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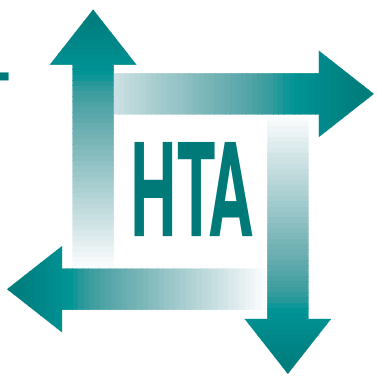
NHS R&D HTA Programme



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

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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.

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The editors and publisher have tried to ensure the accuracy of this report but do not accept liability for damages or losses arising from material published in this report. They would like to thank the referees for their constructive comments on the draft document.

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Contents

List of abbreviations

A&E	Accident and Emergency
ANOVA	analysis of variance
AV	arteriovenous
BNI	British Nursing Index
CAPD	continuous ambulatory peritoneal dialysis
CCA	corrected chronological age
CCN	community children's nurse
CCPD	continuous cyclic peritoneal dialysis
CCTR	Cochrane Controlled Trials Register
CDSR	Cochrane Database of Systematic Reviews
CI	confidence interval
CPN	community psychiatric nurse
CRD	[NHS] Centre for Reviews and Dissemination
CRIB	Current Research in Britain
CRIW	Current Research Worldwide
CV	central venous
CVC	central venous catheter
DARE	Database of Abstracts of Reviews of Effectiveness
DoH POINT	Department of Health Publications on the Internet
DQ	Battelle Development Quotient
EPOC	Effective Practice and Organisation of Care (Cochrane Review Group)
GP	general practitioner
HbA_{1c}	glycosylated (glycated) haemoglobin
HETF	home enteral tube feeding
HH	home health care
HMIC	Health Management Information Consortium
HOME	Home Observation for Measurement of the Environment
HPN	home parenteral nutrition
HV	home visiting
IDDM	insulin-dependent diabetes mellitus
ISI	Institute of Scientific Information
ISTP	Index of Scientific and Technical Proceedings
IVI	intravenous infusion
IVP	intravenous push
MDI	Bayley Mental Development Index
MST	multisystemic therapy
N/A	not available
NHS EED	NHS Economic Evaluation Database
NICU	neonatal intensive care unit
NRR	National Research Register
NS	not significant
PDI	Bayley Psychomotor Development Index
PHC	paediatric home care
RCT	randomised controlled trial
SCI	Science Citation Index
SD	standard deviation
SMD	standard mean difference
SSCI	Social Sciences Citation Index
TPN	total parenteral nutrition
WOS	Web of Science

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

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

Technology-dependent children

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

Children with mental health problems

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

Generic paediatric home care

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

Conclusions

State of research

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

Implications for the health service

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

Recommendations for research

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

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.[1] 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,[2] para.29). The first team of community children's nurses (CCNs) was established in Rotherham in 1948, followed by another in Birmingham in 1954.[3] 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[2] 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 1993 these numbers had risen to 62 and 124, respectively.[4] 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[4,5] 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 focussed on a single condition or group of conditions. Tatman and Woodroffe's[4] 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[3] 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 immuno-compromised" (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] deep vein thrombosis,[19] embolism and septicaemia[20] in parenteral nutrition; higher rates of contamination in enteral feeds at home than in hospital[21] and poor standards of care for enteral nutrition.[22] By contrast, home ventilation therapy seemed to have a somewhat better 'press'[23,24] with suggestions that, compared with prolonged hospital care, it was both safer and cheaper.[25]

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;[26] different policies for life-supporting interventions for different conditions and in different healthcare systems;[27] parents' ability to cope with[28,29] and their motivation to provide, technologically complex interventions;[30,31] urban or rural location[32] and the organisational and supportive structure within which these interventions were delivered at home.[33,34]

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.*

BOX 1 ***Databases searched***

BNI (British Nursing Index)

CINAHL (Cumulative Index of Nursing and Allied Health Literature)

CDSR (Cochrane Database of Systematic Reviews)

CENTRAL/CCTR (Cochrane Controlled Trials Register)

CRIB (Current Research in Britain)

CRIW (Current Research Worldwide)

DoH POINT (Department of Health Publications on the Internet)

EMBASE

HealthSTAR

HMIC (Health Management Information Consortium)

Index to Theses

ISTP (Index of Scientific and Technical Proceedings)

MEDLINE

NHS CRD DARE (Centre for Reviews and Dissemination Database of Abstracts of Reviews of Effectiveness)

NHS CRD NHS EED (NHS Economic Evaluation Database)

NHS CRD HTA (Health Technology Assessment) database

NRR (National Research Register)

PsycINFO

SCI (Science Citation Index – expanded)

SSCI (Social Sciences Citation Index)

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. 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[41] and one in the USA[42] – 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.[43]

TABLE 1 *Checking searches run against all references database*

Search term	Number of references identified
Diabetes and Randomly	16
Diabetes and Randomized	17
Diabetes and Randomised	6
Diabetes and Random	0
Asthma and Randomly	32
Asthma and Randomized	68
Asthma and Randomised	23
Asthma and Random	25
Self management	4
Self-management	25
Total references identified	**216**
Total selected	**1**

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 review[45] 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*

Trial	Number of citations
Brooten *et al.*, 1986[53]	74
Casiro *et al.*, 1993[59]	23
Gillette *et al.*, 1991[58a]	0
Finello *et al.*, 1998[61a]	41
Dougherty *et al.*, 1999[64]	0
Mitchell *et al.*, 1986[65]	19
Hughes *et al.*, 1991[40]	41
Harrington *et al.*, 1998[69]	20
Henggeler *et al.*, 1999[67]	2
Stein and Jessop, 1984[7]	44
Total	**264**

[a] *All citations for these authors since publication of original trial*

Inclusion and exclusion criteria for selection of studies

Decisions about inclusion and exclusion of papers were taken in two stages:

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

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[46] 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 and clinical condition.[47,48]

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[49] 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.

* See: Cameron RJ. Early intervention for young children with developmental delay: the Portage approach. *Child: Care Health and Development* 1997;**23**:11–27.

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 com-pared 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

TABLE 3 *Electronic references selected and proceeding to data extraction*

Search method/ database	Number of references, including duplicates	Number of papers selected for relevance	Number of papers proceeding to data extraction
Scoping	817	147	0
MEDLINE	3629	573	14
EMBASE	1019	247	0
ISTP	81	5	1
MEDLINE search 2	2133	29	0
EMBASE search 2	3010	211	4
CINAHL	1361	283	1
PsycLIT	254	23	0

TABLE 4 *Other database references selected and proceeding to data extraction*

Database	Number of references, including duplicates	Number of papers elected for relevance	Number of studies included but not data-extracted e.g. reviews	Number of papers proceeding to data extraction
DARE	17	2	2	0
NHS EED	36	3	0	0
HTA	4	2	0	0
CCTR	559	22	0	1
CDSR (reviews)	49	0	–	–
CDSR (protocols)	23	4	0	0
ISI + SSCI (combined search)	1701	100	0	0
NRR (completed)	90	16	0	0
NRR (ongoing)	32	4	0	0
MRC trial	1	0	–	–
HMIC	593	43	0	0
BNI	58	16	0	0
Index to Theses	3	0	–	–
CRIB	5	0	–	–
HealthSTAR	0	–	–	–
Paper reference list	–	–	–	7

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[50] and EPOC[51] 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[50] and the Cochrane Effective Practice and Organisation of Care (EPOC) Group's quality criteria for RCTs and controlled clinical trials[51] 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,[46] we excluded Jadad and co-workers'[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[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™ 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 (Brooten and co-workers,[53–56] Gillette and co-workers,[57,58] Casiro and co-workers[59,60] and Finello and co-workers.[61] *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[53,58,61] and one in Canada.[59] The details of the interventions and the treatment with which they were being compared are outlined in *Table 6*. The Finello trial[61] 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[57,59] 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'[57] 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 5 *Details of trials of home care for very low birth weight and/or medically fragile babies*

Authors and title of main paper	Publication details	*n* subjects	*n* controls	Jadad[50] score (max 3)	EPOC[51] score (max 7)
Brooten *et al.*, 1986[53] A randomised clinical trial of early hospital discharge and home follow up of very low birth weight infants	*New England Journal of Medicine* 1986;**315**:934–9	39	40	2	6
Gillette *et al.*, 1991[58] Hospital-based case management for medically fragile infants: results of a randomized trial	*Patient Education and Counseling* 1991;**17**:59–70	19	19	3	6
Casiro *et al.*, 1993[59] Earlier discharge with community-based intervention for low birth weight infants: a randomized trial	*Pediatrics* 1993;**92**:129–34	50	50	2	2
Finello *et al.*, 1998[61] Very low birth weight infants and their families during the first year of life: comparisons of medical outcomes based on after care services	*Journal of Perinatology* 1998;**18**:365–71	61	20	2	3
Total randomised		**169**	**129**		

TABLE 6 *Details of model of home care for very low birth weight and/or medically fragile babies*

Author and year	Country	Condition	Model of care	Compared with	Primary setting	Secondary setting
Brooten *et al.*, 1986[53]	USA	Very low birth weight	Early discharge and home follow-up	Routine discharge procedure	Home	Long-term follow-up carried out either in the hospital's clinic or by private paediatricians
Gillette *et al.*, 1991[58]	USA	Medically fragile infants	Education and counselling services of a hospital-based case management team	Traditional discharge and follow-up services of a NICU	Home	NICU follow-up clinic
Casiro *et al.*, 1993[59]	Canada	Infants < 2000 g birth weight	Early discharge with community-based follow-up, without use of home apnoea monitors. Public health nursing and home maker services for up to 8 weeks	Routine medical and nursing care and being sent home at the discretion of the attending physician	Neonatal unit	Neonate's home
Finello *et al.*, 1998[61]	USA	Very low birth weight (750–1750 g)	HH providing critical care in family home 1–4 weeks after discharge, including 24-hour availability of physician consultation. HV providing prevention and intervention services, focussing on developmental and health monitoring, parent education	No formal in-home assistance. Receiving normal hospital-based follow-up for well-baby care	Own home	

Exclusions were also varied. Brooten[53] 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[59] excluded children with congenital anomalies that were likely to have a negative impact on neuro-developmental outcomes and Finello[61] excluded any children with 'gross abnormality' at discharge. The children in the Gillette trial,[58] 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*

Study	Size of patient 'population' if given	Total number of patients randomised	% of patient population randomised	% of patients randomised included at final follow-up
Brooten *et al.*, 1986[53]	136	79	58	99
Gillette *et al.*, 1991[58]	58	50	86	76
Casiro *et al.*, 1993[59]	356	100	28	92
Finello *et al.*, 1998[61]	Not given	81	–	82

Quality of the trials

As reported in *Table 5*, only one trial[58] met all three Jadad[50] criteria (excluding the blinding criterion) for quality of trials. Two[53,58] met six of the seven EPOC[51] 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[53] and Casiro[59] report mortality, Gillette[58] and Casiro[59] mental function outcomes, Brooten[53] and Casiro[59] cost to the health service, Casiro[59] costs to the social care system, and Gillette[58] social outcomes (for mothers).

