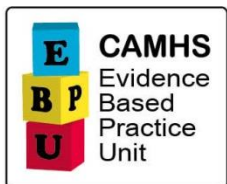# DEFINING AND MEASURING MENTAL HEALTH AND WELLBEING IN CHILDREN

A response mode report requested by the Department of Health for the Policy Research Unit in the Health of Children, Young People and Families

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EXECUTIVE SUMMARY

Background:

The Children and Young People's (CYP's) Health Outcomes Forum was launched in 2012 to bring together expertise in the fields of children and young people's health and care. One of the aims of the Forum was to identify the health outcomes that matter most to children and young people and consider the best ways to capture these outcomes.

Aim:

In light of the requirements of the CYP Health Outcomes Forum, the Department of Health requested the Mental Health Stream of the Policy Research Unit in the Health of Children, Young People and Families (CPRU) conduct a rapid, pragmatic consideration of approaches to defining and measuring mental health and well-being in children.

Procedure:

A Delphi-style consultative exercise was conducted with a range of experts in the fields of clinical practice, research and service use concerning children and young people with mental health problems. The exercise consisted of three rounds: in Round 1, experts responded to a questionnaire; in Round 2, experts convened in a face-to-face meeting; and in Round 3, experts reviewed the findings and conclusions of the project.

Findings:

A good outcome is best reflected by taking consideration of three potential levels: the child or young person level, the interpersonal level and the service/societal level. The range of relevant outcomes could include child, caregiver, teacher and clinician perspectives on symptom improvement/maintenance, achievement of goals, functioning, 'empowerment and self-efficacy', interpersonal relationships, service engagement and service satisfaction (for the full list, see Table 3.1.). The specific outcome prioritised—in terms of who reports, which outcome and at what level—is likely to depend on the age of the child or young person and the nature of the problem.

Recommendations:

Existing data capture procedures—including those developed for Children and Young People's Increasing Access to Psychological Therapies (CYP IAPT), Payment by Results (PbR) and the Child and Adolescent Mental Health Services Minimum Dataset (CMDS)—already capture the majority of relevant outcomes identified through this consultation. 'Empowerment and self-efficacy' was identified as the only domain important to assessing whether a good outcome has been achieved that is not currently captured in existing datasets and it is suggested that selecting an appropriate measure for this domain should be a priority.

What constitutes a good outcome and what does recovery look like?

Respondents of the Round 1 questionnaire and Round 2 meeting identified that it was important to capture a range of outcomes that provide a meaningful picture of the child or young person in context. To do so, outcomes at three levels may need to be captured: the child or young person level, the interpersonal level and the service/societal level.

Potential outcomes at the child or young person level

A good outcome for children and young people could involve symptom improvement/maintenance, achievement of goals, functioning (e.g., attendance at school or work) and appropriate discharge. It was suggested that it might be important to also consider 'empowerment and self-efficacy' or the subjective experience of the individual's capacity to manage mental health and daily life, particularly in instances where the actual presenting problem is unlikely to change substantially.

Potential outcomes at the interpersonal level

A good outcome for children and young people is improved interpersonal relationships, in terms of family or school relationships. This would reflect an improvement in the impact symptoms have on the child or young person's daily life and the daily life of significant others, in addition to significant others' ability to manage the child or young person's symptoms.

Potential outcomes at the service/societal level

A good outcome for children and young people is receiving high quality support from society (i.e., family, school, peers, community/neighbourhood and mental health and other appropriate services). This would reflect improving the support provided to the child or young person, and it could be assessed with service engagement, service user satisfaction, linkage between the child or young person's support network and best practice followed.

GLOSSARY

Term	Definition or Explanation
CAF	Common Assessment Framework; a process whereby a practitioner can identify a range of needs a child or young person has to determine which types of professionals should be involved in providing support
CAMHS	Child and Adolescent Mental Health Services
CBDS	Common Basic Data Set; datasets routinely collected by schools, local authorities and other children's services. It is comprised of the NPD and in future will be linked to CIN data
CGAS	Children's Global Assessment Scale; a measure of emotional and behavioural functioning
CHI ESQ	Commission for Health Improvement Evaluation of Service Questionnaire; a service satisfaction measure
CIN	Children in Need census; covers all children referred to Children's Social Care Services
CMDS	CAMHS Minimum Data Set; datasets routinely collected by NHS funded CAMHS
CP-IS	Child Protection – Information Sharing project; central data storage of information about CYP subject to child protection plans or looked after child status so health professionals will be informed of the CYP's child protection status when registering the CYP at their care setting
CYP	Child or Young Person
CYP IAPT	Child and Young People's Increasing Access to Psychological Therapies
EET	Education, Employment or Training; questions in the CYP IAPT dataset asking about CYP's activities
GBO	Goal Based Outcome; measure used to evaluate progress towards a goal in clinical sessions
HES	Hospital Episode Statistics; dataset containing information on all admissions, outpatient appointments and Accident & Emergency attendances at NHS hospitals in England
HoNOSCA	Health of the Nation Outcome Scales for Children and Adolescents; measures problems and impairment
NPD	National Pupil Database; wide range of data on students in schools and colleges in England
PbR	Payment by Results; a pilot project to ascertain whether payment for CAMHS can be determined according to the amount of clinical resources required by the CYP accessing the service
PSI	Parent Stress Index for identifying dysfunctional parent-child systems
RCADS	Revised Child Anxiety and Depression Scales for assessing anxiety and depressive disorders
SCORE 15	Systemic Clinical Outcomes in Routine Evaluation; a measure of family functioning
SDQ	Strengths and Difficulties Questionnaire for screening behavioural problems

SLDOM	Sheffield Learning Disability Outcome Measure; a measure of parents' perception of their child's symptoms and their ability to cope with their child's symptoms
TAC	Team Around the Child; a process whereby practitioners from a range of backgrounds can gather and assess information on a child or young person's needs
WPES	Woolgar Parental Efficacy Scale; this measure captures parents' perceptions of their confidence and capability to manage their child
YES-MH	Youth Empowerment Scale – Mental Health; a measure of empowerment for CYP with mental health problems

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1. BACKGROUND

The Children and Young People's (CYP's) Health Outcomes Forum was launched in 2012 to bring together expertise in the fields of CYP's health and care (Children and Young People's Health Outcomes Strategy, 2012a). The Forum consulted with over 2,000 CYPs, families and health and social care staff, with the aim of:

- Identifying the health outcomes that matter most to CYP

- Considering how well these outcomes are supported by the NHS and Public Health Outcomes Frameworks

- Planning the contribution that each part of the new health system needs to make in order that these health outcomes are achieved

The Forum set out a number of high level objectives in its Mental Health Strategy (Children and Young People's Health Outcomes Strategy, 2012a). For the Forum to meet its first two objectives, in particular—*"More children and young people will have good mental health"*, *"More children and young people with mental health problems will recover"* (p.11)—it needs to know how to define and measure mental health and well-being in children. The Department of Health (DH) requested the Mental Health Stream of the Policy Research Unit in the Health of Children, Young People and Families (CPRU) conduct a rapid, pragmatic consideration of approaches to defining and measuring mental health and well-being in children, with a particular focus on:

1. Approaches to measuring mental health and well-being

2. Outlining what constitutes a good outcome as defined by key stakeholders (including what 'recovery' looks like)

3. Reviewing current approaches to measuring mental health and well-being in children in existing datasets and identifying any gaps

4. Eliciting views from key stakeholders as to how old a child should be in order to self-report on their mental health and well-being

Work already carried out by those involved in CPRU is of relevance to this response mode project. In particular, a review of mental health and well-being measures, which provided recommendations around measures a) for routine use in CAMHS and b) to gauge population level mental health and well-being (Wolpert et al., 2008). Full recommendations are detailed in the review and focus specifically on self-reported measures of subjective well-being, including quality of life measures. A recent update of this review was also carried out as part of the CPRU mental health strand (Deighton et al., submitted), which details a small range of broad mental health self-report measures suitable for routine use in services, some of which have been used as universal population well-being measures or as broad population-based screening tools. Other recent work of relevance to national population-based measures of well-being has been carried out by the Office for National Statistics and considers a range of domains for well-being including subjective well-being, health (including mental health), education, skills and personal finance (Joloza, 2013).

In terms of measures of mental health and well-being suitable for routine use in CAMHS, the outcomes review described above also identified a number of psychometrically robust measures suitable for this purpose. However, this work has been further advanced by advice on routine outcome monitoring developed as part of the CYP Increasing Access to Psychological Therapies (IAPT) project and the expansion of the CAMHS Minimum Data Set.

Given this groundwork, and the timescales for the current project, it was agreed to focus on the insights of selected experts to:

1. Consider what constitutes a good outcome and what recovery looks like
2. Appraise what exists in national datasets for currently used measures and identify any gaps
3. Explore what age they consider children can reliably self-report

2. METHOD

2.1. Procedure

A Delphi-style (Turoff, 2002) consultative exercise was conducted in order to address the questions outlined above. CYP mental health stakeholders were recruited using existing Child and Adolescent Mental Health Services (CAMHS) Evidence-Based Practice Unit (EBPU) networks (e.g., CAMHS Outcome Research Consortium [CORC], CYP IAPT, CAMHS, Payment by Results [PbR]). The exercise consisted of three Rounds.

Round 1 involved a questionnaire (see Appendix A), which was distributed to key clinicians, researchers, commissioners and service users/advocates.   The questionnaire asked respondents to describe what a good outcome for CYP accessing mental health services is, how the outcome might be captured and who would report the outcome. Respondents were asked to report on outcomes for CYP divided across the age bands of 15-19 years, 10-14, 5-9 and 1-4, consistent with the CYP Outcomes Strategy (Children and Young People's Health Outcomes Strategy, 2012a). Respondents were also asked for outcomes when problems were likely to show change, when problems were unlikely to show change and when the work was assessment-only.

