS</td>
</tr>
<tr>
<td>Mitchell et al., 1986</td>
<td>‘European’</td>
<td>Up to 6 months</td>
<td>4.0 (7.7)</td>
<td>2.5 (1.5) NS</td>
</tr>
<tr>
<td></td>
<td>‘Polynesian’</td>
<td></td>
<td>2.7 (1.4)</td>
<td>3.5 (2.6) NS</td>
</tr>
<tr>
<td>Hughes et al., 1991</td>
<td>‘European’</td>
<td>6 to 18 months</td>
<td>3.1 (2.4)</td>
<td>3.1 (2.4) NS</td>
</tr>
<tr>
<td></td>
<td>‘Polynesian’</td>
<td></td>
<td>4.3 (3.9)</td>
<td>3.3 (2.1) NS</td>
</tr>
<tr>
<td></td>
<td>Up to 12 months</td>
<td>3.67</td>
<td>11.22</td>
<td>$p = 0.02$</td>
</tr>
<tr>
<td></td>
<td>12 to 24 months</td>
<td>5.83</td>
<td>5.33</td>
<td>NS</td>
</tr>
</tbody>
</table>
Health and other care costs

Dougherty’s is the only trial in this section to report costs and these are examined in detail in chapter 4. The overall conclusion from the paper which reports detailed costings is that the number of days of hospital stay saved in the intervention group was insufficient to offset the additional costs to the health service of providing the home-based intervention. However, as parental costs were lower in the intervention group the overall cost to society of the intervention was lowered (from Can$768 to Can$48 per child treated).

Family costs

Again, Dougherty’s is the only trial to report financial impact on the families of the children treated and this is reported in chapter 4. The mean estimated costs to parents (including the value of their time) were Can$720 (SD 188) less in the intervention group than in the control group. Most of this difference seems to be accounted for by the shorter length of initial hospitalisation for intervention group children.

Satisfaction with services

Only Dougherty and Hughes report satisfaction with services (Table 17). The Dougherty trial used a ten-item satisfaction questionnaire developed specially for the trial. Respondents used a five-point rating scale to indicate level of satisfaction with various aspects of the treatment. Reliability and validity of the measure were not tested. Parents and ‘adolescents’ (older than 12 years) completed the questionnaire. Hughes reports aspects of parents’ satisfaction with services but it is not clear how or when this was measured. Changes in parents’ needs for information and in the number of children taking responsibility for their own management are also reported.

There seems little to distinguish intervention group and control group satisfaction with services.
overall in either trial. However, Hughes seems to demonstrate a clear difference, in favour of the intervention, in the extent to which parents’ needs for information were met and children’s own management of their asthma increased over the period of the study.

**Impact on family and/or carers**
Dougherty\textsuperscript{64} reports perceived stress on parents and adolescents at various stages in the study (1, 12 and 24 months), using the Family Impact Scale (for parents) and the Perceived Stress Scale (for parents and adolescents). The only statistically significant difference between intervention and control groups was at one month when adolescents in the intervention group had higher stress scores than those in the control group.

**Impact on education**
All three trials report absence from school as a proxy for impact on the education of the children in the studies. As is clear from Table 18, there was no consistent effect on school attendance as a result of receipt of the intervention. This is confirmed by meta-analysis (I–V pooled SMD = 0.009, 95% CI, –0.184 to 0.203, \(p = 0.924\)).

**Knowledge of condition**
All three studies include some assessment of parents’ and/or children’s knowledge of their condition and report change over time. Dougherty\textsuperscript{64} administered the Diabetes Knowledge Scale and the Diabetes Regimen Adherence Scale for both parents and adolescents (aged over 12 years) at 1, 12 and 24 months. No significant differences between groups are reported on any test at any point. However, as we show in Table 19, there were some differences between the groups in the extent to which their scores changed or not, over time.

Mitchell\textsuperscript{65} reports no changes in knowledge of the child’s condition, for any subgroup.

Hughes\textsuperscript{40} does report some differences in the proportion of children with a ‘good’ metered aerosol technique, but these are difficult to interpret because the numbers of children using metered aerosols changed throughout the study and during the poststudy follow-up. However, it does seem that, of those children using this form of treatment, those in the intervention group were more likely to be judged to have a ‘good’ technique than those in the control group.

<table>
<thead>
<tr>
<th>Study</th>
<th>How measured</th>
<th>Period of follow-up</th>
<th>Subjects</th>
<th>Controls</th>
<th>Reported statistical significance</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dougherty et al., 1999\textsuperscript{64}</td>
<td>Parents’ mean score (SD) on satisfaction scale</td>
<td>1 month</td>
<td>46.2 (6.0)</td>
<td>45.5 (4.6)</td>
<td>NS</td>
</tr>
<tr>
<td></td>
<td></td>
<td>12 months</td>
<td>45.7 (5.4)</td>
<td>46.0 (3.5)</td>
<td>NS</td>
</tr>
<tr>
<td></td>
<td></td>
<td>24 months</td>
<td>45.6 (5.0)</td>
<td>46.0 (3.7)</td>
<td>NS</td>
</tr>
<tr>
<td></td>
<td>Adolescents’ mean score (SD) on satisfaction scale</td>
<td>1 month</td>
<td>42.8 (5.5)</td>
<td>46.3 (3.7)</td>
<td>NS</td>
</tr>
<tr>
<td></td>
<td></td>
<td>12 months</td>
<td>42.6 (8.7)</td>
<td>45.4 (3.2)</td>
<td>NS</td>
</tr>
<tr>
<td></td>
<td></td>
<td>24 months</td>
<td>43.9 (5.1)</td>
<td>43.9 (5.7)</td>
<td>NS</td>
</tr>
<tr>
<td>Hughes et al., 1991\textsuperscript{65}</td>
<td>Not clear, % ‘satisfied with medical care received during study year’</td>
<td></td>
<td>100</td>
<td>86.4</td>
<td>Not reported</td>
</tr>
<tr>
<td></td>
<td>% with expressed need for information about asthma</td>
<td></td>
<td></td>
<td></td>
<td>Not reported</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>At beginning of study</td>
<td>95.5</td>
<td>90.2</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>12 months</td>
<td>45.2</td>
<td>69.8</td>
</tr>
<tr>
<td></td>
<td>% believing child takes responsibility for management all or most of time</td>
<td></td>
<td></td>
<td></td>
<td>Not reported</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>At beginning of study</td>
<td>40.9</td>
<td>40.0</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>12 months</td>
<td>72.1</td>
<td>33.1</td>
</tr>
</tbody>
</table>
Trial results

Home care for children with mental health problems

Two trials are included in this section, reported in five papers (Henggeler and co-workers, Harrington and co-workers). One was based in the UK and one in the USA. Both compared home-based treatment for mental health emergencies with ‘routine’ care, whether hospital or community-based (Table 20). The trials will be referred to hereafter by the name of the first author and the main paper where the trials are reported.

This was an area of the literature where it was difficult to distinguish between place of care and type of clinical intervention. For example, intervention children in the Henggeler trial received a particular form of intervention – multisystemic therapy (MST) – that was “family-based, intensive and multifaceted” delivered in their own homes, while the control group received care in an inpatient unit that had a “behaviorally based milieu program with a point system that is individualised to each youth, targeting the behaviors that precipitated admission” (p.1334). In the Harrington trial, the intervention was a “brief home-based family intervention conducted by child psychiatric social workers” (p.512) and was in addition to routine care. Routine care, received by both the intervention group and the controls, after initial hospital admission and treatment “consisted mainly of out-patient clinic visits with psychiatrists and with psychiatric nurses. None of the hospitals used a home-based family intervention” (p.57). In both trials, then, there was an inevitable confounding of place of care and mode of treatment (see Table 21).

Inclusion and exclusion criteria

Children were included in both trials on the basis of clinical assessment of severity of mental illness. In the Harrington trial, a diagnosis of deliberate self-poisoning according to a standard definition was used to identify children for the study, and in the Henggeler trial, symptoms of suicidal ideation, homicidal ideation, psychosis or threat of harm to self or others due to mental illness, based on the American Academy of Child and Adolescent Psychiatry level of care placement criteria were used. All the children included, then, were seriously ill at the time they were recruited to the study. Inclusion was also based on age – under 16 (with no minimum age specified, but a mean age of around 14 reported) for Harrington and 10–17 (mean reported age 13) for Henggeler. In both trials, the children’s circumstances had to be such that a family or home-based intervention was actually feasible.

Harrington had a number of exclusion criteria based on other clinical or psychiatric contraindications – examples given include severe mental illness, current psychiatric patient status, severe suicide risk, or if the parents or child had ‘significant’ learning difficulties. Children with major depression were not excluded, on the basis of their overall need for intervention. In both trials, children were required to have at least one family member able to attend sessions. In the Harrington trial, a further criterion was that the child’s circumstances had to be such that a home-based intervention was actually feasible.

Table 18: Impact on education

<table>
<thead>
<tr>
<th>Study</th>
<th>How measured</th>
<th>Period of follow-up</th>
<th>Subjects</th>
<th>Controls</th>
<th>Reported statistical significance</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dougherty et al., 1999</td>
<td>Mean (SD) days of absence</td>
<td>24 months</td>
<td>29.7 (28.7)</td>
<td>28.3 (36.4)</td>
<td>NS</td>
</tr>
<tr>
<td>Mitchell et al., 1986</td>
<td>Mean (SD) days of absence</td>
<td>6 months</td>
<td>8.6 (15.1)</td>
<td>6.3 (8.8)</td>
<td>NS</td>
</tr>
<tr>
<td>Hughes et al., 1991</td>
<td>Mean (SD) days of absence</td>
<td>Year before study</td>
<td>10.8 (11.2)</td>
<td>10.4 (10.0)</td>
<td>NS</td>
</tr>
<tr>
<td></td>
<td>for asthma-related reasons</td>
<td>Study year</td>
<td>5.8 (7.6)</td>
<td>8.8 (15.2)</td>
<td>NS</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Follow-up year</td>
<td>3.4 (6.1)</td>
<td>3.4 (4.5)</td>
<td>NS</td>
</tr>
<tr>
<td>Hughes et al., 1991</td>
<td>Mean (SD) days of absence</td>
<td>Study year</td>
<td>10.7 (6.9)</td>
<td>16.0 (15.4)</td>
<td>p = 0.04</td>
</tr>
<tr>
<td></td>
<td>for all causes</td>
<td>Follow-up year</td>
<td>9.8 (7.6)</td>
<td>12.2 (11.7)</td>
<td>NS</td>
</tr>
</tbody>
</table>

The table shows the impact on education for children with mental health problems, with data from different studies reported. The studies included in the table are by Dougherty et al., Mitchell et al., and Hughes et al., with specific details on the method of measurement, period of follow-up, and results for subjects and controls, along with reported statistical significance.
### TABLE 19  Impact on knowledge of condition in home care for children with diabetes or asthma

<table>
<thead>
<tr>
<th>Study</th>
<th>How measured</th>
<th>Period of follow-up</th>
<th>Subjects</th>
<th>Controls</th>
<th>Reported statistical significance</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dougherty et al., 1999⁴⁴</td>
<td>Diabetes Knowledge Scale: change in % correctᵃ</td>
<td>24 months</td>
<td></td>
<td></td>
<td>N/A</td>
</tr>
<tr>
<td></td>
<td>Parents</td>
<td>6.0 – 0.5</td>
<td>N/A</td>
<td></td>
<td>N/A</td>
</tr>
<tr>
<td></td>
<td>Adolescents</td>
<td>13.5 – 4.5</td>
<td>N/A</td>
<td></td>
<td>N/A</td>
</tr>
<tr>
<td></td>
<td>Diabetes Regimen Adherence Scale: change in % correctᵃ</td>
<td>–9.2 – 11.4</td>
<td>N/A</td>
<td></td>
<td>N/A</td>
</tr>
<tr>
<td></td>
<td>Adolescents</td>
<td>–4.8 – 12.1</td>
<td>N/A</td>
<td></td>
<td>N/A</td>
</tr>
<tr>
<td>Mitchell et al., 1986⁶¹</td>
<td>% of children knowing how to prevent an attack of asthma</td>
<td>6 months</td>
<td></td>
<td></td>
<td>N/A</td>
</tr>
<tr>
<td></td>
<td>‘European’</td>
<td>30 – 37</td>
<td>NS</td>
<td></td>
<td>N/A</td>
</tr>
<tr>
<td></td>
<td>‘Polynesian’</td>
<td>39 – 24</td>
<td>NS</td>
<td></td>
<td>N/A</td>
</tr>
<tr>
<td></td>
<td>% of parents knowing how to start additional treatment</td>
<td>96 – 98</td>
<td>NS</td>
<td></td>
<td>N/A</td>
</tr>
<tr>
<td></td>
<td>‘European’</td>
<td>98 – 98</td>
<td>NS</td>
<td></td>
<td>N/A</td>
</tr>
<tr>
<td></td>
<td>‘Polynesian’</td>
<td>98 – 98</td>
<td>NS</td>
<td></td>
<td>N/A</td>
</tr>
<tr>
<td></td>
<td>% of parents knowing when to seek additional advice</td>
<td>98 – 99</td>
<td>NS</td>
<td></td>
<td>N/A</td>
</tr>
<tr>
<td></td>
<td>‘European’</td>
<td>98 – 99</td>
<td>NS</td>
<td></td>
<td>N/A</td>
</tr>
<tr>
<td></td>
<td>‘Polynesian’</td>
<td>95 – 98</td>
<td>NS</td>
<td></td>
<td>N/A</td>
</tr>
<tr>
<td>Hughes et al., 1991⁴⁰</td>
<td>Proportion with ‘good’ metered inhaler technique: changeᵃ</td>
<td>12 months after study</td>
<td>60.2 – 15.4</td>
<td>5 – 4</td>
<td>N/A</td>
</tr>
<tr>
<td></td>
<td>Educational questionnaire score: change in % correctᵃ</td>
<td>Before study</td>
<td>59.6 – 57.4</td>
<td>52.3 – 51.1</td>
<td>NS</td>
</tr>
<tr>
<td></td>
<td>% of families with resident smoker</td>
<td>Before study</td>
<td>44.7 – 52.2</td>
<td>47.7 – 60</td>
<td>Not reported</td>
</tr>
<tr>
<td></td>
<td>12 months</td>
<td>52.3 – 60</td>
<td>NS</td>
<td></td>
<td>N/A</td>
</tr>
</tbody>
</table>

ᵃ Change in reported % calculated by us
N/A, not applicable

### TABLE 20  Details of trials of home care for children with mental health problems

<table>
<thead>
<tr>
<th>Authors and title of main paper</th>
<th>Publication details</th>
<th>n subjects</th>
<th>n controls</th>
<th>Jadad⁵⁰ score (max 3)</th>
<th>EPOC⁵¹ score (max 7)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Harrington et al., 1998⁶⁹</td>
<td>Journal of the American Academy of Child and Adolescent Psychiatry 1998;37:512–18</td>
<td>85</td>
<td>77</td>
<td>3</td>
<td>5 or 6</td>
</tr>
<tr>
<td>Randomized trial of a home-based family intervention for children who have deliberately poisoned themselves</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Henggeler et al., 1999⁶⁷</td>
<td>Journal of the American Academy of Child and Adolescent Psychiatry 1999;38:1331–9</td>
<td>57</td>
<td>56</td>
<td>3</td>
<td>6</td>
</tr>
<tr>
<td>Home based multisystemic therapy as an alternative to the hospitalisation of youth in psychiatric crisis: clinical outcomes</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total randomised</td>
<td></td>
<td>142</td>
<td>133</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
that an earlier study in the same hospitals “had shown that major depression after a deliberate overdose resolved rapidly in most cases” (p.513). Henggeler excluded only children who were autistic or whose families had already received MST home-based treatment. No other children were excluded on the basis of pre-existing physical health, intellectual, or other mental health difficulties.

The wide-ranging exclusion criteria in the Harrington trial inevitably affected the proportion of the patient population recruited to the trial – 37%. Of the 435 children aged 10–16 who had taken an overdose and been referred to child psychiatry teams during the period of the study, 38 were excluded because the overdose had not been deliberate, 48 because of contraindications and 62 because their ‘social situation’ was felt to preclude a home-based intervention. A further 109 refused further treatment or recruitment to the trial and contact was lost with 17. Henggeler does not report the size of the original patient population.

**Quality of the trials**

Both trials were appropriately described as randomised, although Henggeler used a two (treatment type) by three (time) mixed factorial design, which involved ‘yoking’ of pairs of intervention and control children for assessment purposes. There was an initial assessment of children within 24 hours of being accepted into the study (T1), shortly after the control child was discharged from hospital, with the intervention-paired child being assessed at the same time (T2) and a final assessment at the completion of the MST home-based services (an average of 4 months after recruitment) with the yoked control child being assessed at the same time (T3).

Both trials met all three of the Jadad criteria. Harrington’s met five or six of the EPOC quality criteria, although blinded assessment of outcomes was built into the trial it was difficult to achieve practically, because the intervention was so different from usual care. Henggeler met six of the EPOC criteria; the only one that was unclear was protection from contamination.

**Outcomes reported**

There was substantial commonality of outcomes reported in the two trials. Both report length of hospital stay and/or readmission, clinical outcomes, costs for both health and social services, quality of life, satisfaction with services, impact on family and/or carers, and social outcomes. In addition, Henggeler reports impact on education. Neither report other mental function outcomes, costs to families or impact on knowledge about the child’s condition. No deaths are reported in either trial.

**Length of hospital stay and readmission**

Harrington reports hospital use only in the accompanying health economics paper and, as shown in Table 22, does not report whether or not differences between intervention and control groups were statistically significant. All elements of hospital care that were included, however, suggest lower levels of use for intervention than for control children. This is particularly striking for outpatient attendances.

Henggeler shows consistently lower rates of hospital use for intervention children, as would be expected, during the first phase of the study. This does not seem to be maintained into the second phase of the study, although mean length of stay during this period is lower, but not significantly so, for intervention children.
Clinical outcomes
Both trials report a number of clinical outcome measures. As Table 23 shows, few of these suggest any significant effects, although several do favour the intervention. The Henggeler trial used two (treatment) by three (time) analysis of variance (ANOVA) to analyse data collected at the three time points in the trial, and two by two ANOVA where data were collected at only two time points, alongside planned post hoc comparisons where a significant interaction effect was evident. This analysis showed significant intervention effects on the ‘externalising symptoms’ of the Child Behaviour Checklist as reported both by carers and by teachers. In relation to most other measures, however, only time effects, which would have been expected anyway, were statistically significant. With one measure – adolescent self-esteem, as mentioned through self-report on the self-esteem subscale of the Family, Friends and Self Scale – the results favoured the control condition.

Harrington’s analysis did not examine change over time but simply compared results at each follow-up point. This approach perhaps underplays some differences in rates of change between the intervention and control groups, as our calculation of mean difference between randomisation and follow-up suggests.

Costs to the health and other services
The Harrington trial included a cost-effectiveness analysis. This is reported in detail in chapter 4. This was based on service use, collected retrospectively for a 6-month period, using a questionnaire to parents, coupled with an audit of medical records to verify NHS clinical contacts. This covered use of educational and social services as well as both hospital and community-based health services. Service use was then costed using various techniques – bottom-up calculation, data from local providers, national and local salary scales, and published unit cost data.

Without the cost of the intervention itself, the total cost of services used by the intervention group was significantly lower than for the control group.
### TABLE 23  Clinical outcomes in home care for children with mental health problems

<table>
<thead>
<tr>
<th>Study</th>
<th>How measured</th>
<th>Period of follow-up</th>
<th>Subjects</th>
<th>Controls</th>
<th>Reported statistical significance</th>
</tr>
</thead>
<tbody>
<tr>
<td>Harrington et al., 1998&lt;sup&gt;93&lt;/sup&gt;</td>
<td>Mean (SD) Suicidal Ideation Questionnaire score (range 0–180)</td>
<td>Before treatment</td>
<td>63.6 (46.7)</td>
<td>62.9 (46.8)</td>
<td>NS</td>
</tr>
<tr>
<td></td>
<td></td>
<td>2 months</td>
<td>40.0 (50.7)</td>
<td>43.4 (49.2)</td>
<td>NS</td>
</tr>
<tr>
<td></td>
<td></td>
<td>6 months</td>
<td>23.6 (40.0)</td>
<td>28.7 (35.3)</td>
<td>NS</td>
</tr>
<tr>
<td></td>
<td>Mean change&lt;sup&gt;a&lt;/sup&gt;</td>
<td></td>
<td>−40.0</td>
<td>−34.2</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Mean (SD) score on Hopelessness Scale (range 0–17)</td>
<td>Before treatment</td>
<td>6.1 (4.1)</td>
<td>6.6 (4.0)</td>
<td>NS</td>
</tr>
<tr>
<td></td>
<td></td>
<td>2 months</td>
<td>5.6 (4.0)</td>
<td>5.3 (4.1)</td>
<td>NS</td>
</tr>
<tr>
<td></td>
<td></td>
<td>6 months</td>
<td>4.4 (3.3)</td>
<td>4.2 (3.6)</td>
<td>NS</td>
</tr>
<tr>
<td></td>
<td>Mean change&lt;sup&gt;a&lt;/sup&gt;</td>
<td></td>
<td>−1.7</td>
<td>−2.4</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Number (%) with major depression (Schedule for Affective Disorders and Schizophrenia)</td>
<td>Before treatment</td>
<td>56/85 (66)</td>
<td>53/77 (69)</td>
<td>NS</td>
</tr>
<tr>
<td></td>
<td></td>
<td>2 months</td>
<td>25/79 (32)</td>
<td>19/75 (25)</td>
<td>NS</td>
</tr>
<tr>
<td></td>
<td></td>
<td>6 months</td>
<td>12/74 (16)</td>
<td>17/75 (23)</td>
<td>NS</td>
</tr>
<tr>
<td></td>
<td>Mean change&lt;sup&gt;a&lt;/sup&gt;</td>
<td></td>
<td>−50</td>
<td>−46</td>
<td></td>
</tr>
<tr>
<td>Henggeler et al., 1999&lt;sup&gt;72&lt;/sup&gt;</td>
<td>Mean (SD) Global Severity Index – Brief Symptom Inventory (child)</td>
<td>T1</td>
<td>1.01 (0.7)</td>
<td>1.22 (0.8)</td>
<td>Time effect only</td>
</tr>
<tr>
<td></td>
<td></td>
<td>T2</td>
<td>0.71 (0.6)</td>
<td>1.03 (0.9)</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>T3</td>
<td>0.74 (0.9)</td>
<td>0.84 (0.7)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Mean change&lt;sup&gt;a&lt;/sup&gt;</td>
<td></td>
<td>−0.27</td>
<td>−0.38</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Mean (SD) Child Behaviour Checklist (carer): internalising symptoms</td>
<td>T1</td>
<td>68.0 (10.9)</td>
<td>69.5 (10.9)</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>T2</td>
<td>62.1 (12.6)</td>
<td>63.1 (10.5)</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>T3</td>
<td>60.6 (12.8)</td>
<td>60.7 (12.6)</td>
<td>Time effect only</td>
</tr>
<tr>
<td></td>
<td>Mean change&lt;sup&gt;a&lt;/sup&gt;</td>
<td></td>
<td>−7.4</td>
<td>−8.8</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Mean (SD) Child Behaviour Checklist (carer): externalising symptoms</td>
<td>T1</td>
<td>73.3 (10.3)</td>
<td>70.6 (12.3)</td>
<td>Treatment effect, ( p &lt; 0.02 )</td>
</tr>
<tr>
<td></td>
<td></td>
<td>T2</td>
<td>67.4 (12.1)</td>
<td>62.4 (12.2)</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>T3</td>
<td>63.7 (12.4)</td>
<td>64.3 (12.2)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Mean change&lt;sup&gt;a&lt;/sup&gt;</td>
<td></td>
<td>−9.6</td>
<td>+6.3</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Mean (SD) Child Behaviour Checklist (teacher): internalising symptoms</td>
<td>T1</td>
<td>64.6 (12.2)</td>
<td>62.2 (13.9)</td>
<td>Time effect only</td>
</tr>
<tr>
<td></td>
<td></td>
<td>T3</td>
<td>60.1 (12.8)</td>
<td>58.8 (11.3)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Mean change</td>
<td></td>
<td>−4.5</td>
<td>−3.4</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Mean (SD) Child Behaviour Checklist (carer): externalising symptoms</td>
<td>T1</td>
<td>71.1 (10.7)</td>
<td>67.8 (15.1)</td>
<td>( p &lt; 0.5 )</td>
</tr>
<tr>
<td></td>
<td></td>
<td>T3</td>
<td>64.8 (11.8)</td>
<td>68.0 (13.0)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Mean change&lt;sup&gt;a&lt;/sup&gt;</td>
<td></td>
<td>−6.3</td>
<td>+0.2</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Mean (SD) Family, Friends and Self Scale – self-esteem</td>
<td>T1</td>
<td>2.57 (0.9)</td>
<td>2.21 (1.0)</td>
<td>( p &lt; 0.006 ) (favours hospital group)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>T3</td>
<td>2.55 (1.1)</td>
<td>2.73 (0.9)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Mean change&lt;sup&gt;a&lt;/sup&gt;</td>
<td></td>
<td>−0.02</td>
<td>+0.5</td>
<td></td>
</tr>
</tbody>
</table>

<sup>a</sup> Calculated by us
group (means £1177 and £1751, respectively, \( p = 0.044 \)). When the cost of the intervention was included, the average cost of services for the intervention group went up to £1455 which, although still less than for the control group, was no longer significantly so. Within these overall costs there was a very substantial and statistically significant saving to social services providers (median £53.93 for intervention group, £140.21 for control group, \( p = 0.039 \)); this was largely because of lower levels of foster or residential care placements among the intervention group.

Henggeler reports limited costings in a companion paper\(^68\) to the main trial results paper, with the promise of a fuller cost-effectiveness study after collection of follow-up data 12 months after T3. Again, costs to health and social care agencies are considered and the “preliminary accounting of the costs associated with delivering MST… indicates a cost of [US]$5954 per youth” (ibid, p.9) or an average of $46 a day for the immediate intervention. The comparative costs for children admitted to hospital were estimated at $6174, on the basis of an average cost of $700 per day for hospital care and 8.82 days of hospital-based crisis stabilisation between T1 and T3. With the addition of ‘incremental costs’ – subsequent hospitalisation for the intervention group and out-of-home placements for either group – the comparative costs became $8017 for MST and $7878 for hospitalisation. However, the paper emphasises that these are preliminary costings and we await a fuller description after further follow-up.

In both trials, then, costs were broadly similar for the intervention and control conditions.

### Quality of life for the child

The only outcome measured in either trial that might approximate to a quality of life measure was the self-esteem of children, as measured in the Henggeler trial,\(^67\) using a subscale of the Family, Friends and Self Scale. This is reported in the clinical outcomes section (page 29). As this shows, this measure favoured the control group.

### Satisfaction with services

Both trials attempted to assess children’s and parents’ satisfaction with services (Table 24). Harrington\(^69\) used an eight-point Likert scale constructed for the study, while Henggeler\(^67\) used the Lubrecht Family Satisfaction Survey. This was tested only at T2 and T3 and compared at each time point.

Both trials report higher levels of children’s satisfaction with services for the intervention groups, but only in the Henggeler trial did these differences reach statistical significance. By contrast, both trials report statistically significantly higher levels of satisfaction for parents or carers in the intervention group, but at different points in follow-up – at the end of follow-up in Henggeler’s trial\(^67\) and at 2, but not 6 months in Harrington’s.\(^69\)

Overall, again, parents in the intervention group were more satisfied than parents in the control group.

The number of children and parents for whom scores were reported varied at the different points of follow-up for the Harrington trial; for example, satisfaction scores were available for only 69/85 (81%) intervention group parents and 68/77 (88%) control group parents at 6 months follow-up.

**TABLE 24** Satisfaction with services in home care for children with mental health problems

<table>
<thead>
<tr>
<th>Study</th>
<th>How measured</th>
<th>Period of follow-up</th>
<th>Subjects</th>
<th>Controls</th>
<th>Reported statistical significance</th>
</tr>
</thead>
<tbody>
<tr>
<td>Harrington et al., 1998(^69)</td>
<td>Mean (SD) score on Likert scale</td>
<td>2 months</td>
<td>4.6 (2.1)</td>
<td>4.3 (2.4)</td>
<td>NS</td>
</tr>
<tr>
<td></td>
<td>(children; range 0–8)</td>
<td>6 months</td>
<td>4.6 (2.3)</td>
<td>3.9 (2.9)</td>
<td>NS</td>
</tr>
<tr>
<td></td>
<td>Mean (SD) score on Likert scale</td>
<td>2 months</td>
<td>5.0 (2.3)</td>
<td>3.7 (2.5)</td>
<td>( p &lt; 0.001 )</td>
</tr>
<tr>
<td></td>
<td>(parents; range 0–8)</td>
<td>6 months</td>
<td>5.0 (2.3)</td>
<td>4.3 (2.6)</td>
<td>NS</td>
</tr>
<tr>
<td>Henggeler et al., 1999(^67)</td>
<td>Mean (SD) score on Lubrecht Family</td>
<td>T2</td>
<td>15.7 (4.4)</td>
<td>13.3 (4.2)</td>
<td>( p &lt; 0.007 )</td>
</tr>
<tr>
<td></td>
<td>Satisfaction Survey (children)</td>
<td>T3</td>
<td>15.5 (4.5)</td>
<td>12.0 (4.6)</td>
<td>( p &lt; 0.001 )</td>
</tr>
<tr>
<td></td>
<td>Mean (SD) score on Lubrecht Family</td>
<td>T2</td>
<td>17.6 (3.2)</td>
<td>16.5 (3.4)</td>
<td>Not reported</td>
</tr>
<tr>
<td></td>
<td>Satisfaction Survey (carers)</td>
<td>T3</td>
<td>17.9 (3.4)</td>
<td>16.4 (3.9)</td>
<td>( p &lt; 0.044 )</td>
</tr>
</tbody>
</table>
Impact on family and/or carers

Both trials report both generic family functioning outcome measures and specific parent or carer outcomes. These are outlined in Tables 25 and 26.