Mortality

Two babies in the Gillette study[58] 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[59] study and none were reported to have done so in the Finello study.[61] Only Brooten[53] 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,[53] 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[59] and Finello[61] report readmissions or use of emergency care in any detail. Gillette[58] does not report it at all while Brooten[53] 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,[59] 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 8 *Length of initial stay*

Study	Days of initial hospital stay Mean (SD) or median* Subjects	Controls	Reported significance	Shorter or longer stays for subjects
Brooten *et al.*, 1986[53]	46.5 (12.5)	57.7 (17)	$p < 0.05$	Shorter
Gillette *et al.*, 1991[58]	92	78	NS	Longer
Casiro *et al.*, 1993[59]:				
All	23*	31.5*	NS	Shorter
≤ 1500 g	56*	56.5*	NS	(Same)
1501–2000 g	17*	24*	$p < 0.02$	(Shorter)
Finello *et al.*, 1998[61a]:				
All	41.2	35.7	$p = 0.476$	Longer
HH/HV	39.4 (17.1)			
HH	44.8 (18.0)			
HV	39.4 (19.6)			

[a] *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*

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

All means are per child followed up

[a] *Calculated by us*

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

Study	Clincal outcomes				
	Measure used	**Period of follow-up**	**Subjects**	**Controls**	**Reported statistical significance**
Brooten *et al.*, 1986[53]	Number of babies failing to thrive	Not clear, possibly 18 months	0	1	NS
Gillette *et al.*, 1991[58]	Mean (SD) Battelle DQ	2 weeks after discharge	77 (10.8)	76 (8.7)	$p = 0.74$
	Neurological status	2 weeks after discharge	Normal 3 Transient 14 Abnormal 2	2 17 0	Not reported
		6 months CCA	Normal 2 Transient 6 Abnormal 11	3 5 11	Not reported
Casiro *et al.*, 1993[59]	Number of babies failing to thrive	12 months	0	0	N/A
Finello *et al.*, 1998[61]	Number (%) with up to date immunisation status	6 months	HH/HV 19 (95%) HH 15 (71%) HV 20 (100%)	16 (80%)	$p = 0.196$[a]
		12 months	HH/HV 19 (95%) HH 14 (70%) HV 15 (75%)	14 (70%)	$p = 0.038$[b]

[a] *Statistical test results reported on basis only of children followed up. Percentages reported in text are based only on children followed up*
[b] *Statistical test results reported on basis only of children followed up (67/81). Percentages reported in text are based only on children followed up*

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

Study	Physical outcomes				
	Measure used	**Period of follow-up**	**Subjects statistical significance**	**Controls**	**Reported**
Gillette *et al.*, 1991[58]	Mean (SD) Bayley PDI	6 months CCA	78.6 (22.0)	74.3 (2.5)	$p = 0.50$
Casiro *et al.*, 1993[59]	Mean (SD) Bayley PDI	12 months	94 (13)	90 (18)	NS

TABLE 12 *Mental function outcomes in home care for very low birth weight and/or medically fragile babies*

Study	Physical outcomes				
	Measure used	**Period of follow-up**	**Subjects**	**Controls**	**Reported statistical significance**
Gillette *et al.*, 1991[58]	Mean (SD) Bayley MDI	6 months CCA	86.3 (31.6)	75.6 (22.2)	$p = 0.24$
Casiro *et al.*, 1993[59]	Mean (SD) Bayley MDI	12-month follow-up	105 (16)	100 (17)	NS

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[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 multidisciplinary 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"[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[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[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[53] and Finello[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[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,

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-workers[40]). 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 IDDM[35] or asthma,[40,65] which delivered some element of care (for example, monitoring or drug compliance checking). Dougherty[64] 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 Canada[35,40] and one in New Zealand.[65]

TABLE 13 *Details of trials of home care for children with diabetes or asthma*

Authors and title of main paper	Publication details	*n* subjects	*n* controls	Jadad[50] score (max 3)	EPOC[51] score (max 7)
Dougherty *et al.*, 1999[64] Home-based management can achieve intensification cost-effectively in type 1 diabetes	*Pediatrics* 1999;**103**: 122–8	32	31	2	4/5
Mitchell *et al.*, 1986[65] Asthma education by community child health nurses	*Archives of Disease in Childhood* 1986;**61**: 1184–9	178	190	1	2
Hughes *et al.*, 1991[40] Controlled trial of a home and ambulatory program for asthmatic children	*Pediatrics* 1991;**87**: 54–61	47	48	2	6
Total randomised		**257**	**269**		

* 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.

TABLE 14 *Details of models of home care for children with diabetes or asthma*

Author and year	Country	Condition	Model of care	Compared with	Primary setting	Secondary setting
Dougherty *et al.*, 1999[64]	Canada	Type 1 diabetes	Home-management for new diabetics	Hospitalisation and outpatient department follow-up	Child's home	Both groups had outpatient department visits every 3–4 months for follow-up by physician
Mitchell *et al.*, 1986[65]	New Zealand	Asthma	Monthly visits from community child health nurse for 6 months, as well as education programme, drug compliance and correct use of inhalers checked, plus encouragement to attend follow-up and to attend GP rather than emergency department	Not clear	Child's home	None
Hughes *et al.*, 1991[40]	Canada	Asthma	Comprehensive home and ambulatory management: 3-month clinic visits, education and home visits by a specially trained research nurse	Regular care by family physician or paediatrician	Child's home	3-month clinic visits

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

TABLE 15 *Readmissions in home care for children with diabetes and asthma*

Study		Days of (re)admission			
		Period of follow-up	Mean (SD)		Reported statistical significance
			Subjects	Controls	
Dougherty *et al.*, 1999[64]		Discharge	2.2 (1.6)	4.7 (1.6)	Not reported
		24 months	0.94	1.03	NS
Mitchell *et al.*, 1986[65]	'European'	Up to 6 months	4.0 (7.7)	2.5 (1.5)	NS
	'Polynesian'		2.7 (1.4)	3.5 (2.6)	NS
	'European'	6 to 18 months	3.1 (2.4)	3.1 (2.4)	NS
	'Polynesian'		4.3 (3.9)	3.3 (2.1)	NS
Hughes *et al.*, 1991[40]		Up to 12 months	3.67	11.22	$p = 0.02$
		12 to 24 months	5.83	5.33	NS

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[64] 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[64] and Hughes[40] trials report satisfaction with services.

Length of hospital stay and readmission

Dougherty's[64] was the only trial to report initial hospital stay. While the Mitchell trial[65] 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.[64] Another paper from the trial,[35] 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'[40] is the only trial reporting a significant impact on admission, and only in the 12 months during which patients were actually receiving the intervention. Other results suggest both more and less admission for intervention children and at different periods of follow-up and for different subgroups.

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[64] alone suggests any long-term effect. A particularly interesting finding in the Hughes trial[40] 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[40] also carried out a range of other clinical measurements before, during and after the trial – forced expiratory volume in one second (FEV_1), ratio of FEV_1 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[65] 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.

TABLE 16 *Clinical outcomes in home care for children with diabetes or asthma*

Study	Clinical outcomes				
	How measured	**Period of follow-up**	**Subjects**	**Controls**	**Reported statistical significance**
Dougherty *et al.*, 1999[64]	Metabolic control: mean (SD) HbA_{1c} (%) at end of period	12–24 months	6.1 (1.3)	6.8 (1.3)	$p < 0.05$
		24–36 months	6.4 (1.4)	7.1 (1.3)	$p < 0.02$
	Mean number of diabetes-related adverse events	Not clear	0.26	0.34	NS
Mitchell *et al.*, 1986[65]	Mean (SD) number of drugs being taken	6 months			
	'European'		2.7 (1.1)	2.1 (1.0)	$p = 0.012$
	'Polynesian'		2.0 (1.16)	1.98 (1.96)	NS
	% of attacks not responding to home treatment	6 months			
	'European'		48	46	NS
	'Polynesian'		49	44	NS
Hughes *et al.*, 1991[40]	% with evidence of airways obstruction	Before	68.2	68.9	NS
		6 months (difference from baseline[a])	34.1 (34.1)	40.9 (28.0)	NS
		12 months (difference from baseline[a])	13.6 (54.6)	29.5 (39.4)	NS
		12 months after end of study (difference from baseline[a])	35.0 (33.2)	22.5 (46.4)	NS

[a] *Calculated by us*

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[35] 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[35] 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[64] and Hughes[40] 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

TABLE 17 *Satisfaction with services in home care for children with diabetes or asthma*

Study	Satisfaction with services				
	How measured	**Period of follow-up**	**Subjects**	**Controls**	**Reported statistical significance**
Dougherty *et al.*, 1999[64]	Parents' mean score (SD) on satisfaction scale (10–50)	1 month	46.2 (6.0)	45.5 (4.6)	NS
		12 months	45.7 (5.4)	46.0 (3.5)	NS
		24 months	45.6 (5.0)	46.0 (3.7)	NS
	Adolescents' mean score (SD) on satisfaction scale	1 month	42.8 (5.5)	46.3 (3.7)	NS
		12 months	42.6 (8.7)	45.4 (3.2)	NS
		24 months	43.9 (5.1)	43.9 (5.7)	NS
Hughes *et al.*, 1991[40]	Not clear, % 'satisfied with medical care received during study year'	Not clear, possibly at 12 months	100	86.4	Not reported
	% with expressed need for information about asthma	At beginning of study	95.5	90.2	Not reported
		12 months	45.2	69.8	$p = 0.008$
	% believing child takes responsibility for management all or most of time	At beginning of study	40.9	40.0	Not reported
		12 months	72.1	33.1	$p = 0.006$

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[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[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[65] reports no changes in knowledge of the child's condition, for any subgroup.