To help participants generate a comprehensive array of outcomes, clinical experience was drawn on in the project set up phase regarding how to consider different problems types. It was agreed to consider different problems referred for specialist help in terms of three categories: "likely to change" (e.g., acute onset anxiety); "less likely to show change" (e.g., emerging personality disorder, some autistic spectrum disorders); and referred for assessment-only, where the intended outcome might be aimed more at understanding the problem or establishing levels of difficulty (e.g., assessment for autism; see Appendix A for the questionnaire). These categories were used to aid participants' reporting and were not implied to be strict clinical bands.   In the Round 2 face-to-face meeting, attendees commented that these different problem types were useful in considering different types of outcomes and when outcomes may be more or less applicable.

Round 2 involved a face-to-face meeting, reviewing the results from the Round 1 questionnaire (see Table B.1., Appendix B for the results of the Round 1 questionnaire). Attendees added to the list of outcomes and explored reasons for outcome selection. Round 2 also involved follow up email correspondence with attendees clarifying and refining the results of the discussion. Three members of the research team attended the Round 2 consultation: one to facilitate discussion (MW), one to present an overview of the project and coordinate the discussion (JD) and one to present the findings of the Round 1 questionnaire and record notes of the discussion (JC). An external facilitator, independent of the research team, was the overall facilitator of the consultation and reviewed all subsequent material.

Round 3 involved email correspondence and discussion with the original list of Round 1 respondents. Here, the results of the Round 1 questionnaire and Round 2 meeting were summarised and respondents were directed to reach a consensus on which key outcomes should be captured and how these outcomes should be measured.

2.2. Participants

The Round 1 questionnaire was sent to 36 stakeholders who had been identified from national networks as being leading experts in clinical practice, research and service user representation for CYP mental health. Responses to the Round 1 questionnaire were given by four respondents with expertise in clinical practice, three in research[1], one in service user advocacy and four in experience of service use. For Round 1, the service user advocate conducted a consultation with eight CYP with experience of service use. For Round 2, the service user advocate conducted a consultation with four CYP in addition to individual interviews with two CYP. These consultations and interviews with CYP were also summarised in two separate reports, which have informed this final report (see Appendix C for summaries of the CYP consultation reports).

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[1] Some respondents had overlapping areas of expertise and hence are counted as both experts in clinical practice and research.
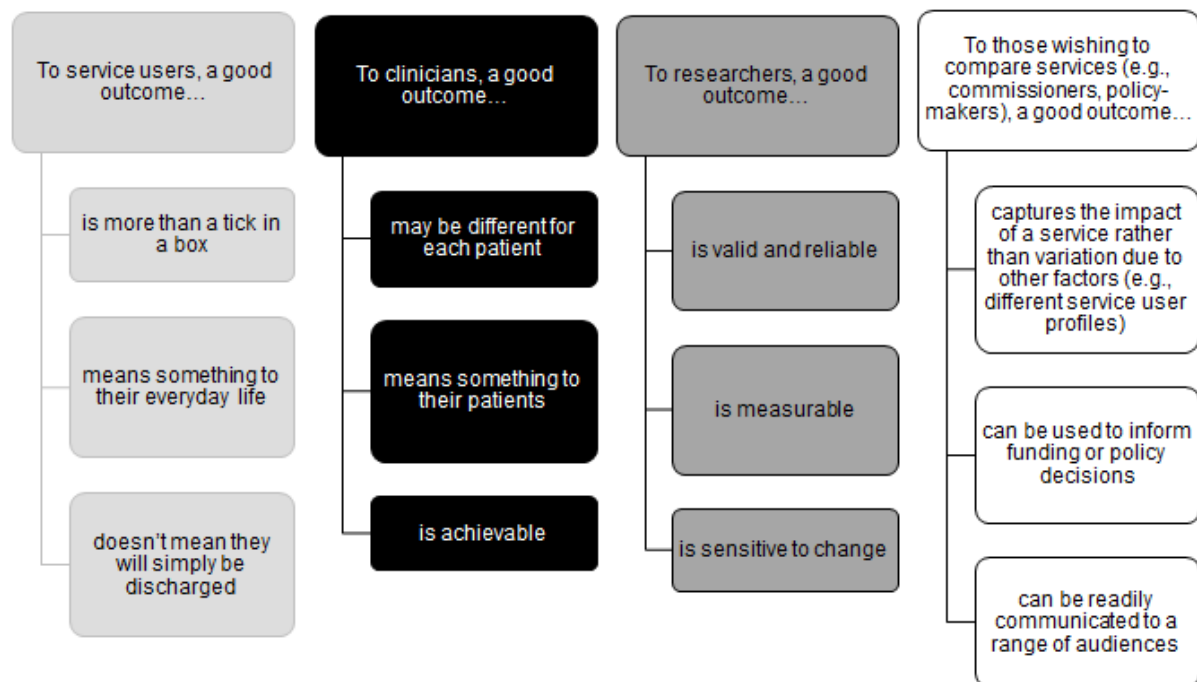
Although not everyone who responded to the Round 1 questionnaire attended the Round 2 consultation, and vice versa, representatives of each stakeholder group who completed the Round 1 questionnaire did attend the Round 2 consultation, in line with the Delphi method (Keeney, Hasson, & McKenna, 2011; Turoff, 2002). In particular, two representatives with expertise in the service user perspective, five with clinical expertise and two with research expertise attended the consultation; in addition, one commissioner attended the consultation although this group had not been represented in the Round 1 questionnaire.

2.3. The context of the results

2.3.1. Underlying assumptions

Following the Delphi method (Keeney et al., 2011; Turoff, 2002), as part of the exercise to understand different perspectives, the research team created a matrix of possible assumptions of particular importance to different stakeholders, underpinning what they might consider to be a good outcome; this matrix was shared with participants to prompt a comprehensive exploration of the range of potential outcomes. Illustrative examples of some particular concerns to different CAMHS' stakeholders are shown in Figure 2.3.1., overleaf.

Figure 2.3.1. CAMHS' stakeholders and illustrative examples of assumptions underpinning what constitutes a good outcome.

To service users, a good outcome…	To clinicians, a good outcome…	To researchers, a good outcome…	To those wishing to compare services (e.g., commissioners, policy-makers), a good outcome…
is more than a tick in a box	may be different for each patient	is valid and reliable	captures the impact of a service rather than variation due to other factors (e.g., different service user profiles)
means something to their everyday life	means something to their patients	is measurable	can be used to inform funding or policy decisions
doesn't mean they will simply be discharged	is achievable	is sensitive to change	can be readily communicated to a range of audiences

Different CAMHS's stakeholders may have different expectations and needs related to outcomes; for example, attendees commented on the importance to CYP and clinicians of being explicit at the start of therapy about what a good outcome might look like: *"Realistic discussions [are needed]…I think people are scared to say 'well, this isn't gonna go away'"* (CYP). Good outcomes may be perceived from a number of complex and, at times, competing viewpoints. Different types of outcomes, or the same outcome presented in a different format, may be necessary to meet these disparate information needs. The focus of this report is on defining and measuring mental health and well-being in light of the requirements of the Forum (Children and Young People's Health Outcomes Strategy, 2012a). Hence, the focus is on informing policy makers and others looking to understand outcomes at the service level about what constitutes a good outcome. However, guidance developed here is mindful of requirements for these other stakeholder groups and of avoiding excessive burden and duplication of work so focuses on approaches that are achieved without sacrificing clinical utility and outcomes of relevance to other CAMHS' stakeholders.

2.3.2. Additional considerations

When determining a good outcome based on an outcome measure, it is important to establish how much change is enough to warrant classification as a 'good outcome'. A range of approaches exist (see Wolpert, Görzig, Deighton, Fugard, & Ford, submitted[2]) but commonly adopted approaches include significance testing of differences between tests for pre-post scores, establishing whether reliable change has occurred (i.e., change beyond that accounted for by measurement error), crossing the clinical threshold and, at a service level, establishing the 'added value' for a service. There are strengths and limitations to each of these approaches so some triangulation across approaches is recommended. Table D.1., Appendix D summarises the outcome measures discussed in this report and the potential means of assessing change.

Attendees commented on the difficulties in comparing services by aggregating patient outcomes to the service level (e.g., the percentage of patients achieving a clinically significant, reliable change with the Revised Child Anxiety and Depression Scales [RCADS], out of all patients seen). These comparisons may be potentially misleading as services will differ in an array of contextual factors pertaining to the types of patients they treat (e.g., symptom severity, case complexity) which will have an impact on outcomes (see Wolpert, Fugard, & Deighton, 2013). The complexity of comparing services dovetails with recommendations to adjust for case-mix (i.e., contextual factors that influence outcomes; DH, 2012b; also see Halsteinli, Kittelsen, & Magnussen, 2010 for an example). For instance, CYP IAPT reports on the percentage of cases reliably changed and the percentage crossing the clinical threshold taking into account some elements of case mix. As part of this consultation process, participants were asked to consider outcomes relevant to the three different problems types (problems likely to show change, problems unlikely to show change and where the work is assessment-only) as different problem types may be one factor necessary to take into account when adjusting for case-mix.

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[2] This research paper was written as a previous CPRU output, which was circulated to DH before submission.