Harrington\(^69\) reports no significant treatment effect on family functioning, although with such a truncated scoring system it is not clear how sensitive to change the measure used actually was. Henggeler\(^67\) reports different types of findings for children and their parents/carers. While children’s self-reports suggested that those who were in the intervention group had improved levels of adaptability, carers’ reports suggested only a time effect. By contrast, children reported no significantly different treatment or time effects on family cohesion, while parents/carers reported a significant treatment effect on cohesion that favoured the intervention group.

Neither trial suggested any significant difference between intervention and control parents/carers in the personal impact of their child’s condition and treatment.

Impact on education

Given the likely impact of hospital admission on children’s ability to participate fully in their education it is surprising to find that only Henggeler measured days missed from school.\(^67\)

This showed, as one might expect, a significantly lower mean number of days missed from the

<table>
<thead>
<tr>
<th>TABLE 25 Impact on family functioning</th>
</tr>
</thead>
<tbody>
<tr>
<td>Study</td>
</tr>
<tr>
<td>--------------------------------------</td>
</tr>
<tr>
<td>Harrington et al., 1998(^69)</td>
</tr>
<tr>
<td>Henggeler et al., 1999(^67)</td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
</tbody>
</table>

*Family Adaptability and Cohesion Evaluation Scales

<table>
<thead>
<tr>
<th>TABLE 26 Impact on parents/carers in home care for children with mental health problems</th>
</tr>
</thead>
<tbody>
<tr>
<td>Study</td>
</tr>
<tr>
<td>------------------------------------------</td>
</tr>
<tr>
<td>Harrington et al., 1998(^69)</td>
</tr>
<tr>
<td>Henggeler et al., 1999(^67)</td>
</tr>
</tbody>
</table>
time of treatment until follow-up (14 days, SD 36.8 compared with 37 days, SD 59.8, \( F = 15.18, p < 0.018 \)). However, there is no indication of whether hospitalisation accounted for all or only part of the difference.

**Impact on child’s social life**

Outcomes used in the trials reported here were more to do with social functioning of the children than to do with impact on their social lives, *per se*. However, on the assumption that social functioning is likely to have an impact on the ability to have a satisfying social life, these results are included in this section. Neither trial demonstrated any statistically significant difference between intervention and control groups on any of the measures used (Table 27).

**Destinational outcomes**

Entry to residential or foster care or other forms of ‘non-family’ care is an outcome that is perhaps more likely among children with mental health problems than it is for any of the other conditions covered in this review. Both trials report outcomes in this general area (Table 28).

Although Harrington reports no significant difference in the proportions of children experiencing foster or residential care, the mean number of weeks in each was clearly much higher for children who were in the control group. Means and SDs are not reported and neither is the result of any statistical testing. However, the costing exercise, within which these results were presented, shows that costs to social services departments were significantly higher for control children, ‘mainly as a result of the controls’ much greater use of foster and residential care’ (p.59).

Similarly, although the Henggeler trial does not report any statistical testing of difference in the number of days in care, both the total and means were higher for control group children than for the intervention group. The difference in the proportion of children who experienced a change of placement appears to be almost entirely accounted for by the fact that all children in the control group had at least one more change of placement because of the need to leave hospital at some time. This does not appear to have been accounted for in the reporting of these results. However, it was also the case that children who had been in the intervention group were less likely to experience changes of placement to more restrictive environments.

**Paediatric home care**

One major and long-running trial of paediatric home care, so described, was identified – that

---

**TABLE 27  Impact on social functioning**

<table>
<thead>
<tr>
<th>Study</th>
<th>How measured</th>
<th>Period of follow-up</th>
<th>Subjects</th>
<th>Controls</th>
<th>Reported statistical significance</th>
</tr>
</thead>
<tbody>
<tr>
<td>Harrington et al., 1998&lt;sup&gt;69&lt;/sup&gt;</td>
<td>Mean (SD) Social Problem Solving Inventory – Generation of Alternative Solutions subscale (range 0–40)</td>
<td>Before treatment 2 months</td>
<td>17.4 (6.4)</td>
<td>17.9 (6.0)</td>
<td>NS</td>
</tr>
<tr>
<td></td>
<td></td>
<td>6 months</td>
<td>17.0 (6.7)</td>
<td>18.4 (6.3)</td>
<td>NS</td>
</tr>
<tr>
<td>Henggeler et al., 1999&lt;sup&gt;67&lt;/sup&gt;</td>
<td>Mean (SD) FFS – conventional involvement of friends subscale</td>
<td>T1</td>
<td>1.97 (0.8)</td>
<td>1.95 (0.8)</td>
<td>NS</td>
</tr>
<tr>
<td></td>
<td></td>
<td>T3</td>
<td>1.89 (0.7)</td>
<td>2.09 (0.8)</td>
<td>NS</td>
</tr>
<tr>
<td></td>
<td>Mean (SD) FFS – antisocial friends subscale</td>
<td>T1</td>
<td>0.99 (0.8)</td>
<td>1.07 (0.9)</td>
<td>NS</td>
</tr>
<tr>
<td></td>
<td></td>
<td>T3</td>
<td>1.09 (1.0)</td>
<td>1.05 (0.9)</td>
<td>NS</td>
</tr>
<tr>
<td></td>
<td>Mean (SD) Child Behaviour Checklist – Social Competence subscales (carer report)</td>
<td>T1</td>
<td>30.2 (6.1)</td>
<td>30.9 (6.3)</td>
<td>NS</td>
</tr>
<tr>
<td></td>
<td></td>
<td>T3</td>
<td>33.5 (6.8)</td>
<td>31.8 (6.9)</td>
<td>Time effect only</td>
</tr>
<tr>
<td></td>
<td>Mean (SD) Child Behaviour Checklist – Social Competence subscales (child’s report)</td>
<td>T1</td>
<td>34.9 (6.1)</td>
<td>36.6 (8.5)</td>
<td>NS</td>
</tr>
<tr>
<td></td>
<td></td>
<td>T3</td>
<td>36.3 (7.9)</td>
<td>38.7 (8.6)</td>
<td>NS</td>
</tr>
</tbody>
</table>
of Stein and Jessop. Six papers describing the programme, the trial and long-term follow up have been identified, published between 1978 and 1994. The programme evaluated in the trial was conducted by an interdisciplinary team, which included paediatricians, primary care paediatric nurse practitioners, and social workers, and that provided comprehensive primary healthcare, support, coordination, patient advocacy and education to chronically ill children and their families. This could include direct ‘hands on’ care for children at home, as well as monitoring and service coordination. In one descriptive paper, the programme is described as an “ambulatory special care unit”. In the UK context, PHC teams for technology-dependent children and others might be considered an equivalent model.

The prime site of delivery of care was the child’s own home, with supplementary input in clinics, inpatient units and primary health centres. The programme was compared with ‘standard’ care for children with complex and long-standing conditions. Conditions covered by the programme were diverse, including asthma, haemoglobinopathies, seizures, heart disease, cancer, diabetes and congenital anomalies. The study and programme were based in the Bronx area of New York, USA.

### Inclusion and exclusion criteria

Children recruited to the trial were under the age of 11, resident in the Bronx and were patients of affiliated hospitals of the Albert Einstein College of Medicine. They had to have a physical condition that was of 3 or more months’ duration or which had necessitated a month or more of continuous hospitalisation and which required care ‘beyond the normal’. Children were excluded from the trial if they were moderately or severely intellectually retarded, expected to die within 12 months, or lived in a household that was other than English or Spanish speaking. Only one child per family was enrolled and a nine-cell stratification design was employed, using Judged Ability to Cope and the Clinician’s Overall Burden Index (both measures were developed for the study and had tested internal reliability). Of the 381 children who came to the attention of the research team during the recruitment period, (June 1978 to January 1980) 92 (24%) did not meet the criteria for recruitment to the trial and a total of 291 were eventually recruited.

### Quality of the trial

The trial met all three of the Jadad criteria employed here but did less well on the EPOC criteria, with a score of 4/5. Primary outcomes

---

**TABLE 28 Use of institutional care in home care for children with mental health problems**

<table>
<thead>
<tr>
<th>Study</th>
<th>How measured</th>
<th>Period of follow-up</th>
<th>Subjects</th>
<th>Controls</th>
<th>Reported statistical significance</th>
</tr>
</thead>
<tbody>
<tr>
<td>Harrington et al., 1998</td>
<td>Number of children entering foster care</td>
<td>6 months</td>
<td>2</td>
<td>4</td>
<td>NS</td>
</tr>
<tr>
<td></td>
<td>Total weeks of foster care</td>
<td></td>
<td>25</td>
<td>54</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Mean weeks per childa</td>
<td></td>
<td>0.34</td>
<td>0.72</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Number of children entering residential care</td>
<td></td>
<td>0</td>
<td>3</td>
<td>NS</td>
</tr>
<tr>
<td></td>
<td>Total weeks of residential care</td>
<td></td>
<td>0</td>
<td>8</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Mean weeks per childa</td>
<td></td>
<td>0</td>
<td>0.11</td>
<td></td>
</tr>
<tr>
<td>Henggeler et al., 1999</td>
<td>Days in out-of-home placements (excluding hospital)</td>
<td>T3 508</td>
<td>996</td>
<td></td>
<td>Not reported</td>
</tr>
<tr>
<td></td>
<td>Mean days per childa</td>
<td></td>
<td>8.9</td>
<td>17.8</td>
<td>p &lt; 0.001</td>
</tr>
<tr>
<td></td>
<td>% experiencing change of placement</td>
<td>T3 56</td>
<td>100</td>
<td></td>
<td>p &lt; 0.01</td>
</tr>
<tr>
<td></td>
<td>Mean (SD) number of changes</td>
<td></td>
<td>1.8 (2.22)</td>
<td>2.8 (1.65)</td>
<td>p &lt; 0.01</td>
</tr>
<tr>
<td></td>
<td>Mean (SD) changes to more restrictive placement</td>
<td></td>
<td>0.78 (1.10)</td>
<td>1.34 (0.92)</td>
<td>p &lt; 0.01</td>
</tr>
</tbody>
</table>

* Calculated by us
were not assessed blind and it is not clear whether or not contamination could have occurred. Long-term follow-up was just under 80% of the original sample.

There are some difficulties understanding the size of the original sample: 219 children are reported at the beginning of the initial trial paper but ten of these were already lost by the time of the first interview. The reasons for this loss are not reported. Of the remaining 209 children, 104 were in the intervention group and 105 in the control group. Only 188 (86% of the original 219) completed the follow-up interview at 6 months and 183 (83%) at 12 months. A complete data set for all three interviews exists for only 174 children (79%) and is higher among the intervention group (93) than for the controls (81). Data for these 174 children form the basis of all of the results subsequently reported.

These 174 intervention and control ‘survivors’ were examined for comparability on a number of characteristics measured at recruitment and are reported to be equivalent on characteristics of the children, their carers, family structure, social context or pretest scores. However, with no reported information on children who were not part of this group of 174, this leaves the possibility that the intervention and control children who were not included were different from one another.

Outcomes reported
A relatively small number of outcomes are reported – physical function, psychological adjustment, satisfaction with services and impact on family and/or carers. In some places results are reported for the strata used for randomisation. However, these were collapsed down from the nine original cells to four, by aggregating the medium and low strata for coping resources and the medium and high strata for burden. The resulting cells for analysis were thus: high coping/low burden, high coping/high burden, low coping/low burden and low coping/high burden.

Physical function
Functional status was measured with an instrument developed and validated specifically for the trial. It was “designed to tap variation in function among children having a wide variety of chronic conditions and to be sensitive to minor differences in function within a given child over time” (p.849) and was based on a child’s ability “to perform age-appropriate roles and tasks” (ibid).

No statistically significant differences were observed between the intervention group and controls before treatment, at 6 months or at 12 months follow-up. Subgroup analysis showed that, at 6 months, the intervention children did relatively less well on this measure when family coping resources were high, and relatively better when family coping resources were low. Statistical testing showed a significant interaction effect ($p < 0.01$). At 12 months, the control children did better in all cells except in low resources/low burden, but this difference did not reach statistical significance.

Psychological adjustment
Children’s psychological adjustment was measured using the 28 item version of the Personal Adjustment and Role Skills (PARS) II scale for children and adolescents (subsequently renamed the CAAP).

Only a small number (70) of the original sample was actually tested using this instrument, largely because the others were too young (< 5 years) for the instrument to have much meaning. Mean scores were adjusted for ‘initial differences in pretest scores’ (Stein and Jessop, Table 3). The two groups had similar scores before treatment and at 6 months the intervention group had a higher (better) score than the controls (adjusted mean 69.39 (SD 6.10) and 65.93 (SD 7.57), respectively, $F = 4.349, p = 0.41$). By 12 months, however, the difference between the groups did not reach conventional levels of statistical significance ($F = 3.24, p = 0.076$).

Subgroup analysis of covariance found no differences at 6 months follow-up but results at 12 months suggested that intervention group children did better than controls when burden was high, and also when both coping resources and burden were low ($p < 0.05$).

Further follow-up was carried out, 4½ to 5 years after recruitment, on 55 of the 81 children (68%) who had been aged 5 and over at recruitment. These were the only children who were still contactable. It is not clear however how the 81 children relate to the 70 children over the age of 5 for whom results were originally reported.

Comparison of these 55 children’s scores over time suggests that psychological adjustment was improved for children who had received the intervention care. By the time of this final follow-up, the mean score of the intervention group had improved from 66.9 (SD 9.3) to 74.3 (SD 6.6) compared with the control group, which
had shown no improvement at all (67.8, SD 9.1 to 67.8, SD 12.3). Analysis of covariance indicated that this difference reached statistical significance ($F = 7.48$, $p = 0.009$). Six factor-based subscores were also tested for this small, long-term follow-up group; this indicated that the intervention group performed significantly better in terms of withdrawal, anxiety/depression, productivity and hostility, but that there were no statistically significant differences in relation to peer relations or dependency.

**Costs to health services**

No formal costing associated with the trial was carried out. An early, descriptive paper published some years before the trial suggested that the ‘cost per patient per day’ of the intervention service was US$6.46, exclusive of the costs of laboratory services, pharmacy or supplies. This was compared to an inpatient cost per day of US$275 (in the early 1970s). However, with no indication of days of hospital stay saved by the intervention it is impossible to draw any conclusions from these figures.

**Satisfaction with services**

This trial examined family satisfaction with care received and also their access to a variety of services, over and above the intervention. Satisfaction with care was measured using a tool developed and tested specifically for the trial. At the start of the trial there were no differences in parental satisfaction with care (intervention group mean 31.95, SD 3.84, control group mean 32.43, SD 4.49). At both 6-month follow-up (intervention group mean 33.03, SD 3.59; control group mean 31.83, SD 3.48, $F = 4.933$, $p = 0.028$) and 12-month follow-up (intervention group adjusted mean 33.25, SD 3.31, control group adjusted mean 32.0, SD 3.52, $F = 5.867$, $p = 0.016$), intervention parents were significantly more likely to be satisfied with care than control parents. Subgroup analysis showed no significant difference between parents with different levels of coping resources or burden.

**Impact on family and/or carers**

Two main measures of family impact are reported in this trial – mothers’ psychiatric symptoms, using the Psychiatric Symptom Index and a scale, developed and tested specifically for the trial, that measured the negative impact of the child’s illness on the family. Neither of these measures indicated any statistically significant differences between intervention and control groups at any stage of follow-up. Subgroup analysis of covariance suggested that, at 12 months, controls fared better than intervention group children, in terms of impact on the family, when resources were high and burden low and when resources were low and burden high. No other subgroup effects were evident.
Chapter 4

Studies including some element of health economics

As discussed in chapter 2, as well as including randomised controlled trials in this review, we also decided to review studies that had attempted some element of health economic evaluation, regardless of their design.

The material is presented in sections, according to the type or model of care being evaluated. As with other sections of this report, some studies could have fallen into more than one subsection. For example, should all studies about intravenous drug administration be grouped together, or is it more useful to keep studies specifically about home chemotherapy separate? Similarly, home care schemes for babies with bronchopulmonary dysplasia who are still dependent on oxygen have the same aims (early discharge from hospital) as have those for very low birth weight babies or those who have received specialist neonatal care. However, we also identified studies that were about home care for older children who were oxygen- or ventilator-dependent. Given the different clinical pictures presented by children in these groups we decided in this section to keep these studies distinct for analytical purposes but to draw out any common issues in chapter 6. All the papers included in this section are detailed in appendix 3, Table 63.

Early discharge for very low weight babies and/or those who have received neonatal intensive care

Type of study

Three studies were included in this category. Two of the studies by Brooten and co-workers\textsuperscript{53} and Casiro and co-workers\textsuperscript{59} could be described as cost minimisation studies (though they are not formally designated as such in the papers themselves) using effectiveness data from randomised trials to demonstrate equivalence. The other study, by Kotagal and colleagues\textsuperscript{76} estimated the cost of the intervention but, as a descriptive evaluation using historical cost data for comparative purposes, made no attempt to combine this with measures of effectiveness. These studies will be referred to hereafter by the name of the first author.

Nature of the intervention

Both the randomised trials\textsuperscript{53,59} involved pre-discharge liaison with and assessment of the parents and the development of individual care plans. Varying degrees and types of postdischarge support were available (further details are given in chapter 3). The descriptive evaluation was of an intervention that was less structured and, as described in the paper, more perfunctory in its preparation of parents for discharge. The clinical team outlined a postdischarge care plan, including the number of home visits anticipated. Follow-up in this study, however, was planned for only 2 weeks after discharge although there was the potential for longer periods if it was thought necessary.

Cost data collected for early discharge studies

As Table 29 shows, the studies collected varying amounts and types of economic data – charges, average costs, estimated average costs and so on. No study reports all the relevant cost data that might have been expected. Further, in at least one study, not all elements of the intervention itself were costed: postdischarge visits by the early discharge scheme’s nurses to the babies’ homes, whether for ‘supervision’ or for illness were not costed in the Casiro study.\textsuperscript{59} While the numbers of these were the same in both intervention and control groups, there was no indication of the length or complexity of such visits and whether or not these varied between groups.

Similar problems arise with readmission and/or hospital visits for emergency care. Brooten\textsuperscript{53} and Casiro\textsuperscript{59} report numbers of readmissions within given periods, and Brooten also reports ‘acute care visits’. Again, the numbers of such events/visits are similar for intervention and control babies, but no information is given on length of readmission or the complexity and costs of the problems dealt with during either type of episode. Kotagal,\textsuperscript{76} by contrast, reports billed charges for both readmission and emergency...
department visits, but only for the intervention period, not for the historical controls.

All three studies, then, have weaknesses in relation to the reporting of costs, both of the intervention itself and of subsequent hospital or community health service use. Further, most data are based on charges (in the US context) rather than on estimated or real costs.

### Reported costs of care

Table 30 reports the total average costs while the average costs per baby for different elements of care, as reported in the various studies, are summarised in Table 31. As indicated above, not all elements were included in the studies, and in some cases we have calculated the average cost.

Although the Kotagal study uses historical control data, the data reported are the fullest of the three studies, especially in the reporting of readmission and emergency care after discharge. This study is also the one to show the lowest cost advantage, although one that is still substantial. However, as already noted, all three studies rely, to varying degrees, on charge data rather than real or estimated costs. Opportunities for generalising results to the UK context are thus limited.

### TABLE 29 Type of cost data collected in studies of early discharge for very low birth weight or NICU babies

<table>
<thead>
<tr>
<th>Data collected</th>
<th>Brooten et al., 1986</th>
<th>Casiro et al., 1993</th>
<th>Kotagal et al., 1995</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hospital care</td>
<td>Charges</td>
<td>Minimum estimated costs</td>
<td>Average daily costs</td>
</tr>
<tr>
<td>Physician fees</td>
<td>Yes</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>Total costs of intervention</td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>Subsequent community health services (outside intervention)</td>
<td>No</td>
<td>Number, not costs</td>
<td>No</td>
</tr>
<tr>
<td>Readmission/A&amp;E care after discharge</td>
<td>Number, not costs</td>
<td>Number, not costs</td>
<td>Charges</td>
</tr>
</tbody>
</table>

### TABLE 30 Reported average costs of care in early discharge for very low birth weight or NICU babies

<table>
<thead>
<tr>
<th>Study</th>
<th>Hospital care ($)</th>
<th>Physician fees ($)</th>
<th>Cost of intervention ($)</th>
<th>Community health services</th>
<th>Readmission/ A&amp;E care</th>
</tr>
</thead>
<tbody>
<tr>
<td>Brooten et al., 1986</td>
<td>47,520</td>
<td>5933</td>
<td>576</td>
<td>Not reported</td>
<td>Not reported</td>
</tr>
<tr>
<td>Casiro et al., 1993</td>
<td>20,079&lt;sup&gt;b&lt;/sup&gt;</td>
<td>Not reported</td>
<td>626&lt;sup&gt;c&lt;/sup&gt;</td>
<td>Not reported</td>
<td>Not reported</td>
</tr>
<tr>
<td>Kotagal et al., 1995</td>
<td>27,912&lt;sup&gt;b&lt;/sup&gt;</td>
<td>Not reported</td>
<td>431&lt;sup&gt;b&lt;/sup&gt;</td>
<td>Not reported</td>
<td>38&lt;sup&gt;b&lt;/sup&gt;</td>
</tr>
</tbody>
</table>

<sup>a</sup> Cost are in US$ apart from Casiro et al. where they are Can$
<sup>b</sup> Calculated by us
<sup>c</sup> Not all elements costed

### TABLE 31 Average costs of care per baby in early discharge for very low birth weight or NICU babies

<table>
<thead>
<tr>
<th>Study</th>
<th>Currency/year</th>
<th>Average cost per baby</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Intervention</td>
<td>Controls</td>
</tr>
<tr>
<td>Brooten et al., 1986</td>
<td>US$ Not clear – 1980s</td>
<td>54,029</td>
</tr>
<tr>
<td>Casiro et al., 1993</td>
<td>Can$ 1990</td>
<td>20,705</td>
</tr>
<tr>
<td>Kotagal et al., 1995</td>
<td>US$ 1992/3</td>
<td>28,343</td>
</tr>
</tbody>
</table>

<sup>a</sup> Calculated by us
Other costs
None of these studies reports costs for families or for other agencies. Given the very frail nature of at least some of these babies after discharge these are significant omissions.

Economic analysis
The Brooten paper53 is one of several published from this trial. As chapter 3 shows, and as is reported in the costs paper, there were no differences between intervention and control babies in terms of the number of rehospitalisations, the number of acute care visits, the incidence of failure to thrive, reported child abuse or foster placement during the 18 months of follow-up. Neither were there any differences in the children’s development, as measured by the Bayley scale. The costs analysis could thus have been presented as a cost minimisation study although this was not actually done.

The Casiro study,59 similarly, showed no significant differences in clinical and developmental outcomes between intervention and control groups.

The Kotagal study76 included no outcome measures other than those related to hospital and healthcare resource use. All it demonstrates, then, is a reduction in length of stay and resource use with no reference to clinical outcomes.

Early discharge and home care for oxygen-dependent babies
Type of study
Two studies, by McAleese and co-workers77 and by Hallam and co-workers78 are included in this subsection. These studies will be referred to hereafter by the name of the first author. Both are descriptive accounts of the costs of early hospital discharge for babies with bronchopulmonary dysplasia who were still dependent on oxygen. In both cases comparative costs were calculated for ‘hypothetical’ continued hospital stays. In neither case were clinical or other outcome measures used. The Hallam78 study states that it followed cost-of-illness methods and that the viewpoint of analysis was the cost of care to the health service and to parents.

The McAleese study77 is of 59 babies discharged between 1981 and 1989 from a single hospital in New Hampshire, USA. The Hallam study78 is of 55 babies discharged from hospitals in the Oxford region of the UK between 1988 and 1992. Some parts of this latter study, however, are based on information gathered from only 31 babies discharged between 1991 and 1992.

Nature of the intervention
In both studies, babies were discharged home before being weaned off oxygen. Home care thus included all necessary respiratory and monitoring equipment and, in the McAleese study,77 a variety of supportive and therapeutic home services. In the Hallam study,78 such therapeutic or supportive services appeared to have been provided through ‘normal’ community health services rather than being part of an integrated service to the babies and their parents. The alternative to ‘early’ discharge in both cases was continued care in an acute hospital setting.

Cost data collected
Both studies collected or estimated a wide range of costs for both home care and the alternative form of care (Table 32). The US-based study77 used charges rather than costs in many areas of direct care, while the UK-based study78 relied on estimates of timed input, multiplied by average hourly costs from the hospitals and community services concerned or published average costs.

In both studies, the costs of the alternative form of care were estimated. In McAleese’s study77 this was based on the costs of care in ‘general’ paediatric wards or step-down nurseries. Hallam,78 by contrast, used estimates of the daily daily

| TABLE 32 | Type of cost data collected in studies of early discharge of oxygen-dependent babies |
| Data collected | McAleese et al., 199377 | Hallam et al., 199678 |
| Initial hospital care, including physicians’ fees, equipment, etc | Charges | No |
| Training for parents | Not mentioned | Yes |
| Home care equipment | Yes | Yes |
| Outpatient and community health services | Yes | Yes |
| Readmission/A&E care after discharge | Yes | Yes |
| Hospital care as alternative | Yes | Yes |
of input of nurses and consultants to oxygen-dependent babies in neonatal units ‘prior to home discharge’, on the assumption that “this level of attention would continue if infants remained in hospital rather than being discharged home” (p.27). In both studies costs and charges were standardised to a single year within the study period (1989/90 for McAleese and 1994 for Hallam).

**Reported costs of care**

Interpretation or synthesis of any of the costs across the two studies is difficult (Tables 33 and 34). The McAleese paper generally reports medians and ranges, with occasional mean values, showing clearly that the data were skewed. However, not all children received all elements of home care and reported medians are based only on those children who did. It is thus difficult to estimate the costs of a day of care in the different settings, or the average costs of different elements of care for all children. Further, the costs of readmission do not appear to have been added to the overall costs of home care reported in the paper.

Ten of the 59 children in this study made substantial use of ‘private-duty’ nursing after their return home and thus skew the overall costings. In places, results for these children are reported separately from those of the 49 children who did not use this service.

The Hallam study provides more in the way of data that can be combined and compared, and also reports home care costs per baby per day of between £8 and £17 for those on the cylinder system and between £9 and £10 for those on the concentrator system. These two groups of babies are reported separately in the costings but it is not clear how many of the total were in each group. Readmission costs are also included in the costs. Further, assumptions for both low and high costs are reported.

**Other costs**

Neither study explored costs falling to other sections of the care system, whether state, private or voluntary.

McAleese claims a potential saving of US$145,881 per child cared for at home, but it is difficult, from the results reported in the paper, to establish how this figure was arrived at. Further, as indicated above, the study does not seem to have included the costs of readmission in the overall home care costs. Hallam reports marginal health service savings (the difference between the cost of home and hospital care) ranging between a mean per baby of £15,378 (£13,868 median) and £50,343 (median £15,378). This, it is estimated, “translates into a saving of between £45 and £146 per day of care”.

Substantial weaknesses, however, are evident in both papers. Hallam takes no account of family costs while the McAleese study is based largely on charges rather than costs, and includes one type of family costs in the hospital costings and another in the home care costings.

Neither study appears to include actual or potential costs to other agencies, and neither makes any assessment of the value of the family members’ input into the care of the child. This latter is a real weakness of the studies. Transfer of children from hospital to home without providing concomitant nursing or care input will, of course, deliver ‘savings’. But, with no assessment of the
<table>
<thead>
<tr>
<th>Expense incurred</th>
<th>McAleese et al., 1993 $^{77}$ (US$)</th>
<th>Hallam et al., 1996 $^{78}$ (£)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Subjects</td>
<td>Controls</td>
</tr>
<tr>
<td>Initial hospital care, including physicians’ fees,</td>
<td>Mean 197,668</td>
<td>Mean 197,668</td>
</tr>
<tr>
<td>equipment, etc.</td>
<td>Median 172,817</td>
<td>Median 172,817</td>
</tr>
<tr>
<td></td>
<td>Range 43,364–86,450</td>
<td>Range 43,364–86,450</td>
</tr>
<tr>
<td>Training for parents</td>
<td>–</td>
<td>–</td>
</tr>
<tr>
<td>Home care equipment</td>
<td>Median 2,250</td>
<td>–</td>
</tr>
<tr>
<td></td>
<td>Range 475–9,000</td>
<td>–</td>
</tr>
<tr>
<td></td>
<td></td>
<td>–</td>
</tr>
<tr>
<td></td>
<td></td>
<td>–</td>
</tr>
<tr>
<td></td>
<td></td>
<td>–</td>
</tr>
<tr>
<td>Outpatient/ community services:</td>
<td>–</td>
<td>–</td>
</tr>
<tr>
<td></td>
<td></td>
<td>–</td>
</tr>
<tr>
<td></td>
<td></td>
<td>–</td>
</tr>
<tr>
<td></td>
<td></td>
<td>–</td>
</tr>
<tr>
<td></td>
<td></td>
<td>–</td>
</tr>
<tr>
<td>Outpatient department follow-up clinic</td>
<td>Median 569</td>
<td>–</td>
</tr>
<tr>
<td></td>
<td>Range 130–3,571</td>
<td>–</td>
</tr>
<tr>
<td>Local paediatrician visits</td>
<td>Median 210</td>
<td>–</td>
</tr>
<tr>
<td></td>
<td>Range 0–2,380</td>
<td>–</td>
</tr>
<tr>
<td>Physiotherapy</td>
<td>Median 585</td>
<td>–</td>
</tr>
<tr>
<td></td>
<td>Range 65–5,720</td>
<td>–</td>
</tr>
<tr>
<td>Occupational therapy</td>
<td>Median 1,560</td>
<td>–</td>
</tr>
<tr>
<td></td>
<td>Range 325–3,575</td>
<td>–</td>
</tr>
<tr>
<td>Health visitor/ community nurse</td>
<td>Median 363</td>
<td>–</td>
</tr>
<tr>
<td></td>
<td>Range 60–1,800</td>
<td>–</td>
</tr>
<tr>
<td>Other nursing</td>
<td>Median 54,684</td>
<td>–</td>
</tr>
<tr>
<td></td>
<td>Range 11,900–10,407</td>
<td>–</td>
</tr>
<tr>
<td>Readmission/A&amp;E</td>
<td>Median 7,449</td>
<td>–</td>
</tr>
<tr>
<td></td>
<td>Range 1,020–91,867</td>
<td>–</td>
</tr>
<tr>
<td></td>
<td></td>
<td>–</td>
</tr>
<tr>
<td></td>
<td></td>
<td>–</td>
</tr>
<tr>
<td>Estimated cost of hospital care as alternative</td>
<td>–</td>
<td>Median 48,116 c</td>
</tr>
<tr>
<td></td>
<td></td>
<td>–</td>
</tr>
<tr>
<td></td>
<td></td>
<td>–</td>
</tr>
<tr>
<td></td>
<td></td>
<td>–</td>
</tr>
</tbody>
</table>

$^{a}$ Low cost assumption  
$^{b}$ High cost assumption  
$^{c}$ Low and high cost figures as reported in Hallam paper $^{78}$ appear to have been transposed  
$^{d}$ Includes parental costs for travel, accommodation and telephone calls to the hospital
immediate and longer-term impact on family members who subsequently deliver care, this is a very partial account of 'savings'. The likely value of such family care is emphasised by the very much higher costs recorded in the McAleese study for children who had substantial home nursing input.