Hughes[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. Other differences in parents' knowledge of their child's condition and the environmental factors that might trigger attacks were tested by examining the proportion who reported being smokers or owning pets. This shows that, despite overall high levels of knowledge about their child's condition, parents

TABLE 18 *Impact on education*

Study	Impact on education				
	How measured	**Period of follow-up**	**Subjects**	**Controls**	**Reported statistical significance**
Dougherty *et al.*, 1999[64]	Mean (SD) days of absence	24 months	29.7 (28.7)	28.3 (36.4)	NS
Mitchell *et al.*, 1986[65]	Mean (SD) days of absence				
	'European'	6 months	8.6 (15.1)	6.3 (8.8)	NS
	'Polynesian'		6.8 (6.6)	12.4 (25.2)	NS
Hughes *et al.*, 1991[40]	Mean (SD) days of absence for asthma-related reasons	Year before study	10.8 (11.2)	10.4 (10.0)	NS
		Study year	5.8 (7.6)	8.8 (15.2)	NS
		Follow-up year	3.4 (6.1)	3.4 (4.5)	NS
	Mean (SD) days of absence for all causes	Study year	10.7 (6.9)	16.0 (15.4)	$p = 0.04$
		Follow-up year	9.8 (7.6)	12.2 (11.7)	NS

did not actually change their behaviour in a way that might have had a positive impact on their children's health.

Home care for children with mental health problems

Two trials are included in this section, reported in five papers (Henggeller and co-workers,[66–68] Harrington and co-workers[69,70]). One was based in the UK[69] and one in the USA.[67] 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"[67] (p.1332) and 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,[69] 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"[70] (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 ill health. In the Harrington trial,[69] a diagnosis of deliberate self-poisoning according to a standard definition was used to identify children for the study, and in the Henggeler trial,[67] 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[69] and 10–17 (mean reported age 13) for Henggeler.[67] 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 contra-indications – 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

TABLE 19 *Impact on knowledge of condition in home care for children with diabetes or asthma*

Study	How measured	Period of follow-up	Knowledge of condition: Subjects	Controls	Reported statistical significance
Dougherty *et al.*, 1999[64]	Diabetes Knowledge Scale: change in % correct[a]	24 months			
	Parents		6.0	–0.5	N/A
	Adolescents		13.5	4.5	N/A
	Diabetes Regimen Adherence Scale: change in % correct[a]				
	Parents		–9.2	–11.4	N/A
	Adolescents		–4.8	–12.1	N/A
Mitchell *et al.*, 1986[65]	% of children knowing how to prevent an attack of asthma	6 months			
	'European'		30	37	NS
	'Polynesian'		39	24	NS
	% of parents knowing how to start additional treatment				
	'European'		96	98	NS
	'Polynesian'		98	98	NS
	% of parents knowing when to seek additional advice				
	'European'		98	99	NS
	'Polynesian'		95	98	NS
Hughes *et al.*, 1991[40]	Proportion with 'good' metered inhaler technique: change[a]	12 months after study	60.2	15.4	
	Educational questionnaire score: change in % correct[a]		5	4	
	% of families with resident smoker	Before study	59.6	57.4	NS
		12 months	52.3	51.1	NS
	% of families with pet	Before study	44.7	52.2	Not reported
		12 months	47.7	60	Not reported

[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*

Authors and title of main paper	Publication details	*n* subjects	*n* controls	Jadad[50] score (max 3)	EPOC[51] score (max 7)
Harrington *et al.*, 1998[69] Randomized trial of a home-based family intervention for children who have deliberately poisoned themselves	*Journal of the American Academy of Child and Adolescent Psychiatry* 1998;**37**:512–18	85	77	3	5 or 6
Henggeler *et al.*, 1999[67] Home based multisystemic therapy as an alternative to the hospitalisation of youth in psychiatric crisis: clinical outcomes	*Journal of the American Academy of Child and Adolescent Psychiatry* 1999;**38**:1331–9	57	56	3	6
Total randomised		**142**	**133**		

TABLE 21 *Details of models of home care for children with mental health problems*

Author and year	Country	Condition	Model of care	Compared with	Primary setting	Secondary setting
Harrington *et al.*, 1998[69]	UK	Deliberate self-poisoning	Home visits by social worker to provide family problem-solving sessions	Routine care	Child's home	Assessment session could be in hospital or home
Henggeler *et al.*, 1999[67]	USA	Severe emotional disturbance	MST: individualised treatment approach addresses multiple determinants of youth and family problems	Hospitalisation: youth division of inpatient psychiatric unit	Adolescents' home	None

that an earlier study in the same hospitals "had shown that major depression after a deliberate overdose resolved rapidly in most cases"[69] (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[69] 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[67] does not report the size of the original patient population.

Quality of the trials

Both trials were appropriately described as randomised, although Henggeler[67] 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.[50] Harrington's[69] met five or six of the EPOC quality criteria;[51] 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[67] 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[67] 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[70] 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[67] 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.

TABLE 22 *Length of hospital stay and readmission in home care for children with mental health problems*

Study	How measured	Period of follow-up	Length of stay		Reported statistical significance
			Subjects	Controls	
Harrington *et al.*, 1998[69]	Number of children hospitalised[a]	6 months	67	70	Not reported
	Inpatient days (mean per subject)		187 (2.20–2.53)	193 (2.51–2.57)	Not reported
	Number of children using day-patient services		0	1	Not reported
	Number of day-patient days (mean per subject)[a]		0	53 (0.69–0.69)	Not reported
	Number of children attending A&E		74	75	Not reported
	Number of A&E attendances (mean per subject)[a]		79 (0.93–1.07)	86 (1.12–1.15)	Not reported
	Number of children attending as outpatients		45	55	Not reported
	Number of outpatient attendances (mean per subject)[a]		162 (1.91–2.19)	244 (3.17–3.25)	Not reported
Henggeler *et al.*, 1999[67]	% Hospitalised	T1 to T2 (see text)	25	100	$p < 0.001$
	Mean (SD) length of stay (days)		0.54 (1.81)	5.77 (3.5)	$p = 0.001$
	% Hospitalised	T2 to T3	28	20	NS
	Mean (SD) length of stay (days)		1.84 (4.43)	3.05 (11.06)	$p = 0.45$
	% Hospitalised	T1 to T3	44	100	$p < 0.001$
	Mean (SD) length of stay (days)		2.39 (4.55)	8.82 (11.55)	$p = 0.001$

[a] *Figures reported in paper for 74/85 intervention and 75/77 control group children; means calculated by us on original* N *and reported* n

A&E, Accident and Emergency

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[67] 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[69] 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.[70] 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

TABLE 23 *Clinical outcomes in home care for children with mental health problems*

Study	Clinical outcomes				
	How measured	**Period of follow-up**	**Subjects**	**Controls**	**Reported statistical significance**
Harrington *et al.*, 1998[69]	Mean (SD) Suicidal Ideation Questionnaire score (range 0–180)	Before treatment	63.6 (46.7)	62.9 (46.8)	NS
		2 months	40.0 (50.7)	43.4 (49.2)	NS
		6 months	23.6 (40.0)	28.7 (35.3)	NS
	Mean change[a]		–40.0	–34.2	
	Mean (SD) score on Hopelessness Scale (range 0–17)	Before treatment	6.1 (4.1)	6.6 (4.0)	NS
		2 months	5.6 (4.0)	5.3 (4.1)	NS
		6 months	4.4 (3.3)	4.2 (3.6)	NS
	Mean change[a]		–1.7	–2.4	
	Number (%) with major depression (Schedule for Affective Disorders and Schzophrenia)	Before treatment	56/85 (66)	53/77 (69)	NS
		2 months	25/79 (32)	19/75 (25)	NS
		6 months	12/74 (16)	17/75 (23)	NS
	Mean change[a]		–50	–46	
	Number (%) with one or more episodes of self-harm	6 months	11/74 (15)	11/75 (15)	NS
Henggeler *et al.*, 1999[67]	Mean (SD) Global Severity Index – Brief Symptom Inventory (child)	T1	1.01 (0.7)	1.22 (0.8)	
		T2	0.71 (0.6)	1.03 (0.9)	
		T3	0.74 (0.9)	0.84 (0.7)	Time effect only
	Mean change[a]		–0.27	–0.38	
	Mean (SD) Child Behaviour Checklist (carer): internalising symptoms	T1	68.0 (10.9)	69.5 (10.9)	
		T2	62.1 (12.6)	63.1 (10.5)	
		T3	60.6 (12.8)	60.7 (12.6)	Time effect only
	Mean change[a]		–7.4	–8.8	
	Mean (SD) Child Behaviour Checklist (carer): externalising symptoms	T1	73.3 (10.3)	70.6 (12.3)	
		T2	67.4 (12.1)	62.4 (12.2)	
		T3	63.7 (12.4)	64.3 (12.2)	Treatment effect, $p < 0.02$
	Mean change[a]		–9.6	+6.3	
	Mean (SD) Child Behaviour Checklist (teacher): internalising symptoms	T1	64.6 (12.2)	62.2 (13.9)	
		T3	60.1 (12.8)	58.8 (11.3)	Time effect only
	Mean change		–4.5	–3.4	
	Mean (SD) Child Behaviour Checklist (carer): externalising symptoms	T1	71.1 (10.7)	67.8 (15.1)	
		T3	64.8 (11.8)	68.0 (13.0)	$p < 0.5$
	Mean change[a]		–6.3	+0.2	
	Mean (SD) Family, Friends and Self Scale – self-esteem	T1	2.57 (0.9)	2.21 (1.0)	
		T3	2.55 (1.1)	2.73 (0.9)	$p < 0.006$ (favours hospital group)
	Mean change[a]		–0.02	+0.5	

[a] *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*

	Satisfaction with services				
Study	**How measured**	**Period of follow-up**	**Subjects**	**Controls**	**Reported statistical significance**
Harrington *et al.*, 1998[69]	Mean (SD) score on Likert scale (children; range 0–8)	2 months	4.6 (2.1)	4.3 (2.4)	NS
		6 months	4.6 (2.3)	3.9 (2.9)	NS
	Mean (SD) score on Likert scale (parents; range 0–8)	2 months	5.0 (2.3)	3.7 (2.5)	$p < 0.001$
		6 months	5.0 (2.3)	4.3 (2.6)	NS
Henggeler *et al.*, 1999[67]	Mean (SD) score on Lubrecht Family Satisfaction Survey (children)	T2	15.7 (4.4)	13.3 (4.2)	$p < 0.007$
		T3	15.5 (4.5)	12.0 (4.6)	$p < 0.001$
	Mean (SD) score on Lubrecht Family Satisfaction Survey (carers)	T2	17.6 (3.2)	16.5 (3.4)	Not reported
		T3	17.9 (3.4)	16.4 (3.9)	$p < 0.044$

