

Evaluating self-care support for children and young people with long-term conditions

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prepared by

- **Susan Kirk**
School of Nursing, Midwifery and Social Work, University of
Manchester
- **Susan Beatty**
School of Community Based Medicine, University of Manchester
- **Peter Callery**
School of Nursing, Midwifery and Social Work, University of
Manchester
- **Linda Milnes**
School of Nursing, Midwifery and Social Work, University of
Manchester
- **Steven Pryjmachuk**
School of Nursing, Midwifery and Social Work, University of
Manchester

Address for correspondence

Susan Kirk

School of Nursing, Midwifery and Social Work, University of Manchester,
Jean McFarlane Building, Oxford Road, Manchester, M13 9PL

E-mail: sue.kirk@manchester.ac.uk

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The Report

1 Introduction

1.1 Background

Self-care has become a major component of United Kingdom (UK) health policy. Although not a new concept it began to be advocated in English health policy in the late 1990s (Department of Health (DH), 1997, 1999, 2000). Its recognition both in the UK and internationally has been attributed to a number of factors: the increasing prevalence of chronic illness; the change from a cure to a care philosophy; dissatisfaction with depersonalised medical care; an increase in lay knowledge due to the wider dissemination of health related information enabled by the internet; consumerism and the desire for personal control; an increased awareness of the importance of life style in relation to longevity and quality of life and the need to control escalating health care costs (Health Canada, 1997; Wanless, 2002; DH, 2005,). In the intervening years policy aspirations relating to self-care have been continually re-emphasised and guidance on implementation provided (DH, 2004a, 2004b, 2005b, 2006a, 2006b, 2008, 2009a). However, the centrepiece of activities within the National Health Service (NHS) has been the Expert Patient Programme (EPP); a lay-led, generic self-management programme based on the Chronic Disease Self-Management Programme developed in the United States (US) (DH, 2001). After piloting work between 2002 and 2004 the programme was mainstreamed throughout the NHS and now provides a range of condition and situation-specific programmes via a Community Interest Company.

The consideration of childhood long-term illness is largely overlooked in policy relating to self-care, although the National Service Framework for Children, Young People and Maternity Services (DH/Department for Education and Skills (DfES), 2004) highlighted the need for services to develop children's and parents' self-confidence and self-management skills to deal with the impact of their condition and to provide support to enable children/young people to enjoy and achieve fully in their lives and make a positive contribution. In addition the need to develop and enable access to the EPP and other self-management programmes for children and young people has been recommended (DH, 2004, 2007a, 2009b). Indeed programmes for children/young people ('Staying Positive') and for their parents ('Supporting Parents') have now been developed and are being

commissioned by a number of Primary Care Trusts (PCT) for their local communities.

The benefits of self-care have been framed in terms of health and system related outcomes that include increased life expectancy, the development of more effective patient-professional relationships; increased patient satisfaction; improved patient knowledge and self-perception of chronic conditions; increased self-confidence and sense of control; decreased pain and depression; improved quality of life; increased concordance and symptom control and reductions in the use of health services. However, it has been noted that the benefits of self-care have been overstated in light of the available evidence (Bury et al., 2005). Similarly a national evaluation of the EPP has produced modest results in terms of effectiveness and certainly ones that fell short of the high expectations of policy makers (Rogers, 2009). Moreover, although couched in a patient-centred language, it has been proposed that the self-care policy agenda is a device to transfer the costs and responsibility for care onto patients and families (Coulter and Ellins, 2006).

1.2 Conceptualising self-care

There are numerous definitions of self-care which vary according to who engages in self-care behaviours (individual, family, community); what the context is (health promotion, prevention of illness, limitation of the impact of illness, restoration of health); and the extent to which health professionals are involved (WHO, 1983; DH 2005). A frequently cited definition describes self-care as being

'the actions individuals and carers take for themselves, their children, their families and others to stay fit and maintain good physical and mental health; meet social and psychological needs; prevent illness or accidents; care for minor ailments and long term conditions; and maintain health and wellbeing after an acute illness or discharge from hospital' (DH, 2005b, p1).

Different types of self-care have been described (Barofsky, 1978): regulatory self-care (routine health maintenance activities such as eating and sleeping); preventive self-care (self-selected practices such as exercising and dieting); reactive self-care (self-initiated responses to symptoms without medical intervention) and restorative self care (compliance with professionally prescribed treatment regimens and behavioural change). This latter category illustrates how self-care can be linked to concepts of compliance and adherence, although it is more usually associated with empowerment and the conceptualisation of patients/users as active, knowledgeable individuals rather than as passive recipients of health care (who may engage in strategic non-compliance).

Self-care in relation to long-term conditions covers a wide range of activities which include (Barlow et al. 2002; DH 2005b, 2006b):

- seeking information (from books/leaflets, the internet, classes/self help groups),
- health behaviours aimed at maintaining and enhancing physical and mental well being (e.g. exercising, diet, lifestyle changes),
- self diagnosis/monitoring and instigating self-treatment (e.g. monitoring vital signs, symptom management, management of medications/therapies),
- managing the psycho-social consequences of illness on daily and family life,
- problem solving – setting goals, decision making and taking action,
- seeking advice via lay/alternative care networks,
- developing supportive social networks,
- consulting health professionals and accessing services,
- developing effective partnerships with professionals; active citizenship and communication.

The terms self-care and self-management are frequently used interchangeably in the literature. In some definitions self-care is seen as the preventive strategies performed by healthy people and self-management as tasks or work that an individual undertakes to control or reduce the impact of a disease (Barlow et al. 2002). In general however, self-care tends to refer to the broad range of activities that people carry out to manage living with a long-term condition, whereas self-management relates to aspects such as condition monitoring, symptom management and the instigation of therapies and medications.

Although self-care has been mainly seen in terms of individual behaviour, it can be positioned on a continuum, with individually centred components as one end (e.g. health literacy) and social activities at the other (e.g. social capital and public engagement) (Bower et al. 2009). Consequently the factors influencing self-care can be related to wider contextual influences as well as the individual (Figure 1).

Figure 1. Factors influencing self-care (summarised from Bower et al. 2009)

Individual Level	Health Service Level	Social Context Level
Illness Beliefs and Lay Epidemiology	Nature of the professional-patient relationship	Organisation of the health system
Emotional Responses to Long-term Conditions	Degree of patient-centredness	Material and community resources
Intentions to change behaviour (driven by perceived advantages and disadvantages, social influences, self efficacy, identity and self image)	Health service incentives (eg GP Contract)	Social incentives and disincentives
		Collective support
Information and skills to support behaviour change		
Processes to implement and normalise behaviour change		
Level of disruption experienced with the onset of illness		
Stages of change		
Pre-existing adaptations		

1.3 Support for self-care

The goal of self-care support has been interpreted as enabling patients to perform three sets of tasks: medical management of their condition (e.g. taking medication); carrying out normal roles and activities and managing the emotional impact of their condition (Lorig & Holman 2003). Although self-care support in the context of a long-term condition is often associated with particular interventions such as educational and skills training programmes or self-care support devices, it is embedded within the 'routine' care of many health professionals, social workers and others (DH, 2007b). This is evident when recommendations are examined on the different ways in which services should support self-care and their underlying principles (Corben and Rosen, 2005; DH 2005b, 2008). These recommendations also reveal how self-care support has largely been constructed in terms of the individual patient rather than at the structural constraints influencing self-care.

One way of providing appropriate self-care support is seen as being through the development of positive patient-professional relationships (or 'partnerships'). Such relationships are characterised as ones where professionals actively listen to patients; identify their main concerns; allow time for discussion; understand how the person experiences their condition and their individual decision making preferences; encourages involvement/participation; and promotes individual control, self-efficacy, and motivation. However this is contingent upon professionals being willing to transfer responsibility to patients (Thorne and Paterson, 2001). As Fox et al. (2005) note while policy might encourage constructing patients as experts it has overlooked entrenched professional power and that governmental enthusiasm for expert patients does not directly translate into professional behaviour change. In addition this way of working is also dependant on professionals being educationally prepared for partnership working with patients and on how to support self-care. Reservations have also been expressed by health professionals about whether there is sufficient capacity to adequately support patients in self-managing their own care (Coulter and Ellins, 2006). Other methods of self-care support are the provision of accessible information and education to increase knowledge and skills; support in accessing and navigating the service system (including lay/peer support networks) and self-management support. The latter is seen as being achieved via a range of tools and resources (e.g. telephone help lines, computer based tools, devices for self-monitoring and personalised self-care plans).

The need for flexibility in provision has been highlighted in order to enable individual patients/users to access a range of different types of support from both formal and informal self-care resources at different times and stages as well as support which takes account of their socio-economic and cultural context (Bury et al. 2005; Corben and Rosen, 2005). It has also been noted that supporting self-care requires a comprehensive approach, involving interventions not only at the level of the patient but also at the professional and the health system levels (Kennedy et al. 2007). In addition to this 'whole system' approach there is increasing recognition of the importance of social networks in determining how individuals access support, their satisfaction with support and the success of self-care (Young 2004).

1.4 Self-care and children/young people with long-term conditions

Medical advances have improved the survival rates for children/young people with long-term conditions (e.g. cystic fibrosis) and at the same time there has been an apparent increase in the incidence of conditions such as asthma, diabetes and attention deficit hyperactivity disorder (ADHD). Children and young people with long-term conditions face a lifetime of health management and how successfully they manage their health and adapt their lifestyles may influence later outcomes. Similar to the policy literature, the majority of self-care research has been conducted with adult

populations. While there is a developing body of research on how parents and children/young people experience living with long-term childhood illness and children's/young people's illness behaviours, we know little about the different self-care support models being used and which are appropriate and effective for this group. Currently systematic reviews suggest that there is limited evidence on a range of interventions in relation to written action/self-management plans (Toelle and Ram, 2004; Bhogal et al. 2006), psycho-social interventions (Hampson et al., 2001; Yorke et al., 2005), education (Hampson et al. 2001; Couch et al. 2008) and family therapy (Bjornstad and Montgomery, 2005; Yorke and Shuldham, 2005). Although there are reviews that suggest that psycho-social, behavioural and educational interventions may improve outcomes (Wolf et al. 2002; Glasscoe and Quittner, 2008; Daley, 2009). To date the main focus of self-care interventions with children/young people is disease management and information provision (particularly in asthma and diabetes), while the psychosocial aspects of living with a long-term condition has received less attention (Barlow and Ellard, 2004).

Conceptualising self-care in relation to children and young people is complex due to the key role parents play in managing their child's condition as well as its psychosocial consequences for the child and family (Kirk et al. 2005). Consequently the 'self' in this context is a combination of the child and adult carers. The role of parents in providing care and supporting children/young people's self-care fluctuates depending on various factors (age of child; stage of independence; parents' attitude to their children's independence; physical and psychological ability of the child) (Schmidt 2003). In the school age years self-care activities start being assumed by children/young people themselves (Hanna and Guthrie, 2000; Leonard et al. 2005; Dashiff et al. 2006; Meah et al. 2009). The complexity of the transfer of responsibilities from parents to children/young people has been highlighted in a number of recent studies (Williams et al. 2007; Kirk, 2008; Newbould et al. 2008). Transition to self-care involves gradual changes in knowledge, attitudes, behaviour and is influenced by parents, peers and health professionals (Giarelli et al. 2008). Conflicting perceptions have been reported between parents and children/young people about how responsibility for self-care is divided and parents themselves appear to differ in terms of when they feel it is appropriate to transfer self-care responsibilities to their children (Buford, 2004). Adolescence is problematised in the long-term condition literature, being seen as a time of conflict, rebellion, lack of adherence to treatment regimens, adoption of risk-taking behaviours and identity struggles; all of which lead to a deterioration in health status (van Es et al. 1998; Christian et al. 1999; Skinner et al. 2000; Dashiff et al. 2006; Bruzzese et al. 2008). However, it has been noted that these deteriorations may be prevented by parents maintaining an ongoing role during adolescence rather than totally devolving responsibility to their children (La Greca et al., 1995; Anderson et al. 1997).

Factors that appear to promote self-care in children/young people are increased levels of knowledge about their illness; the absence of health

problems; positive self-esteem; individualised care; family, peer and professional support and positive beliefs about the effectiveness of treatment regimes (Skinner et al. 2000; Kyngas and Rissanen, 2001; Dashiff et al. 2006; Herrman 2006). Peers play an important role in influencing self-care (Christian et al. 1999; D'Auria et al. 2000). Research with children/young people with a long-term condition has identified the importance of the goal of being 'normal' and 'fitting in' with peers (Ireland 1997, Prout et al. 1999). 'Being normal' appears to have various dimensions, including appearance, function and social relations. Consequently choices about health care can involve 'trade-offs' between different dimensions (e.g. using an inhaler to improve function may make a child appear different to peers).

Given the different context to self-care for children/young people with long-term conditions it is therefore not surprising that the wholesale transfer of self-care support models used with adults has not been successful (Milnes and Callery 2003; Hawley 2005a). There has been a lack of research examining the best ways of reaching and engaging with children/young people and the potential of the internet (e.g. online courses, chat rooms) and other technologies as a way of supporting self-care (Skinner et al. 2000; Nettleton et al. 2005; McPherson et al. 2006).

1.5 Focus of the study

This study focuses on four long-term childhood conditions that are all reasonably prevalent but which differ in terms of the complexity of self-care management, prognosis and potential for involvement of different NHS organisations as well as non-NHS organisations (e.g. social care). These are asthma, diabetes, cystic fibrosis (CF) and ADHD. Asthma is the most prevalent childhood chronic disease and has been estimated to affect around 1.1 million children/young people in the UK and is managed across the primary and secondary care sectors. Diabetes is increasing in prevalence in part due to the increase in childhood obesity and there are currently approximately 22,783 children/young people with diabetes (97% with Type 1 diabetes) (RCPCH, 2009). Its management is complex and needs close attention to prevent later serious complications. In children/young people clinical management occurs within the secondary and tertiary sectors. CF is the most common inherited life-threatening condition with approximately 8,000 people affected in the UK (Cystic Fibrosis Trust, 2009). The management of this multi-organ condition is complex, intensive and occurs within the context of having a life-limiting condition. In recent years life expectancy has increased with a predicted median age of survival ranging between 35.2 years (Cystic Fibrosis Trust, 2009) and over 50 years (Dodge et al., 2007). Complications can significantly threaten not only quality of life but life expectancy. ADHD is one of the commonest mental health problems in childhood and one of the most common reasons for referral to specialist child and mental health services (Bjornstad and Montgomery, 2005; Daley et al. 2009). It has been estimated that 210,000 children/young people are affected by ADHD though only a minority seek or receive treatment (National Institute for Health and Clinical Excellence,

2008). The symptoms children/young people exhibit means that they are at risk of experiencing significant social and academic impairments which may persist into adult life. The contextual focus for the study is England although the findings may have relevancy for Scotland, Northern Ireland and Wales.

The overall aim of this study was to describe and evaluate current self-care support models for children/young people with long term conditions. The specific objectives were:

1. To identify and describe the range and type of self-care support models for children/young people with long-term conditions.
2. To examine how different models support self-care by children/young people and their parents and assess their success from the perspectives of children/young people, parents and professionals.
3. To identify the factors which promote and inhibit the support of self-care in relation to children/young people with long-term conditions.
4. To investigate how professionals can best support self-care for children/young people.

The project comprised three stages. In the first stage we conducted an evidence synthesis to identify, describe and evaluate different self-care support models (reported in Chapter 2). In the second stage a mapping exercise was conducted to investigate how self-care was being developed in England and the models in operation (reported in Chapter 3). The final stage of the project involved conducting case studies of six purposefully sampled self-care support models (reported in Chapter 4). Throughout the project a reference group of lay and professional experts (Appendix 1.1) has contributed to all aspects of the study, in particular the development of a typology to describe self-care support models and the selection of case study sites. In this study we are using the term 'model' conceptually to describe an approach to self-care support that is comprised of different components.

2 Evidence Synthesis of the Literature

This chapter will present the findings from an evidence synthesis of the literature that examined both the effectiveness of self-care support interventions and participants' views of such interventions. An additional aim of the review was to contribute to the development of a typology for categorising self-care support models.

The approach to the review was informed by the methods developed by the Evidence for Policy and Practice Information (EPPI) Centre (Thomas et al. 2004; Oliver et al. 2005) which combines conventional systematic review techniques with analysis of qualitative research. This method aims to preserve the unique contribution of qualitative and quantitative research but provide a way in which each approach can support the interpretation of the other. In order to do this it uses integrative and interpretive approaches to synthesis. The method involves the conduct of two separate reviews - a quantitative systematic review of trials and a qualitative systematic review of studies that obtain the views of participants (which includes both surveys and qualitative studies). The synthesis from both reviews is then combined using a matrix or framework to juxtapose the findings from each synthesis and uses both a priori codes and themes emerging from the syntheses to group and summarise the findings. This enables the findings from the two reviews to be compared and contrasted in terms of their similarities and differences and highlights the different questions answered by different research methodologies. In this review we are also using the self-care support model typology that was developed both from this review and from other stages of the project (reference group and mapping exercise) as the organising framework for the synthesis of both reviews.

The first section of this chapter will describe how the quantitative review was conducted and its results. The second section will present the conduct and findings from the qualitative review and the final section of the chapter will present the synthesis of both reviews.

2.1 Stage one methods

2.1.1 Objectives of the review

- 1) To identify effective self-care support interventions (and their components) in relation to childhood long-term conditions.
- 2) To identify and describe different self-care support models as the first stage of developing a framework for categorising models.

The review question was 'what types of self-care interventions are effective for children/young people aged 0-16 with the long-term conditions of attention deficit hyperactivity disorder (ADHD), asthma, cystic fibrosis (CF) and diabetes?'

2.1.2 Inclusion criteria for the review

Types of studies

- Randomised controlled trials.
- Non-randomised trials (cohort studies with matched, unmatched concurrent controls or historic controls; case control studies; pre-test/post-test designs; multiple baseline designs).

Types of participants

Studies were included if they focused on children and young people aged 0-16 diagnosed with one of the following long-term conditions: ADHD, asthma, cystic fibrosis and diabetes. In addition studies were included if they involved or focused on parents, peers and professionals that related to this age group.

Types of interventions

A broad definition of self-care support was used to ensure that any intervention was included that aimed to help the child/young person take control of and manage their condition, promote their capacity for self-care and/or improve their health. The target of the intervention, whether child/young person, family member or carer, peer group or professional, needed to be actively involved and engaged in the intervention, rather than be a passive recipient of knowledge or instructions.

Types of outcome

Due to the broad scope of the interventions outcomes were not specified prior to the review. The range of outcomes included can be considered under the following broad areas.

- Individual experience.
- Health status.
- Health care use and costs.
- Psycho-social wellbeing.
- Knowledge and skills.

Language

Only studies published in English were included in the review.

Exclusion criteria

Studies were excluded if there was no before and after measures; if the mean age of the children/young people was above 16.5 or if any individual young person was older than 21; if there was no active involvement of participants in the intervention; if the outcome measures were not (either directly or indirectly) measuring some aspect of the child/young person's health or social functioning or if the study was not in the English language.

2.1.3 Search methods

A range of electronic databases were searched for relevant studies published between January 1st 1995 and December 31st 2007 (Appendix 2.1). The search terms included MeSH and 'free text' terms in combination and was adapted according to the particular database (Appendix 2.2). In addition reference lists of retrieved papers and published reviews were searched for potentially relevant papers. References were managed using Endnote. Restrictions were not applied in terms of research design or methods as a single search was used for both stages of the review. Letters, commentaries and papers only available in abstract form were not included in the review. Unpublished data were not sought from authors.

2.1.4 Methods of the review

The abstracts of the retrieved papers were screened to eliminate those that did not meet the review inclusion criteria. If it is was unclear from the abstract whether papers met the inclusion criteria full paper manuscripts were obtained. Each paper that passed the initial screening process was read and assessed independently for quality and eligibility by two reviewers and data were extracted using a detailed data extraction form based on those developed by the Centre for Reviews and Dissemination (2001) and Marshall et al. (2005) (Appendix 2.3). Any discrepancies in assessments that could not be resolved by discussion and consensus were resolved by arbitration by a third independent reviewer and finally, if necessary, by discussion at a project meeting.

Studies were assessed on the following quality elements:

- Adequacy of randomisation.
- Concealment of allocation.
- Blinding of outcome assessors/data analysts.
- Sample size and use of power calculations.
- Comparability of groups at baseline.
- Level of detail provided about the intervention to identify self-care component.
- Intention to treat analysis.
- Use of validated outcome measures.

- Length of follow-up.
- Identification of confounding factors.

The heterogeneity of the studies, interventions and outcomes prevented a meta-analysis being conducted and hence the findings from the review are reported as a narrative synthesis.

2.2 Stage one results

2.2.1 Description of studies

Results of the search

The search strategy identified 2686 papers which were screened against the review inclusion criteria. A total of 178 papers were assessed as being potentially eligible for inclusion. The rest were excluded on the basis of one or more of the following grounds:

- Participants were over 21 or had a mean age of over 16.5.
- There was no before and after measure by which to assess the intervention's effectiveness.
- The intervention was not related to self-care.
- Participants¹ were not actively involved in the intervention but were merely passive recipients of information.
- There was no objective outcome measure of effectiveness.
- The study was not reported in English.

These 178 papers were reviewed for quality and eligibility and 33 papers describing 29 studies were judged as adequate to include in the review. Table 1 shows the numbers of papers for each of the four conditions at each stage of the screening and reviewing process.

¹ This was where children/young people were the target of the intervention. If the targets were adults e.g. parents or professionals the age limits stated applied to the children/young people they were supporting

Table 1. Number of papers screened/assessed for each long-term condition

Screening/assessment stage	ADHD	Asthma	Cystic fibrosis	Diabetes	Total
Identified from databases for initial screening	75	629	156	1673	2533
Identified from reference lists for initial screening	37	73	12	31	153
Total screened	112	702	168	1704	2686
Assessed using data extraction form	19	95	11	53	178
Included papers	3 (2 studies)	18 (16 studies)	3 (3 studies)	9 (8 studies)	33 (29 studies)

2.2.2 Description of the included studies

The key features of the 29 studies (design, type of intervention and results are summarised in Appendix 2.4).

Design

All the included studies were randomised controlled trials. The studies that had used other designs did not meet quality criteria appropriate to their designs. The majority (22) of studies compared one intervention with one control. Five studies compared two interventions with one control and two compared three interventions with one control. Sample sizes ranged from 40 to 1033. Follow-up periods ranged from two months to two years; the most common follow-up period was 7-12 months (Table 2). The majority of the included papers were published between 2003 and 2007 (Table 3).

Table 2. Duration of study participant follow-up (n=29)

Length of follow-up	Number of studies
6 months or less	11
7 - 12 months	12
13 - 24 months	6

Table 3. Year of publication of included papers (n=33)

Publication Year	Number
1995-1998	0
1999-2002	13
2003-2007	20

Setting

The majority of studies (15) were conducted in the United States of America (USA). Seven studies were conducted in the UK, three in Australia and two in Canada. One study was conducted in Spain/Cuba/Uruguay and one study was conducted in Taiwan.

Participants

Overall, the age-range covered was 0 to 20 years, with two interventions aimed only at children under 6 years old (Sonuga-Barke et al., 2001; Stevens et al., 2002) and seven aimed only at adolescents/teenagers (Grey et al. 2000; Shah et al. 2001; Wysocki et al. 2001; Cook et al. 2002; Ellis et al. 2005, 2007; Franklin et al. 2006; Joseph et al. 2007). Most interventions were aimed at children/young people in a specific age range, for example, 5–11 years, 6–12 years, 7–17 years or 8–16 years. All studies included both genders.

Where data on the gender and ethnicity of participants were reported, the majority of studies had a higher proportion of male children and a higher proportion of Caucasian participants in their samples.

Self-care interventions

The majority of the studies (16) focused on asthma, with eight being on diabetes, three on cystic fibrosis and two on ADHD. Eleven studies targeted the child/young person only, with 14 focussing on the family or child/young person and their parent/carer. One study described an intervention targeted at professionals alone (primary care physicians), although a further two interventions included components directed at professionals (physicians and school teachers) as well as families (Table 4). Three asthma studies were targeted at children/young people from urban/inner-city areas and one focussed only on African-American children/young people. Two diabetes interventions were targeted at children/young people with poor glycaemic control. The characteristics of the interventions investigated in each study are presented in Appendix 2.8

Table 4. Target of self-care interventions

Target	Studies
Children under 6 years (2)	Sonuga-Barke <i>et al.</i> (2001); Stevens <i>et al.</i> (2002)
Adolescents/teenagers (7)	Cook <i>et al.</i> (2002); Ellis <i>et al.</i> (2005, 2007); Franklin <i>et al.</i> (2006); Grey <i>et al.</i> (2000); Joseph <i>et al.</i> (2007); Shah <i>et al.</i> (2001); Wysocki <i>et al.</i> (2001)
Children/young people living in inner city/urban areas (3)	Evans <i>et al.</i> (1999)/Sullivan <i>et al.</i> (2002); Guendelman <i>et al.</i> (2002,2004); Joseph <i>et al.</i> (2007)
African-American children/young people (1)	Joseph <i>et al.</i> (2007)
Children/young people with poor glycaemic control (2)	Ellis <i>et al.</i> (2005, 2007); Nunn <i>et al.</i> (2006)
Children/young people only (11)	Joseph <i>et al.</i> (2007); Franklin <i>et al.</i> (2006); Christian and D'Auria (2006); McPherson <i>et al.</i> (2006); Cook <i>et al.</i> (2002); Guendelman <i>et al.</i> (2002,2004); Patterson <i>et al.</i> (2005); Grey <i>et al.</i> (2000); Jan <i>et al.</i> (2007); Shah <i>et al.</i> (2001); Davis <i>et al.</i> (2004)
Parents only (3)	Dolinar <i>et al.</i> (2000); Stevens <i>et al.</i> (2002); Sonuga-Barke <i>et al.</i> (2001)
Child and parent/family (14)	MTA (1999,2004)*; Cicutto <i>et al.</i> (2005); Krishna <i>et al.</i> (2003); Lozano <i>et al.</i> (2004)*; Wesseldine <i>et al.</i> (1999); Murphy <i>et al.</i> (2007); Wysocki <i>et al.</i> (2001); Cano-Garcinuna <i>et al.</i> (2007); Evans <i>et al.</i> (1999)/Sullivan <i>et al.</i> (2002); Walders <i>et al.</i> (2006); Ellis <i>et al.</i> (2005, 2007); Nunn <i>et al.</i> (2006); Svoren <i>et al.</i> (2003); Downs <i>et al.</i> (2006).
Professionals (3)	Clark <i>et al.</i> (2000); Lozano <i>et al.</i> (2004)*; MTA (1999, 2004)*.

*Part of an intervention including both families and professionals

Studies investigated a wide range of interventions and outcomes but all included some element of education or training of the child, parent/family or professional as an intervention component. Other components included behavioural therapy, enhancing communication and problem solving skills, counselling and support.

Location and mode of delivery of the self-care intervention is presented in Table 5. The setting for 12 studies was the home/community, seven were provided in hospital/clinics and four interventions were school-based. In two studies elements of the interventions were delivered in different settings; community and school (MTA, 1999, 2004) and clinic and home (Christian and D'Auria, 2006). For a further four studies it was unclear where the intervention had been provided (Clark *et al.* 2000; Grey *et al.* 2000; Wysocki *et al.* 2001; Cook *et al.* 2002). Only one of the interventions was lay-led (Shah *et al.* 2001).

Table 5. Location and mode of delivery of the self-care intervention

Location of the delivery of the intervention	Studies
Home/community setting (12)	Sonuga-Barke <i>et al.</i> (2001); Cano-Garcinuna <i>et al.</i> (2007) Dolinar <i>et al.</i> (2000) Guendelman <i>et al.</i> (2002,2004) Jan <i>et al.</i> (2007) Lozano <i>et al.</i> (2004) McPherson <i>et al.</i> (2006) Ellis <i>et al.</i> (2005, 2007) Franklin <i>et al.</i> (2006) Nunn <i>et al.</i> (2006) Downs <i>et al.</i> (2006); Evans <i>et al.</i> (1999)/Sullivan <i>et al.</i> (2002)
Hospital (clinic, ward) (7)	Krishna <i>et al.</i> (2003) Stevens <i>et al.</i> (2002) Walders <i>et al.</i> (2006) Murphy <i>et al.</i> (2007) Svoren <i>et al.</i> (2003) Wesseldine <i>et al.</i> (1999) Davis <i>et al.</i> (2004)
School (4)	Cicutto <i>et al.</i> (2005) Joseph <i>et al.</i> (2007) Patterson <i>et al.</i> (2005) Shah <i>et al.</i> (2001)
Combination (2)	MTA (1999,2004); Christian and D'Auria (2006)
Unclear (4)	Clark <i>et al.</i> (2000); Cook <i>et al.</i> (2002); Grey <i>et al.</i> (2000); Wysocki <i>et al.</i> (2001)
Mode of delivery of the intervention	
Individual child/family (18) (includes interventions that are self-directed/self-study)	Guendelman <i>et al.</i> (2002,2004); Joseph <i>et al.</i> (2007); Nunn <i>et al.</i> (2006) Svoren <i>et al.</i> (2003) Wysocki <i>et al.</i> (2001) Lozano <i>et al.</i> (2004)*; Davis <i>et al.</i> (2004) Dolinar <i>et al.</i> (2000) McPherson <i>et al.</i> (2006) Wesseldine <i>et al.</i> (1999) Downs <i>et al.</i> (2006) Jan <i>et al.</i> (2007) Stevens <i>et al.</i> (2002) Ellis <i>et al.</i> (2005, 2007) Sonuga-Barke <i>et al.</i> (2001) Krishna <i>et al.</i> (2003) Walders <i>et al.</i> (2006) Franklin <i>et al.</i> (2006)
Group based (9)	Patterson <i>et al.</i> (2005) Cook <i>et al.</i> (2002) Cano- Garcinuna <i>et al.</i> (2007) Clark <i>et al.</i> (2000) Shah <i>et al.</i> (2001) Grey <i>et al.</i> (2000) Cicutto <i>et al.</i> (2005) Lozano <i>et al.</i> (2004)*; Murphy <i>et al.</i> (2007)
Combination of individual and group based (4)	Evans <i>et al.</i> (1999)/Sullivan <i>et al.</i> (2002); Christian and D'Auria (2006); MTA (1999, 2004) Lozano <i>et al.</i> (2004)*
Use of computer games, internet, mobile phone technology and other e-health modes of delivery (9)	Krishna <i>et al.</i> (2003) Jan <i>et al.</i> (2007) Franklin <i>et al.</i> (2006) Davis <i>et al.</i> (2004) Guendelman <i>et al.</i> (2002,2004) Joseph <i>et al.</i> (2007) McPherson <i>et al.</i> (2006) Nunn <i>et al.</i> (2006) Christian and D'Auria (2006) [#]

*Intervention targeted at families was individually based while the intervention targeted at physicians was group based.

[#] Small component only.

The majority of the interventions (18) were delivered to an individual child or family but in eight studies the intervention was delivered on a group

basis and four interventions used a combination of individual and group processes. In nine studies the intervention was delivered via an e-health² mode of delivery. This included computers (e.g. CD ROMs or internet), text-messaging systems and telephone support and education.

Twenty one interventions reported no explicit underlying theoretical basis (Table 6). Where a theoretical basis was reported the main ones identified were self-regulation (n=2), social cognitive theory (n=2) and the PRECEDE (predisposing, reinforcing, and enabling causes in educational diagnosis and evaluation) health education model (n=2).

Table 6. Theoretical underpinning of self-care interventions (n=29)[#]

Theory	Number
None	21
Self regulation	2
PRECEDE	2
Social Cognitive	2
Developmental	1
Health Belief Model	1
Social Learning Theory	1
Social Ecological Theory	1
Transtheoretical Theory	1

[#]Some interventions identify more than one underpinning theory

Outcomes assessed

The studies assessed a wide range of outcomes in evaluating the effectiveness of the interventions with only 15 identifying a clear primary outcome. The most common were morbidity/health status, knowledge/skills acquisition, health care utilisation and quality of life. Only a minority of studies included an assessment of health care or intervention costs (n=2) or participant satisfaction (n=5). As previously noted, follow up of participants ranged from two months to two years (Table 2).

2.2.3 Results from the intervention studies

Meta-analysis is inappropriate for this review due to the heterogeneous nature of the studies in relation to populations, interventions and outcomes. Instead the results will be narratively reported by condition and in a later section (Section 2.2.5) synthesised across conditions. In this section the

² E-health is the use of emerging information and communications technology, especially the internet, to improve or enable health and healthcare (Eng, 2001)

results from the studies are summarised and presented by condition. Details on their design, their quality and the self-care interventions investigated are provided in Appendices 2.4, 2.5 and 2.8 respectively.

ADHD studies

Information provided in Appendix 2.4 shows that the two ADHD studies (MTA Cooperative Group, 1999, 2004; Sonuga-Barke et al., 2001) were different in terms of study design, sample size, target population and the nature of the intervention. In one trial three interventions were investigated with children/young people aged between seven and nine years of age (MTA Cooperative Group, 1999, 2004). These were medication management carefully titrated to the child's individual needs; behaviour treatment which involved group-based parent skills training, child therapy via a summer camp and school based support for teachers and children/young people; and a combination of medication management and behaviour treatment. Medication management was more effective than behavioural treatment alone or standard community care (the control – which included medication) in reducing ADHD symptoms (inattention, hyperactivity and impulsivity). In addition there were no significant differences between the effects of medication management or combined treatment (medication management and behavioural treatment) on symptoms. In sum all treatment groups improved over time but medication was relatively more effective in reducing symptoms. Combined treatment and medication management alone were superior to behaviour treatment and standard care in reducing symptoms. The three treatments did not differ significantly from each other in relation to their effects on social skills, academic performance, parent-child relationships and anxiety and depression. There is a lack of clarity over who administered the outcome measurements and there are some age differences between the control and intervention groups at baseline but overall this is a well conducted study. It was the first large scale trial for a childhood mental health condition and at the time was controversial in its findings relating to the superiority of medication management. However, the study results are complex and extensive and as a result have been subject to misinterpretation (Cunningham, 1999; Schachar, 1999; Pelham, 1999).

The second study was conducted in the UK and focused on mothers of three year old children with ADHD (Sonuga-Barke et al., 2001). They received individual home-based parent training or counselling/support provided by specially trained health visitors. Parent training involved education about ADHD and behaviour management strategies, whereas the counselling/support intervention focussed on exploring parents' feelings. The study found that parent training was effective in reducing ADHD symptoms whereas parent counselling/support had little effect on symptoms. This study did not investigate the effect of medication management. There were problems with the randomisation in this study which led to fewer children/young people being assigned to the control group and there is unclear reporting of sample attrition. The comparability of the groups at baseline is not reported.

These studies, although different, both suggest that behavioural treatment (including skills training) can be effective in reducing ADHD symptoms.

Asthma studies

The 16 trials focusing on childhood asthma mainly used a two arm design (one intervention group and one control group) to investigate the effectiveness of the intervention (n=14). Sample sizes range between 40 and 961 and length of follow up ranges from three months to two years. Three of the interventions were aimed at children/young people living in urban/inner city areas and one was targeted at African-American children/young people. Two interventions were aimed at parents only and two at professionals. Two studies targeted young people/parents following a hospital admission/Accident and Emergency Department (A&E) attendance (Wesseldine et al., 1999; Stevens et al., 2002). Five studies evaluated computer games or e-health technologies.

All the 16 asthma studies incorporated an educational and/or training component. Common features were the tailoring of the intervention to individual situations and goals and the development of self-management skills (either those of children/young people themselves or their parent's skills in managing their child's condition). Two of the interventions were specifically targeted at practitioners although other interventions had elements that aimed to change practitioner behaviour.

Interventions aimed at only children/young people

A UK based study conducted by McPherson et al. (2006) used an interactive game, 'The Asthma Files', to provide information about asthma and its self-management. The game involves different activities, quizzes, problem solving tasks and allows the child to engage in role play. A researcher visited all intervention group children/young people at home, taking 'The Asthma Files' on a laptop computer. Children/young people used the CD-ROM during the researcher's visit and were given a copy to keep. In addition the child's peak flow measurements and asthma triggers were entered into the programme to produce a self-management plan. At one-month follow-up, the intervention group reported increased asthma knowledge and a greater internal locus of control. No effects were reported on lung function (PEF (Peak Expiratory Flow)), school absences, GP (General Practice) visits or hospital admissions. At six-months, children/young people in the intervention group reported a lower use of oral steroids and fewer school absences. However, an intention to treat analysis revealed that there was no significant difference between groups for these outcomes. Asthma knowledge was not measured again at six months. The data collection method varied at the two follow-up points. At one month data were collected face-to-face and at six months over the telephone. There was also a lack of standardisation in the timing of some of the measurements which may have led to measures being taken at times of the day when the child's asthma was at its worst or best. There were also significant baseline differences between the control and intervention group in relation to age and knowledge. However, appropriate analyses were conducted to examine the potential confounding effects of these factors.

Another study using a computer-based educational programme was that of Joseph et al. (2007) which targeted African-American students in Grades 9-11 at urban high schools. The intervention was a multimedia, web-based asthma management programme, 'Puff City', which students accessed via computers at schools. It focused on the use of controller medication and rescue inhalers as well as smoking behaviour. The programme used the Transtheoretical model and the Health Belief Model to provide health messages and information tailored to the needs of individual students, based on their beliefs, attitudes and barriers to change. The intervention group reported reductions in asthma symptoms, absences from school, hospitalisations for asthma and restricted activity days. However, there were no differences in relation to smoking reduction or cessation between the intervention and the control group. Follow up data at 12 months post intervention were collected irrespective of the number of sessions that students had completed but this potential confounder was accounted for in the analysis.

Another e-health intervention was investigated by Guendelman et al. (2002; 2004) who used an asthma self management and education programme, 'Health Buddy', with 8-16 year old inner city children/young people. This device was connected to a home phone and presented questions and information on a screen to children/young people on a daily basis. The questions and information were designed to help the children/young people to be more aware of their asthma symptoms and their monitoring and to gain more control over their asthma. The child responded to the questions by pressing one of four buttons, and information was automatically transmitted via a data-processing centre to a secure website where a case manager monitored the responses. In the study the device was used every day for 12 weeks. The intervention group was found to report fewer limitations in activities due to asthma; fewer peak flow recordings in the yellow or red zones³ and make less use of health services. Self-care behaviours were also found to have improved more for the intervention group. However it appeared that the 'Health Buddy' only brought about short term improvements as by 12 weeks both intervention and control groups had improved and there was no significant difference between them. There is a lack of well validated outcome measures in this study (recognised by the authors) and substantial missing data in relation to peak flow measurements.

A different type of e-health intervention was investigated by Jan et al. (2007) which used an interactive, internet-based telehealth system, 'Blue Angel', with children/young people aged 6-12 years old for the purposes of symptom monitoring and self-management. Those allocated to the 'Blue Angel' group entered their asthma symptoms, lung function and medication use into a website on a daily basis. Adjustments to their asthma management (if needed) were determined by a decision support system and

³ The American Lung Association classifies peak flow readings into three zones – green, yellow and red. Red indicates a medical emergency (readings <50% of usual PEF) and yellow a significant exacerbation of asthma (readings 50-80% of usual PEF)

by communications from physicians. In addition the system provided an asthma action plan, information about asthma and allowed the child to keep an electronic asthma diary and to review their data. The intervention group reported decreased asthma symptoms, improved lung functioning, increased self-management knowledge, increased adherence and improvements in quality of life. The study used validated outcome measures although it is unclear if an intention to treat analysis was conducted.

Another group of studies used more traditional methods of self-care support. In a UK study school-based weekly asthma clubs were run over eight weeks at lunchtime, delivered by community nurses (Patterson et al. 2005). The theoretical framework for the intervention was the PRECEDE health education model. The programme provided information about asthma and self-management and included games and role play to raise self-esteem. Children/young people were also provided with opportunities to practice their inhaler technique. In addition children/young people completed a workbook and developed an asthma action plan. The intervention was found to improve inhaler technique but neither quality of life nor spirometry results improved significantly compared with the control group. Comparability of the control and intervention groups at baseline and the conduct of an intention to treat analysis were not reported.

The effectiveness of a school-based, peer-led education programme, the 'Triple A Program', was investigated by Shah et al. (2001). This whole school programme was designed to promote children's/young people's asthma self-management and involved training volunteer Year 11 students as asthma peer leaders. These students then worked in teams, delivering three 45 minute sessions to all Year 10 students using games, videos, worksheets and discussions to explore the barriers to asthma self-management. These Year 10 students then presented the key messages that they had taken from the sessions to all Year 7 students using drama and music. In addition teachers at the three intervention schools received asthma related information and local doctors attended a workshop on the management of adolescent asthma. The outcome measures were completed three months after the intervention by children/young people with asthma who had previously been identified at the six schools. Year 7 and Year 10 children/young people with asthma in the intervention schools showed significant improvements in quality of life scores and school absenteeism. The effect of the intervention was reported to be greatest in Year 10 students and female students. However, there were more females in the intervention group but the effect of this was investigated and accounted for in the analysis (as was the possibility of clustering effects).

Interventions aimed at only parents

Two interventions were aimed at parents. One educational intervention was designed to be administered in a hospital setting following a child's hospital admission for an asthma exacerbation (Stevens et al., 2002). This UK study comprised a parent focused intervention that is delivered on an individual basis by two 20 minute structured educational sessions on the day of

discharge and one month later, combined with a written self-management plan and an asthma education booklet. The first educational session was delivered in different locations; it was provided on a ward if the children/young people had been hospitalised or in clinic setting if the child had attended an Accident and Emergency Department. No statistical differences were found between the intervention and control groups for any of the outcomes measured (these related to health care utilisation, reported asthma symptoms, quality of life, asthma knowledge). Minor adaptations were made to two existing validated measures (Index of Perceived Symptoms in Asthmatic Children and Paediatric Asthma Caregiver's Quality of Life Questionnaire) but there is a lack of detail on the nature of the adaptations and their impact on reliability.

A study by Dolinar et al. (2000) also delivered an educational intervention to parents. The intervention in this study was a single two hour home-based education session (plus information booklet) for parents with children under 11 years old that aimed to help them cope with their child's asthma. The intervention was reported to reduce parental concerns and their need for information and increase their use of coping strategies. Parental quality of life was unchanged. However, there are methodological limitations to this study. Reasons for attrition are not reported and the completion of outcome measures is unclear. In addition both the conduct of an intention to treat analysis and the statistical tests used to investigate differences in outcomes scores are not reported.

Interventions aimed at both children/young people and parents

In a school-based asthma education programme, 'The Roaring Adventures of Puff', Cicutto et al. (2005) used certified asthma educators to deliver six group sessions for children/young people. Parents only attended the final session which showcased the children's learning. The programme was underpinned by social cognitive theory and self regulation and included sessions on using a peak flowmeter, identifying triggers, using medications and inhalers. These were delivered via a variety of methods, including puppetry, games, role playing and discussions. Family-based homework activities were included in the programme to involve parents. In comparison with the control group the intervention improved quality of life and self-efficacy and reduced urgent health-care visits, school absences and days disrupted by asthma. However, data on self-efficacy and quality of life were only collected at the two month follow-up whereas other measures (e.g. health care utilisation) were repeated up to 12 months post intervention.

