SDO Protocol - project ref: 10/1008/30
Version: 1.1 (see * below)
Date: 25 Nov 2010

IDENTIFYING AND EVALUATING MENTAL HEALTH SELF CARE SUPPORT FOR CHILDREN AND YOUNG PEOPLE

Chief investigator Dr Steven Pryjmachuk

Sponsor University of Manchester

Funder SDO

NIHR Portfolio number

ISRCTN registration (if applicable) N/A

* Versions:
1.0 – original submitted with full proposal on 18 Jul 2010
1.1 – revisions submitted on 25 Nov 2010 following changes requested by the SDO board
IDENTIFYING AND EVALUATING MENTAL HEALTH SELF CARE SUPPORT FOR CHILDREN AND YOUNG PEOPLE

1. Aims/Objectives:

Aims: To identify and evaluate the types of mental health (MH) self care support used by, and available to, children and young people (C&YP) and their carers, and to establish how such support interfaces with statutory and non-statutory service provision.

Specific objectives:
1. To provide a descriptive overview of the self care support services that exist in England and Wales for C&YP in relation to mental health and wellbeing, including a categorisation of these services according to a self care support typology developed in a previous study.
2. To examine the effectiveness of such services (in terms of their impact on the psychosocial wellbeing and mental health of C&YP and their families).
3. To examine the factors influencing the acceptability of such services to C&YP and their families.
4. To explore the barriers to the implementation of MH self care support services for C&YP.
5. To explore the interface between such services and the NHS and other statutory and non-statutory service providers in order to guide future planning in health and social care.
6. To identify future research priorities for the NHS in this area.

2. Background:

The mental health of C&YP is a major public health concern. Around 1 in 5 C&YP will have (mild-to-moderate) mental health problems (MH Foundation 1999); around 1 in 10, a diagnosable mental disorder (Meltzer et al 2000; Green et al 2005). Recent evidence from England (CAMHS Review 2008) suggests that statutory mental health services for C&YP are not always as comprehensive, consistent or effective as they could be nor are they especially responsive, accessible or child-centred. Moreover, when accessing these services, C&YP and their carers are faced with unhelpful legal and administrative processes, unacceptable regional and local variations, and busy professionals who have little time to understand the evidence base for effective interventions (CAMHS Review 2008). Similar problems have been reported in Wales (Wales Audit Office 2009).

There is, therefore, clear scope for improvement in the delivery and organisation of Child & Adolescent Mental Health Services (CAMHS) - indeed, the SDO has already funded research into alternatives to CAMHS inpatient care (Shepperd et al 2009). The extent to which self care could play a role in overall CAMHS provision has been under researched however, especially at “Tier 1”, the tier of service embedded within non-specialist, universal children’s services (education, childcare, primary care) and concerned with the provision
of MH education and advice, MH promotion, and early assessment and prevention in MH.

**Self care**

Definitions of self care vary according to: (a) who engages in the self care behaviour (individual, family, community); (b) what the context is (health promotion, prevention of illness, limiting the impact of illness, restoration of health); and (c) the extent to which health professionals are involved (WHO 1983; DH 2005). A consistent aspect to the various definitions is the conceptualisation of patients/service users as active, knowledgeable individuals rather than passive recipients of health care. The DH (2005) sees self care as “the actions people take for themselves ... 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”.

Self care has currency for a number of reasons: (a) a changing pattern of illness from one of acute to chronic illnesses; (b) a change in philosophy from cure to care; (c) dissatisfaction with depersonalised (and, in MH, often stigmatising) medical care; (d) increases in lay knowledge due to the easy availability of health-related information; (e) consumerism and the desire for personal control in health matters and in interactions with health care professionals; (f) an increased awareness of the role lifestyle plays in relation to longevity and quality of life; and (g) the need to increase access to care while controlling escalating healthcare costs (Health Canada 2002; DH 2005). Research evidence into the effectiveness of self care (DH 2007) suggests it has many benefits: more effective working relationships with professionals can be developed; patient satisfaction increased; self-confidence and sense of control can be increased; improved quality of life; increased concordance with interventions; more appropriate use of services; and increased patient knowledge. Moreover, self care often couples better outcomes with cost savings (Richardson et al 2008).

**Self care, MH and C&YP**

Though the focus on self care to date has largely been on long term, physical conditions (DH 2006; 2009a), it has made some inroads into adult MH. The recent growth in self help for common MH problems (see Lovell et al 2006) and the current emphasis on recovery (HM Government 2009), for example, map well onto a framework of self care.