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 25 *Impact on family functioning*

Study	Impact on family functioning				
	How measured	Period of follow-up	Subjects	Controls	Reported statistical significance
Harrington *et al.*, 1998[69]	Mean (SD) score on McMaster Family Assessment Device (scale 0–4)	Before treatment	2.3 (0.3)	2.3 (0.2)	NS
		2 months	2.3 (0.3)	2.3 (0.3)	NS
		6 months	2.3 (0.3)	2.2 (0.3)	NS
Henggeler *et al.*, 1999[67]	Mean (SD) score on FACES[a]-III, cohesion subscale (children)	T1	29.6 (9.7)	29.7 (9.5)	
		T2	26.5 (10.4)	30.6 (8.9)	
		T3	29.7 (9.3)	31.6 (9.3)	NS
	Mean (SD) score on FACES-III, adaptability subscale (children)	T1	23.1 (6.7)	22.1 (6.7)	
		T2	21.5 (7.4)	24.9 (7.5)	
		T3	21.8 (8.1)	23.8 (7.4)	$p < 0.039$
	Mean (SD) score on FACES-III, cohesion subscale (carers)	T1	32.2 (8.4)	36.1 (5.3)	
		T2	32.0 (7.1)	36.3 (6.4)	
		T3	34.4 (6.6)	34.7 (6.4)	$p < 0.001$
	Mean (SD) score on FACES-III, adaptability subscale (carers)	T1	23.9 (5.7)	25.0 (5.2)	
		T2	23.2 (5.1)	22.4 (5.7)	
		T3	23.0 (5.3)	22.4 (4.7)	Time effect only

[a] *Family Adaptability and Cohesion Evaluation Scales*

TABLE 26 *Impact on parents/carers in home care for children with mental health problems*

Study	Impact on parents/carers				
	How measured	Period of follow-up	Subjects	Controls	Reported statistical significance
Harrington *et al.*, 1998[69]	Mean (SD) General Health Questionnaire score (range 0–28)	Before treatment	9.8 (8.7)	8.8 (7.2)	NS
		6 months	5.6 (7.5)	5.5 (6.8)	NS
Henggeler *et al.*, 1999[67]	Mean (SD) Global Severity Index – Brief Symptom Inventory	T1	0.52 (0.5)	0.71 (0.8)	
		T2	0.46 (0.5)	0.60 (0.7)	
		T3	0.46 (0.5)	0.57 (0.7)	Time effect only

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"[70] (p.59).

Similarly, although the Henggeler trial[67] 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*

	Social functioning				
Study	**How measured**	**Period of follow-up**	**Subjects**	**Controls**	**Reported statistical significance**
Harrington *et al.*, 1998[69]	Mean (SD) Social Problem Solving Inventory – Generation of Alternative Solutions subscale (range 0–40)	Before treatment	17.4 (6.4)	17.9 (6.0)	NS
		2 months	17.0 (6.7)	18.4 (6.3)	NS
		6 months	17.6 (7.4)	17.9 (7.3)	NS
Henggeler *et al.*, 1999[67]	Mean (SD) FFS – conventional involvement of friends subscale	T1	1.97 (0.8)	1.95 (0.8)	
		T3	1.89 (0.7)	2.09 (0.8)	NS
	Mean (SD) FFS – antisocial friends subscale	T1	0.99 (0.8)	1.07 (0.9)	
		T3	1.09 (1.0)	1.05 (0.9)	NS
	Mean (SD) Child Behaviour Checklist – Social Competence subscales (carer report)	T1	30.2 (6.1)	30.9 (6.3)	
		T3	33.5 (6.8)	31.8 (6.9)	Time effect only
	Mean (SD) Child Behaviour Checklist – Social Competence subscales (child's report)	T1	34.9 (6.1)	36.6 (8.5)	
		T3	36.3 (7.9)	38.7 (8.6)	NS

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

Study	Use of institutional care				
	How measured	**Period of follow-up**	**Subjects**	**Controls**	**Reported statistical significance**
Harrington *et al.*, 1998[69]	Number of children entering foster care	6 months	2	4	NS
	Total weeks of foster care		25	54	
	Mean weeks per child[a]		0.34	0.72	
	Number of children entering residential care		0	3	NS
	Total weeks of residential care		0	8	
	Mean weeks per child[a]		0	0.11	
Henggeler *et al.*, 1999[67]	Days in out-of-home placements (excluding hospital)	T3	508	996	Not reported
	Mean days per child[a]		8.9	17.8	
	% experiencing change of placement	T3	56	100	$p < 0.001$
	Mean (SD) number of changes		1.8 (2.22)	2.8 (1.65)	$p < 0.01$
	Mean (SD) changes to more restrictive placement		0.78 (1.10)	1.34 (0.92)	$p < 0.01$

[a] *Calculated by us*

of Stein and Jessop. Six papers describing the programme, the trial and long-term follow up have been identified, published between 1978 and 1994.[7,71–75] 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".[72] 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[50] employed here but did less well on the EPOC criteria,[51] with a score of 4/5. Primary outcomes

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[7] 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.[7] 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"[7] (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,[71] *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, $4\frac{1}{2}$ 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[72] 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[53] and Casiro and co-workers[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[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[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.[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[53] and Casiro[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,[76] by contrast, reports billed charges for both readmission and emergency

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

Data collected	Brooten *et al.*, 1986[53]	Casiro *et al.*, 1993[59]	Kotagal *et al.*, 1995[76]
Hospital care	Charges	Minimum estimated costs	Average daily costs
Physician fees	Yes	No	No
Total costs of intervention	Yes	No	Yes
Subsequent community health services (outside intervention)	No	Number, not costs	No
Readmission/A&E care after discharge	Number, not costs	Number, not costs	Charges

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[76] 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 30 *Reported average costs[a] of care in early discharge for very low birth weight or NICU babies*

Study		Hospital care ($)	Physician fees ($)	Cost of intervention ($)	Community health services	Readmission/ A&E care ($)
Brooten *et al.*, 1986[53]	Subjects	47,520	5933	576	Not reported	Not reported
	Controls	64,940	7649	–		
Casiro *et al.*, 1993[59]	Subjects	20,079[b]	Not reported	626[c]	Not reported	Not reported
	Controls	27,500[b]		–		
Kotagal *et al.*, 1995[76]	Subjects	27,912[b]	Not reported	431[b]	Not reported	38[b]
	Controls	34,181[b]		–		Not reported

[a] *Costs are in US$ apart from Casiro* et al. *where they are Can$*
[b] *Calculated by us*
[c] *Not all elements costed*

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

Study	Currency/year	Average cost per baby			% Difference[a]	Statistical significance
		Intervention	Controls	Difference		
Brooten *et al.*, 1986[53]	US$ Not clear – 1980s	54,029	72,589	18,560	26	Not reported
Casiro *et al.*, 1993[59]	Can$ 1990	20,705	27,450	6,795	25	Not reported
Kotagal *et al.*, 1995[76]	US$ 1992/3	28,343	34,181	5,838	17	–

[a] *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 paper[53] 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 study[76] 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-workers[77] and by Hallam and co-workers[78] 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 Hallam[78] 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[77] study is of 59 babies discharged between 1981 and 1989 from a single hospital in New Hampshire, USA. The Hallam study[78] 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 study[77] used charges rather than costs in many areas of direct care, while the UK-based study[78] 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 altenative form of care were estimated. In McAleese's study[77] 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 level

TABLE 32 *Type of cost data collected in studies of early discharge of oxygen-dependent babies*

Data collected	McAleese *et al.*, 1993[77]	Hallam *et al.*, 1996[78]
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[77] 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[78] 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.

Hallam[78] used qualitative methods to explore the financial impact of home care for a selection of families but did not attempt to collect any detailed financial data. The conclusion is that, although three families reported reductions in income, it was 'apparent' that such reductions would have occurred regardless of where their baby was cared for. Other items of expenditure related to the babies' home care were identified but not costed. Examples included bigger cars and prams in order to carry equipment around. Family expenses associated with hospital care included travel costs and food while visiting.

McAleese[77] collected detailed information about the costs incurred by families while their baby was still in hospital in respect of travel, overnight stays and telephone calls to the hospital. The median total expenditure was US$1624 with a range of $287 to $8017. Loss of wages was calculated for care at home. Thirty of the 59 families (29 mothers and two fathers) experienced unexpected time away from work in order to care for the baby, with a median loss of US$3083 and a range of $250 to $21,378. The expenditure during hospital care and the income losses during home care were included in the overall costs of care reported in the paper.

Economic analysis

With no outcome measures used in either study and with 'hypothetical' comparators no formal economic analysis is possible.