Another study used a computer-based asthma education programme (IMPACT) with children/young people and parents during routine clinic visits as a means of developing knowledge and skills in decision-making and communication (Krishna et al. 2003). The programme was used by parents of 0-6 year olds and 7-17 year olds used the programme themselves whilst their parents observed. The programme was delivered over the internet

and comprised 44 lessons each lasting about one minute in length. These included decision-making scenarios and exercises to encourage better reporting of symptoms and medication use. The intervention was found to increase both children's/young people's and parents' asthma knowledge; decrease the number of asthma symptom days reported and visits to the emergency room. However, there are significant methodological limitations to this study. The method of randomisation is not reported and the outcome measures are not fully described. The reporting of the data is unclear and the conclusions made about increases in knowledge are not supported by the data presented.

A study by Cano-Garcinuna et al. (2007) delivered an intervention to groups in primary care centres. There were three different intervention arms: children/young people only, parents only, and both children/young people and parents. The intervention comprised three educational sessions, each lasting 45-60 minutes and delivered at fortnightly intervals. The content included causes and triggers of asthma, treatment and use of inhalers, managing asthma attacks and sports activities and the emphasis in all the sessions was on self-management. The language used in the sessions was modified for children/young people but it is unclear if other modifications were made to make the intervention appropriate for children/young people. Reductions in asthma attacks and hospitalisations were only reported in the intervention that involved children/young people (alone or in the parent/child study arm). There was no effect on quality of life for any of the groups. However, the study was underpowered for detecting a significant difference in quality of life, due to a higher than expected standard deviation. In addition, baseline quality of life scores were high. An intention to treat analysis was conducted but only with those who discontinued the intervention and not those who were lost to follow-up.

Some studies have conducted trials of interventions targeted at particular 'at risk' groups. Walders et al. (2006) focused on 'undertreated' children/young people who were defined as those without a written treatment plan and at least two asthma-related emergency department visits or at least one hospital admission over the last year. Families in the intervention arm received a one hour asthma education session from an asthma nurse and an asthma risk profile assessment to identify families' specific barriers to asthma management. Other components of the intervention were a cognitive behavioural problem-solving session tailored to the individual families' needs, a follow-up telephone consultation to reinforce the therapy; access to a 24 hour advice line; a written asthma treatment plan; one month's medication; a peak flow-meter and an inhaler. The intervention group used medical services significantly less than the control group but otherwise there were no differences reported. Indeed both groups reported reductions in asthma symptoms and improvements in quality of life but this may relate to the control group also having been supplied with a written asthma treatment plan; one month's medication; a peak flow-meter and an inhaler. In addition the majority of initial measures were not taken before randomisation and the provision of a written treatment plan.

Another study focused on examining the effectiveness of a discharge package for children/young people admitted to hospital for an acute asthma episode (Wesseldine et al. (1999)). The intervention comprised a nurse-led education session for parents and children/young people that emphasised self-management. Families were also given a self management plan and an asthma information booklet. The intervention was effective in reducing hospital readmissions, GP visits for asthma and accident and emergency attendance over a six month follow-up period. Overall this is a well conducted study with very few methodological limitations.

The final study in this group of interventions aimed at both children/young people and parents is the National Cooperative Inner-City Asthma Study reported in Evans et al. (1999) and Sullivan et al. (2002) and conducted in the USA. This particular intervention used specially trained social workers as asthma counsellors who worked with families living in inner city areas to improve their communication with physicians, to help the families eliminate asthma triggers, and to address any other barriers to effective asthma self-management. Initially parents attended two group asthma education sessions and had one individual meeting with their asthma counsellor. Following on from these sessions, children/young people attended two group sessions. There was ongoing monthly contact with the asthma counsellor by telephone or face-to-face for up to a year or as necessary to address individual needs. The intervention also incorporated environmental control measures (e.g. pillow and mattress covers) to reduce triggers and the childrens' primary care physicians were sent an asthma action plan, the latest clinical guidelines, a peak flow meter and a spacer device. The intervention was associated with a reduction in asthma symptom days and fewer hospitalisations. However, there is a lack of detail regarding the statistical tests used. A cost effectiveness analysis conducted alongside the RCT assessed the intervention to be a cost-effective one particularly for those with the most severe asthma. It improved outcomes at an average additional cost of \$9.20 per symptom free day gained.

Interventions aimed at practitioners or service delivery reorganisation

Two studies described interventions targeted at health professionals (Clark et al., 2000; Lozano et al., 2004). Clark et al. (2000) investigated an educational intervention that aimed to develop the teaching and communication skills of general practice paediatricians using interactive seminars based on self-regulation theory. In addition the latest clinical guidelines were discussed with participants. Physicians in the intervention group were found to be more likely to use treatment protocols and provide guidance on modifying therapies. Parents scored physicians in the intervention group higher on communication behaviours and their children/young people had fewer hospital admissions and emergency department visits. There was no effect on length of consultation time. The study has a number of methodological limitations. The randomisation method is unclear and there is a high level of attrition of parents. It is not reported whether an intention to treat analysis was conducted.

Standardised outcome measures were not used to measure communication behaviour within this study and there is no reporting of reliability and validity.

Another intervention investigated the effectiveness of an intervention that educated primary care physicians using a peer leader programme to become an 'asthma champion' for their practice (Lozano et al. 2004). This programme included education about asthma as well as support in developing a change agent role. This intervention was used with or without a planned care intervention in which a trained asthma nurse worked in conjunction with the physicians to support asthma self-management behaviours in families as well as standardising procedures in the practice for assessment. The nurse visited families four to five times over two years to assess and develop self-management skills and support care planning. Telephone support was provided between visits. Planned asthma care in combination with peer leadership significantly reduced asthma symptom days compared with peer leader education alone. Both interventions reduced the use of steroids and had positive effects on functional status. However, the method of randomisation is not reported and a number of confounding factors were identified that might contribute to the results (there was a greater use of reliever medications in the usual care sample and parental level of education was higher in the planned care intervention group).

Two other studies had interventions incorporating elements that involved professionals but in a more marginal way (see Evans et al. 1999/Sullivan et al. 2002; Shah et al. 2001).

Conclusions

As previously noted the asthma self-care interventions are varied in focus, method of delivery, the outcomes measured and the measurement tools used. They also vary in terms of their methodological quality. The most common outcomes measured are health status (e.g. lung function, asthma symptoms) and health service use. Interventions focusing on children/young people alone or with their parents appear to be able to improve health status and reduce health service use irrespective of whether they use a group or individual approach. Similarly interventions targeted at practitioners appear to be effective in improving health status and reducing health service use. Although all the interventions had an educational element, only two studies measured knowledge as an outcome. Both of these interventions used e-health methods and were found to be effective in increasing children's/young people's and parent's knowledge of asthma and its management. Interventions focusing on children/young people alone demonstrated an increase in children's/young people's quality of life. This effect was not demonstrated in interventions that included parents apart from a short-term effect in one study. Outcomes such as self-efficacy and coping skills have been under-examined in this group of studies.

Cystic fibrosis studies

Three studies focusing on children and young people with cystic fibrosis were included in the review (Davis et al., 2004; Christian and D'Auria, 2006; Downs et al., 2006). The age of the children/young people in the studies ranged between 6 and 17 years old. The studies were similar in design although there were differences in terms of sample size (range 47-116), length of follow-up (2-12 months) and the outcomes measured. There was an educational component to all the interventions (although delivered in different ways) and one also included social skills training (Christian & D'Auria, 2006). Two of the studies targeted the intervention at children/young people only (Davis et al., 2004; Christian & D'Auria, 2006) and the third targeted both children/young people and their parents (Downs et al., 2006). None of the included interventions were aimed only at parents.

One study investigated the effectiveness of a problem-solving and social skills development programme ('Building CF Life Skills') for children/young people aged between eight and 12 (Christian and D'Auria, 2006). It combined a home visit to each child to provide individualised information about CF (via written materials and a computer program) with group work that focused on problem solving and social skills training. The intervention was associated with reductions in reported perceptions of illness impact and of loneliness (Christian and D'Auria, 2006). There was no effect on perceived support from peers or health status (lung function). Self-worth increased in both the control and intervention groups. This is a well conducted study that uses valid and reliable outcome measures, has no sample attrition and which meets all the quality assessment criteria (see Section 2.1.4).

Another study that examined an intervention focused only on children/young people was that of Davis et al. (2004). This intervention was a computer based program 'STARBRIGHT Fitting Cystic Fibrosis Into Your Life Everyday' which aimed to educate children/young people about CF and develop their coping skills. The program covered issues such as eating and breathing and was viewed by children/young people at a routine clinic visit. The intervention was associated with increasing children's/young people's knowledge of CF and the competency of their coping strategies. Although a well conducted study not all the participants completed measures at the same time (time point two ranged from two to three months post intervention) and it is unclear if all participants completed all the follow-up measures. The questionnaire used to measure knowledge was adapted from a more comprehensive knowledge measure. Although the reliability of the adapted questionnaire is high, the questionnaire itself nor the adaptations are described sufficiently.

The study conducted by Downs et al. (2006) investigated the effectiveness of 'Airways', a self-management education programme for primary school aged children/young people and their parents. Described as a 'pen and paper' programme, families were sent written information and exercises to

complete at home together. Every three weeks parents received a telephone call to answer any questions and encourage their participation but this does not appear to have included the provision of other forms of support to the family. The intervention was found to increase adherence to aerosols and children's/young people's knowledge of airway clearance techniques but was reported to have no effect on parents' reports of self-efficacy or self-management behaviours. The study used reliable and valid outcome measures. An intention to treat analysis was conducted which was important given that attrition was higher in the intervention group.

In relation to cystic fibrosis it appears that self-care interventions aimed at children/young people (with or without their parents) may increase their knowledge of the condition and improve their psycho-social adaptation. However, there is a lack of evidence on improvements in health status and studies have under-examined outcomes such as quality of life and health care utilisation.

Diabetes studies

Eight diabetes studies were included in the review. Children/young people in the studies ranged between 3 and 20 years old and all included children/young people up to the age of 16. Five studies compared one intervention group with a control and three had two treatment arms. Follow-up periods ranged from six months to two years and sample sizes ranged from 49 to 299. Two studies targeted the intervention at children/young people with poorly controlled diabetes (Ellis et al., 2005, 2007; Nunn et al., 2006). Three studies involved interventions that aimed to address family relationships (Wysocki et al., 2001; Ellis et al., 2005, 2007; Murphy et al., 2007) and their influence on the control of diabetes. Two studies investigated interventions that focussed on the development of children's/young people's problem solving or coping skills (Grey et al., 2000; Cook et al., 2002). Two studies have examined the effectiveness of different models of service provision (Svoren et al., 2003; Nunn et al., 2006). The final diabetes study examined the effectiveness of a text-messaging support system on self-management and self-efficacy (Franklin et al., 2006).

Three of the studies targeted the intervention at children/young people only (Grey et al. 2000; Cook et al. 2002; Franklin et al., 2006) and five targeted both children/young people and their parents (Wysocki et al. 2001; Svoren et al., 2003; Ellis et al. 2005, 2007; Nunn et al., 2006; Murphy et al., 2007). None of the included studies examined interventions aimed only parents.

Interventions aimed at only children/young people

In one study a problem solving group based diabetes education programme ('Choices') for children/young people aged between 13 and 17 was investigated (Cook et al. 2002). Children/young people in the intervention

group took part in weekly group based sessions for six weeks to discuss the problems they experienced in managing their diabetes, identify solutions and to set individual behaviour change goals. The intervention group were found to test their blood glucose more frequently but otherwise no significant differences were reported between the control and intervention group in relation to problem solving skills or glycaemic control. The randomisation method used in the study is not reported and some details of the intention to treat analysis are unclear.

A study conducted by Grey et al. (2000) examined the effectiveness of a six week group-based coping skills training (in combination with intensive diabetes management). The control group received intensive diabetes management only. Role playing of scenarios that exemplified difficult social situations were used to develop appropriate problem solving and coping skills. The intervention was found to improve glycaemic control, quality of life and self-efficacy. In addition for female participants it was associated with decreased weight gain and a reduction in the number of hypoglycaemic episodes. However, there are a number of limitations with this study. The method of randomisation is unclear and no intention to treat analysis is reported. Data collected to measure the effect of the intervention on psychosocial functioning is not reported in the paper.

A third study investigated an intervention that aimed to support self-management rather than develop problem solving or coping skills and used an e-health medium. Franklin et al., (2006) examined the effectiveness of a text-messaging self-management support system ('Sweet Talk') on glycaemic control and behavioural change. The intervention ('Sweet Talk') was delivered both with and without intensive insulin therapy. Young people received daily text messages, drawn from a database of over 400 messages that were designed to reinforce goals set in clinic. The messages covered topics such as insulin injections, healthy eating and blood glucose testing and provided tips, information or reminders, including a weekly reminder of their personal goal. The study found that Sweet Talk increased self-efficacy and self-reported adherence and when in combination with intensive insulin therapy also improved glycaemic control. There was no treatment group to assess if intensive insulin therapy alone would have the same effect and the reliability of the scales used was unclear, however otherwise this was a well conducted study.

Interventions aimed at both children/young people and parents

In one study Ellis et al., (2005, 2007) investigated the effectiveness of a multi-systemic, psychotherapeutic intervention (MST) for children/young people aged between 10 and 17. There are a number of components to the intervention. Intensive individualised family therapy based on cognitive behavioural therapy, parent training and family systems therapy which focused on areas such as family communications, discipline systems and promoting parental engagement with the diabetes regimen. A school based component which aimed to improve family-school communication about the diabetes regimen; involve school personnel in monitoring and support and

engage peers support. A community component developed strategies to enable the young person's participation in activities while managing their diabetes care. A fourth component targeted the health care system by helping families attend appointments and promoting positive relationships between the family and the diabetes team. It was found that MST improved glycaemic control, increased frequency of blood glucose testing, decreased hospital admissions and improved family relationships for children/young people in two-parent families (but not those living in lone parent families). The analysis however, did not take account of the number of times families were seen by the therapist. In addition the randomisation method was unclear and there were significantly more males in the intervention group.

A study conducted by Wysocki et al. (2001) examined the effectiveness of another multi-component intervention 'Behavioural-Family Systems Therapy' (BFST) for families with a child aged between 12 and 17. This intervention comprised four therapy components (problem-solving training, communication skills training, cognitive restructuring and functional and structural family therapy). Family therapists use the four components in accordance with each family's needs. In addition to the control group, another group received education and support via group based meetings (this excluded family communication and conflict resolution skills). The study found that BFST improved parent-adolescent relationships and adherence to treatment regimen. However, it had no effect on adolescents' adjustment to diabetes or diabetic control. The control and intervention groups in this study differed significantly at baseline although appropriate analyses were conducted to investigate these differences and account for them in the analyses.

A third study that focussed on family relationships tested a family-centred structured education programme and was conducted in the UK (Murphy et al., 2007). The intervention comprised four small group sessions, which focussed on carbohydrate counting, insulin dose adjustment, child-parent responsibilities and communication. The study reported no significant difference between the control and intervention groups in relation to glycaemic control, parental responsibility or quality of life. However, the study was under powered with only 78 of the required 90 families participating. Neither the randomisation method nor the comparability of the intervention and control group at baseline were reported.

Interventions aimed at service delivery reorganisation

Two studies have investigated the effectiveness of different models of service provision (Svoren et al., 2003; Nunn et al., 2006). Nunn et al. (2006) tested the effectiveness of bimonthly scheduled telephone discussions between a paediatric diabetes educator and a young person (parents were included where children/young people were 11 years old or younger). Each discussion lasted 15-30 minutes, and covered day to day management of diabetes (insulin, carbohydrate intake and blood glucose), current events that might affect diabetes management, and diabetes education. There was no specific objective for the telephone calls and goal

setting was not included as part of the intervention. The intervention had no effect on glycaemic control, hospital admission, diabetes knowledge or self-management although parents found the telephone calls helpful (rated on a four point scale). The analysis did not take account of variation in the number or length of phone calls made to the team.

The second study assessed the effectiveness of a case management approach (Svoren et al., 2003). In this intervention 'Care Ambassadors' were assigned to families to help them with appointment scheduling and health insurance issues as well as monitoring their clinic attendance. One intervention group received Care Ambassador support only (CA), while a second group received Care Ambassador support and eight diabetes related psycho-educational modules (CA+). The CA+ intervention group when compared with both the control and the CA group improved glycaemic control in "high risk" children/young people and reduced hypoglycaemic events and hospital utilisation. However, the psycho-educational component appears to have been assessed by combining the standard care (control) group and CA groups and comparing their outcomes with those of CA+. In addition the randomisation method is unclear and the method of dealing with missing data is not reported.

The intervention investigated by Ellis et al. (2005, 2007) included a component directed at schools (including schools in the monitoring and management of diabetes; improving school-family communications) and at the health care system (resolving barriers to hospital attendance, improving relationships between the family and the diabetes team).

Conclusion

The diabetes studies have investigated different types of interventions and used different outcomes to assess their effectiveness. Many of the studies investigate the effect on health status (glycaemic control). Although four of the studies found no effect, two interventions delivered in conjunction with intensive diabetes management found improvements in glycaemic control. One of these suggested that a group coping skills intervention for children/young people can provide additional improvements to glycaemic control than IDM alone. There is also evidence that that family therapy and care management approaches may also improve control. Two child focused interventions improved self-efficacy although they were different in their approach (one used a group based coping skills programme and one a text messaging system). There is also evidence that improvements in family relationships can be achieved by the use of family-based approaches such as family therapy.

2.2.4 Methodological quality

The methodological quality of the 29 studies included in the review is presented in Appendix 2.5 and summarised in Table 7. Seventeen studies reported an adequate method of randomisation. The remaining papers did

not provide sufficient information to assess randomisation. Only 11 papers reported their method of allocation concealment in sufficient detail for us to be reasonably certain that it was adequate. While we consider that it may not be possible to fully blind participants to their allocation group in interventions such as these, only 10 studies described blinding of outcome assessors and/or care providers. For outcomes assessed by postal questionnaires this would be a less important source of potential bias. All the included studies provided information on follow-up rates with 17 achieving a rate of 90% or over. The conduct of an ITT analysis was reported in 13 studies. Nineteen studies reported equivalent study groups as baseline. The length of follow-up was 12 months or more in 13 studies. Eighteen studies reported that a power calculation had been conducted.

Interventions often incorporated multiple components and as a consequence a wide variety of outcomes were reported. Many studies measured multiple outcomes but only 16 clearly identified a primary outcome and in some studies it appeared that there was a selective reporting of outcome data raising the issue of publication bias. In addition a high proportion of statistically significant findings were reported. There was a high reliance on self-report measures without a discussion of their limitations and parents were often used as proxies for their children. In a number of studies it was unclear who administered the questionnaires and measurement tools and who completed them. In some studies changes were made to validated tools without conducting further reliability/validity testing. Moreover in some of these studies there was no discussion of the rationale for the changes made or indeed a description of what actual changes were made. Only a minority of asthma studies took account of seasonal or daily variations in asthma (for example, Evans et al., 1999/Sullivan et al., 2002). A wide range of tools were used to measure outcomes and overall there was poor reporting of their reliability and validity.

None of the studies included an integral process evaluation and few studies looked at satisfaction or participant views on the intervention. In a number of studies not all the potential benefits of programmes were measured, for example, social support benefits, knowledge gain. In a number of studies there was a lack of detail about interventions themselves and how they were implemented.

In conclusion the quality of the research in this area is limited with few rigorously conducted trials being conducted. Consequently it is difficult to draw firm conclusions from the research that has been conducted to date.

Table 7. Summary of the methodological quality of the outcome evaluation studies included in the review (n=29)

Quality Component	Number
Adequate randomisation reported	17
Concealment of allocation reported in sufficient detail	11
Blinding of outcome assessors and/or care providers reported	10
Follow-up of $\geq 90\%$	17
Follow-up of ≥ 12 months	15
Intention to treat analysis reported	13
<i>A priori</i> power calculation reported	18
Equivalent groups at baseline	19

2.2.5 Effective interventions across the four conditions

In this section the effectiveness of the interventions will be synthesised. This synthesis will only include the highest quality studies in the review as assessed by the criteria in Table 7 (11 studies, 12 papers). Effectiveness will be considered in relation to the outcomes of health status; psychosocial wellbeing and health behaviour; knowledge; health service utilisation and cost-effectiveness and satisfaction. Four of the studies were conducted in the UK. All 11 of the interventions can be considered to enable delivery on an individualised basis according to the needs of the particular child/family. Only three studies report a theoretical basis to the intervention. All the interventions have an educational component and eight have this as a key aim. Other aims of the interventions are to enhance self-management (6); develop coping/problem-solving/social skills (4) and improve family or peer relationships (2). Other intervention aims include improving behaviour management, communication with health professionals, psychosocial adjustment and reducing health service use. In terms of the targeting of interventions, six are focused on children/young people; three on both children/young people and parents; one on parents only and one at children/young people, parents and professionals. Four are delivered at home, three in hospital, and one in a school. Others are delivered in a mix of community and hospital settings. Seven interventions are delivered only on an individual basis either in a consultation-type setting or using e-health methods. Other interventions use group based methods either alone to in combination with individual approaches (4). Five interventions include the supplementary use of printed materials (information booklets, self-management plans).

Health status

Health status was an outcome measured by nine studies but was conceptualised and measured in different ways in relation to the particular

condition (Table 8). The outcomes measured included symptom reduction (ADHD, asthma), lung function (asthma), limitations on usual activities/physical functioning (asthma, CF), glycaemic control (diabetes). As shown in Table 8 health status was variously reported on by children/young people themselves, parents and teachers. In two studies physiological measures were taken by the researchers.

In six studies the intervention was effective in improving health status with the remaining three studies finding no effect. Interventions focusing on children/young people alone and those targeting both children/young people and parents were associated with improvements in health status as were those using group or individual child/family approaches. The e-health self-care programmes that were effective were those that included some form of interaction with a HCP or individualised feedback.

Table 8. Summary of health status measurements used in the studies and associated results (n=9)

Study	Health Status	Measurement Tool	Reporter
#MTA (1999, 2004)	ADHD symptoms (inattention, impulsivity)	SNAP Rating Scale (Swanson, Nolan and Pelham)	Parents and teachers
	At 14 months significant reduction in symptoms (inattention, hyperactivity) reported for two intervention groups (medication management only and medication management/behaviour therapy combined) compared with third intervention group (behaviour therapy only) and control (p0.001). At 24 months reduced effect sizes reported in relation to symptoms though differences remained. SNAP Scores (SD) on ADHD subscale (n=526): medication management and behaviour therapy combined (1.17 (0.66)); medication management only (1.21 (0.68)); behaviour therapy only (1.38 (0.69)); control (1.40 (0.68)). SNAP Scores (SD) on Oppositional Defiant Disorder subscale (n=526): medication management and behaviour therapy combined (0.83 (0.70)); medication management only (0.96 (0.76)); behaviour therapy only (1.04 (0.81)); control (1.06 (0.79)).		
#Cicutto <i>et al.</i> (2005)	Limitations in activity due to asthma	Number of days of interrupted activity in previous 3 months	Parents
	Intervention group reported fewer interrupted activity days (6.7 ± 7.3 p<0.01) than control group (9.1 ± 10.5).		
#Evans <i>et al.</i> , 1999; Sullivan <i>et al.</i> , 2002	Asthma symptoms	Maximum asthma symptom days in previous 2 weeks averaged across past year	Unclear if parent or child/young person
	Asthma symptoms days significantly lower in intervention (n=515) than control group (n=518) at one and two years post-intervention. One year: intervention (3.51) control (4.06); difference -0.55; 95% CI -0.92, -0.18; p=0.004. Two years: intervention (2.64) control (3.16); difference -0.51; 95% CI -0.89, -0.13; p=0.007).		
#Guendelman <i>et al.</i> (2002,2004)	Limitations in activity due to asthma	Limitations in activity Peak flow in red or yellow zones	Parent and child/young person
	Limitations in activity lower in intervention than control group (OR 0.52; 95% CI 0.29-0.94; p=0.03). Intervention group reported fewer readings in red/yellow zones than control (OR 0.43; 95% CI 0.23-0.82; p=0.01).		
#Jan <i>et al.</i> (2007)	Lung function	PEF	Unclear if parent or child/young person
	Asthma symptoms	Asthma symptom score	
Asthma symptoms significantly lower in intervention than control group (nocturnal P=0.028; daytime p=0.009). No significant differences between groups for lung function).			

#Franklin <i>et al.</i> 2006	Glycaemic Control	HbA _{1c}	Researcher
	Intervention group 1 = usual therapy and Sweet Talk. Intervention group 2 = intensive insulin therapy and Sweet Talk. Glycaemic control score for control group: 10.3 ($\pm 1.7\%$); intervention group 1: 10.1 ($\pm 1.7\%$); intervention group 2: 9.2 ($\pm 2.2\%$). No significant differences found between intervention group 1 and control (95% CI -0.7,+0.7; $p=0.99$). Significant differences found between intervention groups 1 and 2 (95% CI -1.9, +0.5; $p<0.001$). Differences between control and intervention group 2 not investigated.		
McPherson <i>et al.</i> (2006)	Lung function	FEV ₁ (Forced Expiratory Volume), PEF	Researcher
	No significant differences for mean change in FEV ₁ between intervention group (-3.971, 95% CI -7.83–0.12) and control (-2.41, 95% CI -6.24–1.4). No significant differences for mean change in PEF between intervention group (0.22, 95% CI -5.74–5.30) and control (0, 95% CI -6.44–4.45).		
Stevens <i>et al.</i> (2002)	Asthma symptoms	Index of Perceived Symptoms in Asthmatic Children	Parents
	No significant differences found between intervention and control groups for daytime symptoms (3 months post-intervention $p=0.95$; 12 months post-intervention $p=0.07$); nocturnal symptoms (3 months post-intervention $p=0.50$; 12 months post-intervention $p=0.20$); perceived disability (3 months post-intervention $p=0.76$; 12 months post-intervention $p=0.53$).		
Christian and D'Auria (2006)	Functional health status (CF)	Functional Disability Inventory	Child/young people
	Lung function	FEV ₁ (Forced Expiratory Volume)	
For functional health status no significant differences reported between intervention and control ($p=0.379$) or changes over time ($p=0.052$). No significant differences in lung function reported between intervention and control ($p=0.297$) although a significant intervention effect by time is reported ($p=0.010$).			

#Statistically significant relationship reported between intervention and health status

Psycho-social wellbeing and health behaviour

A range of different psycho-social aspects of living with a long term condition were used as outcomes in eight studies but the commonest ones were quality of life (3 studies) and self-efficacy (2 studies). Interventions were associated with improvements in children's/young people's self-efficacy (Cicutto *et al.* 2005; Franklin *et al.* 2006) and quality of life (Cicutto *et al.* 2005; Jan *et al.* 2007) (Table 9). However, another study found that the intervention had no effect on parental quality of life (Stevens *et al.* 2002).

Table 9. Summary of psycho-social wellbeing measurements and associated results (n=8)

Study	Psycho-Social Wellbeing	Measurement Tool	Reporter
#Cicutto <i>et al.</i> (2005)	Self-efficacy	Child Asthma Self-Efficacy Questionnaire	Child/young person
	Quality of Life	Pediatric Asthma Quality of Life Questionnaire (Juniper)	Child/young person
Intervention group reported higher self efficacy scores (3.6 ± 0.7 $p < 0.05$) than the control group (3.8 ± 0.9) and higher quality of life scores (5.0 ± 1.4 $p < 0.05$) than the control group (5.5 ± 1.4).			
#Jan <i>et al.</i> (2007)	Quality of Life	Pediatric Asthma Quality of Life Questionnaire (Juniper)	Child/young person and caregivers
	Quality of life improved significantly in the intervention group (6.5 ± 0.5 , $p < 0.05$).		
#Franklin <i>et al.</i> (2006)	Self-efficacy	Self-efficacy for Diabetes (SED)	Child/young person
	Intervention group 1 = usual therapy and Sweet Talk. Intervention group 2 = intensive insulin therapy and Sweet Talk. Intervention group 1 reported to have higher scores ($62.1 (\pm 6.6)$; 95% CI +2.6, +7.5; $p = 0.003$) than the control group ($56 (\pm 13.7)$). No results reported in relation to intervention group 2.		
Stevens <i>et al.</i> (2002)	Quality of Life	Pediatric Asthma Caregivers Quality of Life Questionnaire (Juniper)	Parent
	Mean scores (SD) 3 months post-intervention: intervention group 5.41 (1.54); control group 5.38 (1.39); 95% CI -0.45-0.40; $p = 0.90$ (t test). Mean scores (SD) 12 months post-intervention: intervention group 5.45 (1.45); control group 5.73 (1.28); 95% CI -0.14-0.69; $p = 0.19$ (t test).		

#Statistically significant relationship reported between intervention and psychosocial wellbeing

Interventions were associated with a short-term (12 week) improvement in adherence to prescribed medications based on caregiver assessments (Guendelman *et al.* 2002, 2004). Franklin *et al.* (2006) also found improved self-report adherence scores in the groups receiving the intervention.

Interventions were also reported to be effective in improving coping skills (Davis *et al.* 2004), social skills (MTA, 1999, 2004), perceptions of illness impact (Christian and D'Auria, 2006), loneliness (Christian and D'Auria, 2006), locus of control (McPherson *et al.* 2006) and in reducing depression and anxiety in children/young people with ADHD (MTA, 1999, 2004).

Knowledge

All the interventions had an educational element but only five included condition-related knowledge as an outcome (Table 10). Three studies that used e-health type interventions found that children's/young people's knowledge had increased significantly following the intervention (Davis *et*

al. 2004; McPherson et al. 2006; Jan et al. 2007). Two other studies found no significant increase in parental (Stevens et al. 2002) or children's/young people's (Franklin et al. 2006) knowledge.

Table 10. Summary of condition-related knowledge measurements used in the Studies and associated results (n=5)

Study	Knowledge	Measurement Tool	Reporter
#Davis et al. (2004)	Cystic fibrosis	Cystic Fibrosis Knowledge Questionnaire (CFK)	Unclear if parent or child/young person
	Condition related knowledge increased following intervention (combined sample change score 31.4 (SD 17.8); $p < 0.001$; effect size (η^2) 1.76)		
#Jan et al. (2007)	Asthma knowledge	Asthma knowledge questionnaire (10 items)	Parents or caregivers
	Asthma knowledge scores significantly higher in the intervention group than control group ($p < 0.05$)		
#McPherson et al. (2006)	Asthma knowledge	Asthma knowledge assessment (21 items)	Child/young person
	Intervention group reported greater improvements in knowledge than control group ($F = 12.7$; $df = 1.96$; $p = 0.001$)		
Stevens et al. (2002)	Asthma knowledge	Caregivers knowledge of asthma questionnaire (43 items)	Parents or caregivers
	No significant differences in knowledge score between intervention and control group. Median scores: intervention group 35, control group 30; median difference 1.0, 95% CI -2.0-1.0, $K = 2695$.		
Franklin et al. 2006	Diabetes knowledge	Diabetes Knowledge Score (DKN)	Child/young person
	Intervention group 1 = usual therapy and Sweet Talk. Intervention group 2 = intensive insulin therapy and Sweet Talk. Knowledge scores: control 11.2 ± 1.9 ; intervention group 1 10.7 ± 2.4 ; intervention group 2 11.3 ± 2.0 . No significant differences reported between control and intervention group 1 ($p = 0.3$) or between interventions groups 1 and 2 ($p = 0.58$). Differences between control and intervention group 2 not investigated.		

#Statistically significant relationship reported between intervention and condition-related knowledge

Health care use and costs.

The effect of the intervention on health service use was measured in seven studies largely by parental self-report and record review (Table 11). The majority of studies found that the intervention had no effect on hospital admission (Guendelman et al. 2002, 2004; Stevens et al. 2002; McPherson et al. 2006). Although other studies have reported significant reductions in admissions (Wesseldine et al. 1999) or reductions approaching statistical significance (Evans et al., 1999/ Sullivan et al., 2002). The effect of interventions on use of Accident and Emergency Department attendance and GP/Primary Care consultations is mixed with two studies reporting the intervention significantly decreasing use (Wesseldine et al. 1999; Cicutto et al. 2005) and three studies finding no effect (Guendelman et al. 2002, 2004; Stevens et al. 2002; McPherson et al. 2006). Another study reported a significant increase in clinic visits and calls to an emergency hotline for the intervention group although frequency of visits were within clinical protocol

goals (Franklin et al. 2006). Indeed this increase was seen in a positive light with the intervention demonstrating its potential to encourage attendance. None of the e-health interventions were associated with reductions in health service use. The evidence suggests that effective interventions in terms of health service use are those that target both children/young people and parents and use face-to-face methods.

Table 11. Summary of health care use measurements used in the studies and associated results (n=7)

Study	Health Care Use	Measurement	Reporter
#Wesseldine et al. 1999	Readmission to hospital	Number of readmissions within 6 months of discharge	Hospital information system
	A&E department attendance	Number of attendances within 6 months of discharge	Hospital information system
	GP consultation (unplanned)	Number of consultations within 6 months of discharge	GP records
Proportion of children readmitted to hospital significantly lower in intervention group (12, 15%, n=80) than control group (30, 37%, n=80) ($\chi^2 = 10.5$, p=0.001). Intervention group had significantly lower (6, 8%, n=80) rate of A&E attendance than control (31, 38%, n=80) ($\chi^2 = 22$, p<0.001). GP consultations substantially lower in the intervention group (31, 90%, n=78) than control (72, 90%, n=77) ($\chi^2 = 50$, p<0.001).			
#Cicutto et al. (2005)	Urgent health care visits (A&E, GP)	Number of visits	Parents
	Intervention group reported fewer urgent health care visits (1.7 ± 1.9 p<0.01) than control group (2.5 ± 2.5).		
Guendelman et al. (2002,2004)	A&E department attendance	Number of visits in last 6 weeks	Parent and child/young person and record review.
	Admission to hospital	Number of admissions in last 6 weeks	
	Urgent phone calls to hospital	Number of urgent calls in last 6 weeks	
No significant differences between intervention group and control group for A&E attendance (OR 0.59; 95% CI 0.26-1.35; p 0.21) or hospital admissions (OR 0.99; 95% CI 0.25-3.88; p 0.96). Intervention group made fewer urgent calls to hospital than control (OR 0.43; 95% CI 0.18-0.99; p 0.05).			
#Franklin et al. 2006	Clinic visits	Number of visits	Hospital records
	Emergency hotline contacts	Number of contacts	Hospital records
	Intervention group 1 = usual therapy and Sweet Talk. Intervention group 2 = intensive insulin therapy and Sweet Talk. Clinic visits: no significant differences reported between control (3.0 ± 0.92) and intervention group 1 (3.3 ± 1.1 ; 95% CI -0.3, +0.8; p 0.36) but significant differences reported between intervention group 1 (3.3 ± 1.1) and intervention group 2 (3.9 ± 1.0 ; 95% CI -0.1, +0.46; p 0.016). Emergency hotline contacts: no significant differences reported between control (8) and intervention group 1 (3; 95% CI -33%, +7%; p 0.11) but significant differences reported between intervention group 1 (3) and intervention group 2 (18; 95% CI +33%, +44%; p 0.011). Differences between control and intervention group 2 not investigated.		
Evans et al. 1999/ Sullivan et al. 2002)	Admission to hospital	One or more hospitalisations in past year (%)	Unclear if parent or child/young person
	No significant differences between intervention group (14.8%, n=515) and control group (18.9% n=518) difference -4.19; 95% CI -8.75, 0.36; p0.071 at one year. No significant		

	differences between intervention group (10.2%, n=515) and control group (13.8% n=518) difference -3.72; 95% CI -7.86, 0.41; p0.078 at two years.		
McPherson <i>et al.</i> (2006)	Admission to hospital	Number reporting hospitalisation	Parents
	Unplanned GP visits	Number reporting a visit.	Parents
	No significant differences for hospital admissions between intervention (1, 2.3%, n=44) and control groups (1, 2.2%, n=46). No significant differences for unplanned GP visits between intervention (8, 18.2%, n=44) and control groups (14, 21.8%, n=46) Z=1.92, p=0.054).		
Stevens <i>et al.</i> (2002)	Readmission to hospital	Number of readmissions 12 months post-intervention	Hospital records
	A&E department attendance	Number of attendances 12 months post-intervention	Hospital records
	GP consultation (unplanned)	Number of consultations 12 months post-intervention	GP records
	No significant difference between intervention and control groups for GP consultation rate (mean (SD) intervention group 3.87 (3.93), control 4.13 (3.63) 95% CI -1.34-0.81, p=0.63 (t test)); hospital admission (intervention group 26, 26%; control group 19, 19%, $\chi^2=1.11$, p=0.29, 95% CI -0.03-0.17); A&E attendance ((intervention group 17, 17%; control group 19, 19%, $\chi^2=0.02$, p=0.88, 95% CI -0.01-0.03). Sample size ranged between 91-97 for intervention and 94-100 for control).		

#Statistically significant relationship reported between intervention and health care use

Cost-effectiveness was only assessed in one of the asthma studies (Evans et al. 1999; Sullivan et al. 2002). This multi-systemic intervention was concluded to be cost-effective particularly for those with the most severe asthma.

Individual experience

Alongside quantitative measures of effectiveness, three studies (all using e-health methods) obtained participants' views on the intervention. A text messaging service for children/young people with diabetes was seen as helpful by the majority of users (81% n=51) and 57 (90%) reported that they wanted to continue using it after the end of the trial (Franklin et al. 2006). Two studies which provided children/young people with CDs with information about their condition reported high levels of satisfaction with the interventions (Davis et al., 2004; McPherson et al. 2006) with participants reporting that this method was an appropriate way of obtaining information about their condition. However, limited details are provided by these studies about how the conduct of this component of the studies and the results obtained.

In conclusion the range of different outcomes and how they have been measured means that making comparisons across studies is difficult. However, there is evidence to suggest that interventions that target both children/young people and parents can be effective across all the outcome categories. Similarly interventions that use group processes/methods (either alone or combined with individual sessions) are also effective across all outcome categories. E-health interventions demonstrated positive effects

on all outcome categories apart from health service use. Characteristics of interventions that were not associated with having an effect on outcomes were those only delivered in a hospital setting (n=2), that were only delivered to an individual child/family (face-to-face) (n=2) or were targeted only at parents (n=1). However, it should be noted that these findings relate to the same studies.

2.3 Stage two methods

2.3.1 Aims of the review

- 1) To examine the views of children/young people, parents, siblings, peers and professionals (self-care agents) on self-care support interventions.
- 2) To identify and describe different self-care support models as part of developing a framework for categorising models.

2.3.2 Inclusion criteria for the review

Types of studies

Studies using a survey design and qualitative studies.

Types of participants

Studies were included if their focus was on children and young people aged 0-16 diagnosed with one of the following long-term conditions: ADHD, asthma, cystic fibrosis and diabetes. In addition studies including or focusing on parents, peers and professionals that related to this age group were included.

Types of interventions

A broad definition of self-care support was used to ensure that any intervention was included that aimed to help the child/young person either directly or indirectly to take control of and manage their condition, promote their capacity for self-care and/or improve their health. The target of the intervention, whether child/young person, family member or carer, peer group or professional, needed to be actively involved and engaged in the intervention, rather than be a passive recipient of knowledge or instructions.

Types of outcome

The studies had to directly obtain the views, experiences, perceptions of a self-care intervention.

Language

Only studies published in English have been included in the review.

Exclusion criteria

Studies were excluded if there was no active involvement of participants in the self-care intervention; if the study was concerned with developing a self-care intervention; if the study did not directly obtain the views of children/young people, parents, peers, professionals; if the study was not in the English language.

2.3.3 Search methods

The same search methods were used as presented in Section 2.1.3.

2.3.4 Methods of the review

The abstracts of the retrieved papers were screened to eliminate those not meeting the stage two review inclusion criteria. If it was unclear from the abstract whether papers met the inclusion criteria full paper manuscripts were obtained for screening. Papers passing the initial screening process were assessed independently for quality and eligibility by two reviewers and data were extracted using a data extraction form (Appendix 2.6). Any discrepancies in assessments were resolved by discussion and consensus. Studies were assessed on the following quality elements developed from the criteria proposed by Dixon-Woods et al. (2006) and the EPPI Centre (Shepherd et al. 2006):

- Clear statement of the aims of the study.
- Adequate description of the context for the study.
- Clear specification of research design and its appropriateness for the research aims.
- Reporting of clear details of the sample and method of recruitment/sampling.
- Clear description of data collection and data analysis provided.
- Attempts made to establish rigour of data analysis.
- Inclusion of sufficient original data to support interpretations and conclusions.

2.4 Stage two results**2.4.1 Description of studies*****Results of the search***

As reported in 2.2.1 the search strategy identified 2686 unique papers which were screened against the second stage review inclusion criteria. A total of 65 papers were assessed as being potentially eligible for inclusion in

this stage of the review. The rest were excluded on the basis of one or more of the following grounds:

- Participants⁴ were over 21 or had a mean age of over 16.5.
- The intervention was not related to self-care.
- Participants were not actively involved in the intervention but were merely passive recipients of information.
- The study was not reported in English.
- The study did not use a survey or qualitative research design.
- The paper did not report the views of participants on the intervention.

These 65 papers were reviewed for quality and eligibility and eight papers describing eight studies were judged as adequate to include in the review. Table 12 shows the numbers of papers for each of the four conditions at each stage of the screening/reviewing process.

Table 12. Number of papers screened/assessed for each long-term condition

Screening/assessment stage	ADHD	Asthma	Cystic fibrosis	Diabetes	Total
Identified from databases for initial screening	75	629	156	1673	2533
Identified from reference lists for initial screening	37	73	12	31	153
Total screened	112	702	168	1704	2686
Assessed using data extraction form	3	28	8	26	65
Included papers	0	3	1	4	8

2.4.2 Description of the included studies

The main characteristics of the eight studies (type of intervention, sampling, data collection, data analysis, key findings) are presented in Appendix 2.7.

Design

Four studies used a survey design (Anderson, 1997; Nordfeldt and Ludvigsson, 2002; Bruzzese et al., 2004; Carroll et al., 2007) and two studies used a qualitative approach (Trollvik and Severinsson, 2005; Van

⁴ Assuming that children/young people were the target of the intervention. If the targets were adults e.g. parents or professionals the age limits stated applied to the children/young people they were supporting.

der Meer et al., 2007). Two studies employed a similar mixed method design, using a survey followed by qualitative interviews with a subsample (Johnson et al., 2001; Gammon et al., 2005). Sample sizes ranged between nine and 89. The majority of the included papers were published between 2003 and 2007 (Table 13).

Table 13. Year of publication of included papers (n=8)

Publication Year	Number
1995-1998	1
1999-2002	2
2003-2007	5

Setting

Three studies were conducted in the United States of America and three in Scandinavian countries (Table 14). None of the studies included in the second stage review were conducted in the United Kingdom.

Table 14. Setting of intervention (Country) (n=8)

Country	Number
USA	3
Norway	2
Canada	1
The Netherlands	1
Sweden	1

Participants

The age of the children/young people in the studies ranged from one to 18 years. The majority of studies had a sample of secondary school age children. The gender of the sample was reported in three studies (Gammon et al., 2005; Carroll et al., 2007; Van der Meer et al., 2007) and was 50%, 26% and 51.4% female respectively. Only one study reported the ethnicity of the sample (Carroll et al., 2007) and no studies reported on social class.