Self care also dovetails well with general Government policy for C&YP, reflecting themes such as supporting parents and carers in their parenting role, early intervention and the effective protection of children, integrated
working, and the active participation of C&YP. These themes are embedded in Every Child Matters and also contribute towards the realisation of the MH standard (Standard 9) of the Children’s NSF (DH 2004). The need to develop, and enable access to, self care programmes for C&YP is also an inherent part of the more recent Children’s Plan (see DH 2009b). In addition, since self care in MH tends to emphasise interventions that are minimal, empowering and which enhance access to services (Richards et al 2003; Richards 2004), self care is clearly relevant when considering the MH of C&YP.

Self care support

Since self care, by definition, implies that the individual provides the care, our study focuses on self care support rather than self care per se. As the DH (2009a) note, self care support can come in a variety of guises (e.g. information provision, skills training, professional educational) and can be delivered through a variety of platforms (e.g. devices and technologies, real and virtual networks). The NHS has a particular role to play in self care support. Through its organisational structures and networks and the appropriate provision of information, interventions and technologies, it can (indeed, has a responsibility to) create environments that support self care (DH 2005; 2006) - though self care support may, of course, be delivered by other providers in the public, private and third sectors or even spontaneously by service users as is the case in real (physical) or virtual (online) support groups and networks.

Our definitions

Self care is thus “any action a child or YP (or their carers) takes to promote their mental health, to prevent mental ill health, or to maintain or enhance their MH and wellbeing following recovery from illness”.

Self care support is thus “any service, intervention or technology directly or indirectly provided by the public, private or third sectors that aims to enhance the ability of C&YP (or their carers) to self care in relation to their MH and wellbeing”.

Our study, therefore, will not merely focus on self care support for specific MH conditions in C&YP but additionally on self care support that promotes MH, prevents mental ill health or helps maintain MH following recovery.

3. Need:

Given that there is a paucity of research into the area of MH self care in C&YP, our study will make a unique contribution to the existing body of
knowledge while, at the same time, complementing existing research into both children’s services and mental health services.

The need for the study is based on three factors:
- the relative paucity of research on MH self care support for C&YP means that the study has “a capacity to generate new knowledge”, as well as the potential to stimulate “sustained interest and intent” in this area;
- the potential to change and enhance service provision in this area, to the benefit of both the NHS and the service user (there is, therefore, a “health need”, a relevant “organisational focus” and there are certainly “prospects for change”);
- its capacity to build upon existing work.

**Paucity of research**

The MH and wellbeing of C&YP is a relatively under researched area, especially in non specialist (primary care) settings. MH self care support for C&YP is an especially under researched area and how this is currently being commissioned and provided in England & Wales is unknown. There is no Cochrane Library entry for this area of work and the only work we know of that is directly embedded in a self care framework is the work related to ADHD that some of us carried out as part of our previous SDO work (see Kirk et al 2010), a few examples (eating disorders, bedwetting and behaviour disorder) cited in a DH effectiveness report on self care (DH 2007) and a Canadian (non-systematic) review of self-help therapies for childhood disorders (Elgar & McGrath 2008). Some British research has been conducted in primary care settings relating to specific conditions in child MH (e.g. depression in children: the QUEST study; Tylee et al 2008), the promotion of psychological wellbeing in C&YP (especially in schools: the FRIENDS programme; Stallard et al 2007), the generic Social and Emotional Aspects of Learning (SEAL) initiative in schools (Hallam 2009), self help technologies (Ahmead & Bower 2008) and resilience (Hart et al 2007). However, this research has not been systematically explored or coordinated within the wider context of self care support.

**Enhancing service delivery and organisation**

As outlined in the Background section, there is scope for improving service delivery and organisation in both specialist (Tiers 2 to 4) and non-specialist (Tier 1) CAMHS provision. The scope for improvement is perhaps more acute in Tier 1 provision because of: (a) the significant potential it has in promoting MH and preventing mental ill health in C&YP (and so minimising the chances that C&YP might have to be referred to the potentially stigmatising higher CAMHS tiers, though these higher tiers would also benefit through a reduction in inappropriate referrals); (b) improving the quality of life of C&YP and their carers; and (c) reducing inequities in access to services while at the same time...
improving their acceptability and effectiveness. Furthermore, early intervention with C&YP is likely to support healthy psychological development (Herbert 2005) and protect against the long-term impact of childhood mental health problems (Richards et al 2009).