3. RESULTS

3.1. What did stakeholders involved in the consultation consider to be a good outcome?

Attendees suggested it was important to capture a range of outcomes to provide a meaningful picture of the CYP in context. From discussions, three levels of outcomes were identified:

1) Outcomes focusing on the individual CYP,

2) Outcomes reflecting interpersonal relationships, particularly within the family,

3) Outcomes related to wider society, including an impact on the service itself.

For instance, CAMHS aims to improve the mental health of CYP and in many cases also to improve family relationships and functioning; CAMHS may then use these treatment outcomes to inform changes to the way the service and society supports CYP.

It was the view of the group that outcomes reflecting the three levels (i.e., CYP, family and service/society) should be captured in order to provide a full understanding of whether a good outcome has been achieved. Although outcomes at these three levels may be applicable to the majority of CYP accessing CAMHS, the specific outcomes *within* each level may need to be tailored for different presenting problems, age ranges and ethnic or cultural groups. Capturing outcomes at these three levels also enables the triangulation of information. In addition, when outcomes for one level are difficult to capture, data can be complemented with outcomes for another level.

Drawing on the matrix of perspectives (Figure 2.3.1.) and the levels identified above, those involved in Round 2 discussed and expanded on the range of outcomes identified in Round 1 for problems likely to show change, those unlikely to show change and for outcomes of assessment-only work. These are presented in Table 3.1.

Table 3.1.: Measures of good outcomes at the individual child or young person, interpersonal and service/societal levels.

Level	Outcome	Reported with	Reported by	Dataset
Child or Young Person Level	(1) Symptom improvement/maintenance **	SDQ	CYP or caregiver	CYP IAPT; CMDS
		Symptom tracker (e.g., RCADS)	CYP or caregiver	CYP IAPT
		HoNOSCA	CYP or clinician	CYP IAPT; CMDS
	(2) Achievement of goals **	Therapeutic goal attainment (GBO)	CYP, caregiver, clinician or jointly agreed	CYP IAPT; CMDS
	(3) Functioning**	SDQ impact score	Caregivers or teachers	CYP IAPT; CMDS
		School audit data on attendance	Schools records	NPD
		EET questions	Clinician	CYP IAPT
		CGAS	Clinician	CYP IAPT, CMDS
	(4) 'Empowerment and self-efficacy'**	Unknown (could be YES-MH[†])	CYP	Not currently captured
	(5) Appropriate discharge, jointly agreed by CYP and clinician, meaning that the CYP can self-manage and does not need to seek further access to services in the short-term (e.g., 6 months)*	Therapeutic goal attainment (GBO)	CYP and clinician	CYP IAPT; CMDS
		CAMHS re-referrals	Audit data	CMDS
		Accident and emergency attendance	Audit data	HES
		Police or social care referrals	Audit data	CIN
Interpersonal Level	(1) Improved interpersonal relationships***	WPES or SLDOM	Caregivers	CYP IAPT
		SCORE 15	Caregivers	CYP IAPT
		SDQ impact score	Caregivers or teachers	CYP IAPT; CMDS
	(2) Caregivers' management of CYP and reduced caregiver stress***	WPES or SLDOM	Caregivers	CYP IAPT
		SCORE 15	Caregivers	CYP IAPT
		Parental Stress Index	Caregivers	CMDS
Service/Society Level	(1) Service engagement**	Attendance of appointments	Audit data	CYP IAPT; CMDS
	(2) Service user satisfaction**	CHI ESQ	CYP or caregivers	CYP IAPT; CMDS
	(3) Linkage between CYP's support network**	Information sharing	Audit data	Health and social care data linked (CP-IS); Education and social care data linked (CBDS)
		Multidisciplinary team working	Case record data	Indication of TAC/CAF in existing records
	(4) Best practice followed***	Compare presenting problem and treatment received with NICE recommendations	Service data	CYP IAPT; CMDS

Note. * = appropriate for problems likely to show change only, ** = appropriate for problems likely to show change and unlikely to show change, *** = appropriate for problems likely to show change, unlikely to show change and where the work is assessment-only. SDQ = Strengths and Difficulties Questionnaire, RCADS = Revised Child Anxiety and Depression Scales, HoNOSCA = Health of the Nation Outcome Scales for Children and Adolescents, GBO = Goal Based Outcome, EET = Education, Employment or Training, CGAS = Children's Global Assessment Scale, YES-MH = Youth Empowerment Scale-Mental Health, WPES = Woolgar Parental Efficacy Scale, SCORE 15 = Systemic Clinical Outcomes in Routine Evaluation, SLDOM = Sheffield Learning Disability Outcome Measure, CHI ESQ = Commission for Health Improvement Evaluation of Service Questionnaire, TAC = Team Around the Child, CAF = Common Assessment Framework. See Table D.1., Appendix D for a full description of the content, psychometric properties and methods for assessing change for each measure. † = the YES-MH is one measure that could be used to capture the 'empowerment and self-efficacy' concept (see section 3.2.1.4. below) identified by the consultation but further work is needed to determine if more appropriate measures are available.

3.1.1. Potential *outcomes at the child or young person level*

Good outcomes at the CYP level can be seen to cover a range of indicators including symptom improvement/maintenance, achievement of goals, functioning, 'empowerment and self-efficacy' and appropriate discharge/returning to services.

3.1.1.1. Symptom improvement/maintenance is one of the key approaches to establishing good outcomes in CAMHS currently, particularly in CYP IAPT sites and those involved in learning collaborations around outcome measurement (e.g., CORC, Outcomes Orientated CAMHS). This approach to establishing a good outcome perhaps has the most face validity and there is a growing evidence base suggesting that such measures can, to some degree, capture the impact of a service intervention (e.g., Ford, Hutchings, Bywater, Goodman, & Goodman, 2009).

3.1.1.2. Achievement of goals related to mental health symptoms (e.g., being less anxious) or functioning (e.g., getting into less trouble at school) was highlighted as being a central approach to measuring whether or not a good outcome has been achieved, which is routinely used in CAMHS and as part of CYP IAPT. Achievement of goals, as measured using the Goal Based Outcome (GBO) measure, could be used to monitor progress towards goals seen as important to CYP.

Both in the Round 1 and Round 2 responses, participants noted that progress towards goals may be a good outcome as it may be possible to capture change even if symptoms themselves are not changing. A recent study examined the types of goals CYP set using the GBO in CAMHS and found that three overarching themes emerged: 1) relationship/interpersonal goals, around listening, understanding and communicating needs; 2) coping with specific problems and symptoms; and 3) personal growth and functioning, around understanding and improving the self (Bradley, Murphy, Fugard, Nolas, & Law, 2013).

3.1.1.3. Functioning includes one's ability to carry out daily activities, such as attendance at work, education or training settings; for example, *"it helps you do things like get into school more and that's a tangible outcome, to say 'oh, look my attendance has gone up from 70 to 80 per cent'"*. This indicator has strong practical implications (e.g., school dropout has implications for educational attainment and future employment and, therefore, economic implications also). However, it is important to note that capturing functioning will depend on baseline levels, which may make this outcome more or less meaningful; for example, CYP may have high levels of school attendance despite experiencing mental health difficulties, in which case there would be little room for improvement (i.e., a ceiling effect). More reliable patterns in functioning pre-post treatment might be achieved by looking at aggregated service-level data.

3.1.1.4. 'Empowerment and self-efficacy' was the only important approach to capturing a good outcome, identified in the Round 1 questionnaire and Round 2 meeting, that is not currently captured in routine data collection systems. Figure E.1. provides an illustrative summary of how 'empowerment and self-efficacy' were discussed during the Round 2 meeting; this diagram was shared with respondents in the follow up email discussion (see Appendix E). 'Empowerment and self-efficacy' incorporated a number of other concepts and a consensus on how to define it did not emerge in Round 2. However, it does dovetail with the types of goals CYP set during therapy on coping with specific problems/symptoms and personal growth (Bradley et al., 2013; also see section 3.2.1.2. Achievement of goals).

'Empowerment and self-efficacy' was discussed as including aspects of self-management and locus of control over mental health and daily life. It was noted that it was not an easy constellation of outcomes to conceptualise in one phrase. This range of definitions applied to the construct of 'empowerment and self-efficacy' reflects the array of definitions that are provided in the literature (e.g., Aujoulat, d'Hoore, & Deccache, 2007). For example, empowerment is described as a broad *'multilevel concept in that it includes not just a person's confidence relative to achieving individual-level outcomes but also his or her confidence relative to having a positive effect on institutions, organizations, and political systems in the wider community'*, whereas self-efficacy is *'a person's perception that he or*

she is able to take actions that lead to positive mental health care outcomes—either through self-care and coping or through working to optimize the care provided by others' (Walker et al., 2010, p.52). In contrast, self-management can be defined as *'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 well-being after an acute illness or discharge from hospital.'* (Department of Health, 2005, p.1). In our consultation, CYP discussed their experience and understanding of 'empowerment and self-efficacy': *'Understanding how these feelings come about, what may trigger them… Maybe not avoiding situations at whole (sic), but being aware that some things may cause an issue and then taking preventative action or having a plan in place to manage those things.'* (CYP), *'In which case you need to learn how to live with it rather than trying to get rid of it. You need to learn how to live alongside it'* (CYP).

In the Round 2 meeting, 'empowerment and self-efficacy' was discussed as the CYP's performance, and perceived ability to perform, actions that protect against, monitor and manage emotional and behavioural symptoms and functioning. It was described as capturing a holistic view of the CYP—both their mental health and general life: *'It's not necessarily exclusive to mental health. It's what stops us all from turning into raging alcoholics'* (CYP). 'Empowerment and self-efficacy' was also described as a way of protecting against over emphasis on a narrow set of symptoms, which may at times be misleading: *'something might get better, but something else gets worse'* (CYP).