Self-care interventions

In terms of condition focus, four interventions focused on diabetes, three on asthma and one on cystic fibrosis. None of the included papers focussed on ADHD. Three interventions targeted both children/young people and parents (Anderson, 1997; Gammon et al., 2005; Carroll et al., 2007;), three interventions targeted children/young people only (Johnson et al., 2001; Bruzzese et al., 2004; Van der Meer et al., 2007) and one targeted

only the parents of young children (Trollvik and Severinsson, 2005). In one study it was unclear whether the target of the intervention was children/young people, parents or both groups (Nordfeldt and Ludvigsson, 2002) None of the interventions were targeted at a particular 'at risk' group of children/young people and none of the studies included an intervention aimed at professionals.

A description of key characteristics of the interventions is presented in Appendix 2.8. Four of the interventions were educational/training programmes aimed at increasing knowledge about the particular condition and promoting self-management (Anderson, 1997; Nordfeldt and Ludvigsson, 2002; Bruzzese et al., 2004; Trollvik and Severinsson, 2005). The other four studies described e-health type interventions that aimed to facilitate self-monitoring and self-management via mobile phones and the internet (Gammon et al., 2005; Carroll et al., 2007; Van der Meer et al., 2007) or provide an electronic support group and condition related information (Johnson et al., 2001). Education was an element of two of these e-health interventions (Johnson et al., 2001; Van der Meer et al., 2007).

The setting for five of the interventions was the home/community (Johnson, et al. 2001; Nordfeldt and Ludvigsson, 2002; Gammon et al., 2005; Carroll et al., 2007; Van der Meer et al., 2007), two were provided in hospital (Anderson, 1997; Trollvik and Severinsson, 2005) and one was school-based (Bruzzese et al., 2004). Two interventions were delivered to an individual child/family (Anderson, 1997; Nordfeldt and Ludvigsson, 2002), two were delivered on a group basis (Johnson et al. 2001; Trollvik and Severinsson, 2005) and one used a combination of individual and group work (Bruzzese et al., 2004). Two interventions were delivered via the internet (Johnson et al., 2001; Van der Meer et al., 2007), one by mobile phones (Gammon et al., 2005) and one used both the internet and mobile phones (Carroll et al., 2007). None of the interventions were lay-led and only one reported having an underlying theoretical basis to the intervention (self-regulation theory) (Bruzzese et al., 2004). Three studies appeared to have involved children/young people and/or parents in developing the intervention (Nordfeldt and Ludvigsson, 2002; Gammon et al., 2005; Carroll et al., 2007).

Three interventions were individualised to the child's or family's needs (Anderson 1997; Bruzzese et al. 2004; Carroll et al. 2007) and it is possible (though unclear from the papers) that a further two could be (Johnson et al. 2001; Trollvik and Severinsson, 2005).

2.4.3 Methodological quality

Overall the quality of the papers was not high. The studies varied in the level of detail provided about the methods used. While all the studies identified the study aims, few provided sufficient detail about the methods of data collection and data analysis (n=3) and sampling and recruitment (n=4). In the other studies only basic information was provided about how

the data had been collected and analysed. In some cases the questions asked could only be inferred from the findings presented. In those studies using a questionnaire it was unclear whether the data collection tools had been piloted or used in previous studies. The information provided about data analysis was similarly variable. Questionnaires were analysed using descriptive and inferential statistics to examine the proportions of participants responding in a particular way with inferential statistics being used to investigate the strength of associations. Where the method of qualitative data analysis is given it is described as being content analysis or thematic analysis. A number of studies used survey methods with small samples when qualitative methods would have been a more appropriate approach (Bruzzese et al. 2004; Carroll et al. 2007; Gammon et al. 2005). Most studies did not attempt to discuss how rigour had been established.

The studies varied in terms of the participation of young people/parents in the development of the research or its adaptation to their needs. In three studies young people/parents appeared to have been involved in the development of the self-care support intervention itself (Nordfeldt and Ludvigsson, 2002; Gammon et al. 2005; Carroll et al. 2007) and in another study children/young people had been involved in developing the data collection tools (Anderson, 1997). One study appeared to have adapted the data collection methods to the needs of children/young people (Gammon et al. 2005). Little information was provided about whether children/young people themselves had given consent/assent to take part in the study. Only one study clearly appeared to have obtained children's/young people's consent/assent (Anderson 1997) while in another study (Bruzzese et al. 2004) only those children/young people who wished to take part took home consent form for their parents to complete. Overall it appeared that in most studies only parental consent was obtained. None discussed consideration of power relations between children/young people and researchers or ways in which they attempted to minimise this.

2.4.4 Views of self-care interventions

Asthma studies

An evaluation of the feasibility and acceptability of a school-based asthma self-management programme for adolescents in the 9th and 10th Grades (ASMA) is reported by Bruzzese et al. (2004). This was conducted as part of a pilot randomised controlled trial of the intervention. The five week programme consisted of three group workshops, one-to-one coaching and weekly checklists which aimed to help children/young people identify symptom patterns, medication use, trigger exposure and activity restrictions. Fourteen children/young people from the treatment arm of the RCT (n=23) participated in a survey using a self-completion questionnaire to collect their views on the self-management programme. Children/young people appeared to enjoy the workshops and found them useful in terms of helping them to understand their condition (n=20, 86%) and how they could manage it themselves (n=23, 100%). The one-to-one coaching and

checklists were also seen as being helpful (n=17, 72%) but less so than the workshops. There is a lack of detail reported in the paper about how the data was collected and analysed. A minimal amount of data is presented. Given the small sample size the use of survey methods appears to be an inappropriate design.

Children's/young people's views on an internet-based self-monitoring system that aimed to enhance self-management were investigated by Van der Meer et al. (2007). In this system lung function values (FEV1 and PEF) were entered into the web application each morning by children/young people and instant feedback messages then sent expressing these values as a percentage of the expected or personal best value. However, the system did not interpret the values or provide any self-management advice. In addition there is a suggestion in the paper that the system also includes an asthma action plan and that there is the opportunity for e-consultations but this is not clear. Thirty five children/young people aged between 12 and 17 years old from the group who had been using the system (n=56) took part in focus group interviews. While the children/young people saw the system as being a feasible way of monitoring their asthma, they felt that they knew themselves when their condition was worsening and that measuring their lung function was unnecessary. They liked being able to review their recordings online and the ability to communicate via email with health care providers. The information provided was seen as being accessible and they appeared to prefer obtain condition-related information via the internet to receiving leaflets and books. Differences were reported between those categorised as 'well controlled' and those as 'poorly controlled'. The former saw no need to complete the electronic asthma action plans whereas the latter valued the plans. 'Poorly controlled' children/young people also valued receiving messages to warn them of their reduced lung function and advice about how to manage their medications.

The third asthma study (Trollvik and Severinsson, 2005) investigated satisfaction with a group based asthma education programme that was directed at the parents of young children (aged two to six years old). The programme aimed to provide information on asthma and its management as well as providing an opportunity to meet other parents. It was held over one day and one session was peer-led. Semi-structured qualitative interviews were conducted with a purposeful sample of parents (n=9) who had attended the programme. Parents valued a number of aspects of the course – the increase in their understanding of their child's condition; the provision of written information for reference at a later date; the opportunity to meet other parents; the targeting of the course at mothers and fathers which promoted joint responsibility for caregiving; and the involvement of known health care professionals.

Diabetes studies

A mobile phone and internet-based monitoring system for children/young people aged 13-18 years was evaluated by Carroll et al. (2007). The system used mobile phones for glucose monitoring and the transfer of readings to a

website and telephone access for children/young people to discuss self-management with clinicians. Children/young people, parents and clinicians were able to review the readings on the website. Ten children/young people who had been using the system for three months completed questionnaires to assess their views on usability, satisfaction and the impact on relationships with others. Children/young people were reported to like the system, finding it easy to use and helpful with the self-management of their condition. They were positive about its impact on relationships at school but negative on its influence on relationships with parents. Unfortunately the latter issue is not explored. There is a lack of detail regarding the research design and data collection and analysis. In addition the use of a survey design for a sample this size is inappropriate.

A hospital-based education programme for children/young people and parents that aimed to support self-management was examined by Anderson (1997). Little information is provided in the paper about the programme other than it comprised of three monthly consultations to provide self-management education for the first year after diagnosis followed by individualised appointment scheduling. Consultations appear to be jointly attended by children/young people and parents. A postal survey was used to collect children's/young people's views on the programme (n=22, 22% response rate). In addition a chart audit was conducted to collect data on service utilisation and health outcomes. Children/young people found the information provided to be useful for self-management and they felt that they were listened to by staff and able to ask questions. The majority (n=17, 75%) reported that they had received sufficient diabetes information and the main areas identified as being helpful were the caring approach of staff, problem solving orientation of the programme and the learning that had taken place. As noted above a limited amount of information is given about the intervention and the data presented lacks depth and detail. In addition the response rate is low.

Another self-care support system using mobile phone technology was evaluated by Gammon et al. (2005). In this intervention mobile phones were used to text message blood glucose readings from a monitor to the child's mobile phone and then onto their parents mobile phone. The aim of the intervention was to reduce parental anxiety over children's/young people's self-management, encourage independence and reduce conflict. Fifteen families were recruited to the study and the children/young people (aged 9-15 years) used the system for four months. A survey of parents and children's/young people's views was conducted (n=30), followed by a focus group of 10 parents (from 9 families). Parents and children/young people liked the automatic transfer of measurements and the system was seen as facilitating learning about self-management. Children/young people were divided over whether they wanted to be able to control the transfer of data to their parents (however, parents did not want them to have control over this). Parents felt reassured by having information about their child's self-monitoring and that they could intervene if necessary. However, some felt that they were nagging their children more and they experienced a sense of conflict over encouraging independence while at the same time

having a desire to ensure their child's wellbeing. For older children/young people the system appeared to create additional tensions with parents. This is a well conducted study although the opportunity to interview children/young people was not exploited.

A Swedish study (Nordfeldt and Ludvigsson, 2002) investigated an educational programme using self-study materials (booklets, videos) that aimed to promote self-management. It is unclear from the paper if the intervention was aimed at both parents and children/young people and if different materials were developed for each group. A postal survey was used to assess the views of families who had attended the programme. One group of families were asked to assess the booklets (n=73, 65.2% response rate) and one the videos (n=89, 74.2% response rate). Both samples comprised parents and children/young people and it is unclear if there was any overlapping of the samples. The paper reports mainly the findings from the video survey. This suggested that families found the information provided by the video clear and useful to self-management. However, there were negative comments relating to the lack of use of older adolescents in the videos and some respondents felt that the information provided was not new. A lack of detail is provided about sampling, data collection and data analysis as well as a limited amount of data to support the interpretations.

Cystic fibrosis study

The study by Johnson et al. (2001) evaluated 'Teen Central', an internet support group for children/young people (aged 13-18 years) that aimed to provide both social support and condition related information. Eighteen children/young people completed a questionnaire which obtained their views on peer support, professional support and knowledge about CF both before and after using 'Teen Central'. A focus group was also conducted comprising nine children/young people and five parents. The study suggested that children/young people valued having contact with other children/young people CF to discuss both everyday teenage issues as well as ones specific to their condition. There was some indication that using 'Teen Central' might lead children/young people to view peer support more positively. No increase in knowledge of CF was found following use of 'Teen Central'. Parents were concerned about the time the children/young people used the site and worried that it was distracting them from homework and other activities. There is a lack of detail about data collection and analysis in the paper, particularly in relation to the focus groups.

2.4.5 Additional studies

As noted earlier none of the studies included in the second stage review were conducted in the UK. However, we were aware from searching the grey literature and from the reference group of six studies that had been conducted in the UK. Although these studies were not published in peer reviewed journals, they had obtained children/young people's and parents' views about self-care support interventions. The reports from these studies have been included in the evidence synthesis as they can illuminate the views of children/young people and parents on current UK self-care

interventions. However, it should be noted that the majority of these studies would not have met the quality inclusion criteria applied in the second stage review.

The Expert Patient's Programme (EPP)

There have been four studies of the EPP⁵ for children/young people with long-term conditions ('Staying Positive') and for parents who have a child with a long term condition ('Supporting Parents'). Two of these studies have been conducted by people closely involved in the EPP and two are independent studies.

EPP for children/young people with long-term conditions

The study conducted by EPP (Hawley 2005a) was essentially a study to examine the failed implementation of the pilot EPP programme in four PCTs. The aim of this pilot implementation had been to use the adult chronic disease self management programme with children/young people but to obtain their views on how it should be adapted for their needs. However, insufficient children/young people were recruited by the PCTs to enable any courses to be run and some sites were unable to recruit any children/young people at all. There is little detail on the methods of the evaluation in the report but it appears to have comprised of three stages; (i) a survey of children/young people with long term conditions (ii) focus group interviews with children/young people with long term conditions and (iii) letters sent to key stakeholders involved in the organisation of the programme in one of the PCT areas with a request for information on planning and implementation of the programme. Questionnaires (using open questions) were sent to 220 children/young people via a hospital consultant and two general practices along with the leaflets about the EPP. Fifty one questionnaires were returned (23.2% response rate). The majority of the sample (n=33, 65%) reported that they would not have read the leaflet if they had seen it and most stated that they would not have been interested in attending the course (n=36, 70.6%). The main reasons given for not wanting to attend were: not wanting to discuss personal details with strangers, being happy coping with their condition themselves and the fact that the course did not involve helping people to manage condition related symptoms. However, 23 (45%) children/young people were interested in receiving information about future courses and 45 (88%) reported that they would be interested in an online course.

In the focus group stage two PCTs organised a focus group for teenagers in their areas (although one of these was only attended by one young person). At the focus group children/young people completed a questionnaire to obtain their views on the programme before taking part in two sessions from the adult CDSM programme. They then completed a further

⁵ The EPP is based on the chronic disease self-management course (CDSM) developed by Lorig *et al.* (1999) in the US. This is a generic course delivered by volunteer lay tutors in community settings. Sessions are guided by a manual to attempt to ensure consistency of content.

questionnaire that obtained their views about the course. The findings from this stage of the study conflict with those from the survey. The majority of children/young people attending the focus group reported that they would have read the leaflet and would have been interested in attending a course; with the majority stating that they would prefer a face-to-face to an online course. A possible explanation for this conflict may relate to the children/young people's conditions varying between the two groups. In the survey most children/young people had diabetes, epilepsy or chronic fatigue syndrome but in the focus group the commonest condition was cerebral palsy with other children/young people having Asperger's, hemiplegia, learning disability and epilepsy. In reflecting on the implementation, the author's views appear to be that the problems related to poor publicity, lack of collaboration by PCTs with EPP trainers and under-investment of time by PCTs in organising the courses. The key issue to be resolved was how to reach children/young people and provide information about the course to them in a meaningful way.

Two years later the EPP funded an evaluation by Salinas (2007) to evaluate a peer led programme they had developed specifically for children/young people with long term conditions called 'Staying Positive' and which had been piloted in seven areas in 2006-2007. The course was targeted at children/young people between 11 and 19 years old with a range⁶ of long-term conditions and consisted of three self-management workshops addressing medical and psycho-social issues. Based on self-efficacy theory its aim was to enhance self-management skills. In the evaluation all the children/young people who had attended the workshops (n=57) were invited to take part in the study and 26 agreed to be take part in semi-structured interviews about their views on Staying Positive. Thirteen of these children/young people had attended all the workshops and some had subsequently gone on to become facilitators for the programme. What participants valued about the programme was being able to meet other children/young people, share experiences and learn from one another in an 'adult-free' environment. They found the communication skills they developed useful in interactions with health care professionals, parents and friends. Increased self-confidence and problem solving skills were reported as well as an increased awareness of the importance of self-care and medication adherence. All the children/young people reported that they enjoyed the programme and would recommend it to others. However, some children/young people found the workshops to be too long and wanted more breaks and 'fun' sessions. For some the information provided was seen as being too basic for their needs and the activities were criticised for being too childish. Some participants noted that particular topics would be better discussed in groups of the same age. The marketing of the course was again identified as needing improvement in order to engage with children/young people. Overall it appeared that children/young people aged over 14 years old appeared to benefit more than the younger age group. A number of recommendations were made by Salinas (2007) in relation to the

⁶ Originally Staying Positive was a non-condition specific programme but now courses have been developed for young people with specific conditions such as HIV/AIDs and Sickle Cell Disease

marketing and publicity of courses; group composition; content of workshops and consultation with children/young people in relation to future developments.

EPP for the parents of children/young people with long-term conditions

A pilot programme of the EPP for the parents of children/young people with long term conditions was implemented and then evaluated in three PCTs (Hawley 2005b). The seven week programme was based on a course that had been developed (though not tested) in the US in the 1990s – itself based on the CDSM course (Lorig et al. 1999). The programme aimed to improve parental quality of life and enable them to look after themselves (rather than to look after their child). Originally it has been planned to implement the course in four PCTs but one PCT was unable to run a course. Fifteen parents across the three sites took part in focus group interviews at the end of the course in order to evaluate the programme. It is unclear if the focus groups were moderated by the course tutors or by Hawley from the EPP. All the participants were mothers of children/young people aged between three and 17. The conditions of the children/young people varied with the commonest being Autistic Spectrum Disorder (ASD), learning disability, ADHD, cerebral palsy and epilepsy. None of the children/young people had asthma and only one had diabetes and one CF. However, in spite of the range of conditions, parents felt that they had more commonalities than differences. They valued aspects such as the course tutor being a parent of a child with a long-term condition; having time for themselves, sharing ideas with others, not feeling alone and having the opportunity to discuss distressing thoughts in a structured way. Particular aspects of the content that were seen as useful were depression and fatigue management; cognitive therapy and relaxation sessions; managing aspects of child behaviour; action planning and problem solving. Negative aspects of the course were also identified. It was felt that the course content was overcrowded and consequently there had been a rush to cover everything. Parents could feel overloaded with information and a number criticised the use of technical language. Some felt that there was an overemphasis on the negative aspects of their lives. Sessions on healthy eating and exercise were felt to be unnecessary as were the handouts. A therapeutic writing activity was found to be burdensome for parents. Organisational observations made by the author included that there were varying levels of collaboration between PCTs and EPP trainers which influenced the success of the courses. Again publicity issues were noted; largely a failure to clearly communicate information about the course to its potential audience. The delivery of courses in the daytime was also noted to be a barrier for some parents and only one course was at a time that would enable parents with school age children/young people to attend. Course locations were also not always appropriate, although the provision of childminding costs appeared to prevent drop-outs.

An external evaluation of the programme (now termed the 'Supporting Parents Programme') was conducted by Barlow et al. (2007). This evaluation was commissioned by a PCT and examined three separate courses that had taken place in the PCT. The courses comprised six, weekly

sessions lasting two and a half hours. They were facilitated by two tutors and used a manual for consistency. Three focus groups (and telephone interviews with two parents) were used to obtain parents views on the course (n=15) and a separate focus group was held to obtain the views of the tutors (n=6). All the parents were mothers apart from two (a grandmother and an aunt). In terms of the conditions of the children/young people, the commonest conditions were ASD, learning disability and ADHD. Only two children/young people had CF, one had diabetes and one had asthma. Although the children/young people had different conditions, parents reported that they experienced similar problems and emotions and the opportunity to meet with other parents in a similar situation and being able to exchange information and ideas and learn management strategies was seen as valuable. Changes that parents attributed to the programme were the development of skills to use in daily life (e.g. action planning, relaxation, guided imagery) and feeling less isolated and more accepting of their situation. Some parents noted that the programme had led to improved communications with family and HCPs. However, problems were identified. Overall the course was felt to be too short and too rushed which meant that as well as having insufficient time to fully cover issues there was a lack of time for parents to get to know one another. It was felt that it needed to incorporate more information provision or signposting to information about areas such as their child's condition and benefits. Some parents did not like how the manual was used (i.e. read out verbatim) and felt the approach needed to be less rigid. They commented on the fact that the manual seemed to regard them as carers and not parents. Criticisms were again made about the burdensome nature of the action planning activities and that it was unclear who the target group was from the course advertising. Nevertheless, the majority stated that they would recommend the course to others and some wanted to continue meeting and felt 'cast adrift' at the end.

The focus group conducted with course tutors highlighted how the group mix was positive though some tutors found that some issues raised were specific to parents of children/young people with behavioural problems. They also noted that they needed more support and more training relating to counselling and child protection. Its difference from adult programme was emphasised and their beliefs that it needed to be more flexible as the sessions were more likely to raise emotional issues that needed time for discussion and debriefing. Their perception was that it benefited parents in terms of information and emotional support.

'Getting Sorted'

Whereas EPP is a nationally provided programme, 'Getting Sorted' is a lay-led, condition specific, self-care course that has been developed and implemented in one area of the UK (Yorkshire). Originally developed for young people aged 12-17 years with diabetes it has been recently adapted for children/young people with asthma (Webster, 2007; Webster and Newell, 2008). The course comprises four workshops led by young facilitators and is underpinned by principles of empowerment and self-efficacy. The reports about both courses focus on the development work

conducted with children/young people to develop the content and delivery of the courses. Although some evaluation has been conducted in the form of end of course feedback and participant interviews six weeks after the end of the course the details of data collection and analysis are missing. It is reported that children/young people value being able to share experience and problems and feel understood and supported by other young people. They reported enjoying the opportunities for socialisation and the course activities and perceived that they had developed increased self-confidence and self-esteem. Improved communications with others and the development of independence in consultations with HCPs was also reported. In terms of improvements they made suggestions for alterations to some activities and felt that the sessions should be shorter in length. Some children/young people wanted to continue attending a similar group after the end of the course.

2.4.6 Synthesis of the 'views' studies

This group of studies has investigated quite different self-care interventions. One uses self study materials with no contact with peers or professionals (Nordfeldt and Ludvigsson, 2002) and another involves health care professionals delivering one-to-one educational sessions to children/young people and parents (Anderson, 1997). Some interventions use group processes (Johnson et al. 2001; Bruzzese et al. 2004; Trollvik and Severinsson, 2005;) while others use mobile phone technology and the internet to support self-monitoring and self-management (Carroll et al. 2007; Gammon et al. 2005; Van der Meer et al. 2007). The range of interventions limits synthesis as does the lack of analytical depth in many of the studies.

Social networking and group based interventions

There is evidence from a number of studies that group-based self-care interventions are seen as valuable in terms of providing an opportunity to meet (physically or virtually) with other children/young people or parents who are in a similar situation to share experiences, information and strategies (Johnson et al. 2001; Bruzzese et al. 2004; Hawley, 2005b ; Barlow, 2007; Trollvik and Servinsson, 2005; Salinas, 2007; Webster, 2007). These interventions fulfil both a social support and educational role (though the latter may not be explicit) and both parents and children/young people perceive that their self-confidence, communication skills and understanding of their long-term condition has increased as a result of participation.

The use of e-health to support self-management

Studies investigating the appropriateness of e-health methods for self-management support have found that children/young people see them as

usable in practical terms but also as technologies that can be integrated into their everyday lives (Gammon et al. 2005; Carroll et al. 2007; Van der Meer et al. 2007). This is particularly the case when the device is one that is used by their peers (for example, mobile phones). The feedback received can be helpful in managing their condition by alerting them to the need to make alterations to medication or other therapeutic regimens. The opportunity to consult with a health professional via email was similarly valued. Although parents felt reassured when they also had access to self-monitoring information, there was evidence that this parental surveillance could lead to conflict between children/young people and parents, affecting their relationships and creating additional difficulties around transferring responsibility for condition management to children/young people (Carroll et al. 1997; Gammon et al. 2005).

E-health can be used in other ways to condition monitoring. An internet-based group intervention was valued by children/young people for providing social support (Johnson et al. 2001) and there are suggestions that an on-line version of Staying Positive might be viewed as acceptable and appropriate for children/young people (Hawley 2005a).

Self-care support providers

Studies that have examined views on the people who actually provide or deliver the interventions have identified different aspects that are valued by parents and children/young people. In one study the interpersonal skills of health professionals are identified; their ability to listen, be receptive to individual needs, and their approachability (Anderson, 1997). In two other studies it was the position of the provider that was seen as being important though in conflicting ways. In one of the studies parents reported liking that the provider was part of the hospital team that were involved in their child's care as they felt this gave continuity and built mutual trust (Trollvik and Severinsson 2005). In another study parents valued that the courses were led by other parents of children/young people with long-term conditions who could therefore understand and empathise with them (Hawley 2005b).

2.5 Synthesis of findings across study types

This section synthesises the findings from the two stages of the review which is a challenging exercise because of the different types of research that have been included and the lack of analytical depth of the 'views' studies. The synthesis has been conducted using a matrix developed from the themes and propositions emerging from the 'views' studies and informed by the self-care support model typology. These themes are then juxtaposed with the evidence from the robust effectiveness studies in one column of the synthesis matrix and the findings from the remaining included studies in the third column (Appendix 2.9). This enables an assessment to be made of the extent to which effectiveness research has addressed

participants' views. However, caution has to be exercised when interpreting this synthesis as many of the interventions are multi-component and it is not possible to clearly identify the precise 'active ingredient' that influences outcomes.

The synthesis of the 'views' studies suggested that self-care interventions that included a group-based approach were valued for their provision of social support as well as for helping parents and children/young people to learn about their condition and its self-management. While no intervention studies included knowledge as an outcome, there are 'sound' effectiveness studies that associate group based approaches with improvements in health status (Evans et al. 1999/Sullivan et al. 2004; Cicutto et al. 2005) and self-efficacy (Cicutto et al. 2005). Other effectiveness studies have similarly reported improvements in health status (Grey et al. 2000; Patterson et al. 2006,), self-efficacy (Grey et al. 2000) and self-management in terms of increasing the frequency of blood sugar testing (Cook et al. 2007). Social support has only been measured in one effectiveness study and this was in relation to perceptions of support from peers and classmates (Christian and D'Auria, 2006). While the intervention was found to have no effect on perception of support from peers, it was associated with significant reductions in children's/young people's feelings of loneliness and perceptions of the impact that their condition had on their lives. Studies have also associated group-based interventions with improvements in quality of life (Grey et al. 2000; Shah et al. 2001; Cicutto et al. 2005). The 'views' studies suggested that group-based self-care support models enable children/young people to improve their communication skills with professionals and parents. However, no studies have measured communication skills and only one study has included social skills as an outcome (MTA, 1999, 2004).

There is evidence from both the effectiveness and 'views' studies that e-health methods are an acceptable, engaging and feasible method of providing self-care support to children/young people with long-term conditions (Carroll et al. 1997; Guendelman et al. 2002,2004; Krishna et al. 2003; Davis et al. 2004; Gammon et al. 2005; Franklin et al. 2006; McPherson et al. 2006; Jan et al. 2007; Van der Meer et al., 2007). There is also evidence from the high quality trials to suggest that they can be effective in terms of improving health status (Guendelman et al. 2002, 2004; Jan et al. 2007) adherence (Guendelman, 2002, 2004; Franklin et al. 2006; Jan et al. 2007), increasing condition related/self-management knowledge (Davis et al. 2004; McPherson et al. 2006; Jan et al. 2007), increasing competency of coping skills (Davis et al. 2004) and increasing self-efficacy (Franklin et al. 2006). The other effectiveness studies also found an association between e-health interventions and improvements in health status (Krishna et al. 2003; Joseph et al. 2007) and condition related knowledge (Krishna et al. 2003). In addition the 'views' studies highlighted how e-health methods could lead to parent-child conflict, however, this issue has not been examined in the effectiveness studies.

One of the 'views' studies suggested that the interpersonal skills and qualities of those delivering self care interventions are important to

participants (Anderson, 1997). The relationship between the interpersonal skills of the professional or lay person providing the intervention and the impact on outcomes has not been examined in the effectiveness studies. Although one study found that physicians who had received an intervention designed to improve their communication and teaching skills were scored higher by the parents of children/young people with asthma on communication behaviour (Clark et al. 2001). Another characteristic of the deliverer of the intervention identified by parents as being important to them was their position/role in relation to themselves (i.e. a peer, member of clinical team) (Trollvik and Severinsson 2005; Hawley et al. 2005b). All the effectiveness studies could be considered to be professionally-led apart from Shah et al. (2001) where the intervention was delivered by peers. While this was associated with improvements in quality of life and reductions in school absences, it is unknown how important peer leadership was in comparison to other components of the intervention.

As well as identifying the effectiveness of self-care support interventions and participants' views of such interventions, the evidence synthesis has contributed to the development of a self-care support model typology. This was done by identifying typology domains or components through the analysis of the included papers in terms of the intervention characteristics (Appendix 2.10). This development has progressed iteratively through discussions with the study reference group and data collected from the mapping exercise presented in Chapter 3. A table mapping the domains of the typology to the included studies is presented in Appendix 2.11.

2.6 Conclusions

This review has aimed to evaluate the effectiveness of self-care support models for children and young people with long-term conditions and examine the views of participants on them by extracting, quality assessing and synthesising the results from a range of different types of research. In addition the review has contributed to the development of a typology by identifying different components of self-care support models.

From the review it is apparent that a broad range of interventions have been developed for children/young people with long-term conditions. These interventions have taken place in a variety of settings, have had different target groups, used different methods and had different aims. The majority of interventions included in the reviews relate to asthma with few focusing on children/young people with either CF or ADHD. Overall only a small number of studies that have examined self-care support interventions for CF were identified and few studies focusing on ADHD met the quality criteria. It was notable that few interventions focused on professionals or service systems and that there was an absence of process evaluations which would provide information on how and why interventions do and do not work.

The major limitation is the lack of rigorous evaluation in this area which means that the results of the reviews and the combined synthesis have to be viewed with caution. Although 29 effectiveness studies met the minimum

quality criteria, only 11 were assessed as being of sufficient methodological quality to produce reliable results or make firm conclusions on effectiveness. There was frequently a lack of detail in the reporting of studies which made it difficult to judge their adequacy. In particular this relates to randomisation procedures, concealment of allocation, blinding, conduct of a priori sample size power calculations, attrition and the conduct of intention to treat analyses. Although some studies had follow up periods of up to two years and so were able to examine whether the intervention had a sustained effect, in many studies follow-up periods were very short. However, it is acknowledged that long-term follow up of study participants is problematic not only in terms of research costs but also because the presence of uncontrollable factors may make it difficult to attribute changes in health status or other outcomes to an intervention implemented years before.

Only eight of the effectiveness studies identified a theoretical basis to the intervention developed. A theoretical basis is important because it suggests the nature and the content of the intervention as well as the appropriate outcomes to measure and at what time points. It also informs predictions about which outcomes are expected to change and which are expected to be stable. In some of the studies reviewed the outcomes that measured were unclearly defined and many did not identify a primary outcome. Moreover, many studies did not use reliable and valid outcome measures (or did not report on them). A wide variety of outcomes were used to evaluate the interventions but even where different studies have assessed the same outcomes, they have not necessarily used the same measure or even ones of known reliability and validity. This lack of standardisation prevents comparison of findings across studies (and combination of results).

Health status and health service use were often the primary (and sometimes the only) outcomes measured in studies. However, self-care support interventions are essentially psychosocial and educational interventions concerned with changing self-management behaviours, attitudes and beliefs, which are viewed as being the mediators of improved health status. Therefore, it is important that intervention studies assess changes in these behavioural and psychological outcomes. Moreover, parents and children/young people are likely to value improvements in their experiences of living with a long-term condition as well as improvements in health status which means that outcomes such as quality of life, self-efficacy and psychological wellbeing need to be included in assessing the effectiveness of interventions. This suggests that there is a need to ensure that outcome measurement is patient-centred and involves parents and children/young people to ensure interventions are assessed by criteria that are relevant to them. Cost-effectiveness of interventions, an outcome of interest to health service planners and providers, has been under-researched.

Although some studies included children's/young people's reports, others used parents as proxies without justification. Moreover, there were also studies where it was unclear who had actually completed the measures. There was the suggestion of a degree of reporting bias, as some studies did

not report on all the outcomes assessed and overall a large proportion of statistically significant findings were reported. Indeed very few reported the negative effects of the intervention which may mean that the interventions were benign or it may also indicate a lack of investigation of potentially adverse effects as well as selectivity in reporting.

The papers reviewed for Stage 2 were similarly of a poor quality and only eight were included. Even with this selected group of papers there was a lack of detail reported on sampling, data collection and data analysis. The qualitative data generated was often superficial which has limited the synthesis due to the lack of depth in exploring the perceptions and views of children/young people and parents. Many of the studies that used a survey design had a small sample size to the extent that a qualitative approach would have probably been more appropriate and more illuminating of participants' views and perspectives. Although these studies have directly obtained the views of children/young people this has often amounted to asking them to rate a predetermined list of statements.

Only seven studies (excluding those presented in Section 2.4.5) were conducted in the UK which means that interventions may require modifying for use in a UK population. Although the detail provided about the interventions themselves was variable, in relation to their transferability to 'real life' settings, the interventions examined in some studies appeared to be feasible in terms of the resources required to integrate them into current practice. However there were others, particularly those aimed at 'high risk' groups, that would appear to demand significant resources. Moreover most of the interventions studied have been developed by researchers specifically for the purpose of evaluation and have been conducted under experimental conditions which may be very different from the settings (or populations) in which they would be actually delivered. Another difficulty in assessing transferability is a lack of reporting of sample characteristics to allow assessments to be made about how representative the sample might be of the population in question. It was notable in a number of studies (non-ADHD) that there was a disproportionate number of boys.

The majority of self-care interventions reviewed had education as an essential core component and were interventions that could be tailored to individuals' and families' needs, both in terms of the long-term condition, their individual needs and goals and also to their pace of their learning. Although the quality of the studies and the range of different outcomes measured means that making conclusions on effectiveness is problematic, there is evidence to suggest that interventions that target both children/young people and parents, that use group processes/methods (either alone or combined with individual sessions) and e-health interventions are the most promising. The 'views' studies add support to this as they suggested that participants value having the opportunity to interact with others in a similar situation in order to share common experiences and information. Participant views on e-health methods similarly found that this is a medium that engages children/young people and is perceived as supportive of self-management. Although the studies included in the review did not examine child-parent relationships, other than

identifying the potential conflict caused by self-monitoring e-health systems, there is research suggesting that maintaining parental involvement in long-term condition management through adolescence may be important in preventing declines in health status (Anderson et al. 1999). Interventions focusing on child-parent relationships and the transfer of responsibility for self-care from parents to children/young people over time is an important though under-researched area in effectiveness studies. However as noted earlier, the self-care interventions reviewed are comprised of different elements and it is difficult to assess the relative benefits of these different components rather than their global effect.

In the area of self-care support for children/young people with long-term conditions there has been a lack of a cumulative approach to research and of learning from studies that have investigated similar types of interventions but in different conditions. The review has identified that there is a need for well designed trials to be conducted in the UK which test theoretically informed interventions that have been developed with parents and children/young people and which are feasible to transfer into clinical practice.

The next chapter will present the methods and findings from a mapping survey of self-care support initiatives across England.

3 Mapping Self-Care Support

This chapter will describe the methods and findings from the second stage of the research which was a mapping of self-care support projects in England.

3.1 Aims

1. To investigate how self-care support for children/young people is being developed in England and the models currently in operation.
2. To inform our framework for categorising self-care support models.
3. To provide a sampling frame from which to identify a range of different models for in-depth study in the final stage of the project.

3.2 Methods

Originally the mapping of self-care support was going to be conducted via a telephone survey of managers of children's services in PCTs and children's hospitals. However, it proved difficult to acquire a reliable and up-to-date list of key contacts in PCTs and other trusts to use in developing an organisational database and sampling frame. It was also considered that telephone contact may not be the most effective means of obtaining information from health service managers and clinicians. The team assessed that an internet-based questionnaire could potentially resolve these issues as well as enable the mapping exercise to extend its 'reach' to all NHS hospital trusts and CAMHS services as well as to voluntary sector organisations.

Data from the on-line questionnaire was supplemented by searching the internet using Google for projects not identified by the questionnaire as well as projects/programmes identified by reference group members. How this was conducted is detailed in Section 3.2.4

3.2.1 Development of the questionnaire

An on-line questionnaire was designed to identify the projects currently in place across England to support the self-care of children/young people with long-term conditions. The aim was to develop a questionnaire that would be quick and easy to complete, and which could be circulated via email and electronic distribution networks in order to reach a wide target audience of providers and commissioners of self-care support services.

The reference group assisted in its development. The on-line questionnaire was piloted with 23 professionals, 10 reference group members, five people involved with other self-care projects funded by the NIHR SDO programme and five others involved in related work. They were asked to enter test data, note any points of difficulty or ambiguity and suggest improvements to the questionnaire and the introductory email/letter. Following piloting revisions were made to the on-line questionnaire itself and a frequently asked question (FAQ) page was included to provide additional information and explanation. The questionnaire and the FAQ are presented in Appendix 3.1 and 3.2.

3.2.2 Distribution of the questionnaire

A webpage link to the questionnaire was circulated widely in a variety of different ways in July 2008. It was embedded in emails to a range of different networks, email distribution lists, organisations and individuals (Appendix 3.3). It was also included in letters sent to all NHS Trusts in England and all Care Standards Improvement Partnership Regional Children's Change Agents (Appendix 3.4). The study reference group (and other leaders in the area of children's/young people's self-care) also circulated it within their own organisations and networks. Individuals who started but had not completed the questionnaire (n=33) were sent an e-mail to encourage them to complete and submit the questionnaire.

3.2.3 Internet searching

An internet search for self-care support projects relating to asthma, diabetes, ADHD and cystic fibrosis was conducted using Google in order to supplement the information provided via the on-line questionnaire. The search terms used were based on those used in the systematic review (condition and self-care) combined with terms relating to self-care support (e.g. project, programme, service, group). For information to be collected projects had to be current (or have been held since 2006) and to be held in England. In addition reference group members and others identified self-care projects. This data was extracted onto data collection forms (Appendix 3.5)

3.2.4 Data analysis

Data from the online questionnaire were automatically collected on two Excel spreadsheets which were subsequently converted into SPSS 15.0 for analysis. Descriptive statistics were used to summarise the data.

3.3 Findings

Sixty individuals completed the questionnaire while it was live (July to September 2008). The questionnaire's method of distribution means that it

is not possible to calculate a response rate or be able to assess how completely the current provision of self-care support projects has been captured.

The majority of respondents worked in NHS hospitals (n=20, 35.7%) or Primary Care Trusts (n=18, 32.1%) (Table 15). Although the aim was to only map projects in England, respondents from other countries in the United Kingdom did complete the questionnaire and their data are included for additional information. However, these organisations were not included in the sampling frame for the case study stage of the project.

Table 15. Organisation of respondent (n=56)

Organisation	Number	Percentage
NHS hospital	20	35.7
NHS PCT	18	32.1
Voluntary sector	9	16.1
Mental Health Trust	1	1.8
Other	4	7.1
Outside England	4	7.1

3.3.1 Characteristics of self-care support projects for specific long-term conditions

Forty-four respondents (73.3%) reported that they provided self-care support projects for specific childhood long-term conditions. The numbers of respondents identifying one or more self-care projects by condition is shown in Table 16 below, together with the number of projects for each condition. The most frequently reported self-care support projects were for diabetes (n=23) followed by asthma (n=14) and cystic fibrosis (n=14). Many of the other projects reported were for relatively rare congenital and acquired conditions.

Table 16. Self-care projects/programmes for specific long-term conditions (n=109)

<i>Long-term condition</i>	Number of projects or programmes	Number of respondents (n=44)
Diabetes	23	16
Asthma	14	12
Cystic fibrosis	14	11
Juvenile idiopathic arthritis	11	2
ADHD	9	6
Epilepsy	6	4
Autistic spectrum disorder (ASD)	4	4
Allergies	3	2
Anaphylaxis	3	1
Cancer	2	2
Constipation	2	2
Cerebral palsy (CP)	2	2
Eczema	2	2
Neuropathic bladder and bowel	2	1
Craniosynostosis	1	1
Obliterative bronchiolitis	1	1
Chronic pain	1	1
Congenital dislocation of hip	1	1
Bronchopulmonary dysplasia	1	1
Developmental co-ordination disorder	1	1
Smith Magenis syndrome	1	1
Sickle cell disease	1	1
Spina bifida	1	1
Burn and scald injuries	1	1
Chronic infantile neurological, cutaneous and articular (CINCA) syndrome	1	1
Duchenne muscular dystrophy (DMD)	1	1
TOTAL	109	

Self-care support projects were mainly provided by hospital trusts (n=20, 37%) (Table 17). In terms of geographical location, projects were most frequently provided in London, the North West and the East Midlands (Table 18). Seven (13.2%) projects were provided on a national basis.

Table 17. Organisation providing the self-care projects (n=54)

Organisation	Number	Percentage
NHS hospital	20	37.0
NHS PCT	16	29.6
Voluntary sector	9	16.7
Mental Health Trust	1	1.9
Outside England	4	7.4
Other	4	7.4

Table 18. Geographical location of self-care projects (region) (n=53)

Region/Country	Number	Percentage
London	8	15.1
North West	6	11.3
East Midlands	6	11.3
South West	4	7.6
East of England	4	7.6
West Midlands	4	7.6
Yorkshire and Humberside	4	7.6
North East	3	5.7
Northern Ireland	3	5.7
South Central	2	3.8
Wales	2	3.8
Scotland	1	1.9
Isle of Man	1	1.9
Nationally	7	13.2

3.3.2 Self-care support projects for diabetes

Of the 16 respondents who supplied data about diabetes self-care support projects, 12 described one project, one described two projects, and three described three projects. Of the 23 projects described, 20 were targeted at the child/young person, 15 at parents/guardians, seven at educational practitioners, 10 at health care professionals, three at social care practitioners, four at siblings and three at peers. Table 19 provides specific information on targeting. In addition, support workers and student nurses were given as other targets of the project. The types of projects provided included a residential weekend for 8-12 year olds, carbohydrate counting sessions, a structured diabetes education programme (CHOICE) and an interactive diabetes diary using a mobile phone.

3.3.3 Self-care support projects for asthma

Twelve respondents provided data about asthma self-care projects with 10 describing one project and two describing two projects. Of the 14 projects described, all were targeted at the child/young person with nine of these also being targeted at parents/guardians, four at educational practitioners and four at health care professionals (Table 19). In addition, some projects focused on nurses and early years providers. The types of project identified included the use of mobile phones for asthma self-management, behavioural therapy (type unspecified) and a school teenage asthma project.

3.3.4 Self-care support projects for cystic fibrosis

Of the 11 respondents who supplied data about cystic fibrosis self-care projects, nine described one project, one described two projects and one described three. Ten of the projects were targeted at the child/young person, 11 at parents/guardians, eight at educational practitioners, seven at health care professionals, three at social care practitioners, four at siblings and two at peers (Table 19). The types of projects included an educational programme for parents with newly diagnosed babies, a youth work team, and an annual workshop for teachers.

3.3.5 Self-care support projects for ADHD

Six respondents supplied data about ADHD self-care support projects. Three described two projects and three described just one. Of the nine projects described, seven were targeted at the child/young person, eight at parents/guardians, five at educational practitioners, four at health care professionals, three at social care practitioners, one at siblings and none at peers (Table 19). The types of projects included support group meetings for parents/guardians, management and behaviour support and parenting programmes.

3.3.6 Generic self-care support projects

Eight respondents (13.3%) provided information on a total of 10 self-care projects that were not focused on a particular childhood long-term condition. Table 19 presents how they were targeted. The majority of these were for disabled children/young people and/or their parents and were in relation to issues such as transition, health action planning, life skills training, parent support. The others were one that provided bereavement support and one was a youth work team who provided support for children/young people with a range of long term conditions (arthritis, inflammatory bowel disease, respiratory conditions).