**Previous work**

Given the nature of the SDO call, it is essential that our proposal builds upon previous work. The proposed study builds on both our (Kirk; Pryjmachuk) SDO funded work on self care support in C&YP (Kirk et al 2010) which identified a typology of self care support for long-term conditions in child health, and on the SDO funded work on alternatives to CAMHS inpatient care (Shepperd et al 2009). In addition, Pryjmachuk’s work with on engaging school nurses in mental health work (Pryjmachuk et al, submitted), Kendal’s PhD on emotional wellbeing in schools (Kendal 2009) and Bower’s systematic review on self help technologies in YP’s mental health (Ahmead & Bower 2008) also complement the study.

**4. Methods:**

There are two stages to our study, which is an evidence synthesis combined with primary research. Stage 1 has two interrelated elements that will run concurrently, both of which will help us identify the types of MH self care support available to C&YP. In Stage 1a, we will carry out a systematic search and review of the literature in order to evaluate both the effectiveness and acceptability of MH self care support for C&YP; in Stage 1b, we will carry out a wide-ranging search of service provision relating to MH self care support for C&YP in England & Wales, using the pre-existing self care support typology of Kirk et al (2010) as a framework (see Appendix 1). In Stage 2, we will identify cases that are representative of this typology and collect qualitative data from key stakeholders in each of the cases in order to further explore issues such as acceptability, barriers to implementation and the interface between self care support services and statutory/non-statutory sector provision.

Table 1 (overleaf) outlines how the stages of our study map onto our research objectives.

**Theoretical/conceptual framework**

In the course of our study, we may well encounter a variety of theoretical and conceptual frameworks that underpin MH self care support for C&YP so we do not want to limit ourselves to any particular framework. There are, however, a number of models and frameworks which are bound to influence our work: (a) those relating to empowerment, such as “recovery” in MH (see, for example, Shepherd et al 2008; HM Government 2009), self-efficacy (Bandura 1993) and
social cognition (Conner & Norman 2005); (b) those relating to access, especially in hard-to-reach groups, e.g. the SDO funded work on “candidacy” (how people’s eligibility for services is jointly negotiated between service users and providers; see Dixon-Woods et al 2006); and (c) those relating to service development in MH, such as stepped care (Bower & Gilbody 2005; the SDO project of Richards et al 2006), multiple access levels (Lovell & Richards 2000) and early intervention (Marshall & Rathbone 2006).

Table 1: Cross-referencing of our research objectives and study stages.

<table>
<thead>
<tr>
<th>Objective</th>
<th>Dealt with in</th>
</tr>
</thead>
<tbody>
<tr>
<td>(1) To provide a descriptive overview of the self care support services that exist in England &amp; Wales for C&amp;YP in relation to MH and wellbeing, including a categorisation of these services according to a self care support typology developed in a previous study.</td>
<td>Stages 1a and 1b</td>
</tr>
<tr>
<td>(2) To examine the effectiveness of such services (in terms of their impact on the psychosocial wellbeing and mental health of C&amp;YP and their families).</td>
<td>Stage 1a</td>
</tr>
<tr>
<td>(3) To examine the factors influencing the acceptability of such services to C&amp;YP and their families.</td>
<td>Stage 1a; Stage 2</td>
</tr>
<tr>
<td>(4) To explore the barriers to the implementation of MH self care support services for C&amp;YP.</td>
<td>Stage 2</td>
</tr>
<tr>
<td>(5) To explore the interface between such services and the NHS and other statutory and non-statutory service providers in order to guide future planning in health and social care.</td>
<td>Stage 1b; Stage 2</td>
</tr>
<tr>
<td>(6) To identify future research priorities for the NHS in this area.</td>
<td>All Stages</td>
</tr>
</tbody>
</table>

Stage 1a: A systematic review and evidence synthesis of the literature to establish the effectiveness and acceptability of MH self care support for C&YP

The literature review will consider the effectiveness and the acceptability of MH self care support for C&YP concurrently. We will use standard systematic review techniques (e.g. University of York CRD 2009; Higgins & Green 2009) for this stage of the project, though we will be sensitive to the particular issues we expect to encounter (such as significant methodological heterogeneity).