It seems possible that the Hallam study over-estimated the hypothetical cost of continuing hospital care by basing it on the cost of an unspecified period before discharge. Given that the condition of some of the children would have been improving generally in the period up to being weaned off oxygen, it seems likely that the cost of their continued care in hospital would have reduced in line with the lower levels of care needed.

### Home care for children with newly diagnosed diabetes

**Type of study**

One study is included here, by Dougherty and co-workers, and this is one that is also included as an RCT in chapter 3. The data used for this chapter are from a paper specifically devoted to economic evaluation of the home-based intervention. The main focus of the economic evaluation is home care’s ‘social cost’, establishing the net cost-effects for both the healthcare system and parents. Costs were in Canadian dollars, using 1991 values, and were generated through retrospective estimation and through examination of hospital records for the children randomised.

### TABLE 34 Average costs of care per baby in early discharge of oxygen-dependent babies

<table>
<thead>
<tr>
<th>Study</th>
<th>Currency/ year</th>
<th>Intervention</th>
<th>Controls</th>
<th>Difference</th>
<th>% difference</th>
<th>Statistical significance</th>
</tr>
</thead>
<tbody>
<tr>
<td>McAleese et al., 1993&lt;sup&gt;b&lt;/sup&gt;</td>
<td>US$ 1989/90</td>
<td><strong>Home care</strong>&lt;br&gt;Median without private-duty nursing 4,262&lt;br&gt;Range 650–23,278</td>
<td>Hypothetical hospital stay&lt;br&gt;Median without private-duty nursing 33,995&lt;br&gt;Range not given</td>
<td>29,733</td>
<td>88%</td>
<td>Not reported</td>
</tr>
<tr>
<td></td>
<td></td>
<td><strong>Median with private-duty nursing 68,136&lt;br&gt;Range 16,056–132,303</strong></td>
<td><strong>Median with private-duty nursing 134,934&lt;br&gt;Range not given</strong></td>
<td>66,798</td>
<td>50%</td>
<td>Not reported</td>
</tr>
<tr>
<td></td>
<td></td>
<td><strong>Total</strong>&lt;br&gt;Median 5,195&lt;br&gt;Range 650–132,303</td>
<td><strong>Total</strong>&lt;br&gt;Median 48,116&lt;br&gt;Range not given</td>
<td>42,921</td>
<td>89%</td>
<td>Not reported</td>
</tr>
<tr>
<td>Hallam et al., 1996&lt;sup&gt;c&lt;/sup&gt;</td>
<td>£ 1994</td>
<td><strong>Cylinder system</strong>&lt;br&gt;Mean 2,286&lt;sup&gt;c&lt;/sup&gt;&lt;br&gt;Median 1.402&lt;br&gt;Mean 5,623&lt;sup&gt;d&lt;/sup&gt;&lt;br&gt;Median 1.320</td>
<td>**Mean 19,824&lt;sup&gt;e&lt;/sup&gt;&lt;br&gt;Median 17,136&lt;br&gt;Mean 53,490&lt;sup&gt;f&lt;/sup&gt;&lt;br&gt;Median 46,236</td>
<td>17,538</td>
<td>88%</td>
<td>Not reported</td>
</tr>
<tr>
<td></td>
<td></td>
<td><strong>Concentrator system</strong>&lt;br&gt;Mean 3,263&lt;sup&gt;c&lt;/sup&gt;&lt;br&gt;Median 2.410&lt;br&gt;Mean 3.885&lt;sup&gt;d&lt;/sup&gt;&lt;br&gt;Median 2.672</td>
<td>**Mean 19,824&lt;sup&gt;e&lt;/sup&gt;&lt;br&gt;Median 17,136&lt;br&gt;Mean 53,490&lt;sup&gt;f&lt;/sup&gt;&lt;br&gt;Median 46,236</td>
<td>16,561</td>
<td>84%</td>
<td>Not reported</td>
</tr>
</tbody>
</table>

<sup>a</sup> Calculated by us  
<sup>b</sup> Included parental income loss for home care and estimate of parental expenditure for hospital care  
<sup>c</sup> Low cost assumption  
<sup>d</sup> High cost assumption  
<sup>Table 34</sup> Average costs of care per baby in early discharge of oxygen-dependent babies.
Nature of the intervention
This is described in chapter 3. Children with newly diagnosed diabetes were initially admitted to hospital. Those randomised to the intervention were sent home after their metabolic control had stabilised; a trained nurse carried out subsequent insulin adjustments and diabetes management training in the child’s home. For 2 weeks, home visits were twice daily and the nurse was available day and evening, by telephone. Subsequently the nurse remained available for visits and calls for 24 months. Children receiving this form of home care had an additional outpatient clinic visit 7 to 10 days after discharge. The teaching programme was the same as that used for children who remained in the hospital for insulin adjustments and training. The intervention, then, was a form of early discharge programme.

Cost data collected
These are summarised in Table 35.

<table>
<thead>
<tr>
<th>Type of data</th>
<th>Collected?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Days of hospital care</td>
<td>Yes</td>
</tr>
<tr>
<td>Drug costs</td>
<td>Yes</td>
</tr>
<tr>
<td>Supplies</td>
<td>No</td>
</tr>
<tr>
<td>Parent training</td>
<td>Implied in nursing hours</td>
</tr>
<tr>
<td>Dietetic advice</td>
<td>Implied in nursing hours</td>
</tr>
<tr>
<td>Outpatient clinics</td>
<td>Yes</td>
</tr>
<tr>
<td>Laboratory costs</td>
<td>Yes</td>
</tr>
<tr>
<td>X-ray and other tests</td>
<td>Yes</td>
</tr>
<tr>
<td>Readmission and emergency care</td>
<td>Yes</td>
</tr>
<tr>
<td>Indirect costs</td>
<td>No</td>
</tr>
</tbody>
</table>

There were three stages in the cost-effect estimation for the health system. First, data on hospital service use for the children in the study were collected from the day of randomisation and the subsequent 24 months. Secondly, hospital records and staff judgement were used to estimate the effect of home care on the resources needed to manage diabetes. This included an estimation of the number of hours of ward nursing used and also seems to have covered laboratory time. Despite this, however, the authors then go on to say that they could not collect reliable data on the hours nurses spent with individual patients, either in hospital or at home. Consequently, mean nursing hours per patient for each group (hospital and home) were estimated using retrospective information from the nurses involved. The third step was to value the differences in resources used, by examining hospital records and physician fee scales.

To estimate the social cost-effects a questionnaire was used to record parents’ out-of-pocket expenses for the first 32 days after diagnosis. Parents’ time was valued by estimating “the hourly net benefits created for parents and society when parents were employed” (p.589). This method valued time taken from both paid work and unpaid activities, thus avoiding the weakness of most other papers reviewed in this chapter which have failed to ascribe any value to parental caring activities.

Reported costs of care
The paper reports differences, if any, in healthcare resource use between children in the home care arm of the trial and those who remained in hospital for their initial care, both for the initial hospital stay and for 24 months subsequently. These are then used, along with the estimated time spent with diabetes patients in the home and in hospital to produce a series of cost-effect figures. Mean differences and SDs of the difference are reported, rather than actual means (see Table 36). No justification for this approach is given and no t test values or significance figures are given. The only differences in resource use reported in the text are said to be in relation to days of initial hospitalisation (as would be expected) and, consequently, fewer ward nursing hours, biochemistry tests and contacts with diabetic specialists. The mean differences in most other services at diagnosis were small or had relatively large SDs. Very little difference in service use between the groups in hospital and physician services was said to be evident during the 24 months following diagnosis.

Cost estimates for the items in Table 36 are not reported in the paper.

Other costs
As reported earlier, an estimate of the value of parents’ time was included in this study. The baseline estimate of the social value of the net benefits of employment was Can$11.88 per hour. This was based on a number of assumptions: that the wages of parents would be the average hourly earnings for men and women in Quebec at the time of the study; that, if working, parents received no fringe benefits; that half the mothers paid someone else the minimum wage to do housework or look after children, thus making net earnings less than the actual wage; that mothers provided
Studies including some element of health economics

75% of the parental child care; that, on average, parents received no non-pecuniary benefits (including enjoyment) from their work.

Families’ out-of-pocket expenses were also calculated.

The questionnaires answered by parents for the first 32 days after diagnosis are reported as showing that home care parents “required 52.1 fewer hours, on average, for child care (\(p<0.001\)) and spent Can$100.53 less (\(p<0.06\)) during the first month after diagnosis”\(^{35}\) (p.590). All of the parental time difference was in relation to unpaid activities: on average parents in both groups took 43 hours out of paid employment during this period. All the time difference and most of the expenditure difference is said to have occurred during the first 11 days of care.

The authors do not interpret this difference in the hours required for child care but in the discussion section refer to savings in time and money because of the reduced hospital stay. Certainly it is difficult to imagine that the parents of hospital care children spent 5 hours a day more caring for their children than did those whose children were in the home care group. Further, on average, the hospital care group spent only 2.8 more days in hospital than the home care group. It seems likely that a good part of the difference may reflect the amount of time parents actually spent at the hospital, and/or the amount of time the other parent spent looking after other children left at home, while the visiting parent was at the hospital. This is still, however, a large amount of time to spend over 2.8 days, unless parents were routinely staying overnight with their children.

| TABLE 36 Reported average service use in diabetes home care (Dougherty et al., 1998\(^{35}\)) |
|---------------------------------|-----------------|----------------|----------------|----------------|
| **Initial hospital stay**       | Intervention    | Controls       | Mean difference | SD of difference |
| Length of stay (days)           | 2.22            | 5.00           | -2.78           | 0.42            |
| Number of other hospital contacts (clinics, emergencies, etc) | 0.44            | 0.58           | -0.14           | 0.17            |
| Laboratory tests                | 14.94           | 35.42          | -20.48          | 3.00            |
| Other diagnostic services       | 0.56            | 1.13           | -0.57           | 0.21            |
| Drugs (doses)                   | 1.75            | 3.53           | -1.78           | 1.41            |
| Physician contacts              | 7.66            | 16.45          | -8.80           | 1.57            |
| **Use of hospital services in following 24 months** | | | | |
| Length of stay (days)           | 0.94            | 1.03           | -0.09           | 0.79            |
| Number of other hospital contacts (clinics, emergencies, etc) | 14.03           | 13.13          | 0.90            | 1.49            |
| Laboratory tests                | 40.16           | 36.45          | 3.70            | 7.29            |
| Other diagnostic services       | 2.41            | 1.48           | 0.92            | 0.47            |
| Drugs (doses)                   | 0.38            | 1.97           | -1.59           | 0.92            |
| Physician contacts              | 22.06           | 22.26          | -0.20           | 3.48            |
| **Psychosocial counselling and diabetes nursing hours** | | | | |
| Psychosocial counselling (hours) | 15.2            | 12.2           | 3.0             | 6.44            |
| **Diabetes nursing services (hours):** | | | | |
| Initial hospital stay           | 2.0             | 4.5            | -1.5            | Not reported    |
| Telephone consultation and home visits: | | | | |
| Month 1                         | 20.0            | 6.4*           | 13.6            | Not reported    |
| Months 2–24                     | 31.0            | 3.4*           | 27.6            | Not reported    |
| Diabetes clinic and office visits (hours) | 2.2            | 1.8            | 0.4             |                 |
| Consulting^b                    | 3.6             | 1.3            | 2.3             | Not reported    |
| **Total nursing hours**         | 58.9            | 17.3           | 41.6            | Not reported    |

* Telephone consultation only  
^b Consulting about patients with hospital staff and other personnel

---

44
No costs to other service agencies are reported.

**Economic analysis**

Although no detailed costings for the different elements of care are given in the paper, there is a summary of the authors’ baseline estimates of the cost-effects per child cared for at home. These are reproduced in Table 37.

The higher hospital costs are explained in the paper as being due to the savings from shorter hospital stays being less than the additional costs of running the home care programme.

As reported in other papers from this trial, children who received the home care package had better glycaemic control 2 and 3 years after diagnosis than did children who had not received this care. Technically, then, a cost-effectiveness analysis could have been attempted here.

Overall, when estimates of parents’ costs were included, the average cost to society of home care for newly diagnosed diabetes was Can$48, largely because the additional cost to the health care system was offset by the decreased costs for parents. This difference is reported to be not statistically significant, although as Table 37 shows, there was very substantial variation about this mean figure.

These estimates were highly sensitive to the valuation of parent time. If parental time was valued 25% higher, then the estimated social costs of home care were lower than those of hospital care. However, even if valued at 50% higher, the difference does not reach statistical significance. If valued at 25% less then the social costs increase to Can$203 or more. However, only if parental time is valued at less than Quebec’s minimum wage does the difference reach significance. The authors do not discuss this issue, but this presumably indicates that the poorest parents are the ones least likely to derive any economic benefit (as defined in this study) from home care for their children.

Other sensitivity analyses were carried out to test the impact of ‘maximum plausible errors in key data’ used for the baseline calculations. This suggested an upper bound on the social cost increase of Can $689 and a lower bound on a social cost decrease of Can$650.

As the authors themselves acknowledge, the demonstration of savings or otherwise for home care in settings other than their study hospital depends on a variety of factors – average length of stay (and thus the potential to save more days of hospital care), salary costs, the cost of drugs, and so on. We would add, too, the extent to which any additional costs related to clinical care are picked up by families rather than the state. For example, it is not clear from this paper whether the costs of insulin delivered outside the hospital were met by the state or by families. They do not seem to be included in the costings, either for the healthcare system after discharge or for families, although it is clear from the data reported in the main trial paper that children in the intervention group were taking more insulin that the control children.

---

**Table 37** Baseline estimates of cost-effects per child in diabetes home care

<table>
<thead>
<tr>
<th>Type of cost-effect</th>
<th>US$ cost-effect per child (SD)</th>
<th>Statistical significance (t test)</th>
<th>95% CI (US$)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hospital cost-effect borne by government</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Plus increased government contribution to pension plan for hospital staff</td>
<td>889 (87) 32</td>
<td>p = 0.001</td>
<td>711 to 1067</td>
</tr>
<tr>
<td>Less decreased government cost for physician services</td>
<td>–31</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Government cost-effect</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Less value of reduction in workload not ‘captured’ by hospital and government</td>
<td>890 (139) 122</td>
<td>p = 0.001</td>
<td>605 to 1174</td>
</tr>
<tr>
<td>Health system cost-effect</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Parental cost-effect</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Social cost-effect</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Home chemotherapy for children with cancer

Type of study
Three studies, carried out by Jayabose and co-workers, Close and co-workers and Holdsworth and co-workers are included in this subsection, all of which were based on descriptive evaluations of some type, but with some form of historical or comparative costs data. These studies will be referred to hereafter by the name of the first author.

Nature of the intervention
The Jayabose study included two different methods of drug administration – slow intravenous push (IVP) and intravenous infusion (IVI). The first few courses were administered in hospital. For IVP, all parent training was done in the hospital and it appears that no other regular home care was provided. For the first home-based IVI courses, a trained home care nurse visited to teach parents how to use the infusion pump. However, the home care nurses subsequently stayed only with patients receiving 3-hour infusions of high-dose cytosine arabinoside. For IVP chemotherapy, cost ‘savings’ are simply reported as the charges that would have been otherwise incurred for a clinic visit and the fee for the administration of the intravenous chemotherapy. For IVI chemotherapy, the difference between the hospital charges that would be made for a short stay admission for administration and the home care agencies’ charges for medications, other related items, pumps and nursing services is used to demonstrate ‘savings’. In neither case were pharmacy costs included, as they would have been the same regardless of where the course was administered.

Close compared the costs of a subsequent course of chemotherapy at home with the costs of the first two courses delivered in hospital to 14 children. In this study home care nurses visited the families to administer the chemotherapeutic drugs, while parents took responsibility for subsequent hydration, anti-emetic or antibiotic infusions. Nurses stayed throughout the administration of the chemotherapeutic element and, in the case of one regimen (etoposide) monitored vital signs throughout. A nurse was on call for questions or emergency instructions 24 hours per day and the home care nurses had access to hospital-based “fellows and staff oncologists” (p.897) on a 24-hour basis. In most cases, the local ‘referring physician’ was also available for assistance.

Finally, Holdsworth compared the charges for a single course of home-delivered chemotherapy, for a number of drug regimens, with the charges that would have been incurred had a similar course been delivered in the hospital. The difference between the two was multiplied by the number of courses the 44 children in the study actually received over a 3-year period to calculate a total cost saving, standardised to 1993 prices. This study did not rely on parents to administer or monitor treatment, although a ‘family caregiver’ was always at home with the child during administration. Further, nurses were available on-call for 24 hours a day for emergency home visits if necessary.

Cost data collected
As Table 38 shows, the range of cost data reported was very limited; further, in all cases charges rather than costs were reported. Only the Holdsworth paper reports any data about the different elements of chemotherapy care in hospital and at home (inpatient bed fee, chemotherapy, supportive care medications, infusion pump rental, medication preparation fees, nursing fees, ...
intravenous fluids, and intravenous ancillary supplies). However, these data are difficult to interpret and impossible to compare because they are reported as relative values in order, the authors state, “to prevent disclosure of proprietary information” (p.142). To calculate these relative charges, the lowest for the various drug regimens delivered was “assigned a nondollar relative value of 1” (ibid). The relative range that each category contributed to the actual charges was then reported. It is thus impossible to derive real charges for these elements of care.

Some elements of the programme appear not to have been included at all; for example, in two studies, parents had to be trained to deliver chemotherapy or the subsequent hydration and medication but this was not costed, and in one study, it is not clear whether hospital care costs were included in the total charges for a child who returned to hospital for 2 days during treatment.

Different treatment regimens clearly cost different amounts. Holdsworth’s study is the only study to acknowledge this explicitly, indicating that the relative charges for the dearest drug courses delivered at home were almost 20 times those of the cheapest. Further, some courses are more expensive than others simply because they require more hours or even days of treatment. Some regimens thus contributed more to the savings between hospital and home, simply because they saved more hospital-bed-days.

**Reported costs of care**

The variability in and quality of reporting of cost data (Tables 39 and 40) make it almost impossible to say anything overall about the relative costs of home and hospital-based chemotherapy.

**Other costs**

Close’s was the only study to report any costs or charges other than those to the healthcare system. Parental loss of wages and out-of-pocket expenses (food, transport, babysitting, telephone calls) were recorded for treatment in hospital and treatment at home. All these costs are reported to be significantly lower for treatment at home compared to treatment in hospital (Table 41). However, no indication is given of how or when these costs were collected.

**Economic analysis**

No real economic analysis is possible from these studies. None makes comparisons with a proper control group and only the Close and Holdsworth studies make any attempt to judge clinical or quality of life outcomes. In the Close study, the comparison is with earlier, hospital-based, treatment during the first stages of the child’s illness. Quality of the child’s life, costs of care and parents’ costs during hospital treatment may all have been affected by the stage of the child’s illness, making comparison with the next treatment, received at home, potentially spurious. In the Holdsworth study, comparison is with the hypothetical costs of the equivalent course of treatment delivered in hospital. Adverse effects and events and interference with daily activity were logged during 66 courses of home treatment for 16 of the 44 patients treated at home, who had received “highly emetogenic chemotherapy with the anti-emetic combination of ondansetron and methylprednisolone” (p.144). However, the only comparison that was attempted was with 19 patients who had received 51 courses of treatment and been surveyed in a previous, hospital-based survey. Although the results for these patients are given in the paper, they were

---

**TABLE 39 Reported average costs of care in home chemotherapy**

<table>
<thead>
<tr>
<th>Study</th>
<th>Hospital care</th>
<th>Nursing costs</th>
<th>Total cost of intervention (US$)</th>
<th>Statistical significance</th>
</tr>
</thead>
<tbody>
<tr>
<td>Jayabose et al., 1992&lt;sup&gt;79a&lt;/sup&gt;</td>
<td>Home</td>
<td>–</td>
<td>Savings IVP 3022</td>
<td>Not reported</td>
</tr>
<tr>
<td></td>
<td></td>
<td>–</td>
<td>Savings IVP 6897</td>
<td>Not reported</td>
</tr>
<tr>
<td>Holdsworth et al., 1997&lt;sup&gt;9&lt;/sup&gt;</td>
<td>Home</td>
<td>–</td>
<td>Savings ranged from 367 to 5180 per course, depending on drug regimen</td>
<td>Not reported</td>
</tr>
<tr>
<td>Close et al., 1995&lt;sup&gt;80&lt;/sup&gt;</td>
<td>Home</td>
<td>–</td>
<td>1865 (SD 833)</td>
<td>–</td>
</tr>
<tr>
<td></td>
<td>Hospital</td>
<td>–</td>
<td>2329 (SD 627)</td>
<td>$&lt; 0.01, paired t test</td>
</tr>
</tbody>
</table>

<sup>a</sup> Not all elements costed
on different treatment regimens, most were surveyed before the introduction of the anti-emetic drug used in the home treatment and there is no indication of how, if at all, they were similar to the patients treated at home in any other respects.

**Home intravenous antibiotic treatment**

**Type of study**

A single study is included here – of a pilot programme of home intravenous antibiotic treatment for the management of febrile neutropenic episodes in children with cancer.\(^8\) Comparison of cost was made with the ‘average’ hospital stay of 12 days for children with such episodes. The programme was in Canada and the results are reported in Can$ but with no year of study given. The issue of cost is said in the paper to be reported from the point of view of the healthcare system.

Thirteen children who had a total of 22 febrile episodes were included in the study.

**Nature of the intervention**

Children were admitted to hospital with a fever and started on intravenous antibiotics via an indwelling catheter. If they were afebrile after 48 hours on antibiotics and deemed to be clinically stable, their parents were instructed about antibiotic administration. A home care coordinator then arranged for enough supplies to be sent home with the child for a 10- to 14-day course, as appropriate. Twenty-four hour on-call cover was available as part of the normal care offered to these children and their families.

**Cost data collected**

These are summarised in Table 42.

**Reported costs of care**

The comparison of costs of home care is limited, as the authors themselves point out, by their “inability to cost inpatient treatment accurately”\(^8\) (p.146).

They were dependent on an average daily cost for all types of hospital bed which covered many elements including nursing, laboratory services, drugs, nutrition services, housekeeping, supplies and utilities. The authors believe that the presence of an intensive care unit and a NICU may have inflated the overall cost of a hospital bed for their type of patient. The costs of home care, by contrast, were felt to provide a more accurate estimate of the cost of home therapy.

---

**TABLE 40** Average costs of care per course of treatment in home chemotherapy

<table>
<thead>
<tr>
<th>Study</th>
<th>Year</th>
<th>Home</th>
<th>Hospital</th>
<th>Difference</th>
<th>% Difference</th>
<th>Statistical significance</th>
</tr>
</thead>
<tbody>
<tr>
<td>Jayabose et al., 1992(^9)</td>
<td>Not given</td>
<td>–</td>
<td>–</td>
<td>IVI 141(^*) (range 23–255)</td>
<td>Cannot be calculated from data given</td>
<td>Not reported</td>
</tr>
<tr>
<td>Close et al., 1995(^10)</td>
<td>1989/90</td>
<td>1865 (SD 833)</td>
<td>2329 (SD 627)</td>
<td>464</td>
<td>20%</td>
<td>p &lt; 0.01</td>
</tr>
<tr>
<td>Holdsworth et al., 1997(^9)</td>
<td>1993</td>
<td>–</td>
<td>–</td>
<td>2446(^*) (range 357–5180)</td>
<td>Cannot be calculated from data given</td>
<td>Not reported</td>
</tr>
</tbody>
</table>

\(^*\) Calculated by us

---

**TABLE 41** Average daily costs (US$) to families for home chemotherapy (Close et al., 1995\(^8\))

<table>
<thead>
<tr>
<th>Type of cost</th>
<th>Mean (SD)</th>
<th>Statistical significance</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Hospital</td>
<td>Home</td>
</tr>
<tr>
<td>Loss of wages</td>
<td>265 (233)</td>
<td>67 (107) p &lt; 0.005</td>
</tr>
<tr>
<td>Food</td>
<td>24 (11)</td>
<td>3 (2) p &lt; 0.0001</td>
</tr>
<tr>
<td>Transport</td>
<td>20 (9)</td>
<td>6 (4) p &lt; 0.0001</td>
</tr>
<tr>
<td>Telephone</td>
<td>15 (3)</td>
<td>1 (1) p &lt; 0.0001</td>
</tr>
<tr>
<td>Babysitters</td>
<td>9 (6)</td>
<td>1 (3) p &lt; 0.0001</td>
</tr>
<tr>
<td>Total out of pocket</td>
<td>68 (31)</td>
<td>11 (6) p &lt; 0.0001</td>
</tr>
<tr>
<td>Total costs to parents(^*)</td>
<td>333</td>
<td>78</td>
</tr>
</tbody>
</table>

\(^*\) Calculated by us
The costs reported (Tables 43 and 44) are not the average of all the identified costs; rather they are estimated on the basis of an average stay of 3 days in hospital followed by 10 days of care at home. No indication is given of variability around this average but, given that the normal course of antibiotic therapy was for 14 days, this is not likely to be significant.

Other costs

No costs to any other agency or to family members are included.

Economic analysis

No child had to be readmitted to hospital during an episode of home care but no other clinical or other outcome data are reported.

The authors argue that, even if the average cost of a hospital bed that they used in their comparison overestimated the cost of care for their paediatric patients by a factor of two, home therapy would still be substantially cheaper than hospital care. However, as they also point out, their costing exercise took no account either of the value of the parents’ input into care nor of any other costs they might have incurred, such as loss of wages. Further, the cost ‘savings’ identified also represent an “incremental cost to the hospital since every paediatric bed that is vacated by a child going home on antibiotic therapy will invariably be filled by another child, and the hospital is then paying for the newly admitted child as well as the child on home therapy”81 (p.146). However, they argue that the programme increases overall efficiency in health care and relieves pressure in the system.

As with other studies included in this chapter, we would argue that the limited reporting of clinical outcomes and omission of family costs, failing to value family input to care and to explore impact on families makes it very difficult to claim much for such ‘savings’ or increases in efficiency.

Home haemodialysis

Type of study

One study is included in this section82 – a descriptive comparison of the cost of two different methods of home-based dialysis (continuous ambulatory

---

**TABLE 42** Type of costs data collected in study of home intravenous antibiotic treatment (Wiernikowski et al., 1991a)

<table>
<thead>
<tr>
<th>Type of data</th>
<th>Collected?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hospital care</td>
<td>Average daily bed cost only</td>
</tr>
<tr>
<td>Drug costs</td>
<td>Yes</td>
</tr>
<tr>
<td>Supplies</td>
<td>Yes</td>
</tr>
<tr>
<td>Parent training (nursing)</td>
<td>Yes</td>
</tr>
<tr>
<td>Parent training (pharmacy)</td>
<td>Yes</td>
</tr>
<tr>
<td>Laboratory costs</td>
<td>Yes</td>
</tr>
<tr>
<td>Community nurse</td>
<td>Yes</td>
</tr>
<tr>
<td>Readmission/A&amp;E care</td>
<td>No readmissions after discharge</td>
</tr>
</tbody>
</table>

**TABLE 43** Reported average costs of care in home intravenous antibiotic treatment

<table>
<thead>
<tr>
<th></th>
<th>Bed cost</th>
<th>Drugs</th>
<th>Supplies</th>
<th>Once-only parent training</th>
<th>Lab costs per episode</th>
<th>Community nurse per episode</th>
</tr>
</thead>
<tbody>
<tr>
<td>Subjects</td>
<td>1854a</td>
<td>486.50a</td>
<td>237.20a</td>
<td>140.30</td>
<td>28.00</td>
<td>35.00</td>
</tr>
<tr>
<td>Alternative care</td>
<td>7416</td>
<td>–</td>
<td>–</td>
<td>–</td>
<td>–</td>
<td>–</td>
</tr>
</tbody>
</table>

*a Calculated by us

**TABLE 44** Average reported costs of care per child in home intravenous antibiotic treatment

<table>
<thead>
<tr>
<th>Intervention</th>
<th>Controls</th>
<th>Difference</th>
<th>% Differencea</th>
<th>Statistical significance</th>
</tr>
</thead>
<tbody>
<tr>
<td>First episode</td>
<td>2781</td>
<td>4635</td>
<td>63%</td>
<td>Not reported</td>
</tr>
<tr>
<td>Subsequent episodesa</td>
<td>2647</td>
<td>4769</td>
<td>64%</td>
<td></td>
</tr>
</tbody>
</table>

*a Calculated by us
peritoneal dialysis (CAPD) and continuous cyclic peritoneal dialysis (CCPD)) compared with hospital-based haemodialysis with two different methods of surgical setup (arteriovenous (AV) fistula and central venous (CV) line insertion). All the costs were estimated from ‘care protocols’, based on current practice for paediatric dialysis patients in the study hospital, rather than on actual costs incurred for ‘real’ patients. However the authors point out that the costs reflect “underlying resource implications” (p.558) rather than charges and that both direct and indirect costs were identified. Both these factors make the study stronger than many others reported here.