Table 19. Condition specific and generic projects by their target group

Condition	Target							
	Child only	Parent only	Professionals only	Child & parent	Child, parent, siblings, peers	Child, parent, professionals	Child, parent, siblings, peers, professionals	Other
Diabetes (n=23)	5	0	1	6	0	5	4	2
Asthma (n=14)	4	0	0	4	0	4	0	2
Cystic fibrosis (n=14)	2	1	1	1	0	6	3	0
ADHD (n=9)	0	1	0	2	0	4	1	1
Generic ¹ (n=10)	2	2	0	0	3	2	0	1
TOTAL	13	4	2	13	3	21	8	6

¹Includes disability related self-care support projects

This suggests that projects are most frequently directed at children/young people, parents and professionals (n=21), at children/young people and parents (n=13) or at children/young people alone (n=13). Few projects were reported to be focused solely on professionals (n=2).

3.3.7 Commissioning self-care support

Five respondents (8.3%) commissioned self-care support projects from other organisations. Respondents were based in a range of organisations PCTs (n=3), voluntary sector (n=1) and a Strategic Health Authority (n=1). They were commissioning the projects largely from voluntary sector organisations (n=4). Three respondents reported that their organisations both commissioned and provided self-care projects for children/young people.

3.3.8 Links with other organisations in providing or commissioning self-care support

Thirty six respondents (60%) said they linked with other organisations in providing or commissioning self-care support projects for children/young people with long-term conditions. Of these, 33 provided further details of the organisations, some listing more than one. The links were mainly with voluntary sector organisations (n=19) (Table 20).

Table 20. Links with other organisations in providing or commissioning self-care (n=33)

Organisation	Number
Voluntary sector	19
NHS Organisations	7
Local Authority	3
Professional body	1

3.3.9 Use of e-health technologies in self-care support

Thirteen respondents (22%) reported that the self-care support projects they provided or commissioned used e-health technologies. Twelve respondents provided further details. All of these apart from one related to websites that provided condition related information and discussion groups for parents and children/young people. The remaining project was a telecare system provided by a commercial company for use by children/young people with diabetes or asthma and their parents. The system monitored and provided feedback on blood glucose and peak flow readings via a mobile phone and personal webpage (which could be reviewed by a nurse adviser). The system could be privately purchased or commissioned by an NHS organisation on an individual or service wide basis.

3.3.10 Self-care projects identified through the internet or personal contacts.

As Table 21 presents, a further 16 projects were identified from internet searching or through personal contacts with asthma being the most frequently provided.

Table 21. Self-care projects identified from the internet and personal contacts (n=16)

<i>Long-term condition</i>	<i>Number of projects</i>
Asthma	7
ADHD	4
Diabetes	3
Cystic fibrosis	1
Generic	1

The asthma and diabetes projects all focused on children/young people whereas the cystic fibrosis, ADHD and generic projects focused on children/young people and parents. Three projects were described as being pilot projects that had only run once and were awaiting either further evaluation or commissioning.

The generic programme identified is the self-care support project provided by the Expert Patients Programme Community Interest Company (EPPCIC). A number of PCTs across England commission EPPCIC to provide courses for children/young people aged 12-18 years old ('Staying Positive') and for parents ('Supporting Parents Programme'). In addition they provide condition specific courses for children/young people with Sickle Cell Disease and Thalassaemia, HIV and Multiple Sclerosis. A new development is a programme for health and social care professionals ('Wise up') which aims to increase their knowledge, skills and confidence in supporting self-management.

When the data from both the questionnaire and the internet searching are combined, it suggests that the majority of self-care projects are focused on children/young people with diabetes or asthma (Table 22).

Table 22. Self-care projects for target long-term conditions (questionnaire and internet searching) (n=77)

<i>Long-term condition</i>	<i>Number of projects or programmes</i>
Diabetes	26
Asthma	21
Cystic fibrosis	15
ADHD	13
Generic [#]	2

[#]Excludes disability related self-care support projects

3.4 Conclusions

From this mapping exercise it appears that projects for children/young people with diabetes are the most commonly provided self-care support projects for children and young people with long-term conditions. The data suggests that projects are mainly provided by NHS Acute Trusts and that the main areas of activity geographically appear to be London, the North West and the East Midlands. Current self-care support projects are largely targeted at children/young people (either alone or with their parents), while few are directed at professionals, peers or siblings. The use of e-health to support self-care appears to relate mainly to websites providing condition-related information and discussion groups for parents and children/young people.

The commissioners who responded to the questionnaire appear to be mainly commissioning projects from third sector organisations. Providers also identify the third sector as being key partners in the provision of self-care support.

A total of 70 self-care support projects were identified in England for inclusion in a sampling frame to use in selecting case studies for the final stage of the project.

The evidence synthesis (and the study reference group) had contributed to the development of a self-care support model typology by identifying potential domains (Appendix 2.10). The data collected from the mapping exercise were examined in relation to these domains to explore whether new domains or new properties of existing domains were identified. However, the data collected could be mapped to these existing domains and therefore the self-care support typology was not developed further.

The mapping exercise is limited by the method of distribution of the online questionnaire. This means that it is not possible to calculate a response rate

and that assessing the completeness of the data obtained is problematic. Non-response from a Trust could indicate that no projects were being provided or commissioned but it could equally indicate a desire not to participate in the survey. It is also possible that some third sector organisations may not have received information about the survey via the email distribution and their contribution to self-care support may be under-reported. As with all online surveys the sample is likely to be biased towards those with internet access and who are comfortable with using electronic media.

4 Case studies of self-care support projects

This chapter will present the research methods and findings from the case study stage of the research. The research aims will be identified along with a description of the research design, sampling and methods of data collection and analysis. The characteristics of the individual case study sites will then be presented followed by a cross-site analysis of the findings.

4.1 Research methods

This section describes the research design and methods used in the case study stage of the project. The aims of this stage were to examine:

- children's/young people's, parents' and professionals/workers' perceptions of the effectiveness of models in supporting self-care,
- the factors that support self-care and those that inhibit self-care (both at an organisational and individual level),
- how the models integrate with self-care support provided by other organisations.

The case study stage was informed methodologically by case study research and the principles of realistic evaluation. The latter highlights the importance of context in understanding why interventions work, for whom, how and in what circumstances (Pawson and Tilley, 1997). This involves examining the relationships between context, mechanisms and outcomes at an individual and organisational level. Case study research enables a phenomenon to be explored within its real life context, from the perspectives of different stakeholders, using multiple methods (Yin, 2009). The 'case' in this study was defined as being a self-care support project and in order to assist with the descriptive and explanatory analysis and illuminate different contextual issues, multiple comparative case studies were included.

4.1.1 Sampling

Case study sites were purposefully sampled to reflect the different components of the self-care model typology identified from the evidence synthesis and reference group consultation. Ten potential sites were identified from the mapping survey and internet searching in collaboration with the reference group. Additional information was requested from each site before six were formally approached to participate in the study. Three sites declined to participate and a fourth was assessed by the researchers as being problematic to include in terms of potentially low numbers of parents/young people accessing the project. The final six sites were: an asthma camp; a centre for children/young people with ADHD and their

parents; Staying Positive; an online support group for children/young people with CF and their parents; an NHS Diabetes Team; and an NHS Support Team for children/young people with a range of long-term conditions.

Sampling of participants was driven by the characteristics of the particular self-care model and was purposeful in order to include a range in terms of children's/young people's ages, involvement in different activities in the self-care projects and different types of workers and volunteers. However, at some sites all the participants who had been involved with a particular project were approached. At all sites a minimum of one follow-up of potential participants was conducted. Attempts were also made to sample children/young people and parents who had 'dropped out' of projects.

Parents and children/young people were recruited via the projects with organisers either posting out project information sheets and contact forms to participants' homes or handing them out when they attended a self-care project session (if 16 years or over). For children/young people under 16 years old, information about the study was sent first to parents and only with their permission were their children contacted to discuss participation in the study. A range of information sheets were developed for different data collection methods and for different ages groups. Where children/young people had a cognitive impairment parental advice was obtained on the most suitable information sheet for them. Participants responded directly to the researchers to indicate their interest in participating in the research by returning a study contact form to provide their contact details. Following receipt of the contact forms potential participants were then telephoned to further discuss the study, answer questions and arrange a convenient time for the interview or to discuss the timings of the observation periods. Families were excluded where self-care project organisers considered it to be inappropriate to involve them in a research project e.g. recent bereavement, diagnosis of life threatening illness in the family, current child protection issues. A group of children/young people and parents external to the research project were involved in advising the researchers on how to engage parents and children/young people in the study and the data collection methods to use.

The professionals/lay workers involved in the self-care projects were invited to take part and they were also asked to identify other practitioners who had been involved in developing or delivering the project. From this sampling pool workers were purposefully sampled to ensure a range of different types of workers (e.g. unpaid volunteers, nurses, doctors, therapists, project managers). Information sheets were posted or emailed to their place of work and approximately one week later they were contacted to discuss their willingness to take part in the study and arrange a convenient time for interview.

4.1.2 Data collection

Case study methods involve the use of multiple methods of data collection to enable a more complete picture to be developed of the phenomenon of interest. The following methods were used in this stage of the project.

Semi-structured interviews

At five case study sites semi-structured interviews were conducted with children/young people, parents and workers involved in providing the self-care support project. The aim was to capture their views and experiences of the particular project and their perceptions of its appropriateness and effectiveness in supporting self-care. The interviews were mainly conducted by telephone due to the geographical spread of sites although face-to-face interviews were conducted where parents felt this to be a more appropriate method or where participants stated a preference. The interviews were led by topic guides (Appendices 4.1, 4.2, 4.3) and were audio-recorded and transcribed verbatim. The majority of interviews were one-to-one although five were joint interviews with both parents or with parents and children/young people together. The interviews ranged in length from 20 minutes to one and a half hours.

Non-participant observation

At two sites (the asthma camps and the ADHD centre) a sample of self-care support activities was observed in order to examine the context, content, processes and the interactions occurring. The researcher's role was one of 'observer as participant' in that participants were aware of being observed and the researcher related to them as a researcher. Although some degree of interaction occurred between the researcher and participants, the role was mainly confined to note taking and observation. The observations were written-up as field notes which included rich descriptions of real life self-care support as well as the interpretations and reflections of the researcher and accounts of any informal conversations. Virtual non-participation methods were used for the online support group and involved observing and downloading the postings made to two discussion groups over a four month period. Towards the end of the observational period the researcher posted some questions to each discussion group about their perceptions of the effectiveness of the group in supporting self-care with an invitation to respond privately by email or publicly via the discussion group itself.

Documentary review

Documents relating to the development and implementation of the project were collected from each site where available in order to provide background information in which to contextualise the findings as well as data on factors supporting and inhibiting self-care and linkages with other forms of self-care support.

4.1.3 Data analysis

The data analysed were interview transcripts, field notes, online support group postings and documents relating to the case study sites. The data were analysed systematically using the Framework method (Ritchie and Spencer, 1994). A thematic framework was developed to classify and summarise the data for each case study site based on the study aims, self-care model components and the themes emerging from the interviews and observations. This approach was taken to ensure that the analysis was both grounded in participants' own accounts while at the same time enabling the analysis to be focused on the study aims. This framework was then applied to the data with data charts being used to develop descriptions of themes and their dimensions, explore associations and search for explanations. This enabled comparisons to be made both between case study sites and within case study sites. The data were managed using NVivo, a qualitative data analysis program.

4.1.4 Research ethics

NHS research ethics committee approval was obtained for the study and it conformed to NHS Research Governance Framework procedures.

A range of information sheets and assent/consent forms were developed for different data collection methods, for different participant groups and for different ages of the children/young people. Parents and children/young people were involved in developing these documents. Consent/assent was regarded as a continual process with attention paid to any nonverbal signs that suggested that the participants no longer wished to take part. In relation to children/young people the final decision on whether or not to participate rested with the child/young person. For children/young people under 16 years of age, parental consent for their child's participation was obtained as well as the young person's written assent.

Although it was not expected that the interviews/observations would cause distress to participants, procedures were established to manage this if it occurred. Similarly procedures were established for child protection disclosures. The limitations to confidentiality in relation to child protection were highlighted to participants in the information sheets. Participants have been anonymised in the report with pseudonyms used and any potentially identifying characteristics altered. The names of the case study sites have been changed where possible, although one project is unique and therefore anonymisation is not possible.

4.2 *Characteristics of the case study sites*

This section will present the characteristics of the case study sites. Appendix 4.4 presents the key characteristics of the case study sites in relation to the typology components.

Details of the numbers of interviews conducted at each case study site are presented in Table 23. In total 26 children/young people, 31 parents and 36

service providers were interviewed across six sites. Recruitment to the study at all sites was slow and fewer participants were recruited than had initially been planned in spite of following up non-responders.

The children/young people ranged in age from 8 to 18 years old. The service providers included paediatricians, nurse specialists, young facilitators and volunteers. In addition the following observations were carried out: one day of an asthma camp; six hours of a skills building workshop (three two hour sessions) for parents of children/young people with ADHD; six hours of a skills building workshop (six one hour sessions) for children/young people with ADHD; two hours of a club for children/young people with diabetes; four months of postings to two online discussion groups (a total of 153 discussion threads containing between one and 19 individual postings, along with email responses to researcher posted questions).

Table 23. Case study sample

Self-care support project	Interviews with children/young people	Interviews with parents	Interviews with Service Providers	Total
Asthma Camps	6	5	10	21
ADHD Centre	4	7	11	22
Staying Positive*	10	6	6	22
Online support group [#]	N/A	N/A	1	1
Diabetes Team	2	6	6	14
Support team	4	7	2	13
Total	26	31	36	93

*Recruited from six courses across England.

[#]Data collection at this site was mainly observation of discussion group postings.

The findings from the interviews and observations will be presented as a cross case analysis, however in order to contextualise the data a short description of each case study site will be provided.

4.2.1 The asthma camps

The asthma camps are provided by a national asthma charity as part of their work to improve the health and wellbeing of children/young people

with asthma. In addition to the asthma camps other resources are provided for children/young people and their parents such as information sheets, an advice line and online discussion groups. Six camps which each last a week are held across the UK during the summer time and are attended by approximately 200 children/young people. Each camp is divided into one for those aged between 6 and 11 years old and one for those aged between 12 and 17 years old. The aim of the camps is for children/young people to experience an adventurous holiday and to:

- Find out more about asthma and how to control their symptoms.
- Meet other children/young people with asthma and other related conditions.
- Develop new skills, self-confidence and independence by being away from home.
- Take part in new and exciting activities e.g. camping, abseiling.
- Become more independent in controlling their asthma, using their inhalers and knowing why they take them.

The camps are residential and are usually held in boarding schools. Children/young people take part in activities such as raft building, orienteering, kayaking, abseiling, crafts, discos and quizzes. Educational sessions about asthma self-management are also included. The charity subsidises the costs of the camps and costs to families range from £50-£350 depending on ability to pay.

The camps are planned and coordinated centrally by the charity. Each camp is led by a manager who is the only paid member of staff. Many of the volunteers return year after year and are a mixture of adults with asthma (some of whom attended the camps as children), health professionals and young people obtaining volunteering experience (e.g. Duke of Edinburgh Award Scheme). One volunteer supervises a maximum of three children/young people. Volunteers attend a training weekend to learn about the treatment of children/young people with asthma, eczema, anaphylaxis and food allergies. For volunteers with asthma it is seen as being important that their condition is well managed as they are seen as role models.

Future goals for the holidays are to attract more male volunteers and to increase the number of holidays they run annually. However, this expansion is constrained by a lack of funding.

The link between this case study and other forms of self-care support reflect its position as a national charity. It is involved in national campaigns to improve the management of medical issues in schools and physical education teacher's awareness of asthma and is an information resource for children/young people, parents and professionals such as nurses and doctors.

4.2.2 The ADHD centre

The ADHD centre is a voluntary sector organisation that provides a range of support for children/young people aged between 5 and 18 years old with a diagnosis of ADHD and their parents who live in a city in the North of England. Located in a community centre, the aims of the organisation are to help children, young people and parents understand and manage ADHD and to build their self-esteem. Underpinning philosophical beliefs relate to empowerment, social inclusion and partnership working (with children/young people, parents and other agencies). Between 2002 and 2007 over 600 families had been referred to and supported by the Centre.

Following referral to the Centre an individual meeting is held with each family to assess their needs and to provide information about ADHD and the services provided by the Centre. The Centre offers six week skills building courses for parents, children (aged 5 to 11) and young people (ages 12 to 19). Over the course of a year 72 parents and 72 children/young people attend these courses. In addition various groups are held for children/young people and parents who have graduated from these courses as well as pilot projects focusing on particular marginalised groups e.g. young people in the youth justice system, minority ethnic groups as well as individualised support. The Centre also provides training for those working with children/young people with ADHD in educational settings as well as workers in the health service, Connexions, the police force, the fire service and youth offending teams.

Since its establishment the Centre has been funded from multiple sources such as the Local Authority, the local CAMHS, the Parenting Fund, the Children's Fund and the Big Lottery. A major issue for the organisation is the need to constantly apply for and obtain funding in order to maintain the services it provides. This also constrains any planning to expand services beyond the city boundaries and to increase current provision to meet perceptions of local unmet need. In addition the lack of 'hard' evidence on outcomes of activities at the Centre was identified as a barrier to obtaining funding from statutory bodies.

The Centre is led by a manager and staffed by a mixture of paid workers and volunteers. Most of the workers are parents of children/young people with ADHD who have entered the organisation as parents and then moved on to become volunteers and then paid employees. A National Open College accredited programme has been developed to give volunteers and workers the knowledge, skills and experience to work with families.

This case study links with a number of other forms of self-care support. As noted earlier, workers from the Centre are involved in training teachers and schools about ADHD and in conducting awareness-raising sessions for agencies such as Connexions, the police and youth offending teams. Their relationship with CAMHS appears to be as a source of referrals from them rather than joint working. In addition the Centre links with other third sector organisations (e.g. local disability groups) in supporting families and receives funding from local authority for training in schools and for individual support packages.

4.2.3 'Staying Positive'

'Staying Positive' is a lay-led self-management programme for children/young people with a long-term condition who are aged between 12 and 18 years old that is provided by the EPP Community Interest Company (EPPCIC). It is delivered in a range of community settings and is mainly generic although there are courses specifically for children/young people with particular conditions such as Sickle Cell Disease, HIV/AIDs. The aims of the programme are:

- To improve young people's confidence in managing their condition and their medication.
- To reduce feelings of isolation and depression.
- To improve quality of life.

Trained young facilitators (aged between 14 and 25 years old) who have themselves been on the programme lead the sessions. The content and format of the programme have been developed in consultation with children/young people and have evolved since it was first piloted in 2005. A programme consists of three one-day workshops that are held on Saturdays or Sundays and attended by approximately eight children/young people. Areas covered are communication with friends, family, and health care professionals; socialising and friendships; medication adherence; school, careers and the future; feeling down and depressed; independence and transition; sex, drugs and alcohol in the context of having a long-term condition for older participants or issues relating to puberty for young participants. Each session concludes with a 'fun' activity such as learning African drumming, digital photography or how to make a pop video.

EPPCIC fund the organisational core costs but programmes are commissioned by PCTs and Children's Trusts. In addition EPPCIC obtained funding from Vinvolved (an independent charity aiming to inspire a new generation of young volunteers) for facilitator training. The organisation has however, experienced difficulties in obtaining commissions and in recruiting children/young people on to the programme. Like the Asthma Camps, they would like to attract more male facilitators. Evaluations of the programme have been conducted and are presented in Chapter 2. However, the lack of 'hard' evidence on outcomes of the programme was cited as barrier to engaging NHS professionals in recruitment.

Their relationships with other forms of self-care support appear to be mainly in relation to obtaining commissions for courses from the NHS and working with specialist nurses in order to recruit children/young people onto the programme. At least one course has been provided in a school.

4.2.4 The online support groups

The online support groups are provided by a national CF charity as part of a range of informational and support resources. The charity provides separate online groups for teenagers, parents, adults with CF and the partners of

people with CF. This study focused on the ones for teenagers and parents/carers. The aims of the groups are:

- To provide social support and social networking.
- To exchange information and news.

The groups are located on the charity's website. Each group consists of chains of inter-related messages that are structured under topic headings. Participants register with the groups in order to post messages although postings are publicly accessible. Postings are asynchronous and some moderation is provided by the charity which includes message blocking and deletion of discussion threads though this is rarely required.

At the start of data collection across all the groups there were 2,939 registered users (it is not possible to disaggregate membership of different groups); the teenagers group had made 5,982 postings across 573 discussion threads and the parents group 33,749 postings across 4,097 discussion threads. On average the teenagers make approximately 100 postings per month and the parents 1,000 postings. There are generally around 20 to 30 users online at the same time (with the maximum to date being 313). The groups largely provide emotional and informational support. The main topic areas for discussions relate to managing CF, feelings and emotional responses to a long-term condition and relationships with services/professionals.

The groups are funded by the charity and are organised by their communications manager with technical support from two web designers. The latter are also involved as moderators as are a group of adults with CF.

As the charity has a national focus it largely relates to other forms of self-care support through leading and being involved in national campaigns and by providing information resources for children/young people, parents and professionals. However, it also works with CF centres to improve care through for example, the development of clinical pathways, staff training and the provision of lay advisors.

4.2.5 The Diabetes Team

The Diabetes Team is a specialist NHS team based in an acute trust that supports over 200 children/young people. The team consists of two consultants, two specialist nurses, one play worker, one dietician and one youth worker (who is managed by the local authority). In addition to clinical care the team provide a varied and extensive programme of activities with the aims of:

- Educating children/young people and parents about diabetes and its management.
- Building relationships between the team and parents/children.
- Providing parent-to-parent and peer support.

- Improving control of diabetes.

Activities are based in hospital and community settings and target different groups (e.g. young children, teenagers, parents). They include:

- A club for children/young people aged between 5 and 10 years (and their parents and siblings/friends) where they learn about diabetes through play and education. It is held once a month and sessions last for two hours. Monthly themes are mainly led by parent suggestions and concerns with activities carefully planned to support the topic area. The club is led by the team's play therapist with support from parent volunteers. One of the nurse specialists also attends sessions in order to provide information and advice in relation to diabetes management. Approximately 25 children/young people attend the monthly meetings. The club is supported by fundraising events and by Diabetes UK.
- Activities and trips are periodically organised for children/young people aged over 11 years old by the youth worker.
- An annual residential holiday is held for approximately 30 children/young people aged between 8 and 16 years old. The aim of the holiday is to develop their independence in relation to diabetes management; in particular exercise and insulin, diet and managing hypoglycaemic attacks.
- Carbohydrate counting education sessions are provided by the dietician for children/young people and parents. Three age appropriate sessions are provided that are built around games and activities with a final social event to put theory into practice (e.g. picnic, restaurant trip). Parents are the focus for children under six. Older teenagers attend alone and their sessions include alcohol and eating out.
- A training programme for peer mentors is being provided for older teenagers so that they can support younger children in schools and become involved in the club.
- Other occasional educational sessions are held, for example for newly diagnosed children/young people and their parents, and on particular topics such as sickness management.
- School-based educational programme in large secondary schools (e.g. alcohol and drugs; peer support).

In terms of relationships with other forms of self-care support, the integration of self-care support and clinical care provides the opportunity for continuity and consistency of support to families. The team are involved in schools through teaching sessions for staff about diabetes; running school-based clinics and attending meetings to plan and evaluate support for individual children/young people. The team have received support from Diabetes UK to provide the children's club.

4.2.6 The support team

The support team is a hospital-based, NHS, nurse-led team who support children/young people with a range of long-term conditions, e.g. epilepsy, cystic fibrosis, asthma, autism, juvenile rheumatoid arthritis and life limiting/threatening conditions. The team is comprised of four nurse specialists and three nurses. When the team was established in 2004 the initial focus was on home support for children/young people with life-limiting/threatening conditions but this has now extended to other children/young people with ongoing nursing needs as well as those who are part of the caseloads of the nurse specialists in the team. As there is no community children's nursing team in the area, it appears to be filling this gap in service provision as well as providing specialist nursing support. The aim of the team is to provide home support in order to prevent hospital admission and reduce the length of hospitalisations. All activities are provided to families on an individual basis and include:

- Nursing support within the home to families (e.g. teaching parents how to care for their child; provision of equipment; transportation of samples; end of life care).
- Telephone advice for families.
- Taking children/young people and siblings on trips.
- Home-based short-breaks (i.e. 'babysitting').
- Training school support workers.
- Specialist nursing support for children/young people with particular conditions (e.g. nurse-led clinics, liaison between families and consultants, support for schools).

The team originally received three years of charity funding but is now NHS funded which appears to have led to some reconfiguration of the team. In addition a number of staff have left which has reduced the level of support offered to families.

In terms of linkages with other forms of self-care support, the team are involved in teaching staff in schools about the needs of individual children/young people and attending meetings in school about individual support packages as well as educational review meetings. Some use is made of local and national third sector organisations for information.

4.3 Findings from the cross-case analysis

This section will present the findings emerging from the cross-site analysis. Contextual issues of living with a chronic illness, the reasons for accessing the self-care support project and experiences of providing self-care support will be described before participants' perceptions of the effectiveness of self-care support are examined.

4.3.1 Experiences of living with chronic illness

Participants' experiences of living with chronic illness provides the contextual background to their decisions to access the self-care projects as well as their perceptions of effectiveness. Two main themes emerged in relation to living with chronic illness – 'managing the condition' and 'being different'.

Managing the condition

Many parents' narratives commenced at the time of diagnosis. For the parents of children/young people with ADHD their children had originally been labelled as badly behaved which had led them to view themselves as 'bad' parents for their inability to discipline. Consequently obtaining a medical diagnosis was in some sense a relief to them. However, for other parents diagnosis was associated with shock and the onset of a period of information seeking and adjustment.

'no parent wants to hear there's something wrong with their child, this sort of perfect little baby that you've brought up, and all of a sudden someone says that there's something wrong there, and it's, well you have to accept that initially, you have to sit back and say, well no, like to, this child you've now got with a condition is still the same child, and that takes time, it takes time and confidence in what you're dealing with'

Living with a long-term condition involved parents and children/young people in the daily management of symptoms, triggers and therapeutic regimens (largely medications). Over time parents described how they had developed expertise and knowledge that enabled them to identify deteriorations in their child condition at an early stage.

'it's just one of those things that I've got so tuned on to it when she was a baby that to this day I can tell the sound of her breathing when her asthma is getting worse, which sounds really freakish, but it's true. I think once you know it, you can never get rid of it.'

For the parents of children/young people with ADHD the symptoms that parents were managing were their child's behaviour – at home, in social situations and at school. After some deliberation, many of the parents had agreed to their children being prescribed medication which they felt had lead to improvements in their behaviour and educational progress.

Most of the children/young people regarded needing medication and therapy regimens as part of 'normal' life as they had had a long-term condition since infancy.

'all this is just kind of natural now, I don't really think about it'

'well I've had it all the time, since I was little, and I just take my medicines every day, morning and night. And before I do sport I have to take three puffs of ventolin.'

Parents also noted that their children had normalised and integrated the therapy regimens into their daily routines.

'it's just a way of life for her, and she doesn't even necessarily see it as different, until someone mentions it, I think it's just so, so much part of her normal life, she forgets'

'he's just grown up with it reallyhe's always really, in his memory, taken preventative inhalers, and I think then it's, it's like brushing your teeth, it's sort of automatic'

However, there was one young person who had been diagnosed with diabetes later in childhood who noted how he had had to adjust to taking medications and living with dietary restrictions.

'it's just been like a big life change, having to remember to take all the medication, and know that you can't eat that sort of food, and if you do, this is going to happen the next day, and it's taken a lot of getting used to'

Self-care in school

Families described the difficulties they had experienced in relation to self-management of the chronic illness at school. This could relate to a lack of understanding and awareness on the part of teachers about the child's condition which meant that appropriate adjustments were not made for their needs or that the child's self-care was not supported in school.

'he's supposed to have five puffs of his inhaler before he does any sports or anything anyway. If Tom remembers, Tom will do it, but somebody, somebody has got to be there to tell him all the time, you know, you've got to take your inhaler Tom, and he'd sooner just sit there and suffer, I mean I've fetched him from school many a times, and he's literally purple, they're not picking up on that then, you know, it's quite scary knowing that he's at school, and he can't breathe'

'although they're telling him to slow down, they're pushing him at the same time.....they won't let him use his wheelchair, they took him on a day trip and he walked round when I picked him up from school on the Friday evening, he wasn't very good, his legs were hurting him, and he was in his wheelchair for the rest of the weekend, and on the Monday, 'cause he was still sore on Monday'

Younger children could struggle to explain how they were feeling to teachers or other school staff either through a lack of confidence or because they found it difficult to articulate their bodily sensations.

In particular the parents of children/young people with asthma described how teachers at primary schools created barriers to self-management by not allowing children/young people to keep their inhalers with them.

'when she was at Junior School they didn't allow them to have the inhalers on them, they were in the office... obviously nothing really bad ever happened, but now she's at High School, so obviously she's allowed to carry the medicine herself, so she just takes it, if she needs to, as and when'

Children/young people being prevented from having their inhalers with them in school was also identified by workers at the asthma camps who were concerned that the good practice they had been encouraging in children/young people was undermined by schools (particularly primary schools).

'we hear about inhalers being kept in locked offices at lunchtime, you know when the children are running around outside when maybe they might need it, and they can't get to it, and those are the sorts of measure that we're trying to get through, you know, how important it is for the children to have access'

'inhalers are taken away and locked in a cupboard in the Headmaster's office, or something like that, so that if they have an asthma attack on the playing field, by the time someone's got to the medication, and got it back to the child, you now need an ambulance, you know, it, it is terrible really schools, in particular, I would say, are the biggest culprits, they seem to be almost completely clueless as to how to deal with children with asthma'

'they may go back into their schools and find that everything we've taught them is then taken away'

The nature of the additional support that children/young people needed at school varied. It could be for someone to provide actual clinical care (e.g. insulin administration), supervision of their own self-management or it could be educational rather than health related support. The additional support provided in school was variable with some receiving none. Consequently some parents and children/young people could face considerable barriers to self-care in school.

'Well I go in to inject, my, our school isn't too keen on that side of it at the moment ... I go at the moment on the trips. I mean at the moment, the other children are all very accepting of seeing me there, and what I do, check his finger and things, but as he gets older, you don't really know how that might go'

'they've got nobody there to be able to supervise Sam in doing this, so I've had the hospital in at school, the respiratory nurse with the head teacher and everything, and a plan was set up, but that plan has never been, it's never took place, they done it for the first couple of days, writing in the book, when, because it

had to be noted when Sam went to the office to have his inhaler, and then that all just went to pot as well, they don't do that no more'

However, there were children/young people whose self-care was well supported by schools either through the provision of a support worker or through supervision of the child's self-management. Even where children/young people were successfully self-managing their condition in school, parents highlighted that it was important staff were aware of and able to respond to deteriorations in a child's condition either through their own observation or in response to a child's report of feeling unwell.

'they've employed a full time carer to look after Alex, so we've got a really, really lucky because I know of a lot of parents whose kids have got pumps, they've had to home educate them 'cause they can't get someone to, to do it so we've been lucky'

'he just has a classroom assistant who knows what to do, he can go to him if he feels unwell they're just aware rather than they do everything, Harry can do most of it himself but at least they know what's going on and they can always get someone'

It was also important that support extended beyond the clinical management of the condition per se to include parental involvement and the development and monitoring of individualised educational plans in order to ensure that their educational and health needs were met.

'his Senior School were absolutely fantastic, they had a great understanding of ADHD, they did everything for him, they had me in every term and we went over his individual education plan, every single term, what would work, what wouldn't work, and we were inputting into it... they did bend over backwards for him, supported him, and me every step of the way'

In the educational sector it was not only schools where problems were experienced. A small number of children/young people who were at University identified the lack of support they had experienced in terms of allowances being made for the impact of a long-term condition on educational progress or difficulties in obtaining equipment and personal support.

Transition to independent self-management

For children/young people with long-term conditions the transition to independence involves acquiring responsibility for managing their health. Parents described how they commenced this process by encouraging their children to 'know' their own bodies, to be able to articulate their symptoms to others and to decide upon the actions needed. Over time parents described how they provided opportunities for their children to become involved in aspects of managing their condition and in taking more control over decision-making. However, children's/young people's enthusiasm for

taking on responsibility for self-management varied as well as the parts with which they wanted to be involved.

'he's always been encouraged to deal with medication and that kind of thing, I mean don't get me wrong, if I don't literally sit on him, he won't do his eczema creams, but he's more willing to deal with, um the asthma stuff'

[we decided] 'at age six, that we'd give him certain responsibilities, small partial seizures, where he felt a bit funny, bit dizzy, that that would then become his responsibility, not just come to mum, and mum deal with it, let's see what you can do, and he, he absolutely loves that, he loves the responsibility, and being able to sort his condition out himself, as much as he can, he loves that'

Even when children/young people had the main responsibility for self-management of their condition, parents often continued to play a surveillance role, discretely monitoring their health and their adherence to therapeutic regimes.

'I've just sort of had a word with her the other day, she doesn't take her reliever now twice a day, she used to take it religiously, every morning and every night, but now she's not taking it every night, she just, she takes it every morning, but not, as I said, every night, you know what teenagers are like, oh well, you know, I don't feel any worse'

Sources of self-care support other than the project were largely described in terms of health professionals such as paediatricians, specialist nurses and general practitioners. Only a small number of participants had had contact with voluntary sector organisations outside the project and this was largely in relation to information.

Being Different

Children/young people had to contend with feelings of being different to their peer group. These feelings largely arose in the school context and were due to the medical equipment they carried or the need to conduct self-management activities (e.g. blood glucose monitoring). Feeling different also resulted from experiencing physical limitations or from the limitations placed upon them by schools.

'I used to have to carry a big spacer with me all the time, like in a separate bag, it was quite annoying'

'at lunch, just before I eat, I have to go into the nurses office, because we have a nurse at our school, and do it there'

'I can't really go on school trips or anything else anymore'

'I think it's difficult when you've got, when your peers are all, they're all quite healthy, and on a daily basis, or sort of, you're

okay for a few days, and then like you get your aches and your pains, or you're not feeling too good, or you're not feeling too strong'

Parents were also aware that their child's condition could lead to their feeling different to their peer group.

'he stands out,, you know you don't want to have all looking at you when you're testing and injecting, that kind of thing'

'she was a bit wary when she was little, sort of doing it in front of people, especially because she had the spacer, you know, when you're little it kind of looks like you, you're a bit of a freak'

Children/young people did not want to feel different; they wanted to take part in the same activities as their peers and not be set apart by their physical limitations or people's responses to them.

'I just don't want people to feel sympathy, I just want to feel like I'm, like I haven't got anything wrong with me, I feel fine'

'I don't really get support from school, I doubt half the teachers know I'm diabetic, but that's how I like it, just another kid'

A consequence of feeling different was a sense of isolation for children/young people, particularly if they were the only child in their school or class with a medical condition.

'I am the only one with arthritis'

'he tends to sail along and be absolutely fine with his injections and things and then it comes out in more of an emotional way, sometimes behaviour wise and that kind of thing, you just get periods where it's a bit difficult and I think it's all of that storing up of frustrations really, you know the fact that he's injecting all the time, and you're the only one, you know those kind of feelings come out I think'

The parents of a small number of children/young people noted how their child's difference had led to them experiencing bullying from other children at school.

'I knew there was something wrong going by looking at him in the face, and he was getting very withdrawn, he was stopping talking, and then on the Friday, the school pulled me in and told me that on the Monday there was two boys on top of him, and it took two teachers to get them off. I took him to the doctors and he had a broken nose in three places, and I never sent him back to that school again'

'Beth has been going through like a stage where she's been depressed, and she wanted to commit suicide through bullying at school, because of her illnesses, and because she wears a hearing aid and, more to do with the arthritis as well, that she

couldn't do things that other children were doing, it was limiting, you know to her physical side'

Disclosure and peer support

The children/young people varied in whether they had disclosed their condition to their peers or whether they wished to do so. To some extent disclosure was determined by the child's ability to articulate their condition and their peer group's ability to understand this information.

'I don't talk to them [friends] about it'

'she probably pretends she doesn't have it, or doesn't acknowledge she has it as such, um but then if someone asks her it's no big deal, you know, she's not, she doesn't, she, you know, she takes the inhaler before school, and it's not a big deal, she'll do it whether her friends are there or not, um, she's not particularly open about it, but she doesn't sort of deny it either'

'he seems alright about it, talking to them about it, and his, his friends all know, and he seems quite happy with that'

When peers were aware of their long-term condition it provided an opportunity for them to be sources of support by making allowances or by providing practical forms of help.

'I'm generally not too bad at school because most of my friends are okay, understand that if I'm having a problem like and you know just need to sit out for a bit'

'we're constantly trying to build a little circle of friends around Anna, and they all know the words that Anna uses for hypo if she says it they all know to go and get a teacher to come to Anna, so yeah, it is, it is very very important to get that, that bond with certain friends, because when she's in a hypo, she, she you know she be so confused, she doesn't know whether she's supposed to be telling the teacher or going to sleep or whatever, but if her friends can start to recognise the signs, then they can tell the teacher'

Children/young people with asthma noted that as asthma was becoming more commonplace, awareness and understanding of the condition was greater amongst their peers. In addition it was not unusual to see children/young people using inhalers.

'A lot of them are quite understanding because it's becoming more and more common, asthma, and more and more widely accepted. I mean at Primary School it was hard to explain to people, now I've gone into Secondary School and everyone knows what it is'

'I just carry my inhalers in my bag. Even if I need to take them I don't really care if people look at me to be honest. They can stare if they want to. But yeah, most people know what asthma is anyway, and quite a lot of people have got it in my class, so it doesn't really make a difference'

For children/young people it appears that schools are the sites where they negotiate both the management of their condition and their relationships with their peer group.

4.3.2 Accessing self-care support

Most families had referred themselves to the project following information given to them by health professionals such as paediatricians or nurse specialists or by teachers. Other families had seen posters advertising the project, read articles in the media or been mailed or emailed with information about the project by charities. Some parents had heard about the project from their lay networks such as friends, neighbours or other parents they had met at the hospital. The sole way that the Support Team families accessed the project was following a referral by NHS staff e.g. paediatricians prior to discharge home.

Access to the project appeared to be promoted when a health professional or other worker discussed the project with a young person or a parent individually.

'the fact that she sent the letter to Amy and said, oh Amy this looks really interesting, would you like to get involved? Yeah we probably wouldn't have just picked that up at the clinic, it's probably the fact that she said oh, what do you think about this, we thought, well yeah actually that probably could be quite beneficial'

Children/young people highlighted how their parents (largely mothers) had played a key role in their decision to participate in the project. Their parents were either already involved in the project themselves or had seen information about it and had encouraged their children/young people to attend.

'she told me that they were running workshops for young people with long term health conditions, and so in the beginning I was like, hmm, I don't, I don't really want to go on this, but then she was like, you know it's really good, you should go, so I went on the first one and I loved it'

'Well, my mother read an article in the newspaper, and told me about it, and so I agreed to go from there, I don't know which newspaper it was, 'cause I was only told about it, but my mother read about it, and said it had some good reviews, and to try it out, so I did'

Children/young people described how they were anxious about attending the meetings or camps initially and how their parents were important in encouraging them to take the first step.

'I'm a very anxious sort of person, so I felt very anxious, but I don't know, it was a bit strange walking into it at first'

'I was really nervous, because obviously I hadn't really stayed away that long, without my parents before, there was loads of other people there, and at the beginning and then, there was like an ice-breaker stuff, where you just kind of have to talk to people that you've never seen before in your life, quite scary but I think after the first like hour or so, I kind of blended into it, and I remember it being really, really fun'

Parents and children/young people identified a number of reasons why they had wanted to participate in the projects. Parents in particular wanted to learn more about their child's condition, develop ways of managing their child's condition or to receive home support to enable them to continue caring for their child.

'I'd done all the Webster Stratton, I'd done everything that I thought I should do as a parent, and I was still failing to manage this one child'

'it was just a case of getting a break for my husband and I'

Others saw the project as a means of reducing their sense of isolation or that of their child's because it would provide an opportunity to meet other parents or children/young people in a similar situation to themselves.

'I was feeling isolated and helpless at the time. My son was very ill and very down and I needed to connect with hope, to hear that people got through the bad times, and to get the real experiences from people in our situation, and for information, signposts of where to access help'.

'you do feel quite isolated, so it was a chance to, to meet others really, going through the same thing ... giving Joe a chance to see other children, so perhaps he doesn't feel so isolated as well'

For other parents the motivation for encouraging their child to access the project was associated with a desire to promote their child's independence.

'because he was desperate to go somewhere and be a bit more independent, and he said he'd quite like to do that, so, he signed up for it'

As it proved to be difficult to recruit parents and children/young people who had 'dropped out' of the projects, participants were asked for their views on why people might not engage with self-care support projects. Barriers they identified included inconvenient timing and location of projects; lack of a desire or need to talk about themselves in front of others; dislike of focusing on their or their child's condition and a lack of motivation. It is

notable that aspects of projects that participants wished to change related to organisation aspects such as timing, location and length of sessions.

An issue raised by a number of participants was that parents or children/young people had to be at a stage in their illness trajectory when they were 'ready' to access such self-care support projects.

'I think it depends where people are at with their condition, I think, you know, it depends whether they're still, there's so many stages with, depending what the condition is, of whether you've accepted you've got one, whether you're at a stage where it's overtaken you as a person, and I think if you're still in that denial stage, or the stage where your condition is winning then it depends how you approach the workshops whether you're motivated to see what they've got to say, or whether you've come along because you feel you have to if parents have like pushed you into it, or you feel the pressure from say, you know, a nurse or somebody that you've seen at the surgery, I think your head's got to be in a certain place to gain the most from it'

'I think for kids, kids to come on and benefit from our workshops, need to have reached a certain stage in understanding of their condition, it's no good sending somebody who's been diagnosed with diabetes six weeks ago or even six months ago, they, they need to have had time to have gathered all the kind of information and, and absorbed what it is for them'

Parents and children/young people did not report any difficulties in accessing projects in terms of waiting lists or having to fulfil complex eligibility criteria. Indeed in terms of demand, one site (Staying Positive) experienced difficulties in recruiting sufficient participants to the project. For the other sites the issue was more about containing demand in line with the available resources. Some parents at the Support Team site felt that they needed more support than the team were able to provide.

'they just haven't got the staff in place, or the funding in place to offer as much support as we thought we were going to get'

4.3.3 Providing self-care support

The workers involved in providing self-care support had a range of different roles in relation to the projects. Some had a strategic management role and were involved in both developing and organising the project and with aspects of operational management. Others were involved in providing self-care support directly to families through for example, leading activities; peer modelling; facilitating group work and skills training; individual family support and coaching; running clinics, educating workers from other agencies; working with other services. Most of the projects had a mixture of paid workers and volunteers and many of the volunteers had entered the projects initially as participants but had graduated to a volunteering role. Some volunteers had then progressed to a paid worker role.

At the voluntary sector sites some paid workers had a background in children's services (e.g. youth work, teaching) or charity work before being employed on the self-care support project. As noted there was another group who had started with the project as a volunteer (or indeed a participant). Some of these volunteers entered the projects through volunteering schemes such as the Duke of Edinburgh Award scheme, the Do-It organisation or through seeing adverts on the charity websites and although a minority had experience of a long-term condition, their motives for volunteering related to self-development and demonstrating evidence of this on their curriculum vitae. At the asthma camps some volunteers had a health professional background and brought this expertise to the project.

At the ADHD centre the majority of volunteers and paid workers had first entered the project as parents before completing a training programme that enabled them to become volunteers and then paid workers.