Some currently collected measures give an indication of whether self-management is occurring and 'empowerment and self-efficacy' activities are being achieved, such as symptoms (e.g., the Strengths and Difficulties Questionnaire [SDQ]), impact of problems on daily life (e.g., the SDQ impact scale) and goal attainment (e.g., GBO). However, CYP's subjective experience of their capacity to manage mental health and daily life is not currently captured (also see section 3.5.1. How to measure 'empowerment and self-efficacy').

The outcome of 'empowerment and self-efficacy' is consistent with recommendations from the mental health subgroup of the Forum about greater ability for CYP to manage their own lives (Children and Young People's Health Outcomes Strategy 2012a, 2012b) and it also dovetails with broader approaches to health. The White Paper, *Liberating the NHS: No decision about me without me* (Department of Health, 2012a) states that patients should be supported to take an active role in their treatment. Similarly, the mental health recovery model conceptualises recovery as staying in control of life despite experiencing mental health problems (Mental Health Foundation, n.d.). Here, the goals of treatment encompass more than symptom improvement but aim to support the service user's resilience so that, even if symptoms are not controllable, life is.

3.1.1.5. Appropriate discharge, jointly agreed by CYP and clinician, meaning that the CYP can self-manage and does not need to seek further access to services in the short-term (e.g., 6 months). Appropriate discharge should be agreed between the CYP and clinician, when they both feel the CYP is empowered with the self-management and coping skills to manage problems, without direct support from services, and is aware of signs of relapse indicating a need to reengage with services. As one CYP remarked, the aim is not *'getting to a point where you meet criteria so they can discharge you'*. Not needing to seek further access to services in the short-term would indicate that the CYP is successfully self-managing (with services here covering a broad range of services). It aims to capture CYP's attempts to access CAMHS subsequent to case closure but also their presentation at Accident and Emergency (A&E) and/or contact with social services. In individual cases, some of these contacts will have an incredibly low frequency (or be non-existent) meaning floor effects are likely; consequently, the extent to which change can be demonstrated for these cases is small. Such data may be better considered aggregated to a service level.

3.1.2. Potential outcomes at the interpersonal level

A good outcome for CYP at this level includes improved interpersonal relationships, caregivers' management of CYP and reduced caregiver stress.

3.1.2.1. Improved interpersonal relationships means that the CYP and their social context are functioning better (i.e., caregivers, family members, peers and teachers). This outcome reflects the systemic nature of CYP's difficulties and the systemic work CAMHS may use during treatment.

3.1.2.2. Caregivers' management of CYP and reduced caregiver stress involves caregivers having a greater understanding of the CYP's mental health problems and coping strategies; in turn, the CYP's mental health problems have a less deleterious impact on caregivers' well-being and ability to function.

3.1.3. Potential outcomes at the service/societal level

A good outcome for CYP is receiving high quality support from the wider social context (i.e., family, school, peers, community/neighbourhood and mental health and other appropriate services).

3.1.3.1. Service engagement can be explored using appointment attendance data. Here, did not attend rates and the proportion of appointments attended to appointments offered could be examined. However, caution may be required when interpreting such data. For instance, what qualifies as a 'good outcome' for total number of appointments attended was mentioned in Round 2 as being unclear (i.e., are fewer appointments in a course of treatment preferable to a greater number of appointments or vice versa?).

3.1.3.2. Service user satisfaction is routinely captured from CYPs and caregivers. This measure (i.e., Commission for Health Improvement Evaluation of Service Questionnaire [CHI ESQ]) is typically only measured once, on discharge.

3.1.3.3. Linkage between CYP's support network could be assessed by determining the level of data sharing between different services with which a CYP or their caregivers is engaging. However, data sharing is particularly problematic due to difficulties around mismatches in unique reference numbers across datasets and different electronic systems (also see Patalay, Murray, Brown, Deighton, & Wolpert, 2013). Such indicators are important but are

more likely to be long term aims for data capture. Other indicators could include evidence of Common Assessment Frameworks or Team Around the Child in case notes or records. The Common Assessment Framework and Team Around the Child are processes for multidisciplinary practitioners to collaborate and assess CYP's needs. After obtaining consent from the CYP and caregivers, a clinician can use the Common Assessment Framework to request a multidisciplinary meeting wherein practitioners from a range of relevant services meet to form a Team Around the Child, assessing the holistic needs of service users' and deciding actions with the CYP and caregivers. Linkages between a CYP's support networks may, in turn, lead to good outcomes in other domains: *"when I was in year 12/13, I had a fantastic senior tutor and I gave him permission and my CPN [Community Psychiatric Nurse] to communicate. And she sent him a letter every term, updating him. And he, like, sorted out...he was like 'just come to my office or whatever', and he'd come and check I was alright, or after exam results day he would be like 'do you want to go home?'"* (CYP).

3.1.3.4. Best practice followed could theoretically be assessed using routinely collected measures by comparing CYP's presenting problem and treatment received with National Institute for Health and Care Excellence (NICE) guidelines or other recommendations (e.g., Ford et al., 2013). However, such information on treatment offered is typically captured by yes/no responses to a list of modalities (e.g., cognitive behavioural therapy, play therapy), without any indication of competencies or fidelity to model so the quality of such data are likely to be low and, therefore, should be treated with caution.

3.2. Relevance of outcomes for different problem types

As discussed previously in relation to case mix, it is important to acknowledge that there may be young people for whom dramatic change in some of the outcomes discussed above might be less likely to occur; for example, children presenting to CAMHS with problems associated with longstanding difficulties such as emergent personality disorder or autistic spectrum disorders. In these instances, the core focus of intervention may be more on reducing the impact of problems on daily life and providing coping strategies rather than on eradicating symptoms. In such cases, good outcomes are less likely to be reflected in the

domains of symptom improvement/maintenance and more likely to be reflected in the domains of goal attainment, functioning and 'empowerment and self-efficacy'. Hence, outcomes in Table 3.1. have been coded using asterisks to denote how likely they are to be captured for different problem types.

3.3. Relevance of outcomes for different age groups

Responses to the Round 1 questionnaire and discussions in Round 2 revealed that across a number of the age bandings used (15-19 years, 10-14, 5-9 and 1-4) relevant outcomes suggested were similar, particularly across the age group 10-19 years. For CYP under the age of 5 years, the key outcomes were improved interpersonal relationships (i.e., caregiver-child relationship) and caregivers' management of CYP and reduced caregiver stress, which are reported by caregivers and, in some instances, teachers (see table 3.1.). For outcomes at the CYP level, caregiver report was seen as more reliable than CYP report for CYP under the age of 5 years. The age at which a good outcome would be observable at the CYP level—relative to the interpersonal level—was described as being more meaningful than the age at which a child could self-report.

The age at which a child could reliably self-report on standardised measures was discussed as ranging from 6-8 years depending on the complexity of language used in measures. This is consistent with some research evidence, which suggests that CYP aged between 6-8 years can reliably self-report on their mental health (Chorpita, Yim, Moffitt, Umemoto, & Francis, 2000; Curvis, McNulty, & Qualter, 2013; Sharp, Goodyer, & Croudace, 2006), although it should be noted that recommendations for specific measures vary and may be somewhat higher particularly where vocabulary, concepts and sentence structure are more complex.

3.4. Gaps in existing datasets: 'empowerment and self-efficacy'

Mapping of identified domains and measures against existing datasets (predominantly CAMHS Minimum Data Set [CMDS] and CYP IAPT) showed that almost all of the measures identified are already being routinely collected in existing datasets. One domain that did stand out as not currently being captured is 'empowerment and self-efficacy'.

3.4.1. How to measure 'empowerment and self-efficacy'

Existing measures may be used to capture indirect indicators of 'empowerment and self-efficacy'. At one end of the conceptualisation (see section 3.2.1.4.), 'empowerment and self-efficacy' could be captured using indicators of symptom improvement/maintenance (e.g., the SDQ) or functioning (e.g., the SDQ impact scale). This would identify when the CYP was successfully performing self-management activities; for example, to achieve an improvement in symptoms (or a low score on the relevant symptom scale) and functioning (or a low score on the SDQ impact scale), the CYP should be actively self-managing their emotional or behavioural difficulties. At the other end of the conceptualisation, 'empowerment and self-efficacy' could be captured using indicators of achievement of goals (e.g., GBO). This would identify when CYP were progressing towards goals they had agreed were important.

Neither of these indirect indicators, however, captures CYP's voice with regards to their perceived ability to control their mental health and daily life. Moreover, CYP may be achieving their goals during therapy but, if they do not feel empowered or efficacious, gains may not be sustained once treated is terminated: *'if you're in an inpatient unit, for an eating disorder…they have to take in a certain amount of food and they can't expend it, and some of the doctors are like, "oh, well you've gained weight so you must be getting better", so you're discharged…and then the minute they get out they just lose weight again…Because the weight gain doesn't mean anything at all, does it, in that situation, 'cos they've not got a choice about it'* (CYP).

If an additional measure were to be considered in order to capture 'empowerment and self-efficacy', a review of existing validated measures would be necessary. Such a review is beyond the scope of the current project; however, one measure which did come to our attention that captures elements of 'empowerment and self-efficacy' is the self subscale of the Youth Empowerment Scale – Mental Health (YES-MH; Walker et al., 2010) presented in Box 3.4.1 as an example of the sort of items that might be relevant to include. This subscale from the self-report measure captures CYP's confidence and capacity to manage one's own

mental health. Still, it is not currently collected in routine outcome measures. The YES-MH has been used for CYP aged 14 or over so goals may be the only suitable proxy for 'empowerment and self-efficacy' in those under 14, unless further research reveals a measure for this younger age group[3].