The study was carried out in Canada and the costing year was 1994. The perspective of the study was the health service.

**Nature of the intervention**
Care protocols were established for children receiving all three types of dialysis, based on ‘current practice’ for treatment in the study hospital. These were restricted to patients who had chronic end-stage renal disease and were awaiting kidney transplants, were not in a terminal stage, were older than 2 years and weighed more than 20 kg. The protocols covered both surgical ‘setup’ and maintenance care, and several possible complications were also included.

**Cost data collected**
These are reported in Table 45.

Each protocol included a detailed list of services and supplies required, the average length of hospital stay, operating theatre time, an inventory of procedures performed by different clinicians, the frequency of outpatient visits, use of pharmaceutical products, and the type and frequency of diagnostic tests. The number of complications built into the costings was based on recent clinical experience of complications in the first year of treatment in the study hospital and a review of the literature. These risks were set at 45% for an AV clot, three CV line blockages (haemodialysis), and at 15% for an inguinal hernia and 33% for peritonitis requiring hospital admission (peritoneal dialysis). It is not clear from the paper whether the risk figures given for the complications of peritoneal dialysis allow for the possibility of both occurring in the first year of treatment.

Other assumptions were also built into the study – that there were no patient comorbidities, that the operating theatre was available to establish dialysis as soon as the patient arrived in the hospital (i.e. there was no ‘waiting time’ before surgical setup), and that the case mix and volume in the study hospital between April 1993 and March 1994 was representative of the normal annual caseload.

**Reported costs of care**
Reported average costs are presented in Table 46. The data in Table 47 show the simple additive costs of uncomplicated and complicated cases, thus showing the maximum and minimum difference in cost between hospital and home-based care. However, this assumes that complicated hospital cases will always parallel complicated home cases. If this were not the case then the smallest difference in costs would be Can$18,619.02 (uncomplicated CV line haemodialysis in hospital compared with CCPD at home with inguinal hernia), and the largest Can$33883.19 (haemodialysis in hospital with AV fistula compared with uncomplicated CAPD).

The authors themselves present costs that adjust for the complication risk rates outlined earlier. On this basis they conclude that the expected (average) annual cost of haemodialysis would be Can$78,567.84 compared to Can$50,437.69 for home-based dialysis. This gives an overall cost difference of Can $28,130.15 or 35%.

**Other costs**
Costs to other agencies or to families were not considered in this study.

**Economic analysis**
The paper concludes that, overall, peritoneal dialysis (at home) is substantially cheaper to

---

**TABLE 45** Type of cost data collected in home dialysis study (Coyte et al., 199682)

<table>
<thead>
<tr>
<th>Type of data</th>
<th>Collected?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Surgical setup and all aspects of hospital care</td>
<td>Yes</td>
</tr>
<tr>
<td>Drug costs</td>
<td>Yes</td>
</tr>
<tr>
<td>Supplies</td>
<td>Yes</td>
</tr>
<tr>
<td>Parent training</td>
<td>Yes</td>
</tr>
<tr>
<td>Dietetic advice</td>
<td>Yes</td>
</tr>
<tr>
<td>Social work assessment</td>
<td>Yes</td>
</tr>
<tr>
<td>Outpatient clinics</td>
<td>Yes</td>
</tr>
<tr>
<td>Laboratory costs</td>
<td>Yes</td>
</tr>
<tr>
<td>X-ray cost</td>
<td>Yes</td>
</tr>
<tr>
<td>Treatment of possible complications</td>
<td>Yes</td>
</tr>
<tr>
<td>Indirect costs</td>
<td>Yes</td>
</tr>
</tbody>
</table>
the healthcare system than haemodialysis (in hospital). Sensitivity analyses are presented which show both lower and higher risks of complications than those used in the modelling. This showed that, for the range of risks for AV clots, CV line blockages, hernia repairs and peritonitis considered, “expected total costs were always greater with hemodialysis than with peritoneal dialysis” (p.562).

The authors conclude that the differences in the costs of uncomplicated cases between home and hospital-based care were attributable to the larger haemodialysis maintenance costs, and that physicians’ fees, direct treatment costs incurred by the hospital and overhead costs accounted for this difference in maintenance costs. The differences between CAPD and CCPD were due to the rental of the ‘cycler’.

As with so many of the papers considered in this chapter, the main weaknesses of this one (acknowledged by the authors) are its failure to consider the financial and other impacts on families of transferring care to a home setting and the lack of clinical or quality of life outcomes.

© Queen’s Printer and Controller of HMSO 2002. All rights reserved.
for patients, either in the short or long term. Further, the study considered only the estimated costs of care for patients for whom haemodialysis and peritoneal dialysis would have been clinically appropriate, thus limiting its generalisability to the whole population of children with a need for dialysis. Finally, as the study hospital did not provide peritoneal dialysis for patients within the hospital, it was not possible to consider the extent to which cost differentials were actually due to the mode of treatment.

Home care for oxygen-dependent children

Type of study
Two studies are included here, by Hazlett and Fields and co-workers, both about the discharge home of children with long-term oxygen dependence from long or shorter-term hospital care. Both will be referred to hereafter by the name of the main author. Both were carried out in the US, were very small studies – of 15 and 10 children, respectively – and used the costs of care in ‘hypothetical’ alternative care settings as a basis for comparisons. The children involved were largely beyond babyhood – 11 out of 15 in the Hazlett study and eight out of ten in Fields’ study were over 12-months-old.

Neither study reports which year was used as the costing base but the Fields paper states that the children in the study were discharged home between April 1985 and June 1987.

Hazlett’s study was partly retrospective, with telephone interviews of parents taking place anything between 2 and 65 months after the child’s discharge from hospital. It is not clear whether the data collection on costs was also retrospective but this seems likely.

A crucial issue in relation to the Fields study is that it was based on children eligible for a Medicaid waiver for home care. A condition of eligibility for the waiver is that children should meet Medicaid ‘cost-effectiveness’ criteria i.e. that projected home care costs should be lower than projected costs of care in an alternative setting. There was no indication in the paper of what proportion of children who might technically be able to be cared for at home actually met this criterion. The findings of this study, then, can in no way be extrapolated to the population of all ventilator-dependent children who might be cared for at home.

Nature of the intervention
In both cases, the aim of the care was to maintain at home children who had previously been living in hospital because of their need for some form of ventilator or oxygen assistance. The Hazlett study is unspecific about the nature of ventilator assistance while Fields reports on six children who were dependent on mechanical ventilator assistance and four who were oxygen-dependent with tracheostomies but without mechanical assistance.

What constituted home care in the Hazlett study varied, largely dependent on the families’ insurance status. In particular, the quantity of home nursing support received varied substantially from ‘full-time’ care in four cases to none in another. While described as a home care ‘programme’ there is no real sense of coordinated care provision after preparation for discharge. By contrast, the children in the Fields study were patients of a coordinating centre for home and community care that specifically provided case management for children with “respiratory disabilities at home or alternative living facilities” (p.729). This was a not-for-profit consortium of public and private agencies, organisations and institutions which coordinated care for such children.

Cost data collected
These are summarised in Table 48.

Reported costs of care
Apart from some reference to the proportions that different care elements contributed to the total costs in the Fields paper, no detailed costing data are reported in either study (Tables 49 and 50).

The Fields data were based on individualised care plans for all the children studied and costs are reported separately for those with or without mechanically assisted ventilation. Given the Medicaid involvement in tracking ‘cost-effectiveness’ it seems likely that the data used are of high quality. The alternative care was costed on the basis of “the least costly location capable of meeting the needs [of the child] as prescribed in an individualised care plan” (p.730). For all children included in the study this was judged to be a paediatric long-term care hospital. The ‘cost’ was the Medicaid reimbursable charges (96% of the cost) for placement in such care.

The Hazlett study used hospital costs for the last 31 days the children spent in hospital before discharge and an (unspecified) 31 days of home care costs.
### TABLE 48  Type of cost data collected in studies of oxygen-dependent children

<table>
<thead>
<tr>
<th>Data collected</th>
<th>Hazlett, 1989\textsuperscript{25}</th>
<th>Fields et al., 1991\textsuperscript{83}</th>
</tr>
</thead>
<tbody>
<tr>
<td>Training for parents</td>
<td>Not clear</td>
<td>Not clear</td>
</tr>
<tr>
<td>Home care equipment</td>
<td>Included but not reported</td>
<td>Included but not reported</td>
</tr>
<tr>
<td>Outpatient and community health services</td>
<td>Not included</td>
<td>Included but not reported</td>
</tr>
<tr>
<td>Readmission/A&amp;E care after discharge</td>
<td>Not included</td>
<td>Included but not reported</td>
</tr>
<tr>
<td>Alternative care setting</td>
<td>Last 31 days of hospital care</td>
<td>Yes, estimated costs of care in paediatric long-term care hospital</td>
</tr>
</tbody>
</table>

### TABLE 49  Reported average costs of care for oxygen-dependent children

<table>
<thead>
<tr>
<th>Subjects</th>
<th>Controls</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cost of home care</td>
<td></td>
</tr>
<tr>
<td>Mean 6,967</td>
<td>Mean 38,000</td>
</tr>
<tr>
<td>Range 2,844–19,165</td>
<td>SD 20,781</td>
</tr>
<tr>
<td>Estimated cost of hospital care as alternative</td>
<td></td>
</tr>
<tr>
<td>Mean 38,000</td>
<td>Mean 188,909</td>
</tr>
<tr>
<td>Range 19,124–52,586</td>
<td>SD 20,781</td>
</tr>
</tbody>
</table>

*Costs for first year*  

### TABLE 50  Average costs of care per child for oxygen-dependent children

<table>
<thead>
<tr>
<th>Study</th>
<th>Average cost per child (US$)</th>
<th>Year</th>
<th>Intervention</th>
<th>Controls</th>
<th>Difference</th>
<th>% Difference</th>
<th>Statistical significance</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hazlett, 1989\textsuperscript{25}</td>
<td></td>
<td></td>
<td>Not reported</td>
<td>Mean 6,967</td>
<td>Mean 38,000</td>
<td>31,033</td>
<td>82</td>
</tr>
<tr>
<td>Fields et al., 1991\textsuperscript{83}</td>
<td></td>
<td></td>
<td>Not reported</td>
<td>Ventilator-dependent</td>
<td>Ventilator-dependent</td>
<td>79,073</td>
<td>42</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Mean 109,836</td>
<td>Mean 188,909</td>
<td>Mean 146,836</td>
<td>83,186</td>
<td>57</td>
</tr>
</tbody>
</table>

*Calculated by us*
Both studies report lower overall cost for home care, but the percentage difference in the Fields study is considerably lower than in the other. Given that only children who were expected to be cheaper to care for at home were included in this latter study, the finding of lower costs is hardly unexpected. However, the smaller demonstrated cost savings are, perhaps, more likely to be accurate, for the reasons outlined above.

Other costs
Neither study reported any costs to any other agency.

Hazlett\textsuperscript{25} refers to the costs incurred by families whose insurance did not cover all the care their children received. These ranged from US$2 per month to $2500 per annum. Eight of the 15 mothers interviewed reported financial difficulties associated with home care – two had left work, four found home nursing care limited by lack of insurance or other funding, and three reported increased utility bills. The paper states elsewhere that utility and water bills were “frequently twice or three times the pre-home ventilation amount”\textsuperscript{25} (p.289) but these costs were not included in the cost of care.

The Fields study\textsuperscript{83} makes no reference to family costs.

Economic analysis
Hazlett\textsuperscript{25} claims an average saving for home care over hospital care of some 78\%, although our calculations suggest a figure of 82\%. Fields\textsuperscript{83} claims average annual savings of US$79,074 (SD $41,381) but the actual reimbursements were only $74,916 (SD $36,508). The difference was equivalent to 21\% of all the nursing care ordered in the care plan. For the children with tracheostomies, the equivalent figures were US$51,102 (SD $20,183), $37,848 (SD $6397) and 26\%.

Clearly, if the amount of nursing care actually ordered had been available, the cost differentials would have been substantially lower (31\% and 48\%, respectively).

Home-based treatment for children with mental health problems

Type of study
Two papers are included here.

The first paper, by Margolis and Petti\textsuperscript{84} reports a cost simulation of two different strategies as alternatives to long stays in children’s psychiatric hospitals. The exercise was based on data collected retrospectively from records on all 261 children discharged between 1987 and 1989 from a state children’s psychiatric hospital in Michigan, US. These data were used to predict ‘excessive length of stay’, defined as the time between the date at which a child was considered ready for discharge by the hospital and the date at which the child was actually discharged (p.159). Three variables accounted for a large part of the variance in length of stay (age 4–9 years, admission from other than home, and use of private insurance). These variables were used to identify a sample.
of 22 children with all three who were then used for the simulation exercise.

The second paper, by Byford and co-workers\textsuperscript{70} reports a ‘cost-effectiveness analysis’ associated with a trial of a home-based intervention for children and adolescents who have deliberately poisoned themselves. Information on the use of health service, education, social services and voluntary services over the study period was collected retrospectively from parents at a 6-month follow-up interview, using a questionnaire specifically for the study. An audit of medical records was used to verify the health service contact data. Voluntary sector service use is reported but not included in the overall cost analysis. The trial,\textsuperscript{69} which is included in chapter 3, was carried out in the UK and all unit costs were for the financial year 1997–8.

Both studies will be referred to hereafter by the name of the first author.

**Nature of the intervention**

The Margolis study\textsuperscript{84} used two alternatives to simulate the provision of care for children outside hospital. The first was based on the ‘Tacoma Homebuilders’ programme’, described as “intensive, home-based, family-oriented mental health services” (p.157) that provide up to 20 hours of service per week to families in crisis. The second was a financial incentive to private care providers to provide out-of-home care, through increasing board and lodging payments. This latter falls outside the definition of home care as used in this review and this element of the study is not included in detail here. However, reference is made to out-of-home care later on because of some interpretative difficulties in the paper.

The intervention costed in the Byford paper\textsuperscript{70} is described in chapter 3. It was a social work-based intervention, delivered at home, in addition to routine care.

**Cost data collected or simulated**

These are summarised in Table 51.

The cost of excessive length of stay was calculated for the Margolis study\textsuperscript{84} using an average per diem cost of hospitalisation. This was based on hospital billings, divided by the number of days children had actually been in hospital, adjusted for periods of leave of absence. The per diem costs of a residential placement were obtained from information provided by a local department of social services. The average stay for former hospital patients in residential placements is reported to be around 3.3 years, with around 33 children placed each year.

The cost of the home-based alternative was based on the costs of the Tacoma Homebuilders’ programme. It was assumed that such a programme would avert hospital admission for 76% of the children who experienced it. This figure was chosen because “it is the lowest success rate of any for the stratified populations served by Homebuilders”\textsuperscript{84} (pp. 159–60) in the published evaluations of the scheme.

As outlined above, the Byford paper\textsuperscript{70} reports a range of services used by the children, both during the intervention and subsequently (up to 6 months). These were then costed on a unit basis. Service use questionnaires were completed for only 74 of the 85 children who were in the intervention group compared with 75 of the 77 children in the control group. The possible implications of this are not discussed in the paper.

**TABLE 51** Cost data collected or simulated in studies of home-based treatment for children with mental health problems

<table>
<thead>
<tr>
<th>Data collected or simulated</th>
<th>Margolis and Petti, 1994\textsuperscript{84}</th>
<th>Byford et al., 1999\textsuperscript{70}</th>
</tr>
</thead>
<tbody>
<tr>
<td>Inpatient care</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Outpatient care</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>Daypatient care</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>Total costs of intervention</td>
<td>Yes</td>
<td>By implication</td>
</tr>
<tr>
<td>Subsequent community health services</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>(outside intervention)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Readmission</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>A&amp;E attendances</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>Education services</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>Social services and/or residential placement</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Voluntary services</td>
<td>No</td>
<td>Service use only</td>
</tr>
</tbody>
</table>

© Queen’s Printer and Controller of HMSO 2002. All rights reserved.
Reported costs of care

The Margolis study reports per diem costs as US$299.56 for hospital care, US$125.95 for a residential placement, and US$315.5 per client per intervention for the home-based alternative. On this basis the paper simulates the relative costs of different options (Tables 52 and 53). However, the per diem cost of care for extended hospital stays actually used in the calculations is US$113.61, which is the difference in cost between a day in hospital and a day in a residential placement. This choice is not explained anywhere in the text and is puzzling given that it represents the opportunity cost of not discharging children to residential care when they are ready, not that of treating children through a home-based scheme. Further, the text states quite clearly that days of excessive length of stay were, indeed, spent in hospital and not in ‘out-of-home’ placements. Table 52 thus shows costs that have been recalculated by us using the per diem costs of US$299.56 originally referred to. We have also included figures for a comparison that assumes that children are, indeed, discharged to a residential placement and spend their days of excessive length of stay there.

It should be noted that none of these figures includes the costs of days of acute care.

Table 52: Simulated average costs (US$) of home-based treatment for children with mental health problems (Margolis and Petti, 1994)

<table>
<thead>
<tr>
<th>Number of children</th>
<th>Admission status</th>
<th>Cost of programme per child</th>
<th>Cost of excessive length of stay per child</th>
<th>Total cost of excessive length of stay per child</th>
<th>Total cost for 18 children</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hospital care for excessive length of stay</td>
<td>18</td>
<td>Admitted</td>
<td>–</td>
<td>46,115</td>
<td>46,115</td>
</tr>
<tr>
<td>Home-based care</td>
<td>14</td>
<td>Averted</td>
<td>3,155</td>
<td>–</td>
<td>3,155</td>
</tr>
<tr>
<td>4</td>
<td>Admitted</td>
<td>3,155</td>
<td>46,115</td>
<td>49,270</td>
<td>197,080</td>
</tr>
<tr>
<td>Total home-based care</td>
<td>13,403</td>
<td>241,250</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Residential placement after ready for discharge</td>
<td>18</td>
<td>Admitted then discharged to residential placement</td>
<td>–</td>
<td>2,267</td>
<td>2,267</td>
</tr>
<tr>
<td>Home-based care</td>
<td>14</td>
<td>Averted</td>
<td>3,155</td>
<td>–</td>
<td>3,155</td>
</tr>
<tr>
<td>4</td>
<td>Admitted then discharged to residential placement</td>
<td>3,155</td>
<td>24,245</td>
<td>27,400</td>
<td>109,600</td>
</tr>
<tr>
<td>Total home-based care</td>
<td>8,543</td>
<td>153,770</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

a Based on average length of stay of 192.5 days

The figures derived above suggest a different picture from that painted in the original paper (see Table 53 and discussion below).

Table 54 is based on the Byford paper’s account of service use during the 6 months of follow-up. This includes both numbers of children using the named service at all, and total units of service used. No statistical testing of differences in specific service use is reported; however, the paper does report in the text that there were no significant differences in the proportion of intervention and control children who had used any educational services (27% and 31%, respectively) or any social services (19% and 21%, respectively). The data do suggest higher levels of outpatient attendance, school nurse contacts, educational welfare officer contacts, social worker contacts, and weeks in foster or residential care for control group children. By contrast, there seem to be higher levels of community psychiatric nurse (CPN) contacts and counselling sessions (presumably outside the intervention) for the intervention group.

The costs of use of these individual services are not reported but aggregate figures for the health service, educational services and social services are.

* The likely clinical impact of this greater level of contact with potentially therapeutic agents is not discussed in the main paper.
TABLE 53  Average cost (US$) per child for home-based treatment for children with mental health problems (Margolis and Petti, 199494)

<table>
<thead>
<tr>
<th>Intervention</th>
<th>Average cost per child</th>
<th>Standard care</th>
<th>Average cost per child</th>
<th>Difference</th>
<th>% Difference</th>
</tr>
</thead>
<tbody>
<tr>
<td>Home care (plus hospital care)</td>
<td>13,403</td>
<td>Long-stay hospital care</td>
<td>46,115</td>
<td>–32,712</td>
<td>71</td>
</tr>
<tr>
<td>Home care (plus residential placement)</td>
<td>8,543</td>
<td>Residential placement after hospital care</td>
<td>2,267</td>
<td>+6,276</td>
<td>277</td>
</tr>
</tbody>
</table>

All costs were calculated by us

TABLE 54  Number of children using services and number of units of service used during 6 months from randomisation in home-based treatment for children with mental health problems (Byford et al., 199995)

<table>
<thead>
<tr>
<th>Service</th>
<th>Intervention group</th>
<th>Control group</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of children</td>
<td>Number of units of service</td>
<td>Number of children</td>
</tr>
<tr>
<td><strong>NHS</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Intervention assessment sessions</td>
<td>74 74</td>
<td>0 0</td>
</tr>
<tr>
<td>Intervention sessions</td>
<td>70 253</td>
<td>0 0</td>
</tr>
<tr>
<td>Inpatient days</td>
<td>67 187</td>
<td>70 193</td>
</tr>
<tr>
<td>Daypatient days</td>
<td>0 0</td>
<td>1 53</td>
</tr>
<tr>
<td>Intensive care unit days</td>
<td>1 1</td>
<td>1 1</td>
</tr>
<tr>
<td>Outpatient attendances</td>
<td>45 162</td>
<td>55 244</td>
</tr>
<tr>
<td>A&amp;E attendances</td>
<td>74 79</td>
<td>75 86</td>
</tr>
<tr>
<td>GP surgery visit</td>
<td>22 32</td>
<td>18 39</td>
</tr>
<tr>
<td>GP home visits</td>
<td>2 3</td>
<td>2 2</td>
</tr>
<tr>
<td>School doctor contacts</td>
<td>1 3</td>
<td>2 2</td>
</tr>
<tr>
<td>School nurse contacts</td>
<td>8 18</td>
<td>12 95</td>
</tr>
<tr>
<td>CPN contacts</td>
<td>14 112</td>
<td>10 43</td>
</tr>
<tr>
<td>Counselling sessions</td>
<td>3 20</td>
<td>0 0</td>
</tr>
<tr>
<td><strong>Education</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Educational welfare officer contacts</td>
<td>20 57</td>
<td>23 118</td>
</tr>
<tr>
<td>Educational psychologist contacts</td>
<td>0 0</td>
<td>2 5</td>
</tr>
<tr>
<td><strong>Social services</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Social worker contacts</td>
<td>13 50</td>
<td>15 104</td>
</tr>
<tr>
<td>Foster care weeks</td>
<td>2 25</td>
<td>4 54</td>
</tr>
<tr>
<td>Residential care weeks</td>
<td>0 0</td>
<td>3 8</td>
</tr>
<tr>
<td><strong>Voluntary services</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Samaritans</td>
<td>0 0</td>
<td>2 5</td>
</tr>
<tr>
<td>Childline</td>
<td>1 2</td>
<td>4 5</td>
</tr>
<tr>
<td>NSPCC</td>
<td>0 0</td>
<td>1 1</td>
</tr>
<tr>
<td>Alcoholics Anonymous</td>
<td>0 0</td>
<td>1 1</td>
</tr>
<tr>
<td>Other</td>
<td>1 5</td>
<td>6 9</td>
</tr>
</tbody>
</table>

NSPCC, National Society for the Prevention of Cruelty to Children
However, for the latter two, average costs given are only for those children who had had contact with any of the services in that sector, not for the sample as a whole (Table 55). Total and median health service costs for the two groups were not significantly different, although the median for the control group was higher. Similarly, there were no significant differences in costs for those children making any use of educational services although, again, the costs did favour the intervention group. By contrast, there was a statistically significant difference between the two groups in costs for children who had used any social services, again favouring the intervention group. The authors state that this difference was largely accounted for by the higher levels of use of foster or residential care for the control children.

**Other costs**

No costs to any other part of the service system or to families were simulated in this study.

**Economic analysis**

The Margolis paper\(^84\) presents a cost analysis, based on the calculations that used the differential in cost between hospital and residential placements. This suggests that the total cost of a home-based care programme for the 18 children included in the study would be US$145,497 (or $8083 per child) while the benefit (hospital charges averted) would be US$310,473 (or $17,249 per child).

On this basis, the ‘dollars saved’ figure is said to be US$164,976 (or $9165 per child), generating a ‘cost–benefit ratio’ of 0.47.

Table 53 summarises the costs and savings as calculated by us. As this indicates, the savings reported by the authors depend crucially on whether or not excessive length of stay is actually spent in a hospital setting. An alternative strategy, which would be to discharge children who were not able to return home to a residential placement, would be even cheaper, on the basis of the information given by the authors themselves, than the home care option. This is not discussed in the paper.

The Byford paper\(^70\) shows that total service costs, excluding the intervention costs, were significantly lower for intervention children than for controls (Table 56). However, when the costs of the intervention were added, while the overall costs remained lower than for the controls, the difference was no longer statistically significant.

Subgroup analysis of costs for the small number of children without major depression (28 intervention and 23 control children) suggested that the costs for the intervention group might be higher than for the controls. As there had been “statistically significant improvement in suicidal ideation”\(^70\) (p.58) in this intervention subgroup, the authors claim that “the social work intervention may be cost-effective for this group” (ibid).

**TABLE 55** Total cost by service sector in home-based treatment of children with mental health problems (Byford et al., 1999\(^70\))

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Health service</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Number of children with any contact</td>
<td>74</td>
<td>75</td>
<td></td>
</tr>
<tr>
<td>Total cost</td>
<td>95,864.09</td>
<td>95,735.24</td>
<td></td>
</tr>
<tr>
<td>Arithmetic mean</td>
<td>1295.46</td>
<td>1276.47</td>
<td></td>
</tr>
<tr>
<td>Median</td>
<td>323.00</td>
<td>518.00</td>
<td>(p = 0.085)</td>
</tr>
<tr>
<td><strong>Education</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Number of children with any contact</td>
<td>20</td>
<td>23</td>
<td></td>
</tr>
<tr>
<td>Total cost</td>
<td>261.63</td>
<td>652.47</td>
<td></td>
</tr>
<tr>
<td>Arithmetic mean</td>
<td>13.08</td>
<td>28.37</td>
<td></td>
</tr>
<tr>
<td>Median</td>
<td>9.18</td>
<td>9.18</td>
<td>(p = 0.314)</td>
</tr>
<tr>
<td>Overall mean(^a)</td>
<td>3.54</td>
<td>8.70</td>
<td></td>
</tr>
<tr>
<td><strong>Social services</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Number of children with any contact</td>
<td>14</td>
<td>16</td>
<td></td>
</tr>
<tr>
<td>Total cost</td>
<td>11,557.75</td>
<td>34,971.34</td>
<td></td>
</tr>
<tr>
<td>Arithmetic mean</td>
<td>825.55</td>
<td>2185.71</td>
<td></td>
</tr>
<tr>
<td>Median</td>
<td>53.93</td>
<td>140.21</td>
<td>(p = 0.039)</td>
</tr>
<tr>
<td>Overall mean(^a)</td>
<td>156.19</td>
<td>466.28</td>
<td></td>
</tr>
</tbody>
</table>

\(^a\) Calculated by us
However, they also point out that the subgroups were small and the CIs large.

Byford\textsuperscript{70} conducted ‘extensive’ sensitivity analyses and reports the main ones. These largely hinge around professional staff costs and overheads and hospital costs. None of these affected the conclusions of the economic analysis. The overall conclusion of this study is that, as there were no statistically significant differences in costs or the main outcome measures over the 6-month period of the study then “the intervention is as cost-effective as routine care alone” (p.60). However, as the intervention provided greater parental satisfaction at 2-month follow-up it is argued that it could be seen as more cost-effective than routine care “since utility was gained at no extra cost” (ibid). Given that the difference in parental satisfaction was not maintained to the 6-month follow-up (see chapter 3), we have to conclude that the utility gained seems rather small.

### TABLE 56 Average costs for home-based treatment of children with mental health problems (Byford et al., 1999\textsuperscript{70})

<table>
<thead>
<tr>
<th></th>
<th>Intervention group</th>
<th>Control group</th>
<th>Ratio of means (CI)</th>
<th>Reported statistical significance</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Excluding cost of intervention</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>n</td>
<td>74</td>
<td>75</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Arithmetic mean (CI)</td>
<td>1176.61 (809.18–1544.04)</td>
<td>1751.45 (1169.09–2333.82)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Geometric mean (CI)</td>
<td>800.95 (655.70–978.38)</td>
<td>1070.63 (874.80–1310.29)</td>
<td>0.75 (0.56–0.99)</td>
<td>0.044</td>
</tr>
<tr>
<td><strong>Including cost of intervention</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Arithmetic mean (CI)</td>
<td>1455.18 (1087.62–1822.74)</td>
<td>1751.45 (1169.09–2333.82)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Geometric mean (CI)</td>
<td>1141.96 (988.41–1319.36)</td>
<td>1070.63 (874.80–1310.29)</td>
<td>1.07 (0.83–1.37)</td>
<td>0.606</td>
</tr>
<tr>
<td><strong>Subgroup without major depression</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>n</td>
<td>28</td>
<td>23</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Arithmetic mean (CI)</td>
<td>1604.77 (850.37–2359.18)</td>
<td>1459.70 (599.41–2320.00)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Geometric mean (CI)</td>
<td>1229.79 (850.37–2359.18)</td>
<td>979.71 (683.76–1375.26)</td>
<td>1.27 (0.86–1.90)</td>
<td>0.246</td>
</tr>
</tbody>
</table>
Chapter 5

Other comparative studies of paediatric home care

As we have seen, there are relatively few RCTs of PHC services and interventions. We therefore thought it important to review the much larger body of literature describing studies with other designs. However, as noted in chapter 2, despite a large descriptive literature, there seem to be relatively few studies of paediatric home care that have used a design that allows comparison of PHC with ‘normal’ or ‘routine’ models of care.

The 13 studies (14 papers) selected for inclusion in this chapter are listed in appendix 3 (Table 64), which gives publication details, along with summaries of the methods, intervention being tested and findings.

Table 64 (appendix 3) shows that these studies cover a range of illnesses, interventions and models of care, although several clusters can be identified:

(i) schemes involving the early discharge of very low birth weight infants or those who have been in NICUs
(ii) ways of avoiding hospital admission, or reducing the length of admission, for children diagnosed with IDDM
(iii) ‘technological’ care at home in dialysis, chemotherapy, nebuliser therapy, treatment involving central venous catheters (CVCs), and enteral feeding
(iv) home care for children with mental health problems.