'a lot of parents want to come in and do more, and some of them do end up as volunteers. Some of them end up going on the accredited programme, which is the Level Two, and then they're qualified then to co-facilitate on groups and things like that themselves. So we're bringing them in, moving them on, and then after they've delivered themselves, they can move on then as a development worker, then they get constant training as they're going through, and end up working, and having it as a career, I've made a career out of it'

Their reasons for making this transition was described in terms of reciprocity - a desire to give something back to the Centre that had helped them but also as a way of effecting change for this group of children/young people and their families.

'I just never wanted another parent to go through what I went through, and that's why I do what I do'

'I wanted to change the system, and I thought I had to be in part of the system to do that to try and get education to be more flexible, and to approach it in a different way'

As a result of their involvement in the Centre and the skills and self-confidence they had developed whilst there, some parents had entered teacher training and social work courses. This was consistent with the Centre's philosophy of developing individual empowerment and social capital.

Children/young people who had attended the asthma camps or the Staying Positive programme similarly graduated to volunteering or paid roles with the self-care projects once they had completed a training course.

'one of the facilitators asked me if I would not mind becoming a volunteer facilitator as well? And I said, no it sounds great, and so then I went on, I got trained up, and became a facilitator'

'we had two of the 17 year old girls who were on the holiday who have said, yeah, after they've had their compulsory year'

out they want to come back as volunteers the whole thing self-perpetuates then because if you've got, as we have at the moment, children going through the holidays and then coming back as volunteers, then they know even more than just the regular volunteers'

It also appeared (as will be discussed later) that becoming a volunteer was a means of enabling participants to retain contact with the project and thereby continue to receive social support.

For projects the presence of volunteers or workers with the same condition was seen as enabling role modelling. Children/young people could see first-hand adults or other children/young people successfully managing their condition and taking part in activities.

'provided the volunteers are obviously responsible and well controlled themselves, they can see that asthma doesn't have to limit your life, you can get on and do any number of things, you don't have to always be the, you know, the one left out in the class, the one that can't aspire to much, the one that can't take part in sport, all this kind of business. Because you can see the volunteers getting on and doing that, and that I hope would give them the inspiration to get the confidence to do that'

'it's that feeling of also seeing that kind of, maybe if you're a 12 year old and you see an 18 year old who's saying yes I had those problems, but now you're seeing them and they're healthy, healthy, they're happy, they're, they're managing well and they think, oh well that could be me, so yeah, the role modelling I think is completely crucial'

However, a problem many sites faced was a difficulty in recruiting male volunteers or facilitators.

The involvement of other parents or young people in leading the projects was highlighted as being important in terms of empathy with the participant's situation due to their direct experience of a long-term condition.

'it's good as well that the co-facilitators were actually parents, their children had been there, done that, got the tee-shirt, nothing's new to me, you can't shock me or anything so you, you've got a tendency to open up more and say well you know, yeah, our Ben does this, or done that, so it's not sort of on, more medical, where you go to the hospital and they say right, medication'

'the fact that there were other young facilitators, and they weren't adults, I think that was, that was really good for me, it was kind of, it wasn't the kind of, I'm a doctor, I'm going to tell you what to do, it was kind of, I've actually, I'm actually sharing these experiences with you, I've actually gone through what you've gone through and I can actually provide some sort of,

you know, guidance rather than this is what you should do, this is what you should do, kind of thing, so I think that for me, really, really helped'

The volunteers and workers on the project shared this perspective; that there is a shared understanding of experiences and issues that could not be provided by health professionals.

'we've been there, we're not saying that your circumstance is the same as mine, but the common denominator that we have is ADHD, and a lot of the situations that you are experiencing, I have experienced or will experience, and so what we let them understand is that, there's no difference between the parents who are that side of the desk and me over this side of the desk, the difference being is that we understand and we can manage the behaviour, and that's what makes us dif, that's what the difference is between us, and why, the reason why you're here is to get those skills, so you can then put those within your family'

'they do say how important it is that it's run by other young people, they, that they'll often say that to us, it's um I think it would be a completely different dynamic if it was health professionals or other adults running the programme, it's, it's fundamental that it's other young people who understand what they're going through, that's really, really important it's very much, you know, we're all in this together and we're all helping each other and problem solving together in an equal basis, rather than one's the teacher telling the other one'

At the NHS sites self-care support was an integral part of professional roles although at one site (Diabetes Team) some activities were extended roles that had developed in response to the identification of unmet need. While these sites had no or considerably less lay involvement than the ADHD Centre, the Asthma Camps, Staying Positive and the Online Support group, they were seen as having other advantages which related to the integration of self-care support with clinical management. The involvement of nurse specialists and other workers in the activities of the Diabetes Team project was seen as developing and improving relationships between the team and the family as well as obtaining advice on diabetes management issues.

'the nurses, they come, they take it in turns to come, and I think that, that's really good, because that lets the children build a bond with the nurses as a friend, you know, they come as a friend and it's a social setting, and I think if they can build that bond, then as they get older, it encourages them to go for that yearly review, or six monthly review, or whatever, you know they go to see a friend, they're not going to see a nurse, so instead of being scary nurse person, they're just, they're just Laura (nurse specialist) or they're Diane (nurse specialist), or they're Tina, so that as well, that helps the children, um think that's about it'

'the nurse is there as well, so if you've got any questions you like, you can speak to her, so I like, yeah, I like that bit, her being there'

At both NHS sites the nurse specialists were able to play a role in being a point of contact for families for advice and links into the wider NHS system, such as obtaining a review by the paediatrician.

'Alison, she's always like our point of contact, so say if something's going wrong with Adam's medicine or side effects, or we feel that his condition is getting worse, our first point of contact is always with the Support Team, and then she will then go on to the consultant, get his advice, and then come back to us with whatever advice he gives, so she's now really our main source between the consultant and ourselves, in trying to provide the care necessary for Adam .. they get back to me the same day, they always get back to you when they say they're going to, and you need that, you need that security, you need to know that someone's listening at the other end, and they are going to sort out your problem, and that equally they are going to get back to you when they say they are, and that is vitally important when something's going wrong, you need that support'

'we can get an answer from the consultant, sort medication out, or get them seen on the Day Ward, and it can prevent, either prevent a long admission, or prevent them coming through the Emergency Department or sitting for a while there, and having to tell the story over and over again, which is obviously something that's very annoying to parents that have got children with these complex conditions'

In addition the NHS teams were seen as being able to provide continuity and consistency of support for families.

'we have continuity for the patients so, often when the patients have got problems, well you see that obviously it's the parents that ring, they, they kind of, they like to be able to speak, if possible to the same nurse, I think they like consistency of knowing that there's somebody on the team that knows them'

'Alex gets quite unwell sometimes and he has to go into hospital so it's really nice 'cause Jane will often be working so she'll come along and he knows her and she's familiar, so that's really it's really good, I think that's been the best thing for us because he's very he gets very traumatised when he's in, and just to see a familiar face'

4.3.4 Perceptions of the effectiveness of self-care support

A number of features of the self-care projects were consistently identified as being effective in the support of self-care. These were their ability to

provide a sense of community; to promote independence and confidence; to develop knowledge and skills and to engage children/young people.

Providing a sense of community

Participants at all the case study sites apart from the support team highlighted the importance of the self-care project in providing a sense of community for children/young people and parents. Effectiveness was defined in terms of the social support projects provided as well as how they extended the social networks of participants.

Prior to participating in the project parents described how they had felt alone and isolated but accessing the project the project had led to the realisation that there were other parents in the same situation, who were coping with the same feelings and issues such as problematic behaviour and insulin regimens.

'the good thing of having a group is that, that you're so isolated at the beginning, you're on your own, and you feel nobody understands, nobody feels what I'm feeling, because every time I look around me, everyone's, other children are behaving and in a, in a, inverted commas, normal manner, so that does implode on you, you just feel like, oh my goodness, I'm the only person, but when you come here, and when a person talks, they're saying your life, they don't know you, but they're saying the things that are going on in your life, and you think, oh my God, I'm not alone'

'It's just nice just to be able to talk about it, and people understand what you're talking about, you can just use the lingo and everyone knows exactly where you're coming from'

As CF centres strongly discourage people with CF to meet in order to prevent cross infection with *pseudomonas aeruginosa* and *burkholderia cepacia complex*, parents found the online discussion group a particularly valuable means of having contact with others parents and receiving peer social support.

'What I like about the forum is that CF is such a lonely condition. With cross infection rules you can't meet other parents/kids properly so the forum makes me feel that I am not so alone. There are other parents in the same boat'

'It's a good place to talk to other parents who have the same problems. I feel I get support when things are rough as it is very difficult for friends to understand what it is like to have a child with CF'

For the parents of newly diagnosed children/young people it was seen as giving them a sense of hope; that they would adjust and integrate their child's condition into daily life.

'The newly diagnosed children's parents, they come in, you can tell which ones they are straight away, they look completely shell shocked, and for them to sit amongst other parents who have been doing it for a couple of years, like myself and others, to sit amongst us and just say, you know, your daughter looks so well, and how do you do it? And to be able to sit and chat to them and say, well, it does get easier, you know, well not necessarily easier, but it gets better, it becomes easier, it becomes part of your life and you just get on with it'

Parents contact with one another could extend outside that of the self-care project through the use of email, telephones, Microsoft Messenger or in some cases face-to-face meetings.

'I could text someone and just say, do you know what this means? Just to have that extra support, it's like our own little community'

However, not all parents wanted or felt the need for having contact with other parents of children/young people with a long-term condition or preferred it to be an occasional occurrence.

'it sounds really awful, I don't always want to mix with other parents, it's nice sometimes because you know that there are other people going through what you're going through, but sometimes I just want to associate with children who've got no needs, and you get, kind of get a taste of a, a normal life, because the focus, when you've got children with additional needs, the focus is always on them.... sometimes I don't want to talk about it, but it's nice to know that there are other parents there that I can contact if I need to, but sometimes you don't want to talk about it, you just want to live your life really'

The role that the project played in providing parental peer support and in reducing a sense of isolation was recognised by workers at the projects.

'they get the support from other parents, so meeting together, with other parents as well, I think that helps, helps them realise that they aren't the only parents that have got children, having to have four injections a day'

As described earlier in this chapter children's/young people's illness experiences were associated with social isolation and feelings of difference. Participating in the project helped them to realise that they were not alone and that there were other children/young people in the same situation as themselves.

'It makes you feel that you're not alone, makes you feel that you're not the only one, the only child that feels different'

'I found it was good to know that you weren't alone, that there's other people, like you, that you can actually talk to, and make some friends'

Parents and workers identified that providing children/young people with the opportunity to have contact with others with a long-term condition and hence reduce their sense of social isolation was a key way in which projects supported self-care.

'it was good 'cause the other children had ADHD, was the same as him, went through the same on a day to day basis, which was really good for him'

'Amy didn't know that there were other diabetic children I think she just thought it was her, she hadn't got a clue, and then we started going to the club ... I think the realisation that all of these children, every single one of the, had got the same as her, and you know I think that made her feel as though she wasn't just on her own, there were lots of other children with it, and they all looked happy and healthy'

Meeting others with either the same or another long-term condition meant that perhaps for the first time children/young people actually saw others self-managing a long-term condition such as using inhalers or giving themselves insulin. This was seen as a way of increasing children's/young people's confidence about self-management in public.

'It was, it was really good, it was really good spending a weekend with people that, like where everybody is in the same boat, and like everybody's having to sit down at lunchtime and take loads of medication and sort themselves out, and not have to like hide it, in front of people who don't really understand. And it just made you feel more comfortable'

'everybody else is taking their inhaler so Philip don't feel left out, he's not doing something different to everybody else'

Meeting (physically or virtually) with others provided an opportunity for children/young people to express and discuss their feelings and experiences with those who would understand.

'it was nice to know that there were other people who felt the same way as me, I kind of, before I went on that course, I didn't really want to talk about my condition, and I just didn't really want to tell anyone that I had it, but then I realised it wasn't a bad thing, and that I just happened to have a condition, I was a normal teenager. And so I kind, it gave me more confidence to actually talk about it, and I realised that people were actually really supportive'

'I think the other element of it is being able to talk about things that you wouldn't be able to talk about with your parents and teachers, or your friends or your siblings, or anything, and just getting that opportunity to express your frustration and your anger, in a really supportive and safe environment so I think that really, really works'

Parents and workers also highlighted how the projects provided an opportunity for children/young people to discuss their feelings in a non-judgemental, empathetic environment.

'she also enjoyed discussing the issues that she's got and finding out that she wasn't the only one that doesn't want to take her medication, doesn't want to have to have the injections, and she's not the only one that's got the problems that she's got'

'often the children who come have been bullied or, you know, had difficult social interaction because of absence from school and lack of fitness and stamina and things, and again now often talk about their bullying and, and share those kind of, you know, feelings and things, which is, is good for them'

'they come together and all of a sudden it's a relief they can talk openly without judgement, and other people understand them'

However, not all children/young people wanted to or felt comfortable with talking about themselves.

I'm not like one of those people who likes to talk about my condition too much.

As with parents, participating in the self-care project could lead to longer-term friendships which continued after the end of the project.

one of the main things you get from the EPP workshops, or I personally got was a group of friends who sort of accepted you for who you are... I'm still in touch with a lot of them.

I made two, in particular, really, really good friends, that I spoke to a lot throughout that week and I still keep in really good contact with now, it helped me to build my confidence again, and build my self esteem,

Some parents identified the potential role of projects in enabling the development of friendships between children/young people with the same condition as being valuable, particularly as their child grew up and increasingly relied on peers for social support.

'she can still be building some friendships with diabetics of her own age, and she's not, I mean lets face it, she's not going to meet them anywhere else, because you don't, I mean they're so few and far between, it's the only place she's going to meet them'

Embedded within the social support that projects provide for children/young people is a normalisation of chronic illness. The projects provide a setting that normalises illness management, the feelings children/young people experience and the limitations they endure.

'there's a lot of the feeling of normality, because everyone there has got asthma'

'well it's good, because you know you get a lot of activities and stuff, and everyone else there all have asthma, so it's not really, you know, as much of a problem, you don't feel left out if you get, you know, out of breath and you can't do every, and, everything, because everyone else in there has the same problems ... It is quite interesting seeing how other people, sort of, you know, feel about their asthma, and what problems they have'

'when he went to the Staying Positive they all understood where he came from.... they're on the same level as what he is he didn't feel, he didn't feel on his own ... when he's with his friends, he tries to keep up with them, whereas when you're at the Staying Positive, he knew that, that there was like no competition, to like to try and keep up. If he wanted to sit out, he would sit out, if he couldn't keep up, he would just slow down, and, and I think that's what it was, the children were more on his level'

As noted earlier in the chapter, some parents and children/young people moved onto volunteer roles within the projects as a way of continuing to receive support. In situations where this was not possible, for example due to work constraints or age limitations in the case of the Diabetes Team's children's club, there was a sense of loss amongst participants. However, not all parents and young people wished or were able to transfer to volunteering roles but nevertheless wanted to remain connected to projects.

Promoting independence and confidence

Participants identified how projects promoted young people's independence and sense of confidence. As well as the asthma camps both the ADHD Centre and the Diabetes Team had residential elements to their projects. These enabled children/young people to manage their condition independently in a supportive environment as well as an opportunity to take part in challenging activities such as abseiling in order to build their self-esteem and give them a sense of achievement.

Managing their condition away from their parents was seen as enhancing their independence and self-confidence.

'it gives them loads of confidence, to show that they can manage it away from their parents'

'They gain independence, and confidence, in their own abilities, because they're all encouraged to do their own, well they're all made to do their own injections, and carb counting'

For the diabetes team the residential camp also enabled them to observe how the children/young people managed their condition.

'it's good for their education and our education as well, it's good because it helps us see just if some of them are cheating a little bit'

Projects with residential components in particular provided children/young people with the opportunity to take part in a range of challenging physical activities. Previously they had often been limited in the activities they could participate in by their parents or by their schools.

'just being away from home I think, the independence that they have as well, you know, not just maybe around their asthma, but also doing activities they haven't done before, which maybe they haven't had the opportunity because of their asthma, maybe at school, they may not have taken part, and again I know a number of children, who, the holiday for them is their only experience of being away with their peers, because they can't go on holidays with their schools for health and safety reasons, you know, due to their asthma'

Taking part in these activities was seen not only as building the self-confidence of children/young people but demonstrating to their parents their capabilities and appropriate limitation boundaries.

'people are over protective, and things start to go the other way, and as I say the children sort of get the impression that they can't do things, or shouldn't do things that are deemed to be normal, particularly sort of sport, swimming, that sort of thing, and I think really what, it, it's not so much also, not just the fact that the children get the chance to do this thing, and the parents get the chance to see it'

'the things what they was doing what we wouldn't dream of thinking that Tom would do, I mean abseiling last year'

The sessional activities that projects provided were also seen as an opportunity for children/young people to increase their independence and self-confidence by attending events without their parents.

I thought would be a good idea to help her get her self confidence again back, you know build it back up, and it did, it done pretty good for her... that since she's come back from there, she's got more of a positive attitude ... she's really built her, like her confidence up,

As highlighted earlier in the chapter, meeting other children/young people with a long-term condition promoted their self-confidence by highlighting to them that they were not alone in living with chronic illness as well as providing them with the experience of talking to others about their feelings and views.

'it made me more confident with it, because before I didn't really know many people that had asthma, and I kind of used to feel very odd, especially with a big bag with a big spacer in it, but um, yeah, it made me more confident with it'

'it's given me a lot more confidence, I mean before I kind of didn't really tell anyone about my condition, and now it's just it's fine I can talk about it, and say you know, I can't do this because I've got a condition, and people understand and so I think if it wasn't for that course, I would never have done that really, I would have thought that it would have been a really bad thing to start talking about it, and you know, so yeah I can still put it into practice now, which is really good yeah.'

Participating in the self-care support project could give children/young people the confidence to go on to access support from other groups.

'it was the first thing I attended, support group wise, and after that, it then triggered me to get more involved in the things that were happening, so obviously I got involved with another group in the clinic that happened where I attend the hospital. Then obviously that opened more doors for me, met new people, more conditions, so I think it does give you the confidence to be able to like attend other groups'

It was not only children's/young people's confidence that could be developed by the projects. In some instances their participation could encourage parents to feel more confident to transfer responsibility to them (and thereby increase their independence).

'some parents are finding it difficult to hand over the control of their diabetes, their children's diabetes to the children, and I have to admit since we've starting doing specific sessions with the kids they seem to find it a bit easier. It's like, I think it's, I suppose it's that they feel more confident that, okay they've been attending the sessions, therefore they're being taught how to do it'

For parents to allow their children to attend sessions or go away on camps it was seen as being essential that they had trust in the skills of the staff supervising their children and saw the environment as safe.

'I was going to let her go because I knew that there was nurses there, so if she had an attack or anything, you know, there were professionals there that would be able to deal with it, as much, as well as I could'

'I felt he would be in safe hands, because I've never left him, I mean, he's never, other than myself, or family members, he's never stayed with anybody before, I mean, he did go on one school trip, and a couple of nights, but he's never left with anybody that I don't know, and I think that was a big thing for him, and a big thing for me, just to drop him and walk away'

Developing knowledge and skills

The projects were seen as developing participants' knowledge and skills. They provided parents and children/young people with the information and knowledge to enable them to understand their particular long-term condition. Parents of children/young people with ADHD described how they had gained both knowledge about the condition but also understanding of their child and their behaviour.

'it gave me an understanding... that they actually do make you understand what your child's going through, I think that's the main thing, because I don't think, I wouldn't have understood at all, if it wasn't for them, I still would have gone on with the fact that, you know, she's just misbehaving'

'the course has benefited me in the fact that I understand my son now, I don't look at is as, I used to look at him as a naughty child, and I, and I've held my hands up to that, and I used to think at times is he doing this to drive me mad? But when, listening to the course, it really is good for it's made me look at Daniel in a different light, I now look at him to say, well look he's got, he's not a problem, he's got a problem, and he needs, he needs our help, the best way we can'

As well as altering how they saw their child this knowledge and understanding could also change how they defined themselves.

'we always felt that we're bad parents in some way, you know, and it's only now that I've realised that I'm not a bad parent'

Workers explained how the ADHD centre also tried to develop parent's insight and understanding of the difficulties teachers encounter in managing children/young people with ADHD in the classroom as a means of promoting better relationships.

Contact with other parents (face-to-face or virtually) was seen as supportive in terms of obtaining information relating to their child's condition and service support that could be used as a basis for decision making.

'It has also helped me learn about the medical side of the condition, so I can digest the information in my own time and do more research where necessary. It means that I can make informed choices and ask the right questions when I see the consultant. The forum also gives me ideas on what to do when my son has this, that and the other wrong with him. There is normally a solution to be found on the discussion group'

'the main advantage is we get to talk to the parents with similar aged children about how we deal with um, you know, the sort of mechanics of looking after them really, like from the sort of direct health issues, how do we keep them healthy, but also how do we engage with schools and, how do we do things like go on holiday, and just sort of normal things that are actually quite

hard sometimes and, most people once they find a way of doing it, are worth talking to, so it's a sort of useful forum where we can talk to people with similar issues'

The information to be gained from other parents was seen as being different to that provided by health professionals as it was based on other parent's experiential knowledge.

'the doctors and that know from the theory, and from what they've learnt, and obviously, the knowledge. But actually living with it you, you can't really get unless you talk to the parents, so I think it's, it does give you more of a balance that, 'cause some days you just can't control it, it just, his blood sugars a bit all over the place, and you think oh, what're we doing, but I think, people that we've spoken to seem to go through that as well and, it's the case with the children growing up I think and the change, their body's changing and things'

Children/young people also described how they had gained knowledge about their condition from participating in the project.

'it helps me understand more about asthma and what happens inside your body and I've, and one person I always used to see when I went there, he always like used to show me what to do with my asthma and all that'.

'I liked the way you could just, do you know with my medicine, they, they talked to you and tell you the reasons why we have to have it, and it made it, it made me realise better why I need it'.

As with the parents, children/young people learned from one another about managing a long-term condition through the sharing of personal experiences.

'We'd like bounce ideas off each other. If people said, oh you could try doing this, and then, yeah, kind of developing ideas between ourselves'.

'they have had it, and said they know how I feel, 'cause it makes you feel sick and stuff, and like most of them knew what it was like, so they all said to me, you're only normal and like how like to overcome it, like by taking anti sickness or something'

The online support group also played an important role in providing condition related information and advice for children/young people.

'This forum is really good if you need any advice or if you are worried about something, if you post it on here someone will all ways answer'

Parents and workers similarly identified an increase in children's/young people's knowledge and understanding about their condition following participation in the self-care support project.

'it gave her actual knowledge that she didn't have to start off with having been there, that's probably made her always carry the inhalers with her, she's understood the importance that you can actually need it at any given time, and you better know where your inhaler is, because when, you know, if you need it, that's not the time to start panicking and thinking, oh where did I put it'

'we also do educational sessions for their learning about their conditions, and learning what it means and, and how to control it and take care of themselves, and I think once they've got a bit of a better understanding, then yes, often they can explain it more clearly to somebody else'

One young person described how they had learned about themselves as well as their condition how this self-knowledge had increased their self-esteem.

'it just helped me understand me as well as my condition, it helped me realise that they are separate, they're not one and the same. .. this workshop showed me personally that people do like me, it's me that beats myself up, it's me that has these beliefs that aren't true ... it's brought me out of my shell a lot, it's made me a lot more confident in myself, which, in turn, raised my self-esteem'

In addition to increasing the knowledge of parents and children/young people, some projects such as the ADHD Centre were also involved in activities that aimed to promote teachers' understanding of long-term conditions.

'often children are asked to come back later for their medication, or they're asked to remember to go for it themselves...the medication though helps you to remember where you've got to be, and what you've got to do, so without it they're not going to do that, and so very quickly behaviour happens because the medication is not kept at the appropriate level, and in the afternoon behaviour happens and exclusions follow. So if they understand that this child must have the medication at 12 o'clock, then it's part of their package of care to ensure that child gets it at 12 o'clock. If they don't understand the need for that medication to be given, then they will just dismiss it as well he didn't come for it today'

As well as knowledge and understanding the projects were also seen as developing participants' skills in managing their or their child's condition. Parents at the ADHD Centre described how they had learned to manage their child's behaviour by attending a skills based course.

'it really helped me, it's, well, before, before I went on the course I was focusing on his good behaviour and ignoring his naughty behaviour ... 'cause we ignore the naughty behaviour, well that's it, and we praise the good behaviour ... when you sit

and listen, to what they're telling you and how to treat it, it is a not roaring at them, not saying they're naughty and all that'

Children/young people also described how they had learned how to manage their condition after participating in the self-care support project.

We learnt about anger ... I go upstairs to my bedroom I just sit down and have a time out

You learn a lot about asthma, and how to manage it, and when to take, and when to take things, and when not to take things, they offer, kind of little, when I say training courses I don't really mean that, it's kind of experience days where you go out, and they'll teach you how to do things and let you try it, so they do like the carb counting courses and other things. ... I've been to one of the carb counting things ... it was quite nice, yeah, I understood everything, very simple explanations, yeah I've been using it about three years.

Participants identified how projects could improve children's/young people's communication skills with professionals such as doctors and teachers. This appeared to be a result of becoming more knowledgeable about their condition but also for some children/young people having undergone training in communication skills. For example, children/young people could use the skills they developed on the course to explain to teachers the reasons why they had not completed homework or been absent from school due to their condition.

'One thing for me that really stands out was communication skills, where we talked about how we should talk to doctors, and how to talk to teachers, things like that. after I went on the course I actually started telling my teachers what was wrong with me, and they were really, really supportive, and they gave me all the help that I needed, and it was a really crucial time, 'cause it was like the beginning of my A Levels'

'the advice given on such as like how to talk to people about it, you know, like people in College, because I never made contact with College, which meant a lot of people getting quite angry with me for being absent. But to do that, it gave me, you know, sort of what to say in sort of these sort of situations'

Children/young people explained that the project had also given them the confidence and skills to talk to doctors about their condition.

'it will make me feel easier to talk to the doctor and that, about my, about if I've got any problems or anything'

'I was spending a lot more time in the hospital than I was actually used to before, and so, like the skills that you learn with, with communication with doctors and, and all that sort of stuff was really coming through and helping me'

Parents and workers identified how the projects had helped children/young people in gaining control and being more assertive about their needs with teachers, health professionals and adults in general.

'what she's learned at the camp she knows to demand that she wants somebody with her, so that she's going, anybody from the class, that goes with her, so that if anything happens, that's the person that starts running and shouting for help, and not her. What she's learned there is helping her assert her sort of knowledge and whatever in the outside world'

'dealing with communication issues in terms of wanting to take control of their own health and how do they start doing that, so it really, really supports them to build their confidence about talking to other people, adults in particular about what their needs are, and you see real growth in confidence'

In addition children/young people learned how to explain and talk about their condition to others.

'it tells you like how to um, like deal with your asthma, and, yeah, it like, it tells you like how you can tell people about it'

'they learn to recognise their symptoms more, also try to learn to actually tell somebody about it, some children can sit there and get worse and worse and not tell anybody'

Engaging children/young people

Participants identified how it was important that the self-care project engaged young people and was child/young person centred. There were a number of aspects to this. Firstly as well as educational, activities had to be perceived by children/young people as fun and enjoyable.

'you've got the really fun activities, which are all, you know, tailored round that you having asthma, and being able to do it, and then you've got the, you know, the knowledge based stuff'

'we played games, and we had a lady come in to discuss things with us, and that, and we did some artwork as well,... the best thing was when we got to make some animations at the end of our last session'

'the activities are good fun ... we did things like rock climbing, high ropes course, that kind of thing... they're good fun, you take a lot from it'

Parents identified a fun element as being important to both learning and encouraging their child's attendance at the project.

'it's got the right balance of looking at health issues, and encouraging children, and also being fun'

'they do kind of educational games, they do learning through play, you know what foods are good to eat for diabetics, what foods aren't, and even just if a little bit of it sinks in, that, that's a good thing'

Workers noted that projects aimed to develop activities that would make learning about the long-term condition fun for children/young people.

'They loved the running around, and they were learning, they were having fun and it was quite good fun. I think they really enjoyed us sitting down and having a packed lunch, 'cause they were all comparing their lunches, and, and the parents were obviously there, but we tried to do a lot of work with the kids, and what one of us did was ... work with the kids, and the other one answered all the questions from the parents, and ironed out some things, whilst the kids were playing. So they loved doing activities and tasks, without knowing that they're learning, and that works really well, 'cause the next time we see them, we can say, oh, do you remember that game we did? And what did you put in that basket, what did you do there, and they do remember, yeah they do, so it worked quite well'

However, some participants noted that activities could be less attractive to boys or those who do not like outdoor or sports related activities.

'there are opportunities for loads of things, but not everything's my cup of tea, it's all horse riding and canoeing and.....I don't really like outdoor activities much'

'we're doing crafty things, John is trying to look at more, he's done some modelling with the boys, and certainly on the weeks where the boys did the modelling, he found he really engaged them ... boys who are probably eight year olds upwards, who perhaps aren't as crafty, and are more into the computer things, that we, we need to try and engage somehow with some technology, IT technology'

Another aspect of projects that was important in engaging with children/young people was ensuring that they felt that their views were listened to by staff.

'you just get listened to and like your opinion actually does count, they don't just go "oh, look they're saying something again" it's like, it's so what do you think about that'

'it also gives them chance to talk in their, in their voice, rather than have an adult dictating to them and saying you know, well this is what's happening, and this is why you have it'

Related to this feature was the ability of the project to create a friendly atmosphere and one where the workers were approachable.

'I'd say it's probably more, more like a family I'd say than a company ... so people are kind of, people just kind of come and go it's like a big, a big happy house that people live in'.

'there's just somebody there to talk to if you actually need to, but if you need some information or anything like that they actually really friendly about it'

Workers at the projects also noted how the approach of staff and the setting could be important in engaging with children/young people.

'it's this thing about feeling safe and knowing that you're not judged, you know, young people can come in here when they've been excluded from school, and they don't feel, they'll explain what, what they think has happened, but they know they're not going to be judged as being bad, you know, because they've been excluded'

'I think often young people seem to expect quite a school environment when they come along which is I think why, having it in a non-medical non-school venue really helps the style of workshops'

Some workers emphasised how being 'young person friendly' included fitting the medium used by the project to children's/young people's ways of communicating.

'I think it's about bringing ourselves up to date really with how kids communicate and young people communicate'

The Diabetes Team were using email as a means of answering questions about dietary self-management and were examining the potential of using texting to remind children/young people about appointments and electronic self-monitoring systems. They had also implemented diabetic clinics in secondary schools as a means of taking the service to the young person and addressing problems with poor attendance.

'you largely sit in a meeting room, and one of them comes after the other, and sit and have a chat, but it's the regular contact that's the main thing for that age group.... they're getting a reminder from the school nurse, and the fact that it's in school time, it's not in their time, their time's very precious. It's spent on their friends, rushing from one place to the next, and they don't want to sit in for a home visit usually at that age, they're just too busy we've got quite a lot who are disengaged, I think the school clinic is the best place to see them on a regular basis'

The online support group used a used a method that engaged with children/young people and was seen as an important means of obtaining social support and information.

Home support

This section of the chapter has identified the key elements of self-care support projects that emerged from the cross-site analysis as being effective for children/young people and parents. One aspect that was particular to one site, the Support Team, was the provision of home support to parents to enable them to care for their child at home. This included teaching families the clinical skills needed to manage their child's condition as well as the organising equipment and supplies.

'it was really, really helpful because it meant that, if I hadn't had that support at home, I basically wouldn't have been able to take him home, because I wouldn't have been able to do the tubes at home'

As many of this group of families had children/young people with high support needs, the team also provided parents with a break from caring and time to spend with their other children.

'it was just a case of getting a break for my husband and I'

'one day in the week he'll be taken out by the Support Team for the day, which is nice because it gives me a rest from him'

While the residential breaks for children/young people provided by the asthma camps and the ADHD Centre gave parents a break from the demands of caring for their children this was not their primary objective. Moreover they also provided children/young people with a break from their parents, something which they may have had little opportunity for in the past.

4.4 Conclusions

Children's/young people's and parents' experiences of living with chronic illness involves the routinisation of daily life by illness management activities; activities which over time are gradually transferred from parents to children/young people. For children/young people their experiences were also grounded in being different to and set apart from their peers and in negotiating the disclosure of their condition to others. Schools emerged as an important site for both illness and identity management, yet their capacity to support children/young people appeared to be highly variable and idiosyncratic.

The majority of parents and children/young people self-referred themselves to the projects. Although health professionals and teachers were involved in providing information about the projects it appeared that projects were not part of their referral pathways (apart from the two NHS sites) which reflects in some way the relationships and lack of integration between some projects and other forms self-care support. Parents appeared in play a key role in children's/young people's access of self-care projects and in

maintaining their involvement. The motivations underpinning access related directly to individuals experiences of chronic illness and included felt needs for information, skills training and to reduce a sense of isolation. However, at the same time it was highlighted that children/young people and parents had to be at a point in their illness trajectories where they were 'ready' to engage with such projects.

Most of the projects had a significant proportion of volunteers, many of whom had personal experience of a long-term condition. Volunteering appeared to serve two purposes. It was a means for parents and children/young people to retain contact with the project and continue to receive social support. In addition it was identified by participants as helpful for projects and activities to be led by individuals with shared experiences and understandings. However, this is not to say that NHS led projects were not valued by participants or that they did not support self-care. Indeed their integration with clinical care was seen as a strength as they provided the opportunity to develop positive relationships between clinical staff and families and for ensuring the consistency and continuity of support.

The effectiveness of self-care support projects was defined by participants in relation to four key mechanisms – providing a sense of community; promoting independence and confidence; developing knowledge and skills and engaging children/young people. Providing participants with a sense of community reduced children's/young people's and parents' sense of social isolation and developed their social networks. The social networks developed were a site for the normalisation of chronic illness. Projects provided an opportunity for children/young people to develop their independence and confidence both socially and in terms of the self-management of their condition. Their self-confidence was promoted through taking part in challenging activities and recognition of their developing ability to manage social relationships as well as self-care. Projects also enabled children/young people to demonstrate their capabilities to their parents which in turn could serve to develop parental confidence to encourage independence. Participating in the projects was seen as a means of obtaining formal and experiential forms of knowledge as well as developing self-management skills. In addition projects developed children's/young people's communication skills by increasing their knowledge, inter-personal skills and self-confidence to communicate effectively with adults. They also developed the skills and language to explain their condition to others such as their peers. Some projects were involved in increasing the knowledge and understanding of professionals such as teachers about long-term conditions and how to support children/young people. The fourth mechanism was engaging children/young people through providing activities that make learning fun and developing a child/young person centred culture where their views are respected and listened to and their means of communication utilised.

Table 24 presents a summary of what works, how, for whom and in what circumstances and incorporates key barriers and enablers of self-care support.

The next chapter will conclude the report by drawing together the findings from the three stages of the research and considering the implications for research, policy and practice. The limitations of the study will be discussed as well as the contribution it makes.

Table 24. Summary of what works, how, for whom and in what circumstances (including enablers and barriers)

WHAT WORKS	HOW IT WORKS	FOR WHOM	IN WHAT CIRCUMSTANCES
Group based self-care support (virtual or face-to-face)	<p>Builds a sense of community and reduces feelings of social isolation</p> <p>Develops social networks</p> <p>Increases self-confidence</p>	<p>Children/young people</p> <p>Parents</p>	<p>Groups can be face-to face or virtual.</p> <p>Key aspect is sharing of lay experiences.</p> <p>Opportunities for ongoing social support are sought by participants e.g. through volunteering.</p> <p>For individuals who feel comfortable in sharing feelings/experiences or where this is facilitated.</p> <p>For face-to-face groups organisational issues such as timing and location have to be taken into account.</p>
Information provision and skills training	<p>Develops formal and experiential knowledge; self-management and communication skills.</p> <p>Develops self-confidence.</p> <p>Improves self-care support by professionals</p> <p>Perception that hospitalisations and school absences are reduced (but unsubstantiated)</p> <p>Reinforces good practice</p>	<p>Children/young people</p> <p>Parents</p> <p>Professionals e.g. teachers</p>	<p>Opportunities present for participants to learn from one another and share experiential knowledge.</p> <p>Schools are a key area where understanding of long-term conditions and self-care support needs development.</p> <p>Individual learning styles and preferences need to be taken into account as well as differing information needs.</p> <p>Communication skills training can improve relationships with a range of adults such as doctors, teachers as well as peers.</p>

Opportunities to participate in challenging activities and have time away from parents	Independent self-management in a safe environment. Build self-confidence and develops independence.	Children/young people Parents (indirectly)	Parents need to feel confident in skills of project workers. Activities need to take account of a range of interests and gender influences.
Providing a child/young person centred culture	Learning through fun. Listening to and respecting views. Using young person centred communication media Providing a 'friendly', non-judgemental atmosphere	Children/young people	Parental involvement needed to encourage access to projects and children/young people have to be 'ready' to engage in self-care support. Dependent on skills/approach of workers as well as the wider organisational culture
NHS led projects	Integration with clinical care Development of relationships between families and health professionals Continuity of self-care support	Children/young people Parents	Need to include or facilitate lay involvement/participation. NHS organisations need to be supportive of non-traditional methods of support. Resource issues influence response to demand.
Third sector led projects	Workers often have personal experiences of a long-term condition. Flexible, needs led provision.	Children/young people Parents	Links to statutory forms of self-care support can be underdeveloped. Participants mainly self-refer and little joint working apparent. Ongoing chasing of funding can divert staff from self-care support provision and destabilise the project. Absence of 'hard' outcomes to demonstrate project effectiveness and support funding applications and commissions. Available funding determines support provided.

			Links with statutory services (particularly NHS) can be influential in recruitment and referral of children & young people/parents to projects.
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5 Discussion and Conclusions

Children/young people with long-term conditions face a lifetime of managing their health, identities and relationships; how successfully they manage this may influence outcomes in adulthood. Although the National Service Framework for Children, Young People and Maternity Services (DH/DfES, 2004) highlights self-care, government policies on self-care largely overlook childhood long-term illness.

Self-care in relation to children and young people is complex and different conceptually to that of adult self-care. This is due to the central role parents play in managing their child's condition and its psychosocial consequences, the process of transferring self-care responsibilities from parents to children/young people over time and the ongoing physiological and psychosocial changes as children develop into adulthood.

The overall aim of this study was to describe and evaluate current self-care support models for children/young people with long-term conditions through the conduct of an evidence synthesis, a mapping exercise and case studies of different self-care support projects. Combining the findings from the evidence synthesis with the expertise of the study reference group also enabled the development of a self-care support model typology and identified its constituent domains. These domains were then used in the sampling of the case study sites.

The evidence synthesis and mapping study revealed that a broad range of self-care interventions have been developed for children/young people with long-term conditions. The evidence synthesis highlighted their diversity in terms of setting, target group, aims and method of delivery. Education was commonly a core component of interventions and many could be tailored to individuals and families, both in terms of the long-term condition, their individual needs and goals and also to their pace of learning. The majority of self-care support interventions included in the evidence synthesis focused on asthma which is perhaps not surprising given its prevalence in the child population. However few interventions were targeted at practitioners or the service system. The evidence synthesis suggested that group based interventions and those using e-health methods appear to be effective and acceptable and that the knowledge and skills of the self-care support provider may play a mediating role.

The mapping of current self-care support provision found that projects are mainly provided by NHS acute trusts and childhood diabetes is the most frequently reported focus. Most target children/young people (either alone or in conjunction with their parents) and few aim to develop professionals' skills in supporting self-care. Independent and voluntary sector organisations are key partners with the NHS in providing self-care support. However, the representativeness of these findings is unknown.

Case studies of six different self-care support models were conducted. In common with other studies of living with childhood chronic illness and disability, children's/young people's and parents' experiences were associated with the routinisation of daily life by illness management work, feelings of difference and disclosure negotiation (Christian and D'Auria, 1997; Atkin and Ahmad, 2000, 2001; Herrman, 2006). While schools were an important site for illness and identity management, their capacity to support children/young people appeared to be variable and idiosyncratic. The route into self-care support projects was largely by self-referral and parents played a key role in children's/young people's access and in maintaining their engagement. The effectiveness of self-care support projects was defined by participants in relation to four key mechanisms – providing a sense of community; promoting independence and confidence; developing knowledge and skills and engaging children/young people.

5.1 Evaluating self-care support

In this section the key themes emerging from the case studies will be considered in terms of their relationship to the findings from the evidence synthesis.

5.1.1 Group-based approaches

This study found that group-based approaches (either face-to-face or virtual) provided participants with a sense of community that reduced children's/young people's and parents' feelings of social isolation by normalising chronic illness and developing their social networks. As well as providing social support, groups were important mechanisms for learning about long-term conditions and self-management through the sharing of experiences, information and strategies. These findings are supported by the 'views' studies included in the review (Johnson et al. 2001; Bruzzese et al. 2004; Trollvik and Servinsson, 2005; Barlow, 2007). Moreover many participants at the case study sites wished to continue to receive this form of mutual self-care support and could feel bereft when projects came to an end. Volunteering was one means of maintaining contact with projects and continuing to receive social support.

Intervention studies have found statistically significant relationships between group-based approaches and improvements in health status (Evans et al. 1999/Sullivan et al. 2004; Grey et al. 2000; Cicutto et al. 2005; Patterson et al. 2006) self-efficacy (Grey et al. 2000; Cicutto et al. 2005); self-management in terms of increasing the frequency of blood sugar testing (Cook et al. 2007) and reductions in feelings of loneliness (Christian and D'Auria, 2006). Studies have also associated group-based

interventions with improvements in quality of life (Grey et al. 2000; Shah et al. 2001; Cicutto et al. 2005).

Groups do not need to be face-to-face as there is evidence from this study and one of studies included in the evidence synthesis (Johnson et al. 2001) that internet-based group interventions are a valuable method for social support for children/young people with long-term conditions and their parents.

5.1.2 Developing knowledge and skills

Participating in the projects was seen as a means of developing parents' and children's/young people's formal and experiential forms of knowledge about long-term conditions and the related self-management skills. Projects could develop children's/young people's communication skills through increasing their knowledge, inter-personal skills and self-confidence to communicate effectively with adults. In addition they could help children/young people develop the skills, language and confidence to explain their condition to others such as their peers. This is supported by the 'views' studies which similarly suggested that group-based self-care support models enable children/young people to improve their communication skills with professionals and parents. Although none of the intervention studies measured communication skills, the majority had an educational focus in terms of aiming to increase condition-related and self-management knowledge and some aimed to improve communication skills (e.g. Evans et al. 1999/Sullivan et al. 2002; Wysocki et al. 2001).

5.1.3 Developing independence and self-confidence

The case study stage highlighted how participants identified the potential of projects to develop children/young people's independence and self-confidence both socially and in terms of the self-management of their condition. Their self-confidence was promoted through taking part in challenging activities and recognition of their developing ability to manage social relationships as well as self-care. Projects also enabled children/young people to demonstrate their capabilities to their parents which in turn could serve to develop parental confidence to encourage independence.

A goal of self-care in relation to children/young people is independence; nevertheless parental involvement still appears to be important. Parents played a key role in children's/young people's access of self-care projects and in their continued participation. As previously noted the importance of parents maintaining an ongoing role during adolescence rather than totally devolving responsibility to their children may prevent the deterioration in health status sometimes seen during adolescence (La Greca et al., 1995; Anderson et al. 1997).

5.1.4 Engaging children and young people

Another important way of supporting self-care identified through the case studies was the ability of projects to engage children/young people. This appeared to involve both the provision of fun learning activities and the development of a child/young person-centred culture where their views were respected and listened to and their use of communication technologies utilised.