a. Setting - ‘Desk’ research examining MH self care support for C&YP worldwide

b. Design - Systematic review

Review question: Our review question which is “what empirical studies have been undertaken on MH self care support for C&YP, and what is the evidence for the effectiveness and acceptability of such support?”
Inclusion criteria: Using an adaptation of the “PICOS” framework (University of York CRD 2009) our inclusion criteria are as follows:

- Population: “Children and young people”, defined as those under the age of 18. This reflects the definition of the UN Convention on the Rights of the Child, of which the UK is a signatory (UN General Assembly 1989). However, there is often ambiguity at the top of the childhood range (17+) because of differing international views of the age range for a “young person”. Thus, we will consider studies with populations that include young people up to 25 years so long as the majority of participants are under 18. Because children’s services tend to have natural demarcations at 4-5, 11-12 and 16 years, the population will be divided into natural subgroups, e.g. pre-school (0-4), primary school (5-11) and young people (12-17).

- Interventions: Using our definition of self care, we will include any health, social care or educational intervention that facilitates C&YP (or their carers) taking action to promote their mental health, to prevent mental ill health, or to maintain or enhance their MH and wellbeing following recovery from illness. We will, therefore, include self care interventions which support C&YP with specific MH problems as well as those that designed to improve the emotional/psychological wellbeing of C&YP.

- Outcomes: For the effectiveness review, we are interested in whether interventions are effective, that this whether there is a demonstrable positive change in a child or young person’s MH health, psychological, social and emotional wellbeing, family functioning or quality of life, evidenced through formal, validated measures of these outcomes. For the acceptability review, we are interested in outcomes such as uptake of the intervention, adherence to it and participant satisfaction.

- Study design: For the effectiveness review, we will initially consider all quantitative studies in which there is, at minimum, a pre- and post-test outcome measure. However, final decisions about inclusion will be based on the scope and quality of the evidence (e.g. if there are a number of trials in relation to certain self care interventions, we may exclude non-randomised designs if they do not materially add to the evidence base). For the acceptability review, we will include qualitative or quantitative designs in which either participants’ views are expressed or in which participation and/or adherence rates are available.

c. Data collection

Search strategy: We will search research, professional, policy and grey literature using systematic search strategies in appropriate databases. Published searches (e.g. those in the Cochrane Library) and our knowledge of the background literature will be the starting place for the identification of the search terms we will employ, augmented by reference to thesauri (e.g. the Medical Subject Headings (MeSH) thesaurus) and advice from our advisory group. We will search the electronic health (e.g. Cochrane Library, MEDLINE,
CINAHL PsycINFO), social care (e.g. Campbell Collaboration, ASSIA, Social Care Online) and educational (e.g. ERIC) databases. In addition, we will search the reference lists and bibliographies of retrieved articles for relevant materials that our search may have missed, and we will contact authors of any recent or ongoing studies we are aware of to see if publications are available. While no limiters will be applied to our search, the relevance of any international material will be determined following consultation with our advisory group. The concurrent Stage 1b search (see below) may also elicit some appropriate material.

Review strategy: For both the effectiveness and acceptability reviews, two members of the research team will independently screen titles and abstracts for relevance. Disagreements will subsequently be resolved through discussion with other members of the team. Articles will then be allocated to the effectiveness review, the acceptability review or both, and full copies of the articles obtained.

d. Data analysis

Data extraction and quality assessment: Each of the full articles selected for inclusion will be delivered to two members of the team for review, data extraction and quality assessment. Data extraction and quality assessment will be performed by two reviewers independently. Discrepancies will be resolved by referral to the original studies and if necessary through arbitration by a third reviewer. For studies selected for the effectiveness review, we will first use the NICE algorithm for classifying study designs for effectiveness (NICE 2005) to categorise the studies (as RCT, non-randomised trial, time series design, cross sectional study, case control study or cohort study). Data will be extracted and quality assessed using an appropriate combined data extraction/quality assessment sheet for each study design category. For example, we will use the Cochrane Collaboration Risk of Bias tool for RCTs, with relevant modifications when certain criteria (e.g. blinding) are less appropriate for this particular literature. For the acceptability review, we will use a modified version of the data extraction/quality appraisal sheet used in our (Kirk; Pryjmachuk) previous SDO study (Kirk et al 2010). Thus, quality assessment for this aspect of the study will be based on criteria adapted from Dixon-Woods et al (2006) and the EPPI Centre (Shepherd et al 2006).