Box 3.4.1.: **Youth Empowerment 'Self' Subscale – Mental Health** (Walker et al., 2010).

Confidence and capacity to manage own mental health; answered on a 5-point scale from never or almost never (1) to always or almost always (5).

I feel my life is under control.
When problems arise with my mental health or emotions, I handle them pretty well.
I know how to take care of my mental or emotional health.
I feel I can take steps toward the future I want.
I make changes in my life so I can live successfully with my emotional or mental health challenges.
I focus on the good things in life, not just the problems.

This is included as an example of items only, as it was beyond the scope of this project to identify a given measure. Moreover, it should be noted that young people, who had the opportunity to consider the YES-MH as an exemplar of a tool that might assess 'empowerment and self-efficacy', raised a number of concerns about it (see Appendix C).

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[3] The YES-MH is a validated measure, developed in a sample of CYP aged 14-21 years in the USA with experience of significant mental health difficulties. Although further research is needed to examine its psychometric properties in samples of CYP with mental health difficulties the UK, the YES-MH was the only measure the research team or experts involved in the consultation were aware of that approached the concept of 'empowerment and self-efficacy' discussed by our panel of experts. The YES-MH consists of a second 'service' and third 'community' subscale pertaining to CYP's confidence and capacity to manage services (e.g., *'I work with providers to adjust my services or supports so they fit my needs')* and service systems for other CYP with emotional and behavioural difficulties (e.g., *'I help other young people learn about services or supports that might help them')*.

4. CONCLUSION

The aim of this report was to conduct a focused exploration, drawing on the expertise of key stakeholders, of approaches to defining and measuring mental health and well-being in children. Below we summarise findings in relation to the three primary objectives:

1. Consider what constitutes a good outcome and how recovery can be defined
2. Appraise what exists in national datasets for currently used measures and identify any gaps
3. Explore what age they consider children can reliably self-report

4.1. Objective 1: Consider what constitutes a good outcome and what recovery looks like

Stakeholders involved in the consultation identified that it was important to capture a range of outcomes that provide a meaningful picture of the CYP in context. To do so, outcomes should be considered at three levels: the CYP level, the interpersonal level and the service/societal level.

4.1.1. Potential outcomes at the child or young person level

A good outcome for CYP could involve symptom improvement/maintenance, functioning, achievement of goals and appropriate discharge (see Table 3.1. Measures of good outcomes). We suggest it would be advisable to also consider 'empowerment and self-efficacy' or the ability to manage symptoms and daily life, particularly in instances where the actual presenting problem is unlikely to change substantially.

4.1.2. Potential outcomes at the interpersonal level

A good outcome for CYP at this level includes improved interpersonal relationships, in terms of family or school relationships, caregivers' management of CYP and reduced caregiver stress. This would reflect an improvement in the impact symptoms have on the CYP's daily

life and the daily life of significant others, in addition to significant others' ability to manage the CYP's symptoms.

4.1.3. Potential outcomes at the service/societal level

A good outcome for CYP is receiving high quality support from society (i.e., family, school, peers, community/neighbourhood and mental health and other appropriate services). This would reflect improving the support provided to the CYP, and it could be assessed with service engagement, service user satisfaction, linkage between CYP's support network and best practice followed.

4.2. Objective 2: Appraise what exists in national datasets for currently used measures and identify any gaps

Almost all of the measures identified are already being routinely collected in existing datasets (see Table 3.1 p 16.). The one theme not currently directly captured is 'empowerment and self-efficacy'. Potential proxies for 'empowerment and self-efficacy' already being captured in existing data collection (e.g., through CYP IAPT or CMDS) include symptom improvement/maintenance, functioning and progression towards goals jointly agreed with clinicians. These indicators reflect factors necessary to promote 'empowerment and self-efficacy'—or the outcome of 'empowerment and self-efficacy'— rather than directly capturing the core aspects of 'empowerment and self-efficacy', such as CYPs' subjective experience of their capacity to make changes, achieve goals and feel in control of mental health and life (also see Bodenheimer, McGregor, & Sharifi, 2005). Hence, these indicators relate more closely to functioning and self-management whereas a more direct measurement of 'empowerment and self-efficacy' in terms of a short self-report measure might also be advantageous. One such example identified during this consultation was the Youth Empowerment Scale – Mental Health (YES-MH; Walker et al., 2010; see Box 3.4.1.).

While this measure appears to have at least some required item coverage, and it was the only suitable measure identified by the research term or the consultation group, it would be

advisable to further investigate self-report measures of 'empowerment and self-efficacy' to ascertain whether this is the most suitable measure or whether others exist that have more psychometric evidence and/or that are suitable for younger age groups.

4.3. Objective 3: Explore what age they consider children can reliably self-report

The age at which a child could reliably self-report on standardised measures was discussed as ranging from 6-8 years depending on the complexity of language used in measures. This is consistent with some research evidence, which suggests that where specific efforts are made to create measures that are child friendly in terms of reading age and presentation, CYP as young as 6-8 years can reliably self-report on their mental health (Chorpita et al., 2000; Curvis et al., 2013; Deighton et al., 2013; Sharp et al., 2006). However, it should be noted that recommendations for specific measures vary and may be somewhat higher particularly where vocabulary, concepts and sentence structure are more complex.

4. Headline summary

Our group of experts recommended that a good outcome is best reflected by taking consideration of three levels: the child or young person level, the interpersonal level and the service/societal level so the range of relevant outcomes is likely to include child and parent perspectives on symptom improvement/maintenance, functioning, achievement of goals, 'empowerment and self-efficacy', improved interpersonal relationships, service engagement and service user satisfaction (for the full list, see Table 3.1.). However, the specific emphasis—in terms of who reports, which outcome and at what level—is likely to depend on the age of the CYP and the nature of the problem.

It was noted that existing data capture procedures, including those being used for CYP IAPT, PbR and CMDS, already capture the majority of relevant outcome data identified through this consultation. We have identified 'empowerment and self-efficacy' as the only domain important to assessing whether a good outcome has been achieved that is not currently captured in existing datasets. This report has identified one measure that might be used for

these purposes (see Box 3.4.1.) but it is possible that others exist that were not identified through this process so further investigation of existing 'empowerment and self-efficacy' measures may identify other appropriate measures.

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	Outcome	Means of assessing outcome	Who reports	Source of information
Top outcomes for a problem that is likely to show change (e.g., recent onset and specific anxiety)	1. 2. 3. 4. 5.	1. 2. 3. 4. 5.	1. 2. 3. 4. 5.	1. 2. 3. 4. 5.
Top outcomes for a problem that is unlikely to show change, or where focus is on maintenance or non-deterioration (e.g., emerging personality disorder)	1. 2. 3. 4. 5.	1. 2. 3. 4. 5.	1. 2. 3. 4. 5.	1. 2. 3. 4. 5.
Measures (or approaches to measurement) suitable for use where work is purely assessment or advice (e.g. assessment for autism)	1. 2. 3. 4. 5.	1. 2. 3. 4. 5.	1. 2. 3. 4. 5.	1. 2. 3. 4. 5.

Table B.1. Summary of good outcomes for CYP access CAMHS given by respondents to the Round 1 questionnaire.

Theme	For a Problem Likely to Show Change	For a Problem Unlikely to Show Change	For Assessment
Mental health	• **Symptom improvement** CYP self-report (SDQ, RCADS, HoNOSCA, tracker, goal attainment) • **Appropriate discharge** CYP or clinician; questionnaire (e.g., goals) • **No need to return to services (within 6 months)** Service data	• **Symptom improvement or maintenance** CYP or parent; questionnaire (e.g. goals) • **Parent or carer stress** Carer questionnaire (e.g., PSI) • **Reduced service use** Service; referral, admission and A&E attendance rates	• **Well-being / stress** CYP or carer; questionnaire
Self-management	• **Understanding of problem** CYP self-reports • **Coping strategies** CYP or clinician; questionnaire/progress measure	• **Coping strategies** CYP, family or clinician; questionnaire, reflection/progress diary • **Understanding of problem**	• **Understanding of problem** Carer • **Coping strategies**

Impact on life	• **Functioning** CYP, family member or school; questionnaire or discussion • **Days lost from 'usual setting'** School attendance records or CYP self-report • **Goal attainment** CYP, parent or clinician; checklist • **Social isolation** Questions taken from ACORN questionnaires	• **Making shared decisions and feeling in control of MH / life** CYP, family or clinician; self-report • **Developing life skills** CYP or clinician; reflection/progress diary • **Goal attainment** CYP, parent or clinician; questionnaires, checklist or goals review • **Functioning / quality of life** CYP, parent, clinician or service; questionnaire (e.g. SDQ) • **Education**	• **Goal attainment** CYP, parent or clinician; checklist
Impact on service	• **Service outcome (e.g., engagement)** Service records or clinician; service activities • **User satisfaction** CYP or parent; service questionnaire (e.g. CHI ESQ)	• **Risk management** Service with CYP and family; risk assessment monitoring • **Improved support network** Service with CYP and family, or established team around the child; formal and informal network mapping • **Access to services** Service; service data or questionnaire	• **Service access** CYP, parent or service; questionnaire or waiting lists • **Service satisfaction** CYP or parent; questionnaire • **Care plan developed where appropriate** Service audit • **Evidence-based practice** Service audit • **Information sharing** Service audit

Appendix C

Summary of Service User Consultations

Children and young people's views on outcomes

A discussion group was held with 8 young people in May 2013 to explore young people's views on what good outcomes look like. The discussion explored:
- What good outcomes look like for problems that are likely to show change
- What good outcomes look like for problems that are enduring or long-term
- How you could measure change or know things had improved
- Who should determine and/or report on outcomes

Overarching messages

- Good outcomes are subjective. Therefore, a shared understanding of what 'better' means is crucial.