The evidence synthesis did not produce any findings relating specifically to the effectiveness of the learning activities themselves. Some studies investigated self-care support interventions that used electronic media and which could be seen as being 'young people friendly'. In relation to e-health methods, there is evidence from both the effectiveness and 'views' studies that e-health methods are an acceptable, engaging and feasible method of providing self-care support to children/young people with long-term conditions (Carroll et al. 1997; Guendelman et al. 2002, 2004; Krishna et al. 2003; Davis et al. 2004; Gammon et al. 2005; Franklin et al. 2006; McPherson et al. 2006; Jan et al. 2007; Van der Meer et al. 2007). The evidence from intervention studies suggests that they can be effective in terms of improving health status (Guendelman et al. 2002, 2004; Krishna et al. 2003; Jan et al. 2007; Joseph et al. 2007) adherence (Guendelman, 2002, 2004; Jan et al. 2007, Franklin et al. 2006), increasing condition related/self-management knowledge (Krishna et al. 2003; Davis et al. 2004; Jan et al. 2007), increasing competency of coping skills (Davis et al. 2004) and increasing self-efficacy (Franklin et al. 2006). Such technologies appear to be able to be integrated into children's/young people's everyday lives, particularly when they use a normalised device such as a mobile phone (Carroll et al. 1997; Gammon et al. 2005; Van der Meer et al. 2007). Monitoring technologies were found to be helpful in self-management by alerting young people to the need to alter medication and other therapeutic regimens. However, there were suggestions that parental involvement in these systems could increase conflict between children/young people and parents due to the increased opportunity for parental surveillance (Carroll et al. 1997; Gammon et al. 2005).

The opportunity to consult with a health professional via email was valued and there are suggestions that an on-line version of Staying Positive might be viewed as acceptable and appropriate for children/young people (Hawley 2005a; Van der Meer et al. 2007).

5.1.5 Self-care support ethos and skills

The approachability of workers and their willingness to listen and respond to children's/young people's views was identified as being an important element of a child/young person-centred culture in the case studies. One of the 'views studies' identified the importance placed by children/young people on the interpersonal skills of health professionals; their ability to listen, be receptive to individual needs, and their approachability (Anderson, 1997). The relationship between the interpersonal skills of the professional or lay person providing the intervention and the impact on outcomes has

not been examined in the effectiveness studies. However, one study found that physicians who had received an intervention designed to improve their communication and teaching skills were scored higher by the parents of children/young people with asthma on communication behaviour (Clark et al. 2001).

At the voluntary sector led sites, workers and volunteers received education and training to prepare them to provide self-care support; in one case study a nationally accredited scheme was used. At the NHS sites professionals considered that they had already acquired the necessary knowledge and skills for this role through their education for professional practice. As previously noted few studies in the evidence synthesis focused on professional support for self-care (Clark et al., 2000; Lozano et al., 2004).

Lay-leadership and the inclusion of lay volunteers were identified by participants in the case studies as being helpful to them as they shared the same experiences and understandings. Another study has similarly found that parents value self-care support projects being led by individuals who are also parents of children/young people with long-term conditions as they could understand and empathise with their situation (Hawley 2005b). NHS led projects were also valued by participants but for different reasons. As they integrated self-care support with clinical care they were seen as enabling the development of positive relationships between clinical staff and families as well as ensuring the consistency and continuity of support. This is supported by one of the 'views' studies which similarly highlighted that parents felt that continuity and mutual trust was promoted when clinical teams were involved in self-care support projects (Trollvik and Severinsson 2005).

The school is an important environment in the lives of all children/young people and for those with a long-term condition a context where they have to negotiate their illness and identity management. Yet the support provided by schools appeared to be highly variable and for some participants viewed as inadequate. In some instances schools appeared to create barriers to self-care and children's/young people's participation in school activities in spite of government guidance to the contrary (DfES/DH, 2005). As a means of enhancing support some projects were involved in increasing the knowledge and understanding of professionals such as teachers about long-term conditions and how to support children/young people. Some organisations providing the self-care projects were working at a national level to influence change in schools and had formed an umbrella organisation ('Medical Conditions at School') to increase their influence and provide a combined set of resources for schools to use to increase their awareness and improve support.

5.1.6 Accessing projects

Self-referral was the main pathway into self-care projects. Although health professionals and teachers were involved in providing information about the projects it appeared that they were not part of referral pathways unless they were integrated with clinical care and management. This reflects the

nature of the relationships and lack of integration between some projects and other forms self-care support.

The motivations underpinning access related directly to individuals' experiences of chronic illness. They perceived a need for information and skills training as well as a desire to reduce their sense of isolation. At the same time it appeared that children/young people and parents had to be at a point in their illness trajectories where they were 'ready' to engage with such projects. As noted above, parents played an important role in providing information to children/young people about projects and encouraging access. Other studies have noted the importance of maintaining parental involvement (La Greca et al. 1995; Anderson et al. 1997).

5.2 Limitations of the study

The evidence synthesis aimed to evaluate the effectiveness of self-care support models for children and young people with long-term conditions and examine the views of participants on them by extracting, quality assessing and synthesising the results from a range of different types of research. However, the conclusions that can be drawn from the synthesis are limited by a lack of rigorously conducted quantitative and qualitative research in the area and the difficulties in identifying the precise 'active ingredient' in complex, multi-component interventions. There was frequently a lack of detail in the reporting of studies which made it difficult to judge their adequacy. An analysis of the overall methodological quality of the studies is provided in Chapter 2 and summarised in Table 25 below. In addition it should be noted that the papers included in the review are the result of a particular search strategy and quality assessment process. Unpublished data were not sought from authors.

Information about the online questionnaire was distributed via a range of email distribution groups/networks as well as via letters to all NHS Trusts in England. Consequently we are unable to calculate a response rate and are unable to assess the completeness of the data obtained. Non-response from a particular Trust could indicate that no projects were being provided or commissioned but it could equally indicate a desire not to participate in the survey (or a lack of knowledge about the organisation's role in this area). It is also possible that some local authority services and third sector organisations did not receive information about the survey via the email distribution. As with all online surveys the sample is likely to be biased towards those with internet access and who are comfortable with using electronic media. In addition it only provides a picture of what was being provided at the time of the survey (July-September 2008).

The findings from the case studies also have limitations. They cannot be considered to be generalisable in a quantitative sense, however, readers can assess the transferability of findings to other settings from the description of the sites. Recruitment to the study was difficult in spite of repeated follow-ups; the recruitment of any 'drop-outs' from projects proved to be impossible and the final sample was smaller than had been

originally envisaged. Project organisers were involved in recruiting participants which raises the possibility of sampling being skewed to those perceived as being more satisfied with the project. However participants appeared to be candid in their views, expressing both positive and negative views on projects. In addition the sample may be skewed towards those who both wish to access self-care support and who do not experience barriers to access.

Table 25. Summary of the methodological limitations of the research literature

Effectiveness studies	'Views' studies (qualitative and survey studies)
Lack of information provided in papers on key aspects of the studies - randomisation procedures, allocation concealment, blinding, conduct of a priori sample size power calculations, attrition and conduct of intention to treat analyses	Lack of detail provided in papers on sampling; recruitment, methods of data collection and analysis; establishment of rigour.
Lack of a theoretical basis to the intervention	Piloting of questionnaires unclear
Lack of detail reported on the intervention	Survey methods used with very small samples
Unclear identification and definition of outcomes	Use of pre-determined statement response lists to obtain views of children/young people.
Lack of reporting and testing of the reliability/validity of the measures used and lack of use of validated measures.	Generation and/or reporting of superficial data
Lack of standardisation of outcome measurements across studies	
Lack of clear information on who administered and completed measures	
Under-emphasis on measuring behavioural and psychological outcomes as well as satisfaction with intervention.	
Short follow-up periods for collection of outcome data	
Possible selective reporting of outcome data	
Lack of reporting of sample characteristics	
Lack of integral process evaluations and cost-effectiveness studies	

5.3 Contribution of the study

This is the first study that has evaluated self-care support for children and young people across different long-term conditions and across different models.

The evidence synthesis has contributed to knowledge by evaluating self-care support across different childhood long-term conditions; by reviewing and synthesising both qualitative and quantitative studies and by focusing on a broad range of self-care support interventions. Previously reviews have focused on single conditions, on particular types of intervention and/or have not taken a mixed method approach (for example, Hampson et al., 2001; Wolf et al. 2002; Toelle and Ram, 2004; Bjornstad and Montgomery, 2005; Yorke and Shuldham, 2005; Yorke et al., 2005; Bhogal et al. 2006; Glasscoe and Quittner, 2008).

The mapping exercise has provided a picture of the current provision of self-care support in England in relation to children/young people with long-term conditions and has highlighted the complexities in attempting to obtain reliable data in this area. As far as we are aware this is the first time that a national mapping of self-care support for children/young people has been attempted.

The case studies have identified four key mechanisms that participants see as being central to an effective self-care support project (providing a sense of community; promoting independence and confidence; developing knowledge and skills and engaging children/young people). Potential mediating factors (access to projects, knowledge and skills of providers) and contextual factors that may influence self-care support have been highlighted. These findings will help fill current gaps in knowledge about how effective and appropriate self-care support can be developed.

Self-care support is a nebulous concept and the typology developed during the study may aid its articulation. The typology provides a framework for characterising and describing self-care support models and may be transferrable to an adult context. The identification of the components of self-care support models may guide the development of projects for children/young people by public and third sector organisations. Similarly the typology could also be used in research to develop and evaluate self-care support interventions as well as having a potential use in explicating and 'unpacking' interventions in systematic reviews.

5.4 Implications and recommendations

5.4.1 Research implications

The review has identified that there is a need for well designed trials to be conducted in the UK which test theoretically informed interventions that have been developed with parents and children/young people and which are

feasible to transfer into clinical practice. These should include the measurement of psycho-social outcomes as well as health status and health service use as well as the conduct of process evaluations to provide information on how and why interventions do and do not work.

The development and investigation of interventions to support the transfer of responsibility for self-care from parents to children/young people over time is an important though under-researched area in effectiveness studies. Similarly there has been a lack of development and evaluation of interventions that focus on promoting self-care support by professionals/lay workers and whole system approaches. To enable the development of appropriate interventions in this area there is however, a need for more qualitative research to be conducted to examine professional perceptions of the barriers, facilitators, satisfactions and challenges of supporting self-care.

In the main the diversity of individuals, families and communities has been neglected in the development of self-care support interventions. Therefore there is a need for research that investigates what projects are appropriate for individuals who face barriers due to disability, socioeconomic status, education, culture, geography or gender.

In the area of self-care support for children/young people with long-term conditions there has been a lack of a cumulative approach to research and of learning from studies that have investigated similar types of interventions but in different conditions. In developing both interventions and the studies to evaluate them, researchers should build on previous research across long-term conditions and where appropriate enable comparisons and the pooling of results to be made for example by using the same validated outcome measures.

5.4.2 Policy and practice implications

Generic self-care policies and guidance should contain specific reference to children/young people with long-term conditions. This would help to raise awareness of this group within mainstream services and the priority they are given.

Currently there is a lack of information on the investment of NHS organisations in self-care support for children/young people. Including self-care projects commissioned and provided by NHS organisations in the children's services mapping initiative would enable performance monitoring at a local, regional and national level; joint service planning, development and provision; and could support the development and maintenance of local self-care support directories.

Self-care support strategies for children/young people and their parents should be developed by commissioners to meet the needs of their local population and provide a range of self-care support programmes, resources and tools. It is likely that this will involve commissioning projects from independent and voluntary sector organisations as well as specifically including self-care support within contracts/service specifications with NHS providers.

A range of different types of self-care support programmes, resources and tools need to be developed and provided to meet individual needs. Key elements that need to be incorporated in and underpin this 'menu' of choices are:

- Child/parent-centredness which entails involving parents and children/young people in the development and evaluation of projects; using a learner-centred approach; being sensitive to disability, culture, literacy, socio-economic status, age and gender; being aware of the parent's and young person's experience of illness and the wider context of their lives; taking into account the young person's or parent's readiness to engage with self-care support; focusing on the individual's goals for self-care and preferences for self-care support; promoting autonomy and independence.
- Encouragement of social support which involves providing mechanisms through which children/young people and parents can develop a sense of community and belonging and build their social networks
- Promoting learning and personal development in order to increase confidence and self-esteem through the provision of information and skills training as well as the provision of role models and the sharing of lay knowledge. In addition partnership working between professionals, parents and children/young people could be enhanced by providing skills for and encouraging shared decision making.

Similar components to these have been identified in relation to adults (Health Canada, 1997).

The use of e-health methods, either as means of providing social networking or in self-management support, appears to be an acceptable and potentially effective self-care support model for children/young people with long-term conditions and their parents.

There needs to be improved joint working and integration of self-care support between the voluntary sector and the NHS. In many ways they offer complementary forms of support. NHS involvement provides the opportunity for the integration of self-care support with clinical care if there is a culture that encourages diverse ways of providing self-care support and staff have the requisite knowledge and skills. Voluntary sector organisations bring lay knowledge and understandings to self-care support as well as the ability to provide support in a flexible way. Joint working with the NHS may also enable their projects to be included in self-care commissioning as well as improving their access to children/young people with long-term conditions through closer working with health professionals and the inclusion of projects in referral pathways.

Self-care support by schools needs to be improved. Good practice guidance has been developed for the management of medicines in schools that emphasises the importance of supporting children's/young people's own self-management and their participation in activities such as visits and sport, the provision of individual health care plans and having a whole school policy on medicines and children/young people with 'medical needs'

(DfES/DH, 2005). However, its status as good practice guidance means that it is interpreted and implemented in different ways by different schools. Moreover, supporting children/young people with a long-term condition in school is not solely about medicines management but about ensuring that they have the same educational opportunities as their peers as well as providing psychosocial support in relation to managing relationships with peers. Including the assessment of self-care support within schools in OFSTED (Office for Standards in Education, Children's Services and Skills) inspections would be one way of scrutinising schools' performance in this area and of raising its profile with head teachers. Indeed guidance for OFSTED inspectors has recently been issued on this issue (OFSTED, 2009).

Health professionals and other workers need to have the values, attitudes, knowledge and skills necessary to support self-care. Recently the DH (2008), with Skills for Health and Skills for Care, identified a core set of principles for self-care support and their underpinning values (Figure 2). The findings from this study suggest that these principles are transferrable to the context of children/young people with long-term conditions and should be an integral part of all education programmes as well as embedded within individual practice, service provision and commissioning

Figure 2. Core principles for supporting self-care (DH 2008)**Principle 1 – Ensure individuals are able to make informed choices to manage their self care needs.**

Context: The worker's practice is informed by the principles of respect, dignity, choice and independence for individuals. It encourages and supports individuals to make decisions based on the experience of their needs and enhanced by appropriate professional support and guidance. Practice is based on a shift of values from professionals knowing best to them supporting and empowering individuals to be in control of their needs.

Principle 2 – Communicate effectively to enable individuals to assess their needs, and develop and gain confidence to self care

Context: The worker uses communication and relationship skills which encourage and support individuals to work with professionals to identify strengths and abilities as well as areas for development, and to find solutions together building on existing skills.

Principle 3 – Support and enable individuals to access appropriate information to manage their self care needs

Context: The worker encourages and supports individuals in accessing appropriate information, and where possible provides the relevant and evidence based information in an appropriate manner, providing sufficient choice/options.

Principle 4 – Support and enable individuals to develop skills in self care

Context: The worker facilitates access to appropriate training and self care skills development within or outside their organisation in order to develop and support individuals' confidence and competence to self care. The worker also delivers support to individuals in developing self care/self management skills.

Principle 5 – Support and enable individuals to use technology to support self care

Context: The worker ensures appropriate equipment and devices are discussed and when appropriate puts individuals in touch with the relevant agency from where they can procure the item(s), and where possible provides the relevant tools and devices. The worker also engages with individuals to support and enable the use of technology

Principle 6 – Advise individuals how to access support networks and participate in the planning, development and evaluation of services

Context: The worker advises individuals about participation in support networks both to receive from and give support to others. The worker promotes and encourages involvement of individuals in the planning, development and evaluation of services they receive, and supports them to organise care packages to meet their self care needs

Principle 7 – Support and enable risk management and risk taking to maximise independence and choice

Context: The worker encourages and supports individuals to make choices about how to live their lives and manage any identified risks. The worker promotes choice and independence while supporting individuals to manage risks proportionately and realistically.

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Appendix 1

Appendix 1.1 Reference Group Members

Laila Baig
Clinical Lead – Therapy Services
Manchester PCT

Dr. Mark Bone
Consultant Paediatrician
Central Manchester and Manchester Children’s University Hospitals NHS
Trust

Judith Ellis
Director of Nursing, Education and Workforce Development
Great Ormond Street Hospital for Children NHS Trust

Kathy Hawley
Researcher
Consultant to the Expert Patient Programme Community Interest Company

Zoe Lawrence
Deputy Director, Partnerships for Children, Families and Maternity
Department of Health

Simon O’Neil
Director of Care, Information and Advocacy Services
Diabetes UK

Noreen Ryan
Nurse Consultant
CAMHS, Royal Bolton Hospital NHS Trust

Simon Selo
Assistant Director, Policy and Service Development, Nations, Services and
Regions
Asthma UK

Fiona Smith
Adviser in Children's and Young People's Nursing
Royal College of Nursing

Pat Stringer
Cystic Fibrosis Nurse Specialist
Royal Brompton and Harefield NHS Trust
Nominee of the Cystic Fibrosis Trust

Appendix 2

Appendix 2.1 Databases Searched

MEDLINE

PubMed

EMBASE

Scopus

Social Sciences Citation Index

Sociological Abstracts

Applied Social Sciences Index and Abstracts (ASSIA)

Social Care Online

Social Services Abstracts

ChildData

Cumulative Index to Nursing and Allied Health Literature (CINAHL)

British Nursing Index

Allied and Complementary Medicine (AMED)

PsycInfo

Health Management Information Consortium (HMIC)

The Cochrane Library

The North West Grey Literature Service (FADE)

Appendix 2.2 Systematic Review Search Terms⁷

SELF- CARE	INTERVENTION	GROUP	LONG-TERM CONDITION
Self manag*	Plan	Child*	Diabet*
Self-manag*	Checklist	Bab*	Cystic fibrosis
Self care	Coach*	Infant	Mucoviscidosis
Self-care	Educational materials	Toddler	Asthma
Self help	Goal-set*	Teenager*	ADHD
Self-help	Individual* goal*	Adolescen*	ADD
Collaborative care	Action plan*	Young person	Hyperkinetic Disorder
Collaborative manag*	Group education	Young people	Attention Deficit
	Patient education	Youth	Attention Deficit
	Information	Juvenile	Behavio*r* problem*
	Patient-held record	P*ediatric	Behavio*r* disorder*
	Training	Parent*	
	Skills train*	Mother	
	Program*	Father	
	Patient involv*	Guardian	
	Patient participat*	Advocate	
	Share* decision making	Carer	
	Decision aid*	Family	
	Diet*		
	Exercise		
	Telecare		
	Telehealthcare		
	Telemedicine		
	Telemonitor*		

⁷ Outcomes were not specified in the searches.

	Home monitor*		
	Telephone support		
	Virtual communit*		
	Mutual support		
	Peer support		
	Self admin*		
	Self monitor*		
	Self medicat*		
	Self diagnosis		
	Self treatment		
	Provider training		
	Provider education		

Appendix 2.3 Stage One Data Extraction Form

I. PUBLICATION DETAILS

A. Author(s): _____

B. Title: _____

C. Journal/Source: _____

Year: _____ Volume: _____ Issue: _____ Pages: _____

D. Country of Origin: i. US ii. UK iii. Other: _____

E. Date of extraction: _____

F. Reviewer's initials: _____

II. STUDY DESIGN

A. Study type (*circle one*):

- i. RCT
- ii. Cohort study with matched concurrent controls (prospective)
- iii. Cohort study with unmatched concurrent controls (prospective)
- iv. Cohort study with historic controls (retrospective)
- v. Case control study
- vi. Before and after study (simple or time series)

ii. Other: _____

B. Study setting (*circle one*):

- i. Community/home
- ii. Primary care

iii. Specialist care:

- a. outpatient
- b. inpatient
- c. mixed
- d. not specified

iv. Other: _____

C. Target population

- i. Children
- ii. Parents
- iii. Siblings
- iv. Professionals
- v. Other. _____

D. Allocation of intervention/control groups (*circle one*):

i. Randomized

a. Randomization method adequate?

- 1. Yes (use of computerised random number generation or random number tables)
- 2. No/Not reported (use of alternation, case record numbers, birth or other dates)

b. Unit of randomization:

- 1. Children/parents
- 2. Providers
- 3. Organisations

c. Allocation adequately concealed? 1. Yes 2. No/Not reported

ii. Non random allocation

iii. Other/Not reported: _____

iv. Not applicable – no intervention/control groups

E. Blinding

i. Children/parents/professionals (if target of intervention) blinded to intervention status? (*circle one*):

- a. Yes
- b. No/Not reported

ii. Providers blinded to intervention status? (*circle one*):

- a. Yes
- b. No/Not reported

iii. Blinding of others involved in intervention implementation (e.g. outcome assessors)? (*circle one*):

- a. Yes
- b. No/Not reported
- c. Not Applicable

iv. Researchers/investigators blinded to intervention status? (*circle one*):

- a. Yes
- b. No/Not reported

F. Additional information on study design: _____

G. If case control or cohort study design, was the case or the cohort & controls recruited in an acceptable way (ie selection bias minimised)

- a. Yes
- b. No/Not reported

III. SAMPLE INFORMATION

Children/Parents *fill in separate sheet for each if applicable	Providers
A. Sample type (<i>circle one</i>) i. Representative sample ii. Convenience/Other sample iii. Not reported	A. Sample type (<i>circle one</i>) i. Representative sample ii. Convenience/Other sample/Not reported iii. Not reported
B. Sample size (<i>fill in categories as they are reported</i>): <i>Total:</i> _____ <i>Exp: Control:</i> _____ i. Invited: _____ ii. Consented: _____ (_____%) _____ iii. Completed: _____ (_____%) _____ iv. Additional information: _____ v. Power calculation used to determine sample size? Yes No Not reported	B. Sample size (<i>fill in categories as they are reported</i>): <i>Total:</i> _____ <i>Exp: Control:</i> _____ i. Invited: _____ ii. Consented: _____ (_____%) _____ iii. Completed: _____ (_____%) _____ iv. Additional information: _____ v. Power calculation used to determine sample size? Yes No Not reported
C. Significant differences between completers and non-completers? i. Yes/Not reported ii. No iii. NA (all completed)	C. Significant difference between completers and non-completers? i. Yes/Not reported ii. No iii. NA (all completed)
D. Inclusion criteria: i. Category (e.g. ADHD, asthma, cystic fibrosis, diabetes, age group, other): _____ ii. Disease duration (e.g., newly diagnosed, established diagnosis, mixed, not reported/not applicable): _____ iii. Patient relationship to clinic/provider (e.g., known/old patients, new patients, mixed, not reported): _____ iv. Other: _____	D. Inclusion criteria:
E. Exclusion criteria:	E. Exclusion criteria:
F. Participant characteristics i. % Female: _____ ii. Age (mean): _____ iii. SES/Education: _____ iv. Ethnicity _____ v. Other: _____	F. Participant characteristics i. % Female: _____ ii. Age (mean): _____ iii. Level of training/ time in practice: _____ iv. Other: _____
G. Control and intervention groups significantly different at baseline? i. Yes/Not reported ii. No iii. NA (no control/intervention groups)	G. Control and intervention groups significantly different at baseline? i. Yes/Not reported ii. No iii. NA (no control/intervention groups)

IV. **DESCRIPTION OF INTERVENTION(S)** (fill out one column for each intervention in article)

A. Study Compares (circle one/for ii. write in numbers):

- i. One intervention to one control
- ii. ____ (#) interventions, ____ (#) control groups
- iii. Other (describe) _____

B. Type of provider (circle all that apply):

- i. Doctor Special training to apply intervention? Yes No Not reported
- ii. Nurse Special training to apply intervention? Yes No Not reported
- iii. Lay organisation
- iv. Unclear
- v. Other: _____

C. Aim of self-care intervention (e.g. increase self-efficacy)	C. Aim of self-care intervention (e.g. increase self-efficacy)	C. Aim of self-care intervention (e.g. increase self-efficacy)
<ul style="list-style-type: none"> i. Child focus ii. Parent focus iii. Both child & parent focus iv. Child, parents & siblings focus v. Professional vi. Other 	<ul style="list-style-type: none"> i. Child focus ii. Parent focus iii. Both child & parent focus iv. Child, parents & siblings focus v. Professional vi. Other 	<ul style="list-style-type: none"> i. Child focus ii. Parent focus iii.Both child & parent focus iv.Child, parents & siblings focus v. Professional vi.Other

<p>D. Type of intervention (theoretical model, content etc)</p> <p>i. Child focus ii. Parent focus iii. Both child & parent focus iv. Child, parents & siblings focus v. Professional vi. Other</p>	<p>D. Type of intervention (theoretical model, content etc)</p> <p>i. Child focus ii. Parent focus iii. Both child & parent focus iv. Child, parents & siblings focus v. Professional vi. Other</p>	<p>D. Type of intervention (theoretical model, content etc)</p> <p>i. Child focus ii. Parent focus iii. Both child & parent focus iv. Child, parents & siblings focus v. Professional vi. Other</p>
<p>E. Brief description of intervention tools listed above:</p> <p>_____</p> <p>_____</p>	<p>E. Brief description of intervention tools listed above:</p> <p>_____</p> <p>_____</p>	<p>E. Brief description of intervention tools listed above:</p> <p>_____</p> <p>_____</p>
<p>F. Method of delivery of intervention (<i>circle all that apply</i>):</p> <p>i. Mailed ii. In clinic or other health care setting a. Computerized b. Written c. Video d. Face-to-face iii. Telephone iv. Community-based/home v. Internet vi. Other: _____</p>	<p>F. Method of delivery of intervention (<i>circle all that apply</i>):</p> <p>i. Mailed ii. In clinic or other health care setting a. Computerized b. Written c. Video d. Face-to-face iii. Telephone iv. Community-based/home v. Internet vi. Other: _____</p>	<p>F. Method of delivery of intervention (<i>circle all that apply</i>):</p> <p>i. Mailed ii. In clinic or other health care setting a. Computerized b. Written c. Video d. Face-to-face iii. Telephone iv. Community-based/home v. Internet vi. Other: _____</p>

<p>G. Total intervention time (no. of sessions x length of time):</p> <p># hours: ____ / # minutes: _____</p> <p>Detail: _____</p>	<p>G. Total intervention time (no. of sessions x length of time):</p> <p># hours: ____ / # minutes: _____</p> <p>Detail: _____</p>	<p>G. Total intervention time (no. of sessions x length of time):</p> <p># hours: ____ / # minutes: _____</p> <p>Detail: _____</p>
<p>H. Additional description of intervention:</p> <p>_____</p> <p>_____</p>	<p>H. Additional description of intervention:</p> <p>_____</p> <p>_____</p>	<p>H. Additional description of intervention:</p> <p>_____</p> <p>_____</p>

I. What mediating variables were investigated (if any)? _____

J. Description of control group activities: _____

K. Total control activity time:

hours: ____ # minutes: _____

Details: _____

L. Were groups treated equally (aside from intervention)?

- i. Yes
- ii. No/not reported

V. RESULTS MEASUREMENT

A. Results	B. Detail	C. Measurement method <i>(circle all that apply):</i>	D. Assessment tool used	E. Effect of intervention <i>(choose all measurement times reported; for each time, circle one effect)</i>
Outcome A measured (e.g. adherence)		i. Observer-assessed ii. Child-reported iii. Parent reported iv. Provider-reported v. Medical records Extraction vi. Physical exam vii. Laboratory test viii. Other: <i>For (i), (v), (vi), and (vii) were assessors blinded?</i> <input type="radio"/> Yes <input type="radio"/> No	(NB note appropriateness of assessment tool e.g. developed/adapted for children, validity, appropriateness for age group)	i. Results measured ____ after intervention a. Positive effect b. Negative effect c. No effect ii. Results measured ____ after intervention a. Positive effect b. Negative effect c. No effect iii. Results measured ____ after intervention a. Positive effect b. Negative effect c. No effect iv. Other: _____ a. Positive effect b. Negative effect c. No effect
Outcome B measured (e.g. adherence)		i. Observer-assessed ii. Child-reported iii. Parent reported iv. Provider-reported v. Medical records Extraction vi. Physical exam vii. Laboratory test viii. Other: <i>For (i), (v), (vi), and (vii) were assessors blinded?</i> <input type="radio"/> Yes <input type="radio"/> No	(NB note appropriateness of assessment tool e.g. developed/adapted for children, validity, appropriateness for age group)	i. Results measured ____ after intervention a. Positive effect b. Negative effect c. No effect ii. Results measured ____ after intervention a. Positive effect b. Negative effect c. No effect iii. Results measured ____ after intervention a. Positive effect b. Negative effect c. No effect iv. Other: _____ a. Positive effect b. Negative effect c. No effect

A. Results (<i>circle one per row</i>)	B. Detail	C. Measurement Method (<i>circle all that apply</i>):	D. Assessment Tool Used	E. Effect of intervention (<i>choose all measurement times reported; for each time, circle one effect</i>)
Outcome C measured (e.g. adherence)		i. Observer-assessed ii. Child-reported iii. Parent reported iv. Provider-reported v. Medical records Extraction vi. Physical exam vii. Laboratory test viii. Other: <i>For (i), (v), (vi), and (vii) were assessors blinded?</i> <input type="radio"/> Yes <input type="radio"/> No	(NB note appropriateness of assessment tool e.g. developed/adapted for children, validity, appropriateness for age group)	i. Results measured ____ after intervention a. Positive effect b. Negative effect c. No effect ii. Results measured ____ after intervention a. Positive effect b. Negative effect c. No effect iii. Results measured ____ after intervention a. Positive effect b. Negative effect c. No effect iv. Other: _____ a. Positive effect b. Negative effect c. No effect
Outcome D measured (e.g. adherence)		i. Observer-assessed ii. Child-reported iii. Parent reported iv. Provider-reported v. Medical records Extraction vi. Physical exam vii. Laboratory test viii. Other: <i>For (i), (v), (vi), and (vii) were assessors blinded?</i> <input type="radio"/> Yes <input type="radio"/> No	(NB note appropriateness of assessment tool e.g. developed/adapted for children, validity, appropriateness for age group)	i. Results measured ____ after intervention a. Positive effect b. Negative effect c. No effect ii. Results measured ____ after intervention a. Positive effect b. Negative effect c. No effect iii. Results measured ____ after intervention a. Positive effect b. Negative effect c. No effect iv. Other: _____ a. Positive effect b. Negative effect c. No effect

M. Data analysis methods

Outcome	Mean outcome in each group reported			Mean difference reported (with its standard error or standard deviation or confidence interval around it)		
A	Yes	No	Unclear	Yes	No	Unclear
B	Yes	No	Unclear	Yes	No	Unclear
C	Yes	No	Unclear	Yes	No	Unclear
D	Yes	No	Unclear	Yes	No	Unclear

*Add more rows if more than 4 outcomes have been assessed

N. Numbers and reasons for any loss to follow-up reported

- i. Yes
- ii. No/Not reported
- iii. NA

O. Any missing data is identified and the procedure how this has been handled is stated (e.g. sensitivity analysis)

- i. Yes
- ii. No/Not reported
- iii. NA

P. Was an intention-to-treat analysis performed?

- i. Yes
- ii. No/Not reported
- iii. NA

Q. Have the researchers identified important confounding factors?

- i. Yes
- ii. No/Not reported
- iii. NA

R. Have the researchers taken account of confounding factors in their design and analysis?

- i. Yes
- ii. No/Not reported
- iii. NA

NOTES

Verification of study eligibility for SR (correct population, interventions, outcomes and study design) (circle)

Eligible Ineligible Unsure

Individual rater appraisal (circle): Adequate Unclear Inadequate

Joint rater appraisal (circle): Adequate Unclear Inadequate

Where applicable detail how consensus was reached:

Details on any arbitration by a third rater

Appendix 2.4 Characteristics of the Included Effectiveness Studies

Author(s) & country	Design	Participants	Intervention	Outcomes	Summary of findings about effectiveness
STUDIES FOCUSING ON ADHD					
MTA Cooperative Group, 1999, 2004 USA	RCT, 4 arms. Randomisation adequate. Blinding not reported. ITT analysis conducted. Length of follow-up: 14 months.	579 families recruited, 540 completed study. Gender of children: 20% female Sample mean age: 8.5 Ethnicity: 61% Caucasian	Families randomised to medication management (titrated) or intensive behavioural treatment or combined medication management and behavioural treatment. Behavioural treatment had 3 components. (1) Parent skills training – 8 group based weekly sessions led by a therapist . Location unclear. (2) Child focused therapy – an 8 week, 5 days a week summer camp led by counsellors. Group based sessions on areas such as social skills training, problem solving, acceptable classroom behaviour. Location unclear. (3) School based work where therapists worked with teachers twice a week for 10-16 weeks regarding classroom management and classroom aides worked with individual children. Theoretical basis not stated. Leadership: professional Control: standard community care.	Primary: none. Others: ADHD symptoms; oppositional/aggressive symptoms; social skills; anxiety and depression; parent-child relationships; academic achievement	Medication management alone was more effective in reducing ADHD symptoms than behavioural treatment and routine community care. Combined treatment was more effective in reducing symptoms than behavioural treatment alone. Medication management and combined treatment did not differ significantly across the outcomes measured. While both medication management and combined treatment were more effective in reducing symptoms than standard community care, behavioural therapy alone was not.
Sonuga-Barke et al., 2001 UK	RCT, 3 arms Randomisation unclear. Blinding of outcome	78 families recruited, 71 families completed study. Gender of children: 38.5% female.	Mother and child randomised to parent training or parent counselling and support. Both parent training and parent counselling/support are structured 8 week programmes involving 1 hour weekly one-to-one home visits by specially trained Health Visitors.	Primary outcome: ADHD symptoms. Secondary outcome: maternal wellbeing	Parent training was more significantly more effective in reducing ADHD symptoms and improving maternal wellbeing than counselling and support.

	assessors. ITT analysis conducted Length of follow-up: 15 weeks	Sample mean age: not reported Ethnicity: Not reported.	Parent training involves education about ADHD and behaviour management strategies. Parent counselling and support involves no training in behaviour management but focuses on discussing feelings and the impact of the child on the family Theoretical basis not stated. Leadership: professional. Control: waiting list group.		
STUDIES FOCUSING ON ASTHMA					
Cano-Garcinuna at al., 2007 Spain, Cuba and Uruguay	RCT: 4 arms Randomisation : adequate Blinding: not reported. ITT analysis conducted Length of follow-up: 6 Months	245 children recruited, 223 completed the study. Gender of children: 35.1% female. Sample mean age: 11 Ethnicity: 63.3% Spanish	Child and parent group education. 3 sessions with 6-10 participants for 45-60 minutes (separate child and parent sessions). Emphasis on self-management of asthma. Sample randomised to child group education only; parent group education only; child and parent group education. Theoretical basis: none identified Leadership: professional Control: usual care.	Primary: asthma morbidity (asthma attacks, hospitalisation); quality of life. Others: Child and parent asthma knowledge.	Asthma attacks and hospitalisations were reduced in the groups receiving child group education or child and parent group education. Education provided to parents alone was not associated with changes in morbidity. There was no effect on quality of life.
Cicutto et al., 2005 Canada	RCT: 2 arms Randomisation : adequate Blinding: not reported. ITT analysis conducted Length of follow-up: 12	256 children recruited, 239 completed the study. Gender of children: 41% female. Sample mean age: 8.6 Ethnicity: not	School based asthma education program: "Roaring Adventures of Puff". Six 50-60 minute weekly sessions – education about asthma and self-management and communication skills. Family based homework activities. Theoretical basis: social cognitive theory and self regulation. Leadership: professional Control: usual care.	Primary: emergency room visits or office visits for acute asthma episodes; quality of life. Others: self-efficacy; school absences; days on interrupted activity; parental time off work.	The intervention improved self-efficacy and quality of life; the intervention group had fewer urgent health-care visits, days of missed school or interrupted activity. There were no differences for parental time off work.

	Months	reported.			
Clark et al., 2000 USA	RCT: 2 arms. Randomisation : unclear. Blinding: children and parents blind to physicians participation in the study. Other blinding unclear. ITT analysis not reported. Length of follow-up: 2 Years	74 GP paediatricians recruited, 67 completed the study. 637 children recruited, 369 completed. Gender of doctors: 40% female. Mean age of doctors: not reported 57% in single practice. Child gender: 30% female Sample mean child age: not reported. Ethnicity: 70% Caucasian	Interactive seminar for physicians to develop communication and teaching skills and a better partnership with patients; use of therapeutic medical regimens and guidelines for asthma. Two group meetings lasting 2.5 hours held over 2-3 weeks for up to 12 physicians. Theoretical basis: self regulation theory. Leadership: professional Control: usual care provision.	Primary: none Others: physician behaviour changes (teaching/communication, prescribing, time spent in consultation); parents view of physician performance; use of healthcare for asthma. (Disease severity, quality of life and medication use also measured but not reported in paper).	Physicians who had received the intervention were more likely to use protocols in relation to asthma education; guide patients regarding medication adjustments in relation to symptom changes; provide guidelines for modifying therapy. Parents scored treatment group physicians higher on communication behaviours. Children seen by treatment group physicians had fewer asthma related hospitalisations. There was no effect on length of consultation.
Dolinar et al., 2000 Canada	RCT: 2 arms Randomisation : adequate Blinding: unclear ITT analysis not reported. Length of follow-up: 3 months	45 parents with children under 11 years recruited, 40 completed. Gender of parents: 85% female Gender of children: 57% female Mean age of parents: not reported	Single face-to-face asthma education session and an asthma education booklet. Delivered in home and lasted 2 hours. Theoretical basis: none identified. Based on 'Air Force Asthma Program'. Leadership: professional Control: received the asthma education booklet (said to represent conventional care).	Primary: none Others: parental coping, perceptions of asthma change, quality of life.	The intervention reduced parental need for information and parental concerns, increased use of coping strategies, and improved parent's perception of child's asthma. Quality of life remained unchanged.

		<p>Sample mean age of children: not reported</p> <p>Ethnicity: not reported.</p>			
<p>Evans et al., 1999; Sullivan et al., 2002</p> <p>USA</p>	<p>RCT: 2 arms</p> <p>Randomisation : adequate</p> <p>Blinding: adequate</p> <p>ITT analysis not reported.</p> <p>Length of follow-up: 2 years</p>	<p>1033 children living in an inner-city area recruited, 961 completed the study.</p> <p>Gender of children: not reported.</p> <p>Sample mean age: not reported.</p> <p>Ethnicity: not reported.</p>	<p>Individually tailored to families' needs, asthma counsellors worked with caretakers and children on group and individual basis (contact every two months). Caretakers invited to two group sessions and one individual session. Sessions covered education, communication and problem solving skills. There were also two group sessions for children. Program also included environmental control measures – families given pillows and mattress covers. Primary care physicians of the children were sent asthma care plan, spacer, peak flow meter and asthma treatment guidelines.</p> <p>Theoretical basis: none identified. Based on 'A+ Asthma Program'.</p> <p>Leadership: professional</p> <p>Control: usual care</p>	<p>Primary: self-reported asthma symptom days.</p> <p>Others: hospitalisation, unscheduled physician visits, direct medical costs, intervention costs.</p>	<p>The intervention was associated with a reduction in asthma symptom days reported and fewer hospitalisations. Program was cost-effective particularly for those with more severe asthma.</p>
<p>Guendelman et al., 2002; 2004</p> <p>USA</p>	<p>RCT: 2 arms</p> <p>Randomisation : adequate</p> <p>Blinding: unclear</p> <p>ITT analysis conducted.</p> <p>Length of follow-up: 12 weeks</p>	<p>134 inner-city children recruited, 128 completed the study.</p> <p>Gender of children: 42.5% female</p> <p>Sample mean age: not reported.</p> <p>Ethnicity: 76.1% African American</p>	<p>'Health Buddy' – a personal and interactive communication device. Daily questions are sent to the child about asthma symptoms, peak flow readings and use of medications and health services. Each answer receives a response. Aims to help asthma self-management and provide an education program enabling children to assess and monitor their asthma symptoms. Information transferred to health care providers through a website.</p> <p>Theoretical basis: none identified.</p> <p>Leadership: professional</p> <p>Control: completed an asthma diary.</p>	<p>Primary: limitation in activity.</p> <p>Others: self-reported asthma symptoms, school absences, peak flow readings, use of health services, self-care behaviours (assessed by parents).</p>	<p>The intervention reduced limitations in activity. Children in the intervention group were less likely to report peak flow recordings in the yellow or red zone or make urgent calls to hospital. Self-care behaviours also improved more for the intervention group.</p>

Jan et al., 2007 Taiwan	RCT: 2 arms Randomisation : adequate Blinding: unclear ITT analysis: not reported. Length of follow-up: 12 weeks	179 children recruited, 164 completed the study. Gender of children: 61.6% female Sample mean age: not reported. Ethnicity: not reported.	"Blue Angel for Asthma Kids" – an internet-based interactive asthma educational and monitoring program for children. Records asthma symptoms, medication use and lung function and provides information about asthma. Comprises an electronic diary, asthma action plan and a retrieval system to review data. Physician contacts family regarding changes to treatment management as necessary. Theoretical basis: none identified. Leadership: professional Control: traditional asthma care plan, information sheets and usual care.	Primary: none. Others: asthma symptom scores; peak expiratory flow; asthma monitoring and adherence; asthma knowledge; quality of life; satisfaction with intervention.	The intervention group reported decreased asthma symptoms; improved peak expiratory flow values; increased adherence; improved self-management knowledge; and improved quality of life. In addition it appeared to be a well-accepted technology.
Joseph et al., 2007 USA	RCT: 2 arms Randomisation : adequate Blinding: unclear ITT analysis: not reported. Length of follow-up: 12 months	314 children recruited, 273 completed the study. Gender of children: 63.4% female Sample mean age: 15.3 Ethnicity: 98% African-American	A web-based asthma management program ('Puff City') of individualised health messages based on users' beliefs, attitudes and personal barriers to change. Four computer sessions – asthma education, self-management of medications, trigger avoidance, smoking cessation. Tailored to individual and used at school. Theoretical basis: transtheoretical model and health belief model. . Leadership: professional Control: directed to generic asthma websites.	Primary: number of asthma symptom days. Others: number of asthma symptom nights; days of restricted activity; days of changed plans; school absences; asthma related emergency department visits; hospitalisation; quality of life; program costs.	The intervention group reported fewer symptom days, symptom nights, missed school days, restricted activity days and hospitalisations. Intervention group more frequently noted to have positive behaviour change (medication use and adherence). No differences found in relation to smoking reduction/cessation.
Krishna et al., 2003 USA	RCT: 2 arms Randomisation : unclear Blinding: healthcare providers. ITT analysis: conducted.	246 children recruited, 228 completed the study. Gender of parents: 88% female Gender of children: 35% female Sample mean age:	The Interactive Multimedia Program for Asthma Control and Tracking (IMPACT). Consists of vignettes to convey information about asthma and self-management (44 lessons). Aims to develop knowledge and decision making and communication skills of child. Accessed over the internet during clinic visits and takes on average 1 hour and 20 minutes to complete. Theoretical basis: none identified.	Primary: none Others: asthma knowledge; health outcomes (asthma symptoms, medication use, activity limitation, sleep disturbance; school absence); health service use (hospitalisation, urgent physician visits, ER visits); quality of life; satisfaction	The intervention increased asthma knowledge of children and parents, decreased asthma symptom days and ER visits. The intervention group used a significantly lower dose of steroids at 12 months.