The evidence these papers present does not, on the whole, provide a clear and coherent picture, either of effectiveness or costs. This is not perhaps surprising given the disparity of interventions and the wide age range of children across the studies. Further, very different outcomes are measured across the papers. Sometimes, clear contrasts in research findings are apparent. In addition, the methodological quality of the studies is mixed. Towards the end of the chapter we discuss the limitations these factors place both on the value of the evidence presented, and on the scope for generalising from these studies to paediatric home care as a whole.

Given these limitations, we have restricted ourselves here to looking at only three major outcome domains – clinical outcomes, however reported and including mortality; health service use, including initial length of stay and readmission; and any assessment of quality of life, satisfaction with services, or impact, whether for children themselves or their parents/carers. These are reported separately for the four ‘clusters’ of paediatric home care outlined above.

Home care for very low birth weight/NICU babies

Three studies are included here.

Kotagal and co-workers’ prospective case-controlled studies using data from a specified period before the introduction of the intervention for comparative purposes. The third by Örtenstrand and co-workers is a controlled comparison in which babies were assigned to one of two wards depending on bed availability at the time of admission. One ward had access to the intervention while the other did not. A crossover element was included; half way through the study the original control ward became the intervention ward and vice versa. These studies will be referred to hereafter by the name of the first author.

Clinical outcomes

While the Kotagal study shows a very substantial impact (reduction) on the average weight at which babies were being discharged home, and particularly for the babies who were smallest at birth, the other two studies do not show a similar effect (Table 57). Indeed the study babies in the Rieger and Örtenstrand studies were slightly heavier than control babies, although not significantly so. This is a puzzling contrast when all three trials found that study babies were going home earlier than control babies (see below).

Similarly Rieger and Örtenstrand show little difference in mean gestational age at discharge. Kotagal does not report this.
<table>
<thead>
<tr>
<th>Study</th>
<th>Mortality</th>
<th>Weight at discharge (g)</th>
<th>Gestational age at discharge or equivalent point for controls (weeks; mean (SD))</th>
<th>Other clinical outcomes</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Study group</td>
<td>Controls</td>
<td>Study group</td>
</tr>
<tr>
<td></td>
<td>Study</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>group</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Kotagal et al., 1995&lt;sup&gt;6&lt;/sup&gt;</td>
<td>Not reported</td>
<td>By birth weight</td>
<td>Geometric mean (95% CI)</td>
<td>Geometric mean (95% CI)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>500–750</td>
<td>2417 (2116–2760)</td>
<td>2592 (2293–2929)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>750–1000</td>
<td>2228 (1895–2618)</td>
<td>2529 (2312–2756)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>1001–1250</td>
<td>2036 (1924–2154)</td>
<td>2579 (2401–2769)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>2001–2500</td>
<td>2181 (2132–2231)</td>
<td>2339 (2304–2374)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>2501+&lt;sup&gt;a&lt;/sup&gt;</td>
<td>3151 (3055–3249)</td>
<td>3141 (3066–3218)</td>
</tr>
<tr>
<td>Rieger and Henderson-Smarts, 1995&lt;sup&gt;5&lt;/sup&gt;</td>
<td>Not reported</td>
<td>Mean 2311&lt;sup&gt;b&lt;/sup&gt; (range 1780–3337)</td>
<td>2327 (1582–3285)</td>
<td>36.5&lt;sup&gt;c&lt;/sup&gt; (1.3)</td>
</tr>
<tr>
<td>Örtenstrand et al., 1999&lt;sup&gt;6&lt;/sup&gt;</td>
<td>1/43</td>
<td>0/45</td>
<td>Mean 2224&lt;sup&gt;b&lt;/sup&gt; (SD 376)</td>
<td>2122 (301)</td>
</tr>
</tbody>
</table>

<sup>a</sup> ANOVA controlling for birth weight and month of discharge, *p* < 0.0001
<sup>b</sup> NS
<sup>c</sup> Statistical significance not reported
The only other clinical outcomes reported are in the Örtenstrand study. This found that control babies had more respiratory infections than study babies in the period up to the end of home care (or its equivalent for the controls). However, no other differences in a range of health problems, medications or weight gains were evident.

**Health service use**
Again, Kotagal shows substantial and statistically significant reductions, this time in mean length of hospital stay, especially for those babies who were very small at birth (*Table 58*). Örtenstrand also shows a large and statistically significant reduction (16 days overall), but the Rieger intervention achieved ‘savings’ of only 2.1 days.

There is no suggestion from any of the studies that earlier discharge is bought at the price of increased readmission, emergency care or community health service use subsequently. Indeed two suggest lower levels of emergency care and one a lower level of visits to the family doctor for study babies.

**Impact**
Only Rieger reports any form of impact outcome for parents or babies. Neither the Spielberger Anxiety State Test nor the General Health Questionnaire showed any differential impact on mothers, while the Infant Temperament Questionnaire suggested that babies in the study group were less likely to be classified as ‘difficult’ (10% study babies, 23% controls, *p* < 0.05). All these tests were carried out 7 months after discharge.

**Home care for children with insulin-dependent diabetes**
Three studies reported in four papers are included here by Swift and co-workers, Lowes and Davis, Lowes and Couper and co-workers. Two were based in the UK and one in Australia. The studies will be referred to hereafter by the name of the first author.

The Swift study was based entirely on retrospective record review, Lowes’ on retrospective and prospective record review and Couper’s on a controlled design in which children did or did not receive the intervention depending on where they live. Two studies were about home-based care for children with newly diagnosed IDDM and the third was about home-based support for adolescents with poorly controlled IDDM.

**Clinical outcomes**
The only clinical outcome reported in any of the studies was mean glycosylated (glycated) haemoglobin level (HbA1c) – see *Table 59*. The Swift study found no significant differences in levels recorded for children who had had IDDM for 2 or more years. In the Couper study, which tracked change during and after adolescents received home-based support services, there was a significant time by group effect. *Post hoc* analysis showed that the study group’s HbA1c levels dropped significantly between baseline and 6 months (the period of the intervention) but not between baseline and 12 months or baseline and 18 months. There were no changes of note for the control group over time.

The Lowes study does not report any clinical outcomes.

**Health service use**
Both Swift and Lowes report initial length of stay and readmissions (*Table 60*). Both suggest that the introduction or promotion of home-based forms of care for children with IDDM leads to significant reductions in length of initial stay. In the Swift study it also seems that this does not lead to any increases in readmission, although only the numbers of children experiencing readmission and not the number of readmissions are reported.

By contrast, the Lowes study suggests the opposite – children treated before the introduction of a paediatric nurse specialist in diabetes seemed to have fewer readmissions than those treated afterwards. This was the same whether it was examined soon after diagnosis or later on. The introduction of the paediatric diabetes nurse specialist did, however, seem to have a positive impact on Did Not Attend rates at follow-up clinics, both for children and adolescents. Did Not Attend rates for young children were 10% in the study group and 19% in the controls. For adolescents the rates were 23% and 35%, respectively.

**Impact**
The only impact variables reported in any study are a partial assessment of parents’ views of annual education sessions provided by the paediatric nurse specialist and adolescents’ and parents’ knowledge of diabetes. Lowes, on the basis of a 41% response rate to evaluation forms for the education sessions, claims that parents found sessions helpful, especially in sharing experiences, and that they found them comforting and interesting.
### TABLE 58 Health service use in early discharge for very low birth weight/NICU babies

<table>
<thead>
<tr>
<th>Study</th>
<th>Initial length of stay (days)</th>
<th>Emergency visits&lt;sup&gt;a&lt;/sup&gt;</th>
<th>Readmissions&lt;sup&gt;a&lt;/sup&gt;</th>
<th>Other health service use</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Study group</td>
<td>Controls</td>
<td>Study group</td>
<td>Controls</td>
</tr>
<tr>
<td></td>
<td>Geometric mean (95% CI)</td>
<td>Geometric mean (95% CI)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Kotagal et al., 1995&lt;sup&gt;d&lt;/sup&gt;</td>
<td>By birth weight (g)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>500–750</td>
<td>109.7 (81.8–121.6)</td>
<td>129.5 (109.4–153.3)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>750–1000</td>
<td>65.4 (51.9–82.5)</td>
<td>80.8 (72.5–90.1)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>1001–1250</td>
<td>49.0 (43.2–55.7)</td>
<td>64.7 (48.3–71.7)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>1251–1500</td>
<td>33.3 (29.1–38.1)</td>
<td>46.1 (42.6–40.9)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>1501–2000</td>
<td>14.9 (12.7–17.3)</td>
<td>23.6 (21.4–26.0)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>2001–2500</td>
<td>7.2 (6.2–8.3)</td>
<td>11.6 (10.4–13.0)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>2501±&lt;sup&gt;b&lt;/sup&gt;</td>
<td>4.9 (4.3–5.5)</td>
<td>6.8 (6.1–7.5)</td>
<td></td>
</tr>
<tr>
<td>Rieger and Henderson-Smart, 1995&lt;sup&gt;e&lt;/sup&gt;</td>
<td>Discharged 2.1 days earlier than controls</td>
<td>Mean&lt;sup&gt;d&lt;/sup&gt; 0.38</td>
<td>Mean 0.47</td>
<td>Not clear</td>
</tr>
<tr>
<td></td>
<td>Mothers’ rooming-in (days)</td>
<td>Mean 0.78&lt;sup&gt;f&lt;/sup&gt;</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Örtenstrand et al., 1999&lt;sup&gt;g&lt;/sup&gt;</td>
<td>Mean 30.6&lt;sup&gt;e&lt;/sup&gt; (SD 24.4)</td>
<td>Mean 46.3 (SD 23.4)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<sup>a</sup> For Kotagal et al., percentage of study population visiting emergency department within 14 days of discharge or readmitted during the study period; for Rieger and Henderson-Smart, mean number of visits to hospital emergency rooms during follow-up; for Örtenstrand et al., mean number of visits to hospital emergency rooms or readmissions per child during follow-up (12 months)

<sup>b</sup> ANOVA controlling for birth weight and month of discharge, p < 0.0001

<sup>c</sup> p < 0.001

<sup>d</sup> NS

<sup>e</sup> p = 0.017

<sup>f</sup> p = 0.01

<sup>g</sup> p < 0.01
The Diabetes Knowledge Assessment Scale (a validated and reliable scale) was used in the Couper study.89 As with HbA1c, this showed a significant interaction effect between time and group. Both adolescents and parents in the intervention group showed short- and long-term gains in knowledge from baseline. However, change was also evident in the controls, although not between baseline and 6 months. This suggests that adolescents learn more about their diabetes anyway and that the intervention simply hastened this process. By contrast, while intervention parents showed increased knowledge about diabetes as time passed, this was not the case for control parents.

'Technological' care at home

As discussed in chapter 1, change in the technology of care has made it possible to deliver at home a number of health technologies that previously were only available to children if they were in hospital. These include forms of dialysis, intravenous drug administration, parenteral and enteral feeding and nebuliser therapy. The range of conditions treated by such technologies is wide – childhood cancers, cystic fibrosis, any condition which compromises intestinal function, asthma, end-stage renal disease. Six studies were identified in this general area for this chapter. These include studies of dialysis by Brem and co-workers,90 various forms of intravenous therapy by Close and co-workers,80 Rizzari and co-workers91 and Melville and co-workers,17 enteral feeding by Anderton and co-workers92 and nebuliser therapy for asthma by Osundwa and co-workers.15 These studies will be referred to hereafter by the name of the first author.

The designs employed are various – before and after comparisons using children as their own controls,15,80,92 survival analysis of CVC lines in

---

### TABLE 59 Clinical outcomes in home care for children with diabetes

<table>
<thead>
<tr>
<th>Study</th>
<th>Mean glycated haemoglobin concentration (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Study group</td>
</tr>
<tr>
<td>Swift et al., 199356</td>
<td>Children with diabetes 2+ years</td>
</tr>
<tr>
<td></td>
<td>10.2 **</td>
</tr>
<tr>
<td>Lowes;88 Lowes and Davis, 199787</td>
<td>None reported</td>
</tr>
<tr>
<td>Couper et al., 199989</td>
<td><strong>Mean (SD) at:</strong></td>
</tr>
<tr>
<td></td>
<td>Baseline</td>
</tr>
<tr>
<td></td>
<td>6 m</td>
</tr>
<tr>
<td></td>
<td>12 m</td>
</tr>
<tr>
<td></td>
<td>18 m **</td>
</tr>
</tbody>
</table>

* p = 0.37
** Group x time effect, ANOVA, p = 0.006

### TABLE 60 Health service use in home care for children with diabetes

<table>
<thead>
<tr>
<th>Study</th>
<th>Initial length of stay (days)</th>
<th>Readmission</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Study group</td>
<td>Controls</td>
</tr>
<tr>
<td>Swift et al., 199356</td>
<td>Median* 1987/8 3</td>
<td>Median 1979/80 7</td>
</tr>
<tr>
<td>Lowes;88 Lowes and Davis, 199787</td>
<td>Median (range) 1 (0–7)</td>
<td>5 (2–18)</td>
</tr>
<tr>
<td>Couper et al., 199989</td>
<td>None reported</td>
<td>None reported</td>
</tr>
</tbody>
</table>

* p = 0.0001
** p = 0.001
* No statistical testing reported
hospital compared with home\textsuperscript{17,91} and an uncontrolled comparison of children receiving dialysis at home or in hospital.\textsuperscript{80,90} Two of the studies were in the UK,\textsuperscript{17,92} two in the USA,\textsuperscript{80,90} and one each in Italy,\textsuperscript{91} and Qatar.\textsuperscript{15}

**Clinical outcomes**

The range of clinical outcomes reported is, necessarily, varied in this set of studies and covers both physical and psychological domains (Table 6.1). The Close study\textsuperscript{80} reported no clinical outcomes formally but the paper states that there was only one case in 76 courses of chemotherapy where home therapy was disrupted because of a complication (an occluded catheter).

The overall initial impression from these studies is that, with the exception of enteral feeding, technological home care may deliver some real benefits for children or, at least, do them no harm. However, there are substantial limitations to the weight that can be put on these results.

First, most of the studies were very small (12 children in Brem,\textsuperscript{80} 14 in Close,\textsuperscript{80,90} 20 in Melville,\textsuperscript{17,92} 50 in Osundwa\textsuperscript{15} and only six in Anderton\textsuperscript{92}). Only the Rizzari\textsuperscript{91} study had a sample of more than 100 children (135).

Secondly, there were methodological problems with at least some of the studies. For example, it was not at all clear that the higher rates of

<table>
<thead>
<tr>
<th>Study</th>
<th>Technology</th>
<th>Outcome measure used</th>
<th>At what point</th>
<th>Study group</th>
<th>Controls or control condition</th>
<th>Reported statistical significance</th>
</tr>
</thead>
<tbody>
<tr>
<td>Brem et al., 1988\textsuperscript{80}</td>
<td>Home dialysis</td>
<td>Adolescent Coping Orientation Problem Experiences Scale\textsuperscript{a}</td>
<td>Between 3 months and 10 years after initiation of treatment</td>
<td>28.0 (2.3)</td>
<td>20.7 (5.3)</td>
<td>( p &lt; 0.05 )</td>
</tr>
<tr>
<td>Close et al., 1995\textsuperscript{80}</td>
<td>Home chemotherapy</td>
<td>No clinical outcomes reported</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Rizzari et al., 1992\textsuperscript{91}</td>
<td>CVC, mainly in children with haematological malignancy</td>
<td>Incidence of infection per 100 line days</td>
<td>At any point in ‘history’ of CVC in 135 children 1984–9</td>
<td>0.52</td>
<td>0.55</td>
<td>( p = 0.82 )</td>
</tr>
<tr>
<td>Melville et al., 1997\textsuperscript{17}</td>
<td>CVC/parenteral nutrition</td>
<td>Incidence of infection per 100 days of TPN\textsuperscript{b}</td>
<td>At any point in ‘history’ of TPN in 20 children 1986–92</td>
<td>0.25</td>
<td>0.35</td>
<td></td>
</tr>
<tr>
<td>Anderton et al., 1993\textsuperscript{92}</td>
<td>Enteral feeding</td>
<td>Mean occurrence of infection</td>
<td>Every 567 days</td>
<td></td>
<td></td>
<td>( p &lt; 0.00001 )</td>
</tr>
<tr>
<td>Osundwa et al., 1994\textsuperscript{15}</td>
<td>Home nebuliser</td>
<td>Contamination of feeds</td>
<td>Not clear</td>
<td></td>
<td></td>
<td>18/22 (82%) 22/73 (30%)</td>
</tr>
</tbody>
</table>

\( a \) A 53-item scale which yields scores in 12 individual areas of coping

\( b \) Calculated by us
infection of home-administered enteral feeds in the Anderton study92 were not due to the different methods used to collect samples in the hospital and at home. In the Melville study17 it was difficult to understand quite how the distinction between hospital and home infection rates in TPN had been made – for example, was an infection that emerged, say, a day after admission to hospital classed as a hospital infection or a home infection? The Rizzari study,91 by contrast, was quite clear about this and defined infections as hospital or home infections if the CVC had been exclusively hospital- or home-managed in the week preceding the onset of symptoms. The Brem study90 compared children who had elected to have home dialysis with children who had elected to be treated in hospital. As the authors themselves point out, this could, in itself, have accounted for the differences in psychological coping mechanisms which the two groups displayed, and which constituted the only significant differences between them.

Health service use

Only three of the studies report anything about health service use or the costs of care.

Osundwa15 suggests that home nebuliser therapy resulted in a reduction in the mean number of hospitalisations for 50 children with asthma from 2.0 to 0.6 in a 6-month period. At the same time, the mean number of visits to A&E reduced from 6.2 to 1.8. Both these changes were said to be statistically significant (p < 0.05). However, it is not clear how many days of hospital care were involved in the hospitalisations.

The focus of the Close study80 was reduction in billed charges for the health service, and financial impact on parents through loss of wages and out-of-pocket expenses. This is reported in detail in chapter 4. The overall impact of home chemotherapy was reported as positive in all these areas.

The only other study to refer to costs or resource use was that of Melville.17 A speculative costing of assumed days of care needed to treat CVC infection suggested a saving of between £4733 and £6495 per infection. Potential savings on the costs of reinserting CVC lines are also claimed to be of the order of £1,021,504 to the hospital in a year.

Impact

Only one study reports any other kind of measure of impact. Close80 used parent-reported judgements of children’s well-being, independence, appetite, school work, mood, sleep, and level of activity. In five of these domains – well-being, independence, appetite, school work and mood – home chemotherapy was reported to deliver significant improvements in children’s lives. Parents’ quality of life was covered in four domains – keeping up with household tasks, keeping up with work responsibilities, time spent with spouse, and time spent with other children. In all of these, measures were significantly better during home chemotherapy than during hospital-based chemotherapy.

The Likert-scale measure used was developed specifically for the study and there is no reference to its psychometric properties. Further, as the study compared the second and third courses of chemotherapy in hospital with the first course of chemotherapy at home, it is possible that the better results for home-based therapy simply reflect the fact that children were starting to feel better anyway.

Home care for children with mental health problems

Only one study was identified for this section, by Hufford and co-workers93 – of home-based, videoconferencing for adolescents with epilepsy who were ‘at risk’ of mental health problems. This was a pilot study of only three children and employed an ABCBCA design to explore three different ways of delivering sessions of counselling. A was an office-based session, B a home-based ‘speakerphone’ session, and C a home-based videoconferencing session. Video cameras were use in the office-based sessions in order to control for any reactions to the equipment, and the speakerphone sessions were included to examine possible “differential effects of audio-visual communication and audio-only communication on user perceptions of comfort, distractions, and therapeutic alliance” (p.180). The research was based in the US.

Clinical outcomes

The impact of the clinical intervention was assessed using three measures – ratings of issue severity, issue frequency and issue change. These were developed by the authors of the paper specifically to test outcomes of their model of therapeutic counselling – issue-specific family counselling. These measures appeared still to be in development and had been only partially tested for their psychometric properties. Further, the measures
were used simply to assess change between the first and last counselling sessions so could not be related to any particular mode of delivery.

The strength of therapeutic alliance developed between the counsellor and clients was tested using a subscale of the Working Alliance Inventory. This scale’s psychometric properties have been fully measured and it would meet the EPOC criterion for reliability. No individual results are presented for this measure, but the paper states that the speakerphone and videoconferencing sessions showed higher alliance ratings than the office sessions. However, as the authors point out, this is probably attributable to the lower ratings in the first office session, given that this was also the first in the treatment series.

**Health service use**

No reference is made to resource use or costings.

**Impact**

The paper is predominantly concerned with patients’ and families’ responses to the different ways in which counselling sessions were delivered. Using a scale specially developed for the study, few differences were found in how comfortable people felt with the different modes. A more open ended questionnaire was also used, designed to “elicit the adolescent’s and parent’s thoughts and feelings about interacting with the audio-visual equipment” (p.181). Content analysis of responses revealed few differences overall, but did indicate that both mothers and adolescents felt more comfortable with the videoconferencing and with the office sessions than they did with the speakerphone session. It is perhaps not surprising that the adolescents felt more comfortable with the video technology than did their mothers – not least because they were able to play video games on the equipment after the counselling session!

Both adolescents and mothers reported fewer distractions with the office session, compared with the video and speakerphone sessions. In the audiovisual session in particular, “factors unique to home contact were a substantial source of distraction” (p.189). Examples given were neighbours arriving during sessions, pets disrupting the session, and the use of the telephone or other household appliances.

**Discussion**

The main discussion of the implications of the studies reviewed in this chapter is in chapter 6.

Here we summarise the overall messages from the studies reviewed. These are, however, limited, with three main exceptions.

First, there is wide agreement in these papers both on the cost savings that can be made by providing care at home rather than in hospital, and, although often presented in a secondary manner, on the clinical safety of doing so. The analysis of the costs of care in the two locations is a feature of several of the studies analysed, and runs across the clusters identified above. The quality of analysis regarding cost data is, however, mixed, and we discuss this below.

Secondly, schemes that involve admission avoidance, or reductions in the length of hospital stay, consistently report that clinical outcomes are either better, or at least no worse, for children treated at home or discharged early. This is true both for neonatal early discharge schemes, and schemes for avoiding the hospitalisation of children diagnosed with diabetes.

Thirdly, those studies which looked at the views of parents and children, or which also included non-medical outcomes, consistently reported a preference for home care (notwithstanding some important concerns) and, although in a limited number of studies, to the social benefits to be derived from the provision of care at home.

However, there are methodological issues specific to this chapter that need to be taken into account in interpreting these results.

**Comparing like with like**

Several of the papers make claims about the benefits of locating treatment at home, yet on closer inspection they are actually comparing two different forms of treatment, thus compromising the validity of arguments about where that treatment should take place. For example, the studies which looked at infection rates at home and in hospital did not always compare like with like. In the Anderton study, feeds in hospital were prepared using bowls and whisks sterilised with a hypochlorite solution whereas parents in the home-treated group were simply instructed to clean utensils ‘thoroughly’. Further, the procedures for dealing with samples of feeds for subsequent detection of infection were different. Hospital feeds were sampled immediately after preparation, prior to administration and after administration, using sterile collection devices, and placed in refrigerated storage until being collected for microbiological analysis.
within 12 hours of collection. At home, by contrast, parents were simply ‘advised’ to place samples in a refrigerator until collected by the home nurse ‘on her home visit’, at some unspecified point afterwards. After collection, samples were taken to the lab and, again, analysed within 12 hours. However, it is not clear how long the samples spent in the home before collection or whether they were refrigerated on their way to the laboratory. The substantial differences in occurrence and level of infection in home-administered feeds may thus be artefacts of the sampling procedure.

Similarly, in the Rizzari study of CVC infection, washing fluids were prepared daily in hospital but only weekly at home. No statistically significant differences were found in infection rates between hospital and home, despite this difference in procedure, which might suggest that home care was actually safer, overall.

**Costs and benefits of home treatment**

The economic evaluation of paediatric home care is dealt with in greater detail in chapter 4. However, several of the studies included in this section also gathered data on resource use or the cost of providing care in hospital and/or at home, and claim to demonstrate that cost savings can be achieved with the provision of care in the home. This is a consistent message throughout several of the studies – indeed, the aim of reducing costs was the *raison d’être* for many of the changes in care location described. However, there were often flaws in the way in which cost data were gathered which merit brief discussion here. In some studies, costs were only partially described. For example, as already mentioned in chapter 4, Close and co-workers compared the costs of chemotherapy treatment at home and in hospital, but did not cost the programme of ‘parent training’ that was part of the home care. Other studies acknowledge a failure to gather comprehensive data on the cost of community services linked to home provision (for example, Kotagal and co-workers). This and other studies also fail to analyse the costs of home treatment from the perspective of parents. As a whole, then, the studies in this section that have gathered data on the resource use associated with paediatric home care argue for the reduction in costs that can be achieved. However, the data used to support this conclusion are often somewhat limited in depth.
Chapter 6
Integration and discussion of findings

The preceding three chapters draw on different types of studies and have slightly different structures, reflecting the models of care identified in each. Here, however, we bring the material and the models of care together, integrating findings from all types of studies and papers. We also briefly review evidence about the rate at which such services are being implemented and the number of children who might benefit from them. This integration is done under five main headings:

- home care for very low birth weight or medically fragile babies
- home care for children with asthma or diabetes
- home care for technology-dependent children
- home care for children with mental health problems
- generic models of paediatric home care.

We end the chapter with a discussion of general methodological and interpretive issues raised by the material reviewed.

Home care for very low birth weight or medically fragile babies (including oxygen-dependent babies)

The RCTs reported in the review certainly show that earlier discharge, accompanied by home care for very low birth weight babies is achievable, but given the relatively limited reporting of clinical or developmental outcomes it is difficult to judge with what effectiveness. All the trials were small and probably underpowered to detect differences in clinical or developmental outcomes. Indeed there is probably an argument that they were underpowered even to detect whether post-randomisation differences between intervention groups and controls were significant. Casiro's\textsuperscript{59} is the only trial that mentions pre-trial power calculations although Finello\textsuperscript{61} acknowledges, post hoc, that the study was underpowered. The studies employing other designs also suggested that home care can save days of hospital care, but again there is limited reporting of clinical outcomes.

The evidence from the trials of the impact of home care on initial length of stay is unclear: two trials reported shorter\textsuperscript{51,59} and two longer\textsuperscript{58,61} lengths of hospital stay for babies receiving home care. The studies which employed different designs also suggested that home care can save days of hospital care, but again there is limited reporting of clinical outcomes.

The impact of home care on initial length of stay is unclear: two trials reported shorter\textsuperscript{51,59} and two longer\textsuperscript{58,61} lengths of hospital stay for babies receiving home care. The studies which employed different designs also suggested that home care can save days of hospital care, but again there is limited reporting of clinical outcomes.

All the economic studies suggest that home care for these babies is cheaper than the alternative form of care. However, none report any statistical testing of these differences and all have substantial weaknesses in the range of costs collected and the ways in which they were analysed. Further, those studies that were about home care of oxygen-dependent babies included no clinical or other outcome measures.

The most significant issue missing from most of the studies reported here is the impact, either psychological or financial, that early discharge and home care of sick or fragile babies has on family members. Given that some, at least, of these babies will be very dependent in the short term and experience long-lasting effects from their fragility, this omission is an important one.

Home care for children with asthma or diabetes

Despite the growing popularity of home-based support for children with long-standing conditions such as diabetes or asthma, there seems relatively...
little evidence to suggest whether or not it improves outcomes or reduces costs, for children themselves, their families or the health service. This is as much the case in relation to ‘social’ outcomes, such as satisfaction with services and knowledge of the child’s condition, as it is with clinical outcomes. The only cost impact evident is on parents; one trial suggests that early discharge after diagnosis reduces the costs that they bear, largely by reducing the length of their children’s initial hospital admission.

This section was the only one containing a trial that took children’s ethnicity into full account in its design. However, follow-up was much lower in the ‘Polynesian’ group and the subgroup analyses give little impression of differential impact for children of different ethnicity.

Although the overall number of children included in the three trials was not large (526) it was about twice the number randomised in the trials of home care for very low birth weight and/or medically fragile babies. Unfortunately, the largest trial was the one with the lowest scores on both quality measures used. The other two were very small and probably underpowered to detect much in the way of difference at all. However, what the results reported in most outcome areas suggest is, not that there may be some benefit to home care which the trials were too small to pick up, but that there are no differences between home care and the alternative.

Studies using other designs, by contrast, suggest that home-based support for newly diagnosed diabetic children actually improves clinical outcomes, and may save days of hospital care. However, what neither of the studies of this group of children showed was whether the reductions in length of stay might have happened anyway, perhaps as views about the management of children with IDDM have changed over time. One of these studies also raises questions about the impact of home-based care on readmission. The author suggests that the apparent increase in readmission may be explained by a change in the study hospital’s organisation of emergency care. However, the role of poor social circumstances in children’s readmission, particularly soon after diagnosis, also seems to play a part.

The home-based intervention for adolescents with poorly controlled diabetes used goal setting and psychological support as well as clinical monitoring to help improve control. This study suggests that while such support improves clinical outcomes while it is active, improvements are not necessarily maintained over the longer term. However, its impact on Did Not Attend rates, particularly for adolescents, may be important, especially over the much longer term.

Only one trial, and none of the other studies, looked at the costs of resources used to provide these models of home-based care. As chapter 4 outlines, even this had some limitations, although it did include estimates of the financial impact of home care on children’s families. Overall, the costings suggest that the average cost to society of home care for newly diagnosed diabetic children is somewhat higher than the alternative.