- *Explicitness.* Agreeing and measuring outcomes with young people is part of the development of a good relationship. This may be implicit in the practice of professionals, but agreeing and measuring outcomes collaboratively makes this *explicit*. In what is often a confusing time, this brings clarity and focus, builds trust and good communication and helps to avoid misinterpretations.

- *Emphasis*. What are seen as good outcomes may be the same from the perspective of the young person and the professional, and setting this out explicitly with the young person can help the professional to understand where the young person is coming from and their emphasis of what 'good' looks like. For example, a clinician may speak of increased school attendance being a good outcome, whilst a young person may speak of being able to get to lessons because they feel less anxious. It is often simply the same thing spoken differently. This builds trust and is another way of being explicit and showing you are collaborating (actions are louder than words).

During the discussion there were few distinctions for young people in how they thought about good outcomes for problems likely to show change or longer term issues, so the following sections are not mutually exclusive.

What are good outcomes for problems likely to show change?

It's not necessarily being 'cured' but being in control and reaching individual goals for what better looks like.

"Like being able to sleep before midnight, being able to leave the house, or being able to eat with people other than your family."[4]

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[4] Original quotes have been used and may therefore contain grammatical/syntactical errors.

"Yeah, just being able to talk about it openly and people just to be able to acknowledge it."

"Yeah, because the nurses had told me how to safely [self-harm] and how not to get infected and things like that, rather than just saying 'don't do it'"

"Just being able to say that you're happier and more comfortable..."

Feeling ready to move on from services, rather than a set time limit for how long you can get support for.

Young Person (YP): That's what adults say to you, the first appointment you have, they're like 'oh, just to let you know you've got...' I think it 12 sessions and you can choose if you have them once a week, or once a month, but you've only got 12 and then you have to go'...
KM: How does that make you feel?
YP: I left.
KM: Why?
YP: Well, it took me like 6 months to trust my CAHMS CPN, so if I've got like 12 sessions, then I'm not likely to trust them much within that, and even if it happened, the minute I trust them, they're leaving so...what's the point in that?

YP1: I had therapy for 6 months and I was kinda amazed that that was classed as long term.
YP2: That's not long term.
YP1: 'cos it took me ages to talk to her and that it was...I was kinda communicating well with her and it's like...it's over and 'look how well you are'...you know? I...I really got on with her but sometimes she was...I don't know, she seemed to gloss over the things that were still wrong but I think that were because she knew...she err...I could only have it for 6 months.

"Do you ever feel like, it's like a course for 6 months...? And they're gonna have a certificate at the end and say 'you're better, well done!'."

Not needing to return to services within 6 months.

YP1: I think a tangible one is if you have been discharged from services, like not needing to return to them within a certain period of time, because...
YP2: Yeah, I felt like that before.
YP1: ...Otherwise you're like in a revolving door, aren't you?

What are good outcomes for more long-term, enduring problems?

Feeling in control was central to most of the discussion about what good outcomes looked like. This encompassed a wide definition including control over: their condition, the services they received, their wider lives, information held about them and feedback, all of which contributed to their ability and confidence to be more in control of and manage their mental health.

Being and feeling in control.

YP: Things like having more control. Some kind of stability, this could apply both short and long term but more emphasis in long term.
KM: What do you mean by control?
YP: Being in a bit more control of your situation or whatever is going on.

Control and information.

Feeling in control of the information held about them was important for young people to feel like they were in control of their healthcare and mental health; it also helped them to feel that they had a good relationship with their clinician—to feel as if they were partners rather than recipients. This was often as simple as being upfront and explicit about what was being recorded and why.

"Sometimes when I would see a therapist they would be writing things down and making notes and I would not know that they were making notes. I just thought it was a clipboard. And then you have no idea of what they're writing, makes you wary of what you're saying. And I would ask 'what are you writing'? It's a bit secretive and I wouldn't mind if they said that they're just making notes and record some of the core things you've said and make an evaluation at the end. It feels like if it's about you then why is it being hidden from you, why are they keeping it from you?"

"Feeling informed, in control of information and sharing information."

"Especially if they're just sat there writing things down. Some therapists where you just talk and they don't like to interrupt and don't like to give you feedback and they just nod their head. If they are writing away then I think I'm just talking, talking they're judging me. I don't know what conclusions they gonna make. I feel like this impacted me negatively, it made me want to talk less; made me careful of what I was saying–you jump to all kinds of conclusions."

YP1: And like you should be able to look at your file. I have a file with like masses of paper. It would be good to look at it.
YP2: You can apply to look at it.
YP3: I've asked them and they said don't do it, it's too difficult, you'll need to get your mum to ring us, sign a form then we can release it to you. But in between they say don't do it, it's too difficult.
YP2: I think you have to wait until you can read them, you can apply to read them but I think you have to wait until you're discharged.
YP3: Yeah.
YP4: Yeah but I think there needs to be a balance because sometimes it can be detrimental, looking back now I'm a bit healthy but if I had read some of that stuff it might have made me worse or my condition worse, reading things or it might have affected your self esteem, so I do understand not sharing absolutely everything. But you need to be informed at least a little bit, it needs to change a bit.

Feeling in control: Developing coping strategies, learning skills and increasing independence and self-management.

YP1: You know you said...about learning skills...
KM: Yeah
YP1: Like I had CBT, Cognitive Behavioural Therapy, and that's like teaching you skills that you can use, when you're err...feeling down or whatever, if you feel this then you can do...say a little activity, like count how many legs are in the room.
YP2: See they never told me anything like that....
YP1: ...Or like times the number of legs in the room by eyeballs and...just to get your mind off...
KM: Hmm.
YP2: Oh, that's really good.
YP1: Like distracting techniques.
KM: Yeah, OK. So, taking your mind off things?
YP: It's about strategies.

"Not telling you what's going to happen. Discussing it with you rather than, you know, sometimes they talk down to you a bit 'cos they might think you don't know a lot, you're uninformed. But the thing is they need to inform you. Or they might not tell you because they think they're too above your level of intellect and they'll just ignore it and think you don't need to know that."

"It depends though [what a good outcome is], because if the problem is that you can't sleep, and then you can sleep, then it's fixed. But if you've got like a long term mental health condition, the likelihood is that it's probably going to occur at some point in your life or you might always have kind of thoughts and feelings that you have to deal with. In which case you need to learn how to live with it rather than trying to get rid of it. You need to learn how to live alongside it, but it depends because something things are really short term and just get help and deal with it."

Feeling in control: Life skills and making good choices in other life areas.

"Yeah, but they can use it, like, it would help them deal with any further incidences of them having a problem... but then it would just help them with their lives, it's not something they'd forget once they know to do it."

YP1: Sometimes they have to teach you life skills as well. 'Cos if you have had a mental health problem during your teenage years, you do so much growing up between the ages of like 13 and 18, and if you've had a mental health problem when you've not been socialising or seeing people, you're kinda stuck in a 16 year old's body but with the experiences of a 13 year old, all your friends have moved on and you have to kind of learn how to act around them and how to talk to them and that kind of thing. 'Cos you're not really used to being around them and that kind of thing and that can be really hard, so sometimes...
YP2: Then you get used to being by yourself...
YP1: Yeah. Sometimes you need to learn how to talk to people...

Having support in other areas of your life.

"One thing that is a good outcome is getting some kind of practical support in place, in certain circumstances, like in my AS's, the first modules I got like much below my expected grades, and I ended up...ended up quite down and I missed a week off school and all this. All of a sudden I spoke to my CPN and she sent a letter to school. And I went into a room full of dyslexic people, so I was in a room with less people, and my grade boundaries went up by two...by two grade boundaries. And it was a really simple, practical thing and but it had a good outcome. But you wouldn't be able to do that without a letter, or anything like that. You need someone at your school as well who's like responsible for it, because when I was in year 10/11 doing GCSEs I had a really rubbish form tutor who didn't have a clue on what was going on, but when I was in year 12/13, I had a fantastic senior tutor and I gave him permission and my CPN [Community Psychiatric Nurse] to communicate. And she sent him a letter every term, updating him. And he, like, sorted out...he was like 'just come to my office or whatever', and he'd come and check I was alright, or after exam results day he would be like 'do you want to go home? Off you go' and that kind of thing. So I think you need to have someone, like to be responsible for it. You can't do it yourself, you need somebody watching out for you, and kinda of in control of the situation."

YP: That kinda links in with this, which is like agreeing with all services, like your School, your GP, CAHMS. So like, your school understands what you can and can't do.
KM: OK.
YP: Like say CAHMs talk to your school, some schools like just setting unreasonable goals really

YP: I was in a situation where I was leaving school at, like, break-time/lunchtime every day and going home, but by the time I was halfway home and I was feeling all better and I could've happily gone back to school.
KM: Yeah?
YP: And I mentioned it to my tutor and he was like 'oh, it's fine, just come and use this room'...

Reaching goals that young people had determined were problematic at the beginning and being able to reflect back on their progress.

"I guess write positives they've achieved, and as well as what they've been suffering with...so because if you're just thinking about it, it can be negative in your head. But if you're writing it down, 'I did this today', and a few things you can look at because you're calm..."