McAleese[77] 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[78] 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[78] takes no account of family costs while the McAleese study[77] 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 33 *Reported average costs of care in early discharge of oxygen-dependent babies*

Expense incurred	McAleese *et al.*, 1993[77] (US$)		Hallam *et al.*, 1996[78] (£)	
	Subjects	**Controls**	**Subjects**	**Controls**
Initial hospital care, including physicians' fees, equipment, etc.	Mean 197,668 Median 172,817 Range 43,364–86,4504	Mean 197,668 Median 172,817 Range 43,364–864,504	–	–
Training for parents	–	–	93.70 per baby	–
Home care equipment	Median 2,250 Range 475–9,000	–	**Cylinder system** Mean 1,352[a] Median 656 Mean 3,637[b] Median 2,168 **Concentrator system** Mean 1,636[a] Median 307 Mean 1,636[b] Median 1,307	–
Outpatient/ community services:	–	–	Mean 829[a] Median 508 Mean 829[b] Median 508	–
Outpatient department follow-up clinic	Median 569 Range 130–3,571	–	Implied in the above	–
Local paediatrician vists	Median 210 Range 0–2,380	–	Implied in the above	–
Physiotherapy	Median 585 Range 65–5,720	–	Implied in the above	–
Occupational therapy	Median 1,560 Range 325–3,575	–	Implied in the above	–
Health visitor/ community nurse	Median 363 Range 60–1,800	–	Implied in the above	–
Other nursing	Median 54,684 Range 11,900–10,4076	–	Implied in the above	–
Readmission/A&E[c]	Median 7,449 Range 1,020–91,867	–	Mean 967[a] Median 1,590 Mean 555[b] Median 940	–
Estimated cost of hospital care as alternative	–	Median 48,116[d]	Mean 19,824[a] Median 17,136 Mean 53,490[b] Median 46,236	–

[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*

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

Study	Currency/ year	Average cost per baby: Intervention	Controls	Difference	% difference[a]	Statistical significance
McAleese *et al.*, 1993[77b]	US$ 1989/90	**Home care** Median without private-duty nursing 4,262 Range 650–23,278	**Hypothetical hospital stay** Median without private-duty nursing 33,995 Range not given	29,733	88%	Not reported
		Median with private-duty nursing 68,136 Range 16,056–132,303	Median with private-duty nursing 134,934 Range not given	66,798	50%	Not reported
		Total Median 5,195 Range 650–132,303	**Total Median 48,116 Range not given**	**42,921**	**89%**	**Not reported**
		Readmission Median 7,448 Range 1,020–91,867				
Hallam *et al.*, 1996[78]	£ 1994	**Cylinder system**				
		Mean 2,286[c] Median 1,402	Mean 19,824[c] Median 17,136	17,538	88%	Not reported
		Mean 5,623[d] Median 1,320	Mean 53,490[d] Median 46,236	47,867	89%	
		Concentrator system				
		Mean 3,263[c] Median 2,410	Mean 19,824[c] Median 17,136	16,561	84%	Not reported
		Mean 3,885[d] Median 2,672	Mean 53,490[d] Median 46,236	49,605	93%	

[a] *Calculated by us*
[b] *Included parental income loss for home care and estimate of parental expenditure for hospital care*
[c] *Low cost assumption*
[d] *High cost assumption*

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[77] study for children who had substantial home nursing input.

It seems possible that the Hallam[78] 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,[35] 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.[35] 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.

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 35 *Type of cost data collected in study of diabetes home care (Dougherty* et al., *1998[35])*

Type of data	Collected?
Days of hospital care	Yes
Drug costs	Yes
Supplies	No
Parent training	Implied in nursing hours
Dietetic advice	Implied in nursing hours
Outpatient clinics	Yes
Laboratory costs	Yes
X-ray and other tests	Yes
Readmission and emergency care	Yes
Indirect costs	No

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"[35] (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 health-care 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

TABLE 36 *Reported average service use in diabetes home care (Dougherty* et al., *1998[35])*

	Intervention	Controls	Mean difference	SD of difference
Initial hospital stay				
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[a]	13.6	Not reported
Months 2–24	31.0	3.4[a]	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**

[a] *Telephone consultation only*
[b] *Consulting about patients with hospital staff and other personnel*

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.

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,[35,64] 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*[35]

Type of cost-effect	US$ cost-effect per child (SD)	Statistical significance (*t* test)	95% CI (US$)
Hospital cost-effect borne by government	889 (87)	$p = 0.001$	711 to 1067
Plus increased government contribution to pension plan for hospital staff	32		
Less decreased government cost for physician services	–31		
Government cost-effect	890 (139)	$p = 0.001$	605 to 1174
Less value of reduction in workload not 'captured' by hospital and government	–122		
Health system cost-effect	768 (165)	$p = 0.001$	431 to 1105
Parental cost-effect	–720 (188)	$p = 0.001$	–1105 to –335
Social cost-effect	48 (274)	$p = 0.862$	–510 to 606

Home chemotherapy for children with cancer

Type of study

Three studies, carried out by Jayabose and co-workers,[79] Close and co-workers[80] and Holdsworth and co-workers[9] 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 herafter by the name of the first author.

Nature of the intervention

The Jayabose study[79] 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[80] 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[9] 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[9] 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,

TABLE 38 *Type of cost data collected in home chemotherapy studies*

Data collected	Jayabose *et al.*, 1992[79]	Close *et al.*, 1995[80]	Holdsworth *et al.*, 1997[9]
Hospital care	Charges, not costs	Charges, not costs	Relative charges, not costs
Nursing costs	Included but not reported	Included but not reported	Relative charges, not costs
Physician fees	Included but not reported	Included but not reported	Excluded
Training for parents	Not reported	Not reported	N/A
Total costs of intervention	Reported only as difference	Average charge per day	Reported only as difference in relative charges
Subsequent community health services (outside intervention)	Not reported	Not reported	Not reported
Readmission/A&E care after treatment	Not reported	Not reported	None occurred

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,[70,79] parents had to be trained to deliver chemotherapy or the subsequent hydration and medication but this was not costed, and in one study[70] 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[9] 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[80] 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[80] and Holdsworth[9] studies make any attempt to judge clinical or quality of life outcomes. In the Close study,[80] 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,[9] 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"[9] (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*

Study		Hospital care	Nursing costs	Total cost of intervention (US$)	Statistical significance
Jayabose *et al.*, 1992[79 a]	Home	–	–	Savings IVP 3022	Not reported
		–	–	Savings IVI 6897	Not reported
Close *et al.*, 1995[80]	Home	–	–	1865 (SD 833)	–
	Hospital	–	–	2329 (SD 627)	$p < 0.01$, paired *t* test
Holdsworth *et al.*, 1997[9]	Home			Savings ranged from 367 to 5180 per course, depending on drug regimen	Not reported

[a] *Not all elements costed*

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

Study	Average cost per course of treatment (US$)					
	Year	Home	Hospital	Difference	% Difference[a]	Statistical significance
Jayabose *et al.*, 1992[79]	Not given	–	–	IVI 141[a] (range 23–255) IVP 740[a] (range 680–1555)	Cannot be calculated from data given	Not reported
Close *et al.*, 1995[80]	1989/90	1865 (SD 833)	2329 (SD 627)	464	20%	$p < 0.01$
Holdsworth *et al.*, 1997[9]	1993	–	–	2446[a] (range 357–5180)	Cannot be calculated from data given	Not reported

[a] *Calculated by us*

TABLE 41 *Average daily costs (US$) to families for home chemotherapy (Close* et al., *1995[80])*

Type of cost	Mean (SD)		Statistical significance
	Hospital	Home	
Loss of wages	265 (233)	67 (107)	$p < 0.005$
Food	24 (11)	3 (2)	$p < 0.0001$
Transport	20 (9)	6 (4)	$p < 0.0001$
Telephone	15 (3)	1 (1)	$p < 0.0001$
Babysitters	9 (6)	1 (3)	$p < 0.0001$
Total out of pocket	**68 (31)**	**11 (6)**	**$p < 0.0001$**
Total costs to parents[a]	**333**	**78**	

[a] *Calculated by us*

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.[81] 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"[81] (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 42 *Type of costs data collected in study of home intravenous antibiotic treatment (Wiernikowski* et al., *1991*[81]*)*

Type of data	Collected?
Hospital care	Average daily bed cost only
Drug costs	Yes
Supplies	Yes
Parent training (nursing)	Yes
Parent training (pharmacy)	Yes
Laboratory costs	Yes
Community nurse	Yes
Readmission/A&E care after discharge	No readmissions needed

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 section[82] – a descriptive comparison of the cost of two different methods of home-based dialysis (continuous ambulatory

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

	Average cost per child (Can$)					
	Bed cost	**Drugs**	**Supplies**	**Once-only parent training**	**Lab costs per episode**	**Community nurse per episode**
Subjects	1854[a]	486.50[a]	237.20[a]	140.30	28.00	35.00
Alternative care	7416	–	–	–	–	–

[a] *Calculated by us*

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

Average cost per child (Can$)				
Intervention	**Controls**	**Difference**	**% Difference[a]**	**Statistical significance**
First episode 2781	7416	4635	63%	Not reported
Subsequent episodes[a] 2647	7416	4769	64%	

[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.

TABLE 45 *Type of cost data collected in home dialysis study (Coyte* et al., *1996[82])*

Type of data	Collected?
Surgical setup and all aspects of hospital care	Yes
Drug costs	Yes
Supplies	Yes
Parent training	Yes
Dietetic advice	Yes
Social work assessment	Yes
Outpatient clinics	Yes
Laboratory costs	Yes
X-ray cost	Yes
Treatment of possible complications	Yes
Indirect costs	Yes

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 46 *Reported average costs (Can$) of care in home dialysis*[82]

	Home CAPD	Home CCPD	Hospital dialysis (AV fistula)	Hospital dialysis (CV line)
Sugical setup/access	7,216.09	7,216.09	5,594.88	2,579.34
Maintenance	40,353.10	41,442.16	71,634.28	71,634.28
Complications: inguinal hernia	6,936.35	6,936.35	–	–
Peritonitis with hospitalisation	3,394.42	3,394.42	–	–
AV clot	–	–	4,223.22	–
CV block	–	–	–	1,170.53

TABLE 47 *Average reported costs of care per child in home dialysis (1994)*[82]

Average cost per child (Can$)			
Intervention	**Controls**	**Difference**[a]	**% Difference**[a]
CAPD without complications: 47,569.19	AV fistula without complications: 77,229.16	29,659.97	38
CAPD with complications (inguinal hernia): 54,505.84	AV fistula with complications (AV clot): 81,452.38	26,946.54	33
CAPD with complications (peritonitis): 50,963.61	AV fistula with complications (AV clot): 81,452.38	30,488.77	37
CCPD without complications: 48,658.25	AV fistula without complications: 77,229.16	28,570.91	37
CCPD with complications (inguinal hernia): 55,594.60	AV fistula with (AV clot) complications: 81,452.38	25,857.78	32
CCPD with complications (peritonitis): 52,052.67	AV fistula with complications (AV clot): 81,452.38	29,399.71	37
CAPD without complications: 47,569.19	CV line without complications: 74,213.62	26,644.43	36
CAPD with complications (inguinal hernia): 54,505.84	CV line with complications (CV block): 75,384.15	20,878.31	28
CAPD with complications (peritonitis): 50,963.61	CV line with complications (CV block): 75,384.15	24,420.54	32
CCPD without complications: 48,658.25	CV line without complications: 74,213.62	25,555.37	34
CCPD with complications (inguinal hernia): 55,594.60	CV line with complications (CV block): 75,384.15	19,789.55	26
CCPD with complications (peritonitis): 52,052.67	CV line with complications (CV block): 75,384.15	23,331.48	31

[a] *Calculated by us*

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" [82] (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 physicans' 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

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[25] and Fields and co-workers,[83] 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[25] and eight out of ten in Fields' study[83] were over 12-months-old.