This study avoided one of the main weaknesses of almost every other study reviewed here by examining the impact of home care on parents’ other activities and the value of their input to their child’s care. However, as the authors point out, persuading the health service to invest in home care services that cost the healthcare system more ‘up front’, even if they do deliver better clinical outcomes, may be very difficult:

“Hospitals would not share parents’ savings nor would they necessarily reap any future cost savings resulting from any reduction in health care services needed in subsequent years...When considering intensive home care, the hospitals and government probably would not ignore the benefits to children and their parents, but they may attach less weight to the parents’ savings than to their own cost increases...” (Dougherty and co-workers pp. 596–7)

**Home care for technology-dependent children**

In this subsection we bring together all the trials and studies reviewed in relation to the delivery of ‘technological’ interventions at home. These include home therapies reliant on intravenous administration (antibiotics, TPN and chemotherapy) and enteral feeding, home oxygen therapy (other than for neonates), home dialysis, and home nebuliser therapy.

**Home intravenous therapies and parenteral and enteral feeding**

No trials were identified in this area, so this part of the discussion is reliant entirely on the other studies and the economic papers. Clinical outcome reporting was very limited in all of them, with no clinical outcomes reported satisfactorily for home chemotherapy. Only infection rates for parenteral
and enteral nutrition and other CVC-administered therapies were reported, with no statistically significant differences in rates of infection for home intravenous treatment compared to hospital treatment. As explored in chapter 5, the higher rate of infection in enteral feeds at home compared with hospital could well have been an artefact of the sampling methods used.

Intravenous therapy and enteral feeding at home can make substantial demands on families, particularly when it is introduced with only minimal support from health professionals. Given this, it was surprising to find only one study – of home chemotherapy – that addressed such issues, albeit in a limited way. This suggested that parents found that, compared with hospital-based treatment, home chemotherapy had less impact on their ability to keep up with household tasks or work responsibilities, and allowed them to spend longer with their spouse and other children.

Although costing studies predominated in this section, the conclusions that can be drawn from them are very limited. One study of home chemotherapy reports a statistically significant reduction in costs, and the others claim savings without formally testing their significance. However, given the variability in reporting costs, in terms both of detail and quality, and the limitations in design, it is difficult to put much weight on these findings. The single costing study of intravenous antibiotic administration at home also claimed substantially lower costs for home care. But again, there were limitations with the overall design and the costing methods used which would make it difficult to generalise these findings.

**Home oxygen therapy (other than for neonates)**

Again we identified no trials in this area of home care, nor any studies adopting other comparative designs. Two costing studies thus appear to constitute the comparative evidence base for this type of home care. These, however, were very small and one was limited methodologically. Both studies report substantially lower costs to the health service when long-term oxygen support is provided at home rather than in hospital, although the methodologically better study reports a smaller difference than the other. Neither study, however, had a control group or even a control period before home care, making it impossible to judge the clinical or quality of life impact of home care. In neither were costs to families properly dealt with, even though one suggested that some families had incurred much larger water and electricity bills as a result of having their child at home and on ventilation.

**Home dialysis**

Two studies were identified in this area – one a costing study and one in the ‘other’ section. The costing study was based on hypothetical protocols for different forms of hospital and home-based dialysis, with or without a range of complications. Even the ‘worst case’ comparison between uncomplicated hospital care and complicated home care suggested a substantial reduction in costs for home care. However, no account was taken of likely costs to other agencies or families themselves and no clinical or quality of life outcomes were considered.

The other (very small) study reported only psychological outcomes and suggested that children on home dialysis regimes had more active coping strategies than children receiving dialysis in hospital. However, methodological problems make it possible that this difference is an artefact.

**Nebuliser therapy**

Only one comparative study of home nebuliser therapy, for children with asthma, was identified for the review. This was one of the ‘other’ studies and included no clinical outcomes. A comparison of hospitalisations and use of emergency services before and after access to a nebuliser at home suggested that both were significantly reduced.

**Home care for children with mental health problems**

Two trials, two economics papers and one other study were identified in this section.

The total number of children randomised in the two trials was only 275, making it unlikely that anything other than very major clinical effects from the different forms of care would be reported as being of statistical significance. One trial did not report any power calculations while the other was powered to detect a ‘medium’ clinical effect of a 12 point difference in the main outcome measure (suicidal ideation). In reality the difference between the interventions and controls at final follow-up was only five points. The power calculation had been based on a pilot study that reported a mean score on the suicidal ideation measure of 36 following routine after-care. The reported scores for interventions and controls in the main trial were actually 23.6 and
Integration and discussion of findings

28.7, respectively. This raises the interesting question of whether the research process itself had some therapeutic effect on the control children.

Apart from parents' satisfaction with services, other effects, whether on children or on their parents/carers, were hard to detect.

There is some suggestion of lower health service use, subsequent to treatment, with some concomitant effects on health service costs. The main impact on service use, however, may be in relation to residential or institutional care. This is, of course, an important outcome, but given its relative rarity a much larger trial would be needed to establish whether or not the effect is real.

The two economics papers include one simulated costing exercise that seemed to us to have analytic flaws. The other paper was associated with the Harrington trial and demonstrated significantly lower service costs, but only when the cost of the intervention was not included. When included, costs were still lower, but not significantly so. There is some suggestion that the intervention might be cost-effective with a particular subgroup of children (those without major depression) but the numbers were very small and CIs large.

The only other study in this section was a pilot study of a form of telemedicine for children with epilepsy who were ‘at risk’ of mental health problems. All that could be concluded from this study is that telemedicine may have some potential in this field but needs substantial testing of its costs and effectiveness.

Generic models of paediatric home care

All the models of care reviewed so far are, of course, models of paediatric home care but, as described, are largely highly focussed in terms of health condition or specific technology. A more generic model of home care, for children with complex and long-term support needs arising from a range of conditions and treatments, has also been included in the review. This was evaluated in an RCT and reported outcomes (but no formal costing) over a long period of follow-up.

Difficulties with reporting of those who dropped out from the trial, alongside partial testing of some outcomes only on children above the age of five at recruitment, made interpretation of some of the findings of this trial problematic.

No major, lasting, clinical effects on children, either physical or psychological, were evident from the early papers, although it is claimed, on the basis of a very partial follow-up after 5 years or so, that psychological adjustment was significantly better for intervention than for control children.

Family satisfaction with services was significantly higher for the intervention group, although impact directly on the children’s mothers or on the family as a whole was not detected.

With no idea of the likely costs of providing this service it is impossible to make any judgements about the price at which the claimed improvements in long-term psychological adjustment were bought. Further, the methodological and interpretive problems discussed in chapter 3 suggest that this is a model of care that has not yet been adequately evaluated.

Methodological and interpretive issues

As well as pointing to specific areas where research is still needed, this review has also raised questions about the ways in which research in this general area is carried out.

Research design

Randomised trials will not always be possible for the study of PHC for a variety of reasons, including the small numbers available with certain conditions, ethical concerns about the deliberate withholding of new services and, in some cases, the extent to which service development has run ahead of evidence. Studies with non-randomised designs will therefore continue to play an important part in building evidence about paediatric home care.

It is important, then, that studies using other designs are as rigorous as is possible.

The papers reviewed here are diverse, dealing with a wide range of conditions, interventions and service models, and employing different methods of data collection. However, there are several common issues that future research, regardless of its design, will need to address in order fully to evaluate the role and usefulness of PHC services.

Sample size

While in-depth, qualitative studies require only small samples, once one moves to any design with
quantitative aspirations, whether an RCT or not, small sample sizes can be problematic. The relative rarity of serious health conditions in childhood means that single site studies can recruit only low numbers of children, severely limiting the applicability of findings.

Timing of data collection
Whilst several of the non-randomised studies collected prospective data on home-based interventions, data on the control condition were often gathered retrospectively. Even in the trials, retrospective collection of, for example, service use was found. More confidence could be put in findings from studies in which data are gathered prospectively for all children included and/or for different interventions and locations of care.

Objectivity
The rationale behind studies occasionally suggests a lack of objectivity. For instance, Lowes and Davis, evaluating the role of the paediatric diabetes specialist nurse, preface their paper with the argument that: "...to encourage the implementation of these initiatives [schemes to reduce hospitalisation], it is essential to produce evidence that is linked to measurable outcomes, which exemplifies the contribution that paediatric nurses can make towards the quality of care for children"(p.28). In other studies, there appears to be an imbalance between analysis of the cost savings of home care on the one hand, and the efficacy of treatment on the other. Indeed, the approach of several studies appears to have been to demonstrate the significant cost savings of home care first, and to observe that clinical outcomes are ‘no worse’ as a secondary finding.

Several studies can be further criticised on the grounds of objectivity, given the lack of separation between those introducing a new home treatment and those collecting and interpreting the subsequent data. While double-blinding is impossible in studies which evaluate a different form of service provision, blinding of outcome assessment is sometimes possible in both randomised and non-randomised studies. As a very minimum, someone who is completely uninvolved with the service being evaluated should carry out outcome assessment.

Long-term follow-up
There is often inadequate attention paid to the maintenance of the benefits of home treatment over the longer term, or to the possibility that the children and parents in study groups would tend to respond positively to new interventions, particularly where these interventions were more intensive forms of therapy previously unavailable to them (i.e. a Hawthorne effect). Longer-term follow-up poses interesting methodological challenges given that, as children age, different measures of outcome may be needed. However, this indicates a need to develop methods, rather than to ignore the possibility of shifting outcomes.

Description of the model of PHC
Some studies inadequately described the intervention in question, as well as the way in which it was delivered, the roles of acute and community sector staff in delivering it and, crucially, the alternative treatment that it replaced (if any). This has major implications for replication of any successful service models in other places and, indeed, for understanding which elements of a service contribute most to its success.

Impact beyond the hospital
Studies are often ambiguous or incomplete in their attempts to deal with the impact of paediatric home care on demand for community services. Few studies attempted to look systematically at the potential for increased use of such services. This is important given that many of the studies reported home care interventions that included ongoing ‘outreach’ contact with acute sector staff. Clearly, home care will never involve a complete breaking of contact with acute sector staff, particularly given parental fears about the appropriateness of home treatment for very sick children. The precise way in which acute sector and community sector staff work together in supporting families should have a higher priority in future research and evaluation.

Age of children
The data presented in these studies indicate the need for analyses that are more sensitive to the age of children. Home care for infants is likely to have very different aims, methods of care provision and ways of measuring outcomes, from home care for adolescents. Several of the studies reviewed covered a wide age range of children. Some have important findings that must be seen in the context of the age of the children involved. For instance, studies that suggest no overall increase in costs to parents may be peculiar to the parents of infants, who are less likely to lose earnings as a result of a child being cared for at home (given that one parent is likely to be a full-time parent at that point) than the parents of older children receiving care at home.

Case mix: interventions for which children, and in which families?
The quality of evidence regarding the positive benefits of home treatment is, on the whole,
compromised by the ways in which children and families were included in the various studies. In several cases, children were included in studies only once more or less formal assessments had taken place of the skills, behaviours and relationships within the family itself, as well as the quality of the home environment in which children would be cared for. Studies, therefore, had inclusion criteria that served to limit the relevance of their findings to a narrow range of families in which parents were deemed competent and, often, compliant. These are relevant factors in deciding whether or not to treat children at home, particularly when treatment places a high burden on parents and/or requires confidence in the use of technological devices to deliver care. However, the significance of judgments about parental competence and compliance receives too little discussion.

Several studies directly (i.e. through explicit inclusion and exclusion criteria) or indirectly (i.e. through features of the sample of children) under- or over-represented children and families from particular backgrounds. For instance, parental competence in English was employed as an inclusion criterion in many studies. Selection on the basis of competence or compliance may mean that families included in studies come from social backgrounds more supportive of home treatment. Geographical location, and especially proximity to the acute sector provider, were used as inclusion criteria in many of the studies reviewed here, thus indirectly reducing the participation of families from rural areas. Despite this, the issue of the socio-economic background of the families in studies, and its impact both on the interpretation of findings and the practical implications of those findings, are rarely discussed in detail.

These issues do not necessarily invalidate the findings of the studies, but suggest caution in generalising about the value of these models to the larger relevant paediatric populations. This group of studies presents evidence which, when taken as a whole, disproportionately focuses on a relatively narrow group of children and families – those characterised by parental competence and compliance, by their proximity to urban medical centres, and by their membership of majority ethnic groups. The clinical and methodological reasons for drawing from this group of families may be justifiable, but they serve to limit the broad relevance of the data presented, and highlight the need for further research regarding paediatric home care for children and families who do not meet these inclusion criteria.

**The views of children and parents**

Where the perspectives of children and/or parents were included in these studies, interesting data were gathered. On the whole, however, the studies reviewed here did not adequately represent the views of children and parents on the provision of home care. Whilst in some the exclusion of the views of children was entirely understandable on the grounds of age, others appeared to miss an opportunity to hear the voices of children themselves, without obvious justification. We acknowledge that seeking the views of children and parents will not always be possible. However, a centrally important aspect of home treatment is the way in which it is experienced by children and families. This is especially important given the untested assumptions made about children’s behaviour and their responses to illness in some of the papers. Future research should address this relative under-representation of children’s and parents’ views.
Chapter 7

Conclusions, implications and recommendations

“However loving and dedicated parents may be, those caring for a seriously ill child will always need professional support, including guidance on what they should do, advice on the availability of services and on their child’s educational needs, ‘hands on’ care for the child (i.e. care involving some degree of physical contact) and respite care.” (House of Commons Health Committee, 2 para.32).

The review has served to confirm the preliminary impression gained before it was started – that, despite substantial growth in different models of paediatric home care, there are relatively few examples of well-designed and controlled studies that directly compare hospital delivery of interventions or services against home delivery, or that compare different models of home care. As a result we believe that not much can be drawn from the findings of the review in terms of implications for health care. By contrast, we have identified a series of outstanding research questions and these are outlined below set, where possible, against evidence about the rate at which such services are being implemented or the numbers of children who might benefit from them. We also indicate the rate of growth of evidence in this field and its likely impact on the conclusions of this review.

Implications for health care

Models of paediatric home care

The review has shown that paediatric home care, as currently developed, has a number of different dimensions, within which different models of service can be distinguished. First, there is the distinction in focus between ‘specialist’ paediatric home care, which is involved with children with specific conditions or specific home-based technology, and ‘generic’ paediatric home care, which has a wider remit for any children with significant health needs at home. Secondly, there is a distinction in location, with ‘community’ models with strong links to primary care and other local services and ‘hospital outreach’ models with strong links to hospital services. Thirdly, one can also distinguish between the children served by paediatric home care services in terms of the timing of their needs – shorter or more acute (postdischarge or for a defined period of clinical intervention) and longer-term or more chronic.

These dimensions can be used to form a framework within which the different PHC models can be placed (Table 62).

In fact, many of the services described in the literature are spread across the cells created by this framework. For example, some families caring for children on enteral or parenteral feeding at home may find themselves supported by a specialist outreach team from a hospital when waiting, say, for surgery. By contrast, other families, particularly those whose children are disabled and who have long-term needs, may find themselves supported by little else than an occasional visit from a generic community nurse. As we have seen, there is little enough evidence on whether individual services, of themselves, are cost-effective. In the current state of knowledge it is impossible to say anything about the comparative merits of, say, specialist services versus generic services.

However, these services continue to be developed, not least because they have an intuitive appeal both to practitioners and to the public. In the current state of knowledge it seems imperative

### TABLE 62 Dimensions of paediatric home care provision

<table>
<thead>
<tr>
<th>Location</th>
<th>Focus</th>
<th>Generic timing</th>
</tr>
</thead>
<tbody>
<tr>
<td>Community</td>
<td>Shorter</td>
<td>Longer</td>
</tr>
<tr>
<td>Hospital outreach</td>
<td>Shorter</td>
<td>Longer</td>
</tr>
</tbody>
</table>

© Queen’s Printer and Controller of HMSO 2002. All rights reserved.
that new services are set up in such a way that they can be evaluated – against some alternative where this is available, or at the least via rigorous audit of costs and outcomes.

The main policy issue in this area seems to be not whether children should be treated at home or in hospital (when either is feasible) but rather how much care can be delivered at home. The general view, expressed strongly for many years, is that hospital is not the best place for children to be cared for, once the most acute phase of their illness is over. However, this review has raised a number of questions, some of them ethical, about whether this is necessarily the right emphasis in all possible cases, and particularly in relation to children who rely on technological interventions and treatments.

First, it is clear that hospital care for children has been transformed over the past 30 years in order to make it more appropriate and less damaging; indeed, some children, at least, seem to enjoy the experience, if it is not prolonged.41 Careful analysis of which children, with which conditions are better treated at home or in hospital must be used to inform policy in this area.

Secondly, should we always assume that families will necessarily want to provide care for their children at home, particularly when that care involves ‘high technology’? Just because to do so may seem cheaper for the health service is not, of itself, an argument for pushing as much care as possible into the home, particularly if it imposes both short and longer-term costs on parents and other children in the family. The descriptive literature tells us that such costs exist but, again, much of the evaluation literature, such as it is, barely mentions impact on the family.

Thirdly, the considerations about length of life and its quality that have characterised the debate about the use of health service resources on adults are rarely evident in the literature on care for children. Indeed, as we have seen, measurement of children’s quality of life is simply missing from the bulk of the literature. Because we can give some children a slightly longer life by setting up technological solutions at home, does that mean that we should do so regardless of impact on them and their family?

The review was not set up to explore these difficult ethical issues, but they do need exploring. As Lantos and Kohrma94 state in their thoughtful article:

“...if home care is both cheaper and more beneficial for the child than long-term hospitalisation...it would seem to be ethically imperative. However, the benefits of home care are uniquely sensitive to the voluntariness of parent participation. If a family makes a reluctant decision to care for their child at home, they are at a high risk of failure.” (p.922).

It is unfortunate that the evidence that could inform such difficult ethical (and practical) debates is so inadequate.

**Recommendations for research**

**Paediatric home care for very low birth weight babies**

It is difficult to judge the extent to which early discharge for very low birth weight babies, accompanied by home care, is an issue for the health service. Certainly, there is a sense that the barriers to early discharge are being pushed ever lower, but most of the literature is about the minimum weight at which some babies can safely be discharged, rather than about how very low birth weight babies with special needs, and their families can be supported when they do eventually go home. This focus is reflected in most of the trials and papers we reviewed, in that the babies included were those who had fewest complications or needs for technological support. By contrast, the studies of babies who really did have significant needs for support at home — those who were oxygen-dependent — were solely concerned with costs and made no attempt formally to assess clinical or other outcomes or assess impact on families.

Yet we know from the descriptive literature that a high proportion of very low birth weight babies continue to have substantial support needs, some of them technological, over the long term, and some for life. We also know that caring for such children imposes substantial emotional and economic costs on families.95,96 The issue, then, should be not so much whether or not very low birth weight babies can be safely discharged home (it seems that, if carefully selected, they can). Rather, research is needed which asks what support the sickest babies and those most likely to be disabled need and, if this is provided, what benefits it delivers and at what cost? The research reviewed here, unfortunately, allows us to say nothing about this.

**Paediatric home care for diabetes and asthma**

Diabetes and asthma are chronic conditions that relatively rarely require hospital admission for...
treatment. However, there are more and less ‘home-based’ ways of delivering services around initial diagnosis, of delivering ongoing monitoring and adjustment of treatment regimes, and of keeping in touch with groups of children that are hard to reach. But, as Eastwood and Sheldon\textsuperscript{97} argue in relation to asthma, relatively little attention has been given to “how care should be delivered and by whom – the organisational aspects of care, the modes of delivery of service as opposed to the treatments themselves” (p.134).

Until high quality trials have been carried out that are large enough to examine the full range of effects that models of home care for children may or may not have, the evidence on these particular forms of support for children with long-standing conditions remains equivocal. Such research should also attempt to answer questions about which types of children and families would benefit the most from PHC.

Paediatric care for technology-dependent children

**Home intravenous therapy**

A recent survey of home infusion care in England\textsuperscript{98} has argued that acceptance of home infusions has been slow because of the way in which health care is funded, with no direct pressure of the sort experienced in the USA from insurers to reduce costs through reducing length of stay. The survey suggested that only 5\% of health authorities were commissioning home infusion treatment for cancer, although 42\% of hospitals that responded were either providing or purchasing it for their patients. The researchers found it difficult to collect accurate information from respondents about the numbers of patients being treated at the time of the survey but, at the least, hospitals reported treating 990 patients and health authorities reported commissioning care for 33 such patients. Some overlap of patient identification is probably inevitable here and no questions were asked about the ages of the patients being treated.

The authors conclude that while home infusions are gaining acceptability in England, this is not uniform. Further, there was evidence of lack of monitoring of care received by patients at home and of clinical outcomes. They argue for a “review of the mechanisms used to purchase and provide home infusions”, the introduction of a “system whereby all home infusions are purchased via the same mechanism” and emphasise the need to address quality and outcomes monitoring urgently\textsuperscript{56} (p.766).

This technology is evident in the UK, then, and may be increasing\textsuperscript{99} but evidence about its impact and costs is clearly needed. Intravenous therapies of various sorts may or may not deliver real benefits to both children and parents, and may or may not produce savings to the healthcare system. None of the research reviewed here can demonstrate impact with any confidence.

There is a clear need for research in this area, then, particularly in relation to home chemotherapy and home intravenous antibiotics. A national survey of current paediatric practice in this area and a systematic review of clinical outcomes based on case series would be a start. However, there may be a stronger need for controlled studies of home versus hospital care, using multiple sites to guarantee sufficient numbers.

**Home parenteral and enteral therapy**

The use of both enteral and parenteral nutritional support for children at home is also increasing.\textsuperscript{100,101} By the end of 1998, just under 3000 children were registered with the British Artificial Nutrition Survey as receiving home enteral tube feeding (HETF) and 64 home parenteral nutrition (HPN).\textsuperscript{101} This indicates a well-established model of home care.

However, questions about the overall safety of these techniques have been raised. Higher rates of infection among children, compared with adults,\textsuperscript{16} and a high rate of catheter-related thrombosis\textsuperscript{19} have been observed. A recent systematic review of HPN found little other than case series by which to judge its impact in paediatric populations, but these did suggest that children experienced higher rates of catheter sepsis than adults.\textsuperscript{102} Specific questions about the safety of HETF in relation to children with neurological impairments have also been raised; Puntis\textsuperscript{101} has argued the need for “well-designed prospective studies in order to establish the long term benefits and hazards of HETF” (p.296) for such children, who constitute a large group of its users. More generally, he argues that the “balance of risks and benefits” of home nutritional support in some circumstances require “clarification by further follow up”.

Even in the descriptive literature concerned with enteral and parenteral nutrition for children, validated outcome or quality of life measures are rarely used\textsuperscript{22,100} and there has been no health economic appraisal of paediatric HPN.\textsuperscript{102,103}

Family motivation is essential for success in home-based enteral or parenteral nutrition\textsuperscript{100} and the
impact on families of caring for children receiving such care is substantial. Yet descriptive research suggests that families in this country are ill-informed about the implications of artificial nutrition either for their child or for themselves. The support that is offered to families varies substantially from place to place, even within the same region.

All the above suggests, again, a form of home-based technology for children that has not yet been adequately evaluated, particularly in relation to the different subgroups of children for whom it might be considered as a treatment. This is an area where RCTs would be all but impossible. At least, however, there is an argument for updating the previous systematic review that explored clinical outcomes. Our searches revealed a number of recent papers on case series of children that would strengthen the evidence base. If secondary analysis of data from these series was attempted this might also allow researchers to address the question of which children benefit or not from home care of this sort.

**Home oxygen therapy**

The number of children in the UK being supported at home who need oxygen therapy of some kind or another is not known with any accuracy. A recent estimate, using a number of sources, suggested that there are perhaps 1000 children in the UK with tracheostomies, more than 1000 dependent on oxygen and 93 on long-term ventilation support. However, it is inevitable that there will be a degree of overlap in these figures but also, as the authors acknowledge, that the figures will underestimate the real numbers of such children. Others have concluded that the prevalence and incidence of children who are dependent on long-term ventilation support has increased over the past 10 years and that the proportion of such children being supported at home has also grown.

The number of babies being discharged home while still dependent on oxygen is also increasing and at least some of these will remain dependent on oxygen beyond the neonatal period.

Given that the alternative to home oxygen therapy is long-term care in a hospital or institutional setting it is unlikely that anyone would suggest that children should be returned to hospital, even if a perfectly designed RCT showed that home care was substantially more expensive than hospital care. As we know from ventilator-dependent children themselves, they find long stays in hospital at best boring and at worst emotionally damaging. As with less ‘technological’ forms of home care, then, a return to long-term hospital care is simply not on the agenda.

Nonetheless, it is surprising that there is apparently so little robust knowledge about the longer-term clinical impact of home care (compared to hospital care) and how best services might be organised to make sure that any impact is positive rather than negative. Further, despite descriptive accounts of the impact of home oxygen therapy on family life and family members, we have no accurate, comparative, account of the financial, social, or emotional costs that families bear. Rigorous and well-designed, non-RCT research on the relative effectiveness of different models of service delivery, the impact that home oxygen therapy has on children and their families, and the ways in which services can enhance positive outcomes is needed. Given the current uncertainties about the size of the paediatric patient population, some form of survey might be necessary beforehand, not least to ensure adequate sample sizes for evaluative research, drawn from multiple sites.

**Home dialysis**

The development of continuous peritoneal dialysis has made home care for children with renal disease feasible and it is now considered to be the “favoured treatment of choice.” This is an area where one might presume that considerable gains in quality of life and reduced disruption to education and social life are realisable, when children can be treated at home rather than in hospital. However, as Cuttel and colleagues have argued, home dialysis presents families with “enormous challenges” which include not only the dialysis but also “often gastrostomy or nasogastric feeding, dressings, blood pressure measurement, and administration of medicine” (p.16).

Again, however, we seem to have no proper comparison of clinical outcomes, only minimal health economics, and virtually no information about children’s and parents’ own views about the costs and benefits of home versus hospital delivery. It seems that home dialysis for children may now have percolated so far into the service system that an RCT would be impossible. However, both empirical evaluation and additional modelling that includes costs falling to other agencies and families would add to what is currently a very small evidence base in this area.
Nebuliser therapy
Nebuliser therapy at home seems to be an area where there is debate about appropriate care. Nebulisers can be useful for those having frequent acute attacks or for children who are too young to use simpler devices. However, a survey in the mid-1990s suggested that the provision and management of paediatric nebuliser services are poor and that “with the development of simpler, and less expensive, inhalational devices, nebulisers may even be inappropriate for many...children” (p.143).

By contrast, nebuliser therapy is seen as the “mainstay of aerosol delivery” in patients with cystic fibrosis, especially for young patients. However, the descriptive literature displays considerable anxiety about the ways in which nebuliser equipment is maintained and cleaned in patients’ own homes and the resultant levels of infection found. Given the nature of the disease, use of infected equipment may have substantial clinical sequelae. Despite this, we found no comparative study that addressed the issue of how best to enable families to treat their children safely and effectively at home.

Research which explores whether or not children with asthma should have nebulisers at home is apparently needed, especially that which compares it against different modes of drug administration and for different age groups. A systematic review of the clinical safety of home nebuliser use for children with cystic fibrosis to confirm or challenge anxieties about rates of infection is also needed, coupled with evaluation of services or training programmes that enable families to use such equipment as effectively and safely as is possible.

Home care for children with mental health problems
There have been two major systematic reviews of psychiatric care for children recently, one specifically about the treatment of psychiatric disorders in childhood and the other about treatment for deliberate self-harm in adults and adolescents. Although both these identified the trial we included here, neither focuses in any detail on the issue of where children with mental health problems might best be treated and cared for. If hospital is considered a generally inappropriate environment for children who are physically ill, once their acute needs have been attended to, then surely there must at least be an empirical question mark over hospital care for children with mental health problems.

Given the current level of knowledge about this issue there is a clear need for further research. This is an area where an RCT would be both appropriate and feasible but it would need to be carried out over a number of sites in order to obtain samples large enough for differences in clinical outcome (if any) to be detected and for different treatment regimes to be controlled for, post hoc.

Paediatric home care
As we saw in chapter 1, paediatric home care services have a relatively long history in the UK and there has been substantial growth in their numbers over the past 10 years. Despite this, we have been able to find no completed, robust evaluation of generic paediatric home care services in the UK. One trial is ongoing and a descriptive evaluation of a paediatric ‘hospital at home’ service for acute care has recently finished (Wilson A, University of Leicester, personal communication), but results from either are not yet available. In addition, a trial of a ‘hospital in the home’ service for children with common acute problems in the USA has been identified but, again, we have not yet been able to obtain results from this. Further, the very different policy and service systems in the USA may make it difficult to ‘read over’ to the UK context from such a trial. Even with the results of these studies, other aspects of generic paediatric home care models, particularly their role in supporting very dependent children and their families, will remain under-evaluated. At the very least, health service providers planning to initiate such services should be encouraged to do some form of before and after evaluation; at best some form of controlled, prospective evaluation across a number of sites might be considered.

Priorities for research
Given the diversity of conditions and service settings included in this review, prioritising the research recommendations has been difficult. In drawing up the list below we have:

- distinguished between topics that should be addressed because the review has suggested a degree of clinical risk, and those where the questions are more to do with impact of service models – for example, on service costs, on parents and other family members
- used the evidence reviewed above about the rate of growth of interventions and services and the likely size of population served, and
Conclusions, implications and recommendations

- prioritised descriptive surveys and systematic reviews ahead of trials and other evaluative designs, where it is clear that the latter would be difficult or impossible without the former.

Our recommendations for future research are as follows:

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 based on 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) based on case series
8. an RCT of home dialysis for children may now be impossible. Other empirical evaluation, and economic modelling that includes costs falling to other agencies and families, would add to a very small evidence base
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 it is 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.

In addition to these specific suggestions about research, there are some more general recommendations that can be made.

First, there is the issue of children’s own perceptions about their care and their quality of life. As we have shown throughout, this is an area that has been largely neglected in the literature to date. Several quality of life measures for children are now available; a recent review identified 19 generic and 24 disease-specific measures for children. However, only three and two of these, respectively, were judged to meet performance characteristics related to reliability and validity, the availability of a self-report version for children (where appropriate), a proxy measure for adults, and length. Despite this, the authors argue the need to use quality of life measures in paediatric research, not only for their intrinsic usefulness in assessing children’s well-being, but also for experience that could guide the development of the next generation of measures. We would echo this recommendation and extend it to the need to generate more detailed understanding of parents’ attitudes towards different types of care for their children.