Data synthesis: If sufficient effectiveness data are available involving types of self care interventions which can be meaningfully compared, we will undertake a meta-analysis on the data. Relevant outcome data will be translated to a standardized effect size using conventional methods (Higgins & Green 2009). All analyses will be conducted using Stata. Initial meta-analyses will use a fixed or random effects model depending on considerations of clinical and statistical heterogeneity, the latter assessed with the $I^2$ statistic. We will conduct assessments of publication bias using funnel plots, and assess the impact of study quality, population and intervention characteristics using
sensitivity analysis and meta-regression where indicated. If insufficient data are available for a meta-analysis, we will undertake a structured narrative review, assessing strength of evidence for relevant types of self care support interventions (perhaps using our pre-existing typology; see Stage 1b) on the quality of the evidence and the pattern of results across studies.

For the acceptability review, we suspect that we will find a mix of qualitative and quantitative evidence. We will, therefore, use a technique for synthesising both qualitative and quantitative data, e.g. the “integrated” review technique of Thomas et al (2004) that Waller & Gilbody (2009) used in a recent systematic review of barriers to uptake in computerized CBT.

Whatever the literature holds, the team is sufficiently experienced in different evidence synthesis methods to be able to produce, through systematic approaches, a robust evidence synthesis.

Stage 1b: A wide-ranging online and offline search to identify the range and type of MH self care support for C&YP provided in England & Wales.

Our starting point for this stage of the project is the typology from our (Kirk; Pryjmachuk) previous SDO work on self care support (Kirk et al 2010; see Appendix 1). Using this typology, we will conduct an online and offline search to identify the range and type of MH self care support for C&YP provided in England & Wales. We will use the results of this search to confirm or modify our typology before selecting representative case studies.

a. Setting - ‘Desk’ research examining MH self care support for C&YP in England and Wales

b. Design - Systematic online and offline search

Inclusion criteria: The population is the same as for Stage 1a. Since we are concerned with services rather than interventions, we will look for service provision that facilitates C&YP (or their carers) taking action to promote their mental health, to prevent mental ill health, or to maintain or enhance their MH and wellbeing following recovery from illness. Since the work undertaken in this stage will provide the sampling framework for Stage 2, we will limit the search to current services in England & Wales or those that have provided in the previous 2 years.

c. Data collection

Search strategy: For the online (Internet) search we will use a variety of standard and academic Internet search engines such as Google, Intute, Yahoo and Bing. The offline search will be facilitated through the contacts and networks we already have (our advisory group; key third sector organisations such as Young Minds, 42nd Street, and Self Care Connect; professional
groups such as the Royal Colleges of Nursing, General Practice and Psychiatrists, Schools & Students Health Education Unit, Centre for Studies in Childhood & Youth, CAMHS Nurse Consultants network; and electronic networks such as the CAMHS jiscmail group and relevant CHAIN mailing groups). The search terms that we identify for Stage 1a are also appropriate for this stage.

d. Data analysis

*Confirmation or modification of existing typology:* We will examine the data obtained in terms of its fit to our pre-existing typology. Should modifications of the typology be required, this will be discussed and explored with our advisory group.

**Stage 2: Case Studies**

a. *Setting* – Providers of MH self care support for C&YP in England and Wales

b. *Design* - A qualitative, case study design, using data elicited from focus groups, individual interviews and pertinent documents.

*Sampling:* Six cases of services providing self care support will be purposively selected so that they reflect the different dimensions of Stage 1b’s typology, e.g. target (C&YP; carer; professional), location (school; home; clinic), medium (real; virtual), individual or group. The setting/context is thus statutory and non-statutory services providing MH self care support for C&YP. The specific case study sites will be determined in consultation with our advisory group. Sampling within the case study sites will also be purposive in that we will ensure that a range of appropriate stakeholders are invited to participate (e.g. both younger and older children; siblings, parents and carers; health, social care and education professionals; and volunteers).