Neither study reports which year was used as the costing base but the Fields paper[83] states that the children in the study were discharged home between April 1985 and June 1987.

Hazlett's study[25] 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[83] 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[25] is unspecific about the nature of ventilator assistance while Fields[83] 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[25] 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[83] 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,[83] no detailed costing data are reported in either study (*Tables 49* and *50*).

The Fields data[83] 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 involvment in tracking 'cost-effectiveness' it seems likely that the data used are 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[25] 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*

Data collected	Hazlett, 1989[25]	Fields *et al.*, 1991[83]
Training for parents	Not clear	Not clear
Home care equipment	Included but not reported	Included but not reported
Outpatient and community health services	Not included	Included but not reported
Readmission/A&E care after discharge	Not included	Included but not reported
Alternative care setting	Last 31 days of hospital care	Yes, estimated costs of care in paediatric long-term care hospital

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

	Hazlett, 1989[25] (US$)		Fields *et al.*, 1991[83 a] (US$)	
	Subjects	**Controls**	**Subjects**	**Controls**
Cost of home care	Mean 6,967 Range 2,844–19,165		**Ventilator-dependent** Mean 109,836 SD 20,781 **Oxygen-dependent with tracheostomy** Mean 63,650 SD 12,350	
Estimated cost of hospital care as alternative	–	Mean 38,000 Range 19,124–52,586		**Ventilator-dependent** Mean 188,909 SD 20,781 **Oxygen-dependent with tracheostomy** Mean 146,836 SD 23,992

[a] *Costs for first year*

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

		Average cost per child (US$)				
Study	**Year**	**Intervention**	**Controls**	**Difference**	**% Difference[a]**	**Statistical significance**
Hazlett, 1989[25]	Not reported	Mean 6,967	Mean 38,000	31,033	82	Not reported
Fields *et al.*, 1991[83]	Not reported	**Ventilator-dependent** Mean 109,836	**Ventilator-dependent** Mean 188,909	79,073	42	Not reported
		Oxygen-dependent with tracheostomy Mean 63,650	**Oxygen-dependent with tracheostomy** Mean 146,836	83,186	57	Not reported

[a] *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[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"[25] (p.289) but these costs were not included in the cost of care.

The Fields study[83] makes no reference to family costs.

Economic analysis

Hazlett[25] claims an average saving for home care over hospital care of some 78%, although our calculations suggest a figure of 82%. Fields[83] claims average annual savings of US$79,074 (SD $26,558) for ventilator-dependent children and $83,187 (SD $25,028) for oxygen-dependent children with tracheostomies.

Because of the restrospective nature of the Hazlett study,[25] follow-up was between 2 and 53 months for different children. Within this very variable period, eight children were said to have improved their condition, as determined by comparison of ventilator settings with those at the time of hospital discharge. A further two children were said to be stable. However, five had died, with time between discharge and death ranging from 1 month to 53 months.

No outcome data are included in the Fields study,[83] although it appears that all children survived at least 12 months.

The only conclusion that can be drawn from either study, then, is that, within the constraints of the data collected, home care for oxygen-dependent children appeared to be cheaper for the health service. The better of the two studies shows lower levels of cost saving, but ones that are still substantial. However, as with the studies of early discharge of oxygen-dependent babies, no attempt has been made to value the parents' input to the care of the child. Further, as outlined above, the only children eligible for the programme described by Fields[83] were those whose care costs were, in any case, expected to be lower at home than in long-term hospital care. It is thus impossible to extrapolate these findings to all children who might, purely on a technical basis, be able to be cared for at home with the right ventilation or oxygen equipment.

Further, at least part of the savings identified by Fields[83] was explained by the unavailability of skilled nursing care for the children. Before discharge the annual projected cost of nursing per ventilator-assisted child was US$94,704 (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[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[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 designed 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,[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[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[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[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"[84] (pp. 159–60) in the published evaluations of the scheme.

As outlined above, the Byford paper[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*

Data collected or simulated	Margolis and Petti, 1994[84]	Byford *et al.*, 1999[70]
Inpatient care	Yes	Yes
Outpatient care	No	Yes
Daypatient care	No	Yes
Total costs of intervention	Yes	By implication
Subsequent community health services (outside intervention)	No	Yes
Readmission	Yes	Yes
A&E attendances	No	Yes
Education services	No	Yes
Social services and/or residential placement	Yes	Yes
Voluntary services	No	Service use only

Reported costs of care

The Margolis study[84] reports per diem costs as US$239.56 for hospital care, US$125.95 for a residential placement, and US$ 3155 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 $239.56 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.

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[70] 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.

TABLE 52 *Simulated average costs (US$) of home-based treatment for children with mental health problems (Margolis and Petti, 1994[84])*

	Number of children	Admission status	Cost of programme per child	Cost of excessive length of stay per child[a]	Total cost of excessive length of stay per child	Total cost for 18 children
Hospital care for excessive length of stay	18	Admitted	–	46,115	46,115	830,075
Home-based care	14	Averted	3,155	–	3,155	44,170
	4	Admitted	3,155	46,115	49,270	197,080
Total home-based care					**13,403**	**241,250**
Residential placement after ready for discharge	18	Admitted then discharged to residential placement	–	2,267	2,267	40,808
Home-based care	14	Averted	3,155	–	3,155	44,170
	4	Admitted then discharged to residential placement	3,155	24,245	27,400	109,600
Total home-based care					**8,543**	**153,770**

[a] *Based on average length of stay of 192.5 days*

* 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, 1994[84])*

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

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., *1999[70])*

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

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 chidren with mental health problems (Byford* et al., *1999[70])*

Service	Intervention group (1997/8 £)	Control group (1997/8 £)	Reported statistical significance
Health service			
Number of children with any contact	74	75	
Total cost	95,864.09	95,735.24	
Arithmetic mean	1295.46	1276.47	
Median	323.00	518.00	$p = 0.085$
Education			
Number of children with any contact	20	23	
Total cost	261.63	652.47	
Arithmetic mean	13.08	28.37	
Median	9.18	9.18	$p = 0.314$
Overall mean[a]	3.54	8.70	
Social services			
Number of children with any contact	14	16	
Total cost	11,557.75	34,971.34	
Arithmetic mean	825.55	2185.71	
Median	53.93	140.21	$p = 0.039$
Overall mean[a]	156.19	466.28	

[a] *Calculated by us*

TABLE 56 *Average costs for home-based treatment of children with mental health problems (Byford* et al., *1999[70])*

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

However, they also point out that the subgroups were small and the CIs large.

Byford[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.

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[76,85,86]
(ii) ways of avoiding hospital admission, or reducing the length of admission, for children diagnosed with IDDM[36,87–89]
(iii) 'technological' care at home in dialysis,[90] chemotherapy,[80] nebuliser therapy,[15] treatment involving central venous catheters (CVCs),[17,91] and enteral feeding[92]
(iv) home care for children with mental health problems.[93]

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.[76,85,86] Two, by Kotagal and co-workers[76] and Rieger and Henderson-Smart[85] are 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[86] 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[76] 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[85] and Örtenstrand[86] 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 ealier than control babies (see below).

Similarly Rieger[85] and Örtenstrand[86] show little difference in mean gestational age at discharge. Kotagal[76] does not report this.

TABLE 57 *Clinical outcomes in early discharge for very low birth weight/NICU babies*

Study	Mortality		Weight at discharge (g)			Gestational age at discharge or equivalent point for controls (weeks; mean (SD))		Other clinical outcomes
	Study group	Controls		Study group	Controls	Study group	Controls	
Kotagal *et al.*, 1995[76]	Not reported		**By birth weight** 500–750 750–1000 1001–1250 1251–1500 1501–2000 2001–2500 2501+[a]	**Geometric mean (95% CI)** 2417 (2116–2760) 2228 (1895–2618) 2036 (1924–2154) 1980 (1988–2076) 1935 (1920–1989) 2181 (2132–2231) 3151 (3055–3249)	**Geometric mean (95% CI)** 2592 (2293–2929) 2529 (2312–2756) 2579 (2401–2769) 2359 (2297–2423) 2307 (2269–2346) 2339 (2304–2374) 3141 (3066–3218)	–	–	No others reported
Rieger and Henderson-Smart, 1995[85]	Not reported		Mean 2311[b] (range 1780–3337)		2327 (1582–3285)	36.5[c] (1.3)	36.8 (1.4)	No others reported
Örtenstrand *et al.*, 1999[86]	1/43	0/45	Mean 2224[b] (SD 376)		2122 (301)	35.9[b] (SD 1.6)	35.6 (1.2)	More respiratory infections in controls (16) than study group (6) up to end of period of home care or equivalent period for controls. No other differences in health problems, medications or weight gain

[a] *ANOVA controlling for birth weight and month of discharge*, $p < 0.0001$
[b] *NS*
[c] *Statistical signficance not reported*

The only other clinical outcomes reported are in the Örtenstrand study.[86] 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[76] 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*). Örtenstand[86] also shows a large and statistically significant reduction (16 days overall), but the Rieger intervention[85] 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[85] reports any form of impact outcome for parents or babies. Neither the Speilberger 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,[36] Lowes and Davis,[87] Lowes[88] and Couper and co-workers[89]). Two were based in the UK[36,87,88] and one in Australia.[89] 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[36,88] and the third was about home-based support for adolescents with poorly controlled IDDM.[89]

Clinical outcomes

The only clinical outcome reported in any of the studies was mean glycosylated (glycated) haemoglobin level (HbA_{1c}) – see *Table 59*. The Swift study[36] found no significant differences in levels recorded for children who had had IDDM for 2 or more years. In the Couper study,[89] 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 HbA_{1c} 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 [87,88] does not report any clinical outcomes.