"I think that's quite good...yeah. I've had diaries from when I was 12, and going back now and reading them, I think 'wow, I'm so much better, I'm so much healthier', that's quite encouraging. And even if I read them at any point, then I can gradually see myself either getting better or getting worse."

How would you measure change or know things have improved?

Measuring change: Setting goals.

Setting and agreeing goals was an important factor in being able to know whether things had improved and having a shared understanding with their clinician about what good looked like. Key messages about goals included:

- They remind you why you're here and help to focus the work.
- You need to be certain what your goals are when you start, to be able to know whether you've achieved them.
- They make things explicit and support a shared understanding of what's going on.
- Some goals need to be open ended or have no time limit, they are more aspirational but just as important as those that are more short term, tangible or measurable.
- Goals need to be reviewed during your time together as they can change.

"So at the start you like set certain goals that you want to achieve, and they might change as you go through, and all of a sudden if you're in a really bad place you might not be able to see that far ahead so you might want to keep making them and not necessarily set ten on the first day, and once you've reached them you go, kind of thing, but I do think they need to set goals and when you reach them you can say well that is one that's been reached, are we where we want to be or do we need to set up another one? Also, it helps motivate you. I don't know about everyone else but when I was going through CAHMS for about the first nine months I was like 'why am I even going here? I don't want to be'"

Measuring change: Have clear goals.

YP1: It feels like I was going there to be reminded that there's something wrong with me
All YP: Yeah
YP1: And also if you're in the middle of exams it can be really stressful, because it's like, well, I don't feel like you're doing anything, this is an hour I can be revising or I'm missing lessons...
Yp2: I quite like missing lessons...
(Group laughter)

Tracking improvement: Measuring outcomes needs to be regular

YP: I had the 6 months-in one.
KM: OK...
YM: But I'd been there for like three years.
(Group laughter)

"Yeah, it helps you do things like get into school more and that's a tangible outcome, to say 'oh, look my attendance has gone up from 70 to 80 per cent' or something..."

YP1: I think it you can measure some things by like, you know, numbers though. So, like, if you say you've stopped, like, self-harming every day, to once a week, or your weight's gone up, or your bloods are better or whatever. But you have to be careful with that 'cos sometimes it can be a bit like cyclic, like, something might get better, but something else gets worse.

YP2: You do have to be kinda careful though, 'cos sometimes erm...you might like...I know personally sometimes I will be self harming less, but I'll actually be feeling a lot worse, and that's why I did it less because I didn't have that energy to actually do it kind of thing...

Measures need to be set individually, so that they fit the young person.

"Draw a scale on, when you first start working, on a scale of 1-10 ... 10 being great and 1 being really bad...the symptoms. And then after the treatment do the same and see if it has improved...short term."

"I used to hate that question. For one thing, I had a thing about numbers, so I couldn't use even numbers, so I was like this cuts down the scale slightly!!!"

"Like, all that stuff depends on the person. I don't think you can actually say 'this is the way we can measure all young people's mental health and how they can get better'. Which is in some ways what they wanting to do at the moment, like they kinda want you to say 'this is the way to measure'...I think it has to be done on person by person basis, I don't think like you can...even between two people you can't say 'this is gonna work for both of them'."

Measuring needs to be done carefully.

Outcomes don't always show the full story and should be used as part of a wider discussion. It also needs to be the right things that are measured

"But that's why you end up coming back. Because you haven't done it properly, you think you're better, but you're not. The outcome measure from the professionals, it seems, a lot to do with like reducing risk, so, 'this person isn't self harming as much, so they must feel better, or this person's gained weight or this person is going out more', so they automatically think they must be better. And I think that's not always the case."

"One of the most really weird example is if you're in an inpatient unit, for an eating disorder or whatever, I know of people who have been on a meal plan and an exercise plan, so they have to take in a certain amount of food and they can't expend it, and some of the doctors are like, 'oh, well you've gained weight so you must be getting better', so you're discharged and like, well obviously they're gonna have gained weight because you've been doing it for them, and then the minute they get out they just lose weight again. It's, like, I've had friends in that situation, in and out of the inpatients like, 3 or 4 times. Because the weight gain doesn't mean anything at all, does it, in that situation, 'cos they've not got a choice about it."

Who should determine and/or report on outcomes?

- Goals: Young people's opinions should be taken first even if they seem impossible, unreachable or silly
- The young person should report if the outcome has been achieved. *"It's all personal, like; a clinician can't accurately tell you when you're better on their own"*
- Communication with other people in the young person's life can be helpful, but with their full consent. This can give a broader picture of their progress and achievements as the young person may not always be able to see their own achievements.

Young people's views and experiences of self-management

A discussion group with 4 young people and in depth, individual discussions with 2 further young people were undertaken to explore young people's views and experiences of self-management. The discussions covered:

- Their experiences and perspectives of the support they received to develop their self-management skills.
- What self-management means and how it could be improved.
- The Youth Empowerment Scale.

Young people's experiences of support for self-management

The young people felt there had not been an explicit focus on self-management, in the support they had received.

"Not at all … There are very few…I think CBT is the most direct about it, but most analytical therapies... Self-management... Or long term self-management isn't discussed... It's more getting to a point where you meet criteria so they can discharge you, or refer to less extensive support."

They felt there was often a lack of realistic discussion about self-management being a good outcome. The young people felt this was done with good intentions, to give them hope, but was often misguided. They felt that honesty from the start of getting support with their mental health would be better and talking more explicitly about a good outcome being that they will be in control, not that they will be 'cured' of all symptoms.

"I don't think that's something that's explained; certainly in CAMHs...you're never told there isn't a magic cure. And that leads you to believe that one day, you know, you will reach this point of normality. Where you CAN, but you just have to learn how to manage things in a healthy, sustainable way [not expect them to disappear]. I think self-management needs to be healthy ways of getting on top of things.!

"This is why you see people becoming more dependent on therapies [because they are expecting to be able to be cured]."

"Realistic discussions [are needed]... I think people are scared to say 'well, this isn't gonna go away'... Because it isn't... And while hearing that isn't pleasant...it's realistic. I think if you don't say that then people expect things to get magically better, and then don't establish ways of self-management, because they feel that if they do 'this amount of therapy' then something will click and something will magically happen, instead of them having to maintain things long term. I think that's a conversation that no one wants to have."

The young people felt that the focus of support was often on the present or short term goals, rather than on long term self-management.

"I think you mainly just talk about what's going on at that moment in time, so when you are struggling you just talk about the struggling, you don't talk about after you managed the struggle or what could happen if you did start struggling again. And they don't talk about future things that might happen like going to a new school or making new friends. They don't help you with things like that, if that makes sense."

"The focus is on 'are you self harming less? Are you getting better?' Adult services do more of that [self-management]. They [adult services] are very much like, 'if you're not self managing there's nothing I can do for you', which is not necessarily great, but... It's a requirement and that's not in CAMHs."

"I think they don't necessarily think it's important to focus on self-management if someone is 13 or 14... but I disagree. I definitely disagree with that... I think... I think the view is 'the child is in a family, this is how many siblings they have, this is the family dynamic, this is the behaviour, this is the record in school', whatever, whatever. Those sort of factors and getting back to something that resembled a normality for that child before the point that they became unwell. But the thought that this child may have to deal with these issues recurrently in the next 12-24 months isn't there. It's almost like 'if things start getting bad come back to us'. Which is fair enough, but... Things are choppy in adolescence... things will change."

However, too much focus on self-management can also be difficult so there needs to be a balance.

"Sometimes I felt in therapy there was more of a focus on how I could manage rather than what I was feeling, which was intense despair. Need a balance of the two."

What does self-management mean and how could it be improved?

What does self-management mean?

The young people talked about self-management being the stage towards the end of and after therapy where young people develop increasing control over their mental health. Rather than 'curing' all symptoms, it is a process where they develop a range of skills and strategies to effectively manage their mental health and emotional well-being, for the long term.

"[Self-management is] when you're able to pick up some of the functions that other people are doing for you and being able do them yourself. So in the sense of managing a difficult emotion... instead of having to have a reaction and tell someone else and feel like that emotion is going to follow through into a behaviour that is extreme, that you have conversation with yourself or you hold that within yourself, instead of putting an end action or behavior to that. Self-management is more like a sustainable state where you don't require the need for other people in there."

"Self-management is managing symptoms and larger issues...without the intervention of therapies, or groups or any kind of clinical input."

"It's the long term measures that you would have to put into place to manage your mental health condition or your mental health in general... Maybe not cured... But for it not to be so much of an issue. But, there may still be symptoms or relapses , etc., it's knowing how to manage those without crisis."

"Control of emotions, feelings... That is self-management on a wider scale. Just being in control or knowing how to get control."

"Understanding how these feelings come about, what may trigger them... Maybe not avoiding situations at whole, but being aware that some things may cause an issue and then taking preventative action or having a plan in place to manage those things."

The young people felt that self-management was more than just coping, that it was about actively managing your mental health.

"I don't want this to sound like 'because I'm not doing certain behaviours I'm self managing'. That's not self-management... I want to be like 'I'm not doing those things AND I'm doing something else'. And I don't know how you'd measure it... but 'I'm going ahead in my life'. Some people don't self manage, they just sit with things... but they're not able to move on... There's a difference between coping, just existing ... and self-managing."

"Self-management is active... You're doing something. Coping is rigid... You're just putting a lid on things. Self-management is flexible to who you are now. 'I can manage myself now and I can manage myself when I'm about to jump off a bridge....' It's flexible... You will always go up and down."

In addition, they felt it was important to remember that self-management is a life skill we all need to learn. They felt that self-management is really only about giving young people normal skills to cope with life.