c. *Data collection*

Data collection from each of the case study sites will vary according to the nature of the service and the preferences of the participants but we expect to use a range of methods, e.g. individual interviews (in person or by telephone), focus groups and documentary review (of operational manuals, Internet forum postings, service evaluations, etc). Topic guides for the individual and focus group interviews will be informed by the evidence syntheses and in consultation with our advisory group. All of the interviews will be audio recorded and subsequently transcribed. Non-professional participants (e.g. C&YP and parents) will be offered £10 in gift vouchers as a token of thanks for participation.
Across each service, we would wish to collect data from: (a) C&YP; (b) parents, carers and/or siblings; and (c) those providing the service. We expect to exploring some virtual or online services as well as visiting a number of sites in person. Table 2 contains a summary of the data we might typically collect for this stage of the study, based on: (a) our (Kirk; Pryjmachuk) experiences in our previous SDO study; (b) the realities of recruiting research participants; and (c) a need to ensure that we reach data saturation (e.g. Guest et al 2006 suggest a minimum of 12 interviews per participant subset). Because we will not know what services are available across England & Wales until we have completed Stage 1b, it is important to note that Table 2 provides only an example and is not a definitive plan for data collection.

Table 2: Example of how data might be collected across the six cases.

<table>
<thead>
<tr>
<th>Example site</th>
<th>C&amp;YP</th>
<th>Parents/Carers</th>
<th>Professionals</th>
</tr>
</thead>
<tbody>
<tr>
<td>(1) Face-to-face third sector provided service for young people (12-17)</td>
<td>1-2 focus groups of 6-8 C&amp;YP</td>
<td>6-8 email or telephone interviews</td>
<td></td>
</tr>
<tr>
<td>(2) Face-to-face third sector provided service for younger children (under 12s)</td>
<td>6-8 face-to-face interviews with C&amp;YP</td>
<td>6-8 email or telephone interviews</td>
<td></td>
</tr>
<tr>
<td>(3) NHS provided face-to-face service for young people</td>
<td>1-2 focus groups of 6-8 C&amp;YP</td>
<td>6-8 telephone or face-to-face interviews</td>
<td></td>
</tr>
<tr>
<td>(4) NHS provided face-to-face service for parents of younger children</td>
<td>2-3 family focus groups of involving 4-6 parent-child dyads</td>
<td>(See C&amp;YP)</td>
<td></td>
</tr>
<tr>
<td>(5) “Spontaneous” online support service for young people</td>
<td>Individual webcam interviews with 6-8 young people</td>
<td>6-8 email or telephone interviews</td>
<td></td>
</tr>
<tr>
<td>(6) Online support service provided by the third sector for parents of younger children</td>
<td>Transcript of forum discussion (but it may be difficult to access younger children online)</td>
<td>6-8 email or telephone interviews</td>
<td></td>
</tr>
</tbody>
</table>

**Total data sources for all sites**

<table>
<thead>
<tr>
<th></th>
<th>4-7 focus groups</th>
<th>12-16 individual interviews</th>
<th>30-40 individual interviews</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>1 forum transcript</td>
<td>1 forum transcript</td>
<td>Pertinent service-related documents</td>
</tr>
</tbody>
</table>
d. Data analysis

The data obtained from the 6 case study sites will be managed and stored according to the University of Manchester’s Code of Good Research Conduct (2006) and Information Governance in Health and Social Care Research (2007). The data obtained from the focus groups and individual interviews will be transcribed prior to analysis. All of the qualitative data will be analysed using “framework” (Pope et al 2000; Ritchie & Lewis 2003), a matrix based analytic method developed by Ritchie & Spencer (1994) that facilitates rigorous and transparent data management and which is widely used by qualitative researchers where there are pre-determined objectives for analysis. Framework has five stages and how these stages apply to this study is as follows:

(i) data familiarisation – the raw data (transcripts and audio recordings, etc.) will be read/listened to several times to ensure that we are familiar with the data;
(ii) identification of a thematic framework – the study’s aims, literature review and topic guides will be used to draw out issues, concepts and themes;
(iii) indexing – the thematic framework will be organised according to a number of themes and subthemes;
(iv) charting – the data will be “charted” into a matrix (using qualitative data management software such as Nvivo) according to its themes and subthemes; and
(v) mapping and interpretation – the charts from stage (iv) will be employed to map and interpret the data; in particular that data will need to be interpreted in relation to the acceptability and accessibility of self care support services, the barriers to their implementation and the interface between self care support and statutory/non-statutory provision.