	Length of follow-up: 12 months	not reported. Ethnicity (child): 86% Caucasian	Leadership: professional Control: usual care and asthma education (printed materials, teaching sessions with nurse, asthma action plan).	with program.	
Lozano et al., 2004 USA	RCT: 3 arms Randomisation : unclear Blinding of outcome assessors. ITT analysis: not reported. Length of follow-up: 2 years	Physicians in 42 primary care practices (one per practice) and 638 children enrolled in the practices recruited. 554 children completed the study. Gender of children: 40% female Sample mean age: 9.4 Ethnicity: 66% Caucasian No information provided on characteristics of physicians	Randomised practices to have peer leader education (asthma champion) with and without planned asthma care visits to families from a trained asthma nurse. Peer leader education comprised education about asthma and support in role as change agents in asthma management in the practice by coordinator. The planned visits were made by a trained asthma nurse specialist 4-5 times over two years. At each visit the nurse assessed asthma and self-management skills; supported care planning and development of self-management skills. Telephone support provided between visits. Theoretical basis: none identified. Leadership: professional Control: usual care (plus given copy of asthma guidelines and tool kit of asthma education materials).	Primary: none Others: asthma symptom days; medication use; possession of written care plans; asthma specific functional status.	Planned asthma care significantly reduced asthma symptom days and was more effective than peer leader education alone. Both interventions reduced use of steroids and had positive effects on 3 domains of functional health status.
McPherson et al., 2006 UK	RCT: 2 arms Randomisation : adequate Blinding: unclear ITT analysis: conducted. Length of follow-up: 6 months	101 children recruited, 90 completed the study. Gender of children: 46.5% female Sample mean age: not reported Ethnicity: 88.1% Caucasian	Interactive computer game 'The Asthma Files' that provides information about asthma, self-management and role play. Uses games, quizzes and problem solving tasks. Enter peak flow scores and triggers which produces a self-management plan. The game takes 90 minutes to complete over one or more sittings. Theoretical basis: none identified. Leadership: professional Control: usual care (plus given copy of an asthma information booklet used by the	Primary: asthma knowledge (only measured at one month follow-up) Others asthma locus of control; lung function; use of oral steroids; school absence.	At the one month follow-up the intervention was effective in increasing knowledge levels and feelings of control over asthma; there were no effects on PEF, school absences, GP visits, hospital admissions. At 6 months children in the intervention group had lower use of oral steroids and fewer school absences. However, an

			hospitals)		intention to treat analysis revealed that there were no significant differences between the groups.
Patterson et al., 2005 UK	RCT: 2 arms Randomisation : adequate Blinding: unclear ITT analysis: not reported. Length of follow-up: 15 weeks	22 primary schools and 176 children recruited; 173 completed the study. Gender: 48% female Sample mean age: not reported Ethnicity: not reported	School-based weekly asthma clubs for children provided education about asthma, self-management , including exercises to raise self-esteem and decrease anxiety. Eight sessions. Includes workbook, care pathway and action plan development. Theoretical basis: PRECEDE health education model. Leadership: professional Control: usual care, received the intervention at the end of the study.	Primary: quality of life. Others: Lung function (spirometry), inhaler technique.	The intervention improved inhaler technique but had no significant effect on spirometry results or quality of life scores.
Shah et al., 2001 Australia	RCT: 2 arms Randomisation : adequate Blinding: unclear ITT analysis: not reported. Length of follow-up: 3 months	272 children recruited (from six high schools), 251 completed the study. Gender: 54.6% female Sample mean age: not reported Ethnicity: not reported	School-based structured education programme led by peers (the "Triple A Program") designed to promote self management behaviours. In three schools student volunteers (year 11) trained as asthma peer leaders and conducted three 45 minute lessons for year 10 students looking at barriers to asthma management. The Year 10 students then present key messages learnt in these lessons to year 7 students using methods such as drama and music. In addition schools received information about asthma for staff and local doctors attended a workshop on adolescent asthma. Outcome measures were completed by a group of young people with asthma had previously been identified at the six school. Theoretical basis: none reported. Leadership: young people (peers). Control: not reported.	Primary: quality of life. Others: school absences; lung function.	Intervention group showed significant improvement in quality of life scores and significant reductions in school absenteeism. Effect of intervention was greatest in year 10 students and females.
Stevens et al., 2002	RCT: 2 arms Randomisation	200 children recruited, 177	Parents provided with an asthma education booklet, a written guided self-management plan,	Primary: GP consultation rates; hospitalisations; A&E	There were no statistically significant differences

UK	: adequate Blinding: providers only ITT analysis: not reported. Length of follow-up: 12 months	completed the study. Gender: not reported Sample mean age: not reported Ethnicity: not reported.	and two 20 minute structured educational sessions. The first of these was either on the ward prior to discharge or in clinic. The second was one month later in clinic. Theoretical basis: none reported. Leadership: professional Control: usual care	attendance. Others: asthma symptoms; quality of life; care givers knowledge of asthma; parental confidence in caring for child; parental management of asthma changes.	between the two groups for any of the outcomes.
Walders et al., 2006 USA	RCT: 2 arms Randomisation : unclear Blinding of outcome assessors ITT analysis: conducted. Length of follow-up: 12 months	175 'undertreated' children recruited, 124 completed the study (not clearly reported). Gender: 28% female Sample mean age: not reported Ethnicity: 85.1% African American.	Intervention comprised a written asthma plan; inhaler; peak flow meter; one month's supply of medication; one hour asthma education session; cognitive behavioural problem solving session tailored to individual family barriers to asthma management followed up 4 weeks later by a telephone consultation to reinforce problem solving strategies; access to a 24 hour nurse advice line. Theoretical basis: none reported. Leadership: professional Control: usual care; written asthma plan; inhaler; peak flow meter; one month's supply of medication.	Primary: change in asthma symptoms. Others: health care utilisation; quality of life.	The intervention group demonstrated less frequent health care utilisation. Both groups reported reductions in asthma symptoms and improvements in quality of life (no between group differences).
Wesseldine et al., 1999 UK	RCT: 2 arms Randomisation : adequate Blinding: unclear ITT analysis: conducted. Length of follow-up: 6 months	160 children recruited, 150 completed the study. Gender: 38.8% female Sample mean age: not reported Ethnicity: 85.1% African American	A structured nurse-led discharge package for children admitted with acute severe asthma. Comprised a 20 minute patient education session emphasising guided self-management; an individual self-management plan; asthma education booklet. Theoretical basis: none reported. Leadership: professional Control: usual care.	Primary: hospital readmission in the 6 months after discharge. Others: hospital reattendance without admission; GP consultations; school absences.	The intervention reduced readmission rates, attendance at A&E departments and visits to GPs for asthma.

STUDIES FOCUSING ON CYSTIC FIBROSIS					
Christian & D'Auria, 2006 USA	RCT, 2 arms. Randomisation : adequate Blinding: adequate ITT analysis: N/A Length of follow-up: 9 months	116 children recruited, 116 completed study. Gender of children: 49.2% female Sample mean age: 9.27 Ethnicity: 87.9%	The 'Building CF Life Skills' intervention is an educational problem solving and social skills programme for children aged 8-12. Delivered by an individual, tailored home visit followed by a structured, small group session 2 weeks later. Theoretical basis: based on previous qualitative work, developmental frameworks and social ecological theory. Leadership: professional Control group: usual care.	Primary outcome: none. Others: psycho-social adjustment, functional health status, physiological health status.	The intervention decreased perceived impact of illness and decreased loneliness.
Davis et al., 2004 USA	RCT: 2 arms Randomisation : adequate Blinding: unclear ITT analysis: N/A Length of follow-up: 2-3 months	47 children recruited and 47 completed study. Gender: 38.3% female Sample mean age: not reported. Ethnicity: not reported	The 'STARBRIGHT CD-ROM Program: Fitting Cystic Fibrosis into your Life Everyday'. Children viewed CD while at a clinic visit. The content focuses on eating, breathing and a question and answer element and takes 30 minutes to complete. Theoretical basis not reported. Leadership: professional. Control: usual care (waitlist control).	Primary outcome: none reported Others: knowledge of cystic fibrosis, coping skills, satisfaction.	The intervention increased knowledge of cystic fibrosis and the competence of coping strategies in children and adolescents.
Downs et al., 2006 Australia	RCT: 2 arms Randomisation : unclear Blinding: unclear ITT analysis conducted	65 families recruited, 43 completed study. Gender of children: 44.2% female Sample mean age: not reported.	'Airways': a self-management education programme. Information sheets about airway clearance techniques and aerosol administration posted to caregivers. 3 weekly telephone consultations over 9 weeks to answer questions. Theoretical basis not reported Leadership: professional	Primary outcome: none Others: adherence, care-giver self-management behaviours, child knowledge, child feelings about treatment regimens, care-giver self-efficacy.	The intervention had positive effects on adherence & child knowledge of airway clearance techniques (ACT). Trend towards increasing child positive feelings about implementing regular aerosol and ACT treatments

	Length of follow-up: 15 months	Ethnicity: not reported	Control group: usual care		but this was not significant. No effect on self-efficacy or self-management behaviours.
STUDIES FOCUSING ON DIABETES					
Cook et al., 2002 USA	RCT: 2 arms Randomisation : unclear. Blinding: not reported. ITT analysis conducted. Length of follow-up: 6 months.	53 children were recruited and 49 completed the study. Gender: 56.5% female. Sample mean age: not reported. Ethnicity: 85% Caucasian	A 6 week problem-solving diabetes education program ('Choices') which encourages young people to recognise and identify problems with their diabetes self-management and to generate solutions. Group based approach where participants attend two hourly weekly sessions. Theoretical basis not reported. Based on previous study that identified problems adolescents faced in managing diabetes. Leadership: unclear. Control group: standard care.	Primary outcome: none reported. Others: Problem solving skills; self-management responsibility; HbA1c level (glycaemic control); diabetes management style hospitalisations; family relationships.	The intervention resulted in better problem-solving skills, more frequent blood glucose testing, and improved HbA _{1c} . when comparing baseline and post-program scores for the intervention group. However there were no significant differences between control and intervention group for diabetes responsibility scores, problem solving scores or HbA _{1c}
Ellis et al., 2005; 2007 USA	RCT: 2 arms Randomisation : unclear. Blinding: unclear. ITT analysis conducted. Length of follow-up: 7 months.	127 children with poorly controlled Type 1 diabetes. were recruited and 110 completed the study. Gender: 51.2% female. Sample mean age: unclear Ethnicity: 63% African American.	Multisystemic therapy – an intensive, home-based psychotherapy intervention. Tailored goals and interventions are developed for each family following a multisystemic assessment. Delivered by trained therapists 2-3 times a week for 6 months. Targets adherence related problems within family, peer group and community. Components aimed at the school, community and health care system as well as the family. Theoretical basis not reported. But reported to draw upon CBT, parent training and behavioural family systems therapy. Leadership: professional. Control: standard medical care.	Primary outcome: none reported. Others: Adherence; HbA1c level (glycaemic control); hospitalisations; family relationships.	The intervention improved frequency of blood glucose testing, decreased hospital admissions and improved glycaemic control. It improved family relationships for young people in two-parent but not in single parent families.

Franklin et al., 2006 UK	RCT: 3 arms Randomisation : adequate Blinding: not reported ITT analysis conducted. Length of follow-up: 12 months	92 children were recruited and 78 completed the study. Gender: 46.2% female. Sample mean age: not reported Ethnicity: 96.7% Caucasian	Sweet Talk: a text-messaging support system. Daily text message are sent to reinforce self-management goals set in clinic. A weekly message reminder of goals set is also sent by text. Occasional text newsletters are sent about topical diabetes issues. One group received Sweet Talk with conventional insulin therapy and another Sweet Talk with intensive insulin therapy. Control: usual care and conventional insulin therapy. Theoretical basis: social cognitive theory. Leadership: professional.	Primary outcomes: HbA1c level (glycaemic control) and behavioural change. Others: episodes of ketoacidosis; severe hypoglycaemia; BMI; health service utilisation, satisfaction	Sweet Talk with intensive insulin therapy improved HbA _{1c} . Both Sweet Talk groups showed improved self-efficacy, self-reported adherence, and social support from the diabetes team.
Grey et al., 2000 USA	RCT: 2 arms Randomisation : unclear. Blinding: adequate. ITT analysis: not reported. Length of follow-up: 12 months.	77 young people were recruited and 75 completed the study. Gender: 57% female. Sample mean age: not reported Ethnicity: 92% Caucasian.	Coping skills training in combination with intensive diabetes management (IDM). Coping skills training aims to increase sense of competence and mastery. Role playing of scenarios that exemplify difficult social situations and discussion of appropriate problems solving and coping skills. Small groups led by a trainer. Six sessions once a week for six weeks lasting 1.5 hours. Theoretical basis not reported. Leadership: professional. Control: intensive diabetes management only.	Primary outcome: none reported. Others: HbA1c level (glycaemic control); self-efficacy; depression; quality of life; difficult diabetes-related issues; hypoglycaemia events; weight/height; insulin dosage; self-monitoring of blood glucose.	The intervention resulted in improved metabolic control and quality of life; increased self-efficacy and in females decreased weight gain and hypoglycaemia.
Murphy et al., 2007 UK	RCT: 2 arms Randomisation : unclear. Blinding: not reported. ITT analysis	78 children were recruited and 67 completed the study. Gender: % unclear. Sample mean age:	A family-centred structured education programme. Four small group sessions each lasting one hour at 3 month clinic visits. Two sessions are skills based and two are about communication and child-parent responsibilities. 3-5 families attend sessions. Theoretical basis: some elements based on social	Primary outcome: none reported. Others: HbA1c level (glycaemic control); quality of life; family responsibility.	No significant difference in HbA _{1c} , parental responsibility or quality of life between the two groups.

	conducted Length of follow-up: 12 months	unclear. Ethnicity: not reported.	learning theory. Leadership: professional. Control: wait-list.		
Nunn et al., 2006 Australia	RCT: 2 arms Randomisation : adequate Blinding: not reported ITT analysis: not reported Length of follow-up: 7 months	139 children with poorly controlled Type 1 diabetes were recruited. 123 completed the study. Gender: 44% female. Sample mean age: 11.9 Ethnicity: 100% Caucasian.	Twice a month for 7 months scheduled telephone calls were made by a paediatric diabetes educator to children (parents included if 11 years or younger). Lasted 15-30 minutes and covered 3 topics (insulin, diet and blood glucose levels; current events; educational programme about diabetes). Theoretical basis not reported. Leadership: professional. Control: usual care.	Primary outcome: HbA1c level (glycaemic control). Others: hospitalisations; knowledge of diabetes, compliance, psychological functioning.	The intervention did not improve HbA1c level, admission rates, diabetes knowledge, psychological function or self-management. Mean HbA1c levels and number of admissions in both groups increased
Svoren et al., 2003 USA	RCT: 3 arms Randomisation : unclear. Blinding of outcome assessors. ITT analysis not reported Length of follow-up: 2 years.	301 children were recruited and 299 completed the study. Gender: 57% female. Sample mean age: not reported Ethnicity: not reported.	A case manager (called a "Care Ambassador") was assigned to families to help them with appointment scheduling, health insurance issues, monitor their clinic attendance and provide follow-up of missed appointments. One group received only 'Care Ambassador' support (CA) and one group received 'Care Ambassador' and 8 psycho- educational modules relating to diabetes (CA+) over the course of 2 years. Delivered in hospital setting. Control: standard care. Theoretical basis not reported. Leadership: professional (trained graduates).	Primary outcome: none reported. Others: HbA1c level (glycaemic control); frequency of hypoglycaemia; hospitalisations.	The CA+ intervention compared with the other 2 groups improved glycaemic control in "high-risk" young people and reduced hypoglycaemic events and hospital utilisation. Both interventions increased frequency of routine medical visits.

Wysocki et al., 2001 USA	RCT: 3 arms Randomisation : unclear. Blinding: not reported. ITT analysis: not reported. Length of follow-up: 12 months.	119 families were recruited and 108 completed the study. Gender: 57.1% female. Sample mean age: 14.3. Ethnicity: 79% Caucasian	Behavioural –Family Systems Therapy (BFST) comprises four therapeutic components – problem-solving training, communication skills training, cognitive restructuring and family therapy. Families received an individualised treatment plan. Attend 10 sessions (length of sessions not reported) and complete homework tasks. Theoretical basis: not reported. Leadership: professional Second intervention group received education and support (ES) – ten group meetings (90 minutes) of 2-5 families that provided diabetes education and support. Control: Standard care.	Primary outcome: none reported. Others: parent-adolescent relationship; adjustment to diabetes; adherence; glycaemic control.	BFST improved parent- adolescent relationships and adherence but had no effect on adolescents' adjustment to diabetes or diabetic control. [N.B. the 3 groups differed significantly at baseline].

Appendix 2.5 Quality of the Effectiveness Studies

Author(s) & country	Randomisation	Concealment	Blinding	Sample Size Use of Power Calculation	Comparability of groups at baseline	Length of Follow-up and attrition	ITT
MTA Cooperative Group, 1999, 2004 USA	Adequate	Adequate	Not reported	540 Yes	Comparable apart from age. Age of medical management intervention group 0.3 years older than behavioural management intervention group.	14 months 540/579 completed (93.3%)	Conducted
Sonuga-Barke et al., 2001 UK	Unclear	Unclear	Adequate	71 Yes	Not reported	15 weeks 71/78 completed (91%)	Conducted
Cano-Garcinuna et al., 2007 Spain, Cuba and Uruguay	Adequate	Unclear	Not reported	223 Yes	Not reported	6 months 223/245 (91%)	Conducted

Cicutto et al., 2005 Canada	Adequate	Adequate	Not reported	239 Not reported	Yes	12 months 236/265 (89.1%)	Conducted
Clark et al., 2000 USA	Unclear	Not reported	Adequate	67 (Doctors 369 children) Unclear	Not reported	2 years 67/74 (Doctors) (90.5%) 369/637 (children) (57.9%)	Not reported
Dolinar et al., 2000 Canada	Adequate	Not reported	Unclear	40 Yes	Yes	3 months 40/45 (88.9%)	Not reported
Evans et al., 1999; Sullivan et al., 2002 USA	Adequate	Unclear	Adequate	961 Yes	Yes	2 years 961/1033 (93%)	Not reported
Guendelman et al., 2002; 2004 USA	Adequate	Not reported	Unclear	128 Yes	Yes	12 weeks 128/134 (95.5%)	Conducted

Jan et al., 2007 Taiwan	Adequate	Adequate	Unclear	164 Yes	Yes	12 weeks 164/179 (91.6%)	Not reported
Joseph et al., 2007 USA	Adequate	Not reported	Unclear	273 Not reported	Yes	12 months 273/314 (86.9%)	Not reported
Krishna et al., 2003 USA	Unclear	Not reported	Adequate	228 Yes	Yes	12 months 228/246 (92.7%)	
Lozano et al., 2004 USA	Unclear	Not reported	Adequate	554 Yes	Yes	2 years 554/638 (86.8%)	Not reported
McPherson et al., 2006 UK	Adequate	Adequate	None	90 Yes	Intervention group significantly older and had higher levels of asthma knowledge	6 months 90/101 (89%)	Conducted
Patterson et al., 2005 UK	Adequate	Not reported	Not reported	173 Yes	Not reported	15 weeks 173/176 (98.3%)	Not reported

Shah et al., 2001 Australia	Adequate	Adequate	Unclear	251 Not reported	More females in the intervention group	3 months 251/272 (92.3%)	Not reported
Stevens et al., 2002 UK	Adequate	Adequate	Adequate	177 Yes	Yes	12 months 177/200 (88.5%)	Not reported
Walders et al., 2006 USA	Unclear	Not reported	Adequate	124 Yes	Yes	12 months 124/175 (70.6%)	Conducted
Wesseldine et al., 1999 UK	Adequate	Not reported	Unclear	150 Yes	Yes	6 months 150/160 (93.8%)	Conducted
Christian & D'Auria, 2006 USA	Adequate	Adequate	Adequate	116 Yes	Yes	9 months 116/116 (100%)	Not applicable
Davis et al., 2004 USA	Adequate	Adequate	Not reported	47 Not reported	Yes	2-3 months 47/47 (100%)	Not applicable

Downs et al., 2006 Australia	Unclear	Unclear	Unclear	43 Yes	Yes	15 months 43/65 (66.2%)	Conducted
Cook et al., 2002 USA	Unclear	Unclear	Not reported	49 Not reported	Yes	6 months 49/53 (92.5%)	Conducted
Ellis et al., 2005; 2007 USA	Unclear	Adequate	Unclear	110 Yes	Comparable apart from there being significantly more males on one of the intervention groups.	7 months 110/127 (86.6%)	Conducted
Franklin et al., 2006 UK	Adequate	Adequate	Not reported	78 Yes	Yes	12 months 78/92 (84.8%)	Conducted
Grey et al., 2000 USA	Unclear	Unclear	Adequate	75 Not reported	Yes	12 months 75/77 (97.4%)	Not reported
Murphy et al., 2007 UK	Unclear	Adequate	Not reported	67 Not reported	Not reported	12 months 67/78 (85.9%)	Conducted

Nunn et al., 2006 Australia	Adequate	Unclear	Not reported	123 Yes	Yes	7 months 123/139 (88.5%)	Not reported
Svoren et al., 2003 USA	Unclear	Not reported	Adequate	299 Not reported	Yes	2 years 299/301 (99.3%)	Not reported
Wysocki et al., 2001 USA	Unclear	Unclear	Not reported	108 No reported (possibly some calculation of power during analysis)	Significant differences in relation to demographic characteristics and outcome measures at baseline. More lone parents on one intervention group. Divorce rate lower in control group. Higher levels of conflict and poorer adaptation to diabetes in one intervention group.	12 months 108/119 (90.8%)	Not reported

Appendix 2.6 Stage Two Data Extraction Form

Publication

Authors:

Title:

Year: _____ Country: _____

Journal Title: _____

Condition(s)

(please circle all that apply)

Asthma ADHD

Diabetes CF

Generic

Approach

Qualitative Quantitative (survey)

Qualitative and quantitative Other _____

If qualitative is a particular methodology used (e.g ethnography, grounded theory, phenomenology)

Study participants and number (ie sample size):

(please circle all that apply)

Child/young person ___ Peers ___

Parents ___ Professionals ___

Siblings ___

Other *(please state)* _____

Data collection method

(please circle all that apply)

Postal q/n Focus group interviews

Telephone q/n Observation

Individual interviews Diaries/documents

Other (chat rooms etc) _____

Brief description of type of self-care support investigated

Participants' Views of Self-Care Support (key messages)

CRITERIA	YES	NO	UNSURE
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Are the aims and objectives clearly stated?			
Is the research design clearly specified and appropriate for the research aims?			
Is there a clear description of context?			
Is there a clear description of sampling and recruitment?			
Is there a clear account of the process by which the findings have been produced?			
Is there a clear description of the methods of data collection and analysis?			
Do the researchers display enough data to support their interpretations and conclusions?			
Have attempts been made to establish 'reliability' and 'validity' of analysis (appropriate to methodology)?			

Include in review? Yes No Unsure

Appendix 2.7 Characteristics of Included 'Views' Studies

Study	Self-care intervention	Sampling and Sample Characteristics	Data Collection	Data Analysis Approach	Main Findings	Quality criteria met
<p>Anderson (1997)</p> <p>Canada</p> <p>Diabetes</p> <p>Aims:</p> <p>To describe the level of satisfaction of adolescents with the diabetes education programme.</p> <p>To assess resource use utilisation by adolescents.</p> <p>To describe the health profile of adolescents receiving the diabetes education programme.</p>	<p>Education programme for children and parents to support self-management . Delivered in a hospital setting. Three monthly consultations for first year after diagnosis followed by individualised scheduling appointments.</p> <p>[Little information on intervention provided]</p> <p>Theoretical basis: none identified</p> <p>Leadership: professional</p>	<p>100 young people meeting inclusion criteria and who had attended the programme sent postal questionnaire. 22 completed questionnaires returned (22% response rate).</p> <p>Sample characteristics:</p> <p>Age range: 13-17 years</p> <p>Gender: not reported.</p> <p>Social Class: not reported.</p> <p>Ethnicity: not reported</p>	<p>Postal survey collected young people's views and satisfaction with the programme using closed and open questions.</p> <p>[In addition a chart audit was used to collect data on health service utilisation and health outcomes]</p>	<p>Descriptive and inferential statistics.</p>	<p>Young people reported that the information provided was useful for self-management. They felt that they were listened to by staff who were receptive to their needs and felt able to ask questions. Young people who were interested in learning about their diabetes had a lower glycated haemoglobin.</p>	<p>ACD</p>

<p>Bruzzese et al. (2004)</p> <p>USA</p> <p>Asthma</p> <p>Aims: To establish the feasibility of delivering ASMA. To receive feedback regarding the sessions.</p>	<p>Asthma self-management for adolescents (ASMA) – a school based 5 week programme consisting of three group workshops, one-to-one coaching and weekly checklists relating to symptoms, medication use, triggers and activities.</p> <p>Theoretical basis: self-regulation theory</p> <p>Leadership: professional</p>	<p>Part of a pilot RCT of the self-care intervention. 14 young people in the pilot treatment arm (n=23) participated in this study. This was the total number attending the 3rd group workshop.</p> <p>Sample characteristics:</p> <p>Age range: not reported ('9th and 10th grade')</p> <p>Gender: not reported.</p> <p>Social Class: not reported</p> <p>Ethnicity: not given</p>	<p>Survey of participant's views via a questionnaire completed at the workshop. ? all closed questions</p>	<p>Descriptive statistics</p>	<p>Majority of young people reported that the workshops were enjoyable and helpful in terms of helping them to understand their condition and how to manage it. The majority also found the one-to-one coaching and checklists helpful (though less than the workshops).</p>	<p>ABG</p>
<p>Carroll et al. (2007)</p> <p>USA</p> <p>Diabetes</p> <p>Aims</p>	<p>Mobile phone used for glucose monitoring with transfer of readings to a website for review by young people, parents and clinicians and use in self-management. Young people also able to use phone to discuss self-management with clinicians.</p> <p>Theoretical basis: none</p>	<p>10 young people from a larger sample who had been involved in developing the system and testing it for 3 months. Parents involved also in learning to use the system.</p> <p>Sample characteristics:</p>	<p>Survey (postal?) of young people using open and closed questions to assess views on usability, satisfaction and impact on relationships with others.</p>	<p>Descriptive statistics.</p>	<p>Young people liked the system, found it easy to use and helpful with their self-management. Positive regarding impact on relationships at school but negative about impact on relationships with parents (no further details given).</p>	<p>ABG</p>

To evaluate user satisfaction with the system.	cited Leadership: professional	Age range: 13-18 years (mean 15.5) Gender: 50% female. Social Class: not reported Ethnicity: 80% Caucasian				
Gammon et al. (2005) Norway Diabetes Aims Obtain user insights into the appropriateness of the concept, feasibility of use in daily life and desired system functionality. Obtain indications of relevant approaches for future developments of monitoring and messaging systems for self-management.	Mobile phone technology used to send blood glucose readings from a glucose monitor to children's and then onto parent's phones via text messaging. Aims to reduce parental anxiety about child's self-management, encourage independence and reduce conflict. Theoretical basis: none cited Leadership: professional	All 55 families of children with diabetes at one hospital were invited to participate in the study. The first 15 families wishing to participate were recruited. 15 young people then used the system for 4 months. Sample characteristics: Age range: 9-15 years Gender: 26% female. Social Class: not reported Ethnicity: not reported	Survey of parent's and children's views. Separate questionnaires completed by all parents and children (n=30). 10 parents from 9 families took part in semi-structured interviews. Young people were not interviewed.	Descriptive statistics used to analyse questionnaire data. No specific approach to analysis of qualitative data analysis cited. Generic thematic analysis.	Both parents and children liked the automatic transferral of measurements which was used when children were at school or away from home. Children were divided on whether they wanted to decide about having readings automatically sent to parents. Most parents did not want children to make this decision and this was supported by the interview data. Parents felt reassured knowing whether or not children were monitoring their diabetes and that they could intervene if there were problems. Some aware that they were nagging their children more. Parents continued to experience difficulties encouraging children's independence and their own desire to ensure children's health. For older children the system appeared to create additional tensions with parents. Seen as facilitating learning. None of the parents felt the system would be helpful in interactions with professionals.	ABCDEFGF

Johnson et al. (2001) USA Cystic fibrosis Aims To explore issues concerning the creation and maintenance of an electronic support group (ESG). In particular to examine the impact of such a group on adolescents' perceptions of their disease, their peer support and their assessment of the usefulness of ESGs.	'Teen Central' – an internet support group for young people that provides condition related information and social support Theoretical basis: none cited Leadership: professional	37 young people aged 13-18 years approached at a CF clinic. 18 recruited to the study. Sample characteristics: Age range: 13-18 years Gender: not reported Social Class: not reported Ethnicity: not reported	Two stages: (1) Survey of young people's views on support received from peers and HCPs; CF knowledge; views on potential value of Teen Central in providing support. Survey conducted before and after accessed the website. (2) Focus group of 9 young people and 5 parents about views on Teen Central	Survey analysed using descriptive and inferential statistics. No details provided on how Focus Group data were analysed	Young people valued having contact with other young people with CF to discuss both typical adolescent issues as well as ones relating to CF. Some young people experienced technical difficulties with accessing the website. Parents were concerned about how often young people used the site and some were concerned that it was diverting them homework and other activities. There was some indication from the survey that it changed young people's perception of the value of peer support Analysis of survey data found that there was no increase in knowledge following use of Teen Central	ABC
Nordfeldt and Ludvigsson (2002) Sweden Diabetes	Education programme involving self-study materials (booklets and videos) regarding self-management and prevention of hypoglycaemia. Not clearly stated if aimed at parents and/or children or whether different materials were developed for	Two samples 112 asked to comment on the booklets with responses received from 73 (25 young people; 29 young people and parents together; 19	Postal survey using questionnaire with open and closed questions.	Descriptive and inferential statistics.	The video was found to be valuable with the majority finding the information provided clear and useful. Negative comments related to the lack of use of older adolescents in the videos, lack of provision of new information. It was felt that it would be most useful close to the time of diagnosis. The booklets were reported to have been read but no further data is reported from this part of the study.	ACG

<p>Aims</p> <p>To study the use of self-study material aimed at preventing hypoglycaemia.</p> <p>To compare the incidence of severe hypoglycaemia before and after the intervention.</p>	<p>different groups.</p> <p>Theoretical basis: none cited</p> <p>Leadership: professional</p>	<p>parents).</p> <p>120 asked to assess the videos and responses received from 89 families (no breakdown given). Unclear if overlap of samples.</p> <p>Sample characteristics (video group):</p> <p>Age range: mean age 11.6</p> <p>Gender: not reported</p> <p>Social Class: not reported</p> <p>Ethnicity: not reported</p>				
<p>Trollvik and Severinsson (2005)</p> <p>Norway</p> <p>Asthma</p> <p>Aims</p> <p>To illuminate the influence of an asthma education programme for</p>	<p>One day group education programme for parents. Partly peer led. Provided information on asthma and its management and peer networking.</p> <p>Theoretical basis: none cited</p> <p>Leadership: professional (one session given by a peer)</p>	<p>5 families (9 parents) with children aged 2-6 years purposefully sampled from parents attending the asthma education programme.</p> <p>Sample characteristics</p> <p>Age range (children): 2-6 years</p> <p>Gender of</p>	<p>Semi-structured interviews conducted with families mainly in the home. Unclear if parents were interviewed separately or together. One family was a lone parent family.</p>	<p>Qualitative content analysis informed by phenomenology</p>	<p>Parents felt that they had an increased understanding of their child's condition (medication and asthma triggers). They valued being able to share their experiences with other parents and would have liked more meetings for this. Others aspects valued were the written information provided that could be referred to after the course; the involvement of known HCPs; how it was targeted at both parents which meant that both could then share responsibility for managing their child's condition.</p>	<p>ABCDEFGF</p>

parents. To explore to what extent the educational programme met their needs.		children/parents: not reported Social Class: not reported Ethnicity: not reported				
Van der Meer et al. (2007) Netherlands Asthma Aims To reveal intrinsic barriers to current asthma management To explore the barriers and benefits of internet based self-management in patients with good and poor asthma control.	Internet based lung function and symptom monitoring system for self-management by young people. Theoretical basis: none cited Leadership: professional.	56 young people aged 12-17 years who had been using the system for one month were invited participate in the study. 35 recruited. Sample characteristics Age range: 12-17 years: Gender: 51.4% female Social Class: not reported Ethnicity: not reported	Eight focus groups lasting 1-1.5 hours. 4-8 participants per group.	Content analysis using predetermined and data driven inductive categories. Data also quantitatively analysed.	Young people saw the system as a feasible way of monitoring their condition but felt that they knew themselves if their condition was worsening without measuring their lung function. They found the information provided accessible and they liked being able to review their lung function tests. The ability to communicate via email and the electronic consultation was seen as useful. The majority of those with well controlled asthma saw no need to complete electronic action plans. This was in contrast to poorly controlled young people who valued these plans. This latter group also reported limited perceived ability to control their asthma.	ABCDEF

- A: Aims of the study clearly stated
- B: Context for the study adequately described
- C: Specification of the research design is clearly described and is appropriate for research aims
- D: Clear details of the sample and how it was recruited reported
- E: Clear description of data collection and data analysis provided
- F: Attempts to establish rigour of data analysis made
- G: Sufficient original data included to support interpretations and conclusions.

Appendix 2.8 Summary of the Characteristics of Self-care Support Interventions of Studies Included in the Review

Study	Theoretical/ philosophical basis	Target	Location	Leadership	Type (Group and/ or one-to-one delivery or self-directed)	Key Aims (themes)	Medium	Individualisation
MTA (1999, 2004)	Not stated	Children, parents and professionals	Home and school	Professional	Combination	Behaviour management. Social skills. Family relationships.	Parent training via individual and group work. Child therapy at a summer camp Teacher support. Medication management.	Yes
Sonuga-Barke et al. (2001)	Not stated	Parents	Home/ community	Professional	One-to-one	Behaviour management Education	Parent training – individual visits, diary.	Yes
Cano-Garcinuna et al. (2007)	Not stated	Children and parents	Home/ community	Professional	Group	Education Self-management	Group education. Information sheets.	No

Cicutto et al. (2005)	Social cognitive theory, self regulation theory	Children and parents	School	Professional	Group	Education Self-management	Group education, role play and discussion. Homework activities with parents.	Possible
Clark et al. (2000)	Self regulation theory	Professionals	Unclear	Professional	Group	Partnership working with patients. Self-management support.	Interactive seminars – lectures on latest guidelines and group work regarding communication.	Possible
Dolinar et al. (2000)	Not stated	Parents	Home/ community	Professional	One-to-one	Education	Educational session in the home, written booklet.	No
Evans et al. (1999); Sullivan et al. (2002)	Not stated	Children and parents	Home/ community	Professional	Combination	Education Problem solving Communication with HCPs	Group work One individual meeting and follow-up phone calls. Environmental intervention e.g. pillow/mattress covers. Primary care physician sent asthma management tools.	Yes
Guendelman et al. (2002, 2004)	Not stated	Children	Home/	Professional	One-to-one	Education	Computer program and	Yes

			community			Self-management	website for symptom monitoring; information. Daily review and communication by nurse specialist.	
Jan et al. (2007)	Not stated	Children	Home/ community	Professional	One-to-one	Education Self-management	Internet based symptom monitoring site; action plan, information. Daily review and communication by physician.	Yes
Joseph et al. (2007)	Trans-theoretical and health belief models	Children	School	Professional	Self-directed	Education	Computer program – information on asthma and its management.	Yes
Krishna et al. (2003)	Not stated	Children and parents	Hospital	Professional	Self-directed	Education Self-management	Computer program – information about asthma and its management. Scenarios for problem solving.	No
Lozano et al. (2004)	PRECEDE health education model	Children, parents and professionals	Home/ community	Professional	Children and parents - One-to-one. Professionals - Combination	Primary care improvement strategy consisting of: (1) Peer leader education (primary care) (2) Planned care – specialist nurse	Workshops to train peer leaders, support from coordinator and learning network. Toolkits for practices. Nurses trained in self management support.	Possible

						supports families and primary care practices		
McPherson et al. (2006)	Not stated	Children	Home/ community	Professional	Self-directed	Education Self-management	CD-ROM Information booklet	Yes
Patterson et al. (2005)	PRECEDE health education model	Children	School	Professional	Group	Education Self-management	Group education Workbook Action plan	Possible
Shah et al. (2001)	Not stated	Children	School	Peer	Group	Education (those with & without asthma in two year groups)	Workshop to train peer leaders. Peer leaders and other peers deliver educational sessions (using drama, music etc)	No
Stevens et al. (2002)	Not stated	Parents	Hospital	Professional	One-to-one	Education Self-management	Information booklet. Self-management plan. Structured educational sessions.	Yes
Walders et al. (2006)	Not stated	Children and parents	Hospital	Professional	One-to-one	Education Problem solving	Self-management plan. Asthma education and problem solving	Yes

							sessions. Telephone support.	
Wesseldine et al. (1999)	Not stated	Children and parents	Hospital	Professional	One-to-one	Education Reduce hospitalisation	Education session. Self-management plan. Information booklet.	Yes
Christian and D'Auria (2006)	Developmental and social ecological theories	Children	Home and hospital	Professional	Combination	Life skills Psychosocial adjustment Peer relationships.	Individualised information via written materials, activities and computer program. Group work for problem solving & social skills training.	Yes
Davis et al. (2004)	Not stated	Children	Hospital	Professional	Self-directed	Education. Coping strategies	CD-ROM	None
Downs et al. (2006)	Not stated	Children and parents	Home/ community	Professional	Self-directed study	Self-management Adherence Education	Written information and exercises Parents telephoned every three weeks to answer questions and encourage participation.	None

Cook et al. (2002)	Not stated	Children	Unclear	Professional	Group	Problem solving. Self-management	Group activities to discuss and demonstrate problem solving. Workbooks.	Some – problems and solutions generated by group but programme is structured by a manual.
Ellis et al. (2005, 2007)	Not stated	Children and parents	Home/ community	Professional	One-to-one	Family relationships Adherence. Glycaemic control.	Family therapy (incl. CBT, discipline systems). Also components focusing on school and health services.	Yes
Franklin et al. (2006)	Social Cognitive Theory	Children	Home/ community	Professional	N/A	Self-efficacy Self-management Glycaemic control.	Self-management support via automatic text messaging of goals and information.	Yes
Grey et al. (2000)	Not stated	Children	Unclear	Professional	Group	Coping skills Glycaemic control	Group role playing exercises and modelling of appropriate behaviour.	Possible.
Murphy et al. (2007)	Social Learning Theory	Children and parents	Hospital	Professional	Group	Parent-child responsibility for condition management Glycaemic control	Group work – education, activities and discussion.	Possible
Nunn et al. (2006)	Not stated	Children and	Home/	Professional	One-to-one	Self-	Telephone	Yes

		parents	community			management. Education.	education and support for self-management.	
Svoren et al. (2003)	Not stated	Children and parents	Hospital	Professional	One-to-one	Care coordination. Education.	Care coordinator. Written teaching modules.	None (educational element). Care coordinator helped families with appointments and insurance.
Wysocki et al. (2001)	Not stated	Children and parents	Unclear	Professional	One-to-one	Parent-child relationships. Adjustment. Adherence. Glycaemic control.	Family therapy (problem-solving, communication skills, cognitive restructuring).	Yes
Anderson et al. (1997)	Not stated	Children and parents	Hospital	Professional	One-to-one	Education Self-management	Individual educational sessions	Yes
Bruzzese et al. (2004)	Self-regulation theory	Children	School	Professional	Combination	Education Self-management	Group workshops. One to one coaching; checklists.	Yes
Carroll et al. (2007)	Not stated	Children and parents	Home/ community	Professional	One-to-one	Self-management	Mobile phone technology; internet;	Yes

							telephone support	
Gammon et al. (2005)	Not stated	Children and parents	Home/ community	Professional	N/A	Parental anxiety reduction. Child independence. Conflict reduction	Mobile phone technology to transfer monitoring information between child and parent.	No
Johnson et al. (2001)	Not stated	Children	Home/ community	Professional	Group	Social support; Education	Internet support group	Possible
Nordfeldt and Ludvigsson (2002)	Not stated	Unclear	Home/ community	Professional	Self-study	Education Self-management	Self study materials – booklets and videos.	No
Trollvik and Severinsson (2005)	Not stated	Parents	Hospital	Professional (some peer involvement)	Group	Education Social networking.	One day group workshop.	Possible
Van der Meer et al. (2007)	Not stated	Children	Home/ community	Professional	Self-directed	Self-management	Internet symptom monitoring system.	No

Appendix 2.9 Synthesis Matrix

Views on Models of Self-Care Support	'Sound' Effectiveness Studies	Other Effectiveness Studies
<p>Models that involve groups provide social support to young people with long-term conditions and their parents</p> <p>v1, v2, v3, v4, v5, v6, v7</p>	<p>The 'Building CF Life Skills' intervention is an educational problem solving and social skills programme for children aged 8-12 that is delivered by a combination of group work and a tailored home visit. It was associated with reducing children's feelings of loneliness and their perceptions of the impact of illness on their lives (E1). However, the intervention had no effect on perceived support from peers/classmates.</p> <p>A school based asthma education program: "Roaring Adventures of Puff" which included six 50-60 minute weekly groups sessions was found to be effective in increasing children's quality of life (E2).</p> <p>No studies have measured social support as an outcome apart from E1.</p>	<p>No studies have measured social support as an outcome</p> <p>A school-based structured asthma education programme led by peers (the "Triple A Program") which included group discussion on the barriers to asthma management was found to be effective in improving quality of life. The intervention was though more related to improving awareness and acceptance of asthma within the general school population (E3).</p> <p>A coping skills training programme (in combination with intensive diabetes management) that involved young people attending six, weekly group sessions was associated with increasing their quality of life (E4).</p>
<p>Models that involve groups help young people and parents learn about their long-term condition</p> <p>V2, v5, v6</p>	<p>No studies with a group-based component have included knowledge as an outcome measure.</p>	<p>No studies with a group-based component have included knowledge as an outcome measure</p>

<p>Models that involve groups help young people/parents self-manage their condition</p> <p>V2, v5, v6</p>	<p>A school based asthma education program: "Roaring Adventures of Puff" which included six 50-60 minute weekly groups sessions was found to be effective in increasing children's self-efficacy and improving their health status (days disrupted by asthma, urgent health care visits, school absences) (E2).</p> <p>The National Cooperative Inner-City Asthma Study that evaluated the effectiveness of a multi-component intervention included group sessions for both parents and children. The intervention was associated in improving children's health status (reductions in asthma symptom days and hospitalisations). (E5)</p>	<p>School-based weekly asthma clubs for children that provided group based education about asthma and self-management as well as exercises to raise self-esteem and decrease anxiety were found to be effective in improving children's inhaler technique. (E6)</p> <p>A coping skills training programme (in combination with intensive diabetes management) that involved young people attending six, weekly group sessions was associated with improving health status (improved glycaemic control) and self-efficacy (E4).</p> <p>A 6 week problem-solving diabetes education program ('Choices') was designed to encourage young people to recognise and identify problems with their diabetes self-management and to generate solutions. Group based approach where participants attend two hourly weekly sessions. The intervention was found to increase the frequency of blood glucose testing. (E7)</p>
<p>Models that involve groups improve young people's communication skills</p> <p>V5, v7</p>	<p>No studies have measured communication skills as an outcome.</p> <p>In a study focusing on children with ADHD (E8) the intervention was associated with increasing children's social skills.</p> <p>Social skills (including communication skills) are an under-researched outcome in this body of research.</p>	<p>No studies have measured communication skills or social skills as an outcome.</p>