Health service use

Both Swift[36] and Lowes[87,88] 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[88] and adolescents' and parents' knowledge of diabetes.[89]

Lowes,[87,88] 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*

Study	Initial length of stay (days)		Emergency visits[a]		Readmissions[a]		Other health service use	
	Study group	Controls	Study group	Controls	Study group	Controls	Study group	Controls
Kotagal *et al.*, 1995[76]	**By birth weight (g)** / **Geometric mean (95% CI)** 500–750 109.7 (81.8–121.6) 750–1000 65.4 (51.9–82.5) 1001–1250 49.0 (43.2–55.7) 1251–1500 33.3 (29.1–38.1) 1501–2000 14.9 (12.7–17.3) 2001–2500 7.2 (6.2–8.3) 2501+[b] 4.9 (4.3–5.5)	**Geometric mean (95% CI)** 129.5 (109.4–153.3) 80.8 (72.5–90.1) 64.7 (48.3–71.7) 46.1 (42.6–40.9 sic) 23.6 (21.4–26.0) 11.6 (10.4–13.0) 6.8 (6.1–7.5)	2.7%[c]	8.0%	0.6%[d]	0.4%		
Rieger and Henderson-Smart, 1995[85]	Discharged 2.1 days earlier than controls Mothers' rooming-in (days) Mean 0.78[f]	 0.17	Mean[d] 0.38	Mean 0.47	Not clear		Visits to family doctor Mean 4.0[e]	5.6
Örtenstrand *et al.*, 1999[86]	Mean 30.6[g] (SD 24.4)	Mean 46.3 (SD 23.4)	**During period of domiciliary care** 0.4	Not reported	**During period of domiciliary care** Mean 0.2 (SD 0.5)	Not reported		
			During 12-month follow-up Mean 0.8[d] (SD 0.9)	Mean 1.3 (SD 1.4)	**During 12-month follow-up** Mean 0.5[d] (SD 1.0)	Mean 0.5 (SD 1.3)	**During 12-month follow-up** Outpatient/ GP visits Mean 2.2[b] (SD 3.1) Child Health Centre Visits Mean 1.6[d] (SD 2.9)	 Mean 1.7 (SD 2.3) Mean 1.5 (SD 4.4)

[a] *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)*
[b] *ANOVA controlling for birth weight and month of discharge,* $p < 0.0001$
[c] $p < 0.001$
[d] *NS*
[e] $p = 0.017$
[f] $p = 0.01$
[g] $p < 0.01$

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

Study	Mean glycated haemoglobin concentration (%)		
	Study group		Controls
Swift *et al.*, 1993[36]	Children with diabetes 2+ years 10.2[a]		10.0
Lowes;[88] Lowes and Davis, 1997[87]	None reported		
Couper *et al.*, 1999[89]	**Mean (SD) at:**		
	Baseline	11.1 (1.3)	10.5 (1.6)
	6 m	9.7 (1.6)	10.3 (2.2)
	12 m	10.5 (1.8)	10.7 (2.0)
	18 m[b]	10.0 (1.5)	10.5 (1.8)

[a] p = *0.37*
[b] *Group x time effect, ANOVA*, p = *0.006*

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

Study	Initial length of stay (days)		Readmission	
	Study group	Controls	Study group	Controls
Swift *et al.*, 1993[36]	Median[a] 1987/83	Median 1979/807	31[b] children/138 (22%)	40/98 (39%)
Lowes;[88] Lowes and Davis, 1997[87]	Median (range) 1 (0–7)	5 (2–18)	Newly diagnosed[c] 16/38 Mean 0.42	11/40 Mean 0.28
			Established[c] 87/38 Mean 2.29	61/40 Mean 1.53
Couper *et al.*, 1999[89]	None reported		None reported	

[a] p = *0.0001*
[b] p = *0.001*
[c] *No statistical testing reported*

The Diabetes Knowledge Assessment Scale (a validated and reliable scale) was used in the Couper study.[89] As with HbA_{1c}, 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-workers[91] and Melville and co-workers,[17] enteral feeding by Anderton and co-workers[92] 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

hospital compared with home[17,91] and an uncontrolled comparison of children receiving dialysis at home or in hospital.[90] Two of the studies were in the UK,[17,92] two in the USA,[80,90] and one each in Italy,[91] and Qatar.[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 61*). The Close study[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,[90] 14 in Close,[80] 20 in Melville,[17] 50 in Osundwa[15] and only six in Anderton[92]). Only the Rizzari[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 61 *Clinical outcomes in studies of technology at home*

Study	Technology	Outcome measure used	At what point	Study group	Controls or control condition	Reported statistical significance
Brem *et al.*, 1988[90]	Home dialysis	Adolescent Coping Orientation Problem Experiences Scale[a]: Mean (SD) low level activity	Between 3 months and 10 years after initiation of treatment	28.0 (2.3)	20.7 (5.3)	$p < 0.05$
		Self-reliance		18.3 (2.0)	15.8 (1.2)	$p < 0.05$
		Friendship		6.7 (2.7)	4.3 (1.0)	$p < 0.05$
Close *et al.*, 1995[80]	Home chemotherapy	No clinical outcomes reported				
Rizzari *et al.*, 1992[91]	CVC, mainly in children with haematological malignancy	Incidence of infection per 100 line days	At any point in 'history' of CVC in 135 children 1984–9	0.52	0.55	$p = 0.82$
		Incidence of infection per 100 line days: presence of neutropenia		1.12	0.90	$p = 0.54$
		Incidence of infection per 100 line days: absence of neutropenia		0.46	0.29	$p = 0.13$
Melville *et al.*, 1997[17]	CVC/parenteral nutrition	Incidence of infection per 100 days of TPN[b]	At any point in 'history' of TPN in 20 children 1986–92	0.25	0.35	
		Mean occurence of infection		Every 567 days	Every 142 days	$p < 0.00001$
Anderton *et al.*, 1993[92]	Enteral feeding	Contamination of feeds	Not clear	18/22 (82%)	22/73 (30%)	–
Osundwa *et al.*, 1994[15]	Home nebuliser	No clinical outcomes reported				

[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 study[92] were not due to the different methods used to collect samples in the hospital and at home. In the Melville study[17] 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 study[90] 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.

Osundwa[15] 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 study[80] 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. Close[80] 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-workers[93] – 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[51] 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"[93] (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"[93] (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,[92] 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,[91] 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[80] 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[76]). 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[59] is the only trial that mentions pre-trial power calculations although Finello[61] acknowledges, *post hoc*, that the study was underpowered. The studies employing other designs were also limited in their reporting of clinical outcomes.

There is some suggestion that physical and mental development might be enhanced through early discharge schemes evaluated in two of the trials,[58,59] but this is an issue that could be established with confidence only in an adequately sized trial in the future.

The impact of home care on initial length of stay is unclear: two trials reported shorter[53,59] and two longer[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 evidence from the trials of the impact of home care on subsequent hospital and emergency care use is also equivocal, where reported at all. Indeed, our reanalysis suggested that home care was associated with higher levels of readmission than the published papers had indicated. By contrast, the other types of studies suggested that subsequent hospital and emergency care was at a similar level for both home care and control babies.

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[64] 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.[65] 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[35,40,64,65] 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[65] 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[35,83,84] 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.[88] 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[89] 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,[35] 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[35] 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 chemo-therapy) 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[80] – 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[80] reports a statistically significant reduction in costs, and the others[9,79] 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[81] of intravenous antibiotic administration at home also claimed substantial savings 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[25,83] 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[82] and one in the 'other' section.[90] The costing study[82] 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[90] 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.[15] 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,[67,69] two economics papers[70,84] and one other study[93] 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[67] while the other[69] 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 aftercare. The reported scores for interventions and controls in the main trial were actually 23.6 and

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[84] that seemed to us to have analytic flaws. The other paper[70] 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[93] 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.[7] 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,[87] 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.[88,90] 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*

	Focus			
Location	**Specialist timing**		**Generic timing**	
Community	Shorter	Longer	Shorter	Longer
Hospital outreach	Shorter	Longer	Shorter	Longer

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 Kohrma[94] 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[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[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[98] (p.766).

This technology is evident in the UK, then, and may be increasing,[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.[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).[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,[16] and a high rate of catheter-related thrombosis[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.[102] Specific questions about the safety of HETF in relation to children with neurological impairments have also been raised; Puntis[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[22,100] and there has been no health economic appraisal of paediatric HPN.[102,103]

Family motivation is essential for success in home-based enteral or parenteral nutrition[100] and the

impact on families of caring for children receiving such care is substantial.[104] 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.[105] The support that is offered to families varies substantially from place to place, even within the same region.[22]

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 the least, however, there is an argument for updating the previous systematic review[102] 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.[106] 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.[107]

The number of babies being discharged home while still dependent on oxygen is also increasing[78] 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.[108] 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,[108,109] 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".[38] 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,[38] 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.[13] 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"[13] (p.143).

By contrast, nebuliser therapy is seen as the "mainstay of aerosol delivery" in patients with cystic fibrosis, especially for young patients.[10] 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.[10] 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[110] and the other about treatment for deliberate self-harm in adults and adolescents.[111] 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[41] 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

- 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.[112] 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.[113] Three other papers,

described as 'reviews' of economic aspects of HPN,[114] of home oxygen therapy,[115] and of generic paediatric home care[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.[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,[118–121] HPN,[122–124] home intravenous therapy,[125–127] and home nebulisers[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.

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The review team

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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 test*
#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.
21 (home and package$).tw.
22 (outreach and home).tw.
23 (alternative setting$ 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

#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*1: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 AID-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 SCHOOLCHILD*
#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*
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*

CRIW, date and database producer details not available, 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*

DoH POINT 1996 to 2000, 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*

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

#4 explode 'home care' / all subheadings
#5 #1 or #2 or #3
#6 #4 and #5

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

#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 pre school* or newborn*)

MEDLINE 1991, 1995, 1999, Ovid Biomed version, search undertaken December 1999 (initial scoping search)

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

17 home.tw.
18 16 and 17
19 domiciliary.tw.
20 home based.tw.
21 homebased.tw.
22 (social support and home$).tw.
23 homecare.ti.
24 (home and package$).tw.
25 (outreach and home).tw.
26 (alternative setting$ and home).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/
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$).tw.
28 homecare.ti.
29 (home and package$).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 – diabetes)

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 (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$).tw.
28 homecare.ti.
29 (home and package$).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 – cystic fibrosis)

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.