5. Contribution of existing research:

Our study is complementary to a number of completed, ongoing and planned studies and initiatives that have the potential to influence NHS service delivery and organisation in C&YP’s mental health. These studies and initiatives include: the completed SDO work of Kirk et al (2010) and Shepperd et al (2008); NICE guidance on emotional wellbeing in primary and secondary education, depression in C&YP and parent training; the Children’s Services Mapping initiative (see www.childrensmapping.org.uk); systematic reviews on self care (e.g. Bower et al 2001; Ahmead & Bower 2008); major randomized trials that contain elements of self care support (e.g. the QUEST trial on depression in C&YP, Tylee et al 2008; HTA funded SHIFT trial on self harm in C&YP, Cottrell et al 2009); and potential future research by members of the team such as a planned RfPB bid on engaging school nurses in supporting C&YP who self-harm (PI: Pryjmachuk; Kendal and Young Minds will be co-
Our service user involvement is via Young Minds, a specialist mental health charity for C&YP and their carers. This is the first time that Young Minds have been involved in an NIHR application and it paves the way for Young Minds and the C&YP they work with to have a greater voice in NHS-commissioned research relating to the mental health of C&YP. Given Young Minds’ expertise in communicating and disseminating information relating to C&YP’s mental health, applications such as this are mutually advantageous in that Young Minds is able to work in partnership with an organisation - the NHS - that is a key provider of services to the C&YP it speaks on behalf of and the NHS gains a valuable platform for the dissemination of any relevant research it commissions.

Our study will have a number of outputs. We will provide:

- syntheses of evidence for the effectiveness and acceptability of MH self care support for C&YP;
- local/national intelligence from our synthesis of service provision data (which may, for example, be useful for the national Children's Services Mapping programme);
- the identification of future NHS research priorities;
- an SDO monograph.

Salient findings of the study will be disseminated in a variety of media to suit a variety of audiences. For example, we plan an end of project ‘workshop’ for appropriate stakeholders. For the academic and research community, we expect several papers to be published in high-quality, peer-reviewed journals, and to present at national/international conferences; we also expect to publish papers and brief reports in the professional and third sector press (Young Minds’ experience will be invaluable here) and at suitable professional events, especially those targeted at NHS managers; and we will provide reports suitable for lay audiences, C&YP and their families in particular. Young Minds’ experience will also be invaluable here, especially if their trained young people - “Very Important Kids” or VIKs (see the Service user/public involvement section) - are involved. We intend to take advantage of electronic channels of communication (websites, mailing lists, social networking sites, podcasts, blogs, etc.) to further disseminate our work, and will seek advice from Young Minds, their VIKs and from our advisory group as to which of these are likely to be the most fruitful.

6. Plan of Investigation:

Prior to the study starting: pre-study liaison with SDO; appointment of the advisory group; appointment of full-time researcher. Months 1-3: first advisory group meeting; develop search/review protocol; review/modify data extraction sheets. Months 2-6: refining search strategies for concurrent stages 1a and 1b; conducting Stage1 searches; Stage 1a data extraction and quality
assessment. **Months 6-8:** data synthesis for Stage 1a; confirmation/modification of the typology for Stage 1b. **Months 7-12:** deal with ethical aspects of Stage 2. **Months 7-9:** identify case study sites. **Months 8-11:** write up Stage 1. **Months 8-16:** data collection at case study sites. **Months 9-17:** transcribing of case study data. **Months 11-13:** prepare interim report. **Month 12:** second advisory group meeting. **Month 13:** submit interim report. **Months 17-19:** case study data analysis and Framework mapping. **Months 19-22:** writing up of case studies. **Months 21-23:** writing of final report. **Months 23-24:** internal peer review of report (by advisory group). **Month 23:** third (final) advisory group meeting. **Month 24:** Final report submission. **Month 24 and onwards:** dissemination.

### 7. Project Management:

The study will be managed principally by Pryjmachuk who is experienced in managing both educational and research projects.

The study will be guided and supported through ongoing consultation with a Stakeholder Advisory Group, drawn from our networks of contacts within the statutory (e.g. health, social care and education) and non-statutory/third sector organisations. Health representatives will include CAMHS professionals such as psychiatrists, nurses and occupational therapists; social care representatives will include professionals such as social workers; and education will be represented by teachers and pastoral care and welfare professionals. The group will also include parents, carers and, if not C&YP themselves, independent advocates for C&YP. We will appoint one member of the advisory group as an independent chair. There is nothing to prevent a young person from having this particular role, though whether a young person takes on this role or not and whether C&YP will join a single Stakeholder Advisory Group will be guided by: (a) the age of the young people involved, given that Young Minds’ VIKs (see the Service user/public involvement section) are aged up to 24; (b) INVOLVE’s recommendations (*Guide to Actively Involving Young People in Research*; Kirby 2004), particularly those relating to asking young people how they want to be involved and ensuring that their participation is not token or manipulated by adults; and (c) co-applicant Catchpole’s expertise in this area. The advisory group will meet face-to-face three times; ongoing communication with the advisory group will occur through the use of a private electronic mailing list, open only to the research team and the advisory group.