<p>Models that use e-health are seen as feasible and as being an appropriate method of self-care support for young people</p> <p>V8, v9, v10, v11</p>	<p>Studies that obtained participant views on e-health methods report them to be acceptable to young people (E9, E10, E11, E12, E13).</p>	<p>One study reported that young people found the e-health method acceptable (E15)</p>
<p>Models that use e-health enable self-management</p> <p>V8, v9, v10</p>	<p>An interactive computer game 'The Asthma Files' that provides information about asthma, self-management and role play and uses games, quizzes and problem solving tasks was found to increase children's asthma related knowledge (at one month follow-up), increase locus of control and improve health status (decreased use of oral steroids and school absences.(E9). However, there were no significant differences between the intervention and control group when an intention to treat analysis was conducted.</p> <p>An evaluation of 'Health Buddy' a personal and interactive communication device which sends daily questions to children about asthma symptoms, peak flow readings and use of medications and health services and responds to their answers found that it was effective in improving their health status (reduced limitations in activities, improved lung function, reduced urgent calls to hospital) and adherence. (E10). However, the intervention only appeared to have a short term effect because at 12 weeks post intervention there was no difference between the control and intervention group.</p> <p>"Blue Angel for Asthma Kids" is an internet-based interactive asthma educational and monitoring program for children that records asthma symptoms, medication use and lung</p>	<p>A web-based asthma management program ('Puff City') of individualised health messages based on users' beliefs, attitudes and personal barriers to change was associated with improvements in health status (fewer symptom days, symptom nights, missed school days, restricted activity days and hospitalisations) (E14).</p> <p>The Interactive Multimedia Program for Asthma Control and Tracking (IMPACT) which consists of vignettes to convey information about asthma and self-management and is accessed by children and parents (if child aged 0-6 years) over the internet during clinic visits was found to increase asthma knowledge and improve health status (reductions in asthma symptom days and visits to ER) (E15).</p>

	<p>function and provides information about asthma. In addition it includes an electronic diary, asthma action plan and a retrieval system to review data; physicians contact families if changes are needed to asthma management. It was found to be effective in improving health status (reducing asthma symptoms, improving lung function) as well as increasing self-management knowledge and adherence (E11).</p> <p>An evaluation of the 'STARBRIGHT CD-ROM Program: Fitting Cystic Fibrosis into your Life Everyday' which as designed to be worked through by children during a clinic visit found that it was associated with increasing children's knowledge of CF and the competency of their coping skills. (E12)</p> <p>'Sweet Talk', a text-messaging support system which sends daily text messages to young people with diabetes to reinforce self-management goals set in clinic and occasional text newsletters about topical issues was found to be effective in improving young people's self-efficacy and self-reported adherence (E13). In combination with intensive insulin therapy it was also associated with improvements in glycaemic control.</p>	
<p>Models that use e-health for self-monitoring have the potential to lead to conflict between parents and children</p> <p>V8, v9</p>	<p>No e-health studies have examined the effect of this type of intervention on parent-child relationships.</p>	<p>No e-health studies have examined the effect of this type of intervention on parent-child relationships.</p>

<p>Interpersonal skills of those delivering self-care models are important</p> <p>V12</p>	<p>No studies have examined professional interpersonal or communication skills as a component or an outcome of the intervention.</p>	<p>Physicians who had received an intervention to improve their communication and teaching skills received significantly higher communication behaviour scores from parents (E16).</p>
<p>The social position/role of the individual/group delivering the self-care model is important for parents</p> <p>V6, V11,</p>	<p>No studies examine the effect of the role/position of the provider of the intervention. All studies can be considered to be professionally led.</p>	<p>School-based structured asthma education programme led by peers (the "Triple A Program") was associated with improving quality of life scores and significant reductions in school absenteeism for children with asthma (E3). However, the particular influence of peer educators from other components of the intervention is unclear.</p>

Key to studies

V1 Barlow <i>et al.</i> (2007)	V7 Webster (2007)	E1 Christian and D'Auria (2006)	E9 McPherson <i>et al.</i> (2006)
V2 Bruzzese <i>et al.</i> (2004)	V8 Carroll <i>et al.</i> (1997)	E2 Cicutto <i>et al.</i> (2005)	E10 Guendelman <i>et al.</i> (2002)
V3 Hawley (2005b)	V9 Gammon <i>et al.</i> (2005)	E3 Shah <i>et al.</i> (2001)	E11 Jan <i>et al.</i> (2007)
V4 Johnson <i>et al.</i> (2001)	V10 Van der Meer <i>et al.</i> (2007)	E4 Grey <i>et al.</i> (2000)	E12 Davis <i>et al.</i> (2004)
V5 Salinas (2007)	V11 Hawley <i>et al.</i> (2005a)	E5 Evans <i>et al.</i> (1999)	E13 Franklin <i>et al.</i> (2006)
V6 Trollvik & Severinsson (2005)	V12 Anderson (1997)	E6 Patterson <i>et al.</i> (2005)	E14 Joseph <i>et al.</i> (2007)
		E7 Cook <i>et al.</i> (2002)	E15 Krishna <i>et al.</i> (2003)
		E8 MTA (1999, 2004)	E16 Clark <i>et al.</i> (2000)

Appendix 2.10 Self-Care Support Model Typology

THEORETICAL BASIS: e,g, social learning theory, CBT					
TARGET	LOCATION	LEADERSHIP	FOCUS	AIMS/OBJECTIVES	MEDIUM
Child/young person	Home	Lay led	Generic	Increased knowledge	<u>Face-to-face</u> Group. Dyadic. Individual
Parent	Community (school, camps)	Professional led	Condition specific	Increased self-management skills	Activities e.g. role play. Discussion Lectures
Child & parent	Hospital			Improved physical health outcomes	<u>Printed materials</u> Workbooks Diaries
Siblings				Prevention of long-term consequences of condition	Self-care guides e.g. action plans.
Peers				Improved communication skills (with HCPs, parents/young people)	<u>E-health</u> Websites Chat rooms
Professionals				Improved family functioning & relationships	Mobile phone systems Remote monitoring DVDs
Health care system				Improved relationships with HCPs	Computer and other electronic games.
				Improved psycho-social well-being <ul style="list-style-type: none"> • Increased self-efficacy • Enhanced adjustment to the condition • Improved social skills • Improved problem solving skills • Improved coping skills • Increased self-esteem • Improved quality of life • Increased adherence • Increased health locus of control. 	
				Reduced health care utilisation	
INDIVIDUALISATION – tailoring self-care support to the individual/group/locality					

Appendix 2.11 Summary of Self Care Interventions in Relation to Typology Domains

Domain	Studies
<i>Target of Intervention</i>	
Child/young person	Guendelman <i>et al.</i> (2002,2004) Jan <i>et al.</i> (2007) McPherson <i>et al.</i> (2006) Christian and D'Auria (2006) Davis <i>et al.</i> (2004) Franklin <i>et al.</i> (2006) Bruzzese <i>et al.</i> (2004) Johnson <i>et al.</i> (2001) Van der Meer <i>et al.</i> (2007) Grey <i>et al.</i> (2000) Joseph <i>et al.</i> (2007) Patterson <i>et al.</i> (2005) Shah <i>et al.</i> (2001) Cook <i>et al.</i> (2002)
Parent	Stevens <i>et al.</i> (2002) Trollvik and Severinsson (2005) Dolinar <i>et al.</i> (2000) Sonuga-Barke <i>et al.</i> (2001)
Professional	Clark <i>et al.</i> (2000)
Child and parent	Cicutto <i>et al.</i> (2005) Evans <i>et al.</i> (1999)/Sullivan <i>et al.</i> (2002) Wesseldine <i>et al.</i> (1999) Anderson (1997) Carroll <i>et al.</i> (1997) Gammon <i>et al.</i> (2005) Nunn <i>et al.</i> (2006) Ellis <i>et al.</i> (2005,2007) Murphy <i>et al.</i> (2007) Downs <i>et al.</i> (2006) Walders <i>et al.</i> (2006) Cano- Garcinuna (2007) Krishna <i>et al.</i> (2003) Svoren <i>et al.</i> (2003) Wysocki <i>et al.</i> (2001)
Child, parent and professionals	MTA (1999,2004) Lozano <i>et al.</i> (2004)
<i>Location of Intervention</i>	
Home only	Guendelman <i>et al.</i> (2002,2004) Jan <i>et al.</i> (2007) McPherson <i>et al.</i> (2006) Van der Meer <i>et al.</i> (2007) Johnson <i>et al.</i> (2001) Nordfeldt and Ludvigsson (2002) Dolinar <i>et al.</i> (2000) Sonuga-Barke <i>et al.</i> (2001) Downs <i>et al.</i> (2006) Nunn <i>et al.</i> (2006)
School only	Cicutto <i>et al.</i> (2005) Bruzzese <i>et al.</i> (2004) Joseph <i>et al.</i> (2007) Patterson <i>et al.</i> (2005) Shah <i>et al.</i> (2001)
Community/primary care only	Cano- Garcinuna <i>et al.</i> (2007)
Home, School and Community/primary care settings	Carroll <i>et al.</i> (1997) Gammon <i>et al.</i> (2005) Franklin <i>et al.</i> (2006)
Hospital only	Stevens <i>et al.</i> (2002) Wesseldine <i>et al.</i> (1999) Davis <i>et al.</i> (2004) Anderson (1997) Trollvik and Severinsson (2005) Krishna <i>et al.</i> (2003) Walders <i>et al.</i> (2006) Murphy <i>et al.</i> (2007) Svoren <i>et al.</i> (2003)
School and other setting (unclear)	MTA (1999, 2004)
Home and Community/Primary Care	Evans <i>et al.</i> (1999)/Sullivan <i>et al.</i> (2002) Lozano <i>et al.</i> (2004)
Home and Hospital	Christian and D'Auria (2006)
<i>Leadership of Intervention</i>	
Lay/peer	Shah <i>et al.</i> (2001)
Professional	All other studies
<i>Focus of Intervention</i>	
Generic	Hawley <i>et al.</i> (2005 a,b); Salinas (2007) Barlow <i>et al.</i> (2007)
Condition-specific	All other studies
<i>Medium</i>	
Face to Face – individual child or family	Stevens <i>et al.</i> (2002) Wesseldine <i>et al.</i> (1999) Anderson (1997) Nordfeldt and Ludvigsson (2002) Wysocki <i>et al.</i> (2001) Svoren <i>et al.</i> (2003) Ellis <i>et al.</i> (2005,2007) Downs <i>et al.</i> (2006) Walders <i>et al.</i> (2006) Lozano <i>et al.</i> (2004) Dolinar <i>et al.</i> (2000) Sonuga-Barke <i>et al.</i> (2001)

Face to Face – group	Cicutto <i>et al.</i> (2005) Trollvik and Severinsson (2005) Cook <i>et al.</i> (2002) Grey <i>et al.</i> (2000) Patterson <i>et al.</i> (2005) Clark <i>et al.</i> (2000) Shah <i>et al.</i> (2001) Cano-Garcinuna <i>et al.</i> (2007) Murphy <i>et al.</i> (2007)
Printed materials only	Nordfeldt and Ludvigsson (2002)
E-health (computer based)	Guendelman <i>et al.</i> (2002,2004) Jan <i>et al.</i> (2007) Franklin <i>et al.</i> (2006) Van der Meer <i>et al.</i> (2007) Johnson <i>et al.</i> (2001) Carroll <i>et al.</i> (1997) Gammon <i>et al.</i> (2005) McPherson <i>et al.</i> (2006) Davis <i>et al.</i> (2004) Joseph <i>et al.</i> (2007) Krishna <i>et al.</i> (2003) Nunn <i>et al.</i> (2006)
Face to face individual and group	Evans <i>et al.</i> (1999)/Sullivan <i>et al.</i> (2002) Lozano <i>et al.</i> (2004) Christian and D'Auria (2006) MTA (1999,2004) Bruzzese <i>et al.</i> (2004)

Nine reported an underlying theoretical basis to the intervention and 18 could be described as individualising the intervention (with a further 9 possibly being individualised).

Appendix 3

Appendix 3.1 FAQ page from online questionnaire

FAQ: Evaluating self-care support for children and young people with long-term conditions

Q. What do you mean by a self-care project or programme?

A. We mean any project or programme over and above the 'usual' self-care support that health care professionals or other practitioners provide as part of their everyday practice. The project or programme may focus on the child/young person, their peers, their parents or carers, other family members, or on professionals who are providing the self-care support. The self-care support may help the child/young either directly or indirectly by focussing on exercise, diet, lifestyle choices, social relationships, how to manage their condition, self-awareness, monitoring health, seeking advice, solving problems, improving self-efficacy, communication, family functioning or on other aspects of self-care.

Q. What age-range are you interested in?

A. We're interested in any self-care project or programme for children and young people aged 0-18. However, if you run a self-care project or programme that includes people older than 18 as well as younger people, please tell us about it. We would like to know its aims, what age group is covered and what proportion of people would be 18 or younger.

Q. Can I get part-way through the questionnaire and return to it later?

A. Yes, your responses will be saved as far as you got and you can access the questionnaire by entering the same e-mail address as you originally used. However, once you press the final Submit button you will not be able to re-open the questionnaire. If you think of something later that you would like to tell us about then just e-mail it to susan.beatty@manchester.ac.uk Contact details are accessible as soon as you click on the link.

Q. What happens if I want to change my responses before I submit the questionnaire?

A. Just click "Review Your Answers" then click whichever question you want to change. Please note that you have to click Yes on Q1 to be able to complete Q2-Q6. If the response to Q1 is No, you will automatically skip to Q7. So if you want to provide information about any condition specific projects or programmes, please ensure that you've answered Yes to Q1.

Q. What if I want to provide more information than there's room for?

A. We've tried to provide enough opportunities for you to give us information on a number of different projects/programmes. However, if you run a large number of projects or programmes you may need to use the additional information boxes provided at the ends of questions 6 and

7, and at the end of the questionnaire. If you want to tell us more about your projects and there is not enough space then please e-mail susan.beatty@manchester.ac.uk We're also happy to receive leaflets or other information through the post if they add to what you have already told us. Please post information to: Dr. Susan Beatty, School of Nursing, Midwifery and Social Work, Room 5.322, University Place, University of Manchester, M13 9PL

Q. What if I need to ask different people in my organisation to complete different parts of this questionnaire?

A. Just send them the link to the questionnaire, tell them which sections you want them to do and ask them to be sure to enter the name of the organisation on the final page before clicking the final Submit button. We can then link together different people's responses for the same organisation. Please note that you have to click Yes on Q1 to be able to complete Q2-Q6. If the response to Q1 is No, you will automatically skip to Q7

Q. What type of information about projects or programmes do you want?

A. We are interested in what the aims of the project/programme are; the age-group it is targeted at, how long it lasts, how often it runs and who runs it, where it takes place, or anything else you feel is important for us to know.

Q. Can I tell other people about this survey?

A. Yes, please tell anyone who you think is doing relevant work, anywhere in England. We want to be as comprehensive as possible so please circulate the link through any appropriate network you know about.

Appendix 3.2 Internet Questionnaire

Evaluating self-care support for children and young people with long term conditions. - Microsoft Internet Explorer

File Edit View Favorites Tools Help

Back Forward Stop Home Search Favorites Refresh Print Mail Stop

Address http://www.nursing.manchester.ac.uk/learning/nihrsdop2/login_open.asp Go Links

MANCHESTER
1824

The University of Manchester

Evaluating self-care support for children and young people with long term conditions.

Please enter your email address and click on the submit button. This will take you to the questionnaire.

email address:

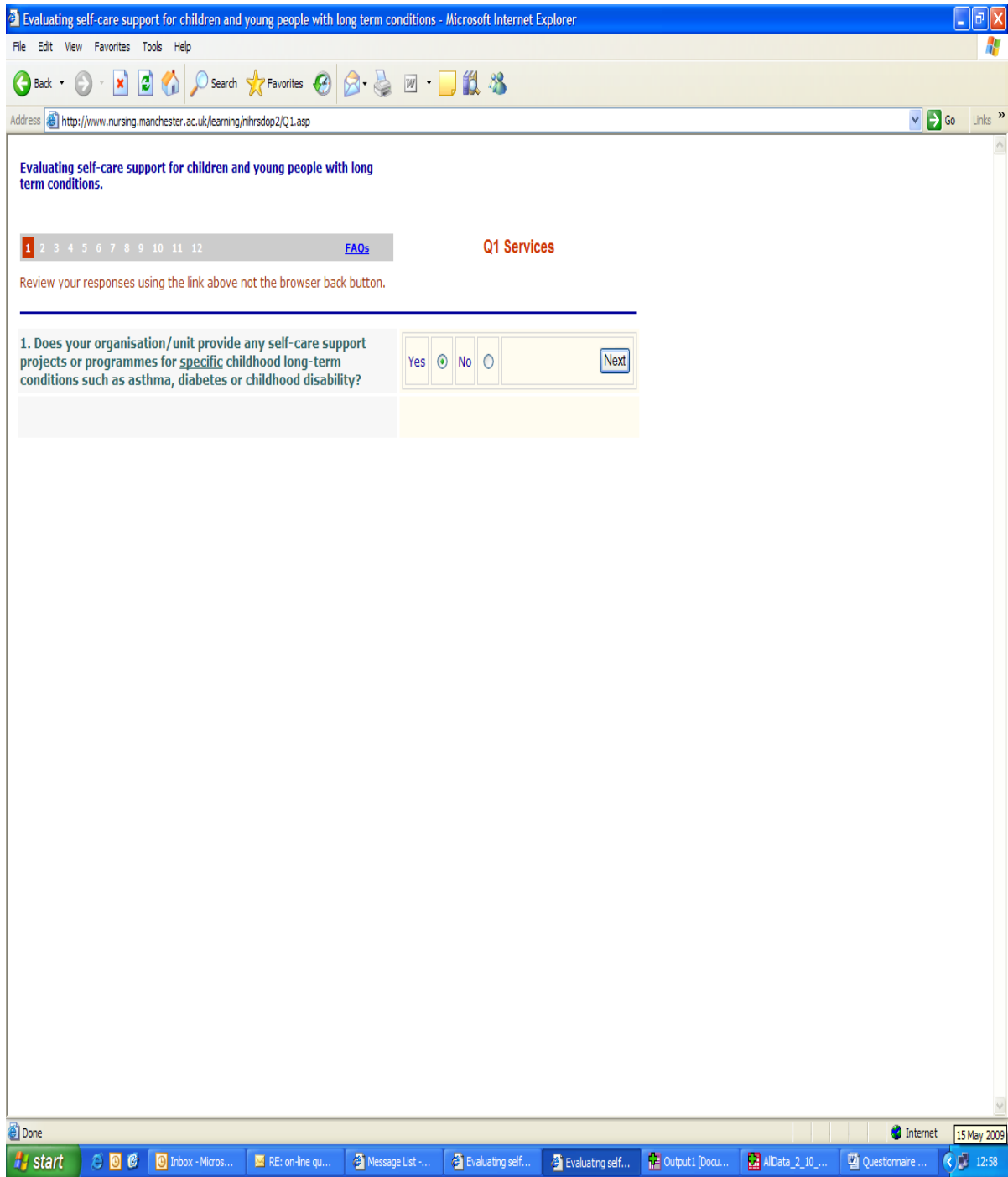
retype email address:

Important things to note: The information you give will be used to provide a picture of self-care support available across England for children and young people with long-term conditions. Completion of this survey will be taken as consent to participate and for responses submitted to be used as above. We would like to reassure you that your responses will be confidential and we will not be identifying organisations or individuals by name in any published material. The survey is hosted on a University of Manchester server and responses are protected against outside access. Once the survey is closed, all responses will be removed from the server and will be stored in a safe place.

Thank you for your participation in the survey.

Done Internet

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Evaluating self-care support for children and young people with long term conditions. - Microsoft Internet Explorer

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Address http://www.nursing.manchester.ac.uk/learning/nhrsdp2/Q2.asp

Evaluating self-care support for children and young people with long term conditions.

1 2 3 4 5 6 7 8 9 10 11 12 [Review Your Answers](#) [FAQs](#) Review your responses using the link to the left not the browser back button.

Q2 Asthma: These questions are about projects or programmes targeted at childhood **asthma**. You can enter information about three different projects or programmes.

2a. Does your organisation/unit provide a self-care support project or programme for childhood **asthma**? Yes No

PROJECT/PROGRAMME 1

2b. Who is the target of this self-care support project or programme?
(Please tick all that apply)

Individual child/young person with asthma	<input checked="" type="checkbox"/>
Parents/guardians	<input checked="" type="checkbox"/>
Siblings	<input type="checkbox"/>
Peers	<input type="checkbox"/>
Health care practitioners (e.g. Nurses, Doctors, Therapists)	<input type="checkbox"/>
Social care practitioners (e.g. Social Workers)	<input type="checkbox"/>
Educational practitioners (e.g. Teachers)	<input type="checkbox"/>
Others (please detail)	<input type="text"/>

2c. Please provide some brief information on this project or programme.

2d. Does your organisation/unit provide any more self-care support projects or programmes for childhood asthma? Yes No

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Evaluating self-care support for children and young people with long term conditions. - Microsoft Internet Explorer

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Address http://www.nursing.manchester.ac.uk/learning/nhrsdp2/Q3.asp

Evaluating self-care support for children and young people with long term conditions.

1 2 3 4 5 6 7 8 9 10 11 12 [Review Your Answers](#) [FAQs](#) Review your responses using the link to the left not the browser back button.

Q3 Diabetes: These questions are about projects or programmes targeted at childhood **diabetes**. You can enter information about three different projects or programmes.

3a. Does your organisation/unit provide any self-care projects or programmes for childhood **diabetes**? Yes No If 'No' please click 'Next'

PROJECT/PROGRAMME 1

3b. Who is the target of the self-care support project or programme?
(Please tick all that apply)

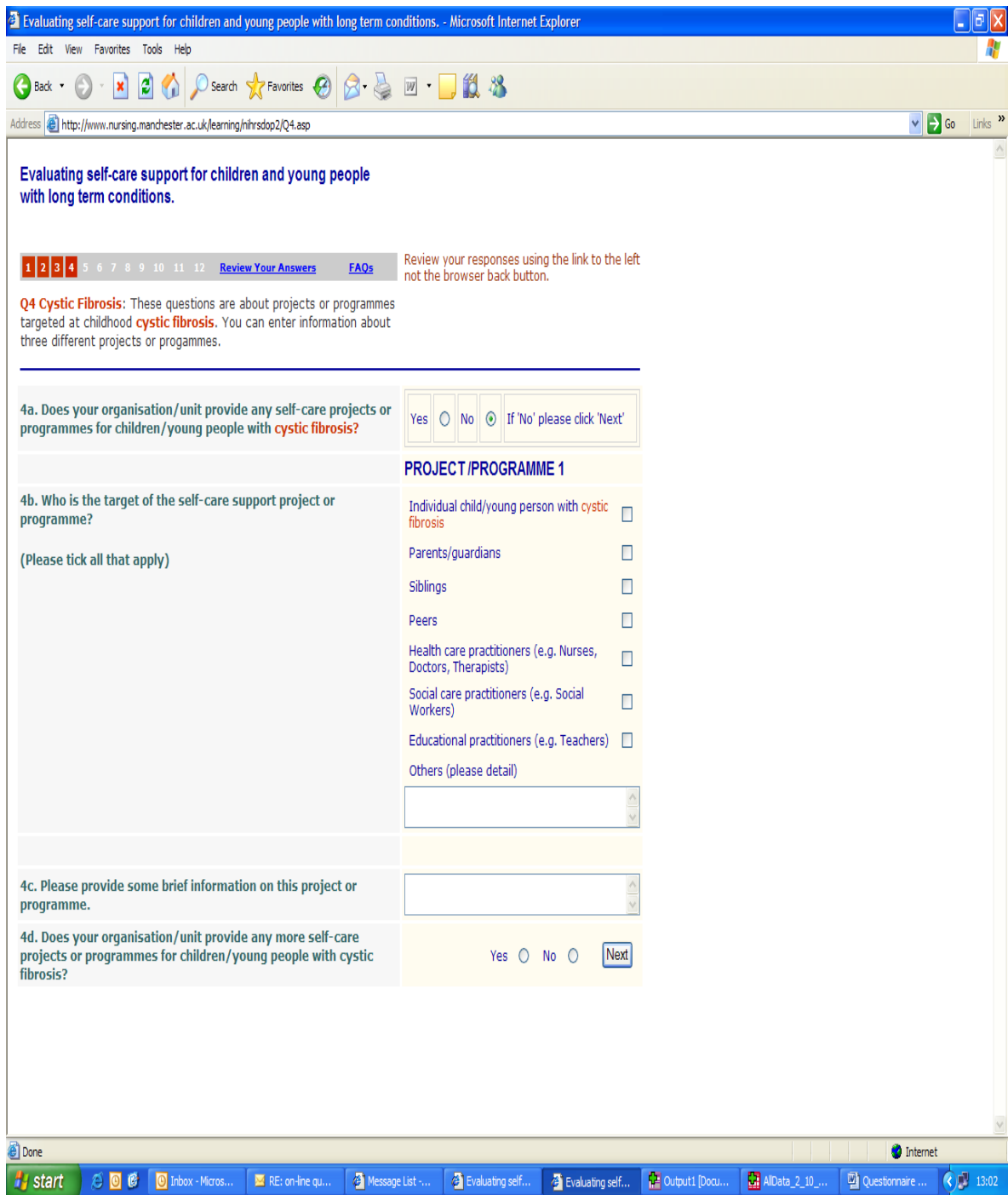
- Individual child/young person with diabetes
- Parents/guardians
- Siblings
- Peers
- Health care practitioners (e.g. Nurses, Doctors, Therapists)
- Social care practitioners (e.g. Social Workers)
- Educational practitioners (e.g. Teachers)
- Others (please detail)

3c. Please provide some brief information on this project or programme.

3d. Does your organisation/unit provide any more self-care projects or programmes for childhood diabetes? Yes No [Next](#)

Done Internet 15 May 2009

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Evaluating self-care support for children and young people with long term conditions. - Microsoft Internet Explorer

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Address http://www.nursing.manchester.ac.uk/learning/nhrsdp2/Q5.asp Go Links

Evaluating self-care support for children and young people with long term conditions.

1 2 3 4 5 6 7 8 9 10 11 12 [Review Your Answers](#) [FAQs](#) Review your responses using the link to the left not the browser back button.

Q5 ADHD : These questions are about projects or programmes targeted at childhood **ADHD**. You can enter information about three different projects or programmes.

5a. Does your organisation/unit provide any self-care projects or programmes for children/young people with **ADHD**? Yes No If 'No' please click 'Next'

PROJECT/PROGRAMME 1

5b. Who is the target of the self-care support project or programme?
(Please tick all that apply)

- Individual child/young person with **ADHD**
- Parents/guardians
- Siblings
- Peers
- Health care practitioners (e.g. Nurses, Doctors, Therapists)
- Social care practitioners (e.g. Social Workers)
- Educational practitioners (e.g. Teachers)
- Others (please detail)

5c. Please provide some brief information on this project or programme.

5d. Does your organisation/unit provide any more self-care projects or programmes for children/young people with **ADHD**? Yes No [Next](#)

Done Internet

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Evaluating self-care support for children and young people with long term conditions. - Microsoft Internet Explorer

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Address http://www.nursing.manchester.ac.uk/learning/nhrsdp2/Q6.asp

Evaluating self-care support for children and young people with long term conditions.

1 2 3 4 5 6 7 8 9 10 11 12 [Review Your Answers](#) [FAQs](#)

Review your responses using the link to the left not the browser back button.

Q6 Other Long term conditions : These questions are about projects or programmes targeted at other **specific** long term childhood conditions You can enter information about three different projects or programmes for each of three different conditions. If you run more than this please give details in the additional information section.

6a. Does your organisation/unit provide self-care projects or programmes for any other childhood long-term conditions? Yes No If 'No' please click 'Next'

PROJECT/PROGRAMME 1

6b. Long-term Condition

6c. Who is the target of the self-care support project or programme? (Please tick all that apply)

- Individual child/young person with long term conditions
- Parents/guardians
- Siblings
- Peers
- Health care practitioners (e.g. Nurses, Doctors, Therapists)
- Social care practitioners (e.g. Social Workers)
- Educational practitioners (e.g. Teachers)
- Others (please detail)

6d. Please provide some brief information on this project or programme.

6e. Does your organisation/unit provide any more self-care projects or programmes for this condition? Yes No

Done Internet

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Evaluating self-care support for children and young people with long term conditions. - Microsoft Internet Explorer

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Address <http://www.nursing.manchester.ac.uk/learning/nhrsdp2/Q7.asp> Go Links

Evaluating self-care support for children and young people with long term conditions.

1 2 3 4 5 6 7 8 9 10 11 12 [Review Your Answers](#) [FAQs](#)

Review your responses using the link to the left not the browser back button.

Q7 General self-care projects or programmes : You can enter information for three different projects or programmes that are not targeted at specific long-term conditions. If you run more than this, please choose the **three that you consider the most important** and list the others in the additional information section.

7a. Does your unit/organisation provide any self-care projects or programmes for children/young people with long-term conditions that are NOT targeted at a PARTICULAR childhood long-term condition?

Yes No If 'No' please click 'Next'

PROJECT 1

7b. Who is the target of the self-care support project or programme?
(Please tick all that apply)

Individual child/young person	<input checked="" type="checkbox"/>
Parents/guardians	<input checked="" type="checkbox"/>
Siblings	<input checked="" type="checkbox"/>
Peers	<input type="checkbox"/>
Health care practitioners (e.g. Nurses, Doctors, Therapists)	<input type="checkbox"/>
Social care practitioners (e.g. Social Workers)	<input type="checkbox"/>
Educational practitioners (e.g. Teachers)	<input type="checkbox"/>
Others (please detail)	<input type="text"/>

7c. Please provide some brief information on this project or programme.

7d. Does your unit/organisation provide any more self-care projects or programmes for children/young people with long-term conditions that are NOT targeted at a PARTICULAR childhood long-term condition?

Yes No

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Address <http://www.nursing.manchester.ac.uk/learning/nhrsdp2/Q8.asp> Go Links

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1 2 3 4 5 6 7 8 9 10 11 12 [Review Your Answers](#) [FAQs](#) Review your responses using the link to the left not the browser back button.

Q8 Commissioning other services/organisations:

8a. Does your organisation commission other services/organisations to provide self-care projects or programmes for children/young people with long-term conditions?

Yes No If 'No' please click 'Next'

8b. Please describe which condition(s) and with which organisations you commission self-care projects or programmes:

Next

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Address http://www.nursing.manchester.ac.uk/learning/nhrsdp2/Q9.asp Go Links

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1 2 3 4 5 6 7 8 9 10 11 12 [Review Your Answers](#) [FAQs](#) Review your responses using the link above not the browser back button.

Q9 Links with other organisations:

9a. Does your unit/organisation link with other organisations in providing or commissioning projects or programmes to support the self-care for children/young people with long-term conditions (e.g. voluntary sector/charities, Social Service Departments, Schools, NHS organisations)?

Yes No If 'No' please click 'Next'

9b. Please identify the types of organisations with whom you link.

Next

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Address http://www.nursing.manchester.ac.uk/learning/nhrsdp2/Q10.asp Go Links

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1 2 3 4 5 6 7 8 9 10 11 12 [Review Your Answers](#) [FAQs](#) Review your responses using the link above not the browser back button.

Q10 e-health type technologies

10a. Do any of the self-care support projects or programmes provided or commissioned use e-health type technologies (e.g. telehealthcare, the Internet) to support the self-care of children/young people with long-term conditions and their families?

Yes No If 'No' please click 'Next'

10b. Please describe which condition(s) and what technologies you are using to provide self-care support.

We have part of our website dedicated to children and young people to provide info and advice.

Next

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Address http://www.nursing.manchester.ac.uk/learning/nhrsdp2/Q11.asp

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1 2 3 4 5 6 7 8 9 10 11 12 [Review Your Answers](#) [FAQs](#)

Review your responses using the link above not the browser back button.

Q11 Your details

We may like to contact you to find out more about the self-care support you are providing/commissioning. Please could you provide your name, role, the name of your organisation and a contact phone number. [If you do not wish to provide this information please could you indicate the type of organisation you work within e.g. children's hospital, primary care trust.]

11a. Name

11b. Role

11c. Organisation

11d. Phone Number

Please give any further information in the box below, or send it as a separate e-mail to susan.beatty@manchester.ac.uk

Additional information

If you wish to send additional information e.g. leaflets about projects or programmes, please post it to:

Dr Susan Beatty
 Research Associate
 Child & Family Health and Social Care Research Team
 School of Nursing, Midwifery and Social Work
 Room 5.322, University Place
 M13 9PL
 0161 306 7666

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Address http://www.nursing.manchester.ac.uk/learning/nhrsdp2/Q12.asp Go Links

Evaluating self-care support for children and young people with long term conditions.

1 2 3 4 5 6 7 8 9 10 11 12 [Review Your Answers](#) [FAQs](#) **Q12 Submit**

Review your responses using the link above not the browser back button.

If you are happy with answers you have provided please click on the **Submit Button**. This will close the questionnaire.

Thank you for completing this survey.

Done Internet

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Appendix 3.3 Networks and Organisations Involved in Distributing Information about the Mapping Exercise

CHAIN

Self-care Connect;
 Royal College of Nursing
 Royal College of Paediatrics and Child Health
 Association of Directors of Children's Hospitals
 General Practice Airways Group (GPIAG)
 Association of Respiratory Nurse Specialists
 School and Public Health Nurses Association
 Education for Health;
 Paediatric Nursing Forum;
 North West Nurses in CAMHS;
 National Multidisciplinary CAMHS Group;
 Association for Chief Children's Nurses;
 UK Health and Learning Disability Network;
 Cystic Fibrosis Trust
 Asthma UK
 Diabetes UK;
 National Cystic Fibrosis Clinical Nurse Specialist Group;
 Arthritis Care,
 Long-Term Conditions Alliance,
 RCN CAMHS Distribution List
 Association of Children's Diabetes Clinicians;
 Association of British Paediatric Nurses;
 Child Health Research Network
 Children and Young People's Partnership for Health;
 Children's Workforce Network
 Eastern Paediatric Epilepsy Network
 Greater Manchester, East Cheshire and High Peaks Children, Young People and Families Network
 North Central London Children's Community Nursing Network;
 North East London Paediatric Palliative Care Network;
 Paediatric and Adolescent Rheumatology Network Group;
 Pan London Community Children's Nursing Network;
 RSM Paediatrics and Child Health Section;
 Specialist Obstetrics and Paediatrics (SOAPS) Network;
 Thames Paediatric Oncology Centre;
 UK Children on Long Term Ventilation;
 Juvenile Diabetes Research Foundation (JDRF);
 Sickle Cell Society;
 t+medical;
 Axon Telehealthcare
 Department of Health via the Children, Families and Maternity E-bulletin
 (sent to managers and front line staff in education, social care, and health
 and to voluntary sector organisations who work with children, young people,
 and pregnant women.

Appendix 3.4 Letter sent to NHS organisations



School of Nursing, Midwifery and Social Work,
Room 5.322, University Place,
University of Manchester,
M13 9PL

Tel: 0161 306 7666
e-mail: susan.beatty@manchester.ac.uk

21st July 2008

Dear Colleague,

Evaluating Self-Care Support for Children and Young People with Long-term Conditions

We have been funded by one of the Department of Health's research programmes (National Institute for Health Research Service Delivery and Organisation programme) to evaluate self-care support for children and young people with long-term conditions. This will provide important information for future service planning in relation to the National Service Framework.

I am contacting you because I believe you may be able to help us find out what self-care support exists across England for children and young people with long-term conditions.

We are interested in self-care support projects or programmes that are:

- Targeted at children and young people aged between 0 and 18;
- Either generic or focus on specific conditions such as asthma, ADHD, cystic fibrosis and diabetes;
- Aimed at children and young people themselves, or at their parents, other family members, peers, carers, or professionals.
- Over and above the "usual" self care support that health care professionals or other practitioners provide as part of their everyday practice.

We need to obtain as full and comprehensive a picture of activity as possible. If you are involved in or know about any self-care projects/programmes in your organisation or area then we would be grateful if you could complete a short on-line survey. It should take between 5 and 15 minutes.

Additionally, it would be most useful if you could contact other colleagues by sending them this information e.g. by passing this letter on to other people in your organisation or emailing any networks/distribution lists to which you belong.

Please enter the URL: <http://www.nursing.manchester.ac.uk/learning/nihrsdop2/index.html> for more information before starting the survey.

Thank you for reading this, and thank you for your help.

Yours sincerely,

Dr Susan Beatty
Research Associate

Appendix 3.5 Extraction Sheet For Self-Care Models (Internet Searching, Personal Contact)

Publication

Authors: _____

Year: _____ Country: _____

Title: _____

Journal/Report Title: _____

URL _____

Name of Project/Service _____

Condition(s)

Asthma ADHD

Diabetes CF

Generic

Note here if the model/service is aimed at a particular subgroup of children with the condition:

Who is the model/service targeted at:

Child/young person Peers

Parent Professionals

Siblings

Other (*please state*) _____

Note here the age range of the children/young people:

Note here the professional group(s) targeted:

Mode/medium of delivery

Individual (child/parent/family) consultation Group discussion/work

'Paper-based' (workbooks, action plans etc) Videos/DVDs

e-health (internet, chat rooms, games, telehealthcare – mobile phones etc)

Other: *(please state)* _____

Note here the location(s) (e.g.home, clinic)

Overall aims

Increase knowledge (education)

Increase/improve psycho-social wellbeing

Increase (life) coping skills

Increase self-management skills

Improve family relationships

Improve physical health

Other: *(please state)* _____

Who leads the model (ie lay-led or professionally led)?

NOTES

Appendix 4

Appendix 4.1 Topic Guide for Children and Young People

Context/history

- Length of time of condition
- Self-care before the project – what did they do and who helped them.
- Difficulties experienced around self-care

The self-care project

- Who told them about the project
- Why were they interested in going/taking part
- What do they like about it
- What don't they like about it.
- Do they feel it has helped them? If so how.
- Could the project be improved? If so how.

Self-care

- Who can best support them
- How would like to receive the support.
- Barriers and enablers

Appendix 4.2 Topic Guide for Parents

Context/history

- Length of time child has had condition
- Self-care before the project
 - Who helped/supported them.
 - Difficulties experienced around self-care and/or encouraging child's involvement.

The self-care project

- Who told them about the project
- Why were they interested in going/taking part
- What do they like about it
- What don't they like about it.
- Do they feel it has helped them? If so how.
- [Do they feel it has helped their child? If so how].
- Could the project be improved? If so how.

Self-care

- Who can best support them
- Who can best support their child.
- How would like to receive the support.
- How do they think their child should receive the support.

Appendix 4.3 Topic Guide for Practitioners

Role in the self-care project

- current role
- previous role (development of project)

Preparation for role in self-care project

- specific training/education
- additional needs for training/education in the area of self-care

View of the project

- What works well and why (enablers)
- What does not work well and why (barriers)
- Perception of its impact on children/parents (long and short term)
- Perception on the impact of the model on use of primary care, hospital and other support services.

Integration with other self-care support

- How does the project fit/link with 'mainstream' health service support
- How does the project fit/link with lay forms of self-care support
- How does the project fit/link with self-care support from social care/educational sectors.

Appendix 4.4 Dimensions from Typology of Self-Care Models and Case Study Sites

Dimensions from Typology	Case Study 1 (Asthma Camps)	Case Study 2 (ADHD Group)	Case Study 3 (Staying Positive)	Case Study 4 (Online support group)	Case Study 5 (Diabetes Team)	Case Study 6 (Support team)
Theoretical or philosophical basis	Self-efficacy Social support	Empowerment Self-efficacy	Self-efficacy Empowerment	Social support	None identified	None identified
Target	Children/YPs aged 6-17 (6-11; 12-17)	Children/YPs aged 5-18, parents/carers and professionals	YPs aged 12-18 Parents/carers	Children/YP Parents (separate groups)	Children/YP up to 18 Parents?	Children/YP up to 18 Parents
Location	Community National coverage	Community Local area coverage	Community National coverage	Home National coverage	Hospital Home Community Local area coverage	Home Community Local area coverage
Leadership	Voluntary sector Lay volunteers and HCPs One paid manager per camp	Voluntary sector. Lay volunteers and paid workers.	Independent sector. Lay facilitators aged 15-25	Voluntary sector. Moderation only.	NHS Professionals	NHS Professionals
Focus	Asthma	ADHD	Generic	CF	Diabetes	Generic
Aims/objectives #	<ul style="list-style-type: none"> For children to find out more about their asthma and how to control their symptoms To meet other children and young people with asthma 	<ul style="list-style-type: none"> To look at different ways of encouraging good behaviour, communicating effectively, and helping children to gain self-esteem, self-control and social 	<ul style="list-style-type: none"> To improve young people's confidence in managing their condition and their medication. To reduce feelings of isolation and 	<ul style="list-style-type: none"> To provide social support and social networking. To exchange information and news.¹ 	<ul style="list-style-type: none"> To impart knowledge about the management of diabetes To develop the skills to self-manage diabetes 	<ul style="list-style-type: none"> To provide home support in order to prevent hospitalisation and reduce length of stay. To be a first

	<p>and other related conditions</p> <ul style="list-style-type: none"> To develop new skills, self confidence and independence by being away from home To take part in new and exciting activities - from camping to abseiling To become more independent in controlling their asthma, using their inhalers & knowing why they take them¹ 	<p>skills</p> <ul style="list-style-type: none"> To help the child to get organised, and to tackle negative attention seeking, oppositional behaviour and conflict To help the parents gain self-esteem, become advocates for their children, build on new skills and seek new solutions. 	<p>depression</p> <ul style="list-style-type: none"> To improve quality of life 			<p>point of contact for parents with the hospital services</p>
Medium	Face-to-face in a holiday location	Face-to-face groups (discussion, activities) in community centre. Separate groups for parents and children, activity programme for YPs.	Face-to-face groups (discussion, activities) in non-NHS locations.	Internet based discussion groups	Face-to-face groups (discussion, activities) in community and hospital settings; residential holidays;	Face-to-face home based support and telephone advice for individual families; trips for children and siblings.
Individualisation	Structured activity programme, one-to-one guidance	One-to-one tailored guidance, structured programmes for parents and young people.	Structured programmes for younger and older young peoples.	Individualised in that issues raised emanate from participants themselves and peer support attempts to account for individual situation.	Structured group activities; individualised support for families.	Individualised to needs of child and family

As described in 'official' sources and/or interpretation of interview data

Disclaimer:

This report presents independent research commissioned by the National Institute for Health Research (NIHR). The views and opinions expressed by authors in this publication are those of the authors and do not necessarily reflect those of the NHS, the NIHR, the NIHR SDO programme or the Department of Health. The views and opinions expressed by the interviewees in this publication are those of the interviewees and do not necessarily reflect those of the authors, those of the NHS, the NIHR, the NIHR SDO programme or the Department of Health"

Addendum:

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

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