"Everyone has their issues...they might not have had psychological intervention but they might find things difficult and they learn what to do about it... That's self-management... It's not necessarily exclusive to mental health. It's what stops us all from turning into raging alcoholics."

Gaining and using healthy, sustainable coping strategies.

The young people felt that a key element of self-management is developing healthy and sustainable coping strategies, to replace coping strategies that can be destructive. For example, they talked about how self harm is often a coping strategy, but developing *healthy* coping strategies was crucial to shift from coping to effective self-management.

"'If this happens, I would do this'. All these measures are healthier than the original behaviour. Sometimes people talk about self-management in a way that normalises destructive behavior. To manage oneself... self harming to manage suicidal feelings is

destructive [but may be perceived as the best option at that time]. Self-management and healthy, sustainable self-management are two very different things."

"Self-management may escalate [some] symptoms... When someone becomes more on top of their eating disorder, their self harm might increase but then in the long term the self-harm will decrease as they find something else healthier or is more sustainable."

"Knowing you have them... Knowing you would know what to do, of how you would cope."

Self-management is a process: Shifting from intervention to independence.

We discussed what they felt the different stages of therapy and support were and where they felt self-management sat within this. Some of the young people used the metaphor of a see-saw to describe how, over time, clinical input should decrease and self-management should increase. This should include finding ways of making use of other support networks, such as friends and family, to replace the clinical support. Instead of talking to the therapist the young person would be able to communicate in a healthy way with friends, family or others around them.

"You know talking, but in a way that instead of being clinical is still constructive."

"The feelings may not change, or they may lesson... but they're still there. It's learning how you can manage without the therapeutic intervention."

"It's how to channel things elsewhere. Make better use of existing support networks."

The see-saw metaphor was also used to talk about how through the process of therapy and support, some of the issues or symptoms young people had experienced should decrease (although not necessarily disappear) and their ability to manage them should increase. Rather than their feelings controlling them, the balance should tip with them learning to control their feelings.

"You assume by the time you've left that the therapy has worked enough so that you're reflective enough and the therapy has worked enough so that some of those really intense emotions you felt have lessened, so that's the kind of downward bit... and then there's also the upward bit that's erm... You will have learnt a new way of doing things or you will have been able to practice a new way of doing things. And I think maybe I don't know, maybe group work or CBT... But the idea of strategies and alternatives and doing and practicing...that sort of action... should be implemented with everyone."

The young people felt that the core stages of self-management included:

- Understanding yourself: *"[Developing an] understanding of how you feel and why you feel that way."*
- Learning about a range of coping strategies; this involves getting support to learn about what strategies are available.

- Being able to self-manage and use a range of coping strategies, and being able to adapt these as your life changes and you develop.
- Getting support to trial and test different strategies out to see what works for you. The young people felt that coping strategies have to be tailored to individual needs and that having time and support to reflect on what works and what doesn't is important. They also felt that young people need time and support to learn how to use different strategies in practice and gain confidence in doing so.

"Because there isn't a... No matter how similar people's situations may be, people react to different things in different ways. Finding out what works for you and then capitalising on that. Erm, and it being sustainable... Not saying spending £400 on shopping spree is OK... It might help ... but it's not sustainable. Look at what it is you get from that ... and then how else can we get that. Managing rather than getting rid of. Where does that urge come from... Work backwards to find a behaviour that's helpful or sustainable..."

"People say why don't you...instead of self harming, why don't you draw red lines on yourself... Why don't you cut up bits of paper... Why don't you put ice on yourself... Why don't you put an elastic band on your wrist? None of those may work for someone ... but something else may work. But discussing it and discussing it and discussing it doesn't help that young person to find what works..."

"I think the step before self-management is relapse prevention. I think that should be done as an approach or an approach coming towards the end... As a standard part of therapy. You need to be in a place where you can manage it"

"You need to test it, and it will fail [at first], but maybe if I say it this way... I feel like some of the errors that CAMHs services make is to discharge people too early before they can do that [use coping strategies] themselves... Which is why people fall back. You need to get someone to the state that you know they could be doing that [using coping strategies effectively] before you stop seeing them."

Planning for self-management from the start.

The young people felt that self-management should be an explicit focus from the start and should be linked to personal goals.

"Skills [for coping] are often throw at you... Sleep hygiene, winding down before bed, exercise ... you're thrown loads of things you could do if you weren't doing X ... but if you were to, almost, approach it in that way from the beginning and say 'these are our goals to find an alternative', then the onus is on finding one [coping strategy] that works... Not just any one... One that works for that person."

"To begin a process that's different... That's not just a winding down of therapy, but is a relapse prevention approach... I don't know the right word for it..."

The young people thought that an increased focus on self-management throughout could help prevent someone's mental health getting worse and help them to engage more with the support they are getting (i.e., collaborative practice).

"...prevent people having to go down the route of 'I've got to show you how ill I am to get help' or down the route of learning no one listens... That stuff affects someone for the rest of their lives... It shapes who they are."

"Especially if doing that [planning from the start] and starting on your aftercare during the process of the therapy, it gives you something to look forward to. It makes you look forward, think ahead, it gives you that positive thought."

Developing skills as an individual and getting the right support in other areas of your life.

The young people suggested it would be helpful to develop a self-management plan that outlined the different coping strategies that had been developed. This would cover how a young person would manage in different areas of their life and outline what support others need to provide (e.g., the young person's school).

"Need to identify, like I said before, in an inpatient unit, you have to put things in place first. They do have safety plans, but when you make safety plans, it's basically for when you're in there and they didn't make one for when you came out. So I think that's a key thing, having a proper plan of what's going to happen next."

"[It could be called] The safety plan: The sequel!"

"The transition back into school for me, I had like a risk assessment thing when I went back and we looked at the triggers and I got given a mentor and a time out card. So I just put the card on the table in the classroom and I could walk out and find my mentor, because I knew the triggers and because that was in place I managed to get through. It's all [about] compromise ... with the place and with yourself. I obviously couldn't abuse the card and just say 'oh right I hate that so I'm gonna go in for 5 mins and not go back.' You have to compromise with yourself too and say 'I've got this power and I'm going to be mature about it' but the school's compromise is to give you this card."

The Youth Empowerment Scale

Whilst the young people felt it would be helpful to have a measure or tool for self-management, they felt the Youth Empowerment Scale was not the right tool. Their feedback included that:
- The questions were too broad and vague.
  - They could see what it was trying to get at, but felt that it needed refining.
- They felt the questions needed to be more specific. Initial suggestions included:
  - I have a range of positive, healthy coping strategies.
  - I feel confident to use my coping strategies.
  - My coping strategies stop my mental health getting worse.
  - I feel in control of my mental health.

- I know what to do when my mental health starts to get worse.
- I know what my triggers are.
- A question about knowing what to do if they make the wrong choice or a coping strategy doesn't work.

Kate Martin, 2013
Common Room

Appendix D

Outcome measures discussed in this report

Table D.1. Outcome measures discussed in this report.

Name of measure	Authors and year	Number of items	Sample items	Number of subscales	Reliability	How change can be assessed
CGAS	Schaffer et al. (1983)	1	Clinicians are asked to record a general score for the CYP's functioning in a number of domains (e.g., home, school)	n/a	n/a	Crossing the clinical threshold, significance testing (e.g., t test)
CHI ESQ	Attride-Stirling (2002)	12	"Did the people who saw you listen to you?", "Was it easy to talk to the people who saw you?"	2	Intraclass correlation .06-.13 (Brown, Ford, Deighton, & Wolpert, submitted)	None as measured only after treatment
Education, Employment and Training Questionnaire	CYP IAPT (2013)	2	Questions regarding problems in attendance and attainment	n/a	n/a	Significance testing
GBO	Law (2011)	2	"My goal is to…", "Today I would rate my progress to this goal as?"	n/a	n/a	Reliable change criteria, significance testing
Parental Stress Index	Abidin (1995)	120 or 36 (short form)	Not available	13	.80-.91	Reliable change criteria, crossing the clinical threshold, significance testing
RCADS	Weiss & Chorpita (2011)	47	"I worry about things", "I have trouble sleeping"	6	.78-.88 (Chorpita, Moffitt, & Gray, 2005)	Reliable change criteria, crossing the clinical threshold, significance testing
SCORE 15	Stratton, Bland, Janes, and Lask (2010)	21	"In my family we talk to each other about the things that matter to us", "People often don't tell each other the truth in my family"	3	.58-83 (Fay et al., 2013)	Reliable change criteria, crossing the clinical threshold, significance testing
SDQ	Goodman (2001)	25 plus an impact supplement	"I get very angry and often lose my temper", "I usually do as I am told"	5	.73	Added-value score, reliable change criteria, crossing the clinical threshold

SLDOM	Sheffield Children's NHS Trust (n.d.)	8	"I feel I understand my child's behaviour", "I am confident about managing my child's behaviour"	Unknown	Not available	Reliable change criteria, significance testing
WPES	Woolgar et al., (n.d.)	5	"Even though I may not always manage it, I know what I need to do with my child", "I am able to do the things that will improve my child's behaviour"	0	.75	Reliable change criteria, significance testing
YES-MH	Walker, Thorne, Powers, and Gaonkar (2010)	20	"I work with providers to adjust my services or supports so they fit my needs", "I understand how my services and supports are supposed to help me"	3	.85-.91	Reliable change criteria, significance testing

Appendix E

Figure E.1. Diagrammatic summary of attendees' discussion of the 'empowerment and self-efficacy' outcome during the Round 2 meeting.