### 8. Service users/public involvement:

Often the best perspectives on services come from those who use them; it is essential, therefore, that research into healthcare service delivery and organisation includes the voice of the service user. Our principal service user involvement will come from Young Minds, for whom one of the co-applicants
(Catchpole) works. Though Young Minds have already been involved in the study’s design through critical review of this proposal, we are keen to explore the potential of Young Minds’ Very Important Kids (VIKs) being involved in this study. The VIKs are a group of 25 C&YP aged 11 to 24, who represent young people across the UK and advise Young Minds on policy and campaign objectives. As explained in the Project management section, the VIKs may be able to join the Stakeholder Advisory Group. However, if the advice we receive from Catchpole and, indeed, from the VIKs themselves is that the advisory group is unsuitable (perhaps because of worries about their voices being drowned out by professionals, parents and adults in general), we will establish a Young Person’s Advisory Group in parallel to that of the Stakeholder Advisory Group. We have, therefore, costed the VIKs into the bid (via payments to Young Minds) on the basis that they will play a significant role in the study (see Table 3 below). We will also ensure that the contribution of individual VIKs is acknowledged through appropriate hospitality and reimbursement of expenses.

As outlined in the Project management section, we will ensure that parents and other family members, who may well be service users by proxy, are represented on the Stakeholder Advisory Group.

In terms of service user involvement in each of the various stages of the study, Table 3 below outlines our expectations of their involvement.

<table>
<thead>
<tr>
<th>Stage</th>
<th>Details of potential VIK involvement</th>
</tr>
</thead>
<tbody>
<tr>
<td>Drafting of the study proposal</td>
<td>Senior members of Young Minds have reviewed, and commented on, the outline and full proposals</td>
</tr>
<tr>
<td>Stage 1a: systematic review of effectiveness and acceptability</td>
<td>Advising on the search terms and synthesis themes</td>
</tr>
<tr>
<td>Stage 1b: Search to confirm/modify the typology of self care support</td>
<td>Advising on the search strategy, particularly in relation to the contacts and networks they may have; advising on the “fit” of our data to the typology; confirming the typology or recommending modification</td>
</tr>
<tr>
<td>Stage 2: Case studies</td>
<td>Advising on: case study site selection; strategies for recruiting participants; the design and content of information sheets, and consent/assent forms; the topic guides for focus groups/ interviews; methodology (e.g. viability of e-methods such as email discussions or webcam interviews); critical readers of data analyses</td>
</tr>
<tr>
<td>Production of a report for the SDO</td>
<td>Giving feedback on any initial findings; critical review of final report</td>
</tr>
<tr>
<td>Dissemination</td>
<td>Advising on a dissemination strategy, especially to lay audiences and C&amp;YP, and in relation to the media channels used</td>
</tr>
</tbody>
</table>
9. References:


Routledge.


Thomas J, Harden A, Oakley A, Oliver S et al (2004). Integrating qualitative research with trials in systematic reviews. *British Medical Journal, 328*, 1010-1012.


*This protocol refers to independent research commissioned by the National Institute for Health Research (NIHR). Any views and opinions expressed therein are those of the authors and do not necessarily reflect those of the NHS, the NIHR, the SDO programme or the Department of Health.*
# Appendix 1

Self-care support typology (Kirk et al 2010)

<table>
<thead>
<tr>
<th>THEORETICAL BASIS: e.g. social learning theory, CBT</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>TARGET</strong></td>
</tr>
<tr>
<td>Child/young person</td>
</tr>
<tr>
<td>Parent</td>
</tr>
<tr>
<td>Child &amp; parent</td>
</tr>
<tr>
<td>Siblings</td>
</tr>
<tr>
<td>Peers</td>
</tr>
<tr>
<td>Professionals</td>
</tr>
<tr>
<td>Health care system</td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
</tbody>
</table>

**INDIVIDUALISATION** – tailoring of self care support to the individual/group/locality