Secondly, there is the issue of health economics and its application in this field. As chapter 4 shows, the quality of much of what was described as health economics in the material we identified was poor. It is difficult to understand why research in this area of paediatrics has not taken on board the need for rigorous health economic approaches, especially when cost saving appears to be the rationale for service development, particularly in the USA. Weaknesses are evident in examining costs to the health sector and even more so in relation to impact on other service sectors and children’s families. We therefore recommend the need for good quality health economics input to any research in this field in the future.

Rate of growth of research base

Evaluative research activity in this area still seems limited, while the descriptions of new paediatric home care services increase. A rerun of the main MEDLINE search immediately prior to publication of this review identified 502 articles, 27 of which seemed to be of relevance. Of these only one would definitely have been included in an updated review: an RCT of inpatient versus home care for children with mental health problems. Three other papers,
described as ‘reviews’ of economic aspects of HPN,\textsuperscript{114} of home oxygen therapy,\textsuperscript{115} and of generic paediatric home care\textsuperscript{116} might have been included in the sections on economics and other designs, along with a paper describing parents’ experiences of hospital or home care for diagnosis of diabetes.\textsuperscript{117} Further, as described earlier, results of two trials of generic paediatric home care, one from the UK and one from the USA are still awaited.

Several new papers reporting outcomes and complications in case series of children receiving home oxygen therapy,\textsuperscript{118–121} HPN,\textsuperscript{122–124} home intravenous therapy,\textsuperscript{125–127} and home nebulisers\textsuperscript{128} were found. This strengthens the recommendation for new or updated systematic reviews of clinical outcomes in these areas.

Beyond this, the searches found accounts of services or interventions that were not identified in the original work. Of these, the most significant seem to be the role of telemedicine and the Internet in supporting parents of technology-dependent babies and children (three papers), and the treatment of respiratory syncytial virus in babies at home (two papers).

None of this suggests the existence of an evidence base that is increasing at great speed.
Acknowledgements

This review was commissioned by the NHS R&D Health Technology Assessment Programme, project number 98/05/03.

The review team
Thanks go to all members of the review team whose responsibilities were as follows:

- Suzy Paisley, ScHARR, University of Sheffield – identification and retrieval of electronic and paper searches
- Padma Bhakta and Gillian Parker, Nuffield Community Care Studies Unit (NCCSU), University of Leicester – maintenance of research ‘diary’, scoping exercise, downloading searches, construction and maintenance of Procite databases, selection of studies, identification of ‘other’ studies, development of data extraction forms for RCTs and economic studies, quality assessment of RCTs and economic studies, data extraction of RCTs and economic studies, selection of qualitative evaluation studies, and report writing
- Caroline Lovett, NCCSU – selection of studies, data extraction, database editing, forward citation searching
- David Turner, NCCSU – preliminary selection of economic studies, advice on quality of economic studies and development of economic data extraction form.
- Mike Silverman (Department of Child Health), Andrew Wilson (Department of General Practice and Primary Care), Bridget Young and Keith Abrams (Department of Epidemiology and Public Health), all University of Leicester, Adrian Brooke, Elizabeth Anderton (Leicestershire and Rutland NHS Trust) – participation in review team meetings to discuss databases to be searched, formulation of inclusion and exclusion criteria, selection of papers, and provision of advice relating to their specific professional backgrounds
- Teresa Faulkner, NCCSU – clerical assistance, entering studies into reference database and production of final report.

We would like to thank:

Professor Mike Silverman, Dr Andrew Wilson, Professor Keith Abrams, Dr Adrian Brooke and Dr Elizabeth Anderson who, as described above, provided invaluable clinical and professional input to the review team; the librarians at the University of Leicester libraries for their practical support; the referees for their helpful comments and the commissioning and editorial teams at the National Coordinating Centre for Health Technology Assessment for their support throughout.

The views expressed in this review, however, are those of the authors alone, who are also responsible for any errors.
References


References


47. Marlow N, Roberts L, Cooke R. Outcome at 8 years for children with birth weights of 1250 g or less. *Archives of Disease in Childhood* 1993;68:286–90.


References


Appendix 1

Other sources consulted

**Searches undertaken December 2000**

AAP (American Academy of Pediatrics)
AÉTMIS (Agence d'Évaluation des Technologies et des Modes d'Intervention en Santé.)
AHFMR (Alberta Heritage Foundation for Medical Research)
AHRQ (Agency for Healthcare Research and Quality)
Alberta Clinical Guidelines Programme
ARIF (Aggressive Research Intelligence Facility)
CCOHTA (Canadian Coordinating Office for Health Technology Assessment)
CCT (Current Controlled Trials)
CenterWatch trials register
Centre for Clinical Effectiveness, Monash University
Centre for Health Economics, York University
CPG Infobase (Canadian Medical Association, Clinical Guidelines Programme)
Department of Child Health, University of Dundee
Department of Child Life and Health, University of Edinburgh
ESRC (Economic and Social Research Council)
European Society for Paediatric Research
Global ChildNet
Harvard CUA (Cost–utility analysis) database
HealthWeb Pediatrics
HERC (Health Economics Research Centre), Oxford University
HERG (Health Economics Research Group), Brunel University
HERU (Health Economics Research Unit), Aberdeen University
HSRU (Health Services Research Unit), Aberdeen University
HSRU (Health Services Research Unit), Oxford University
HSTAT (Health Services/Technology Assessment Text, US National Library of Medicine)
IHE (Institute of Health Economics), Alberta
INAHTA (International Network of Agencies for Health Technology Assessment) Clearing House
Institute of Child Health
Manitoba Guidelines and Statements
MRC (Medical Research Council) Funded Projects Database
National Guideline Clearinghouse
NCCHTA (National Coordinating Centre for Health Technology Assessment)
NHMRC (National Health and Medical Research Council), Australia
NHS Centre for Reviews and Dissemination, University of York
NHS R&D programmes
NICHD (National Institute of Child Health and Human Development)
NIH (National Institutes of Health) Consensus Development Programme
NIH Clinical Trials database (ClinicalTrials.gov)
North of England Guidelines, University of Newcastle
Pediatric Points of Interest
Royal College of Paediatrics and Child Health
SBU (Swedish Council for Health Technology Assessment)
SHPIC (Scottish Health Purchasing Intelligence Consortium)
SIGN (Scottish Intercollegiate Guidelines Network)
Therapeutics Initiative (Vancouver)
TRIP database
UNICEF (United Nations Children’s Fund)
Wales, Health Evidence Bulletins
Wessex DEC reports
West Midlands DES reports
Appendix 2

Electronic search strategies

**BNI 1994 to 2000, SilverPlatter**

*WebSpirs 4.0 version, search undertaken December 2000*

1. domiciliary
2. home based
3. homebased
4. social support and home
5. home care
6. homecare
7. home and package*
8. outreach and home
9. alternative setting and home
10. technolog* depend*
11. home text*
12. home visit*
13. homevisit*
14. home manage*
15. home therap*
16. home treatment
17. model* home*
18. model* and home*
19. home program*
20. home monitor*
21. home and team*
22. home and (aftercare or after care)
23. home and (self care or selfcare)
24. home and continuity
25. #1 or #2 or #3 or #4 or #5 or #6 or #7 or #8 or #9 or #10 or #11 or #12 or #13 or #14 or #15 or #16 or #17 or #18 or #19 or #20 or #21 or #22 or #23 or #24
26. child* or adolescen* or teenage* or pediat* or paediat*
27. #25 and #26

**CINAHL 1982 to 2000, Ovid Biomed version, search undertaken September 2000**

1. exp Home health care/
2. “Home care equipment and supplies”/
3. exp Saba's home health care classification/
4. 1 or 2 or 3
5. exp Multidisciplinary care team/
6. After care/
7. exp Self care/
8. Continuity of patient care/
9. Program evaluation/
10. exp “Process assessment (health care)”/
11. Nursing models, theoretical/
12. or/5-11
13. home.tw.
14. 12 and 13
15. domiciliary.tw.
16. home based$.tw.
17. homebased.tw.
18. (social support and home$).tw.
19. home care.tw.
20. homecare.tw.
22. (outreach and home).tw.
23. (alternative setting$ and home).tw.
24. technolog$ depend$.tw.
25. home test$.tw.
26. home* visit$.tw.
27. homevisit$.tw.
28. home manag$.tw.
29. home therap$.tw.
30. home treatment$.tw.
31. model$ home$.tw.
32. home program$.tw.
33. home monitor$.tw.
34. or/15-33
35. 4 or 14 or 34
36. exp Child/
37. exp Adolescence/
38. “Minors (legal)”/
39. exp Child welfare/
40. exp Child health services/
41. Adolescent health services/
42. Child care providers/
43. Child health/
44. Adolescent health/
45. exp Pediatric care/
46. exp Pediatric nursing/
47. Pediatric occupational therapy/
48. Pediatric physical therapy/
49. Rehabilitation, pediatric/
50. exp Pediatrics/
51. or/36-50
52. exp Adult/
53. 51 not 52
54. 35 and 53

**Cochrane Library 2000, Issue 3, Update**

*Software, CD-ROM version, search undertaken September 2000 (including CDSR, CCTR and NHS CRD DARE, NHS EED and HTA database)*

1. HOME-CARE-SERVICES*:ME
2. AFTERCARE*:ME
3. GROUP-HOMES*:ME
4. NURSING-PRIVATE-DUTY*:ME
Appendix 2

#5 OUTCOME-AND-PROCESS-ASSESSMENT-(HEALTH-CARE):*ME
#6 ((PROCESS-ASSESSMENT- and HEALTH-CARE) and *:*ME)
#7 CONTINUITY-OF-PATIENT-CARE*:ME
#8 COMPREHENSIVE-HEALTH-CARE:ME
#9 PATIENT-CARE-TEAM*:ME
#10 INTERVENTION-STUDIES*:ME
#11 PATIENT-CARE-PLANNING*:ME
#12 SELF-CARE*:ME
#13 MODELS-NURSING*:ME
#14 PROGRAM-EVALUATION*:ME
#15 ((((((((#4 or #5) or #6) or #7) or #8) or #9) or #10) or #11) or #12) or #13) or #14) #16 HOME
#17 (#15 and #16) #18 DOMICILIARY
#19 (HOME and BASED) #20 HOMEBASED
#21 ((SOCIAL next SUPPORT) and HOME*) #22 HOMECARE
#23 (HOME and PACKAGE*) #24 (OUTREACH and HOME) #25 ((ALTERNATIVE next SETTING*) and HOME)
#26 (TECHNOLOG* next DEPEND*) #27 (HOME next TEST*) #28 (HOME next VISIT*) #29 (HOME next MANAG*) #30 HOMECARE
#31 (HOME next CARE) #32 (HOME next THERAP*) #33 (MODEL* next HOME*) #34 (HOME next PROGRAM*) #35 (HOME next MONITOR*) #36 (((((((((#18 or #19) or #20) or #21) or #22) or #23) or #24) or #25) or #26) or #27) or #28) or #29) or #30) or #31) or #32) or #33) or #34) or #35) #37 (((#1 or #2) or #3) or #17) or #36) #38 CHILD*:ME
#39 CHILD-HEALTH-SERVICES*:ME #39 PEDIATRICS:ME #40 AIDS-TO-FAMILIES-WITH-DEPENDENT-CHILDREN*:ME #41 CHILD-WELFARE:ME #42 CHILD-ADVOCACY:ME #43 CHILD-CARE*:ME #44 PEDIATRIC-NURSING:ME #45 (((((#38 or #39) or #40) or #41) or #42) or #43) or #44) or #45) #46 TEENAGE*
#47 SCHOOLSCHOOLCHILD*
#48 PUPIL*
#49 (SCHOOL next AGE*) #50 PRESCHOOL
#51 (PRE next SCHOOL)

#52 (((((#47 or #48) or #49) or #50) or #51) or #52) #53 (#46 or #53) #54 (#37 and #54)

CRIB 1996 to 2000, COS (Community of Science), CD-ROM version, search undertaken December 2000
home* and child*
home* and paediat*
home* and pediat*
domiciliary and child*
domiciliary and paediat*
domiciliary and pediat*
domicil* and adolescen*
outreach and child*
outreach and paediat*
outreach and pediatric*
outreach and adolescen*

CRIB, date and database producer details not available, search undertaken December 2000
home* and child*
home* and paediat*
home* and pediat*
domiciliary and child*
domiciliary and paediat*
domiciliary and pediat*
domicil* and adolescen*
outreach and child*
outreach and paediat*
outreach and pediatric*
outreach and adolescen*

DoH POINT 1996 to 2000, search undertaken December 2000
home* and child*
home* and paediat*
home* and pediat*
domiciliary and child*
domiciliary and paediat*
domiciliary and pediat*
domicil* and adolescen*
outreach and child*
outreach and paediat*
outreach and pediatric*
outreach and adolescen*

EMBASE 1980 to 2000, SilverPlatter WebSpirs 4.0 version, search undertaken March 2000 (Initial specific search)
#1 explode ‘adolescent’ / all subheadings
#2 explode ‘child’ / all subheadings
#3 explode ‘newborn’ / all subheadings
EMBASE 1980 to 2000, SilverPlatter WebSpirs 4.0 version, search undertaken July 2000 (follow-up sensitive search)

#1 home based
#2 homebased
#3 home management
#4 home care
#5 homecare
#6 home treatment
#7 family based
#8 home visit*
#9 homevisit*
#10 home nursing
#11 home setting
#12 home patient*
#13 at home
#14 home intravenous
#15 home therapy
#16 family oriented
#17 home program*
#18 #1 or #2 or #3 or #4 or #5 or #6 or #7 or #8 or #9 or #10 or #11 or #12 or #13 or #14 or #15 or #16 or #17
#19 explode ‘home-care’ / all subheadings
#20 pediatric*
#21 paediatric*
#22 children
#23 child
#24 childhood
#25 #20 or #21 or #22 or #23 or #24
#26 explode ‘newborn-’ / all subheadings
#27 explode ‘child-’ / all subheadings
#28 explode ‘adolescent-’ / all subheadings
#29 #26 or #27 or #28
#30 #25 or #29
#31 #18 and #30
#32 #31 not #19
#33 #18 or #19
#34 #25 and #33
#35 #34 not #29
#36 #32 or #35
#37 ‘adult-’ / all subheadings
#38 ‘aged-’ / all subheadings
#39 #37 or #38
#40 #36 not #39

HealthSTAR 1990 to 2000, SilverPlatter WinSpirs 3.0 version, search undertaken December 2000

#1 explode “Home-Care-Services” / all subheadings
#2 “Aftercare” / all subheadings
#3 “Group-Homes” / all subheadings

#4 “Nursing-Private-Duty” / all subheadings
#5 explode “Program-Evaluation” / all subheadings
#6 “Outcome-and-Process-Assessment-(Health-Care)” / all subheadings
#7 “Process-Assessment-(Health-Care)” / all subheadings
#8 “Continuity-of-Patient-Care” / all subheadings
#9 “Comprehensive-Health-Care” / all subheadings
#10 “Continuity-of-Patient-Care” / all subheadings
#11 explode “Patient-Care-Team” / all subheadings
#12 “Intervention-Studies”
#13 explode “Patient-Care-Planning” / all subheadings
#14 explode “Self-Care” / all subheadings
#15 “Models-Nursing”
#16 #4 or #5 or #6 or #7 or #8 or #9 or #10 or #11 or #12 or #13 or #14 or #15
#17 home
#18 #16 and #17
#19 domiciliary in ti, ab
#20 home based in ti, ab
#21 homebased in ti, ab
#22 (social support and home*) in ti,ab
#23 homecare in ti, ab
#24 (home and package*) in ti, ab
#25 (outreach and home) in ti, ab
#26 (alternative setting* and home*) in ti, ab
#27 technolog* depend* in ti, ab
#28 home test* in ti, ab
#29 home visit* in ti, ab
#30 home manag* in ti, ab
#31 homecare in ti, ab
#32 home care in ti, ab
#33 home therap* in ti, ab
#34 model* home* in ti, ab
#35 home program* in ti, ab
#36 home monitor* in ti, ab
#37 #19 or #20 or #21 or #22 or #23 or #24 or #25 or #26 or #27 or #28 or #29 or #30 or #31 or #32 or #33 or #34 or #35 or #36
#38 #1 or #2 or #3 or #18 or #37
#39 explode “Child” / all subheadings
#40 explode “Child-Health-Services” / all subheadings
#41 “Pediatrics” / all subheadings
#42 “Aid-to-Families-with-Dependent-Children” / all subheadings
#43 “Child-Welfare” / all subheadings
#44 “Child-Advocacy” / all subheadings
#45 explode “Child-Care” / all subheadings
#46 “Pediatric-Nursing” / all subheadings
#47 #39 or #40 or #41 or #42 or #43 or #44 or #45 or #46
#48 teenage* in ti, ab
#49 schoolchild* in ti, ab
Appendix 2

#50 pupil* in ti,ab
#51 school age* in ti,ab
#52 preschool* in ti,ab
#53 pre school* in ti,ab
#54 #48 or #49 or #50 or #51 or #52 or #53
#55 #38 and #54
#56 #55 and (SB = "MED")
#57 #55 not #56

**HMIC 1975 to 2000, SilverPlatter WinSpirs 3.0 version, search undertaken December 2000**
#1 domiciliary
#2 home base
#3 homebased
#4 social support and home
#5 home care
#6 homecare
#7 home and package*
#8 outreach and home*
#9 alternative setting and home
#10 technolog* depend*
#11 home test*
#12 home visit*
#13 homevisit*
#14 home manage*
#15 home therap*
#16 home treatment
#17 model* and home*
#18 home program*
#19 home monitor*
#20 home and team*
#21 home and (aftercare or after care)
#22 home and (self care or selfcare)
#23 home and continuity
#24 #1 or #2 or #3 or #4 or #5 or #6 or #7 or #8 or #9 or #10 or #11 or #12 or #13 or #14 or #15 or #16 or #17 or #18 or #19 or #20 or #21 or #22 or #23
#25 child* or adolescen* or teenage* or pediat* or paediat*
#26 #24 and #25
#27 inspection in ti
#28 #26 not #27
#29 #28 and (PY >= "1975")

Index to Theses 1975 to 2000, Internet version, search undertaken December 2000
home* and child*
home* and paediat*
home* and pediat*
home* and adolescen*
domiciliary and child*
domiciliary and paediat*
domiciliary and pediat*
domicil* and adolescen*
outreach and child*
outreach and paediat*
outreach and pediatric*
outreach and adolescen*

**ISTP 1990 to 2000, WOS version, search undertaken September 2000**
(homecare or home care or aftercare or group home* or domiciliary or homebased or home based or technolog* depend* or home test* or homevisit* or home visit* or homemanage* or home manage* or home therap* or model* home* or home program* or home monitor* or home intravenous* or home patient* or home setting* or home nursing or homenursing or home treatment) and (adolescen* or child* or pediat* or paediat* or teenage* or schoolchild* or pupil* or school age* or schoolage* or preschool* or preschool age* or newborn*)

1 exp Home care services/
2 exp child/
3 1 and 2
4 limit 3 to randomized controlled trial
5 limit 3 to clinical trial
6 Case-control studies/
7 3 and 6
8 Cohort studies/
9 3 and 8
10 exp Adult/
11 2 not 10
12 1 and 11
13 limit 12 to yr=1991
14 limit 12 to yr=1995
15 limit 12 to yr=1999
16 or/13-15

**MEDLINE 1975 to 2000, Ovid Biomed version, search undertaken March 2000 (full search)**
1 exp Home care services/
2 Aftercare/
3 Group homes/
4 Nursing, private duty/
5 exp Program evaluation/
6 “Outcome and process assessment (health care)”/
7 “Process assessment (health care)”/
8 Continuity of patient care/
9 Comprehensive health care/
10 Continuity of patient care/
11 exp Patient care team/
12 Intervention studies/
13 exp Patient care planning/
14 exp Self care/
15 Models, nursing/
16 or/4-15
1 exp Diabetes mellitus/
2 exp child/
3 exp adult/
4 2 not 3
5 1 and 4
6 exp Home care services/
7 Aftercare/
8 Group homes/
9 Nursing, private duty/
10 exp Program evaluation/
11 "Outcome and process assessment (health care)/"
12 "Process assessment (health care)/"
13 Continuity of patient care/
14 Comprehensive health care/
15 Continuity of patient care/
16 exp Patient care team/
17 Intervention studies/
18 exp Patient care planning/
19 exp Self care/
20 Models, nursing/
21 or/9-20
22 home.tw.
23 21 and 22
24 domiciliary.tw.
25 home based.tw.
26 homebased.tw.
27 technolog$ depend$.tw.
28 home test$.tw.
29 home visit$.tw.
30 home manag$.tw.
31 homecare.tw.
32 home care.tw.
33 home therap$.tw.
34 model$ home$.tw.
35 home program$.tw.
36 home monitor$.tw.
37 or/19-36
38 1 or 2 or 3 or 18 or 37
39 exp Child/
40 exp Child health services/
41 Pediatrics/
42 Aid to families with dependent children/
43 Child welfare/
44 Child advocacy/
45 exp Child care/
46 Pediatric nursing/
47 or/39-46
48 teenage$.tw.
49 schoolchild$.tw.
50 pupil$.tw.
51 school age$.tw.
52 preschool.tw.
53 pre school.tw.
54 or/48-53
55 47 or 54
56 38 and 55
57 limit 56 to yr=1975-2000
58 exp Adult/
59 57 not 58
60 review.pt.
61 57 and 58 and 60
62 59 or 61

MEDLINE 1998 only, Ovid Biomed version, search undertaken September 2000 (condition-specific search – asthma)
1 exp Asthma/
2 exp child/
3 exp adult/
4 2 not 3
5 1 and 4
6 exp Home care services/
7 Aftercare/
Appendix 2

14 Comprehensive health care/
15 Continuity of patient care/
16 exp Patient care team/
17 Intervention studies/
18 exp Patient care planning/
19 exp Self care/
20 Models, nursing/
21 or/9-20
22 home.tw.
23 21 and 22
24 domiciliary.tw.
25 home based.tw.
26 homebased.tw.
27 (social support and home$).tw.
28 homecare.ti.
29 (home and package$).tw.
30 (outreach and home).tw.
31 (alternative setting$ and home).tw.
32 technolog$ depend$.tw.
33 home test$.tw.
34 home visit$.tw.
35 home manag$.tw.
36 homecare.tw.
37 home care.tw.
38 home therap$.tw.
39 model$ home$.tw.
40 home program$.tw.
41 home monitor$.tw.
42 or/24-41
43 6 or 7 or 8 or 23 or 42
44 5 not 43
45 limit 44 to yr=1998

MEDLINE 1998 only, Ovid Biomed version, search undertaken September 2000 (condition-specific search – epilepsy)
1 exp Epilepsy/
2 exp child/
3 exp adult/
4 2 not 3
5 1 and 4
6 exp Home care services/
7 Aftercare/
8 Group homes/
9 Nursing, private duty/
10 exp Program evaluation/
11 “Outcome and process assessment (health care)”/
12 “Process assessment (health care)”/
13 Continuity of patient care/
14 Comprehensive health care/
15 Continuity of patient care/
16 exp Patient care team/
17 Intervention studies/
18 exp Patient care planning/
19 exp Self care/
20 Models, nursing/
21 or/9-20
22 home.tw.
23 21 and 22
24 domiciliary.tw.
25 home based.tw.
26 homebased.tw.
27 (social support and home$).tw.

1 Cystic fibrosis/
2 exp child/
3 exp adult/
4 2 not 3
5 1 and 4
6 exp Home care services/
7 Aftercare/
8 Group homes/
9 Nursing, private duty/
10 exp Program evaluation/
11 “Outcome and process assessment (health care)”/
12 “Process assessment (health care)”/
13 Continuity of patient care/
14 Comprehensive health care/
15 Continuity of patient care/
16 exp Patient care team/
17 Intervention studies/
18 exp Patient care planning/
19 exp Self care/
20 Models, nursing/
21 or/9-20
22 home.tw.
23 21 and 22
24 domiciliary.tw.
25 home based.tw.
26 homebased.tw.
27 (social support and home$).tw.
1 exp Hiv/
2 exp Hiv infections/
3 1 or 2
4 exp child/
5 exp adult/
6 4 not 5
7 5 and 6
8 exp Home care services/
9 Aftercare/
10 Group homes/
11 Nursing, private duty/
12 exp Program evaluation/
13 “Outcome and process assessment (health care)”/
14 “Process assessment (health care)”/
15 Continuity of patient care/
16 Comprehensive health care/
17 Continuity of patient care/
18 exp Patient care team/
19 Intervention studies/
20 exp Patient care planning/
21 exp Self care/
22 Models, nursing/
23 or/11-22
24 home.tw.
25 23 and 24
26 domiciliary.tw.
27 home based.tw.
28 homebased.tw.
29 (social support and home$).tw.
30 homecare.ti.
31 (home and package$).tw.
32 (outreach and home).tw.
33 (alternative setting$ and home).tw.
34 technolog$ depend$.tw.
35 home test$.tw.
36 home visit$.tw.
37 home manag$.tw.
38 homecare.tw.
39 home care.tw.
40 home therap$.tw.
41 model$ home$.tw.
42 home program$.tw.
43 home monitor$.tw.
44 or/26-43
45 8 or 9 or 10 or 25 or 44
46 7 not 45
47 limit 46 to yr=1998

#1 HOME-CARE-SERVICES*:ME
#2 AFTERCARE*:ME
#3 GROUP-HOMES*:ME
#4 NURSING-PRIVATE-DUTY*:ME
#5 OUTCOME-AND-PROCESS-ASSESSMENT-(HEALTH-CARE):ME
#6 ((PROCESS-ASSESSMENT: and HEALTH-CARE) and *:ME)
#7 CONTINUITY-OF-PATIENT-CARE*:ME
#8 COMPREHENSIVE-HEALTH-CARE:ME
#9 PATIENT-CARE-TEAM*:ME
#10 INTERVENTION-STUDIES*:ME
#11 PATIENT-CARE-PLANNING*:ME
#12 SELF-CARE*:ME
#13 MODELS-NURSING*:ME
#14 PROGRAM-EVALUATION*:ME
#15 (((((((((#4 or #5) or #6) or #7) or #8)
or #9) or #10) or #11) or #12) or #13)
or #14)
#16 HOME
#17 (#15 and #16)
#18 DOMICILIARY
#19 (HOME and BASED)
#20 HOMEBASED
#21 ((SOCIAL next SUPPORT) and HOME*)
#22 HOMECARE
#23 (HOME and PACKAGE*)
#24 (OUTREACH and HOME)
#25 ((ALTERNATIVE next SETTING*) and HOME)
#26 (TECHNOLOG* next DEPEND*)
#27 (HOME next TEST*)
#28 (HOME next VISIT*)
#29 (HOME next MANAG*)
#30 HOMECARE
#31 (HOME next CARE)
#32 (HOME next THERAP*)
#33 (MODEL* next HOME*)
#34 (HOME next PROGRAM*)
#35 (HOME next MONITOR*)
Appendix 2

PsycINFO 1967 to 2000 (date limit facility caused database to crash so not applied), SilverPlatter WebSpirs 4.0 version, search undertaken December 2000

1. ‘Home-Care’ in DE
2. ‘Home-Care-Personnel’ in DE
3. ‘Home-Visiting-Programs’ in DE
4. explode ‘Children-’ in DE
5. explode ‘Adults-’ in DE
6. #4 not #5
7. #1 or #2 or #3
8. #6 and #7

SCI and SSCI 1981 to 2000, WOS version, search undertaken September 2000

(homecare or home care or aftercare or group home* or domiciliary or homebased or home based or technolog* depend* or home test* or homevisit* or home visit* or homemanage* or home manage* or home therap* or model* home* or home program* or home monitor* or home intravenous* or home patient* or home setting* or home nursing or homenursing or home treatment) and (adolescen* or child* or pediat* or paediat* or teenage* or schoolchild* or pupil* or school age* or schoolage* or preschool* or pre school* or newborn*)
### Appendix 3

Details of all papers included

<table>
<thead>
<tr>
<th>TABLE 62 RCTs included in chapter 3</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Authors</th>
<th>Title</th>
<th>Journal details</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Home care for very low birth weight/medically fragile babies</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Shapiro C</td>
<td>Shortened hospital stay for low birth weight infants: nuts and bolts of a nursing intervention project</td>
<td><em>Journal of Obstetric, Gynecologic and Neonatal Nursing</em> 1995;24:36–42</td>
</tr>
<tr>
<td><strong>Home care for children with insulin-dependent diabetes or asthma</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mitchell EA, Ferguson V, Norwood M</td>
<td>Asthma education by community child health nurses</td>
<td><em>Archives of Disease in Childhood</em> 1998;61:1184–9</td>
</tr>
<tr>
<td>Hughes D, McLeod M, Garner B, Goldbohm R</td>
<td>Controlled trial of a home and ambulatory program for asthmatic children</td>
<td><em>Pediatrics</em> 1991;87:54–61</td>
</tr>
<tr>
<td><strong>Home care for children with mental health problems</strong></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
### TABLE 62 contd  RCTs included in chapter 3

<table>
<thead>
<tr>
<th>Authors</th>
<th>Title</th>
<th>Journal details</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Paediatric home care</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Stein REK, Jessop DJ</td>
<td>Does pediatric home care make a difference for children with chronic illness? Findings from the Pediatric Ambulatory Care Treatment Study</td>
<td>Pediatrics 1984;73:845–53</td>
</tr>
<tr>
<td>Stein R</td>
<td>A home care program for children with chronic illness</td>
<td>Child Health Care 1983;12:90–2</td>
</tr>
<tr>
<td>Jessop DJ, Stein REK</td>
<td>Providing comprehensive health care to children with chronic illness</td>
<td>Pediatrics 1994;93:602–7</td>
</tr>
</tbody>
</table>
### TABLE 63 Details of economics papers included in chapter 4