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 – HIV/AIDS)

1 exp Hiv/
2 exp Hiv infections/
3 1 or 2
4 exp child/
5 exp adult/
6 4 not 5
7 3 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

NRR 2000 Issue 2, Update Software, CD-ROM version, search undertaken September 2000

#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*1: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 AID-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 SCHOOLCHILD*
#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)

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 62 *RCTs included in chapter 3*

Authors	Title	Journal details
Home care for very low birth weight/medically fragile babies		
Brooten D, Kumar S, Brown L, Butts P, Finkler S, Bakewell-Sachs S, *et al.*	A randomized clinical trial of early hospital discharge and home follow-up of very low birth weight infants	*New England Journal of Medicine* 1986;**315**:934–9
Brooten D, Kumar S, Brown L, Butts P, Finkler S, Bakewell-Sachs S, *et al.*	A randomized clinical trial of early hospital discharge and home follow-up of very low birth weight infants	*NLN Publications* 1987;**21**:95–106
Brooten D, Gennaro S, Knapp H, Jovene N, Brown L, York R	Funtions of the CNS in early discharge and home follow-up of very low birthweight babies	*Clinical Nurse Specialist* 1991;**4**:196–201
Termini L, Brooten D, Brown L, Gennaro S, York R	Reasons for acute care visits and rehospitalizations in very low birth weight infants	*Neonatal Network* 1990;**8**:23–6
Gillette Y, Hanson NB, Robinson JL, Kirkpatrick K, Grywalski R	Hospital-based case management for medically fragile infants: results of a randomized trial	*Patient Education and Counseling* 1991;**17**:59–70
Gillette Y, Hansen NB, Robinson JL, Kirkpatrick K, Grywalski R	Hospital-based case management for medically fragile infants: program design	*Patient Education and Counseling* 1991;**17**:49–58
Casiro O, McKenzie M, McFadyen L, Shapiro C, Seshia M, MacDonald N, *et al.*	Earlier discharge with community-based intervention for low birth weight infants: a randomized trial	*Pediatrics* 1993;**92**:129–34
Shapiro C	Shortened hospital stay for low birth weight infants: nuts and bolts of a nursing intervention project	*Journal of Obstetric, Gynecologic and Neonatal Nursing* 1995;**24**:56–62
Finello KM, Litton KM, deLemos R, Chan LS	Very low birth weight infants and their families during the first year of life: comparisons of medical outcomes based on after care services	*Journal of Perinatology* 1998;**18**:365–71
Home care for children with insulin-dependent diabetes or asthma		
Dougherty G, Schiffrin A, White D, Soderstrom L, Sufragegui M	Home-based management can achieve intensification cost-effectively in type 1 diabetes	*Pediatrics* 1999;**103**:122–2
Dougherty G, Soderstrom L, Schiffrin A	An economic evaluation of home care for children with newly diagnosed diabetes	*Medical Care* 1998;**36**:586–98
Mitchell EA, Ferguson V, Norwood M	Asthma education by community child health nurses	*Archives of Disease in Childhood* 1986;**61**:1184–9
Hughes D, McLeod M, Garner B, Goldboom R	Controlled trial of a home and ambulatory program for asthmatic children	*Pediatrics* 1991;**87**:54–61
Home care for children with mental health problems		
Henggeler S, Rowland M, Pickrel S, Miller S, Cunningham P, Santos A, *et al.*	Investigating family based alternatives to institution based mental health services for youth: lessons learned from the pilot study of a randomised field trial	*Journal of Clinical Child Psychology* 1997;**26**:226–33
Henggeler S, Rowland M, Randall J, Ward D, Pisckrel S, Cunningham P, *et al.*	Home based multisystemic therapy as an alternative to the hospitalisation of youth in psychiatric crisis: clinical outcomes	*Journal of American Academy of Child and Adolescent Psychiatry* 1999;**38**:1331–9
Schoenwald S, Ward D, Henggeler, S, Rowland M	Multisystemic therapy versus hospitalisaton for crisis stabilisation of youth: placement outcomes 4 months post referal	*Mental Health Services Research* 2000;**2**:3–12
Harrington R, Kerfoot M, Dyer E, McNiven F, Gill J, Harrington V, *et al.*	Randomized trial of a home-based family intervention for children who have deliberately poisoned themselves	*Journal of the American Academy of Child and Adolescent Psychiatry* 1998;**37**:512–18
Byford S, Harrington R, Torgerson D, Kerfoot M, Dyer E, Harrington V, *et al.*	Cost-effectiveness analysis of home-based social work intervention for children and adolescents who have deliberately poisoned themselves	*British Journal of Psychiatry* 1999;**174**:56–62

continued

***TABLE 62* contd** *RCTs included in chapter 3*

Authors	Title	Journal details
Paediatric home care		
Stein REK, Jessop DJ	Does pediatric home care make a difference for children with chronic illness? Findings from the Pediatric Ambulatory Care Treatment Study	*Pediatrics* 1984;**73**:845–53
Stein REK, Jessop DJ	Long-term mental health effects of a paediatric home-care program	*Pediatrics* 1991;**88**:490–6
Stein REK	Pediatric home care: an ambulatory 'special care unit'	*Journal of Pediatrics* 1978;**92**:495–9
Stein R	A home care program for children with chronic illness	*Child Health Care* 1983;**12**:90–2
Jessop DJ, Stein REK	Who benefits from a pediatric home care program?	*Pediatrics* 1991;**88**:497–505
Jessop DJ, Stein REK	Providing comprehensive health care to children with chronic illness	*Pediatrics* 1994;**93**:602–7

TABLE 63 *Details of economics papers included in chapter 4*

Authors	Title	Journal details
Brooten D, Kumar S, Brown LP, Butts P, Finkler S, Bakewell-Sachs S, *et al.*	A randomized clinical trial of early hospital discharge and home follow-up of very low birth weight infants	*New England Journal of Medicine* 1996;**315**:934–9
Byford S, Harrington R, Torgerson D, Kerfoot M, Dyer E, Harrington V, *et al.*	Cost-effectiveness analysis of a home-based social work intervention for children and adolescents who have deliberately poisoned themselves. Results of a randomised controlled trial	*British Journal of Psychiatry* 1999;**174**:56–62
Casiro OG, McKenzie ME, McFadyen L, Shapiro C, Seshia MM, MacDonald N, *et al.*	Earlier discharge with community-based intervention for low birth weight infants: a randomized trial	*Pediatrics* 1993;**92**:128–34
Close P, Burkey E, Kazak A, Danz P, Lange B	A prospective, controlled evaluation of home chemotherapy for children with cancer	*Pediatrics* 1995;**95**:896–900
Coyte PC, Young LG, Tipper BL, Mitchell VM, Stoffman PR, Willumsen J, *et al.*	An economic evaluation of hospital-based hemodialysis and home-based peritoneal dialysis for pediatric patients	*American Journal of Kidney Diseases* 1996;**27**:557–65
Dougherty GE, Soderstrom L, Schiffrin A	An economic evaluation of home care for children with newly diagnosed diabetes: results from a randomized controlled trial	*Medical Care* 1998;**36**:586–98
Fields AI, Rosenblatt A, Pollack MM, Kaufman J	Home care cost-effectiveness for respiratory technology-dependent children	*American Journal of Diseases of Children* 1991;**145**:729–33
Hallam L, Rudbeck B, Bradley M	Resource use and costs of caring for oxygen-dependent children: a comparison of hospital and home-based care	*Journal of Neonatal Nursing* 1996;**2**:25–30
Hazlett DE	A study of pediatric home ventilator management: medical, psychosocial, and financial aspects	*Journal of Pediatric Nursing* 1989;**4**:284–94
Holdsworth MT, Raisch DW, Chavez CM, Duncan MH, Parasuraman TV, Cox FM	Economic impact with home delivery of chemotherapy to pediatric oncology patients	*Annals of Pharmacotherapy* 1997;**31**:140–8
Jayabose S, Escobedo V, Tugal O, Nahaczewski A, Donohue P, Fuentes V, *et al.*	Home chemotherapy for children with cancer	*Cancer* 1992;**69**:574–9
Kotagal UR, Perlstein PH, Gamblian V, Donovan EF, Atherton HD	Description and evaluation of a program for the early discharge of infants from a neonatal intensive care unit	*Journal of Pediatrics* 1995;**127**:285–90
Margolis LH, Petti RD	An analysis of the costs and benefits of two strategies to decrease length of stay in children's psychiatric hospitals	*Health Services Research* 1994;**29**:155–67
McAleese KA, Knapp MA, Rhodes TT	Financial and emotional cost of bronchopulmonary dysplasia	*Clinical Pediatrics* 1993;**32**:393–400
Wiernikowski JT, Rothney M, Dawson S, Andrew M	Evaluation of a home intravenous antibiotic program in pediatric oncology	*American Journal of Pediatric Hematology – Oncology* 1991;**13**:144–7

TABLE 64 *Details of papers from non-RCT comparative research included in chapter 5*

Paper number	First author and date	Country	Methods/intervention	Summary of findings
Home care for very low birth weight or medically fragile babies				
76	Kotagal (1995)	USA	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	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 over-seeing the programme
85	Rieger (1995)	Australia	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	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'
86	Örtenstrand (1999)	Sweden	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	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
Home care for children with insulin-dependent diabetes				
36	Swift (1993)	UK	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)	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 glycosolated haemoglobin (HbA_{1c}) was found between the two groups

continued

***TABLE 64* contd** *Details of papers from non-RCT comparative research included in chapter 5*

Paper number	First author and date	Country	Methods/intervention	Summary of findings
***Home care for children with insulin-dependent diabetes* contd**				
87	Lowes and Davis (1997)	UK	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	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
88	Lowes (1997)	UK	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	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
89	Couper (1999)	Australia	Sixty-nine children (aged 12–17), with a mean HbA_{1c} 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 HbA_{1c}. Study and control groups were decided geographically	Significant reductions in HbA_{1c} 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
'Technological' care at home				
Dialysis				
90	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				
80	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

continued

***TABLE 64* contd** *Details of papers from non-RCT comparative research included in chapter 5*

Paper number	First author and date	Country	Methods/intervention	Summary of findings
'Technological' care at home				
Nebuliser therapy				
15	Osundwa (1994)	Qatar	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	The study found that home nebuliser therapy led to a 74% reduction in emergency room visits and a 70% reduction in hospital admissions
CVC treatment at home				
91	Rizzari (1992)	Italy	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	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
17	Melville (1997)	UK	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	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
Enteral feeding				
92	Anderton (1993)	UK	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	Higher rates of bacterial infection were found in home feeds (70% of hospital feeds, and 18% of home feeds were free from contamination)
Home care for children with mental health problems				
93	Hufford (1999)	USA	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 ABCBCA pattern. The interactions were measured using both specially generated and existing scales assessing parental and adolescent comfort and distraction	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

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