<table>
<thead>
<tr>
<th>Authors</th>
<th>Title</th>
<th>Journal details</th>
</tr>
</thead>
<tbody>
<tr>
<td>Holdsworth MT, Raisch DW, Chavez CM, Duncan MH, Parasuraman TV, Cox FM</td>
<td>Economic impact with home delivery of chemotherapy to pediatric oncology patients</td>
<td>Annals of Pharmacotherapy 1997;31:140–8</td>
</tr>
<tr>
<td>McAleese KA, Knapp MA, Rhodes TT</td>
<td>Financial and emotional cost of bronchopulmonary dysplasia</td>
<td>Clinical Pediatrics 1993;32:393–400</td>
</tr>
</tbody>
</table>
## TABLE 64 Details of papers from non-RCT comparative research included in chapter 5

<table>
<thead>
<tr>
<th>Paper number</th>
<th>First author and date</th>
<th>Country</th>
<th>Methods/intervention</th>
<th>Summary of findings</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Home care for very low birth weight or medically fragile babies</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>76</td>
<td>Kotagal (1995)</td>
<td>USA</td>
<td>A new early discharge programme, involving the appointment of a part-time nurse as coordinator, and recruiting community staff to provide more intensive support for families once at home, is described. Costs and clinical outcomes for a cohort of 257 study infants, discharged from NICU after the onset of the scheme, were compared with 477 controls discharged during a prior 1-year period</td>
<td>Earlier discharge of infants led to decreases in hospital charges 30 times greater than the cost of the early discharge scheme, without causing excessive morbidity. It also enabled earlier discharge of the infants from physician care. Comprehensive acute sector costings were generated, as were those for community facilities used by those in the study group, including administrative costs of overseeing the programme</td>
</tr>
<tr>
<td>85</td>
<td>Rieger (1995)</td>
<td>Australia</td>
<td>A description of a neonatal early discharge programme, where NICU patients were transferred home earlier with social and nursing support, from a team including three ‘family support nurses’, a paediatrician, a paediatric physiotherapist and a clinical psychologist, the latter three acting in a consultative role. A retrospective case control design was used comparing a study group (n = 58) of those treated after the onset of the scheme, with a control group (n = 62) from prior to the scheme. Effects on the mother were assessed using various scales. Cost data were gathered on rooming-in time, the number of visits to the family doctor in the first 7 months and the number of visits to the emergency room</td>
<td>The scheme achieved an average reduction in hospital stay of 2.1 days per baby. There were statistically significant reductions in maternal rooming-in days. In addition, there were significant reductions in the number of visits to the family doctor postdischarge amongst those in the study group. The authors conclude that maternal anxiety did not rise and the patients were ‘less difficult’</td>
</tr>
<tr>
<td>86</td>
<td>Örtenstrand (1999)</td>
<td>Sweden</td>
<td>An evaluation of the effect of early discharge on infant health and utilisation of health services. Eighty-eight physiologically stable infants were quasi-randomly allocated to home treatment with nursing support (n = 45) or to conventional neonatal care (n = 43). Outcome measures were infant health during the study period compared with the same period for the control group, use of neonatal services (length of hospital stay, domiciliary visits, telephone contacts, outpatient visits, rehospitalisations) and the need for health services up to the end of the first year of life (when 41 in each group were followed up). Home care infants received scheduled and unscheduled visits from an experienced nurse during ‘office hours’ with mobile phone access at other times</td>
<td>There were no significant differences in outcomes in terms of infant health, apart from fewer respiratory infections in the home-treated group. Similarly, there was no increase in re-admissions for each group after discharge. The authors argue that the study provides evidence that early discharge has no effect on infant morbidity, or on use of health services</td>
</tr>
<tr>
<td><strong>Home care for children with insulin-dependent diabetes</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>36</td>
<td>Swift (1993)</td>
<td>UK</td>
<td>A retrospective case control study, comparing (n = 236, aged 10–14 years) those admitted and not admitted to hospital on diagnosis of insulin-dependent diabetes mellitus between 1979 and 1988 (since the appointment in 1979 of a paediatrician and physician with interest in childhood diabetes leading to initiation of joint clinics)</td>
<td>Those not admitted had lower re-admission rates for diabetes-related issues than those hospitalised at the outset (although the authors acknowledge the potential role of different case mixes in this). For those hospitalised, median length of stay fell from 7 to 3 days over the study period. No difference in glycosylated haemoglobin (HbA1c) was found between the two groups</td>
</tr>
</tbody>
</table>

continued
### Table 64 contd Details of papers from non-RCT comparative research included in chapter 5

<table>
<thead>
<tr>
<th>Paper number</th>
<th>First author and date</th>
<th>Country</th>
<th>Methods/intervention</th>
<th>Summary of findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>87</td>
<td>Lowes and Davis (1997)</td>
<td>UK</td>
<td>A comparison between 16 children diagnosed with IDDM in a 9-month period following the appointment of a diabetes specialist nurse, and 40 children diagnosed with IDDM in the previous 2 years. The main aim of the new post was to reduce the length of hospitalisation, and this was the main outcome measure.</td>
<td>Significant reductions in hospitalisation length were achieved. The description of the sample is not clear, and the research focuses solely on whether hospitalisation, and length of stay, could be reduced without consideration of clinical outcomes in the longer term, parental and child anxiety about home treatment, and so on.</td>
</tr>
<tr>
<td>88</td>
<td>Lowes (1997)</td>
<td>UK</td>
<td>Analysis of the role of the pediatric diabetes specialist nurse comparing the first 2 years of the post with the previous 2 years. The nurse helped establish treatment at home for newly diagnosed children, and ran age-banded education sessions with all children aged 5–14, who were invited to attend with their parents. Data were collected contemporaneously after appointment of the nurse so this is therefore prospective for the study group, and retrospective for the comparison group.</td>
<td>The length of stay halved for newly diagnosed hospitalised children, and clinic non-attendance reductions were also achieved. However, after the introduction of the specialist nurse, re-admission of existing patients increased.</td>
</tr>
<tr>
<td>89</td>
<td>Couper (1999)</td>
<td>Australia</td>
<td>Sixty-nine children (aged 12–17), with a mean HbA1c greater than 9.0% over the last year, took part. Thirty-seven received routine diabetes care plus home- and phone-based support from a diabetes ‘nurse-educator’, and 32 received routine care only – both for 6 months. Both groups then received 12 months of routine care only. Outcome measures were diabetes knowledge (of child and parents) and HbA1c. Study and control groups were decided geographically.</td>
<td>Significant reductions in HbA1c were achieved in the study group, but not in the control group. However, this improvement was not sustained at 12- and 18-month follow-up. Increases in parental knowledge were sustained.</td>
</tr>
</tbody>
</table>

**‘Technological’ care at home**

| Dialysis     | Brem (1988)          | USA     | Comparison of psychological functioning amongst 12 children (aged 10–19) with end-stage renal failure, of whom 6 were treated in hospital with haemodialysis, and 6 at home with peritoneal dialysis. A range of psychometric scales were administered to all 12 children. | Anxiety, depression and hostility did not vary from the wider population, but personal and social adjustment scores were lower, with no differences between treatment groups. Home-treated patients utilised ‘low level’ coping skills more often than the hospital-treated group. |
| Chemotherapy | Close (1995)         | USA     | Comparison, in terms of billed medical charges, of out-of-pocket expenses and quality of life in 14 children treated with one course of chemotherapy in hospital and an identical course at home (children acting as their own controls). Fourteen children (31 months–16 years) took part. Members of the home group were visited on a daily basis by a nurse who carried out physical assessments, as well as administering the infusion although parents did administer antibiotics. Quality of life was measured by a parent-scored Likert scale, using seven child-items and four parent-items developed for this study. | The home-treated group had better outcomes in terms of quality of life. Billed medical charges were significantly lower for the home-treated group, as were loss of parental wages. Significant improvements were also reported in quality of life across five of the seven items for children, and all four items on the parent scale. |
### TABLE 64 contd Details of papers from non-RCT comparative research included in chapter 5

<table>
<thead>
<tr>
<th>Paper number</th>
<th>First author and date</th>
<th>Country</th>
<th>Methods/intervention</th>
<th>Summary of findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>15</td>
<td>Osundwa (1994)</td>
<td>Qatar</td>
<td>A retrospective chart review of 50 asthmatic children (range 2–12 years, mean 3.95 years) having spent 6 months on home nebuliser therapy, matched with themselves in a prior 6-month period. Emergency room visits and hospitalisations were the outcome measures</td>
<td>The study found that home nebuliser therapy led to a 74% reduction in emergency room visits and a 70% reduction in hospital admissions</td>
</tr>
<tr>
<td>91</td>
<td>Rizzari (1992)</td>
<td>Italy</td>
<td>A retrospective comparison of hospital and home management of catheter infections in 125 children with CVCs and haematology malignancies. One hundred and thirty-five CVCs, in 125 children (aged 3 months to 17 years) were analysed for infection rates over a 61-month period. Cleaning was performed by nurses in hospital using various solutions, and at home by parents every day for the first 3 years of observation and every other day thereafter</td>
<td>The study found some evidence of higher rates of CVC infection during periods of home treatment, compared with periods of hospital treatment, but only in the presence of neutropenia and not at a level that reached statistical significance. The authors recommend better training for parents in CVC management, leading to reductions in infection</td>
</tr>
<tr>
<td>17</td>
<td>Melville (1997)</td>
<td>UK</td>
<td>A study of hospital and home CVC survival in one group of 20 children (aged 0–15) with chronic intestinal failure. A total of 28 patient years in hospital and 48 patient years at home were studied. Sepsis rates, and safety differences between the two locations were analysed, as well as cost differences</td>
<td>Sepsis rates were significantly lower at home, and line survival rates significantly better at home. The authors acknowledge that for differences in sepsis and survival rates between home and hospital to be attributed to location of care, a full randomised trial should be conducted. They speculate that the key factor underpinning the differences between home and hospital infection rates was the handling of catheters in the hospital by nurses, who might require further training in cross-contamination</td>
</tr>
<tr>
<td>92</td>
<td>Anderton (1993)</td>
<td>UK</td>
<td>A prospective comparison of feeds prepared at home with feeds prepared in hospital during a 3-month study period. Six children with cystic fibrosis took part in the study. Bacteria in 22 home-prepared feeds and 73 hospital-prepared feeds were analysed at preparation, prior to feeding and after feeding</td>
<td>Higher rates of bacterial infection were found in home feeds (70% of hospital feeds, and 18% of home feeds were free from contamination)</td>
</tr>
<tr>
<td>93</td>
<td>Hufford (1999)</td>
<td>USA</td>
<td>Three adolescents with epilepsy and their mothers were recruited to the study and received office-based counselling (A), home-based speakerphone counselling (B) and home-based videoconferencing (C), in an ABCBC pattern. The interactions were measured using both specially generated and existing scales assessing parental and adolescent comfort and distraction</td>
<td>There is some evidence that the counselling in general was effective, with parents and adolescents reporting improvements in outcomes (e.g. reductions in frequency of family problems) sustained over a 6-month follow-up period. Parental and adolescent views of the therapeutic relationship were positive, with both technological modalities (B and C) leading to higher scores than office-based counselling (A), although the authors attribute this partly to lower ratings in the first of the six session, which were office-based</td>
</tr>
</tbody>
</table>
### Prioritisation Strategy Group

**Members**

<table>
<thead>
<tr>
<th>Chair, Professor Kent Woods, Director, NHS HTA Programme, &amp; Professor of Therapeutics, University of Leicester</th>
</tr>
</thead>
<tbody>
<tr>
<td>Professor Shah Ebrahim, Professor in Epidemiology of Ageing, University of Bristol</td>
</tr>
<tr>
<td>Dr Ron Zimmern, Director, Public Health Genetics Unit, Strangeways Research Laboratories, Cambridge</td>
</tr>
<tr>
<td>Professor Bruce Campbell, Consultant Vascular &amp; General Surgeon, Royal Devon &amp; Exeter Hospital</td>
</tr>
<tr>
<td>Dr John Reynolds, Clinical Director, Acute General Medicine SDU, Oxford Radcliffe Hospital</td>
</tr>
</tbody>
</table>

### HTA Commissioning Board

**Members**

<table>
<thead>
<tr>
<th>Programme Director, Professor Kent Woods, Director, NHS HTA Programme, &amp; Professor of Therapeutics, University of Leicester</th>
</tr>
</thead>
<tbody>
<tr>
<td>Professor John Brazier, Director of Health Economics, University of Sheffield</td>
</tr>
<tr>
<td>Dr Alastair Gray, Director, Health Economics Research Centre, Institute of Health Sciences, University of Oxford</td>
</tr>
<tr>
<td>Professor Mark Haggard, Director, MRC Institute of Hearing Research, University of Nottingham</td>
</tr>
<tr>
<td>Professor Jenny Hewison, Academic Unit of Psychiatry &amp; Behavioural Sciences, University of Leeds</td>
</tr>
<tr>
<td>Professor Peter Jones, University Department of Psychiatry, University of Cambridge</td>
</tr>
<tr>
<td>Professor Alison Kitson, Director, Royal College of Nursing Institute, London</td>
</tr>
<tr>
<td>Professor Sarah Lamb, Research Professor in Physiotherapy, University of Coventry</td>
</tr>
<tr>
<td>Dr Donna Lamping, Head, Health Services Research Unit, London School of Hygiene &amp; Tropical Medicine</td>
</tr>
<tr>
<td>Professor David Neal, Department of Surgery, University of Newcastle-upon-Tyne</td>
</tr>
<tr>
<td>Professor Tim Peters, Social Medicine, University of Bristol</td>
</tr>
<tr>
<td>Professor Martin Severs, Professor in Elderly Health Care, University of Portsmouth</td>
</tr>
<tr>
<td>Dr Jonathan Shapiro, Senior Fellow, Health Services Management Centre, Birmingham</td>
</tr>
<tr>
<td>Dr Sarah Stewart-Brown, Director, Health Services Research Unit, University of Oxford</td>
</tr>
<tr>
<td>Dr Gillian Vivian, Consultant in Nuclear Medicine &amp; Radiology, Royal Cornwall Hospitals Trust, Truro</td>
</tr>
</tbody>
</table>

Current and past membership details of all HTA 'committees' are available from the HTA website (see inside front cover for details)
Diagnostic Technologies & Screening Panel

Members

Chair, Dr Ron Zimmern, Director, Public Health Genetics Unit, Strangeways Research Laboratories, Cambridge

Mrs Stella Burnside, Chief Executive, Altnagelvin Hospitals Health & Social Services Trust, Londonderry

Dr Paul O Collinson, Consultant Chemical Pathologist & Senior Lecturer, St George’s Hospital, London

Dr Barry Cookson, Director, Laboratory of Hospital Infection, Public Health Laboratory Service, London

Professor Howard Cuckle, Professor of Reproductive Epidemiology, University of Leeds

Dr David Elliman, Consultant in Community Child Health, St. George’s Hospital, London

Dr Tom Fahey, Senior Lecturer in General Practice, University of Bristol

Dr Antony J Franks, Deputy Medical Director, The Leeds Teaching Hospitals NHS Trust

Professor Adrian K Dixon, Professor of Radiology, Addenbrooke’s Hospital, Cambridge

Dr J A Muir Gray, Programmes Director, National Screening Committee, NHS Executive, Oxford

Dr Howard Cuckle, Professor of Reproductive Epidemiology, University of Leeds

Dr Tom Fahey, Senior Lecturer in General Practice, University of Bristol

Dr Peter Howlett, Executive Director – Planning, Portsmouth Hospitals NHS Trust

Dr Paul O Collinson, Consultant Chemical Pathologist & Senior Lecturer, St George’s Hospital, London

Dr Tom Fahey, Senior Lecturer in General Practice, University of Bristol

Professor Jennie Popay, Professor of Sociology & Public Health, Institute for Health Research, University of Lancaster

Dr Barry Cookson, Director, Laboratory of Hospital Infection, Public Health Laboratory Service, London

Dr David Elliman, Consultant in Community Child Health, St. George’s Hospital, London

Dr Tom Fahey, Senior Lecturer in General Practice, University of Bristol

Professor Jennie Popay, Professor of Sociology & Public Health, Institute for Health Research, University of Lancaster

Pharmaceuticals Panel

Members

Chair, Dr John Reynolds, Clinical Director, Acute General Medicine SDU, Oxford Radcliffe Hospital

Professor Tony Avery, Professor of Primary Health Care, University of Nottingham

Professor Iain T Cameron, Professor of Obstetrics & Gynaecology, University of Southampton

Mr Peter Cardy, Chief Executive, Macmillan Cancer Relief, London

Dr Christopher Gates, GP & Cochrane Editor, Bushey Health Centre, Bushey, Hers

Dr Felicity J Gabbay, Managing Director, Transcript Ltd, Milford-on-Sea, Hants

Mr Peter Golightly, Director, Trent Medicines Information Services, Leicester Royal Infirmary

Dr Alastair Gray, Director, Health Economics Research Centre, Institute of Health Sciences, University of Oxford

Dr Dr Anthony J Franks, Deputy Medical Director, The Leeds Teaching Hospitals NHS Trust

Professor Adrian K Dixon, Professor of Radiology, Addenbrooke’s Hospital, Cambridge

Dr J A Muir Gray, Programmes Director, National Screening Committee, NHS Executive, Oxford

Dr Howard Cuckle, Professor of Reproductive Epidemiology, University of Leeds

Dr Tom Fahey, Senior Lecturer in General Practice, University of Bristol

Professor Jennie Popay, Professor of Sociology & Public Health, Institute for Health Research, University of Lancaster

Dr Barry Cookson, Director, Laboratory of Hospital Infection, Public Health Laboratory Service, London

Dr David Elliman, Consultant in Community Child Health, St. George’s Hospital, London

Dr Tom Fahey, Senior Lecturer in General Practice, University of Bristol

Professor Jennie Popay, Professor of Sociology & Public Health, Institute for Health Research, University of Lancaster

Dr Barry Cookson, Director, Laboratory of Hospital Infection, Public Health Laboratory Service, London

Dr David Elliman, Consultant in Community Child Health, St. George’s Hospital, London

Dr Tom Fahey, Senior Lecturer in General Practice, University of Bristol

Professor Jennie Popay, Professor of Sociology & Public Health, Institute for Health Research, University of Lancaster

Pharmaceuticals Panel

Members

Chair, Dr John Reynolds, Clinical Director, Acute General Medicine SDU, Oxford Radcliffe Hospital

Professor Tony Avery, Professor of Primary Health Care, University of Nottingham

Professor Iain T Cameron, Professor of Obstetrics & Gynaecology, University of Southampton

Mr Peter Cardy, Chief Executive, Macmillan Cancer Relief, London

Dr Christopher Gates, GP & Cochrane Editor, Bushey Health Centre, Bushey, Herts

Dr Felicity J Gabbay, Managing Director, Transcript Ltd, Milford-on-Sea, Hants

Mr Peter Golightly, Director, Trent Medicines Information Services, Leicester Royal Infirmary

Dr Alastair Gray, Director, Health Economics Research Centre, Institute of Health Sciences, University of Oxford

Mrs Sharon Hart, Managing Editor, Drug & Therapeutics Bulletin, London

Dr Dr Anthony J Franks, Deputy Medical Director, The Leeds Teaching Hospitals NHS Trust

Professor Adrian K Dixon, Professor of Radiology, Addenbrooke’s Hospital, Cambridge

Dr J A Muir Gray, Programmes Director, National Screening Committee, NHS Executive, Oxford

Dr Howard Cuckle, Professor of Reproductive Epidemiology, University of Leeds

Dr Tom Fahey, Senior Lecturer in General Practice, University of Bristol

Professor Jennie Popay, Professor of Sociology & Public Health, Institute for Health Research, University of Lancaster

Dr Barry Cookson, Director, Laboratory of Hospital Infection, Public Health Laboratory Service, London

Dr David Elliman, Consultant in Community Child Health, St. George’s Hospital, London

Dr Tom Fahey, Senior Lecturer in General Practice, University of Bristol

Professor Jennie Popay, Professor of Sociology & Public Health, Institute for Health Research, University of Lancaster

Dr Barry Cookson, Director, Laboratory of Hospital Infection, Public Health Laboratory Service, London

Dr David Elliman, Consultant in Community Child Health, St. George’s Hospital, London

Dr Tom Fahey, Senior Lecturer in General Practice, University of Bristol

Professor Jennie Popay, Professor of Sociology & Public Health, Institute for Health Research, University of Lancaster

Dr Barry Cookson, Director, Laboratory of Hospital Infection, Public Health Laboratory Service, London

Dr David Elliman, Consultant in Community Child Health, St. George’s Hospital, London

Dr Tom Fahey, Senior Lecturer in General Practice, University of Bristol

Professor Jennie Popay, Professor of Sociology & Public Health, Institute for Health Research, University of Lancaster

Mr Peter Golightly, Director, Trent Medicines Information Services, Leicester Royal Infirmary

Dr Alastair Gray, Director, Health Economics Research Centre, Institute of Health Sciences, University of Oxford

Dr Dr Anthony J Franks, Deputy Medical Director, The Leeds Teaching Hospitals NHS Trust

Professor Adrian K Dixon, Professor of Radiology, Addenbrooke’s Hospital, Cambridge

Dr J A Muir Gray, Programmes Director, National Screening Committee, NHS Executive, Oxford

Dr Howard Cuckle, Professor of Reproductive Epidemiology, University of Leeds

Dr Tom Fahey, Senior Lecturer in General Practice, University of Bristol

Professor Jennie Popay, Professor of Sociology & Public Health, Institute for Health Research, University of Lancaster

Dr Barry Cookson, Director, Laboratory of Hospital Infection, Public Health Laboratory Service, London

Dr David Elliman, Consultant in Community Child Health, St. George’s Hospital, London

Dr Tom Fahey, Senior Lecturer in General Practice, University of Bristol

Professor Jennie Popay, Professor of Sociology & Public Health, Institute for Health Research, University of Lancaster

Dr Barry Cookson, Director, Laboratory of Hospital Infection, Public Health Laboratory Service, London

Dr David Elliman, Consultant in Community Child Health, St. George’s Hospital, London

Dr Tom Fahey, Senior Lecturer in General Practice, University of Bristol

Professor Jennie Popay, Professor of Sociology & Public Health, Institute for Health Research, University of Lancaster

Dr Barry Cookson, Director, Laboratory of Hospital Infection, Public Health Laboratory Service, London

Dr David Elliman, Consultant in Community Child Health, St. George’s Hospital, London

Dr Tom Fahey, Senior Lecturer in General Practice, University of Bristol

Professor Jennie Popay, Professor of Sociology & Public Health, Institute for Health Research, University of Lancaster

Dr Barry Cookson, Director, Laboratory of Hospital Infection, Public Health Laboratory Service, London

Dr David Elliman, Consultant in Community Child Health, St. George’s Hospital, London

Dr Tom Fahey, Senior Lecturer in General Practice, University of Bristol

Professor Jennie Popay, Professor of Sociology & Public Health, Institute for Health Research, University of Lancaster
Members

Chair, Professor Bruce Campbell, Consultant Vascular & General Surgeon, Royal Devon & Exeter Hospital

Professor John Bond, Professor of Health Services Research, Centre for Health Services Research, University of Newcastle-upon-Tyne

Ms Judith Brodie, Head of Cancer Support Service, Cancer BACUP, London

Ms Tracy Bury, Head of Research & Development, Chartered Society of Physiotherapy, London

Mr Michael Clancy, Consultant in A & E Medicine, Southampton General Hospital

Professor Collette Clifford, Professor of Nursing & Head of Research, School of Health Sciences, University of Birmingham

Dr Carl E Counsell, Senior Lecturer in Neurology, University of Aberdeen

Dr Keith Dodd, Consultant Paediatrician, Derbyshire Children’s Hospital, Derby

Mr Jonothan Earnshaw, Consultant Vascular Surgeon, Gloucestershire Royal Hospital, Gloucester

Professor Gene Feder, Professor of Primary Care R&D, St Bartholomew’s & the London, Queen Mary’s School of Medicine & Dentistry, University of London

Professor Richard Johanson, Consultant & Senior Lecturer, North Staffordshire Infirmary NHS Trust, Stoke-on-Trent (deceased Feb 2002)

Mr John Dunning, Consultant Cardiothoracic Surgeon, Papworth Hospital NHS Trust, Cambridge

Mr Jonothan Earnshaw, Consultant Vascular Surgeon, Gloucestershire Royal Hospital, Gloucester

Professor Gene Feder, Professor of Primary Care R&D, St Bartholomew’s & the London, Queen Mary’s School of Medicine & Dentistry, University of London

Professor Richard Johanson, Consultant & Senior Lecturer, North Staffordshire Infirmary NHS Trust, Stoke-on-Trent (deceased Feb 2002)

Dr Duncan Keeley, General Practitioner, Thame, Oxon

Dr Keith Dodd, Consultant Paediatrician, Derbyshire Children’s Hospital, Derby

Mr George Levy, Chief Executive, Motor Neurone Disease Association, Northampton

Mr John Dunning, Consultant Cardiothoracic Surgeon, Papworth Hospital NHS Trust, Cambridge

Dr Philip Leech, Principal Medical Officer for Primary Care, Department of Health, London

Mr George Levy, Chief Executive, Motor Neurone Disease Association, Northampton

Professor James Lindsay, Professor of Psychiatry for the Elderly, University of Leicester

Mr Jonothan Earnshaw, Consultant Vascular Surgeon, Gloucestershire Royal Hospital, Gloucester

Professor Gene Feder, Professor of Primary Care R&D, St Bartholomew’s & the London, Queen Mary’s School of Medicine & Dentistry, University of London

Mr John Dunning, Consultant Cardiothoracic Surgeon, Papworth Hospital NHS Trust, Cambridge

Dr Philip Leech, Principal Medical Officer for Primary Care, Department of Health, London

Mr John Dunning, Consultant Cardiothoracic Surgeon, Papworth Hospital NHS Trust, Cambridge

Dr Philip Leech, Principal Medical Officer for Primary Care, Department of Health, London

Dr Ken Stein, Senior Lecturer in Public Health, Peninsular Technology Assessment Group, University of Exeter

Dr John C Pounsford, Consultant Physician, Frenchay Healthcare Trust, Bristol

Professor Mark Sculpher, Professor of Health Economics, Institute for Research in the Social Services, University of York

Dr Steven Long, Consultant General Surgeon, St George’s Hospital, London

Professor Richard Johanson, Consultant & Senior Lecturer, North Staffordshire Infirmary NHS Trust, Stoke-on-Trent (deceased Feb 2002)

Dr Mike McGovern, Senior Medical Officer, Heart Team, Department of Health, London

Dr Mike McGovern, Senior Medical Officer, Heart Team, Department of Health, London

Dr Ken Stein, Senior Lecturer in Public Health, Peninsular Technology Assessment Group, University of Exeter

Dr John C Pounsford, Consultant Physician, Frenchay Healthcare Trust, Bristol

Professor Mark Sculpher, Professor of Health Economics, Institute for Research in the Social Services, University of York
Members

Expert Advisory Network

Mr Gordon Aylward,
Chief Executive,
Association of British
Health Care Industries,
London

Mr Shaun Brogan,
Chief Executive,
Ridgeway Primary Care Group,
Aylesbury, Bucks

Mr John A Cairns,
Reader in Health Economics,
Health Economics
Research Unit,
University of Aberdeen

Professor Nicky Callum,
Director of Centre for
Evidence-Based Nursing,
University of York

Dr Katherine Darton,
Information Unit,
MIND – The Mental
Health Charity, London

Professor Carol Dezateux,
Professor of
Paediatric Epidemiology,
Institute of Child Health,
London

Professor Pam Enderby,
Dean of Faculty of Medicine
Institute of General Practice
& Primary Care,
University of Sheffield

Mr Leonard R Fenwick,
Chief Executive,
Freeman Hospital,
Newcastle-upon-Tyne

Professor David Field,
Professor of
Neonatal Medicine,
The Leicester Royal
Infirmary NHS Trust

Mrs Gillian Fletcher,
Antenatal Teacher &
Tutor & President,
National Childbirth
Trust, Henfield,
West Sussex

Ms Grace Gibbs,
Deputy Chief Executive
Director for Nursing,
Midwifery & Clinical
Support Services,
West Middlesex
University Hospital,
Ikeworth, Middlesex

Dr Neville Goodman,
Consultant Anaesthetist,
Southmead Hospital, Bristol

Professor Robert E Hawkins,
CRC Professor & Director
of Medical Oncology,
Christie Hospital NHS Trust,
Manchester

Professor F D Richard Hobbs,
Professor of Primary Care
& General Practice,
University of Birmingham

Professor Allen Hutchinson,
Director of Public Health &
Deputy Dean of SChARR,
University of Sheffield

Professor David Mant,
Professor of General Practice,
Institute of Health Sciences,
University of Oxford

Professor Alexander Markham,
Director,
Molecular Medicine Unit,
St James’s University Hospital,
Leeds

Dr Chris McCall,
General Practitioner,
The Hadleigh Practice,
Corfe Mullen, Dorset

Professor Alistair McGuire,
Professor of Health Economics,
London School of Economics,
University of London

Dr Peter Moore,
Freelance Science Writer,
Ashtead, Surrey

Dr Andrew Mortimore,
Consultant in Public
Health Medicine,
Southampton City Primary
Care Trust

Dr Sue Moss,
Associate Director,
Cancer Screening
Evaluation Unit,
Institute of Cancer Research,
Sutton, Surrey

Mrs Julietta Patnick,
National Coordinator,
NHS Cancer
Screening Programmes,
Sheffield

Professor David Price,
Director of Clinical Research,
Bayer Diagnostics Europe,
Stoke Poges, Berks

Ms Marianne Rigge,
Director, College of Health,
London

Dr William Rosenberg,
Senior Lecturer &
Consultant in Medicine,
University of Southampton

Professor Ala Szczepura,
Director, Centre for
Health Services Studies,
University of Warwick

Dr Ross Taylor,
Senior Lecturer,
Department of General
Practice & Primary Care,
University of Aberdeen

Mrs Joan Webster,
Consumer member,
HTA – Expert
Advisory Network

Current and past membership details of all HTA ‘committees’ are available from the HTA website (see inside front cover for details)
Feedback

The HTA Programme and the authors would like to know your views about this report.

The Correspondence Page on the HTA website (http://www.ncchta.org) is a convenient way to publish your comments. If you prefer, you can send your comments to the address below, telling us whether you would like us to transfer them to the website.

We look forward to hearing from you.